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END-OF-LIFE CARE: IDENTIFYING AN APPROPRIATE LEGAL FRAMEWORK FOR SPECIALIST PALLIATIVE CARE IN IRELAND

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Doctoral Thesis in Law (PhD, Law)

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Faculty of Law

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DECLARATION OF NON-PLAGIARISM

I declare that this thesis is the result of my own research, all sources have been properly acknowledged and this work contains no plagiarism.

I further declare that I have not previously submitted this thesis or any version of it for assessment for any other qualification or award offered by University College Cork or any other institution.

Student's Signature:

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ABSTRACT

This thesis examines the legal framework in Ireland for specialist palliative care. End-of-life care has become increasingly medicalised and this has given rise to substantial legal and ethical issues. On this basis, it is necessary to examine how we protect people during this vulnerable stage. This thesis argues that the legal framework in Ireland for specialist palliative care is inadequate and consequently a more appropriate legal framework must be identified. This research is guided by three central research questions. The first central research question examines the legitimacy of the distinction between specialist palliative care and euthanasia. The second central research question asks what legal framework currently exists in Ireland for specialist palliative care. The third central research question examines an alternative legal framework for specialist palliative. This thesis utilises doctrinal and comparative legal research to address these central research questions.

This thesis is composed of seven chapters. The first Chapter is an introduction to the thesis and defines the terminology and the central research questions. Chapter Two explores the development and practice of palliative care in Ireland. Chapter Three examines the distinction in criminal law between specialist palliative care practices and euthanasia. Chapter Four examines the human rights framework for specialist palliative care. Chapter Five critiques the regulatory framework in Ireland for specialist palliative care. Having gained a thorough understanding of the provision of palliative care and the related legal framework, this thesis then engages in comparative analysis of the Netherlands which is used as a source of ideas for reform in Ireland. Chapter Seven is the concluding chapter and, in it, the main findings of this thesis are summarised. The main findings being that: the distinction between specialist palliative care and euthanasia is not sufficiently supported by justifications such as a double effect or the acts and omissions distinction, there is no clear decision-making framework in Ireland for specialist palliative care, and the current legal framework lacks clarity and does not promote consistency between providers of specialist palliative care. This Chapter also proposes that detailed professional standards and guidelines are likely to be the most appropriate way to effect individual and institutional change in the provision of specialist palliative care.

ABBREVIATIONS

AOD	Acts and Omissions Distinction
DNR	Do Not Resuscitate Order
EAPC	European Association of Palliative Care
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
HIQA	Health Information Quality Authority
HSE	Health Service Executive
IAPC	Irish Association of Palliative Care
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
IHF	Irish Hospice Foundation
IKNL	Integraal Kankercentrum Nederland (Comprehensive Cancer Centre the Netherlands)
IMC	Irish Medical Council
KNMG	Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association)
RDE	Rule of Double Effect
TS	Terminal Sedation
VIKC	Vereniging Integrale Kankercentra (Association of Comprehensive Cancer Centres)

VSED	Voluntary Stopping Eating and Drinking
WHO	World Health Organization

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INTRODUCTION

In 'Aubade' the poet Philip Larkin wrote '[m]ost things may never happen: this one will'.[1] This set out that death is something which cannot be avoided and is a reality which is to be accepted. It is a reality which is bundled with much philosophical analysis as well as religious and social mores.[2] Our understanding of death and the ability to treat pain experienced at the end of life by the patient has developed in line with advancements in science and technology.[3] As such, technology now has a substantial impact on the way people both live and die. This leads to a degree of friction between the treatment of the patient and the philosophical, religious and social mores associated with death and dying. Hanafin suggests that, as a result of death becoming increasingly medicalised, this signals the first move towards 'the need for legal intervention in this area.'[4] In this regard, end-of-life care raises important legal and ethical issues about the treatment and care available to patients. End-of-life care may take a variety of forms[5] but this thesis concentrates on specialist palliative care practices and the legal framework in Ireland in respect of these practices. This thesis will advance the argument that the current legal framework in Ireland for specialist palliative care is inadequate. Consequently, a more appropriate legal framework which addresses the challenges raised in practice must and will be identified in this thesis. Three central research questions will be addressed in this thesis in order to advance the main argument.

The central research questions are structured in such a manner so as to build upon each other and provide a logical progression for this thesis. They address key issues raised

[1] Philip Larkin, 'Aubade' in Harold Pinter, Geoffrey Godbert and Anthony Astbury (eds), *100 Poems by 100 Poets* (Methuen 1986) 93.
[2] Phillipe Ariès, *Western Attitudes toward Death: From the Middle Ages to the Present* (Patricia Ranum tr, John Hopkins University Press 1975); Phillipe Ariès, *The Hour of Our Death* (Random House 1991); Bryan S Turner, *The Body and Society* (Sage 1996) cited by Jane E Seymour, Rien Janssens and Bert Broaeckaert, 'Relieving suffering at the end of life: Practitioners' perspectives on palliative sedation from three European countries' (2007) 64 Social Science & Medicine 1679, 1679 'Questions about how to manage the dying process are now matters of intense clinical and societal debate, alerting us to how death is both a socially organised and profoundly physical transition and related to beliefs and values at an individual, social and societal level.'; John Lombard, 'The Definition of Death' (2012) 11 Hibernian Law Journal 63.
[3] Lombard (n2).
[4] Patrick Hanafin, *Last Rights: Death, Dying and the Law in Ireland* (Cork University Press 1997) 7.
[5] See p6.

by the provision of specialist palliative care and underline the necessity of examining the current legal framework for this form of care. The aim of this chapter is to introduce the subject and structure of this thesis. This not only includes setting out the central research questions but also setting out why these questions are relevant and how they will be answered in order to develop the central argument of this thesis. As such, the first step in achieving this is to outline the central research questions for this thesis. This will be a concise introduction to the questions as they are drawn out in detail over the course of this Chapter. Second, the main terms used in this thesis will be defined. The terms are defined at an early stage in order to provide clarity in the subsequent use of these terms and to highlight similarities and differences that may go beyond the purely semantic.

The parameters of this thesis will be outlined and justified in the third section. This discussion will locate the central research questions in relation to existing literature on end-of-life care, and will identify gaps in the current state of knowledge about the legal framework for specialist palliative care. This section will demonstrate the importance of examining the legal framework in Ireland for specialist palliative care. Furthermore, in this section the issues outside the scope of this thesis will be explained and justified.

The theoretical framework and methodological approach utilised in this thesis will be outlined in the fourth section. Their selection will be justified based on their suitability to examine, develop, and respond to the three central research questions. In the fifth section the chapter structure for this thesis will be set out. This will detail the key arguments made in each chapter and demonstrate how the central argument is developed and advanced over the course of the thesis. This section will also set out the manner in which the three central research questions in this thesis are resolved.

Central Research Questions

The first central research question examines the legitimacy of the distinction between specialist palliative care practices and euthanasia. This analysis clarifies the legality of practices such as palliative sedation and the withdrawal of artificial nutrition and hydration in Ireland. This will be achieved by examining the legal status of euthanasia in Ireland and comparing it against a jurisdiction, the Netherlands, where this practice

is legislated for. This approach allows for a practical distinction between specialist palliative care practices and euthanasia to be identified. Responding to this central research question also requires legal justifications such as double effect and the acts and omissions distinction to be examined. These justifications may be relied upon in cases where the actions of a healthcare professional suggest an intention other than providing appropriate palliative care and/or pain management. This central research question is a necessary first step to take before analysing the existing legal framework for specialist palliative care, and consequently, before making any suggestions for reform. In effect, this central research question allows for the legal status of palliative sedation and the withdrawal of artificial nutrition and hydration to be clarified as well as identifying potential failings in this part of the legal framework.

The second central research question asks what legal framework currently exists in Ireland for specialist palliative care. This thesis focuses on the legal framework applicable to specialist palliative care for adults and not paediatric palliative care. This distinction is made due to the differences between paediatric and adult palliative care as well as the additional challenges raised in providing palliative care to children such as issues of patient autonomy.[6] At present, there is no legislation drafted in Ireland with specialist palliative care as its central concern. Therefore, it is necessary to take a broad approach to this question and consider constitutional provisions, common law, domestic legislation, international legal instruments, and professional standards and guidelines applicable to doctors and nurses in Ireland. These are examined over the course of several chapters and build to ensure that a comprehensive picture of the current legal framework is identified.

The third central research question examines an alternative legal framework for specialist palliative care which could address the legal and ethical challenges posed by specialist palliative care in this jurisdiction. In order to adequately address this research question it is necessary to engage in comparative legal research. This methodology will assist in the identification of suggestions for reform through analysis

[6] Department of Health and Children and the Irish Hospice Foundation, 'A Palliative Care Needs Assessment for Children' (2005); Department of Health and Children, 'Palliative Care for Children with Life-Limiting Conditions in Ireland: A National Policy' (Department of Health and Children 2009).

of and comparison with another jurisdiction. Overall, these three central research questions are closely linked and, when combined, address the central argument of this thesis that the current legal framework in Ireland for specialist palliative care is inadequate and consequently a more appropriate legal framework must and will be identified.

Terminology

The terms 'palliative care', 'specialist palliative care', 'palliative medicine', and 'euthanasia' are used throughout this thesis. As such, it is necessary to define these terms at an early stage to provide for a clearer discussion. Defining these terms begins to illustrate the complexity of distinguishing between several of these practices from a legal and ethical perspective. Legal and ethical concerns are closely aligned in specialist palliative care given the condition of the patient and they often serve to complicate discussion.

Palliative Care

In the case of *Fleming v Ireland & Ors*,[7] Dr. Tony O'Brien[8] described palliative care as:

> a medical intervention which is concerned with quality of life. It involves pain and symptom management where the patient is also given psychological, social, emotional and spiritual support so that they can live a life of their choosing in the place where they choose to live it to the greatest possible extent.[9]

This description encompasses many of the characteristics of palliative care. For instance, this explanation of palliative care highlights the focus placed on the 'quality of life'[10] as well as the wide range of care it includes, e.g. 'psychological, social, emotional and spiritual support'.[11] These forms of care demonstrate the multi-

[7] *Fleming v Ireland & Ors* [2013] IEHC 2.
[8] *Fleming v Ireland & Ors* [2013] IEHC 2, [34] 'Dr. Tony O'Brien is a consultant physician in palliative medicine and former chair of the Council of Europe Expert Committee on Palliative Care.'
[9] *Fleming v Ireland & Ors* [2013] IEHC 2, [35].
[10] *Fleming v Ireland & Ors* [2013] IEHC 2, [35].
[11] *Fleming v Ireland & Ors* [2013] IEHC 2, [35]; Deirdre Madden, 'Is There a Right to a "Good Death"?' (2013) 19(2) Medico-Legal Journal of Ireland 58, 61 'In recent years, palliative care has

disciplinary nature of palliative care. The description also serves to illustrate that palliative care may be provided in a variety of locations. Hence, several characteristics of palliative care begin to emerge in this description.

A more formal definition of 'palliative care' has been set out by the World Health Organization [hereinafter 'WHO']. The WHO defines palliative care as:

> an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[12]

This is the definition of palliative care which will be used throughout this thesis. It is broadly similar to the description set out by Dr. Tony O'Brien and has often been cited by journal articles[13] and reports such as that of the National Advisory Committee on Palliative Care.[14] On this basis, the WHO definition of palliative care is well established and the international acceptance of this definition facilitates use of comparative legal research. It is notable that for a form of care so closely associated with death and dying that neither the description of Dr. Tony O'Brien nor the WHO definition of palliative care referred to the death of a patient. Instead the focus is placed on the 'quality of life' and appropriate pain management for the patient.

The 'Report of the National Advisory Committee on Palliative Care' outlined the characteristics of palliative care. This report highlighted that palliative care 'affirms

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encouraged medicine to be gentler in its acceptance of death, yet some medical services continue to regard death as something to be resisted, postponed or avoided.'

[12] Cecilia Sepúlveda and others, 'Palliative Care: The World Health Organization's Global Perspective' (2002) 24(2) Journal of Pain and Symptom Management 91, 94; See also Health Service Executive, 'Palliative Care Services – Five Year/Medium Term Development Framework' (Health Service Executive 2009) 12; Mary McCarron and others, 'Evaluation of the Programme to Support Palliative and Hospice Care in the Republic of Ireland' (Atlantic Philanthropies 2013) 5.

[13] FEM Murtagh, 'Patterns of dying: palliative care for non-malignant disease' (2004) 4(1) Clinical Medicine 39; Harvey Max Chochinov, 'Dying, Dignity, and New Horizons in Palliative End-of-Life Care' (2006) 56(2) A Cancer Journal for Clinicians 84; Tiny Jaarsma and others, 'Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology' (2009) 11(5) European Journal of Heart Failure 433.

[14] Department of Health and Children, 'Report of the National Advisory Committee on Palliative Care' (Department of Health and Children 2001); Text to n45 in Chapter Two for discussion of the National Advisory Committee on Palliative Care.

life and regards dying as a normal process',[15] 'neither hastens nor postpones death',[16] and 'provides relief from pain and other distressing symptoms'.[17] Overall, the role of palliative care can be summarised as aiming 'to reduce and, if possible, eliminate suffering, and improve the quality of living and dying.'[18] However, palliative care is not a single type of care. Rather, it has different levels of provision. This is reflected in the WHO description of palliative care as an 'approach'.[19] In this regard, palliative care can be provided by way of the palliative care approach, general palliative care or specialist palliative care.

The palliative care approach is the application of the principles of palliative care by 'all health care professionals.'[20] This type of care is not limited by location and concentrates largely on the provision of care based on palliative care principles such as focussing on the quality of life.[21] General palliative care is an 'intermediate level' of palliative care.[22] This level of care is provided by a healthcare professional who has 'additional training and experience in palliative care'[23] but does not specialise in palliative care. The third level is specialist palliative care.

[15] Department of Health and Children (n14) 20; McCarron (n12) 5.
[16] Department of Health and Children (n14) 20; McCarron (n12) 5.
[17] Department of Health and Children (n14) 20; McCarron (n12) 5.
[18] Kieran McKeown and others, 'Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life, Report 5' (Irish Hospice Foundation 2010) 100; Robin Cohen and others, 'Changes in quality of life following admission to palliative care units' (2001) 15(5) Palliative Medicine 363; Annette S Strömgren and others, 'A longitudinal study of palliative care' (2005) 103(8) Cancer 1747; David Casarett and others, 'A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life' (2008) 11(1) Journal of Palliative Medicine 68; Edouard Ferrand and others, 'Circumstances of Death in Hospitalized Patients and Nurses' Perceptions: French Multicenter Mort-a-l'Hôpital Survey' (2008) 168(8) Archives of Internal Medicine 867.
[19] Sepúlveda (n12) 94.
[20] Department of Health and Children (n14) 10; McCarron (n12) 5 'Palliative care principles should be practiced by all healthcare professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.'
[21] Department of Health and Children (n14) 31 'The key principles of the palliative care approach include a focus on quality of life, which includes good symptom control; a holistic approach that takes into account the person's life experience and current situation; care that encompasses both the dying person and those who matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues.'
[22] Department of Health and Children (n14) 32; McCarron (n12) 5.
[23] Department of Health and Children (n14) 32; McCarron (n12) 5.

Specialist Palliative Care

The National Advisory Committee on Palliative Care describe specialist palliative care as 'services whose core activity is limited to the provision of palliative care.'[24] This level of care is provided in settings such as 'specialist palliative care units, hospitals and the community.'[25] Specialist palliative care units refer to healthcare facilities such as hospices, although this is not the only level of palliative care which hospices provide.[26]

The pain management and broader practices associated with specialist palliative care raise the legal and ethical difficulties which this thesis will address.[27] For example, the issue of what constitutes appropriate pain management is a key concern for the first and second central research questions in this thesis. This relates to the provision of palliative sedation and the associated practice of withdrawing artificial nutrition and hydration. The absence of an appropriate legal framework for these practices lends support to arguments that specialist palliative care practices closely resemble euthanasia.

Palliative Medicine

An additional term which arises in the context of end-of-life care is 'palliative medicine'. This has been described as 'the medical component of what has become known as palliative care.'[28] Palliative medicine is a particular aspect of the end-of-life care provided to a terminally ill patient. For the purposes of this thesis, the term palliative medicine will only be used when referring to a report or article which uses this term. In general, the term 'palliative care' or 'specialist palliative care' will be used. The final term to define in this section is 'euthanasia'.

[24] Department of Health and Children (n14) 32; McCarron (n12) 5.
[25] Department of Health and Children (n14) 44.
[26] See pp43-49.
[27] See p44.
[28] Max Watson and others, *Oxford Handbook of Palliative Care* (2nd edn, Oxford University Press 2009) xxviii; McCarron (n12) 5 'Palliative medicine is the appropriate medical care of patients with active, progressive and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the patient's death.'

Euthanasia

The term 'euthanasia' has its origins in the Greek term 'eu thanatos' which means 'good or easy death.'[29] The interpretation of this term has become much more complex and may take several forms. On this point, Keane has noted that 'Euthanasia is another ambiguous term which is often misused.'[30] This may be due to the various ways in which euthanasia can be categorised. For example, euthanasia may be active[31] or passive,[32] and may be voluntary,[33] involuntary[34] or non-voluntary,[35] as well as direct[36] or indirect[37] in nature. The combination of these terms can serve to confuse the discussion in this area.

Black's Medical Dictionary defines 'euthanasia' as 'a deliberate act or omission whose primary intention is to end another person's life.'[38] This simple definition does not discuss the role capacity has in categorising the form of euthanasia or what such an act or omission may entail. For instance, euthanasia may be by way of a lethal

[29] Tony Hope, *Medical Ethics: A Very Short Introduction* (Oxford University Press 2004) 11; Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (Oxford University Press 1997) 4.

[30] Emma Keane, 'Withdrawal of Life Support for Patients in PVS' (2011) 17(2) Medico-Legal Journal of Ireland 83, 92; Sonya Donnelly and Sophia Purcell, 'The evolution of the law on assisted suicide in the United Kingdom and the possible implications for Ireland' (2009) 15(2) Medico-Legal Journal of Ireland 82, 83 'it is necessary to understand the difference between the two concepts of euthanasia and physician assisted suicide which are often mistakenly used interchangeably.'

[31] Otlowski (n29) 5 'a deliberate act to end the life of a terminal or incurable patient, which in fact results in the patient's death.'

[32] ibid 'deliberate withholding or withdrawing of life-prolonging medical treatment or incurable patient, with the object of hastening the patient's death, and as a result dies at an earlier time than he or she would have died, had the treatment been carried out.'

[33] ibid 7 'euthanasia which is performed at the request of the patient. This, in turn, involves an assumption about patient competence and decision-making capacity.'; John Keown, *Euthanasia, Ethics and Public Policy* (Cambridge University Press 2002) 9 'VAE is generally understood to mean euthanasia at the request of the patient'.

[34] Otlowski (n29) 7 'performed without the consent or against the will of a competent patient.'

[35] ibid 'Euthanasia is 'non-voluntary' where it is performed on persons who are incompetent and therefore not capable of giving a consent.'

[36] ibid 8 'direct euthanasia implies that the intended effect of an act, such as the administration of a dose of narcotic, is to cause the patient's death'.

[37] ibid 'the same dose may be administered with the same effect, but the intention is to relieve the patient's suffering rather than to kill the patient.'

[38] Harvey Marcovitch (ed), *Black's Medical Dictionary* (41st edn, A & C Black Publishers 2005) 252; Peter Singer, *Practical Ethics* (2nd edn, Cambridge University Press 1993) 175 'the killing of those who are incurably ill and in great pain or distress for the sake of those killed, and in order to spare them further suffering or distress.'; Lars Johan Materstvedt and others, 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force' (2003) 17(2) Palliative Medicine 97, 98 'A doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request.'

injection, the withdrawal of treatment in certain circumstances, or the provision of drugs which would have the effect of hastening the death of the person.[39]

Physician Assisted Suicide

Physician assisted suicide involves the doctor providing the patient with 'the means to terminate his or her own life but does not act positively to terminate the life of the patient.'[40] In cases of physician assisted suicide the patient is competent to request death and retains the physical ability necessary to commit suicide. As such, it is not the doctor who performs the act which actually ends the patient's life, although, they do assist the patient in committing suicide.

The Objective of Identifying an Appropriate Legal Framework for Specialist Palliative Care in Ireland: Justifications and Limitations

This section will outline why it is necessary to identify an appropriate legal framework for specialist palliative care. First, it will be shown that palliative care is an increasingly prevalent form of care provided to patients in Ireland and it is likely that the number of patients receiving palliative care will continue to increase in the coming years. Second, this section will demonstrate that there is a significant gap in the knowledge in this area as the legal framework in Ireland for specialist palliative care practices has not yet been comprehensively examined in academic material. Discussion of specialist palliative care has largely been from a medical perspective with little discussion of patient rights or the decision-making framework needed for these practices. Third, examining the legal framework and identifying areas of reform is needed to promote certainty for healthcare professionals. This approach also benefits patient care by ensuring that all healthcare professionals are provided with a clear legal and ethical framework in which to practise. The fourth factor to be considered is that in recent years an audit culture has emerged in Irish healthcare but palliative care has only been briefly referred to and many providers of specialist palliative care are excluded from review. However, it is likely that a greater focus will

[39] Bryan A Garner, *Black's Law Dictionary* (9th edn, Thompson/West 2009) 1571 'providing a person with the medical means or the medical knowledge to commit suicide.'

[40] Rosanne O'Connor, 'Physician-Assisted Suicide: The Way Forward?' (2004) 22 Irish Law Times 182, 183; Brian Hunt, *Murdoch's Dictionary of Irish Law* (5th edn, Tottel Publishing 2009) 76-77 [assisted suicide] '… the practice of providing a person with the means of ending their own life, and may include the physical assistance of another person.'

be placed on the legal framework for specialist palliative care practices in the future, particularly given the increase in its use. The final factor to be discussed for undertaking this thesis is the need to distinguish between specialist palliative care practices and euthanasia. The legitimacy of this distinction has often been questioned and is an issue which needs to be addressed in detail as part of identifying an appropriate legal framework.

Palliative care has an increasingly important role in Irish healthcare owing to a variety of factors.[41] Palliative care is a relatively recent development[42] and is being provided to an increasing number of patients near the end of life. In 2006, 4% of deaths occurred in hospices[43] and based on the rise in the number of people dying in hospitals and other healthcare facilities instead of at home,[44] it is likely that the numbers who receive palliative care in the future will continue to rise.[45] This signals the greater medicalisation of the dying process and demonstrates that the legal framework in this area will become increasingly important over the coming years. The National Advisory Committee on Palliative Care suggested that factors such as an ageing population and expected rise in cancer rates would result in an increased use of palliative care services.[46] This underlines the importance of examining the legal

[41] McKeown (n18) 105 'A number of studies have documented how palliative care improves the quality of living and dying for patients with advanced disease.'; Patricia Classens and others, 'Palliative Sedation, Not Slow Euthanasia: A Prospective, Longitudinal Study of Sedation in Flemish Palliative Care Units' (2010) Journal of Pain and Symptom Management 1, 2 'Given that care for patients with life threatening illnesses will become even more important because of an aging population and the subsequent increase in cancer and nonmalignant but chronic incurable disorders … there is a pressing need for reliable information concerning palliative sedation.'

[42] Text to n42 in Chapter Two.

[43] McKeown (n18) 35.

[44] ibid 37; A Eve, AM Smith and P Tebbit, 'Hospice and Palliative Care in the UK 1994-1995, including a summary of trends 1990-1995' (1997) 11 Palliative Medicine 31 cited by David Field and Julia Addington-Hall, 'Extending specialist palliative care to all?'(1999) 48 Social Science and Medicine 1271, 1271 'Nearly one-fifth (17.5%) of cancer patients in the UK now die in a hospice or specialist palliative care unit, and a further 39% die whilst in the care of a palliative home-care team or Macmillan community nurse.'; Ciara McGlade, William Molloy and Suzanne Timmons, 'Decision-Making in Incompetent Older Adults: Clinical, Social and Legal Issues' (2011) 11(2) Medico-Legal Journal of Ireland 70, 74 'The location of death has switched from the home to hospitals and Nursing Homes, with about 20 per cent of deaths in older people occurring in long term care facilities. Dying has become more public, and involves healthcare workers in the decision-making process at the end of life.'

[45] Department of Health and Children (n14) 23-24 Increased use of palliative care is based on an ageing population in Ireland, expected increase in cancer rates, earlier provision of palliative care and greater availability of specialist palliative care services; S Whelan, 'Recent Trends in Mortality and Morbidity in Ireland: Projecting Population Mortality for Ireland' (2008) XXXVII Journal of the Statistical and Social Inquiry Society of Ireland 135.

[46] Department of Health and Children (n14) 11; International Agency for Research on Cancer, 'World Cancer Report 2014' (Bernard Stewart and Christopher P Wild eds, World Health Organization 2014).

framework for specialist palliative care at this time as stresses on the healthcare system will only increase in the future.

Despite the role of palliative care and the legal and ethical issues which are raised by end-of-life care, there has been no substantial legal engagement with specialist palliative care practices in this jurisdiction. This is demonstrated in two ways. First, there are very few cases which have examined specialist palliative care practices. In *Re a Ward of Court*,[47] the withdrawal of artificial nutrition and hydration was discussed but the patient at the centre of this case was in a near persistent vegetative state rather than terminally ill. On this basis, the provision of artificial nutrition and hydration was not a part of specialist palliative care. Nevertheless, *Re a Ward of Court* will be discussed in this thesis as it can provide a degree of clarity as to the legality of this practice. In *Fleming v Ireland & Ors*,[48] the role of palliative care was referred to but the focus of this case was the law against assisted suicide. Furthermore, the discussion of palliative care in *Fleming v Ireland & Ors* highlighted the need for clarity on the legitimacy of and legal framework for specialist palliative care practices.[49] The second factor which demonstrates the gap in knowledge is the absence of academic material addressing the legal framework for specialist palliative care in this jurisdiction. Consequently, the standard of the legal framework remains to be examined and suggestions for reform may need to be advanced. This thesis can therefore contribute significantly to discussion on the legal framework in Ireland for specialist palliative care due to this gap in knowledge. It is from this gap in the knowledge that the research questions stem.

The third justification for identifying an appropriate legal framework for specialist palliative care is the importance that the framework has for healthcare professionals as well as the patient. This thesis argues that the legal framework for specialist palliative care has a considerable impact on the standard of palliative care provided. The value and role of a clear legal framework has been demonstrated by other areas

[47] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.
[48] *Fleming* v *Ireland & Ors* [2013] IEHC 2, [2013] IESC 19.
[49] *Fleming* v *Ireland & Ors* [2013] IEHC 2, [37] Dr. Tony O'Brien commented that 'Professor Battin's view of terminal sedation, involving necessarily the withdrawal of food and hydration, was inconsistent with his experience of the practice of sedation in this jurisdiction.'

of medicine such as the use of genetic materials,[50] and abortion.[51] The background and development of these areas in medicine underlines the importance of having a well-defined legal framework in place which allows healthcare professionals an unambiguous understanding of the type of care which can be provided to the patient. As such, a legal framework should not function to unnecessarily constrain the decision-making autonomy of doctors. Instead, it should provide clarity as to what objects may be pursued and how this can be achieved for the benefit of the terminally ill patient. The challenge of achieving this has been recognised by Quill et al who noted that:

> Similar professional safeguards should be considered for TS (terminal sedation) and VSED (voluntary stopping eating and drinking), even if these practices are already sanctioned by the law. The challenge of safeguards is to be flexible enough to be responsive to individual patient dilemmas and rigorous enough to protect vulnerable persons.[52]

Such an approach may result in a harmonisation of minimum standards of care across healthcare providers. This would be of considerable benefit as over the course of an illness a person will interact with a wide range of healthcare professionals and it is important that the care provided to the patient is at a consistent level and meets clearly identifiable standards. This demonstrates not only how a clear legal framework can be beneficial for healthcare professionals but how it can also benefit the care of the patient.

A high standard of patient care can also be achieved by ensuring that human rights are given effective protection. It is widely accepted in case law that patients have rights which must be protected.[53] This is further evidenced by protection offered by the Irish

[50] The Madden Report on Post Mortem Practice and Procedures (Department of Health and Children 2006); Draft Proposals for General Scheme of the Human Tissue Bill 2009.
[51] Health Information and Quality Authority, 'Investigation into the safety, quality and standards of services provided by the Health Service Executive to patients, including pregnant women, at risk of clinical deterioration, including those provided in University Hospital Galway, and as reflected in the care and treatment provided to Savita Halappanavar' (Health Information and Quality Authority 2013); Protection of Life During Pregnancy Act 2013.
[52] Timothy E Quill, Bernard Lo and Dan W Brock, 'Palliative Options of Last Resort: A Comparison of voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia' in Torbjőrn Tännsjő (ed), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004) 10.
[53] See Chapter Four.

Constitution, domestic legislation, and international legal instruments such as the European Convention on Human Rights and Fundamental Freedoms. Relevant rights include the right to life, right of autonomy, right to bodily integrity, and the protection from inhuman and degrading treatment. In addition, the issue of dignity will also be discussed. It is necessary to examine how these rights along with the principle of dignity are protected and promoted in the context of specialist palliative care. Patient rights should be to the fore in providing effective and appropriate palliative care. This view also has a significant impact on the theoretical framework being utilised in this thesis.[54]

The fourth justification for examining the legal framework in Ireland for specialist palliative care is the audit culture which has emerged in Irish healthcare in recent years. There has been a move towards clearly defined and measurable standards in many areas of patient care. The Health Information and Quality Authority [hereinafter 'HIQA'][55] has responsibility for the audit of hospitals in Ireland and has published standards which healthcare providers are required to meet. However, HIQA has only published one standard in relation to end-of-life care[56] and this is not applicable to hospices.[57] As a result, a significant provider of specialist palliative care in Ireland is excluded from the audit process. Nevertheless, specialist palliative care is provided in a variety of locations other than hospices. This form of care is provided in hospitals, nursing homes, and in community settings. As the audit culture expands it is likely that standards for end-of-life care will be introduced which will place a greater focus on the legal framework for specialist palliative care. As it stands, the Department of Health and Children have recently published a number of reports aimed at addressing and improving paediatric palliative care.[58] This reflects the fact that palliative care for children raises a number of additional issues. However, it was noted earlier that this thesis will not focus on paediatric palliative care due to the additional challenges it

[54] Text to n94.
[55] Text to n192 in Chapter Five.
[56] Health Information Quality Authority, 'National Quality Standards for Residential Care Settings for Older People in Ireland' (Health Information Quality Authority 2008) standard 16.
[57] ibid 5-6; Select Committee on Health and Children Deb 7 March 2007, <http://debates.oireachtas.ie/HES/2007/03/07/00004.asp> accessed 8 June 2014. Minister for Health, Mary Harney, stated 'We are not providing for an inspectorate of the acute and palliative care sectors for the very good reason that these areas require a different form of expertise.'
[58] Department of Health and Children and the Irish Hospice Foundation (n6); Department of Health and Children (n6).

raises but will instead concentrate on the legal framework for specialist palliative care for adults.[59]

The fifth justification for undertaking this thesis is the need to clearly distinguish specialist palliative care practices from euthanasia. The majority of palliative care practices do not raise significant legal or ethical considerations. This is not the case for the provision of palliative sedation and the practice of withdrawing artificial nutrition and hydration from the patient. The regulation and standard of professional guidance in this area is particularly important due to the combination of different palliative care providers and the legally, ethically, and medically complex decisions which have to be made in relation to these palliative care practices by doctors and nurses. Consequently, it is necessary to have a complete picture of the current legal framework. The legitimacy of the distinction between specialist palliative care practices and euthanasia has often been called in to question, for example, it has been argued that palliative sedation is euthanasia in disguise.[60] In a similar vein, Boyle commented that 'some may accept terminal sedation but regard efforts to distinguish it from euthanasia to be sleight of hand'.[61] The basis for such suggestions will be outlined in Chapter Two and Chapter Three. This chapter structure ensures the legality of specialist palliative care practices is firmly established prior to discussing professional standards and guidelines for specialist palliative care.

The importance of examining specialist palliative care practices has been recognised by Quill et al. who commented that 'hidden, ambiguous practices, inconsistent justifications, and failure to acknowledge the risks of accepted practices may also undermine the quality of terminal care and put patients at unwarranted risk.'[62] This thesis will unpack the criticism of these practices. It will also identify and examine the impact of the current legal framework. It is necessary to highlight that this thesis does not examine the morality of specialist palliative care practices but focuses upon the legal framework for these practices. Therefore, this thesis does not examine arguments

[59] See p3.
[60] Magna Andreen Sachs, 'Sedation – Unconsciousness – Anaesthesia! What are we Talking About?' in Tännsjő (n52) 31; Emily Jackson and John Keown, *Debating Euthanasia* (Hart Publishing 2012).
[61] Joseph Boyle, 'Medical Ethics and Double Effect: The Case of Terminal Sedation' (2004) 25 Theoretical Medicine 51, 55.
[62] Quill (n52) 11.

raised around palliative sedation such as the effect this practice may have on the patient-doctor relationship.[63] While identifying an appropriate legal framework for specialist palliative care is the central objective in this thesis, an accompanying goal is to ensure that the proposed legal framework is workable in practice. This thesis has adopted strategies to ensure that the reforms which are proposed here hold a real prospect of yielding practical improvements in specialist palliative care. First, this thesis remains cognisant of patient rights. Rights serve as a foundation for the legal framework and, at a minimum, must be protected by the healthcare professional. Second, it adopts a multi-faceted methodology in order to fully assess the legal framework for specialist palliative care.

Theoretical Framework and Methodological Approach

The theoretical framework adopted in this thesis is based on biomedical ethics. In particular, the four principles approach as advanced by Beauchamp and Childress will be utilised.[64] Ethics have a substantial role in the practice of medicine and are often relied on by healthcare professionals in guiding day-to-day practice. The use of the four principles set out by Beauchamp and Childress also informs the methodology employed in this thesis. The methodological approach involves doctrinal and comparative legal research. Both of these approaches provide insight into the way a legal framework impacts on the provision of specialist palliative care. The combination of this theoretical framework and methodological approach will provide an effective approach to answering the central research questions posed in this thesis.

Theoretical Framework: Biomedical Ethics

The legal framework in Ireland for specialist palliative care will be examined through the lens of biomedical ethics. Madden describes biomedical ethics as 'the application of ethical principles to the biological sciences, medicine and health care.'[65] This underlines the utility of biomedical ethics for this thesis. This is due in part to the practical nature of identifying an appropriate legal framework which protects human rights and provides clarity and consistency for healthcare professionals. For example,

[63] Alisdair MacLean, 'Autonomy, Consent and Persuasion' (2006) 13 European Journal of Health Law 321.
[64] Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013).
[65] Deirdre Madden, *Medicine, Ethics and the Law* (2nd edn, Bloomsbury 2011) 42.

a central research question of this thesis seeks to distinguish between specialist palliative care practices and physician assisted suicide and euthanasia primarily on a practical level rather than basing a distinction on abstract moral reasoning alone. Furthermore, Madden outlined three reasons which support the role of medical ethics in 'the practice of medicine, and … to any understanding of medical law'.[66]

The first reason set out by Madden is that many healthcare professionals consult ethics instead of law when looking for guidance in making a decision.[67] The second reason is that 'some legal principles have been influenced by the evolution of ethical principles'.[68] The third reason in support of the role of medical ethics is that in Ireland the development of medical law is at an early stage 'with relatively sparse legislation and few judicial precedents.'[69] These points underline the significant role which ethics have in examining the current legal framework for specialist palliative care. Nonetheless, the examination of bioethics is not the primary focus of this thesis. Biomedical ethics can be interpreted in a variety of ways. For example, alternate approaches to biomedical ethics have been set out by Downie and Calnan,[70] Engelhardt,[71] Veatch,[72] and Macer.[73] However, in considering the application of biomedical ethics to issues in specialist palliative care this thesis will utilise the principles-based approach as espoused by Beauchamp and Childress.[74]

The interpretation developed by Beauchamp and Childress is based on respect for autonomy, nonmaleficence, beneficence, and justice. This is known as the four principles approach and 'is generally regarded as the origin of the principles-orientated

[66] ibid 41.
[67] ibid.
[68] ibid.
[69] ibid.
[70] Robert Silcock Downie and Kenneth Charles Calman, *Healthy Respect: Ethics in Health Care* (2nd edn, Oxford University Press 1994); Madden (n65) 44 The approach advanced by Downie and Calman is based on 'utility, justice, non-maleficence, compassion (benevolence) and self-development', governed by the principle of 'respect for the autonomous individual' as the consensus principles'.
[71] H Tristram Engelhardt, *The Foundations of Bioethics* (2nd edn, Oxford University Press 1996) The relevant principles according to Engelhardt are principles of 'permission' and 'beneficence'.
[72] Robert M Veatch, 'Theories of Bioethics' (4th World Congress of Bioethics, Japan 1998) Principles of right actions recognized by Veatch are utility, veracity, fidelity to promises, avoid killing, justice and autonomy.
[73] Madden (n65) 44 'Macer argued that love should be foundation of bioethics in the form of "self-live [sic] (autonomy), love of others (justice), loving life (do no harm), and loving good (beneficence).'
[74] Beauchamp (n64).

bioethics method in Western societies.'[75] Beauchamp and Childress have suggested that the purpose of these principles is to 'function as general guidelines for the formulation of the more specific rules.'[76] In this regard, the principles outlined by Beauchamp and Childress have been utilised by the Irish Association of Palliative Care in their discussion paper on palliative sedation.[77] In the discussion paper, the Irish Association of Palliative Care cited the principles of beneficence, nonmaleficence, and autonomy as the 'Ethical Principles Involved'[78] in palliative sedation. This discussion paper provides an example of how these principles can be expanded on for the formulation of more specific guidance. This is an example of specification which is 'a methodological tool that adds content to abstract principles, ridding them of their indeterminateness and providing action-guiding content for the purpose of coping with complex cases.'[79] The process of specification is necessary 'in order to achieve more concrete guidance',[80] and to develop 'rules with action-guiding content.'[81] As such, when the four principles are correctly applied they serve as much more than 'names, checklists, or headings for values worth remembering'.[82]

The specification of the four principles may be 'shaped by empirical data and by information available in fields such as medicine, nursing, public health, … law'.[83] Therefore, this thesis draws on doctrinal and comparative legal research as a means by which to examine and specify the application of the four principles to specialist palliative care. This approach takes account of the challenges facing healthcare professionals and identifies the human rights of most relevance for this form of care.

Criticism of the principles-based approach has stemmed from the suggestion that there is a lack of clear guidance from the four principles which means that moral agents are

[75] Madden (n65) 44.
[76] Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (6th edn, Oxford University Press 2008) 12; Beauchamp (n76) 13 'Principles do not function as precise guides to action that direct us in each circumstance in the way that more detailed rules and judgments do.'
[77] Irish Association of Palliative Care, 'Palliative Sedation' (Irish Association of Palliative Care 2011).
[78] ibid.
[79] Tom L Beauchamp, 'Making Principlism Practical: A Commentary on Gordon, Rauprich, and Vollmann' (2011) 25(6) Bioethics 301, 301.
[80] Beauchamp (n64) 17.
[81] ibid 17.
[82] ibid 394.
[83] ibid 10.

free to address problems in whatever way they choose. [84] Based on this view, moral agents assign principles 'whatever weight they wish, or even no weight at all.'[85] In responding to this criticism, Beauchamp and Childress note that 'Any norm, principle, or rule will have this problem if it is underspecified for the task at hand.'[86] This highlights the need for the four principles to be comprehensively specified so as to minimise subjective specification and balancing.[87]

A further criticism of the four principles is that they are regularly in conflict and that the approach outlined by Beauchamp and Childress 'is too indeterminate to provide a decision procedure to adjudicate the conflicts.'[88] Moreover, it was argued by Holm that methods to specify and balance the four principles are 'inadequate.'[89] This criticism stems from the lack of 'an organizing meta-principle … that decides which of the four principles or particular specifications should prevail when people are faced with a deep moral conflict'.[90] However, Vollmann suggests that reference to the common morality is a way by which the specifications can be organised.[91] Common morality is composed of rules of obligation,[92] virtues,[93] and human rights.[94] These are to be drawn on as part of the specification and balancing of the four principles.[95] In particular, the positive and negative obligations required under human rights will be

[84] ibid 394; K Danny Clouser and Bernard Gert, 'A Critique of Principlism' (1990) 15 The Journal of Medicine and Philosophy 219.
[85] Beauchamp (n64) 394.
[86] ibid 395.
[87] ibid 20 'Balancing is the process of finding reasons to support beliefs about which moral norms should prevail. Balancing is concerned with the relative weights and strengths of different moral norms, whereas specification is concerned primarily with their scope (i.e., range).'
[88] ibid 394; Clouser (n84).
[89] Søren Holm, 'Not just autonomy – the principles of American biomedical ethics' (1995) 21 Journal of Medical Ethics 332, 332.
[90] John-Stewart Gordon, Oliver Rauprich and Jochen Vollmann, 'Applying the Four-Principle Approach' (2011) 25(6) Bioethics 293, 298.
[91] ibid 299 'Of course, we do not hold the view that common morality is able to provide a unique correct answer, but it can be seen as a constraining framework that, first, separates ethical from unethical answers, and secondly, indicates which ethical answer seems more appropriate with regard to the ideal of common morality without saying that this is the only correct available answer.'; Beauchamp (n64) 164.
[92] Beauchamp (n64) 3. Examples of rules of obligation listed by Beauchamp and Childress are: '(1) Do not kill, (2) Do not cause pain or suffering to others, (3) Prevent evil or harm from occurring, (4) Rescue persons in danger, (5) Tell the truth, (6) Nurture the young and dependent, (7) Keep your promises, (8) Do not steal, (9) Do not punish the innocent, and (10) Obey just laws.'
[93] ibid Examples of virtues listed by Beauchamp and Childress are: '(1) nonmalevolence, (2) honesty, (3) integrity, (4) conscientiousness, (5) trustworthiness, (6) fidelity, (7) gratitude, (8) truthfulness, (9) lovingness, and (10) kindness.'
[94] ibid 4.
[95] ibid 'An undue emphasis on any one of these areas disregards the full scope of the common morality.'

analysed in Chapter Four. These human rights will serve as the foundation for suggestions for reform later in this thesis. Overall, this highlights how the four principles require careful analysis and development in order to establish more specific guidance.

Despite the existence of such criticism, the four principles are a suitable theoretical framework for this thesis. For example, the principles-based approach can and has been applied in the context of double effect,[96] the withdrawal of artificial nutrition and hydration,[97] and can be specified for specialist palliative care practices.[98] Gillon argued that the four principles 'help us bring more order, consistency and understanding to our medico-moral judgments'.[99] This underlines the impact which this theoretical framework can have on the legal framework for specialist palliative care. The four principles will be referred to throughout the thesis but they will be briefly outlined at this point. This will demonstrate their meaning and relevance for examining the legal framework in Ireland for specialist palliative care and, at a later stage, in formulating suggestions for reform.

Nonmaleficence establishes an obligation 'to abstain from causing harm to others.'[100] This principle provides guidance on justifications such as double effect and the acts and omissions distinction. These are important factors in distinguishing between specialist palliative care practices and euthanasia. A closely related principle is that of beneficence. This requires a person to 'act for the benefit of others.'[101] The principle of beneficence establishes an 'obligation to help others further their important and legitimate interests.'[102] In the context of specialist palliative care the principle of beneficence requires attentive monitoring of the patient's condition as well as ensuring effective pain management and symptom control is provided. Beauchamp and Childress have noted several ways in which rules of beneficence are different from rules of nonmaleficence. In this regard, they comment that rules of nonmaleficence

[96] ibid 164.
[97] ibid 177.
[98] Irish Association of Palliative Care (n77).
[99] Raanan Gillon, *Philosophical Medical Ethics* (John Wiley & Sons 1986) viii.
[100] Beauchamp (n64) 149.
[101] ibid 203.
[102] Irish Association of Palliative Care (n77).

are 'negative prohibitions of actions',[103] 'must be followed impartially',[104] and lastly they 'provide moral reasons for legal prohibitions of certain forms of conduct.'[105] In contrast to this, rules of beneficence set out 'positive requirements of action',[106] 'need not always be followed impartially',[107] and in general they 'do not provide reasons for legal punishment when agents fail to abide by them.'[108] The meaning of nonmaleficence and beneficence will be outlined fully as part of the examination of specialist palliative care practices.

The principle of justice as advanced by Beauchamp and Childress is based on 'recognition of global rights to health and enforceable rights to a decent minimum of health care within a framework for allocation that incorporates both utilitarian and egalitarian standards.'[109] This position may lead to conflict between the principles of beneficence and justice. As such, there is a degree of balancing between these principles in practice. The principle of beneficence also comes into conflict with the principle of autonomy in certain circumstances due to paternalistic elements present in beneficence.

The principle of autonomy relates to 'self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding.'[110] Respect for autonomy is a significant issue in this thesis as it impacts on the decision-making framework for specialist palliative care along with the respect given to advance care directives and do not resuscitate orders. The principle of autonomy is essential for ensuring that a patient is allowed to make decisions in relation to their medical treatment. However, this principle may result in conflict between the autonomy of the healthcare professional and the autonomy of the patient. Specialist palliative care raises complex legal and ethical issues in relation to the care of a patient and it is important that an appropriate balance is identified and

[103] Beauchamp (n64) 204.
[104] ibid.
[105] ibid.
[106] ibid.
[107] ibid.
[108] ibid.
[109] ibid 293.
[110] ibid 101; Raanan Gillon, 'Medical ethics: four principles plus attention to scope' (1994) 309(6948) British Medical Journal 184, 185 'the moral obligation to respect the autonomy of others in so far as such respect is compatible with equal respect for the autonomy of all potentially affected.'

established for this form of healthcare. The current legal framework in place for specialist palliative care and possibilities for reform will be recognised through a combination of the theoretical framework and methodology utilised in this thesis.

Methodology

The research methodologies employed in this thesis will be set out and their selection will be justified in this section. The potential strengths and weaknesses of each approach will be outlined, as will the way in which each advances the understanding of the current legal framework for specialist palliative care. This thesis will utilise doctrinal and comparative legal research. The use of these methodologies will be informed by the theoretical framework set out above. The types of methodology used combine to identify the existing legal framework in Ireland as well as the framework which has developed in jurisdictions such as the Netherlands. Furthermore, their use also assists in identifying suggestions for reform.

Doctrinal Analysis

Doctrinal analysis will serve to identify and examine the current legal framework for specialist palliative care. This will be achieved by using both an internal and an external approach to doctrinal research. The internal approach to doctrinal research concentrates on 'statutes and decided cases, supplemented where possible with lawyers' literature expounding the rules and occasionally reflecting on them.'[111] This type of analysis is not merely descriptive of the law but also has the effect of demonstrating 'the multiple possible readings and contradictions of existing "law"'.[112] The benefit of this is demonstrated by later chapters when the legitimacy of the distinction between specialist palliative care practices and euthanasia and physician assisted suicide is considered. In addition to case law and legislation, the internal approach to doctrinal research also focuses on the use of authoritative texts. The advantage of this is that a broader range of sources can be drawn on. Nevertheless, the internal approach offers a narrow view of the law and in order to appreciate the complexity of the legal framework for specialist palliative care it is necessary to couple this internal viewpoint with the external approach.

[111] David Ibbetson, 'Historical Research in Law' in Peter Cane and Mark Tushnet (eds), *The Oxford Handbook of Legal Studies* (Oxford University Press 2003) 863, 864.
[112] ibid.

The external approach to doctrinal research provides a study of 'the law in practice, of legal institutions at work in society rather than legal rules existing in a social, economic and political vacuum'.[113] This approach to doctrinal analysis is especially important in the context of specialist palliative care due to the lack of legislation and case law in Ireland on this form of care. Consequently, the coupling of an internal and external approach to doctrinal research has the potential to offer a rounded approach to the examination of the legal framework in Ireland for specialist palliative care. The success of this depends on understanding how the internal and external approaches merge to form the legal framework for specialist palliative care.

The interpretation of the combined internal and external approaches to doctrinal research has been described as an 'attempt to draw out the patterns of normative understanding that enable us to see the wood and the trees together as constituting a working whole.'[114] In undertaking such an approach to doctrinal research it is important to be aware of any bias towards a particular viewpoint which may begin to emerge from primary, secondary or other resources. It is also necessary to take account of the theoretical framework when utilising doctrinal analysis. For example, Morris and Murphy suggest that in certain cases doctrinal analysis is 'based on the idea that the law is underpinned (or should be) by a particular moral or political philosophy and therefore needs to be analysed in light of its closeness to the ideal situation.'[115] In this thesis, the legal framework will be examined for how it satisfies the principles of autonomy, nonmaleficence, beneficence, and justice as outlined by Beauchamp and Childress. A thesis with a significant doctrinal element 'would not argue that the law needs reform because it is inconsistent with wider social values or is unfair to a sector of society, but because it is vague, or is inconsistent, and thus leads to uncertainty in its application.'[116] In any case, the use of doctrinal research allows for the clear identification of the legal framework in Ireland for specialist palliative care.

[113] ibid 864.
[114] Christopher McCrudden, 'Legal Research and the Social Sciences' (2006) 122 Law Quarterly Review 632, 634.
[115] Caroline Morris and Cian Murphy, *Getting a PhD in Law* (Hart Publishing 2011) 31.
[116] ibid.

Comparative Legal Research

Comparative legal research is the second research methodology used in this thesis. Kamba defined comparative legal research as 'the study of, and research in, law by the systematic comparison of two or more legal systems; or of parts, branches, or aspects of two or more legal systems.'[117] The use of comparative legal research provides a tool for identifying the advantages and disadvantages of an approach taken in another jurisdiction. The benefit of drawing on comparative legal research is well summarised by Zweigert who wrote:

> the different systems of the world can offer a greater variety of solutions than could be thought up in a lifetime by even the most imaginative jurist who was corralled in his own system. Comparative law is an 'école de vérité' which extends and enriches the 'supply of solutions' and offers the scholar of critical capacity the opportunity of finding the 'better solution' for his time and place.[118]

This underscores the significant benefits of drawing on comparative research. However, this methodology will not be used until specialist palliative care practices have been fully outlined. This ensures a focussed approach to comparative legal research. As Valcke commented, 'comparatists cannot begin their work without first circumscribing that which is to be compared, the distinct wholes between which the comparison is to take place.'[119] Furthermore, in order to make effective use of this methodology this thesis will follow the steps set out by Kamba. These include the 'descriptive phase',[120] 'identification phase',[121] and 'explanatory phase'.[122]

Kamba suggests that the 'descriptive phase' may involve 'a description of the norms, concepts and institutions of the systems concerned or it may consist in the examination of the socio-economic problems and the legal solutions provided by the systems in

[117] WJ Kamba, 'Comparative Law: A Theoretical Framework' (1974) 23(3) International and Comparative Law Quarterly 485, 486.
[118] Konrad Zweigert and Hein Kötz, *An Introduction to Comparative Law* (3rd edn, Clarendon Press 1998) 15.
[119] Catherine Valcke, 'Comparative Law as Comparative Jurisprudence: The Comparability of Legal Systems' (2004) 52(3) The American Journal of Comparative Law 713, 718.
[120] Kamba (n117) 511.
[121] ibid 511-512.
[122] ibid 512.

question.'[123] This thesis will set out both the institutions involved as well as the legal solutions identified due to their close relationship in specialist palliative care. Such an approach is necessary in order to achieve a holistic analysis of other jurisdictions. The 'identification phase' focuses on the 'identification or discernment of differences and similarities between the systems under comparative consideration.'[124] It is important to go further than just outlining another legal system and for this reason it is necessary to explain the 'differences and similarities' which are highlighted.[125] Accordingly, the third stage is the 'explanatory phase' in which 'the divergences and resemblances are accounted for.'[126] This ensures that comparison is not undertaken at a purely surface level. On this basis, the broader elements and influences on the legal framework in each jurisdiction will be taken into account. These are the steps which will be followed in this thesis but there are other considerations to be factored in for effective comparative research.

Kamba sets out a number of questions to evaluate the effectiveness of engaging in comparative research. These included whether the research served to 'promote the better understanding of one's own law, the formulation of reliable theories of law, the promotion of law reform'[127] and whether the comparative legal research can be 'safely depended on as accurate'.[128] The careful selection of jurisdictions for comparative research and an awareness of the problems which may arise mean that comparative research can be conducted effectively for the purposes of the thesis.

Comparison will mainly be made with the legal framework for specialist palliative care in the Netherlands. Among the reasons for considering the Dutch approach is that they have established clear and comprehensive professional standards for the provision of specialist palliative care rather than introducing legislation. These are standards which have been reviewed, revised and published in English which greatly assists a comparative law approach. In addition to this, the Netherlands publishes

[123] ibid 511.
[124] ibid 512.
[125] Esin Őrűcű, 'Methodology of comparative law' in Jan M Smits (ed), *Elgar Encyclopedia of Comparative Law* (Edward Elgar Publishing 2006) 449 'Yet comparative inquiry should not end at description, but move on into explanation where the real comparison starts, and then, on into confirmation of findings.'
[126] Kamba (n117) 512.
[127] ibid.
[128] ibid.

reports on end-of-life care which provide information on the impact of palliative care guidelines and the wider healthcare system. Furthermore, exceptions allowing for voluntary active euthanasia exist in very few countries and of these the Netherlands is the most appropriate jurisdiction to examine. This is due to the legislation on euthanasia in the Netherlands and the case law which allows for a greater understanding of what the limits of the legislation are. An examination of this jurisprudence demonstrates the impetus behind the introduction of the legislation. The combination of legislation and case law provides a rounded picture of this practice and is necessary in order to accurately examine the legitimacy of the distinction between specialist palliative care practices and euthanasia.

The challenges presented by engaging in comparative legal research need to be highlighted to ensure that they are avoided in this thesis. Potential failings include comparison of widely different legal systems and a lack of consideration for the differing political, social, economic and cultural differences between the countries.[129] These are significant factors to bear in mind given the social and ethical issues raised by specialist palliative care. A further problem when engaging in comparative research is a potential over-emphasis on the positive aspects of another jurisdiction. This challenge could be linked to the potential for 'legocentric' bias[130] when identifying suggestions for reform. Legocentric bias means that 'law is treated as a given and a necessity, as the natural path to ideal, rational or optimal conflict resolutions and ultimately to a social order guaranteeing peace and harmony.'[131] This thesis avoids the issue of legocentrism as it does not presuppose that legislation is the solution. Instead, it first identifies whether there are weaknesses in the current legal framework and this thesis is open to considering solutions for reform beyond the introduction of legislation. A further challenge in utilising comparative legal research is the need to recognise that certain functions may be achieved not through a particular legal rule but by way of an extra-legal norm of practice. These factors will be kept in mind when utilising comparative legal research and will be referred to as a benchmark for Chapter Six.

[129] ibid 511.
[130] Peer Zumbansen, 'Comparative Law's Coming of Age? Twenty Years after Critical Comparisons' (2005) 6(7) German Law Journal 1073, 1075; Gűnter Frankenberg, 'Critical Comparisons: Re-thinking Comparative Law' (1985) 26(2) Harvard International Law Journal 411, 445.
[131] Frankenberg (n130) 445.

Structure of Thesis

This thesis is divided into seven chapters. These chapters utilise the theoretical framework and methodologies outlined in the previous section to build a cohesive argument and to draw out the reforms which are necessary to ensure appropriate specialist palliative care can be provided in this jurisdiction. This section will outline the evolution of the argument in this thesis and demonstrate how chapters build to examine the current legal framework and identify an appropriate legal framework for specialist palliative care.

Chapter two of the thesis provides an introduction to palliative care. The purpose of this Chapter is to outline the challenges which arise in the provision of specialist palliative care. In effect, this Chapter will provide a roadmap for the discussion to take place in later chapters of the thesis. The first point this Chapter will address is the development of palliative care, which requires discussion of the historical origins of palliative care. It is also necessary to identify the illnesses and symptoms for which palliative care may be provided. The identification of palliative care patients assists in highlighting issues which will be addressed in later chapters such as challenges of respecting patient autonomy, access to appropriate palliative care, and the need to respect the dignity of the patient. Additionally, this Chapter will set out the main providers of palliative care. In particular, issues of consistency and the relationship between providers of palliative care will be considered. The final issue this Chapter will address is the practices associated with specialist palliative care. In particular, this chapter will focus on palliative sedation and artificial nutrition and hydration due to the legal and ethical issues they raise. In short, the second Chapter provides an overview of palliative care and establishes the importance of this topic.

Chapter Three examines the legitimacy of the distinction between specialist palliative care practices and physician assisted suicide, and euthanasia. This will be achieved by focussing on the distinction first from the doctors' perspective. The reason for focussing on the potential role of the doctor is due to comparison with palliative care practices which emphasised the role of the doctor. In taking this approach it is necessary to set out what physician assisted suicide and euthanasia entail, thereby clarifying the role of the doctor in such practices. The Chapter does this by drawing,

in particular, on the Dutch experience in order to provide a practical example of euthanasia in operation and to help identify points of similarity and points of departure between this practice and specialist palliative care practices.

The forms of sedation administered by the healthcare professional along with the possible withdrawal of artificial nutrition and hydration in palliative care has led to suggestions that it is a form of euthanasia.[132] A necessary step in addressing this criticism is to consider the *Criminal Law (Suicide) Act 1993* and *Criminal Justice Act 1964*. This will demonstrate the illegality of assisted suicide and euthanasia and provides another way in which to examine the legitimacy of the distinction between these practices and specialist palliative care. Following this, it is necessary to examine the justification provided by the doctrine of double effect as well as the acts and omissions dichotomy. These concepts relate to the form and level of treatment which may be administered by the healthcare professional. Overall, this ensures a rounded approach to examining the legitimacy of the distinction between assisted suicide, euthanasia, and specialist palliative care practices.

Chapter Four examines the rights of the patient which are particularly pertinent for the provision of specialist palliative care. Considering the rights of the patient and how these rights have been interpreted allows for a greater appreciation of the legal issues in specialist palliative care practices. In particular, the right to bodily integrity, protection from inhuman or degrading treatment, the right of autonomy, and the concept of dignity will be discussed. The focus is placed on these rights as they have formed the central arguments in cases which address end-of-life care such as *Re a Ward of Court*[133] and *Fleming v Ireland & Ors*.[134] There are several reasons for concentrating on the rights of the patient. First, human rights are fundamental under the Irish Constitution and the European Convention on Human Rights and are therefore a central part in providing an appropriate legal framework for specialist palliative care. Second, it allows for the examination of the legitimacy of the distinction between euthanasia and specialist palliative care practices from the

[132] Text to n178 and n179 in Chapter Two.
[133] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.
[134] *Fleming v Ireland & Ors* [2013] IEHC 2, [2013] IESC 19.

patient's perspective. The Chapter achieves this by drawing on the case law and legislation discussed in Chapter Three. This method also demonstrates a third reason for concentrating on the rights of the patient in that it assists in identifying the legal framework which currently exists for specialist palliative care practices in Ireland. Therefore, discussion of human rights also serves to define the common morality as set out by Beauchamp and Childress.[135] The common morality is an important element in guiding the specification and balancing of the four principles. In addition to this, identifying the current legal framework for specialist palliative care allows for any failure to adequately protect patient rights to be highlighted. It also serves to identify the limits of what a patient may request in terms of their medical treatment and care. These limits impact on the provision and withdrawal of specialist palliative care practices such as palliative sedation and artificial nutrition and hydration. Consequently, it will be demonstrated that the rights of the patient occupy a central role in the provision of palliative care and it is vital that the appropriate respect be given to these rights.

Chapter Five addresses the existing regulatory framework in place for specialist palliative care. The aim of this Chapter is to examine the legislation and guidance that currently exists in Ireland for specialist palliative care. In so doing, the Chapter will demonstrate the lack of national, detailed, and clearly applicable guidance. It will highlight that guidance in respect of specialist palliative care is being drawn from a range of different sources. This results in a piecemeal approach and fails to provide a suitable framework for consistent decision making. Chapter Five is divided into three main sections. The first and second section set out legislation relevant to palliative care. There is no legislation which directly addresses its provision and for this reason it is necessary to consider a broad range of legislation which may have an impact on palliative care. This includes legislation establishing HIQA as well as legislation establishing the Irish Medical Council and An Bord Altranais (Nursing and Midwifery Board of Ireland). The guidance issued by these bodies will also be considered as they serve to establish a base line for the practice of palliative care by doctors and nurses in Ireland. The third section will discuss the guidance issued by organisations involved in the promotion of palliative care. Guidance developed by the Irish Association of

[135] Beauchamp (n64) 4.

Palliative Care and the European Association of Palliative Care will be considered for their potential to impact on the development of local policy by Irish palliative care providers.

Chapter Six will examine the regulation of palliative care in the Netherlands. The aim of this is to assist in identifying an appropriate legal framework for specialist palliative care. The development of palliative care in the Netherlands will be outlined so as to provide greater context for the use of comparative legal research. This not only establishes the motivation behind the current system of regulation but also highlights the range and structure of palliative care provided in the Netherlands. This Chapter will also examine the Dutch guidelines for palliative care. In particular, the guidelines of the Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association) and Vereniging Integrale Kankercentra (Association of Comprehensive Cancer Centres) will be discussed in detail.

Chapter Seven provides the conclusion to this thesis. This Chapter reviews the main arguments raised in the course of the thesis and makes recommendations for possible future directions for the law in this area.

Conclusion

This thesis addresses a complicated and important issue which has, up to this point, been largely overlooked in the Irish legal system. Over the course of several chapters this thesis will uncover the legal and ethical issues raised by specialist palliative care practices and, in doing so, will provide much needed clarity on the legal framework for these practices. As part of this, it is necessary to not only recognise the strengths but also the failings in the current legal framework and propose suggestions for reform accordingly. Although it raises many legal and ethical issues, it is submitted that palliative care is a legitimate facet of medical care and thus requires regulation. As Francis Bacon wrote, 'I esteem it the office of a physician not only to restore health, but to mitigate pains and dours; and not only when such mitigation may conduce to recovery, but when it may serve to make a fair and easy passage.'[136]

[136] Francis Bacon, *The Advancement of Learning* (GW Kitchin ed, JM Dint and Sons 1973) 114. These comments were made at a time when palliative care had not yet developed and were directed at the practice of euthanasia. Nonetheless, these comments can be applied to the current role of the healthcare professional in providing a terminally ill patient with the appropriate level of palliative care.

THE DEVELOPMENT AND PRACTICE OF PALLIATIVE CARE IN IRELAND

Introduction

This Chapter outlines the practice of palliative care and highlights the challenging and controversial aspects of palliative care which will be examined over the course of this thesis. This Chapter is composed of three main sections which will discuss the development and practice of palliative care in general and as it is currently provided in Ireland. The historical development of palliative care will be discussed in the first section. This discussion will consider the origins of palliative care and the organisations which have led to the promotion and provision of palliative care. It will be demonstrated that representative bodies and non-governmental organisations have made a significant contribution to the development of palliative care in Ireland. Representative bodies in palliative care aim to promote palliative care and are generally composed of people who work, research, or have an interest in the provision of palliative care. This section will therefore draw attention to the fragmented state involvement in the development and regulation of this area of healthcare.

The development of palliative care will be further outlined by reference to reports on palliative care in Ireland, namely the 'Report of the National Advisory Committee on Palliative Care'[1] and the 'Programme to Support Palliative and Hospice Care in the Republic of Ireland'.[2] Examining the content of these reports reveals the manner in which the provision of palliative care has evolved over the years. These reports also draw attention to some of the main challenges facing palliative care in Ireland. A significant shift in the development of palliative care is that this form of care is no longer limited to the cancer patient. Instead, it is now of broad applicability and has a correspondingly important role in the Irish healthcare system. On this point, it is necessary to outline the types of illness for which palliative care may be provided. Different illnesses raise certain unique problems but over the course of this section key overlapping challenges to the provision of palliative care will be identified.

[1] Department of Health and Children, 'Report of the National Advisory Committee on Palliative Care' (Department of Health and Children 2001) 21.
[2] Mary McCarron, and others, 'Evaluation of the Programme to Support Palliative and Hospice Care in the Republic of Ireland' (Atlantic Philanthropies 2013).

The main providers of palliative care in Ireland are considered in the second section of this Chapter. Hospices, acute general hospitals and the provision of palliative care in a community setting will be discussed. The discussion of these providers will demonstrate the growth in palliative care and it raises the question of whether the current legal framework in Ireland for specialist palliative care is appropriate given the breadth of palliative care providers and the practices which occur. This section also lends further weight to the argument that palliative care has largely developed through the actions of representative bodies and non-governmental organisations rather than being driven by state led initiatives.

The third section provides an introduction to specialist palliative care practices. The focus here is on palliative sedation and artificial nutrition and hydration given the legal and ethical issues which they raise. This section will highlight the controversy surrounding these practices and will demonstrate the importance of examining the legal framework for their provision. For instance, these practices represent a substantial part of specialist palliative care and it is important for both the patient and the healthcare professional that the legal framework is clear, consistent, and protects the patient's human rights. The combination of these three sections provides a rounded introduction to the development and practice of palliative care in Ireland as well as highlighting the legal and ethical issues which later chapters will address.

The Development of Palliative Care

The development of palliative care as a distinct form of care was closely linked to care of the cancer patient.[3] This becomes clear in considering the background to the early providers of end-of-life care such as hospices. The word 'hospice' is derived from the Latin word 'hospes' which translates as host, guest or stranger.[4] Accordingly, between the 11th and 18th Century the term hospice referred to 'a place of shelter for pilgrims

[3] David Clark, 'From margins to centre: a review of the history of palliative care in cancer' (2007) 8 Lancet Oncology 430, 430 'This worldwide development of palliative care is deeply rooted in the specialty of oncology, which has shaped the conceptual model of palliative care, produced some of its major leaders and innovators, and provided a population of patients with the obvious potential to benefit from a new approach to the management of those with advanced disease.'

[4] JRV Marchant and Joseph F Charles, *Cassell's Latin Dictionary (Latin-English and English-Latin)* (Cassell and Company 1948) [hospes] 254; Michael de Vaan, *Etymological Dictionary of Latin and the other Italic Languages* (Brill 2008) [hospes] 291.

and travellers.'[5] This understanding of the term began to change when in 1842 Mme Jeanne Garnier founded the Dames de Calaire in Lyon which provided end-of-life care.[6] In Ireland, hospices were opened in Cork and Dublin in the 19th century. Marymount Hospice in Cork opened in 1870 and originally cared for cancer and tuberculosis patients.[7] In 1879, the Congregation of the Religious Sisters of Charity opened Our Lady's Hospice in Dublin.[8] This hospice originally concentrated on the care of patients with tuberculosis but near the end of the 1950's more and more cancer patients were admitted.[9] These hospices cared for patients who were not admitted to hospital. An inability to pay for care, lack of appropriate facilities or the worry that the infection would be passed to other patients were among the reasons for a patient being refused care in a hospital.[10] Consequently, hospices began to take on a distinct role in the care of the terminally ill patient; a role which hospitals were unwilling and/or unable to provide at the time. Nevertheless, there were limits to what could be achieved by this early form of palliative care.

Initially, the standard of end-of-life care had been restricted by the level of medical knowledge on pain management,[11] and the lack of appropriate medicines.[12] A culture of research into end-of-life care and pain management began to emerge in the 1950's,

[5] Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003, 19.
[6] Sandra L Regan and others, *Communication as Comfort: Multiple Voices in Palliative Care* (Taylor & Francis 2008) 22 'The term was first used by Madame Jeanne Gernier [sic] who founded the Dames de Calaire in Lyon, France in 1842.'; Cicely Saunders, 'The evolution of palliative care' (2000) 41 Patient Education and Counseling 7 'The first use once again of the word 'hospice' in the UK was by the Irish Sisters of Charity at St. Joseph's Hospice in Hackney, East London, which opened in 1905 following the opening of their founding hospice outside Dublin in 1879. There was no connection with Mme. Garnier's seven homes. Other homes without such a link – Catholic, Protestant and Jewish – were founded in the United Kingdom, the United States and Australia around the turn of the century. There were doubtless other similar institutions in Europe, such as Kaiserwerth in Germany which opened in 1836.'
[7] Kieran McCarthy, *A Dream Unfolding: Portrait of St Patrick's Hospital & Marymount Hospice* (St. Patrick's Hospital/Marymount Hospice 2004) 43.
[8] Our Lady's Hospice & Care Services, 'Our Heritage' <http://www.olh.ie/6-about-us/38-our-heritage/> accessed 8 June 2014; Religious involvement did not limit who can be cared for in these hospices. See James Gilbert, 'Palliative medicine: a new specialty changes an old debate' (1996) 52(2) British Medical Bulletin 296, 299. 'Even the most overtly religious hospices are at pains to make clear that those of any faith, and those of none, are welcomed.'
[9] Our Lady's Hospice & Care Services (n8).
[10] ibid.
[11] Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003, 19.
[12] ibid.

as signaled by research on cancer carried out by Bailey,[13] Aitken-Swan[14] and, in particular, Dame Cicely Saunders.[15] This led to a greater understanding of the care required for cancer patients and, ultimately, resulted in infrastructural changes which were a sea change in the practice of palliative medicine. In this regard, it was the opening of St. Christopher's Hospice in London in 1967 which marked the beginning of modern palliative care.[16] St. Christopher's Hospice was developed for the sole purpose of providing end-of-life care and signaled a more focused attempt to manage pain experienced by the patient. Additionally, St. Christopher's Hospice proved a suitable location to conduct research specific to palliative care practices.[17] This research was valuable in understanding the effect and role of medication for pain relief, as evidenced by subsequent World Health Organization engagement on this subject.[18] This included the publication of 'Cancer Pain Relief'[19] which set out a three-step analgesic ladder; the third step being the use of strong opioids. The availability of opioids for pain relief was among the early concerns of the World Health Organization in relation to palliative care but another significant issue to emerge was the appropriate use of this drug given its potential to hasten the death of a patient.[20]

[13] M Bailey, 'A survey of the social needs of patients with incurable lung cancer' (1959) 11 *The Almoner* 379.

[14] Ralston Paterson and Jean Aitken-Swan, 'Public opinion on cancer; a survey among women in the Manchester area' (1954) 23 Lancet 857; Jean Aitken-Swan and Ralston Paterson, 'The cancer patient: delay in seeking advice' (1955) 1 British Medical Journal 623.

[15] Cicely Saunders, 'Drug treatment of patients in the terminal stages of cancer' (1960) 1(1) Current Medicine and Drugs 16; Cicely Saunders, 'The symptomatic treatment of incurable malignant disease' (1964) 4 Prescriber's Journal 68; Cicely Saunders, 'The care of the terminal stages of cancer' (1967) 41 Annals of the Royal College of Surgeons 162.

[16] St. Christopher's Hospice, 'History' <http://www.stchristophers.org.uk/about/history> accessed 8 June 2014. St. Christopher's Hospice was founded by Dame Cicely Saunders.

[17] Robert Twycross, a Clinical Research Fellow in St. Christopher's Hospice, conducted research into methods of pain relief such as the Brompton Cocktail. Robert G Twycross 'Choice of strong analgesic in terminal cancer: diamorphine or morphine?' (1977) 3 Pain 93; Robert G Twycross, 'The Brompton cocktail' in JJ Bonica and V Ventafridda (eds), *International symposium on pain of advanced cancer* (Vol. 2, Raven Press 1979).

[18] World Health Organization, 'The Solid Facts: Palliative Care' (World Health Organization 2004) 7 'One powerful element of the work that developed into the whole spectrum of palliative care was a breakthrough in the attitude to pain, as it became recognized in all its complexity in the 1960s. It began with a concentration on cancer pain. This focus made possible the early research that led to the booklet *Cancer pain relief*, published by WHO in 1986.'

[19] World Health Organization, 'Cancer Pain Relief' (World Health Organization 1986).

[20] ibid 16.

Modern Palliative Care

Modern palliative care began to emerge in Ireland in the 1980s.[21] This evolution in care can be demonstrated through changes in medical practice, new support organisations, and the creation of consultant positions in palliative medicine. For example, it was not until 1980 that a specialist palliative care unit was established in Marymount Hospice in Cork.[22] The position of consultant physician in palliative medicine was first created in 1989,[23] and in 1986 the Irish Hospice Foundation [hereinafter 'IHF'] was established.[24]

The purpose of the IHF is to act 'as a voluntary support organization for the development and improvement of hospice services.'[25] The early work of the IHF included raising money for research and training,[26] developing hospice home-care services[27] and eventually the opening of a number of hospices.[28] In recent years, the IHF has established several programmes aimed at improving the provision of palliative care such as 'Hospice Friendly Hospitals',[29] the 'Palliative Care for All' programme[30] and the 'Primary Palliative Care' programme.[31] These programmes

[21] Department of Health and Children (n1) 21 'The modern palliative care movement in Ireland began to gather momentum in the early 1980's.'
[22] McCarthy (n7).
[23] Deirdre Rowe, Ann Keating and Eithne Walsh, 'Palliative care teamwork in the Republic of Ireland – the key to physical and psychological function' in Julie Ling and Liam O'Síoraín (eds), *Palliative Care in Ireland* (Open University Press 2005) 85.
[24] Irish Hospice Foundation, 'About Us' <http://hospicefoundation.ie/about-us/> accessed 8 June 2014.
[25] Department of Health and Children (n1) 21.
[26] Padraig O'Morain, 'The Irish Hospice Foundation 1986-2006: The First 20 Years' (Irish Hospice Foundation 2006) 10 'For the IHF to set out, as it did, to raise the bulk of the £2 million cost of an Education and Research Centre at Our Lady's Hospice, Harold's Cross, was daring, almost audacious, in the late 1980s.'
[27] ibid 11.
[28] ibid 16.
[29] Irish Hospice Foundation, 'Hospice Friendly Hospitals Programme' <http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/> accessed 8 June 2014.
[30] Irish Hospice Foundation, 'Palliative Care for All' <http://hospicefoundation.ie/what-we-do/palliative-care-for-all/> accessed 8 June 2014 'The Irish Hospice Foundation's *Palliative Care for All* Programme seeks to provide support, direction and guidance to those who work with these patients, in order to facilitate the incorporation of appropriate palliative care principles in their care.'; Irish Hospice Foundation, 'Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks' (Irish Hospice Foundation 2008).
[31] Irish Hospice Foundation, 'Primary Palliative Care' <http://hospicefoundation.ie/what-we-do/primary-palliative-care/> accessed 8 June 2014 'The initial aim of this programme was to identify specific areas where steps might be taken to enhance the care of those with palliative care needs.' This report was motived by worry that 'the absence of a formalised approach to this type of care may result in the palliative care needs of people with life limiting disease going unrecognised, and in these cases they will not receive the holistic approach to care that is associated with those in receipt of specialist palliative care services.'; Irish Hospice Foundation, 'Primary Palliative Care in Ireland' (Irish Hospice Foundation 2011).

along with the investment in research, training, and hospice development demonstrate the influence of the IHF in developing modern palliative care in Ireland.

Despite the considerable impact of the IHF, they were not the only body which contributed to the development of palliative care in Ireland. Palliative care continued to develop in Ireland in the 1990's as demonstrated by the establishment of the Irish Association of Palliative Care [hereinafter 'IAPC'] in 1993. The IAPC is 'an all island body with the purpose of promoting palliative care nationally and internationally'[32] and its members come from a range of disciplines.[33] The work of the IAPC has included publishing position and discussion papers on artificial hydration,[34] voluntary euthanasia,[35] and palliative sedation.[36] These will be discussed later in this Chapter when outlining specialist palliative care practices.

Bodies such as the IHF and the IAPC had led the development of palliative care in Ireland up to this point. There was no single national strategy to influence or guide the development of palliative care. The first government engagement with palliative care was seen in the publication of the national health strategy in 1994.[37] This strategy acknowledged the importance of palliative care services in improving quality of life and set the goal of promoting 'the continued development of such services in a structured manner.'[38] However, this strategy provided no additional details on how this was to be achieved and the services referred to were largely provided by voluntary organisations such as the Irish Cancer Society and hospices established by the IHF.

In 1995, the Irish Medical Council recognised palliative medicine as a medical specialty. As a result, Ireland was only the 'second country in Europe'[39] to do so. The recognition of palliative medicine as a medical specialty demonstrates that it 'has a

[32] Irish Association of Palliative Care, 'What does the Irish Association of Palliative Care do?' <http://www.iapc.ie/what-we-do.php> accessed 8 June 2014.
[33] ibid.
[34] Irish Association of Palliative Care, 'Artificial Hydration in Terminally Ill Patients' (Irish Association of Palliative Care 2011).
[35] Irish Association of Palliative Care, 'Voluntary Euthanasia' (Irish Association of Palliative Care 2011).
[36] Irish Association of Palliative Care, 'Palliative Sedation' (Irish Association of Palliative Care 2011).
[37] Department of Health, 'Shaping a Healthier Future: A strategy for effective healthcare in the 1990's' (Stationery Office 1994).
[38] ibid 68.
[39] European Association of Palliative Care, 'Atlas of Palliative Care in Europe' (EAPC 2006) 94.

clearly defined patient population, clearly defined disease processes, and clearly defined research interests.'[40] This categorisation also underlines the importance of an appropriate legal framework which supports both the doctor and patient as specialist palliative care raises issues unique to it. These issues will be demonstrated in the third section of this Chapter.

National Advisory Committee on Palliative Care

Government involvement in the development of palliative care was again seen from the mid-1990's to the early 2000's. This was demonstrated with the launch of the 'National Cancer Strategy'[41] in 1996, the 'Report of the Commission on Nursing'[42] in 1998, the 'Action Programme for the Millennium',[43] and the establishment of the National Advisory Committee on Palliative Care in 1999.[44] The National Advisory Committee on Palliative Care is a milestone in the development of palliative care in Ireland. The Committee reported in 2001 and highlighted many of the challenges facing the provision of palliative care.[45]

Under the terms of reference, the National Advisory Committee on Palliative Care was to consider and issue recommendations on issues such as: '[t]he principles underlying the development of specialist and non-specialist palliative care services nationally and regionally',[46] '[t]he organisation and development of an integrated palliative care service involving both statutory and voluntary providers',[47] and '[a]ny other matters relating to palliative care which the National Advisory Committee considers appropriate'.[48] In making recommendations on these points the National Advisory

[40] Randall C Wetzel and Carol E Nicholson, 'Research in Prediatric Critical Care' in Bradley P Fuhrman and others (eds), *Pediatric Critical Care* (4th edn, Elsevier 2011) 41.
[41] Department of Health and Children, 'Cancer Services in Ireland: A National Strategy' (Stationery Office 1996); Department of Health and Children (n1) 22 'The Cancer Strategy sought to promote appropriate models of care that would best address the palliative care needs of patients and their families. It gave an undertaking that there would be a programme of phased development of specialist palliative care in regional cancer services, in consultation with health boards and others involved in palliative care.'
[42] Department of Health and Children, 'Report of The Commission on Nursing: A blueprint for the future' (Stationery Office 2008).
[43] Department of the Taoiseach, 'Action Programme for the Millennium' (Stationery Office 2008) 7 A key priority was the development of a 'National hospice plan'.
[44] Department of Health and Children (n1).
[45] Department of Health and Children (n1) 23 'Issues of responsibility, reporting structures and funding may be of an ad-hoc nature, leading to unsatisfactory and often divisive arrangements.'
[46] ibid 26.
[47] ibid.
[48] ibid.

Committee on Palliative Care was to have regard to factors such as 'the best interests of patients and their families',[49] 'relevant national and international research, analysis and standards',[50] and 'the palliative care requirements of persons with non-malignant diseases.'[51] It has been suggested that as the terms of reference recognised the importance of considering the 'best interests of patients and their families' that this 'set the tone and context for the discussions.'[52] In effect, the focus was placed on the patient and how optimum care should be provided. The patient should occupy a central role when examining the legal framework for the provision of specialist palliative care but it is important to also bear in mind the role of the healthcare professional. In a situation where legal and ethical uncertainty around practices is shown to exist then guidance greater than 'best interests' is needed to ensure appropriate specialist palliative care is provided.

The National Advisory Committee on Palliative Care issued recommendations on issues such as specialist palliative care services, specialist palliative care units, and the standards in palliative care. These included recommendations that '[e]ach health board area should have a comprehensive specialist palliative care service to meet the needs of patients and families in the area',[53] '[s]pecialist palliative care services should be available to all patients wherever and whenever they require them',[54] and that '[s]uitable performance indicators and outcome measures should be identified and utilised in specialist palliative care services in order to evaluate and maintain quality standards'.[55] These recommendations are aimed at improving the availability of specialist palliative care and ensuring that a high standard of specialist palliative care is provided. However, achieving these aims requires consistency across providers of palliative care and needs a clear legal framework to support specialist palliative care practices. The absence of such a framework would result in a variety of problems such as ad-hoc decision-making structures and inconsistency between healthcare

[49] ibid 25.
[50] ibid.
[51] ibid.
[52] Tony O'Brien and David Clark, 'A national plan for palliative care – the Irish experience' in Ling (n23) 9.
[53] Department of Health and Children (n1) 58.
[54] ibid 119.
[55] ibid 121.

professionals, and would undermine attempts to ameliorate the provision of specialist palliative care in Ireland.

In order to draw these recommendations together, it was suggested that a National Council for Specialist Palliative Care be established.[56] The purpose of this Council would be to advise the Minister for Health and Children on 'national policy'.[57] This Council was seen as a necessary step in developing the provision of palliative care in Ireland. The National Advisory Committee on Palliative Care made this recommendation based on previous reports on palliative care in Ireland[58] and a World Health Organization report[59] which set out that 'one of the major obstacles to the implementation of palliative care appears to be the absence of national policies on cancer pain relief and other aspects of palliative care.'[60] However, a National Council for Specialist Palliative Care has not yet been established. As a result, palliative care has continued to develop through the work of bodies such as the IHF, the IAPC, and the Irish Cancer Society. Many of the reports and papers issued by these bodies will be discussed in the course of this thesis. These reports will further demonstrate how the development of palliative care in Ireland has largely been led by voluntary groups rather than developed through clear and consistent national policy. This fragmented approach to developing palliative care is likely to impact negatively on the standard of patient care, particularly if the legal framework is vague on the legality and limits of specialist palliative care practices. In this regard, a point yet to be clarified in this Chapter is the types of illness for which palliative care may be provided.

[56] ibid 132 'The Minister for Health and Children should establish a National Council for Specialist Palliative Care to offer advice on the ongoing development and implementation of national policy on palliative care services in Ireland, having regard to this Committee's report.'
[57] ibid 17.
[58] Irish Hospice Foundation and Irish Association for Palliative Care, 'Position Paper on the Development of Hospice and Specialist Palliative Care Services in Ireland' (1996); D Haslett, 'A Study of Partnership between Voluntary and Statutory Sectors in Palliative Care in Ireland' (Irish Hospice Foundation 1998); Department of Public Health, Eastern Health Board, 'Needs Assessment for Specialist Palliative Care Services in the Eastern Health Board Area' (1999).
[59] World Health Organization, 'Cancer Pain Relief and Palliative Care: Report of a WHO Expert Committee' (WHO 1990).
[60] Department of Health and Children (n1) 132.

The Expansion in Categories of Palliative Care Patients

The close link between the development of palliative care and oncology was highlighted in the previous section.[61] Palliative care is no longer limited to patients with a cancer diagnosis. It has expanded to provide care for people suffering from a wide range of serious illnesses.[62] Palliative care may be provided to patients suffering from motor neurone disease,[63] AIDS,[64] chronic obstructive pulmonary disease,[65] chronic kidney disease[66] dementia,[67] or it may be provided to older people based on their medical condition.[68]

The variety of illnesses for which palliative care may be provided raises a number of challenges. Among these challenges is the need to assess the patient's disease trajectory. This is a relevant concern for all illnesses as it impacts on the decision to begin palliative care and, subsequently, the level of palliative care which is to be provided. It has previously been set out that specialist palliative care is of most relevance near the end of the patient's life however '[a] hard and fast objective clinical

[61] David Field and Julia Addington-Hall, 'Extending specialist palliative care to all?' (1999) 48 Social Science and Medicine 1271, 1272-1273 'alleviating the physical, psychological and spiritual distress associated with dying from cancer, on enabling cancer patients to continue living full lives until they died' citing Cicely Saunders, 'On dying well' (1984) Feb Cambridge Review 49; Department of Health and Children (n1) 42 'Over 95% of all patients currently availing of specialist palliative care services suffer from cancer.'

[62] ibid. The value of expanding palliative care was recognised at an early stage in its development, see Cicely Saunders, *The Management of Terminal Disease* (Edward Arnold 1978); Eric Wilkes, 'Terminal Care: Report of a Working Party' (HMSO 1980); Bronwen Biswas, 'The Medicalisation of Dying: A Nurse's View' in David Clark (ed), *The Future for Palliative Care: Issues of Policy and Practice* (Open University Press 1993); Irene Higginson, 'Palliative Care: A Review of Past Changes and Future Trends' (1993) 15 Journal of Public Health Medicine 308; David Field, 'Palliative Medicine and the Medicalisation of Death' (1994) 3 European Journal of Cancer Care 58; Cicely Saunders, Mary Baines and Robert Dunlop, *Living with Dying: A Guide to Palliative Care* (3rd edn, Oxford University Press 1995); Sam Ahmedzai, 'Making a success out of life's failures' (1996) Progress in Palliative Care 4, 1-3.

[63] David Oliver, 'Palliative Care for Motor Neurone Disease' (2002) 2 Practical Neurology 68.

[64] Department of Health and Children (n1) 24; Department of Health (n37) 68 'Proper recognition will be given to the importance of palliative care for terminally ill patients, and the continued development of these services will be promoted in a structured manner.'

[65] CM Roberts and others, 'Clinician perceived good practice in end-of-life care for patients with COPD' (2008) 22 Palliative Medicine 855; Sarah J Goodlin, 'Why should palliative care clinicians learn about heart failure?' (2008) 16 Progress in Palliative Care 215; Richard Harding and others, 'Provision of palliative care for chronic heart failure inpatients: how much do we need?' (2009) BMC Palliative Care 8.

[66] Sara N Davison and Charles J Ferro, 'Management of pain in chronic kidney disease' (2009) 17(4) Progress in Palliative Care 186.

[67] Elizabeth L Sampson and others, 'Palliative care in advanced dementia; A mixed methods approach for the development of a complex intervention' (2008) BMC Palliative Care 8.

[68] National Council on Ageing and Older People, 'End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland' (National Council on Ageing and Older People 2008).

distinction as to when the dying process commences is not always possible'.[69] This lack of a '"brightline" test'[70] is particularly difficult in relation to non-cancer patients.[71] As a consequence of this, it is often a more difficult task to identify a non-cancer patient as being close to the end of life.[72] This may limit the number of patients receiving specialist palliative care and it demonstrates the wider difficulty in making decisions in relation to this form of care. As palliative care continues to expand there is a need for greater support and clarity in the decision-making framework for patient care. This not only relates to the decision to begin palliative care but extends throughout the continuum of decisions on end-of-life care.

Ongoing Challenges in Specialist Palliative Care

The challenge of providing specialist palliative care in Ireland is well demonstrated in a study conducted by O'Leary and Tiernan.[73] This study concentrated on the provision of 'specialist palliative care services for noncancer patients in Ireland and perceived barriers'.[74] This was a comprehensive study due to a 100% response rate from surveys which had been sent to 'clinical managers of all SPC services listed in the directory of

[69] Michael Ashby and Brian Stoffell, 'Artificial Hydration and Alimentation at the End of Life: A Reply to Craig' (1995) 21(3) Journal of Medical Ethics 135, 137; Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death" (1968) 205(6) Journal of the American Medical Association 337; Irish Working Party on Brain Death, "Memorandum on Brain Death" (1988) 81(1) Irish Medical Journal 42; John Lombard, 'The Definition of Death' (2012) 11 Hibernian Law Journal 63; *Lee v State of Oregon* 891 F. Supp. 1429 'The problem of inadequate mental evaluation is compounded by imprecision in defining "terminal disease." Even for physicians who specialize in treating a terminal disease, no precise definition is medically or legally possible, since only in hindsight is it known with certainty when someone is going to die. As the Ninth Circuit noted, the terminally ill category is "inherently unstable." Compassion in Dying, 49 F.3d at 590.'

[70] *R(Burke) v General Medical Council* [2005] QB 424, [2006] QB 273 [46].

[71] Field (n61) 1275.

[72] ibid 1274 'The limited available evidence therefore strongly suggest that about a fifth of people who die from non-malignant disease have unmet needs for symptom control, psychological support, family care and open communication with health professionals, which are comparable to (although not identical to) those of cancer patients who currently receive specialist palliative care services.'; CM Roberts, and others, 'Clinician perceived good practice in end-of-life care for patients with COPD' (2008) 22(8) Palliative Medicine 855, 855 'There is evidence from recent studies that patients with chronic obstructive pulmonary disease (COPD) are less able to access or be offered appropriate palliative care at the end-of-life compared with patients suffering from cancer.'; Norma O'Leary and Eoin Tiernan, 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers' (2008) Palliative Medicine 77, 77 'Twenty four percent of services limited availability for noncancer patients in some way. Of those services available for noncancer patients, the type of care provided to them was the same as for cancer patients in 81% of services.'

[73] O'Leary (n72) 77.

[74] ibid.

SPC services in Ireland'.[75] The results of this survey revealed that 24% of specialist palliative care services restricted care for noncancer patients in some manner.[76] In instances where care was available to noncancer patients, the type of care was 'the same as for cancer patients in 81% of services.'[77] In 2004, 7.21% of patients cared for by specialist palliative care services had an illness other than cancer.[78] On the basis of this survey, it appears that there are considerable barriers to the expansion of palliative care. Among the barriers recognised by O'Leary and Tiernan were 'the unpredictable non-cancer disease trajectory, the resultant difficulties with developing referral criteria and the lack of noncancer disease specific expertise.'[79] In effect, the role of the general practitioner in referring a patient to specialist palliative care services may be inconsistent due to the lack of clear referral criteria.[80] This further highlights the lack of clear national guidance on the provision of palliative care and, in particular, specialist palliative care.

One respondent to O'Leary and Tiernan's study, a nurse manager, suggested that 'Clear national guidelines need to be put in place to ensure uniformity when dealing with nonmalignant patients requiring palliative care.'[81] The reality of the situation is that policy on end-of-life care has developed at a local level.[82] These policies may be influenced by various reports and recommendations on palliative care issued by bodies such as the IHF, IAPC, and the European Association of Palliative Care among others. The reliance on local policy means that 'uniformity' across providers of palliative care is not readily achievable. The lack of clear national guidance undermines consistency in specialist palliative care and could hamper the care of the patient. This highlights the need for a clear legal framework which allows healthcare professionals to practise under consistent and well defined legal and ethical guidelines. Any such framework will also have to take account of the variety of palliative care providers if a harmonious standard of specialist palliative care is to be achieved.

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[75] ibid.
[76] ibid.
[77] ibid.
[78] ibid.
[79] ibid 79-80.
[80] ibid 81 'The lack of explicit written referral policies in 31% of services in Ireland in 2005 is surprisingly high. Only 22 services (35%) have a written referral policy that made explicit reference to noncancer patients.'
[81] ibid 79.
[82] Text to n196 in Chapter Five.

Palliative Care Providers

Palliative care in Ireland is provided by hospices, acute general hospitals, or in a community setting such as nursing homes. Discussing these palliative care providers facilitates the later identification of the existing legal framework in Ireland for specialist palliative care. As there is no distinct legal framework in Ireland for specialist palliative care it is necessary to consider how this form of care falls within the broader ambit of regulation. As a result, the legislation and guidance applicable to healthcare facilities forms a substantial part of the legal framework in Ireland for specialist palliative care. Second, it ensures that any suggestions for reform of the legal framework made in this thesis can take account of the variety of palliative care providers which exist. It is important that a holistic view be taken in relation to reform so as to ensure that suggestions are workable and appropriate in reality.

Hospice Care

Hospices in Cork and Dublin were established by religious congregations and there was no central plan for the development and expansion of this type of care to other parts of Ireland. As a result, the provision of hospice care in Ireland can be seen as sporadic and has resulted in certain 'geographical regions without an inpatient hospice to serve as the hub around which comprehensive community services can develop.'[83] This has been highlighted by the IHF as a key challenge to the development of palliative care.[84] At present, there are nine inpatient hospices in Ireland.[85] Hospices in Ireland provide a broad range of palliative care services including home care, day care, respite care, and inpatient care.

Admission to a hospice may be organised through a patient's general practitioner. Patients who are already receiving care in a hospital may be referred by the consultant in charge. This is standard practice for all nine inpatient hospices but in order for this to be effective there must be a common understanding of palliative care shared among healthcare professionals. In this regard, O'Leary and Tiernan highlighted that barriers to the greater provision of specialist palliative care included the 'difficulties with

[83] Irish Hospice Foundation, 'Strategic Plan: 2012-2015' (Irish Hospice Foundation 2012) 8.
[84] ibid.
[85] Our Lady's Hospice & Care Services, Dublin; Blackrock Hospice, Dublin; St. Francis Hospice, Dublin; St. Brigid's Hospice, Kildare; Marymount Hospice, Cork; Milford Care Centre, Limerick; Galway Hospice, Northwest Hospice, Sligo; Donegal Hospice.

developing referral criteria'.[86] As such, the potential exists that the patient would not be referred to the appropriate palliative care service in a timely manner. Unfortunately, this may also undermine a patient's involvement in later decisions relating to their healthcare depending on the disease trajectory. Nonetheless, the range of services offered by hospices in Ireland means that patients may come into contact with staff at an early stage in the disease trajectory. Despite this, inpatient hospices are mainly associated with the provision of specialist palliative care.

Acute General Hospitals

In 2001 the 'Report of the National Advisory Committee on Palliative Care' noted that specialist palliative care services in hospitals are 'currently at an early stage of development in Ireland.'[87] In general, hospitals are less associated with the provision of specialist palliative care. Part of the reason for this is that hospitals are seen as focusing on curative treatments whereas specialist palliative care signals a serious change in the condition of the patient to a point where curative treatment is no longer a reality.[88] This view tends to neglect the fact that approximately 48% of deaths in the Republic of Ireland occur in acute hospitals.[89] Recently, there have been moves towards increasing the role hospitals have in the provision of various forms of palliative care including specialist palliative care. This has been demonstrated by the work of the 'Hospice Friendly Hospitals Programme'.

Hospice Friendly Hospitals is a programme which was launched in 2007 by the IHF. The programme focuses on ensuring that 'end-of-life care is central'[90] in hospital care, on bringing it 'from the margins to the mainstream',[91] and on altering the culture of end-of-life care in hospitals.[92] At present, there are a total of 31 acute hospitals which seek to implement the 'Hospice Friendly Hospitals Programme'.[93] Again, this

[86] O'Leary (n72) 79-80.
[87] Department of Health and Children (n1) 13.
[88] Task Force on Palliative Care, Last Acts Campaign, and Robert Wood Johnson Foundation, 'Precepts of Palliative Care' (1998) 1(2) Journal of Palliative Medicine 109, 110.
[89] Irish Hospice Foundation, 'Hospital Friendly Hospitals Programme' <http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/> accessed 8 June 2014.
[90] ibid.
[91] Hospice Friendly Hospitals, 'Quality Standards for End-of-Life Care in Hospitals: Making end-of-life care central to hospital care' (Irish Hospice Foundation 2010) 15.
[92] Irish Hospice Foundation (n89).
[93] Irish Hospice Foundation, 'Acute Hospital Network' <http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/acute/> accessed 8 June 2014.

demonstrates that the provision of palliative care in hospitals is still in the early stages. Incorporating palliative care into hospitals might be difficult if professional standards are vague about end-of-life care. This could also give rise to disagreement between doctors and nurses who practice under different professional standards. On this basis, it is possible that there is some confusion among healthcare professionals as to what constitutes palliative care. This is a problem which has been shown to exist by a Hospice Friendly Hospitals report titled 'Dying in Hospital in Ireland: Nurse and Doctor Perspectives'.[94]

The Hospice Friendly Hospitals report examined the decisions made about the patient's care in the last weeks of their life. This report demonstrated differences in how doctors and nurses perceived end-of-life care. The difference was demonstrated by a '48% response agreement on whether a patient was in pain all or most of the time'[95] while a similar level of agreement was seen in relation to symptom management.[96] Decisions on palliative care and specialist palliative care were examined separately in the report. It was shown that palliative care is of a high standard,[97] but there is a lack of clarity about 'what palliative care decisions were made and documented, and substantially more disagreement on the frequency and management of the patient's symptoms.'[98] This suggests an ad-hoc approach to palliative care which fails to provide healthcare professionals with legal certainty on the type of care to be provided. In particular, healthcare professionals appeared reluctant to 'withhold or withdraw treatment, even when death is expected.'[99] The Hospice Friendly Hospitals report suggested that this may be caused by 'the absence of clear practice guidelines.'[100] This situation hampers the consistent protection of patients' human rights as there are likely to be different approaches to palliative care adopted by different healthcare providers. In any case, the provision of treatment

[94] Kieran McKeown, Trutz Haase and Shelagh Twomey, 'Dying in Hospital in Ireland: Nurse and Doctor Perspectives, Report 2' (Irish Hospice Foundation 2010).
[95] ibid 28.
[96] ibid 29 'The level of agreement between the responses of nurses and doctors on symptom management falls to 42%, on average, and indicates that, in the majority of cases, there is no agreement on whether the patient was kept comfortable.'
[97] ibid iii 'nurses and doctors estimate that 80-90% of patients are kept relatively comfortable during the last week of life. In the national audit of patients on the LCP in English hospitals, about 75% were assessed as comfortable in these symptom areas.'
[98] ibid 30-31.
[99] ibid 30.
[100] ibid 31.

which may be invasive, painful, and of questionable value is unlikely to be in the patient's best interests. This further underlines the importance of a clear legal framework which provides guidance on the legal and ethically complex decisions made in relation to the care of a terminally ill patient.

There were notable differences in the perception of doctors and nurses as to whether a patient had actually received specialist palliative care. Doctors believed 22% of patients had received specialist palliative care compared to the nurses' response of 32%.[101] The knowledge of specialist palliative care practices can also be questioned as a result of a response that 'in over a quarter of cases (26% according to nurses and 29% according to doctors)'[102] it is not clear whether specialist palliative care would have been of benefit to the patient.[103] These professions work closely in the provision of specialist palliative care and it is important that they share a common understanding of palliative care practices. Inconsistency between these professions ultimately impacts on the care of the patient. Nonetheless, it is difficult to accurately explain the basis for this difference in opinion but it could also be attributed to the lack of 'clear practice guidelines'.[104]

The Hospice Friendly Hospitals report does not provide a categorical explanation for differences but suggests that each hospital must reflect on their practice. Nevertheless, several interpretations of this data were put forward in the report. For instance, it was suggested that:

> there is not a common understanding of what specialist palliative care actually means; that there is lack of information about the role of specialist palliative care; that the palliative care needs of these patients were not been properly assessed; that nurses and doctors have different perceptions of when a patient requires a specialist palliative care service; that there is no systematic procedure for calling upon the expertise of the specialist palliative care team when a diagnosis of dying is made.[105]

[101] ibid 33.
[102] ibid 32.
[103] ibid 33 In 14% of cases the patient would have benefited from specialist palliative care but did not receive it.
[104] ibid 31.
[105] ibid 33.

There is no single solution to address all of these issues but professional standards and guidance can have a considerable bearing on the type of care offered. This influence is due to their role in defining the conduct and standards expected from healthcare professionals regardless of the type of setting in which they are practising. Furthermore, the difference in opinion between doctors and nurses in the Hospice Friendly Hospitals report demonstrates the need to examine how the current professional standards impact on specialist palliative care and, as part of this, how they address co-operation with other healthcare professionals. This extends beyond specialist palliative care in hospices or hospitals and includes other locations where this form of care is provided such as in a community setting.

Community Setting

The general practitioner and public health nurse are the main providers of palliative care in a community setting.[106] Other disciplines involved in the provision of palliative care in the community include the specialist palliative care nurse, 'the physiotherapist, the occupational therapist, the speech and language therapist and social workers.'[107] Locations where palliative care may be provided in the community include 'the patient's own home, in a local community hospital, in a nursing home or any other setting in the community.'[108] The practice of providing palliative care in the community began shortly after the opening of St Christopher's Hospice in 1967.[109] This service was 'based on the needs of patients at home, after consultation with general practitioners and district nurses who were already working in the community.'[110] Dame Cicely Saunders encouraged the development of this service and set out that 'The hospice will provide continuity of care for those able to return home.'[111] This service has continued to develop over the years and in 2008 there were

[106] Department of Health and Children (n1) 86; Julia Addington-Hall and Mark McCarthy, 'Dying from cancer: results of a national population-based investigation' (1995) 9 Palliative Medicine 295; Sheila Payne, 'To supplant, supplement or support? Organisational issues for hospices' (1998) 46(11) Social Science and Medicine 1495.
[107] Department of Health and Children (n1) 86.
[108] ibid 34.
[109] Mary Baines, 'From pioneer days to implementation: lessons to be learnt' (2011) 18(5) European Journal of Palliative Care 226.
[110] Mary Baines, 'The origins and development of palliative care at home' (2010) 18(1) Progress in Palliative Care 4, 4.
[111] Cicely Saunders, 'St Christopher's Hospice' (1967) 77(10) Br Hosp J Soc Serv Rev 2127 quoted in Baines (n110) 4.

314 such teams in the United Kingdom.[112] Similar developments have also taken place in Ireland.

The Irish Cancer Society[113] has been involved in the 'development of home-care nursing services in the community'[114] since 1985.[115] Services include 'Night Nursing' which provides 'end of life care for cancer patients and their families in their own home.'[116] This care not only focuses on physical pain but also provides emotional care of the patient. In 2011, 2,015 patients availed of this service.[117]

Palliative care in the nursing home is generally provided by the patient's general practitioner with support provided by the nursing staff. The provision of specialist palliative care may involve 'consultation with the staff of the specialist palliative care unit, or may involve visits to the nursing home by the specialist palliative care team in the community.'[118] As such, the provision of specialist palliative care does not have a central role in nursing home care. Nonetheless, it is important to bear in mind when examining the existing legal framework and in advancing suggestions for reform.

Specialist palliative care has evolved from hospices to become a more central part of the healthcare system. It is a practice which is still developing as evidenced by the emergence of programmes such as Hospice Friendly Hospitals and the growth in home care. Regardless of location, doctors and nurses are to the fore in providing specialist palliative care. In order to provide effective palliative care it is necessary that these professions share a common understanding of the nature of this type of care and are supported by a clear legal framework when providing specialist palliative care. In this regard, guidelines and standards must directly address the provision of specialist palliative care practices. Consequently, it is necessary to highlight the legal and ethical issues raised by these specialist palliative care practices.

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[112] Baines (n110) 8.
[113] Liam O'Síoraín, Orla Keegan and John McCormack, 'The voluntary sector' in Ling (n23) 26 'the major national cancer charity whose remit includes all cancer care from screening programmes to hospice home care.'
[114] Department of Health and Children (n1) 22.
[115] O'Síoraín (n113) 26.
[116] Irish Cancer Society, 'Home Night Nursing' <http://www.cancer.ie/how-we-can-help/nursing/home-night-nursing> accessed 8 June 2014.
[117] ibid.
[118] Department of Health and Children (n1) 90.

Palliative Care Practices

There are a broad range of palliative care practices such as medication management,[119] prevention of bed sores,[120] and treating elimination problems experienced by patients.[121] These practices are relatively uncontroversial and raise few legal issues other than providing respect for patient autonomy and ensuring that the patient is treated with dignity. However, the specialist palliative care practices of palliative sedation and the decision to withdraw artificial nutrition and hydration are more challenging. This section will outline these practices and, in doing so, will illustrate the complicated decisions faced by the healthcare professional in providing specialist palliative care. In addition to this, it provides an introduction to many of the difficult legal and ethical issues which will be discussed in the course of this thesis.

Sedation in Palliative Care

Sedation in palliative care has been described as a 'contested practice'.[122] Seymour et al. neatly summarised this position in commenting that:

> Contemporary debates focus on how its use relates to euthanasia, issues of informed or advance consent, its role in 'death with dignity' and its relationship to the withholding or withdrawing of life prolonging medical treatments, particularly artificial feeding and hydration.[123]

This section will set out the background to several of these issues and will highlight the importance of examining the legal framework in Ireland for these specialist palliative care practices.

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[119] Holly M Holmes and others, 'Reconsidering medication appropriateness for patients late in life' (2006) 166(6) Archives of Internal Medicine 605; David C Currow, 'Prescribing in Palliative Care as Death Approaches' (2007) 55(4) Journal of the American Geriatrics Society 590.

[120] M Walding and C Andrews, 'Preventing and managing pressure sores in palliative care' (1995) 11(1) Professional Nurse 33; J Chaplin, 'Pressure sore risk assessment in palliative care' (2000) 10(1) Journal of Tissue Viability 27; Jean Galvin, 'An audit of pressure ulcer incidence in a palliative care setting' (2002) 8(5) International Journal of Palliative Nursing 214.

[121] Philip J Larkin and others, 'The management of constipation in palliative care: clinical practice recommendations' (2008) 22(7) Palliative Medicine 796.

[122] Jane E Seymour, Rien Janssens and Bert Broaeckaert, 'Relieving suffering at the end of life: Practitioners' perspectives on palliative sedation from three European countries' (2007) 64(8) Social Science & Medicine 1679, 1679.

[123] Luc Deliens and others, 'End-of-life decisions in medical practice in Flanders, Belgium: A nationwide survey' (2000) 356 The Lancet 1806 cited by Seymour (n122) 1680.

The use of sedation in palliative care developed due to the greater focus placed on pain management by palliative care providers[124] as well as developments in the provision of medication.[125] Levels of sedation include mild sedation, respite sedation and deep sedation.[126] Mild sedation involves lowering the consciousness of the patient but the patient is awake. Respite sedation involves sedating the patient for 'a predetermined interval, such as 24 to 48 hours, then downwardly titrating the sedative until consciousness reappears.'[127] The benefit of this form of sedation is that it may assist in easing the anxiety and distress experienced by the patient.[128] However, it is the practice of deep sedation which is the most controversial.

There are a number of terms for this form of sedation, including: continuous sedation,[129] deep sedation,[130] sedation for intractable distress in the dying,[131] total pharmacological sedation,[132] sedation-induced sleep,[133] and terminal sedation.[134] This thesis will use the most commonly used term of 'palliative sedation'. Previously, 'terminal sedation' was the most commonly used term to describe this level of

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[124] See p34.

[125] Improved accuracy of medication delivery e.g. use of intrathecal therapies which began to develop in 1976. TL Yaksh and TA Rudy, 'Analgesia mediated by a direct spinal action of narcotics' (1976) 192(4246) Science 1357; ME Leavens and others, 'Intrathecal and intraventricular morphine for pain in cancer patients: initial study' (1982) 56 Journal of Neurosurgery 241; B Roquefeuil and others 'Analgesia by intraventricular injection of morphine' (1982) 23 Agressologie 119; Shawn Belverud, Alon Mogilner and Michael Schulder, 'Intrathecal pumps' (2008) 5(1) Neurotherapeutics 114.

[126] Alexander de Graeff and Mervyn Dean, 'Palliative Sedation Therapy in the Last Weeks in Life: A Literature Review and Recommendations for Standards' (2007) 10 Journal of Palliative Medicine 67, 73-74.

[127] Paul C Rousseau, 'Palliative Sedation' (2002) 19 American Journal of Hospice Palliative Care 295, 296.

[128] ibid 'With respite sedation, an indeterminate number of patients may break the cycle of anxiety and distress that precipitated the request and need for palliative sedation, thereby nullifying the need for further sedation.'

[129] Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2009).

[130] Nathan I Cherny, Lukas Radbruch and The Board of the European Association for Palliative Care, 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care' (2009) 23(7) Palliative Medicine 581.

[131] Susan Chater and others, 'Sedation for Intractable Distress in the Dying – a survey of experts' (1998) 12 Palliative Medicine 255.

[132] C Peruselli and others, 'Home palliative care for terminal cancer patients: a survey on the final week of life' (1999) 13 Palliative Medicine 233.

[133] V Ventafridda and others, 'Symptom prevalence and control during cancer patients' last days of life' (1990) 6 Journal of Palliative Care 7.

[134] RE Enck, 'Drug-induced terminal sedation for symptom control' (1991) 8 American Journal of Hospice and Palliative Care 2; John D Cowan and Declan Walsh, 'Terminal sedation in palliative medicine – definition and review of the literature' (2001) 9 Support Cancer Care 403; Alexandra Beel, Susan E McClement and Mike Harlos, 'Palliative sedation therapy: a review of definitions and usage' (2002) 8 International Journal of Palliative Nursing 190, 191-192.

sedation.[135] However, there is a lack of clarity as to whether the word 'terminal' means that the patient is terminally ill or that the sedation is aimed at allowing the patient to die. The words used are particularly important given the legally and ethically sensitive nature of specialist palliative care. For instance, it was suggested by Jackson that the 'words we use in medical discourse reveal much about our truest conceptions and (and subconscious assumptions) about the practice of the profession'.[136] At present, the term 'palliative sedation' is the most prominent term used to describe this level of sedation.[137]

Palliative sedation has been defined by the European Association for Palliative Care as:

> the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering, in a manner that is ethically acceptable to the patient, family and health-care providers.[138]

The main indication for this type of sedation is the presence of a 'refractory symptom' which is a 'symptom for which all possible treatment has failed or it is estimated that no methods are available for palliation within the time frame and the risk–benefit ratio'[139] that is tolerable to the patient. Despite a change in terms, criticism persists that this form of sedation may have the effect of hastening the death of the patient.[140]

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[135] JG Hasselaar, SC Verhagen and KC Vissers, 'When cancer symptoms cannot be controlled: the role of palliative sedation' (2009) 3 Current Opinion in Supportive and Palliative Care 14 cited in Marco Maltoni, Emanuela Scarpi and Oriana Nanni, 'Palliative sedation in end-of-life care' (2013) 25(4) Current Opinion in Oncology 360, 360 'Hasselaar et al. reported that in 1998–1999 all studies referred to the procedure as 'terminal sedation', an inappropriate choice of words as it gives the impression of an intervention aimed at terminating life.'

[136] W Clay Jackson, 'Palliative sedation vs. terminal sedation: What's in a name?' (2002) 19 American Journal of Hospice Palliative Care 81, 82.

[137] Maltoni (n135) 360 'By 2006–2008, 83% of studies were using the term "palliative sedation"'.

[138] Cherny (n130) 581; Sjef Gevers, 'Terminal Sedation: A New Legal Approach' (2003) 10 European Journal of Health Law 359, 360 'the administration of sedative drugs with the aim to reduce the consciousness of a terminal patient in order to relieve distress'; See also de Graeff (n126) 71 'In the case of continuous and deep PST, the disease should be irreversible and advanced, with death expected within hours to days.'; Maltoni (n135) 360 'Palliative sedation is a medical procedure used to deal with the refractory symptoms occurring in the advanced stages of cancer. It has clinical, nursing, relational and ethical implications, making it a highly sensitive issue.'

[139] Maltoni (n135) 362.

[140] Torbjőrn Tännsjő, 'Terminal Sedation: A Substitute for Euthanasia' in Torbjőrn Tännsjő (ed), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004) 15 'By 'terminal sedation' I denote, in the present chapter, a procedure where through heavy sedation a terminally ill patient is put into a state

This would blur the distinction between specialist palliative care and euthanasia. The legitimacy of this distinction is a central issue which this thesis addresses and it will be drawn out through discussion of criminal law, human rights, and professional standards over the course of several chapters.

Sedation may be administered for differing forms of distress such as delirium,[141] dyspnoea,[142] pain,[143] nausea,[144] existential distress,[145] restlessness,[146] and vomiting.[147] Existential distress is the emotional or mental distress experienced by the patient. The administration of palliative sedation for suffering such as existential distress and restlessness alone is controversial[148] as it involves treating psychological distress rather than physical pain experienced by the patient. In this respect, existential distress may occur earlier in the disease trajectory at a time when the patient is not experiencing refractory symptoms. In effect, it is possible for existential distress or anxiety to occur at times other than the end of life. Consequently, if palliative sedation is administered for existential distress in circumstances where a patient is not experiencing a refractory symptom then this would blur the purpose of palliative sedation. It also begins to blur the time at which palliative sedation can legitimately be provided. For example, the administration of palliative sedation to a young and physically healthy person who happens to be experiencing existential distress could in no way be considered an aspect of specialist palliative care. Instead it may be viewed

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of coma, where the intention of the doctor is that the patient should stay comatose until he or she is dead. No extraordinary monitoring of the medical state of the patient is undertaken. Normal hydration is ignored. All this means that in some cases where patients are being terminally sedated, death is hastened; if the disease does not kill the patient, some complication in relation to the sedation, or the withdrawal of treatment and hydration, or the combination of these, does.'

[141] Nathan I Cherny, 'Sedation in response to refractory existential distress: Walking the fine line' (1998) 16 Journal of Pain Symptom Management 404; Cowan (n134) 406.

[142] Beel (n134) 193.

[143] ibid.

[144] Maltoni (n135) 362 'The symptoms most frequently requiring palliative sedation are physical symptoms such as delirium and dyspnea, whereas pain and vomiting are less frequently involved.'

[145] Beel (n134).

[146] ibid.

[147] ibid.

[148] Cherny (n141); Tatsuya Morita and others, 'Terminal sedation for existential distress' (2000) 17 American Journal of Hospice Palliative Care 189; Paul C Rousseau, 'Existential suffering and palliative sedation: A brief commentary with a proposal for clinical guidelines' (2001) 18 American Journal of Hospice Palliative Care 151; Tatsuya Morita, 'Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients' (2004) 28 Journal of Pain Symptom Management 445; Brigit R Taylor and Robert M McCann, 'Controlled sedation for physical and existential suffering?' (2005) 8 Journal of Palliative Medicine 144.

as a practice more closely aligned with euthanasia.[149] Nonetheless, a person experiencing existential distress alone near the end of life may benefit from lower forms of sedation such as respite sedation and should receive an appropriate level of palliative care.[150]

In short, the administration of palliative sedation for existential distress alone would be outside the usual criteria for the practice of palliative sedation, and would blur the distinction between specialist palliative care and euthanasia. In an examination of the literature in this area de Graeff suggests that sedation for 'psychological or existential distress should be initiated only under exceptional circumstances and only after consultations with experts in this area.'[151] In effect, the symptoms which may require palliative sedation should be clearly set out to ensure that patients can receive appropriate care regardless of location. Nevertheless, the identification of symptoms giving rise to palliative sedation is only one aspect of this practice.

It is necessary to recognise that while doctors regularly commence the sedation of a patient this is a practice which nurses may also perform.[152] Benzodiazepines, opioids and barbiturates are commonly used forms of palliative medication.[153] An opiate such as morphine functions primarily as a painkiller, whereas benzodiazepines serve to sedate the patient so they do not feel the same level of pain. Opiates therefore are 'not reliable sleep-inducing agents by themselves.'[154] Consequently, benzodiazepines or barbiturates[155] are increasingly used for palliative sedation.

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[149] Text to n40 in Chapter Three.
[150] Irish Association of Palliative Care, 'Palliative Sedation' (March 2011).
[151] de Graeff (n126) 71; Rousseau (n127) 295 This form of suffering 'can be just as consequential and distressful as refractory physical symptoms.'; A Bruce and P Boston, 'Relieving existential suffering through palliative sedation: discussion of an uneasy practice' (2011) 67(12) Journal of Advanced Nursing 2732; Tony Morita, 'Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients' (2004) 28(5) Journal of Pain and Symptom Management 445.
[152] Text to n173 in Chapter Five.
[153] Carmen Selva, 'International control of opioids for medical use' (1997) 4(6) European Journal of Palliative Care 194, 194 'Opioids are mainly used for analgesia - acute or severe pain (eg, morphine, pethidine), mild to moderate pain (eg, codeine, dextro propoxyphene)'.
[154] Eric L Krakauer and Thomas E Quinn, 'Sedation in palliative medicine' in Geoffrey Hanks, Nathan I. Cherny, Nicholas A. Christakis, Marie Fallon, Stein Kaasa, and Russell K. Portenoy (eds), *Oxford Textbook of Palliative Medicine* (4th edn, Oxford University Press 2011) 1566.
[155] Paul Rousseau, 'Palliative Sedation in the Management of Refractory Symptoms' (2004) 2(2) The Journal of Supportive Oncology 181, 185; Josep Porta-Sales, 'Palliative sedation: clinical, pharmacological and practical aspects' in Sigrid Sterckx, Kasper Raus, and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013) 69.

Strong opioids used in palliative care include oxycodone, fentanyl, morphine, and hydromorphone. Morphine is the the drug of choice for pain management when the pain is moderate to severe.[156] Fears about addiction, respiratory depression, and excessive sedation have been shown to be largely unfounded.[157] The use of opioids in palliative care has been recommended by the World Health Organisation. For example, the early work of the World Health Organisation on this topic emphasised the importance of opioid products being available for pain management.[158]

There is considerable support for the argument that opioids and sedatives do not hasten the death of the patient. For example, Sykes and Thorns demonstrated that 'there is no evidence that initiation of treatment, or increases in dose of opioids or sedatives, is associated with precipitation of death.'[159] Furthermore, Sykes and Thorns concluded that '[s]edation is generally used over a short period and most of the evidence suggests that in the context of specialist palliative care it is not associated with shortening of life.'[160] This research drew on the seventeen studies which 'addressed the use of sedatives in the care of cancer patients in the final stages of life.'[161] It also included a systematic review which examined three studies published in Spanish. These studies were retrospective and prospective. They included sedation administered in the home, as part of hospital care, in palliative care units, and in a combination of these locations. Consequently, these studies reflect the various ways and locations in which specialist palliative care practices may be provided. Research published in 2009 by Maltoni et al. also serves to underline the fact that appropriate use of palliative sedation does not hasten the death of the patient.[162] This point was again demonstrated by a subsequent literature review conducted by Maltoni et al.[163] The cumulative effect of these studies

[156] Päl Klepstad and others, 'Pain and pain treatments in European palliative care units. A cross sectional survey from the European Association for Palliative Care Research Network' (2005) 19 Palliative Medicine 477, 479.
[157] Henry McQuay, 'Opioids in pain management' (1999) 353 Lancet 2229.
[158] World Health Organisation, *Cancer Pain Relief: With a guide to opioid availability* (2nd edn, World Health Organization 1996) 50.
[159] Nigel Sykes and Andrew Thorns, 'The use of opioids and sedatives at the end of life' (2003) 4 The Lancet Oncology 312, 312
[160] ibid 317.
[161] ibid 314.
[162] Marco Maltoni and others, 'Palliative sedation therapy does not hasten death: results from a prospective multicenter study' (2009) 20 Annals of Oncology 1163.
[163] M Maltoni, E Scarpi, and O Nanni, 'Palliative sedation in end-of-life care' (2013) 25(4) Current Opinion in Oncology 360, 360 'Over the last 12 months, a number of authors have published interesting

is to demonstrate that the primary purpose of administering opioids and sedatives is that of pain relief, and this is not achieved through hastening the death of the patient.

Palliative medication may be administered in a number of different ways including injection, oral, suppository or through intrathecal pump. The intrathecal pump functions by delivering 'small doses of medication directly to the spinal fluid.'[164] This has the effect of increasing the 'relative strength of the drug compared to its oral or intravenous equivalent.'[165] This approach can minimise potential side effects of sedative drugs. The control exercised over the administration of sedative drugs is particularly important due to the harmful consequences associated with an excessive dose. Naturally, it follows that sedation should be the 'lowest necessary to provide adequate relief of suffering.'[166] In the context of morphine it appears that when it is administered at such a level there is 'little data to support the belief that appropriate use of opioids hastens death in patients dying from cancer and other chronic diseases.'[167] The challenge which this presents is the identification of what constitutes an appropriate level of sedative. This level will vary over the course of a patient's care, for example, after the initial sedation the risk of hastening death decreases. This is based on the fact that the 'risk of respiratory depression is greatest when opioids are

new findings on different areas of palliative sedation, that is prevalence, indications, monitoring, duration and choice of drugs. In particular, a clear definition of palliative sedation and of its more pronounced form, deep continuous sedation (DCS), has emerged. It has been confirmed that, when performed in the correct way and with the right aims, palliative sedation does not have a detrimental impact on survival.'

[164] Belverud (n125).

[165] ibid.

[166] Cherny (n130) 586; de Graeff (n126) 67 'The initial dose of sedatives should usually be small enough to maintain the patients' ability to communicate periodically.'; Rousseau (n149) 153 'Finally, once PS is initiated, the dosage of the sedative agent should not be increased unless the patient awakens, is restless or grimaces, withdraws from touch and other stimuli, or has any other findings that could reasonably be interpreted as evidence of suffering, including tachypnea or tachycardia.'

[167] Susan Anderson Fohr, 'The Double Effect of Pain Medication: Separating Myth from Reality' (1998) 1(4) Journal of Palliative Medicine 315, 318; Nigel Sykes and Andrew Thorns, 'The use of opioids and sedatives at the end of life' (2003) 4 The Lancet Oncology 312, 312 'there is no evidence that initiation of treatment, or increases in dose of opioids or sedatives, is associated with precipitation of death.'; de Graeff (n126) 77 'Retrospective studies strongly suggest that appropriately used PST does not shorten life.'; Richard Huxtable, *Euthanasia, Ethics and the Law: From Conflict to Compromise* (Routledge-Cavendish 2007) 88-91; Johan Legemaate and others, 'Palliative Sedation in the Netherlands: Starting-points and Contents of a National Guideline' (2007) 14 European Journal of Health Law 61, 64 'The committee has taken the view that palliative sedation is a normal medical procedure and must be clearly distinguished from termination of life, because there is no evidence that palliative sedation — if administered carefully — hastens death.'; B Barathi and Prabha S Chandra, 'Palliative Sedation in Advanced Cancer Patients: Does it Shorten Survival Time? - A Systematic Review' (2013) 19(1) Indian Journal of Palliative Care 40.

first begun.'[168] As treatment progresses, the ability of a patient to cope with respiratory side effects increases,[169] but over time toxicity may occur.

The level of sedation which results in toxicity varies among people.[170] Toxicity depends on factors such as 'the degree of responsiveness of the pain to opioid, prior exposure to opioids, rate of titration of the dose, concomitant medication, and renal function.'[171] Similarly, patients may often develop a tolerance to benzodiazepines over the course of sedation. This should be factored in when commencing palliative sedation through the use of a benzodiazepine.[172] The combination of these factors underlines the difficulty in accurately judging an appropriate level of the sedative drug. A patient experiencing toxicity may demonstrate agitation which could be seen as pain which is not being adequately controlled.[173] Consequently, in demonstrating these symptoms further sedation may be given to control the presumed pain.[174] This has been described as a 'vicious cycle'[175] and results in even greater toxicity.[176] The potential effect of this is that an excessive dose may be administered.

It has been mentioned by some that palliative care needs to 'accept that there are some occasions when the process of death is hastened, either unknowingly or knowingly.'[177] This has led to suggestions that palliative sedation may amount to 'slow euthanasia'[178]

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[168] Anderson Fohr (n167) 316 citing CS Hill, 'The barriers to adequate pain management with opioid analgesics' (1993) 20 Seminars in Oncology 1 Note that opioids are used far less frequently.
[169] Ann Alpers, 'Criminal Act or Palliative Care? Prosecutions Involving the Care of the Dying' (1998) 26 Journal of Law, Medicine and Ethics 308, 310 'Significant respiratory depression rarely occurs in a patient whose opioid dose has been gradually adjusted against pain.'; Anderson Fohr (n157) 316.
[170] Bill O'Neill and Marie Fallon, 'ABC of Palliative Care: Principles of Palliative Care and Pain Control' (1997) 315(7111) British Medical Journal 801, 804.
[171] ibid.
[172] Josep Porta-Sales, 'Palliative sedation: clinical, pharmacological and practical aspects' in Sigrid Sterckx, Kasper Raus, and Freddy Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013) 70-71; Helga Kuhse, *The Sanctity-of-Life Doctrine in Medicine: A Critique* (Clarendon Press 1987) 87 constant monitoring of the level of palliative medication administered is essential in avoiding what Kuhse describes as 'pyramid' pain-killing i.e. 'the administration of increasing and finally lethal doses of pain-killing drugs.'
[173] ibid.
[174] ibid.
[175] ibid.
[176] ibid.
[177] Michael Ashby, 'Death Causation in Palliative Medicine' in Ian Freckelton and Danuta Mendelson (eds), *Causation in Law and Medicine* (Hampshire 2002) 228, 247.
[178] J Andrew Billings and Susan D Block, 'Slow euthanasia' (1996) 12 Journal of Palliative Care 21; BM Mount, 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes' (1996) 12 Journal of Palliative Care 31; H Brody, 'Commentary on Billings and Block's 'Slow Euthanasia'' (1996) 12 Journal of Palliative Care 38; Russell K Portenoy, 'Morphine Infusions at the End of Life: the Pitfalls in reasoning from anecdote' (1996) 12 Journal of Palliative Care 44.

or 'backdoor euthanasia'.[179] Furthermore, Mason and Laurie describe the practice as 'euthanasia hiding under the emollient terminology which can do little other than still further confuse the taxonomy of assisted dying.'[180] Such suggestions have resulted in an increased focus on the manner in which palliative sedation is used,[181] and a need to accurately distinguish this practice from euthanasia. Consequently, it is vital that the legality of palliative sedation be demonstrated in this jurisdiction. However, any dividing line would be viewed as illusory if there is an inadequate legal framework to support this distinction.

Further criticism of palliative sedation comes from the slippery slope argument.[182] The slippery slope argument is based on the fear that palliative sedation would be abused and applied broadly.[183] It has been noted that palliative care in the hospice 'focuses on symptom control and support rather than cure or life prolongation';[184] a worry of this is that medical practitioners may begin to view their work in a fatalistic way. This leads to the slippery slope argument that medical practitioners may begin to focus on death alone.[185] Linked with this argument is the concern that where sedation is readily accepted or available it may result in patients or doctors choosing sedation where 'less drastic options are still available.'[186] The validity of the slippery slope argument was

[179] Gevers (n138) 360; Select Committee on Dying with Dignity (Québec, March 2012) 38 'For some physicians, continuous palliative sedation is very different from euthanasia. For others, it is simply euthanasia in disguise.'

[180] J Kenyon Mason and Graeme T Laurie, *Mason & McCall Smith's Law & Medical Ethics* (9th edn, Oxford University Press 2013) 615.

[181] Bert Gordijn and Rien Janssens, 'Euthanasia and Palliative Care in the Netherlands: An Analysis of the Latest Developments' (2004) 12(3) Health Care Analysis 195, 204 'The issue of terminal sedation has only recently attracted public attention in the Netherlands, whereas it has been more extensively under debate abroad.'

[182] Eric Lode, 'Slippery Slope Arguments and Legal Reasoning' (1999) 87 California Law Review 1469; Eugene Volokh, 'The Mechanisms of the Slippery Slope' (2003) 116 Harvard Law Review 1026; Stephen W Smith, 'Evidence for the practical slippery slope in the debate on physician-assisted suicide and euthanasia' (2005) Medical Law Review 17; Stephen W Smith, 'Fallacies of the logical slippery slope in the debate on physician-assisted suicide and euthanasia' (2005) Medical Law Review 224.

[183] Nathan I Cherny, 'The use of sedation to relieve cancer patients' suffering at the end of life: addressing critical issues' (2009) 20 Annals of Oncology 1153, 1154 'Abuse of palliative sedation occurs when clinicians sedate patients approaching the end of life with the primary goal of hastening the patient's death.'

[184] J Andrew Billings, 'What is Palliative Care?' (1998) 1(1) Journal of Palliative Medicine 73, 73.

[185] Gillian M Craig, 'On Withholding Nutrition and Hydration in the Terminally Ill: Has Palliative Medicine Gone Too Far? (1994) 20(3) Journal of Medical Ethics 139, 139 'There is a risk that if all the staff in an institution are orientated towards death and dying and non-intervention, treatable illness may be overlooked. Not everyone who is referred for terminal care proves to be terminally ill, and no physician should accept such a diagnosis without reviewing the evidence personally.'

[186] Timothy E Quill and others, 'Last-Resort Options for Palliative Sedation' (2009) 151(6) Annals of Internal Medicine 421, 422.

examined in detail by Volokh.[187] This article demonstrated how the slippery slope argument must also rely on a judicial slippery slope for change to occur. The judiciary and the legislature provide valuable safeguards in demarcating the grounds of acceptable medical practice. Unfortunately, this also means that the slippery slope argument may gain greater traction if the legal framework is shown to be inadequate. The legitimacy of the distinction between palliative sedation and euthanasia will be drawn out over Chapters Three, Four, Five, and Six as will the existing legal framework for specialist palliative care. In any case, uncertainty does not benefit the level of care provided and it has been suggested that a lack of clarity on the sedation of a patient could be seen as 'a major cause of under treatment of cancer pain.'[188] However, uncertainty is not limited to palliative sedation. It is important to recognise that the withdrawal of artificial nutrition and hydration often accompanies the administration of palliative sedation and must be examined.[189]

Artificial Nutrition and Hydration

The withdrawal of artificial nutrition and hydration often accompanies palliative sedation but it is necessary to distinguish the two as they are 'separate decisions supported by different legal and ethical principles.'[190] Artificial nutrition involves the provision of nutrition through non oral methods such as nasogastric tube,[191] percutaneous endoscopic gastrostomy tube,[192] or the use of total parenteral nutrition.[193] Artificial hydration refers to:

> the administration of fluids to patients who are unable to tolerate oral fluids by any of the following routes: intravenous, subcutaneous, nasogastric, gastrostomy or jejunostomy. A distinction is generally made between such

[187] Volokh (n182).
[188] Anderson Fohr (n167) 319.
[189] Gevers (n138) 360.
[190] ibid 364; RJ Dunlop and others, 'On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?: A reply' (1995) 21 Journal of Medical Ethics 141 cited in GM Craig, 'On Withholding Artificial Hydration and Nutrition from Terminally Ill Sedated Patients. The Debate Continues' (1996) 22(3) Journal of Medical Ethics 147; *Fleming* v *Ireland & Ors* [2013] IEHC 2 [37]; Maltoni (n135) 365 'The decision-making processes to start palliative sedation and to stop nutrition and hydration are actually two different processes.'
[191] 'Nutritional support (artificial feeding)' (Macmillan Cancer Support, 1 January 2013) <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Eatingwell/Nutritionalsupport/Nutritionalsupport.aspx#DynamicJumpMenuManager_6_Anchor_6> accessed 8 June 2014.
[192] ibid.
[193] ibid.

> 'artificial' means and ordinary means, as in the use of a cup or spoon to administer fluids orally to a patient.[194]

Reasons given for withdrawing artificial nutrition and hydration include the suggestion that its provision would 'lengthen the dying process',[195] it may be judged that the patient 'has nothing to gain from it',[196] or the patient may have requested that artificial nutrition and hydration be stopped. It has been suggested that withdrawing hydration may be beneficial as it results in a reduction in coughing, vomiting, and interventions such as suctioning.[197] However, such positions are to be questioned, particularly in light of a 2008 literature review by Good et al.[198] and a 2011 literature review carried out by Raijmakers et al.[199] which are discussed in turn below.

The purpose of the review by Good et al. was to examine the impact of artificial hydration on the 'quality and length of life'[200] of patients receiving palliative care. This review identified five relevant studies. Three of these studies identified no 'significant differences in outcome'[201] between patients who had received hydration and those who had not. Another study examined by Good et al. 'found that sedation and myoclonus (involuntary contractions of muscles) were improved'[202] in the group which had artificial hydration withdrawn. The final study showed that 'some fluid retention symptoms were significantly higher in the hydration group'.[203] As such, no clear position can be identified in relation to the withdrawal of artificial hydration. In this regard, the review by Good et al. set out that 'There are insufficient good quality studies to make any recommendations for practice with regard to the use of medically assisted hydration in palliative care patients.'[204] Furthermore, Good et al. noted that one of the main ethical controversies in artificial hydration is 'whether medically

[194] Irish Association of Palliative Care (n34).
[195] Gevers (n138) 361.
[196] ibid.
[197] de Graeff (n126) 76.
[198] Phillip Good and others, 'Medically Assisted Hydration for Adult Palliative Care Patients' (2008) 2 Cochrane Database of Systematic Reviews.
[199] NJH Raijmakers and others, 'Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects' (2011) 22 Annals of Oncology 1478.
[200] Good (n198).
[201] ibid 1-2.
[202] ibid 1.
[203] ibid 1.
[204] ibid 2.

assisted hydration is a medical intervention or a basic provision of comfort.'[205] This was among the issues addressed by the Court in *Re a Ward of Court*.[206]

A literature review has also been carried out by Raijmakers et al. which focussed on the provision of artificial hydration as well as artificial nutrition. Two of the papers in this literature review identified positive effects stemming from the provision of artificial hydration[207] while two recognised negative effects.[208] In contrast to this, four papers did not identify any effect on 'terminal delirium, thirst, chronic nausea, and fluid overload.'[209] This literature review concludes that 'little is known concerning the life-shortening or prolonging effect'[210] of artificial nutrition or artificial hydration. In effect, the position of existing research is such that it makes it difficult to establish appropriate guidelines for practice and makes court decisions on these practices more challenging. On this basis, a lack of national guidance on the withdrawal of artificial nutrition and hydration combined with the prevalence of local policy would only serve to generate inconsistency between the providers of specialist palliative care in this jurisdiction. This is an issue which will be examined over the course of this thesis.

Conclusion

The aim of this Chapter was to introduce the subject of palliative care and highlight the issues which will be addressed in the course of this thesis. The expansion in palliative care providers, the breadth of illnesses which palliative care treats, and the challenges presented by specialist palliative care practices were examined. Several key points emerged over the three sections in this Chapter. First, the limited state involvement in the development of palliative care was clearly underlined. Representative bodies and non-governmental organisations have taken on much of the responsibility for developing what is now a recognised medical specialty. This has

[205] Good (n198) 2.
[206] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401; Denis A Cusack, 'Re A Ward of Court: Medical Law and Medical Ethics Diverge, a Medico-Legal Analysis' (1995) 1(2) Medico-Legal Journal of Ireland 43; Kenneth Kearon, 'Re A Ward of Court: Ethical Comment' (1995) 1(2) Medico-Legal Journal of Ireland 58; John Harrington, 'Withdrawal of Treatment from an Incompetent Patient' (1995) 2(1) Dublin University Law Journal 120; John Keown, 'Life and Death in Dublin' (1996) 55(1) Cambridge Law Journal 6.
[207] Raijmakers (n199) 1478 Positive effects were 'less chronic nausea, less physical dehydration signs'.
[208] ibid Negative effects were 'more ascites, more intestinal drainage'.
[209] ibid.
[210] ibid 1485.

resulted in the fragmented provision of palliative care and a reliance on local policy to provide guidance on complex issues. Second, the value of national guidelines was especially clear in the second and third sections of this Chapter. Clear guidelines are required to support and protect both the healthcare professional and the patient. Third, the legitimacy of the distinction between specialist palliative care practices and euthanasia must be examined. This will clarify the legality of specialist palliative care practices and will also draw out the strengths and weaknesses in the current legal framework. This ensures that the legal framework for specialist palliative care is comprehensively examined and that appropriate suggestions for reform can be advanced in due course.

THE DISTINCTION IN CRIMINAL LAW BETWEEN SPECIALIST PALLIATIVE CARE PRACTICES AND EUTHANASIA

Introduction

The term 'palliative' comes from the Latin word 'pallium' which means 'mask' or 'cloak'.[1] It was suggested by the Council of Europe that this demonstrates the true role of palliative care which is to hide 'the effects of incurable disease, or providing a cloak for those who are left in the cold, because they cannot be helped by curative medicine.'[2] However, there is another way in which palliative care may serve as a cloak. Suggestions have, for example, been made that 'morphine drips in such cases are a form of "slow euthanasia"'[3] and that 'palliative care is an alternative to permitting euthanasia on grounds of compassion'.[4] These comments suggest that specialist palliative care practices are not easily distinguished from euthanasia. The confusion over this distinction has the potential to hamper the care offered to patients if healthcare professionals do not have a clear legal framework in which to practise. The aim of this Chapter is to examine the legitimacy of the distinction between specialist palliative care practices and euthanasia. It will be shown that a distinction can be made and this will clarify the legality of palliative sedation and the withdrawal of artificial nutrition and hydration from the terminally ill patient. As such, this Chapter has a significant role in defining the current legal framework and, in particular, highlighting areas of ambiguity which need to be addressed.

The legality of specialist palliative care practices will be drawn out over the course of three sections. In the first section, the practice of euthanasia in the Netherlands will be outlined. An examination of the Dutch system, as it operates in practice, provides

[1] JRV Marchant and Joseph F Charles, *Cassell's Latin Dictionary (Latin-English and English-Latin)* (Cassell and Company 1948) [pallium] 390; William Smith and John Lockwood, *Chambers Murray Latin-English Dictionary* (Chambers 1976) [pallium] 504.

[2] Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003 Explanatory Memorandum [43].

[3] J Andrew Billings and Susan D Block, 'Slow euthanasia' (1996) 12 Journal of Palliative Care 21; B Mount, 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts' (1996) 12 Journal of Palliative Care 31; H Brody, 'Commentary on Billings and Blocks "Slow Euthanasia"' (1996) 12 Journal of Palliative Care 38.

[4] James Gilbert, 'Palliative medicine: a new specialty changes an old debate' (1996) 52(2) British Medical Bulletin 296, 297.

greater insight into the practice of voluntary active euthanasia and physician assisted suicide than can be achieved from merely setting out the definition of these practices. Additionally, addressing the position in the Netherlands at an early point in the Chapter allows for the Irish legal framework to subsequently be compared and contrasted against the legal framework in the Netherlands for euthanasia. Voluntary active euthanasia rather than physician assisted suicide is of most relevance to this Chapter due to the similarities this practice shares with palliative sedation. For instance, it is the healthcare professional who ultimately administers the drug to the patient in both voluntary active euthanasia and palliative sedation. The patient does not act to administer or take the drug as would be the case in physician assisted suicide. Voluntary active euthanasia can be performed, subject to certain criteria, in jurisdictions including Belgium,[5] Luxembourg,[6] and the Netherlands.[7] Of these, the Netherlands is the most appropriate jurisdiction to examine for the purposes of this thesis. This is due to the legislation on euthanasia and case law in the Netherlands which allows for a greater understanding of what the limits of the legislation are, as well as demonstrating the motivation behind the introduction of the legislation. The combination of legislation and case law provides a more detailed image of this practice and is necessary in order to accurately examine the basis of the distinction between specialist palliative care practices and euthanasia.

In contrast to the position in the Netherlands, there are no exceptions to the illegality of voluntary active euthanasia and assisted suicide in Ireland.[8] If a doctor provides voluntary active euthanasia in this jurisdiction it is likely to lead to a charge of murder or manslaughter. As a result of this, it is necessary to set out the law on homicide and assisted suicide in Ireland. This will be addressed in the second section of this Chapter and will begin to expose elements of uncertainty in the distinction between specialist palliative care practices and euthanasia. The offence of murder and the requisite elements which must be established in such a case will be discussed. The role of

[5] The Belgian Act on Euthanasia of May, 28th 2002; John Griffiths, Heleen Weyers and Maurice Adams, *Euthanasia and law in Europe* (Hart Publishing 2008) 257.
[6] Legislation Reglementant les Soins Palliatifs ainsi que L'euthanasie et L'assistance au Suicide, 16 mars 2009 Memorial Journal Officiel du Grand-Duché de Luxembourg 609.
[7] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001; Griffiths (n5) 11.
[8] Criminal Law (Suicide) Act 1993, s 2.

intention will be given particular attention due to the challenges it poses in the context of specialist palliative care and its importance in the doctrine of double effect.

The doctrine of double effect will be examined in the third section of this Chapter. It has a substantial role in distinguishing between specialist palliative care practices and euthanasia as it provides a justification for practices which begin to blur the lines of this distinction. The doctrine of double effect will be examined for its theoretical background and its application in case law. Again, this allows for a comprehensive approach by examining the legitimacy of the doctrine itself and considering how it is being applied and interpreted by the courts.

In Chapter Two it was highlighted that palliative sedation is often accompanied by the withdrawal of artificial nutrition and hydration but they are distinct practices.[9] The withdrawal of artificial nutrition and hydration is regularly justified based on slightly strained reasoning around the acts and omissions distinction.[10] The third section of this Chapter will also examine the acts and omissions distinction in order to distinguish the withdrawal of artificial nutrition and hydration from euthanasia. In particular, the cases of *Airedale N.H.S. v Bland*[11] and *Re a Ward of Court*[12] will be referred to when discussing the legality of withdrawing artificial nutrition and hydration. It will be highlighted in the third section that there is no single approach to the application of the doctrine of double effect or the acts and omissions distinction. The application of these justifications will vary based on factors such as the ethical lens through which these practices are viewed. The scope for differing interpretations undermines a consistent application of double effect and the acts and omissions distinction. Consequently, in this Chapter it will be shown that it is not sufficient to justify specialist palliative care practices based on double effect or the acts and omissions

[9] Text to n187 in Chapter Two.
[10] *Airedale N.H.S. v Bland* [1993] AC 789, [1993] 2 WLR 350; *W Healthcare NHS Trust v KH*, [2004] WLR 834, patient not in a persistent vegetative state; *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403; *Swindon and Marlborough NHS Trust v S* [1995] 3 Medical Law Review 84; *An NHS Trust v M* [2001] 2 FLR 367; *An NHS Trust v H* [2001] 2 FLR 501; *In re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2011] EWHC 2443 (Fam), [2012] 1 WLR 1653; *W(by her litigation friend B) v M(by her litigation friend, the Official Solicitor) and S and A NHS Primary Care Trust* [2011] EWHC 2443 (Fam); *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.
[11] *Airedale N.H.S. v Bland* [1993] AC 789, [1993] 2 WLR 350.
[12] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.

distinction alone. Therefore, a more substantial legal framework is needed to support specialist palliative care practices. Overall, the combination of the three sections in this Chapter allows for the legality of specialist palliative care practices to be drawn out over the course of the Chapter while highlighting issues which need to be addressed in subsequent chapters.

Euthanasia in Practice: The Netherlands

The introduction of legislation for voluntary active euthanasia and physician assisted suicide in the Netherlands was motivated by several cases which came before the Dutch courts. In 1973, a Dutch doctor was prosecuted for administering a fatal dose of morphine to her mother.[13] The doctor's mother was 'partially paralyzed on one side, was incontinent, scarcely able to read any longer, and very hard of hearing'.[14] As a result of this, the doctor's mother repeatedly expressed a wish to die. The facts of this case suggest it is an example of voluntary active euthanasia. The court held the doctor to be guilty of taking the life of a patient by request but the doctor was given a suspended sentence of one week in prison.

Subsequent cases such as *Schoonheim*,[15] *Chabot*,[16] and *Brongersma*[17] developed the reasoning to a point where a doctor could act in a direct way subject to certain criteria. Eventually this reasoning was put on a legislative footing by the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*. This legislation has been described as establishing 'A delicate balance … between statutory law that prohibits euthanasia, case law that stipulates conditions for non-prosecution, and controlled acceptance in practice.'[18] This demonstrates that case law must be referred

[13] *Nederlandse Jurisprudentie* 1973, no. 183, District Court of Leeuwarden, 21, February 21, 1973; Walter Lagerway (tr), (1988) 3 Issues in Law and Medicine 439.
[14] ibid 441.
[15] Hoge Raad (Supreme Court of the Netherlands), 27 November 1984, NJ 1985, No. 106; Jurriaan De Haan, 'The new Dutch law on euthanasia' (2002) Medical Law Review 57, 59 'Schoonheim was a general practitioner who had administered euthanasia to a 95-year-old woman in a very bad medical condition on her explicit and repeated request. In the Schoonheim case, the Supreme Court opened up the possibility of a successful appeal to the general defence of necessity, i.e. to section 40 of the Criminal Code … In particular, Schoonheim may have faced a conflict of duties: on the one hand, the duty to obey the law which categorically forbids euthanasia; on the other hand, the duty to relieve suffering and to respect his patient's wishes. Where there exists such a dilemma of law and medical ethics, it is possibly justified to commit euthanasia.'
[16] Hoge Raad (Supreme Court of the Netherlands), 21 June 1994, NJ 1994, 656.
[17] Hoge Raad (Supreme Court of the Netherlands), 24 December 2002, NJ 2003, 167.
[18] Sjef Gevers, 'Euthanasia: law and practice in The Netherlands' (1996) 52(2) British Medical Bulletin 326, 332.

to alongside the legislation in order to provide greater detail on the circumstances in which euthanasia may be permitted.

The *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001* amended Article 293 and Article 294 of the Dutch Criminal Code. Article 293 addressed the practice of voluntary active euthanasia, while Article 294 amended the law on physician assisted suicide. Article 293 is of most relevance to this Chapter as its focus is on voluntary active euthanasia. Both palliative sedation and voluntary active euthanasia are largely doctor led practices and this similarity is central to distinguishing euthanasia from palliative sedation. It is the medical practitioner who normally administers the sedative drug or administers the drug for euthanasia.[19] Article 293(1) of the Dutch Criminal Code now sets out that 'Any person who terminates another person's life at that person's express and earnest request shall be liable to a term of imprisonment not exceeding twelve years or a fifth category fine.'[20] On this basis, voluntary active euthanasia is not permitted in the Netherlands. However, an exception to this is provided by Article 293(2) of the Dutch Criminal Code which stipulates that the act will not be illegal in circumstances where 'it is committed by a physician who fulfils the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act'.[21] In effect, if a doctor complies with Article 293(2) there would be 'nothing legally wrong'[22] with their conduct. Similarly, physician assisted suicide is illegal under Article 294 of the Dutch Criminal Code except in circumstances where the due care criteria have been complied with.[23]

The due care criteria are set out in section 2 of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001* and reflect the case law on euthanasia in the Netherlands prior to the introduction of this Act.[24] The due care criteria are satisfied in cases where the doctor:

[19] The nurse has an increasing role in this area as demonstrated by the role of the nurse prescriber in this jurisdiction. Text to n173 in Chapter Five.
[20] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, Article 293(1).
[21] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, Article 293(2).
[22] Jurriaan De Haan, 'The new Dutch law on euthanasia' (2002) Medical Law Review 57, 58.
[23] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, Article 294(2).
[24] De Haan (n22) 58-59 'The new Act on euthanasia is the result of a process of public debate and legal change in the Netherlands which has taken place during the last thirty or so years.'; *Carter v Canada (Attorney General)* 2012 BCSC 886, [457] 'The Dutch Act is in part the codification of a permissive

> holds the conviction that the request by the patient was voluntary and well-considered,
> holds the conviction that the patient's suffering was lasting and unbearable,
> has informed the patient about the situation he was in and about his prospects,
> and the patient hold the conviction that there was no other reasonable solution for the situation he was in,
> has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care,
> has terminated a life or assisted in a suicide with due care.[25]

All of these criteria must be met in order to comply with the exemption provided by Article 293(2) of the Dutch Criminal Code. The most challenging of these criteria may be the need to recognise suffering which is 'lasting and unbearable'. The challenges presented by this criterion can be demonstrated in the case law on euthanasia prior to and subsequent to the introduction of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*.

Defining 'Lasting and Unbearable Suffering'

Examining this criterion outlines the scope and availability of euthanasia in the Netherlands and further assists in distinguishing between specialist palliative care practices and euthanasia. In this regard, it is to be remembered that the main indication for palliative sedation is the presence of a 'refractory symptom'.[26] As such, the distinction between 'lasting and unbearable' suffering and a 'refractory symptom' is a significant element in distinguishing specialist palliative care from euthanasia.

regime that had developed through a series of judicial decisions and professional guidelines issued over the preceding three decades.'

[25] Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, Article 293(2).

[26] Nathan I Cherny and RK Portenoy 'Sedation in the management of refractory symptoms: guidelines for evaluation and treatment' (1994) 10 Journal of Palliative Care 31 quoted in Marco Maltoni, Emanuela Scarpib and Oriana Nannib, 'Palliative sedation in end-of-life care' (2013) 25(4) Current Opinion in Oncology 360, 362 'The milestone definition of 'refractory symptom' is 'symptom for which all possible treatment has failed or it is estimated that no methods are available for palliation within the time frame and the risk–benefit ratio that the patient can tolerate'

Article 293(2) of the Dutch Criminal Code requires Dutch physicians to be able to identify 'suffering' and to recognise when that suffering is 'lasting' and 'unbearable'. The due care criteria clearly establishes a number of hurdles which doctors must overcome. The term 'suffering' is defined in a position paper on euthanasia published by the Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association) [hereinafter 'KNMG'] as 'the experience of pain or distress.'[27] This is a very broad definition and underlines the subjective nature of deciding what level of pain or distress is 'unbearable' and 'lasting'. In relation to the identification of 'lasting' suffering, the KNMG position paper suggests that this will be significantly influenced by the 'physician's professional opinion about the treatment and care options still available to the patient'.[28] Other concerns which can be factored in to a decision include the likely trajectory of the disease,[29] whether there is 'loss of function',[30] and the nebulous concept of whether the patient could still 'lead a meaningful life'.[31] The KNMG position paper and the corresponding legislation clearly provides a broad range of discretion to the physician in identifying 'lasting' suffering. Furthermore, the lack of a clearly defined timeframe in the legislation or in the KNMG position paper suggests that the doctor is to look beyond a timescale and consider the cumulative impact of an illness on a person's life.

The criterion that the suffering be 'unbearable' is equally difficult to accurately identify. The KNMG position paper sets out that 'The question of whether suffering is unbearable is one that only the patient can answer.'[32] Despite this quote emphasising the subjective nature of pain,[33] it is the doctor who makes the final decision. The doctor must be satisfied as to the nature of the suffering as well as its duration. For a majority of patients the source of suffering is due to 'somatic problems and ailments, with 80-

[27] KNMG, 'The role of the physician in the voluntary termination of life' (June 2001) 20; KNMG, 'The role of the physician in the voluntary termination of life' (June 2001) 13 'The purpose of this memorandum is to present the KNMG's current standpoint on the role, responsibilities, possibilities and limitations that physicians have with regard to the issue of the voluntary termination of life.'
[28] ibid 20.
[29] ibid 'Is it likely that the patient's condition will improve to a satisfactory degree? Or is it more likely that it will only deteriorate?'
[30] ibid.
[31] ibid.
[32] ibid.
[33] ibid 'Suffering is an expression of the whole being and is influenced by personal experiences and conceptions and by cultural values and standards.'

90% of notified cases concerning malignancies.'[34] However, this demonstrates that lasting and unbearable suffering may also have a non-somatic origin.[35] The manner in which non-somatic suffering such as existential distress is treated is particularly challenging. This point was highlighted in Chapter Two in the context of palliative sedation[36] but it has also posed challenges for the Dutch Criminal Code.

The issue of non-somatic suffering arose in the Dutch cases of *Chabot* and *Brongersma*. The case of *Office of Public Prosecutions v Chabot* provided a degree of clarity about the type of suffering for which physician assisted suicide could be provided in the Netherlands.[37] It is important to note that this case arose prior to the introduction of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*. However, this type of case influenced the drafting of the 2001 Act.

In *Chabot*, a psychiatrist assisted in the death of a 50 year old woman who was named as Mrs. B. Dr. Chabot had several meetings with Mrs. B which lasted 24 hours in all,[38] and also spoke with Mrs. B's sister and brother-in-law. On a number of occasions, Dr. Chabot discussed the case with several consultants and provided them with a detailed account of the situation so as to encourage 'suggestions concerning matters which he might have overlooked in the psychiatric investigation of Mrs B'.[39] Dr. Chabot was of the opinion that Mrs. B was 'experiencing intense, long-term psychic suffering that, for her, was unbearable and without prospect of improvement.'[40] This again demonstrates the importance placed on the subjective experience of pain. Moreover, Dr. Chabot believed that the woman's 'request for assistance with suicide was well-

[34] ibid 21; Harvey Marcovitch (ed), *Black's Medical Dictionary* (41st edn, A & C Black Publishers 2005) 656. Defines somatic as '(1) A term describing tissues of the body that do not form any part of the reproductive process. (2) It is also used to refer to the body rather than the mind.'
[35] Marilyn Lewis Lanza, 'Nurses as patient assault victims: An update, synthesis, and recommendations' (1992) 6(3) Archives of Psychiatric Nursing 163 cited by Ian Needham and others, 'Non-somatic effects of patient aggression on nurses: a systematic review' (2005) 49(3) Journal of Advanced Nursing 283, 284. Non-somatic effects were identified as 'bio-physiological, emotional, cognitive, and social reactions.'
[36] Text to n148 in Chapter Two.
[37] Hoge Raad (Supreme Court of the Netherlands), 21 June 1994, NJ 1994, 656.
[38] John Griffiths, 'Assisted Suicide in the Netherlands: The Chabot Case' (1995) 58(2) The Modern Law Review 232, 234.
[39] ibid.
[40] ibid 235.

considered … and showed that she understood her situation and the consequences of her decision.'[41]

Dr. Chabot concluded that the only solution was a course of treatment which would bring about the death of the patient. Dr. Chabot was prosecuted and acquitted in the first instance and on appeal. The case came before the Supreme Court which 'refused to distinguish between psychological and physical suffering, as proposed by the prosecution.'[42] In effect, the Court interpreted the experience of pain and suffering in a broad manner. For example, the case demonstrated that the identification of suffering can be 'abstracted from its cause.'[43] However, adopting this line of reasoning in the provision of palliative sedation would have troublesome consequences for the legitimacy of the distinction between specialist palliative care and euthanasia. It was recognised in Chapter Two that the administration of sedation for existential distress and restlessness alone is controversial[44] as it would be treating psychological distress rather than physical pain experienced by the patient. Furthermore, existential suffering may occur when a patient is not imminently dying. The provision of palliative sedation in such an instance would be outside the standard criteria for refractory symptoms and would therefore blur the distinction between specialist palliative care practices and euthanasia. Consequently, there exists the potential for confusing specialist palliative care and euthanasia if healthcare professionals do not have an appropriate legal framework in this respect. In short, ambiguity on this subject undermines clarity and consistency in specialist palliative care.

The limits of physician assisted suicide in the Netherlands were again tested in the case of *Brongersma*.[45] In contrast to *Chabot*, the case of *Brongersma* was heard during

[41] ibid.
[42] Ubaldus De Vries, 'Can a Legal Right to Euthanasia Exist? A Dutch Perspective on a Universal Medico-Ethical Dilemma' (2003) 9(1) Medico-Legal Journal of Ireland 24, 25.
[43] ibid 26.
[44] Nathan I Cherny, 'Sedation in response to refractory existential distress: Walking the fine line' (1998) 16 Journal of Pain Symptom Management 404; Tatsuya Morita and others, 'Terminal sedation for existential distress' (2000) 17 American Journal of Hospice Palliative Care 189; Paul C Rousseau, 'Existential suffering and palliative sedation: A brief commentary with a proposal for clinical guidelines' (2001) 18 American Journal of Hospice Palliative Care 151; Tatsuya Morita, 'Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients' (2004) 28 Journal of Pain Symptom Management 445; Brigit R Taylor and Robert M McCann, 'Controlled sedation for physical and existential suffering?' (2005) 8(1) Journal of Palliative Medicine 144.
[45] Hoge Raad (Supreme Court of the Netherlands), 24 December 2002, NJ 2003, 167. Mr. Brongersma was a former lawyer and Senator in the Netherlands; Griffiths (n6) 35.

and after the introduction of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*.[46] Mr. Brongersma suffered from his physical deterioration and a feeling of senselessness in his existence. He was seen by a psychiatrist who concluded that the patient did not suffer from any psychiatric illness that would explain his desire to die. However, the sincerity of Mr Brongersma's desire to die was confirmed by another doctor. In April 1998 Mr. Brongersma committed suicide with the assistance of his doctor, Philip Sutorius.

The key issue in the case of *Brongersma* was the legality of assisted suicide for existential suffering. The District Court accepted the opinion that Mr. Brongersma's suffering was unbearable and hopeless. This led to the acquittal of Dr. Sutorius. However, the Court of Appeals reversed the decision of the District Court and Dr. Sutorius was convicted for 'purposefully aiding another person to commit suicide and providing him with the means to do so, resulting in the suicide'.[47] On appeal, the Supreme Court followed this ruling but did not impose any penalty on the doctor for his involvement. The approach taken by the Supreme Court demonstrated that the suffering of a patient 'should have its principal basis in one or more medically classifiable somatic or psychological illnesses or conditions.'[48] This suggests that euthanasia is legal in the Netherlands provided that the non-somatic condition is 'medically classifiable'.[49] The result of this is that many patients may come within the due-care criteria for euthanasia based on how their mental suffering is classified. This has also been reflected in a broader interpretation by doctors as to what constitutes 'lasting and unbearable suffering'.

The KNMG position paper suggests that a 'less restrictive'[50] approach began after the ruling in *Brongersma*. In this position paper it is also suggested that issues such as 'loss of function, loneliness and loss of autonomy'[51] may form part of the discussion in considering a request for physician assisted suicide. This would be another

[46] Stuart J Youngner and Gerrit K Kimsma, *Physician-Assisted Death in Perspective: Assessing the Dutch Experience* (Cambridge University Press 2012) 59 'The first trial took place in October 2000, on the same day as initial parliamentary deliberation on the government's bill.'
[47] Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst, 'The role of the physician in the voluntary termination of life' (June 2001) 10.
[48] ibid.
[49] ibid.
[50] ibid 26.
[51] ibid 40.

significant expansion in terms of access to physician assisted suicide but remains to be confirmed by the courts. Regardless of any future expansion, it is evident from the cases of *Chabot* and *Brongersma* that the treatment of mental suffering is a complex issue which is not easily addressed by the healthcare professional. These cases underline the need for a clear legal framework in Ireland which addresses the issue of sedation for patients experiencing non-somatic suffering such as existential distress.[52] This would provide clarity on the identification of a 'refractory symptom' and give healthcare professionals a coherent and consistent decision-making framework in which to provide specialist palliative care. The existence of gaps in the legal framework on this issue results in a lack of clarity and uncertainty around specialist palliative care practices and adds further weight to claims that these practices are a form of 'slow euthanasia'.[53] In order to avoid this perception around specialist palliative care it is essential that an appropriate legal framework is in place.

Euthanasia and Assisted Suicide in Ireland: Law and Practice

In Ireland, the *Criminal Law (Suicide) Act 1993* removed the offence of suicide but made it illegal to assist in the suicide of another.[54] Nonetheless, the illegality of euthanasia and assisted suicide in Ireland does not prevent suggestions that specialist palliative care practices resemble euthanasia.[55] This section will examine the effect of the *Criminal Law (Suicide) Act 1993* and case law on euthanasia and the right to life. The aim of this is to identify areas of the legal framework where specialist palliative care tends to blur the distinction with assisted suicide and euthanasia, and raises legally and ethically complex issues for healthcare professionals. These are the issues which should be addressed by an appropriate legal framework for specialist palliative care.

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[52] In Chapter Five it will be shown that the sedation of terminally ill patients experiencing existential distress has not been addressed adequately by professional standards or guidelines in Ireland.

[53] Andrew Billings (n3) 21; Mount (n3); Brody (n3).

[54] Criminal Law (Suicide) Act 1993 s2.

(1) Suicide shall cease to be a crime.

(2) A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be guilty of an offence and shall be liable on conviction on indictment to imprisonment for a term not exceeding 14 years.

(3) If, on the trial of an indictment for murder, murder to which s. 3 of the Criminal Justice Act 1999 applies or manslaughter, it is proved that the person charged aided, abetted, counselled or procured the suicide of the person alleged to have been killed, he may be found guilty of an offence under this section.

(4) No proceedings shall be instituted for an offence under this section except by or with the consent of the Director of Public Prosecutions.

[55] Andrew Billings (n3) 21; Mount (n3); Brody (n3).

This section will first examine the manner in which the courts in Ireland have interpreted the right to life and the *Criminal Law (Suicide) Act 1993*. The cases of *Re a Ward of Court*[56] and *Fleming v Ireland & Ors*[57] will be discussed in this section. These cases demonstrate the legal limits of medical practice and, in certain respects, highlight the legal challenges posed by specialist palliative care. As noted earlier in this Chapter, euthanasia, if provided in this jurisdiction, is likely to result in a charge of murder or manslaughter. On this basis, the second part of this section will examine the requisite elements which must be established in such a case. Among the requisite elements to be established for a charge of murder is that of intention. The element of intention is of considerable significance in drawing out the distinction between specialist palliative care and euthanasia due to the central role of the medical practitioner in euthanasia and in providing palliative sedation. The main Irish cases which have discussed the meaning of intention will be discussed in order to provide greater elucidation on what is meant by intention in Irish criminal law. In effect, this section serves to define a significant proportion of the legal framework in Ireland for specialist palliative care as well as highlighting aspects of the framework which need greater clarity for the healthcare professional and patient.

Legal Status of Euthanasia and Assisted Suicide in Ireland

The fundamental nature of human rights in the Irish Constitution means that they should be a central element in end-of-life care. For instance, the manner in which the right to life has been interpreted is especially relevant to the distinction between specialist palliative care and euthanasia as it also raises questions about the existence of a right to die. The right to life is protected by Article 40.3.2° of Bunreacht na hÉireann which sets out that 'The State shall, in particular, by its laws protect as best it may from unjust attack and, in the case of injustice done, vindicate the life, person, good name, and property rights of every citizen.'[58] The constitutional right to life has

[56] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.
[57] *Fleming v Ireland & Ors* [2013] IEHC 2, [2013] IESC 19.
[58] Bunreacht na hÉireann, Article 40.3.2°.

been examined in cases such as *McGee v Attorney General*,[59] *G v An Bord Uchtála*,[60] *Re a Ward of Court*, and *Fleming v Ireland & Ors*. The two latter cases are of most relevance in the context of specialist palliative care due to the focus on the withdrawal of artificial nutrition and hydration displayed in *Re a Ward of Court*, and assisted suicide in *Fleming v Ireland & Ors*.

The person at the centre of *Re a Ward of Court* was a middle aged woman who was in a near persistent vegetative state rather than a persistent vegetative state. This distinction was drawn on the basis that the woman never got used to the nasogastric tube through which she received artificial nutrition and hydration, as demonstrated by the fact that she pulled out this tube 'over a thousand times'.[61] This could not be attributed to a purely reflex action but may have been indicative of some cognitive function. In the first five to six months after the incident there were minimal signs of recovery but these did not continue and there was no prospect of recovery. The woman had been made a ward of court and an application was made by the family for the withdrawal of life support. The life support at the time consisted of medication as well as artificial nutrition and hydration. Initially, Lynch J in the High Court held that artificial nutrition and hydration could be withdrawn from the ward. This decision was appealed to the Supreme Court which upheld the High Court's decision by a 4:1 majority. It is to be noted that the Supreme Court did not order the withdrawal of treatment but permitted the medical practitioners to do so. In other words, the Supreme Court's decision was permissive rather than mandatory.

In *Re a Ward of Court*, one of the issues before the Court was whether a right to die existed in Ireland as a corollary of the constitutionally protected right to life. In considering the withdrawal of artificial nutrition and hydration, Hamilton CJ and

[59] *McGee v Attorney General* [1973] IESC 2, [1974] IR 284; Gerard Hogan and Gerry Whyte, *Kelly: The Irish Constitution* (4th edn, Butterworths 2003) 1395 'In McGee v Attorney General the constitutional right to life began for the first time to develop a profile independent of this, when Walsh J derived from it the right of a woman, whose condition of health made pregnancy hazardous for her, not to have her life put at risk in consequence of the laws of the State'

[60] *G v An Bord Uchtála* [1980] IR 32; Hogan (n59) 1396 '[A child] has the right to life itself and the right to be guarded against all threats directed to its existence whether before or after birth … The right to life necessarily implies the right to be born, the right to preserve and defend, and to have preserved and defended, that life, and the right to maintain that life at a proper human standard in matters of food, clothing and habitation.'

[61] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 96.

Denham J based part of their reasoning on their interpretation of the right to life.[62] Hamilton CJ expanded on the reasoning of Walsh J in *G v An Bord Uchtála* to the point where he states:

> As the process of dying is part, and an ultimate, inevitable consequence, of life, the right to life necessarily implies the right to have nature take its course and to die a natural death and, unless the individual concerned so wishes, not to have life artificially maintained by the provision of nourishment by abnormal artificial means, which have no curative effect and which is intended merely to prolong life.[63]

The use of the term 'prolong' instead of 'sustain' suggests that there is no prospect of recovery for a patient in such a condition and that if the medical technology did not exist then the patient would have died.[64] This underlines the reference made by Hamilton CJ to the 'right to have nature take its course',[65] 'die a natural death',[66] and 'not to have life artificially maintained'.[67] This reasoning would be particularly relevant for specialist palliative care where the patient is terminally rather than chronically ill as the patient would be close to death, thereby allowing nature to take its course. In following this line of reasoning, the right to life does not provide for 'the right to have life terminated or death accelerated and is confined to the natural process of dying.'[68]

Denham J also referred to the right to life in *Re a Ward of Court* and set out that:

> In respecting a person's death we are also respecting their life - giving to it sanctity. That concept of sanctity is an inclusive view which recognises

[62] Hogan (n59) 1398.
[63] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 124.
[64] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 131 O'Flaherty J 'the advance of medical science may result in rendering a patient a prisoner in a ward from which there may be no release for many years without any enjoyment or quality of life: indeed without life in any acceptable meaning of that concept except in the sense that by means of various mechanisms life is kept in the body.'; Recommendation Rec(1976) 779 on the rights of the sick and dying, adopted by the Assembly on 29 January 1976 [6] 'the prolongation of life should not in itself constitute the exclusive aim of medical practice, which must be concerned equally with the relief of suffering'.
[65] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 124.
[66] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 124.
[67] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 124.
[68] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 124.

> that in our society persons, whether members of a religion or not, all under the Constitution are protected by respect for human life. A view that life must be preserved at all costs does not sanctify life.[69]

The reference to the sanctity of life in this quote complicates the interpretation of the right to life as well as rights such as the right of autonomy.[70] It was highlighted by Hogan and Whyte that different formulations of the sanctity of life could impact on the permissibility of euthanasia or the refusal of treatment for terminally ill patients. These are points which could have been clarified in *Re a Ward of Court* through more comprehensive discussion on the sanctity of life and the right to life. For instance, Hogan and White wrote that:

> this important philosophical debate is ignored in the majority judgments and no judge makes explicit his or her understanding of the principle of the sanctity of life in this context. Until this is clarified, the precise extent of the right to die and of society's power to authorise a course of action leading to death will remain unclear.[71]

This demonstrates certain shortcomings in the judgment of the Court. Additionally, the woman in this case was not in a full persistent vegetative state and 'the majority judgments offer no useful assistance in determining at what point along the scale of consciousness this ruling ceases to apply.'[72] As such, the woman was not terminally ill and this decision can therefore be interpreted as including people who are chronically ill.[73] The nature of the right to life was discussed further in the case of *Fleming v Ireland & Ors*.

The *Criminal Law (Suicide) Act 1993* was central in the case of *Fleming v Ireland & Ors*. In this case, the plaintiff sought an order that section 2(2) of the *Criminal Law (Suicide) Act 1993* is 'invalid having regard to the provisions of the Constitution of

[69] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 161.
[70] Hogan (n59) 1400-1401 '[t]here are different philosophical understandings of the sanctity of life, resulting in different conclusions as to the extent of personal autonomy.'
[71] Ibid; Helga Kuhse, *The Sanctity-of-Life Doctrine in Medicine: A Critique* (Oxford University Press 1987) Kuhse argues in favour of adopting an approach based on the quality of life rather than the sanctity of life.; Helga Kuhse (ed), *Unsanctifying Human Life: essays on ethics* (Blackwell Publishers 2002); John Keown, *The Law and Ethics of Medicine* (Oxford University Press 2012).
[72] ibid 1400.
[73] ibid.

Ireland',[74] and 'is incompatible with the rights of the plaintiff pursuant to the European Convention on Human Rights and Fundamental Freedoms'.[75] As an alternative, the plaintiff sought the introduction of guidelines which would set out the factors to be considered in deciding 'whether to prosecute or to consent to the prosecution of any particular person in circumstances such as those that will affect a person who assists the plaintiff in ending her life.'[76] The first and second claims are largely based on the interpretation of human rights.

Assisted suicide is illegal in Ireland. Section 2(2) of the *Criminal Law (Suicide) Act 1993* provides that is an offence to aid, abet, counsel or procure the suicide of another individual, or an attempt by another individual to commit suicide. A person found guilty of this offence will face a maximum prison sentence of fourteen years. Nevertheless, it will be outlined later in this Chapter that a competent adult has the right to refuse medical treatment which would result in their death or even request that medical treatment keeping them alive be withdrawn. However, as will be demonstrated, this does not amount to a right to die by artificial means or a right to die with the assistance of a third party such as a healthcare professional.

The plaintiff in *Fleming v Ireland & Ors* was a 59 year old woman who was diagnosed with multiple sclerosis in 1989. As a result of her illness she stopped working in 1995. At the time of bringing the claims the plaintiff was 'unable to walk or to use her lower or upper limbs.'[77] She was 'confined to a wheelchair',[78] had 'no bladder control',[79] and was 'almost physically helpless and requires assistance with all aspects of her daily living.'[80] The illness made communication increasingly difficult, and resulted in choking episodes.

The three-judge divisional High Court held that section 2(2) of the *Criminal Law (Suicide) Act 1993* did not amount to a disproportionate interference with the plaintiff's right of autonomy. The Court recognised a distinction between the refusal

[74] *Fleming v Ireland & Ors* [2013] IESC 19, [3].
[75] *Fleming v Ireland & Ors* [2013] IESC 19, [3].
[76] *Fleming v Ireland & Ors* [2013] IESC 19, [3].
[77] *Fleming v Ireland & Ors* [2013] IESC 19, [12].
[78] *Fleming v Ireland & Ors* [2013] IESC 19, [12].
[79] *Fleming v Ireland & Ors* [2013] IESC 19, [12].
[80] *Fleming v Ireland & Ors* [2013] IESC 19, [12].

of medical treatment which might lead to death and the taking of active steps by another party to bring about a person's death. For example, 'the Court believes there is a real and defining difference between a competent adult patient making the decision not to continue medical treatment … and the taking of *active steps* by *another* to bring about the end of that life of the other.'[81] The Court was influenced by the possibility that allowing for assisted suicide could negatively impact on vulnerable members of society who might feel that they should avail of this practice so as not to be a burden to their family.[82] Nonetheless, vulnerable patients could also potentially refuse medical treatment which would result in their death. This underlines the importance of the legal framework in place for specialist palliative care practices such as the withdrawal of artificial nutrition and hydration.

Research by Ganzini et al. was cited by the Court in support of their position.[83] This research suggested that 'depression is missed or overlooked'[84] in some cases of assisted suicide. The Court's concern about assisted suicide in circumstances where a patient may be depressed highlights the importance of safeguards in this area for palliative sedation also. In Chapter Two and earlier in this Chapter, it was highlighted that palliative sedation for non-somatic suffering such as existential distress is a controversial practice and further blurs the distinction between specialist palliative care and euthanasia. This illustrates the importance of a clear legal framework in Ireland for specialist palliative care practices which would protect patients who are at a vulnerable point in their lives.

In addition to rejecting the constitutional claim, the High Court also rejected the claim under the European Convention on Human Rights. The Court referred to the cases of *R(Pretty) v Director of Public Prosecutions*[85] and *Haas v Switzerland*[86] which

[81] *Fleming v Ireland & Ors* [2013] IEHC 2, [53] (emphasis in original).
[82] *Fleming v Ireland & Ors* [2013] IEHC 2, [76].
[83] *Fleming v Ireland & Ors* [2013] IEHC 2, [63]; Linda Ganzini, Elizabeth R Goy and Steven K Dobscha, 'Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey' (2008) 337 British Medical Journal 973.
[84] Ganzini (n83) 974.
[85] *R(Pretty) v Director of Public Prosecutions* [2001] UKHL 61, [2002] 1 AC 800.
[86] *Haas v Switzerland* (2011) 53 EHRR 33; *Fleming v Ireland & Ors* [2013] IEHC 2, [116] The High Court noted that in *Haas v Switzerland* 'the applicant was a Swiss national who suffered from bi-polar disorder and who wished to commit suicide. For this purpose he sought sufficient quantities of a powerful barbiturate which he proposed to self-administer. This drug is only available on prescription

demonstrated that the State has considerable discretion in addressing issues such as assisted suicide due to Article 8(2) of the European Convention on Human Rights.[87] Consequently, the breadth of this discretion meant that there was no incompatibility between the human rights of the plaintiff and section 2(2) of the *Criminal Law (Suicide) Act 1993*.

The final aspect of the High Court judgment to consider relates to the plaintiff seeking guidelines to be introduced which would set out the factors to be considered in deciding whether a person would be prosecuted for assisting in another person's suicide. In response to this, the Court noted that the *Prosecution of Offences Act 1974* does not provide for this type of guideline to be developed. In this respect, it is only the Oireachtas that can alter the law on assisted suicide. However, the Court noted that the Director of Public Prosecutions could exercise discretion if there is compliance with specified factors which would be given to the Director *ex post facto* the event.[88] This approach means that a person who assists in the suicide of another person would not know if they would be charged by the Director of Public Prosecutions until after the event. This reflects a point which will be made later in this Chapter in the context of double effect and the withdrawal of artificial nutrition and hydration that it is not sufficient to be guided by justifications which are of relevance after the fact. Instead, clear guidelines must be in place at an earlier stage which guide medical practice and can consistently promote the principles of autonomy, beneficence, nonmaleficence, and justice. The plaintiff subsequently appealed the decision of the High Court.

The Supreme Court in *Fleming v Ireland & Ors* held that there 'is no explicit right to commit suicide, or to determine the time of one's death, in the Constitution.'[89] The appellant based her case on 'the express right to life in Article 40.3.2.'[90] Denham CJ referred to the case of *Re a Ward of Court* and stated that:

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and the Swiss public health authorities refused to permit the applicant to acquire this drug without prescription.'

[87] *Fleming v Ireland & Ors* [2013] IEHC 2, [119] 'It will be seen, therefore, that the European Court of Human Rights has consistently taken the view that a ban on assisted suicide will always be justifiable by reference to Article 8(2) ECHR inasmuch as Contracting States are entitled to think that such is necessary to prevent abuse and the exploitation of the vulnerable.'

[88] *Fleming v Ireland & Ors* [2013] IEHC 2, [157].

[89] *Fleming v Ireland & Ors* [2013] IEHC 2, [99].

[90] *Fleming v Ireland & Ors* [2013] IEHC 2, [104].

> While the words of Hamilton C.J. stating positively that no person has a right to have his or her life terminated were strictly *obiter*, they are a persuasive authority on the analysis of a right to life under the Constitution.[91]

This made it clear that the right to life does not currently allow for active steps to be taken which would result in the death of the patient. However, the Court questioned the extent of the obligation on the State to protect life. The Court in *Fleming* noted that:

> The precise extent of the State's obligation in any given circumstance is, however, a matter which may require careful analysis and, at least in some cases, require a careful balancing of other constitutional considerations.[92]

These constitutional considerations include rights such as the right to bodily integrity[93] and the right to autonomy.[94] The Court was clear in stating that the State had an 'obligation to vindicate the right to life'[95] but also suggested that it was open to the Oireachtas to legislate to allow assisted suicide with appropriate safeguards.[96] Therefore, it was recognised by the Court that if the Oireachtas did enact such legislation then it would need to be drafted in a manner which did not breach the obligation on the State to protect the right to life.[97] As such, the Oireachtas would have to engage in a difficult balancing of human rights and interests.

The approach taken by the Court could be interpreted as suggesting that there are certain cases where a person's life need not be sustained. In such circumstances, the act or omission leading to the person's death would not be criminally liable and would therefore not constitute assisted suicide. These points will be explored in more detail later in this Chapter and will again refer to *Re a Ward of Court* and *Fleming v Ireland & Ors*.[98] Nonetheless, the cases of *Re a Ward of Court* and *Fleming v Ireland & Ors*

[91] *Fleming v Ireland & Ors* [2013] IEHC 2, [105].
[92] *Fleming v Ireland & Ors* [2013] IEHC 2, [106].
[93] See p117.
[94] See p137.
[95] *Fleming v Ireland & Ors* [2013] IESC 19, [107].
[96] *Fleming v Ireland & Ors* [2013] IESC 19, [108].
[97] *Fleming v Ireland & Ors* [2013] IESC 19, [108].
[98] See p100 and p95.

illustrate the emphasis placed on the protection of the right to life. As the law stands, the provision of euthanasia in this jurisdiction is likely to lead to a charge of murder. This is a distinct offence to assisted suicide and carries a much harsher custodial sentence. It was set out earlier in this Chapter that a person found guilty of assisted suicide would face a maximum prison sentence of fourteen years. Whereas, a person found guilty of murder faces a mandatory sentence of life imprisonment as set out s.2 of the *Criminal Justice Act 1990*. Given the severity of this crime, the manner in which specialist palliative care practices are distinguished from euthanasia in criminal law must be discussed. However, the lack of case law on specialist palliative care practices means that it is necessary to extrapolate from case law more generally and this is the approach which will be taken in the next section.

Murder: The Role of Intention

The offence of murder is made up of three elements which are the actus reus, mens rea and the lack of a valid defence.[99] The actus reus refers to 'what the defendant must be proved to have done (or sometimes failed to do), in what circumstances, and with what consequences.'[100] Therefore, the actus reus may be performed by an action or an omission.[101] The circumstances in which an omission may satisfy the actus reus requirement will be set out in the third section of this Chapter.

The mens rea is the 'mental element of a crime.'[102] The mental element for murder in Ireland is set out by section 4 of the *Criminal Justice Act 1964*.[103] This section provides that:

[99] David Lanham, 'Larsonneur Revisited' (1976) Criminal Law Review 276, 276 'made up of three ingredients, actus reus, mens rea and (a negative element) absence of a valid defence'; Liz Campbell, Shane Kilcommins and Catherine O'Sullivan, *Criminal Law in Ireland: Cases and Commentary* (Clarus Press 2010) 80 'The *actus reus* and the *mens rea* may be described as the "building blocks" of crime, in other words these elements must be proven for an act to be legally deemed a crime. Without the *actus reus* and *mens rea*, there is no crime and thus no criminal liability.'

[100] Jonathan Herring, *Criminal Law: Texts, Cases, and Materials* (2nd edn, Oxford University Press 2012) 85.

[101] Conor Hanly, *An Introduction to Irish Criminal Law* (2nd edn, Gill and Macmillan 2006) 48 'The *actus reus* is the action necessary for the crime to have been committed. It is often described as the physical element of the crime.'; Gerard Coffey, *Criminal Law* (Round Hall 2010) 36 'The actus reus is sometimes referred to as the external, physical or action element of criminal offences.'

[102] Campbell (n99) 120; Hanly (n101) 73 '*Mens rea* is the mental element of the offence.'; Herring (n100) 85 'Mens rea: the mental element of the offence.': Herring (n100) 146 '*Mens rea* is the legal term used to describe the element of the criminal offence that relates to the defendant's mental state.'

[103] Criminal Justice Act 1964.

> (1) Where a person kills another unlawfully the killing shall not be murder unless the accused person intended to kill, or cause serious injury to, some person, whether the person actually killed or not.
> (2) The accused person shall be presumed to have intended the natural and probable consequences of his conduct; but this presumption may be rebutted.[104]

Section 4(2) of the *Criminal Justice Act 1964* establishes that the determination of intention is subjective.[105] This is notable given that, in the context of specialist palliative care, it will be difficult to state with certainty what the exact intention of the healthcare professional was in administering the sedative drug.[106]

Guidance on the meaning of 'intention' in the *Criminal Justice Act 1964* can be found in the case of *People v Murray*.[107] This was the first Irish case to examine the meaning of 'intention'.[108] Walsh J in the Supreme Court decision of *People v Murray* noted that 'To intend to murder, or to cause serious injury … is to have in mind a fixed purpose to reach that desired objective.'[109] This means that for there to be intention there must be foresight as well as willing 'the possible consequences of his conduct.'[110] In his judgment, Walsh J also distinguished the elements of intention, foresight of consequences and recklessness. For example, Walsh J noted that 'foresight of probable consequences must be distinguished from recklessness which imports a disregard of

[104] Criminal Justice Act 1964, s 4.
[105] Law Reform Commission, Report on Homicide: Murder and Involuntary Manslaughter (LRC 87 – 2008) 25.
[106] Timothy E Quill, 'The Ambiguity of Clinical Intentions' (1993) 329(14) The New England Journal of Medicine 1039; Timothy E Quill, 'Death and dignity – a case of individualized decision making' (1991) 324 New England Journal of Medicine 691.
[107] *The People (DPP) v Murray* [1977] IR 360. The background to *People* v. *Murray* involved an off-duty Garda in plain clothes who pursued a number of people who had robbed a bank. The Garda gave chase to their car and subsequently chased them on foot. The Garda grabbed one of the bank robbers, Noel Murray, by the shoulders. Noel Murray's wife was also one of the bank robbers. She shouted at the Garda to let go of her husband and when the Garda did not comply she shot and killed him. Husband and wife were found guilty of capital murder as well as a number of other charges and were sentenced to death. Capital murder included the murder of a member of the Garda Síochána while they were acting in the course of their duty. The decision was appealed to the Court of Criminal Appeal with a further appeal to the Supreme Court on the basis that the decision related to a point of law of considerable public importance. The issue being that when Marie Murray shot the Garda she was not aware that he was a Garda and was acting in the course of his duty as a Garda. Consequently, the argument was that she could not have had the mens rea for capital murder.
[108] Criminal Justice Act 1964, s 4.
[109] *The People (DPP) v Murray* [1977] IR 360, 386.
[110] *The People (DPP) v Murray* [1977] IR 360, 386.

possible consequences.'[111] The cumulative effect of this finding is to demonstrate that the mens rea for murder 'is limited to a specific intention to either kill or cause really serious injury.'[112] In a Law Reform Commission report on homicide it was noted that the Supreme Court in *People v Murray* appeared 'to understand intention in this context as a "purpose" to kill or "willingness" to kill. It does not appear that foresight that one's action will probably kill is the same as intention.'[113] This point is central to the distinction between sedative drugs given for the purpose of treating a patient's pain as opposed to the administration of sedative drugs with the intention of hastening the death of a patient. Nevertheless, in certain circumstances the healthcare professional may foresee the potential for hastening the patient's death but act with the intention of easing the patient's pain. This highlights the crux of this issue as people may act with a variety of intentions and the identification of a single intention is not a straightforward task.[114]

The meaning of intention was subsequently discussed by the Court of Criminal Appeal in *The People (DPP) v Douglas and Hayes*.[115] Although the discussion of 'intention' in this case was obiter, it is helpful in understanding the concept of 'intention'. The Court of Criminal Appeal noted that 'unless an accused has actually expressed an intent to kill, his intent can only be ascertained from a consideration of his actions and the surrounding circumstances.'[116] In the context of specialist palliative care this may involve consideration of the patient's medical history, notes made on the patients chart or conversations with other healthcare professionals regarding the treatment and care of a patient.[117] The Court of Criminal Appeal held that foresight and recklessness was

[111] *The People (DPP) v Murray* [1977] IR 360, 387.
[112] Law Reform Commission (n105) 31.
[113] ibid.
[114] PJ Van der Maas and others, 'Euthanasia and Other Medical Decisions at the End of Life' (1992) 22 *Health Policy* 1 and 2 cited by Glenys Williams, 'The Principle of Double Effect and Terminal Sedation' (2001) 9 Medical Law Review 41, 48. 'In the Netherlands, it is specifically recognised that a doctor acting with the intention of relieving pain, can also act partly with the intention of hastening death'.
[115] *The People (DPP) v Douglas and Hayes* [1985] ILRM 25; Law Reform Commission, Consultation Paper on Homicide: The Mental Element in Murder (LRC CP 17 – 2001) 18 'In Ireland the law would appear to be as set out by the Court of Criminal Appeal in *People v Douglas & Hayes*. Foresight of death as a natural and probable consequence of one's actions does not amount to intention *per se*, although it may be evidence from which intention can be inferred.'
[116] *The People (DPP) v Douglas and Hayes* [1985] ILRM 25, 27.
[117] Joseph Boyle, 'Medical Ethics and Double Effect: The Case of Terminal Sedation' (2004) 25 Theoretical Medicine 51, 51-52 'Evidence of physician intent can be found in notations on the patient's chart and in the recorded dosages and titration of analgesics.'

not the equivalent of intention but they could potentially be 'evidence from which an inference of intention could be drawn.'[118] This approach would also require the broader facts of the case to be considered in deciding whether the intention to kill or seriously injure was present.

Section 4(2) of the *Criminal Justice Act 1964* establishes a rebuttable presumption that the accused is 'to have intended the natural and probable consequences of his conduct'.[119] The Law Reform Commission report on homicide notes that a jury is to approach this presumption in two parts. The first part is to 'decide whether the natural and probable consequence was to cause death or serious injury.'[120] If this is answered in the affirmative the next step is to 'consider whether the accused had successfully rebutted the presumption.'[121] The doctrine of double effect and the acts and omissions distinction are means by which the presumption may be rebutted as 'the requisite *mens rea* for murder will not have been established.'[122] This has led to double effect being described as 'an ethical cornerstone in the medical treatment of the terminally ill.'[123] This underlines the necessity of examining not only the application of the doctrine of double effect but also the validity of the doctrine itself.

Justification for Specialist Palliative Care Practices

The previous section highlighted the importance of intention in distinguishing between specialist palliative care practices and euthanasia. Unfortunately, the administration of sedative drugs to a patient or the withdrawal of artificial nutrition and hydration does not always lend itself to the identification of a clear intention on the part of the

[118] Law Reform Commission, Report on Homicide: Murder and Involuntary Manslaughter (LRC 87 – 2008) 33; *The People (DPP) v Douglas and Hayes* [1985] ILRM 25, 28 'In the circumstances of any particular case evidence of the fact that a reasonable man would have foreseen that the natural and probable consequence of the acts of an accused was to cause death and evidence of the fact that the accused was reckless as to whether his acts would cause death or not is evidence from which an inference of intent to cause death may or should be drawn, but the court must consider whether either or both of these facts do establish beyond a reasonable doubt an actual intention to cause death'.

[119] Criminal Justice Act 1964, s 4(2).

[120] Law Reform Commission (n118) 35.

[121] ibid.

[122] Suzanne Ost, 'Euthanasia and the defence of necessity: advocating a more appropriate legal response' (2005) Criminal Law Review 355, 356.

[123] Quill (n106) 1039; Double effect has been described as 'immense practical importance' by Daniel P Sulmasy and Edmund D Pellegrino, 'The Rule of Double Effect: Clearing-up the Double Talk' (1999) 159(6) Archives of Internal Medicine 545, 545 quoted by Williams (n114) 52; Double effect has been the subject of criticism, see RK Portenoy, 'Morphine Infusions at the End of Life: The Pitfalls in Reasoning from Anecdote' (1996) 12 Journal of Palliative Care 44; Andrew Billings (n3).

healthcare professional.[124] The complexity of identifying the intention of healthcare professionals is evident in justifications such as double effect and the acts and omissions distinction.[125] Nevertheless the doctrine of double effect has been utilised, albeit mainly in academic texts, to distinguish palliative sedation from euthanasia.[126]

The legitimacy of double effect and its consistent application in practice is vital in supporting the distinction between euthanasia and specialist palliative care practices. However, the doctrine of double effect is not particularly suited to justifying the withdrawal of artificial nutrition and hydration and this is best dealt with through discussion of the acts and omissions distinction.[127] Overall, in this section it will be argued that specialist palliative care practices and euthanasia can be distinguished on the basis of double effect and the acts and omissions distinction but that these justifications do not provide a sufficiently strong foundation on which to provide specialist palliative care.[128] Therefore, it is necessary that an appropriate legal framework which addresses these practices in a clear manner is identified.

The Doctrine of Double Effect

It would be incorrect to speak of a single doctrine of double effect.[129] Rather, there are differing views as to the necessary criteria for the application of the doctrine. A simple interpretation is that double effect is a doctrine which 'distinguishes between the consequences a person intends and those that are unintended but foreseen'.[130] This

[124] Timothy E Quill, Bernard Lo and Dan W Brock, 'Palliative Options of Last Resort: A Comparison of Voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia' in Torbjőrn Tännsjő, *Terminal Sedation: Euthanasia in Disguise?* (Kluwer Academic Publishers 2004) 6. 'The issue of intention is particularly complicated because the determination of what is intended by the patient or physician is often difficult to verify and because practices that are universally accepted may involve the intention to hasten death in some cases.'

[125] Glenys Williams, 'Acts and Omissions in Treatment Withdrawal: Conceptual Problems and Policy Decisions' (2008) 39 Cambrian Law Review 75, 87 'This is precisely why the AOD (and double effect) are seen as justificatory "defences"'.

[126] Quill (n124) 6 'The doctrine of double effect has also been used to distinguish TS from PAS and VAE.'

[127] Williams (n114) 52 'It must and should always be confined to excluding situations involving withdrawing artificial nutrition and hydration.'

[128] Quill (n124) 8 'The application and the moral importance of both the active/passive distinction and the doctrine of double effect are notoriously controversial and should not serve as the primary basis of determining the morality of these practices.'

[129] Donald B Marquis, 'Four Versions of Double Effect' (1991) 16 The Journal of Medicine and Philosophy 515, 515 'There is no longer *one* doctrine of double effect.' (emphasis in original).

[130] Williams (n114) 41; Lynn A Jansen and Daniel P Sulmasy, 'Sedation, Alimentation, Hydration, and Equivocation: Careful Conversation about Care at the End of Life' (2002) 136(11) American College of Physicians-American Society of Internal Medicine 845, 847 'The rule of double effect calls attention

reflects the distinction between intention and foresight raised by section 4 of the *Criminal Justice Act 1964*. However, there is no clear reference to the doctrine in Irish legislation. Double effect can be called upon as a justification[131] or defence where the actions of a medical professional appear to demonstrate some of the characteristics normally associated with euthanasia. In this regard, Foster et al. suggest that the focus placed on the doctrine by academics and practitioners 'is best explained by its tremendous practical utility.'[132] This utility is based on the point that practices which might otherwise be illegal and labelled as murder or manslaughter can be justified based on this doctrine.[133] However, this 'practical utility' depends on the doctrine itself having a legally sound foundation.

The Development of Double Effect

The origin of the doctrine of double effect has been credited to Thomas Aquinas in his discussion on self-defence.[134] Aquinas set out that:

> Nothing hinders one act from having two effects, only one of which is intended, while the other is beside the intention. … Accordingly, the act of self-defence may have two effects: one, the saving of one's life; the other, the slaying of the aggressor.[135]

Such acts may be justified provided there is an element of proportionality, e.g. 'though proceeding from a good intention, an act may be rendered unlawful if it be out of proportion to the end.'[136] In the context of palliative sedation, this may relate to the

to the moral difference between bringing about harm as merely a foreseen effect of an action aimed at some good end and intentionally bringing about harm as a means to that end.'; Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 164 'This rule incorporates a very influential distinction between intended effects and merely foreseen effects.'

[131] Williams (n114) 44 'It is a justification (rather than an excuse) because ''justification is founded on the law's preference for one course of action, rather than another"'.

[132] Charles Foster and others 'The Double Effect Effect' (2011) 20 Cambridge Quarterly of Healthcare Ethics 56.

[133] *Vacco v Quill* (1997) 138 L.Ed. 2d. 834. Professor Tribe's argument to the Court on terminal sedation was that it had the effect of drugging the patient into a coma, and then starving the patient to death due to the withdrawal of artificial nutrition and hydration. Professor Tribe argued that this practice was the equivalent of assisted suicide. Attorney-General Vacco responded that sedation in the final stages of life was not intended to kill and was justified by the principle of double effect.

[134] Thomas Aquinas, *Summa Theologica* (Fathers of the English Dominican Province tr, Benziger Brothers 1947) (II-II, Qu. 64, Art.7); See also Joseph T Mangan, 'An Historical Analysis of the Principle of Double Effect' (1945) Theological Studies 41.

[135] Aquinas (n134) 1471.

[136] ibid.

strength and timing of the dose administered to the patient. The actual application of the doctrine will be discussed later in this section. Aquinas did not set out to establish the basis of the doctrine of double effect but was instead concerned with intention 'as a way to know God better'.[137] This reflects the Catholic origins of the doctrine which had a considerable influence on its development. The doctrine of double effect has continued to be modified in various respects over the years and there is no single correct version or interpretation of this doctrine.

The next contributor to the doctrine of double effect in the Catholic faith has been identified as Cardinal Cajetan.[138] His interpretation of double effect can be said to reflect more recent interpretations of the doctrine.[139] The work of the Salmanticenses has also been influential in the development of the doctrine of double effect.[140] In particular, their approach to the doctrine served to expand it to 'the whole field of moral theology'[141] instead of restricting it to self-defence. An updated approach to double effect was set out in 1874 by Gury,[142] and a formulation of double effect was set out by the Catholic scholar, Joseph Mangan, in 1949.[143] Mangan suggests that the uncertainty around the doctrine of double effect is reflective of a broader inconclusiveness about the content of the morally good action.[144] This reflects the fact that it is not possible to achieve universal agreement on what constitutes an exceptionless morally proper action. This will always be a challenge in any legal framework for an ethically sensitive subject such as specialist palliative care.

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[137] Foster (n132) 57.
[138] Mangan (n134) 52.
[139] ibid 'There is no doubt in the wording of Cajetan, that he interprets II-II, q. 64, a. 7 in terms of the principle of the double effect as we understand it today.'
[140] Salmanticenses, *Cursus Theologicus* (Brussels 1879); Mangan (n134) 57; Foster (n132) 57.
[141] Mangan (n134) 56.
[142] Joannes P Gury, *Compendium Theologiae Moralis* (5th edn, Ratisbon 1874) quoted in Mangan (n134) 57 'It is lawful to actuate a morally good or indifferent cause from which will follow two effects, one good and the other evil, if there is a proportionately serious reason, and the ultimate end of the agent is good, and the evil effect is not the means to the good effect. The reason for this principle is that such an action could be unlawful only from the intention of the evil effect, or from the very actuating of the cause itself, or from the foreseeing of the evil effect. But the action is not unlawful under any one of these headings.'
[143] Mangan (n134) 43 A formulation of double effect by Mangan explicitly requires that 'the action in itself from its very object be good or at least indifferent', 'that the good effect and not the evil effect be intended', 'that the good effect be not produced by means of the evil effect', and 'that there be a proportionately grave reason for permitting the evil effect'. This interpretation requires that all four criteria be present at the same time.
[144] ibid 41.

The following section will consider more recent interpretations of the doctrine of double effect which are largely outside of Catholic theology. In particular, the interpretation of double effect outlined by Williams will be discussed and applied in the context of specialist palliative care practices.[145] Moreover, case law which addresses the doctrine of double effect will be set out. This will demonstrate the difference between the religious origins of the doctrine and its application in criminal law. This will also clarify the legal status of the doctrine and highlight shortcomings in its application.

The Criteria for Double Effect

The criteria for the doctrine of double effect as outlined by Williams will be the primary interpretation of the doctrine discussed in this section. This interpretation has been selected as it reflects various formulations of the doctrine of double effect. For example, it resembles the criteria for the doctrine of double effect which have been outlined by Kuhse[146] and Keown.[147] Importantly, the criteria outlined by Williams also resemble the criteria for double effect as set out by Beauchamp and Childress who noted that 'Another venerable attempt to specify the principle of nonmaleficence appears in the role of double effect'.[148] Williams' discussion of double effect was based on its application to terminal sedation and therefore offers much to draw on in the context of this thesis. Prior to setting out the requirements for double effect it is necessary to recognise the challenges which specialist palliative care practices present to the application of the doctrine of double effect. This will assist in discussing the individual requirements for the doctrine.

Beauchamp and Childress recognised that palliative sedation 'challenges the boundaries and use of the RDE.'[149] Palliative sedation raises particular problems for

[145] Williams (n114).
[146] Kuhse (n71).
[147] John Keown, *Euthanasia, Ethics and Public Policy* (Cambridge University Press 2002).
[148] Beauchamp (n130) 164; Beauchamp (n130) 154 'The act must be good, or at least morally neutral, independent of its consequences', 'The agent intends only the good effect, not the bad effect. The bad effect can be foreseen, tolerated, and permitted, but it must not be intended', 'The bad effect must not be a means to the good effect. If the good effect were the causal result of the bad effect, the agent would intend the bad effect in pursuit of the good effect', 'The good effect must outweigh the bad effect. That is, the bad effect is permissible only if a proportionate reason compensates for permitting the foreseen bad effect.'
[149] ibid. RDE stands for rule of double effect.

the concept of double effect and has been described as being 'unjustified',[150] 'hypocritical',[151] and 'sophistic'.[152] In particular, 'The precise timing of death is unpredictable, and verification of the relative causal contributions to that timing of disease, physiological and pharmacological factors is not usually measurable.'[153] Beauchamp and Childress summarised this position in stating that:

> Much depends on the description of terminal sedation in a particular set of circumstances, including the patient's overall condition, the proximity of death, and the availability of alternative means to relieve pain and suffering, as well as the intention of the physician and other parties.[154]

As a result, the intention of the healthcare professional in administering palliative sedation may be a stumbling block in the effective application of the doctrine of double effect in practice. It is suggested by Beauchamp and Childress that '[f]or an action to be intentional, it must correspond to the agent's plan for its performance.'[155] Reliance is to be placed on the physician to state his intention truthfully[156] and this 'cannot be easily resolved.'[157] It has been suggested that the intention of the doctor can be gauged by asking 'whether the doctor could have opted for less risky measures, had such measures existed.'[158] These issues suggest that it may be difficult to adequately apply the doctrine of double effect if it is not possible to accurately identify the intention of

[150] Ernlé Young, 'Ethical Issues at the End of Life' (1998) 9 Stanford Law and Police Review 267 cited by Williams (n114) 52; Timothy E Quill, Rebecca Dresser and Dan W Brock, 'The Rule of Double Effect: A Critique of its Role in End-of-Life Decision-Making' (1997) 337 *New England Journal of Medicine* 1768, 1771 'the rule's absolute prohibitions, unrealistic characterization of physicians' intentions, and failure to account for patients' wishes make it problematic in many circumstances.'
[151] Ann-Marie Begley, 'Acts, Omissions, Intentions and Motives: A Philosophical Examination of the Moral Distinction between Killing and Letting Die' (1998) 28(4) Journal of Advanced Nursing 865, 873.
[152] Tim Helme and Nicola Padfield, 'Setting Euthanasia on the Level' (1993) 15 *Liverpool Law Review* 75, 83.
[153] Michael Ashby, 'Death Causation in Palliative Medicine' in Ian Freckelton and Danuta Mendelson, *Causation in Law and Medicine* (Ashgate Dartmouth 2002) 228, 236.
[154] Beauchamp (n130) 168.
[155] ibid 166.
[156] Ost (n122) 356.
[157] ibid 358-359; Lynn A Jansen, 'Disambiguating Clinical Intentions: The Ethics of Palliative Sedation' (2010) 35 Journal of Medicine and Philosophy 19, 19 'It is often claimed that the intentions of physicians are multiple, ambiguous, and uncertain — at least with respect to end-of-life care.'; Charles Douglas, Ian Kerridge and Rachel Ankeny, 'Managing Intentions: The End-of-Life Administration of Analgesics and Sedatives, and the Possibility of Slow Euthanasia' (2008) 22(7) Bioethics 388.
[158] Torbjörn Tännsjö, 'Terminal Sedation: A Substitute for Euthanasia' Euthanasia' in Torbjörn Tännsjö (ed), *Terminal Sedation: Euthanasia in Disguise* (Springer 2010) 24.

the healthcare professional.[159] However, this issue has been considered by the House of Lords Select Committee on Medical Ethics which stated that 'Some may suggest that intention is not readily ascertainable. But juries are asked every day to assess intention in all sorts of cases, and could do so in respect of double effect'.[160] These comments were made in response to suggestions that double effect was a cloak for euthanasia and it demonstrates that intention, albeit complex, is possible to identify.[161] This is to be borne in mind when considering the formulation of double effect as advanced by Williams.

Williams describes the criteria for double effect as follows:

> (1) The nature of the action must be morally good
> (2) The bad effect (such as death) must not be a means of achieving the good effect
> (3) The good effect is directly intended; the bad effect is merely foreseen and tolerated
> (4) Proportionally, the reasons for performing the good action must outweigh the unintended bad consequences[162]

These requirements will be examined individually to understand how they contribute to the distinction between euthanasia and palliative sedation. It is important to emphasise that this Chapter is concerned with a particular application of the doctrine of double effect. In this respect, the focus is placed on cases where the same person experiences the good effect and potentially experiences the harmful effect.[163] This ensures the analysis remains relevant to specialist palliative care as the patient may

[159] Jansen (n157) 24 'Critics of the principle of double effect, at least as it is applied in the context of end-of-life palliative care, contend that the intentions of clinicians frequently are uncertain and ambiguous in this way. For this reason, they claim that the principle of double effect cannot function effectively as a guide for making ethical assessments of aggressive, extraordinary pain management techniques.'
[160] House of Lords, Report of the House of Lords Select Committee on Medical Ethics (Paper 21-1 of 1993-1994) [243] '… They would no doubt consider the actions of the doctor, how they compared with usual medical practice directed towards the relief of pain and distress, and all the circumstances of the case.'
[161] ibid 'We reject that charge while acknowledging that the doctor's intention, and evaluation of the pain and distress suffered by the patient, are of crucial significance in judging double effect.'
[162] Williams (n114) 45; See also Beauchamp (n130) 165.
[163] An alternative version of this is a situation where one person experiences the good effect but it is a second person who potentially experiences a negative effect.

have their pain treated but the sedative drug could potentially hasten their death. As such, a terminally ill patient receiving specialist palliative care has the potential to experience the good effect but also the harmful effect.

The first criterion for double effect as set out by Williams requires that the 'action must be morally good'.[164] In applying this to specialist palliative care the question which arises is whether the administration of the sedative drug is morally good. This is likely to be answered in the positive as the sedative drug is administered to lessen the pain experienced by the terminally ill patient. This line of reasoning has also been followed by Williams[165] and Foster[166] who suggest that relieving the pain experienced by a person is morally good.

The second criterion requires that the negative effect 'must not be a means of achieving the good effect.'[167] The negative effect is the potential to hasten a patient's death but this is 'not necessary to achieve the beneficial outcome'[168] in specialist palliative care. The definition of palliative care set out in Chapter One made it clear that this form of care focuses on the 'quality of life'[169] and the treatment of pain rather than seeking to hasten the death of a patient. Those that argue that palliative sedation is a form of 'slow euthanasia' may be of the opinion that sedation relieves pain by hastening the death of the patient.[170] In such an instance, the doctrine of double effect would not be applicable. However, the shortening of life due to opioids has been described as a 'persistent fantasy',[171] and it was highlighted in Chapter Two that an

[164] Williams (n114) 45.
[165] ibid 50 'The administration of pain-killing medication satisfies the first condition of the principle of double effect because the treatment is beneficial to the patient if it alleviates pain and relieves suffering.'
[166] Foster (n132) 59 'For example, when applying the doctrine to giving pain relief (with the possibility of shortening life), the act of pain relief itself is clearly good.'
[167] Williams (n114) 45.
[168] ibid 50.
[169] *Fleming v Ireland & Ors* [2013] IEHC 2 [35]; Cecilia Sepúlveda and others, 'Palliative Care: The World Health Organization's Global Perspective' (2002) 24(2) Journal of Pain and Symptom Management 91, 94; Also cited by Health Service Executive, 'Palliative Care Services – Five Year/Medium Term Development Framework' (Health Service Executive 2009) 12; Mary McCarron and others, 'Evaluation of the Programme to Support Palliative and Hospice Care in the Republic of Ireland' (Atlantic Philanthropies 2013) 5.
[170] Williams (n114) 50 'Although some people may perceive terminal sedation as the deliberate induction of coma to relieve suffering by hastening death. If this were the case, then condition two would obviously not be satisfied.'; Foster (n132) 59 'Again note that the doctrine is only relevant if the first requirement is met: that the earlier death is seen in itself as a bad consequence.'
[171] Robert Twycross, 'Where there is hope, there is life: a view from the hospice' in John Keown (ed), *Euthanasia Examined* (Cambridge University Press 1995) 161.

appropriate level of sedative drug is unlikely to hasten the death of the patient.[172] On this basis, the second criterion could be satisfied by the administration of palliative sedation.

The third criterion for the doctrine of double effect is that 'The good effect is directly intended; the bad effect is merely foreseen and tolerated.'[173] Again, the intention in palliative care is directed towards the relief of suffering, although the healthcare professional 'may foresee death as an unavoidable outcome.'[174] On this point Beauchamp and Childress noted that a supporter of double effect 'must elect a similarly narrow conception of what is intended to avoid the conclusion that an agent intentionally brings about all the consequences of an action that the agent foresees.'[175] The significance of distinguishing between intention and foresight goes back to section 4 of the *Criminal Justice Act 1964*. The ability to consult patient charts and consider the surrounding circumstances in such cases means that intention is not solely based on the doctor's stated intention. This does not mean that intention can always be clearly identified but does demonstrate that it is not an insurmountable challenge to the application of the doctrine.[176]

The fourth criterion for double effect is based on proportionality. Proportionality will be influenced by a variety of factors which are not always obvious. For instance, the balance may vary between people who assign different values to the sanctity of life. A person who places a very high value on the sanctity of life will take a different approach to proportionality than a person who regards the sanctity of life as being of a lower value.[177] Nevertheless, proportionality does not allow a pure utilitarian

[172] Text to n160 in Chapter Two.
[173] Williams (n114) 45; Beauchamp (n136) 167 'It is more suitable in these contexts to discard the language of "wanting" and to say that foreseen, undesired effects are "tolerated."' 'In this conception a physician can desire not to do what he intends to do, in the same way that one can be willing to do something but, at the same time, reluctant to do it or even detest doing it.'
[174] Williams (n114) 50.
[175] Beauchamp (n130) 166; Beauchamp (n130) 167 'In this conception a physician can desire not to do what he intends to do, in the same way that one can be willing to do something but, at the same time, reluctant to do it or even detest doing it.'
[176] ibid 168 'Such facts about the physician's motivation and character can make a decisive difference to a moral assessment of the action and the agent. But this moral conclusion can also be reached independently of the RDE.'
[177] Foster (n132) 60 'Thinkers differ as to the relative weight of values and the means by which to evaluate them. Whereas some, including Catholic theologians, will work within an ordering framework of prior convictions (for instance, that the sanctity of life is the highest good around which all other goods can be organized), others have different criteria for assessing values.'

approach to be taken.[178] In relation to sedation, Williams suggests that '"adequate relief of unendurable symptoms is an appropriately compelling reason to place the patient at risk" of the unwelcome consequences'.[179] The appropriate use of sedative drugs would appear to also satisfy the fourth criterion for the doctrine of double effect. The discussion above illustrates that all four criteria for double effect as set out by Williams can be satisfied for the administration of palliative sedation. Nonetheless, it is important to recognise that these criteria could be interpreted in a manner which is unlikely to lead to a homogenous interpretation of the role of double effect in cases of palliative sedation. As such, it is necessary to look beyond theory and question whether the requirements for this doctrine are clearly enunciated by the courts. This will highlight whether the courts have followed a particular interpretation of the doctrine of double effect or whether they have approached it in a manner which is more adaptable depending on the facts before the court.

Case Law on Double Effect

It has been suggested that the role of double effect in English case law was first acknowledged by Devlin J in *R v Adams*.[180] In *R v Adams*, the doctor was on trial for the murder of an elderly patient. It was alleged by the prosecution that the doctor had killed the patient for the purposes of inheriting property which she had left him in her will, and 'that he had done so by deliberately injecting her with excessively large doses of morphine.'[181] In discussing this case Devlin J commentated that:

> If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life.[182]

Devlin J also set out that if the defendant did some act which was capable of being murderous, if the requisite intent was present at the time, then the prosecution also

[178] ibid 68.
[179] Williams (n114) 50.
[180] *R v Adams* [1957] Crim LR 773; Glenys Williams, *Intention and causation in medical non-killing: the impact of criminal law concepts on euthanasia and assisted suicide* (Routledge-Cavendish 2007) 35; See also the United States cases of *Quill v Vacco* 80 F. 3d 716; 1996 US App Lexis 6216 and *Compassion in Dying v Washington* 79 F. 3d 790; 1996 US App Lexis 3944.
[181] Keown (n147) 24.
[182] Patrick Devlin, *Easing the Passing* (The Bodley Head 1985) 171.

needed to prove the intention to murder was present. This direction to the jury provided scope for the jury to acquit Dr. Adams if they were of the opinion that the intention of the doctor was to relieve the pain experienced by the patient or that the drugs had the effect of hastening the patient's death due to the poor medical condition of the patient. However, this was a direction to the jury and 'does not make law in itself'.[183]

Foster et al. have argued that this case did not actually introduce the doctrine of double effect in English law. In support of this argument, Foster et al. highlights that the term 'double effect' is not used by Devlin J.[184] There are also issues in relation to the direction to the jury as it appears to focus on issues of causation rather than intention.[185] In discussing this point Foster et al. stated, 'The direction is opaque: it is hard to read into it anything as complex as the doctrine of double effect.'[186] However, the case does demonstrate a judicial willingness to adopt an approach similar to double effect even though the criteria for double effect were not fully enunciated in this case.[187] Nonetheless, these factors led Foster et al. to argue that 'to see Adams as introducing the doctrine of double effect into English law is reading far too much into a rather amorphous direction to a jury.'[188] Despite this, the doctor in *R v Adams* was found not guilty.[189] Regardless of whether or not this case introduced the doctrine of double effect in to English law, there have been subsequent cases in which the doctrine was utilised as a defence.

The doctrine of double effect was employed unsuccessfully by the defence counsel in *R v Cox*.[190] Dr. Cox was charged with the murder of one of his patients as he injected the patient with 'a slow-acting tranquiliser and potassium chloride.'[191] The prosecution argued that the injection of potassium chloride did not have a therapeutic quality but was instead intended to hasten the death of the patient. This case centred around the issue of intention which was a contrast to *R v Adams* in which causation

[183] Foster (n132) 60-61.
[184] ibid 62.
[185] ibid.
[186] ibid.
[187] ibid 'Devlin J does not hint at, let alone discuss, either the second or the fourth element in Keown's formulation.'
[188] ibid.
[189] Williams (n180) 36.
[190] *R v Cox* (1992) 12 BMLR 38.
[191] Williams (n180) 36.

was to the fore.[192] The direction to the jury by Ognall J did not explicitly mention the doctrine of double effect but instead indirectly referred to some of the requirements for the doctrine. The requirement that '[t]he bad effect must not be a means of achieving the good effect'[193] was addressed by Ognall J when it was stated that 'Alleviation of suffering means the easing of it for so long as the patient survives; not the easing of it in the throes of, and because of, deliberate purpose killing.'[194] However, not all requirements were clearly set out as was demonstrated by the requirement of proportionality.[195] Although this case focussed on issues of intention, it did not adopt a clear step-by-step approach to the doctrine of double effect. In any case, the injection of potassium chloride made the successful application of the doctrine particularly challenging for the defence counsel given its lethal nature and lack of pain-relieving qualities.

The doctrine of double effect was also raised in the case of *Moor*.[196] Dr. Moor was charged with the murder of one of his patients. Dr. Moor claimed that the death 'was the result of an administration of diamorphine for the purposes of pain relief and the defence relied squarely on this.'[197] The patient in this case was not terminally ill and the post mortem revealed that 'up to six times the claimed amount of the drug was found in his body'.[198] However, this level did not seem to be consistent with the level of morphine found in other parts of the patient's body.[199] Hooper J put a number of questions to the jury to assist in making their decision. Among the questions were whether 'Dr. Moor has caused his patient's death',[200] whether Dr. Moor had intended to do something other than relieve the suffering of the patient, and 'was the jury satisfied that the injection he gave to his patient was intended to kill?'[201] Ultimately, Dr. Moor was found not guilty but this case demonstrates a disconnect between the

[192] ibid 37 'this is very much an intention based judgment.'
[193] Williams (n114) 45.
[194] *R v Cox* (1992) 12 BMLR 38.
[195] *R v Cox* (1992) 12 BMLR 38, 39. 'If a doctor genuinely believes that a certain course is beneficial to his patient, either therapeutically or analgesically, then even though he recognises that that course carries with it a risk to life, he is fully entitled, nonetheless, to pursue it. If in those circumstances the patient dies, nobody could possibly suggest that in that situation the doctor was guilty of murder or attempted murder.'
[196] *Moor*, The Times, 12 May 1999.
[197] Williams (n180) 38.
[198] ibid.
[199] ibid.
[200] ibid.
[201] ibid.

approach to intention in case law and the criteria set out for the doctrine of double effect.

A recent Irish case which provides a brief reference to the issues giving rise to the doctrine of double effect is *Fleming v Ireland & Ors*.[202] In bringing this case, the plaintiff was in the final stages of the illness and did not want to avail of specialist palliative care but wanted physician assisted suicide instead. This resulted in a certain amount of discussion in the High Court about the categorisation of specialist palliative care practices including palliative sedation and the withdrawal of artificial nutrition and hydration.

In the High Court, Dr. Tony O'Brien[203] was of the opinion that 'sedation does not hasten death.'[204] This is of course based on an appropriate use of sedation where the sedative drug is 'carefully titrated.'[205] However, during cross examination Dr. O'Brien went on to reject 'the assertion that sedatives are never administered as a primary purpose of shortening life'[206] but accepted that 'it is sometimes done knowing that that is what will happen.'[207] This illustrates the complexity of specialist palliative care, and the role which the doctrine of double effect has for the healthcare professional and also the patient receiving care at the end of life. Despite this, there was little judicial engagement in the High Court or in the Supreme Court case with this point as the case focussed on assisted suicide.

Overall, it has been demonstrated that double effect can be interpreted in a manner which provides a justification for the administration of palliative sedation but it is equally open to a contradictory interpretation. Furthermore, there has been little judicial engagement with the actual criteria for double effect. The cases cited above have elements of double effect reasoning and are often cited in discussion of double

[202] *Fleming v Ireland & Ors* [2013] IEHC 2, [2013] IESC 19.
[203] *Fleming v Ireland & Ors* [2013] IEHC 2, [34]. 'Dr. Tony O'Brien is a consultant physician in palliative medicine and former chair of the Council of Europe Expert Committee on Palliative Care.'
[204] *Fleming v Ireland & Ors* [2013] IEHC 2, [37].
[205] *Fleming v Ireland & Ors* [2013] IEHC 2, [38]; See comments of Professor Robert George at [2013] IEHC 2, [47] 'Finally, he concurred with Dr. O'Brien on the correct use of opioids and said that the notion that "by giving opioids at the very end of life we are bringing about death simply isn't true in our experience and the evidence doesn't support it at all."'
[206] *Fleming v Ireland & Ors* [2013] IEHC 2, [38].
[207] *Fleming v Ireland & Ors* [2013] IEHC 2, [38].

effect but none examine the application of the doctrine in a head-on or sustained manner.[208] Foster et al. were critical of the approach to double effect in case law and commented that that judges' references to double effect have often been:

> in a slapdash, shorthand way, either failing to identify clearly or at all the constituents of the doctrine they say they are applying, or referring to versions of the doctrine that do not reflect the more common formulations.[209]

This has been reflected in the case law set out in this Chapter.[210] Lord Mustill in *Bland*[211] highlighted that the doctrine of double effect has not 'been the subject of a specific decision but seems to have been generally assumed to be the law by criminal practitioners.'[212] Given the status of double effect it appears that the medical profession also practise under a similar belief. For example, the doctrine of double effect has been cited in the Irish Association of Palliative Care Discussion Paper on Palliative Sedation.[213] The doctrine of double effect was set out under the ethical principles concerned in the discussion paper. Nonetheless, the cumulative effect of the issues highlighted in this section serve to significantly weaken the status of the doctrine as relied upon by healthcare professionals. Consequently, much greater legal and ethical clarity is needed in distinguishing specialist palliative care from euthanasia so healthcare professionals have a clear understanding of what care can be provided to the terminally ill patient.[214]

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[208] Other cases which have discussed but not 'applied' the doctrine include *R(Pretty) v DPP* [2002] 1 All ER 1; *R(Nicklinson) v Ministry of Justice* [2013] HRLR 36.
[209] Foster (n132) 66.
[210] *R v Adams* [1957] Crim LR 773; *R v Cox* (1992) 12 BMLR 38; *Moor*, The Times, 12 May 1999.
[211] *Airedale N.H.S. v Bland* [1993] AC 789, [1993] 2 WLR 350.
[212] *Airedale N.H.S. v Bland* [1993] AC 789, 892 cited in *R(Nicklinson) v Ministry of Justice* [2013] HRLR 36 [26].
[213] Irish Association of Palliative Care, 'Palliative Sedation' (March 2011).
[214] Keown (n71) 319-320. 'Lord Joffe, explaining a clause in his Bill on assisted dying for the terminally ill, which would have entitled a terminally ill patient to request and receive such medication as may be necessary to keep him or her as free as possible from pain and distress, said that it was clear that some doctors were frightened of prosecution for using "double effect."'

Withdrawal of Artificial Nutrition and Hydration: The Acts and Omissions Distinction

It was previously highlighted that the withdrawal of artificial nutrition and hydration might accompany palliative sedation.[215] The withdrawal of artificial nutrition and hydration is best addressed by considering the acts and omissions distinction. Additionally, it must be questioned whether the acts and omissions distinction has deficiencies similar to those of double effect. The manner in which the withdrawal of artificial nutrition and hydration is justified is of particular importance as the failure to provide nutrition and hydration may amount to murder.[216] The distinction between palliative sedation and the withdrawal of artificial nutrition and hydration was highlighted in Chapter Two.[217] For example, they are 'separate decisions supported by different legal and ethical principles.'[218] This point was repeated by Dr. O'Brien in *Fleming v Ireland & Ors* when he commented that palliative sedation does not necessarily involve the withdrawal of artificial nutrition and hydration.[219] In circumstances where artificial nutrition and hydration is withdrawn from the patient this raises particular legal and ethical issues. A significant issue is whether artificial nutrition and hydration is categorised as medical treatment or medical care. Following on from this, the legality of withdrawing artificial nutrition and hydration depends largely on whether it is categorised as an act or an omission. The importance of this categorisation will be outlined when examining the case law on the withdrawal of artificial nutrition and hydration.

The elements of the offence of murder were set out in the second section of this Chapter. The 'building blocks'[220] of a charge are the actus reus and mens rea. The actus reus may be performed by an action or an omission based on the

[215] Text to n180 in Chapter Two.
[216] *R v Gibbins and Proctor* (1918) 13 Cr App R 134, *R v Stone and Dobinson* [1977] QB 354.
[217] Text to n180 in Chapter Two.
[218] Sjef Gevers, 'Terminal Sedation: A New Legal Approach' (2003) 10 European Journal of Health Law 359, 364; RJ Dunlop and others, 'On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?: A reply' (1995) 21 Journal of Medical Ethics 141 cited in GM Craig, 'On Withholding Artificial Hydration and Nutrition from Terminally Ill Sedated Patients. The Debate Continues' (1996) 22(3) Journal of Medical Ethics 147, 148; *Fleming* v *Ireland & Ors* [2013] IEHC 2 [37].
[219] *Fleming v Ireland & Ors* [2013] IEHC 2, [37].
[220] Campbell (n99) 80 'The *actus reus* and the *mens rea* may be described as the "building blocks" of crime, in other words these elements in the formula will be satisfied, the individual will not be guilty of the crime.'

circumstances.[221] An act is defined by Black's Law Dictionary as '[s]omething done or performed'.[222] It has also been described as 'events or states of affairs for which a person might be responsible according to the principles of responsibility that guide such judgments'.[223] In general, liability does not attach in situations where a person fails to act unless a person is 'under a legal duty to take positive action.'[224] The withdrawal of artificial nutrition and hydration has been considered an omission by the courts, and its withdrawal could therefore meet the actus reus requirement only if a legal duty exists to provide artificial nutrition and hydration.[225] In this regard, Mills set out that a duty of care does actually arise 'between the clinician and her patient when she undertakes to care for the patient, whether on foot of a request for care from the patient himself or following a referral from a colleague.'[226] As a result of this duty of care, a doctor or nurse might satisfy the actus reus requirement unless it could be shown that the withdrawal of treatment was in the patient's best interests. This is the line of reasoning which was taken in *Airedale N.H.S. v Bland*[227] and followed in *Re a Ward of Court*.

Case Law on the Acts and Omissions Distinction

In the case of *Airedale N.H.S. v Bland,* Tony Bland had been in a persistent vegetative state for three years and was reliant on life support. Healthcare professionals responsible for the care of Tony Bland were of the opinion that 'no useful purpose was to be served by continuing that medical care and that it was appropriate to stop the

[221] Hanly (n101) 48; Coffey (n101) 36.
[222] Bryan A Garner, *Black's Law Dictionary* (9th edn, Thompson/West 2009) 27 [act].
[223] Hyman Gross, *A Theory of Criminal Justice* (Oxford University Press 1979) 56; Williams (n179) 58 'In order to omit to do something, there must have been an obligation or a requirement to do it. Not doing it must therefore involve a conscious decision not to do it.'
[224] Coffey (n101) 51; Herring (n100) 87 'Generally, a person will not be liable for simply failing to act.'
[225] Williams (n179) 62 'As has been seen, omissions liability is based on a prerequisite duty (and thus can be avoided in the absence of that duty), whereas liability in the case of acts is simply based on the sanctity of life (Elkington 1968: 744)'; Williams (n179) 64 'Put simply, Simester argues that '… the moral distinction between act and omission … depends upon questions of responsibility'; if there is a duty, then a person would be just as responsible for omitting to comply with that duty as he would if he was an actor for whom the duty requirement was not a prerequisite condition.'
[226] Simon Mills, *Clinical Practice and the Law* (2nd edn, Tottel Publishing 2007) 140-141; Duty of care also demonstrated by *Barnett v Chelsea and Kensington Hospital Management Committee* [1969] 1 QB 428.
[227] *Airedale N.H.S. v Bland* [1993] AC 789, [1993] 2 WLR 350; Rob Heywood, 'Moving on from *Bland*: The Evolution of the Law and Minimally Conscious Patients' (2014) 0(0) Medical Law Review 1; Richard Huxtable, 'Autonomy, Best Interests and the Public Interest: Treatment, Non-Treatment and the Values of Medical Law' (2014) 0(0) Medical Law Review 1.

artificial feeding and other measures aimed at prolonging his existence.'[228] In order to clarify the legality of terminating ventilation and withdrawing artificial nutrition and hydration the hospital sought clarification from the court. At first instance, the Court held that it was in the best interests of the patient that the medical treatment be withdrawn. This decision was appealed by the Official Solicitor who was acting on behalf of Tony Bland. The decision at first instance was affirmed by the Court of Appeal and was again appealed by the Official Solicitor.

The general issue before the House of Lords was described as follows, 'In what circumstances, if ever, can those having a duty to feed an invalid lawfully stop doing so?'[229] In particular, can an attending physician 'lawfully discontinue all life-sustaining treatment and medical supportive measures designed to keep the defendant alive in his existing persistent vegetative state'?[230] The Court questioned whether artificial nutrition and hydration amounted to medical treatment or medical care. The next step was to consider whether the removal of artificial nutrition and hydration was an act or an omission. As doctors and nurses owe a duty of care, an omission can amount to the actus reus.[231] However, this situation was avoided by 'deciding that although the conduct was an omission, any pre-existing duty ceased to exist when it became obvious that it would not be in Anthony Bland's best interests to continue treatment.'[232] The treatment was viewed as 'futile',[233] had no 'affirmative benefit',[234] and 'no longer fulfils any therapeutic purpose.'[235] Consequently, there would be no criminal liability incurred by withdrawing his treatment.[236] This was described by Williams as, 'the *only* method by which the doctors could be found to have acted lawfully.'[237] Williams went on to state that the judgement 'only relied upon the AOD

[228] *Airedale N.H.S. v Bland* [1993] AC 789, 856.
[229] *Airedale N.H.S. v Bland* [1993] AC 789, 857.
[230] *Airedale N.H.S. v Bland* [1993] AC 789, 856.
[231] Hazel Biggs, 'Euthanasia and death with dignity: still poised on the fulcrum of homicide' (1996) Criminal Law Review 878, 882 'In Bland the proposed withdrawal of treatment was defined as an omission; accordingly it would only form the actus reus of homicide if there existed a duty to continue to treat this patient.'
[232] Williams (n125) 78.
[233] *Airedale N.H.S. v Bland* [1993] AC 789, 837; Beauchamp (n130) 169 'Physicians have no obligation to provide pointless, futile, or contradicted treatment.'; Beauchamp (n130) 170 'Our conclusion is that a genuinely futile medical intervention – one that has no chance of being efficacious in relation to accepted goals – is morally optional and in many cases ought not be introduced or continued.'
[234] *Airedale N.H.S. v Bland* [1993] AC 789, 884.
[235] *Airedale N.H.S. v Bland* [1993] AC 789, 873.
[236] Williams (n125) 78.
[237] ibid 80 (emphasis in original).

because it "existed" certainly there is no expression of confidence in the AOD as the foundation of treatment withdrawal cases.'[238] In a similar manner, Jackson described the approach taken in this case as '"backwards reasoning", in which a judge decides what outcome they wish to reach, and then finds a line of legal reasoning which enables them to secure this result.'[239] Nevertheless, this approach has been relied on by courts in subsequent decisions on the withdrawal of artificial nutrition and hydration.[240]

In Ireland, the issue of withdrawing artificial nutrition and hydration arose in the case of *Re a Ward of Court*.[241] In the High Court, Lynch J held that the artificial nutrition and hydration could be withdrawn from the ward. This decision was appealed to the Supreme Court which upheld the High Court's decision by a 4:1 majority. Among the issues to be determined by the Supreme Court included 'whether the course proposed by the committee and family of the ward and consented to by the learned trial judge was in the best interests of the ward',[242] and whether there was adequate evidence to support the finding of the trial judge that the withdrawal of artificial nourishment was in the patient's best interests.[243] The focus on best interests is due to the High Court's adoption of the test proposed by Lord Goff in *Airedale N.H.S. v Bland*.[244] This test questioned 'whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care'.[245] This approach requires a number of steps to be taken in order to justify the withdrawal of artificial nutrition and hydration and ensure that no liability attaches to the omission by the healthcare professional. In short, artificial nutrition and hydration had to be categorised as medical treatment rather than medical care. This categorisation allowed

[238] ibid 78. AOD stands for acts and omissions distinction; Williams highlights that there are policy reasons which support the use of this line of reasoning in allowing the medical practitioner to withdraw artificial nutrition and hydration from the patient.
[239] Emily Jackson and John Keown, *Debating Euthanasia* (Hart Publishing 2012) 26.
[240] *W Healthcare NHS Trust v KH*, [2004] WLR 834, patient not in a persistent vegetative state; *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403; *Swindon and Marlborough NHS Trust v S* [1995] 3 Medical Law Review 84; *An NHS Trust v M* [2001] 2 FLR 367; *An NHS Trust v H* [2001] 2 FLR 501; *In re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2011] EWHC 2443 (Fam), [2012] 1 WLR 1653; *W(by her litigation friend B) v M(by her litigation friend, the Official Solicitor) and S and A NHS Primary Care Trust* [2011] EWHC 2443 (Fam).
[241] *Ward of Court (withholding medical treatment) (No 2), Re*, [1995] IESC 1, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.
[242] *Ward of Court (withholding medical treatment) (No 2), Re*, [1995] IESC 1, [114].
[243] *Ward of Court (withholding medical treatment) (No 2), Re*, [1995] IESC 1, [114].
[244] *Ward of Court (withholding medical treatment) (No 2), Re*, [1995] IESC 1, [80], [265].
[245] *Airedale N.H.S. v Bland* [1993] AC 789.

for the withdrawal of treatment if it was not in the best interests of the patient. On this basis, the omission which is the withdrawal of treatment, would not amount to a breach of the duty of care owed to the patient. Consequently, the actus reus for murder would not be present and therefore could not be established.

In *Re a Ward of Court* artificial nutrition and hydration was administered by way of a nasogastric tube and this was seen as being 'intrusive'[246] and as constituting 'an interference with the integrity of her body and cannot be regarded as normal means of nourishment.'[247] This reasoning was supported by reliance on the US case *Cruzan v Director Missouri Department of Health*.[248] In this case Brennan J commented that 'The artificial delivery of nutrition and hydration is undoubtedly medical treatment.'[249] In *Re a Ward of Court* it was argued for the institution that artificial nutrition and hydration was merely 'the equivalent of food and drink which everybody required for survival'[250] and the nasogastric tube had become normal due to its duration.[251] Separately, Mason and Laurie stated that 'any form of feeding which requires some *medical* training and expertise can be considered medical treatment'.[252] Distinctions of such importance will attract criticism in any such case. However, there is no clear line between what constitutes medical treatment or medical care and it has been described by Beauchamp and Childress as 'unacceptably vague'.[253]

Both the High Court and the Supreme Court were of the opinion that artificial nutrition and hydration constituted a form of medical treatment rather than medical care. As such, once the treatment was withdrawn the patient would die from her original injuries rather than lack of food and water. The Supreme Court accepted the best

[246] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 124.
[247] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 125.
[248] *Cruzan v Director Missouri Department of Health* (1990) 497 US 261.
[249] *Cruzan v Director Missouri Department of Health* (1990) 497 US 261, 307.
[250] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 143.
[251] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 143.
[252] J Kenyon Mason and Graeme Laurie, *Mason & Mccall Smith's Law & Medical Ethics* (8th edn, Oxford University Press 2011) 576 (emphasis in original); Williams (n114) 50 Williams commented that the categorisation of artificial nutrition and hydration as a medical treatment is a position which has been taken by 'both the legal and medical professions'.
[253] Beauchamp (n130) 162 'Unfortunately, neither a long history nor precedent guarantees clarity or adequacy. The distinction between ordinary and extraordinary means of treatment is unacceptably vague and morally misleading.'

interests test which had been adopted by the High Court.[254] For instance, O'Flaherty J stated that the best interests of the ward would mean that 'nature should take its course in this case without artificial means of preserving what technically is life, but life without purpose, meaning or dignity.'[255] In arriving at this decision, the Supreme Court not only utilised the best interests test but also considered what the ward would choose 'if she could be granted a momentary lucid and articulate period'.[256] The subjective nature of this choice renders this particularly challenging but the Court drew on 'the evidence of the family on this aspect of the case'.[257] This case demonstrated a judicial acceptance in Ireland of the permissibility of withdrawing artificial nutrition and hydration when it was in the best interests of the patient to do so.

The wider circumstances around the withdrawal of artificial nutrition and hydration in general need to be considered. For example, it is important to consider why the patient is not able to take nutrition and hydration naturally. If the patient has been sedated to the point requiring the administration of artificial nutrition and hydration then it is 'the physician-created state of diminished consciousness that renders the patient unable to eat, not the patient's underlying disease.'[258] In such a case, if artificial nutrition and hydration is removed from a terminally sedated patient it may be a leap in logic to attribute the death to the original illness rather than the removal of treatment. Although, this does depend on the patient's condition prior to beginning palliative sedation. This underlines the importance of an appropriate legal framework which provides clarity and consistency for specialist palliative care practices such as the decision to begin palliative sedation or the circumstances in which artificial nutrition and hydration should be provided or withdrawn.

Chapter Two highlighted the lack of a clear position on the value of artificial nutrition and hydration for terminally ill patients.[259] As such, the merits and demerits of this

[254] *Ward of Court (withholding medical treatment) (No 2), Re,* [1995] IESC 1, [172]. In discussing the decision of Lynch J, Hamilton CJ stated 'he adopted the proper test'; Accepted by O'Flaherty J at [1995] IESC 1, [216]; Accepted by Egan J at [1995] IESC 1, [224]; Accepted by Blayney J at [1995] IESC 1, [265]; Accepted by Denham J at [1995] IESC 1, [365].
[255] [1995] IESC 1, [216].
[256] *Ward of Court (withholding medical treatment) (No 2), Re,* [1995] IESC 1, [82].
[257] *Ward of Court (withholding medical treatment) (No 2), Re,* [1995] IESC 1, [82].
[258] David Orentlicher, 'The Supreme Court and Physician-Assisted Suicide: Rejecting Assisted Suicide but Embracing Euthanasia' (1997) 337(17) New England Journal of Medicine 1236, 1237.
[259] Text to n188 and n189 in Chapter Two.

form of medical treatment are not entirely clear. On this basis, the principles of nonmaleficence and beneficence could be drawn on to argue in favour of providing artificial nutrition and hydration for the patient. Despite this, Beauchamp and Childress noted that such an argument 'does not entail that it is always obligatory to provide the treatments.'[260] In this respect, it was also noted by Beauchamp and Childress that '[f]or imminently dying patients, responsibilities are not fixed by obligations to provide treatments that serve only to extend the dying process; they are fixed by obligations to provide appropriate care in dying.'[261] This may be the case where a broader balancing of principles and facts is taken into account. For example, in *Re a Ward of Court*, it appears that a broader value judgment was made by the court which included consideration of the patient's quality of life.

The distinction between acts and omissions has attracted a considerable amount of criticism,[262] and it has been described as 'more of a hindrance than an aid to resolving the legal problems in this area.'[263] Hanafin recognised the problems posed by the acts and omissions distinction and considered it 'a shaky foundation on which to build a right-to-die jurisprudence.'[264] In addition to this, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research set out that 'the fact that the distinction is conceptually unclear and has no solid foundation upon which it can rest unchallenged, is problematic'.[265] However, it is a distinction which is still being employed to support the withdrawal of artificial nutrition and hydration. Jackson examines the distinction between acts and omissions in the context of treatment withdrawal, and argues that 'the differences between the two sorts of conduct, while not non-existent, are in this case insufficient to bear the

[260] Beauchamp (n130) 169; Beauchamp (n130) 164 'In our judgment, caregivers may justifiably forego MN&H for patients in some circumstances, as holds true for other life-sustaining technologies. No morally relevant difference exists between the various life-sustaining technologies, and the right to refuse medical treatment for oneself or others is not contingent on the type of treatment. There is no reason to believe that MN&H is always an essential part of palliative care or that it necessarily constitutes beneficial medical treatment.'
[261] Beauchamp (n130) 172.
[262] James Rachels, 'Active and passive euthanasia' (1975) 292 New England Journal of Medicine 78; See also Kuhse (n71) 38; Begley (n151) 865.
[263] Patrick Hanafin, *Last Rights*: *Death, Dying and the Law in Ireland* (Cork University Press 1997) 24.
[264] ibid 25.
[265] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 'Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions' (1983) 61 cited by Williams (n179) 87.

moral weight that is placed upon them by the law.'[266] All of this suggests that specialist palliative care requires a legal framework with a more coherent foundation in order to ensure that healthcare professionals and patients have certainty about the limits of care and the type of care which can be provided.[267]

The absence of a clear legal framework for specialist palliative care can just as easily lead to overtreatment of the patient as it can undertreatment of the patient;[268] neither of which protects the human rights of a patient or accurately reflects the goals of palliative care. Overall, the legal framework needs to provide greater certainty for healthcare professionals and a solid legal foundation on which to practise. On this point, the acts and omissions distinction does not provide a particularly solid foundation for these practices and results in an unsatisfactory situation for both patients and healthcare professionals.

Conclusion

The aim of this Chapter was to examine the legitimacy of the distinction between specialist palliative care practices and euthanasia. In achieving this, the legality of palliative sedation and the withdrawal of artificial nutrition and hydration was discussed and contrasted against the practice of euthanasia. This approach assisted in further defining the legal framework for specialist palliative care in Ireland and, importantly, it highlighted areas of ambiguity which need to be addressed by professional standards and guidelines.

In the first section, the legal framework for euthanasia in the Netherlands was outlined. This provided an example of euthanasia in practice and highlighted the importance of defining the type of suffering for which specialist palliative care can be provided. In particular, the issue of non-somatic suffering can be a challenging symptom to address and it may cause the distinction between specialist palliative care and euthanasia to

[266] Jackson (n238) 30.
[267] Quill (n124) 11 'However, hidden, ambiguous practices, inconsistent justifications, and failure to acknowledge the risks of accepted practices may also undermine the quality of terminal care and put patients at unwarranted risk.'
[268] Beauchamp (n130) 160 'Giving priority to withholding over withdrawing treatment can lead to overtreatment in some cases, that is, the continuation of no longer beneficial or desirable treatment for the patient. Less obviously, the distinction can lead to undertreatment. Patients and families worry about being trapped by biomedical technology that, once begun, cannot be stopped.'

become blurred. As a result of this, it is important that the legal framework in Ireland for specialist palliative care provides guidance on the identification of refractory symptoms which may require sedation and that a clear decision-making framework exists for such practices. The lack of such guidance would serve to undermine efforts to distinguish specialist palliative care from euthanasia. This is a point which also emerged in the second and third sections of this Chapter.

In the second section, the law on homicide and assisted suicide in Ireland was set out. This served to define the limits of medical practice in this jurisdiction and was in contrast to the legal position adopted in the Netherlands. The second section also outlined the law on intention in Ireland. This was relevant for the third section of this Chapter which considered justifications such as the doctrine of double effect and the acts and omissions distinction for specialist palliative care practices.

In relation to double effect, it was shown that palliative sedation satisfied the four criteria for the doctrine of double effect as set out by Williams. Unfortunately, the use of this doctrine in case law could be described as vague and uncertain. The lack of judicial engagement and legislative support for the doctrine of double effect undermines the distinction between specialist palliative care and euthanasia. As such, greater clarity is needed in distinguishing these practices. In any case, the doctrine of double effect is of most relevance after the fact, i.e. it serves as a legal justification after an act has occurred. It is not appropriate for healthcare professionals to be guided by a justification when providing palliative care; a form of care which, if administered appropriately, is unlikely to hasten the death of the patient. In this regard, reliance on the doctrine of double effect further suggests that palliative sedation is inextricably linked with the hastening of death. Instead, greater guidance is needed at an earlier stage in patient care. This guidance should, at a minimum, be clear on indications for palliative sedation, the decision-making framework for palliative sedation, and the practice of commencing palliative sedation. Such guidance needs to be clear, consistent, and drafted in a manner which recognises the co-operation which takes place between doctors and nurses in caring for the terminally ill patient.

The same conclusions can also be drawn from considering the acts and omission distinction. This distinction does not provide a strong or coherent foundation from

which to provide specialist palliative care. The complexity of the decision to withdraw artificial nutrition and hydration was evident in the case of *Re a Ward of Court*. Healthcare professionals will always face difficult decisions about end-of-life care but these decisions should be supported by a clear and consistent legal framework.

Overall, the doctrine of double effect and the acts and omissions distinction serve to distinguish specialist palliative care practices from euthanasia but do not provide the certainty which is necessary for both the healthcare professional and the care of the patient. Consequently, it is important that other parts of the legal framework provide a stronger base on which to provide specialist palliative care. Chapter Four will examine the distinction based on human rights while also identifying the rights which must be met in the provision of specialist palliative care. Furthermore, professional standards and guidance must provide a clear foundation on which healthcare professionals can practise. The role and impact of professional standards will be examined in Chapter Five.

THE HUMAN RIGHTS FRAMEWORK FOR SPECIALIST PALLIATIVE CARE

Introduction

This Chapter outlines and examines the human rights framework for specialist palliative care in Ireland. It will be demonstrated that human rights occupy a central role in the legal framework in Ireland for specialist palliative care and that it is vital for appropriate respect to be given to these rights in practice. There are many human rights engaged by specialist palliative care including the right to health, the right to bodily integrity, protection from inhuman or degrading treatment, the right of autonomy, the right to equality, and the right to family life. The principle of dignity is also engaged by specialist palliative care. However, it is not possible within the scope of this thesis to examine all of these rights. As a result, the human rights which will be examined are rights which have been prevalent in case law relating to end-of-life care,[1] and in reports[2] and academic commentary on palliative care. These are rights which will also influence the specification of autonomy, nonmaleficence, beneficence, and justice when advancing suggestions for reform later in this thesis.[3] In addition to this, the previous chapters have highlighted a number of human rights issues in the context of specialist palliative care which need to be addressed. The issues identified in previous chapters include: the need to respect the dignity of the terminally ill patient,[4] access to appropriate palliative care,[5] participation in decision-making,[6] equality of palliative care provision across different institutions,[7] and the lack of clarity

[1] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401; *Fleming v Ireland & Ors* [2013] IEHC 2, [2013] IESC 19; *D v United Kingdom* (1997) 24 EHRR 423.

[2] Eamon O'Shea and others, 'End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland' (Hospice Friendly Hospitals and National Council on Ageing and Older People 2008); Kieran McKeown, Trutz Haase and Shelagh Twomey, 'Dying in Hospital in Ireland: Nurse and Doctor Perspectives, Report 2' (Irish Hospice Foundation 2010); See also Eric Wilkes, 'Terminal Care: Report of a Working Party' (London 1980); World Health Organisation, 'Cancer Pain Relief and Palliative Care: Report of a WHO Expert Committee' (Geneva 1990); Resolution 1649 (2009) 'Palliative care: a model for innovative health and social policies' adopted by the Assembly on 28 January 2009 [14] The Council Of Europe considers palliative care to be a vital element of 'appropriate health care based on a humane concept of human dignity, autonomy, human rights, civic rights, patient rights and a generally acknowledged perception of solidarity and social cohesion.'

[3] Text to n94 in Chapter One.

[4] Text to n123 in Chapter Two.

[5] Text to n76 in Chapter Two.

[6] See p42.

[7] Text to n73 in Chapter Two.

in providing specialist palliative care practices.[8] These concerns will further guide the manner in which human rights are examined in this Chapter. Overall, the discussion of human rights provides a measure against which to examine professional standards and guidance in subsequent chapters, as well as clarifying a substantial proportion of the legal framework in Ireland for specialist palliative care.

In this Chapter, the right to bodily integrity, protection from inhuman or degrading treatment, the right of autonomy, and dignity, as they apply to specialist palliative care will be examined. This Chapter does not focus on the theoretical underpinnings of the rights discussed but will concentrate on the manner in which the courts have interpreted and applied these rights. As such, the selected rights have a significant body of associated jurisprudence which provides insight into the meaning of these rights and illustrates the consequences of failing to protect and vindicate a recognised human right. The adoption of this approach allows for professional standards and guidance to be examined from a position which concentrates on the law in practice. This reflects the practical focus of this thesis in examining the legal framework in which healthcare professionals provide care to terminally ill patients. In this context, rights are not to be viewed as abstract concepts but as guidance in terms of the minimum level of care which a healthcare professional should provide to a patient.[9]

There are five main sections in this Chapter. This is larger than any preceding or subsequent Chapter in this thesis but it is necessary due to the importance and scale of the rights framework for specialist palliative care. The rights framework can be viewed as providing a foundation on which to develop other aspects of the legal framework for specialist palliative care. For instance, professional standards and guidance must, at a minimum, protect the human rights of a patient. The first section involves setting out the background to human rights in Ireland such as the identification of human rights in the Irish Constitution and the status of the European Convention on Human Rights and Fundamental Freedoms [hereinafter 'ECHR'] in this jurisdiction. The

[8] Text to n92 in Chapter Two.

[9] *Airey v Ireland* App no 6289/73 (Chamber Decision, 9 October 1979) [24] 'The Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective'; *Tysiąc v Poland* (2007) 45 EHRR 42, [113]; Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 369-370 'The reason that rights are special, and especially cherished, is that individuals hold justified claims that they can exercise. They are not beholden to the moral beneficence of other persons.'

nature of many of the human rights discussed in this Chapter is such that their interpretation and application often overlap with each other. However, for the purposes of clarity the ensuing sections will each concentrate on an individual human right while recognising that a degree of overlap cannot be completely avoided.

The meaning and impact of the right to bodily integrity will be examined in the second section of this Chapter. The interpretation of this right has been discussed by courts in Ireland and by the European Court of Human Rights [hereinafter 'ECtHR']. Although not expressly contained in the ECHR, a right to physical integrity has been recognised as part of other expressly recognised rights.

The right to be protected from torture and from inhuman or degrading treatment or punishment will be discussed in the third section. This has been recognised as an unenumerated right in the Irish Constitution and is set out by Article 3 of the ECHR. For the most part, the focus will be on inhuman and degrading treatment rather than torture. In particular, the level of treatment or non-treatment which could result in a breach of this right will be discussed in this section.

The right of autonomy will be examined in the fourth section of this Chapter. Discussion of the right of autonomy assists in identifying the limits of what a patient can request or refuse in terms of their medical treatment and care. The right of autonomy, as will be demonstrated, has a considerable impact in the area of specialist palliative care. On this point, the scope of the right is such that this section will also discuss the use of advance care directives in Ireland. It will emerge from this section that the legal framework for advance care directives in this jurisdiction has long been inadequate but forthcoming legislation may address some of the problems in this area.

Dignity will be examined in the fifth section of this Chapter. The term dignity is often used in end-of-life care without a clear understanding of what dignity entails. For example, the phrase 'death with dignity' is regularly used in the medical and legal articles on end-of-life care without any great precision.[10] This section will draw on

[10] Christopher Mil Cope 'Death with dignity' (1997) 27(5) Hastings Center Report 37 Cope suggests that this term should be abandoned due to a lack of clarity as to what it means.

legal instruments and case law in the same way as other sections but it is especially important to take account of the criticism of the characterisation of dignity and recognise what it may mean for specialist palliative care. In this regard, questions arise as to whether dignity should be recognised as a right or whether it is instead a constitutional value.[11] Cumulatively, these sections will build to demonstrate a significant part of the legal framework in Ireland for specialist palliative care. Moreover, these sections will also demonstrate a number of shortcomings in the existing framework which need to be addressed in order to ensure appropriate specialist palliative care can be consistently provided in this jurisdiction.

The Protection of Human Rights in Ireland

Human rights are set out in international and regional treaties, in the Irish Constitution, and in legislation. This Chapter will, for the most part, refer to sources of human rights which are directly enforceable as they can be drawn upon by the person in their individual circumstances. Despite this, reference will be made to other treaties and conventions which lack direct enforceability but which serve to 'promote a culture of rights recognition and protection and a benchmark for assessment of rights.'[12] A main source of directly enforceable human rights in Ireland is the Irish Constitution which contains both enumerated and unenumerated rights. Human rights relevant to the provision of palliative care are also contained in the ECHR which has a more complex status in Ireland; the impact of which will be outlined in the course of this section. In addition to the ECHR, reference will be made to sources of human rights such as the Charter of Fundamental Rights,[13] the Universal Declaration of Human Rights[14] and the related International Covenant on Civil and Political Rights[15] and the International Covenant on Economic, Social and Cultural Rights.[16]

The Irish Constitution

The Irish Constitution entered into force on the 29th December 1937. The Constitution is superior to all legislation and other sources of law in this jurisdiction.[17] It established

[11] See p161.
[12] Ita Mangan, 'Older People in Long Stay Care' (The Human Rights Commission 2002) 49.
[13] Charter of Fundamental Rights of the European Union [2010] OJ C83/380.
[14] Universal Declaration of Human Rights (1949).
[15] International Covenant on Civil and Political Rights (1966).
[16] International Covenant on Economic, Social and Cultural Rights (1966).
[17] Bunreacht na hÉireann, Article 15.4

the main institutions of the State such as organs of government[18] and the court system,[19] as well as setting out the fundamental rights of the citizen.[20] The fundamental rights referred to are natural rights which an individual possesses due to the simple fact that they are human beings.[21] However, the Irish Constitution does not set out an exhaustive list of the rights an individual may have. In this respect, the existence of unenumerated rights has been recognised by Irish courts. These are rights which, although not expressly set out in the Irish Constitution, can be derived from the Constitution. This point will be considered fully when examining unenumerated rights such as the right to bodily integrity later in this chapter.[22]

The European Convention on Human Rights

The ECHR was drafted by the Council of Europe in 1950 and entered into force in 1953.[23] The ratification of the ECHR by a State results in a legal obligation 'to guarantee to individuals within their jurisdiction a select number of civil and political rights.'[24] The ECHR was incorporated[25] into Irish domestic law by way of the *European Convention on Human Rights Act 2003* [hereinafter '*ECHR Act 2003*']. The approach to incorporation in this piece of legislation is 'indirect or interpretative incorporation at a sub-constitutional level.'[26] This method of incorporation maintained the supremacy of the Irish Constitution.

1° The Oireachtas shall not enact any law which is in any respect repugnant to this Constitution or any provision thereof.
2° Every law enacted by the Oireachtas which is in any respect repugnant to this Constitution or to any provision thereof, shall, but to the extent only of such repugnancy, be invalid.

[18] Bunreacht na hÉireann, Article 15-27.
[19] Bunreacht na hÉireann, Article 34-37.
[20] Bunreacht na hÉireann, Article 40-44.
[21] Seamus Henchy, 'Precedent in the Irish Supreme Court' (1962) 25 Modern Law Review 544, 557. This article was prior to the appointment of Henchy J to the High Court.
[22] Text to n68.
[23] Ed Bates, *The Evolution of the European Convention on Human Rights: From its Inception to the Creation of a Permanent Court of Human Rights* (Oxford University Press 2011) 1-2.
[24] ibid 2.
[25] The term 'incorporation' is used in this section for simplicity but the difficulty of using this term is recognised. *Foy v An t-Ard Chlaraitheori* [2007] IEHC 470, [93] per McKenchie J, 'It is a misleading metaphor to say that the Convention was incorporated into domestic law. It was not. The rights contained in the Convention are now part of Irish law. They are so by reason of the Act of 2003. That is their source. Not the Convention. So it is only correct to say, as understood in this way, that the Convention forms part of our law.'
[26] Donncha O'Connell, 'The ECHR Act 2003: A Critical Perspective' in Ursula Kilkelly (ed), *ECHR and Irish Law* (Jordan Publishing 2004) 2.

Individuals who feel that their rights under the Convention have been violated by the State can ultimately bring a case to the ECtHR. States are obliged to comply with the decision of the ECtHR in circumstances where the Court holds there to be a violation of the Convention. In this regard, the Committee of Ministers of the Council of Europe has responsibility for monitoring whether States have complied with the judgment of the ECtHR. As such, there are two sources of rights stemming from the ECHR. There is the ECHR itself which can be drawn on before the ECtHR, and the *ECHR Act 2003* which is applicable in the domestic sphere. Particularly relevant to the provision of palliative care is the recognition by the ECtHR of a right to physical integrity, albeit as part of several other rights. In addition to this, the ECHR also protects a right to privacy,[27] and a right to be protected from torture and inhuman or degrading treatment.[28] The meaning of these rights will be drawn out in this Chapter through discussion of ECtHR case law.

Section 2 of the *ECHR Act 200*3 addresses the interpretative requirements of the courts. This requires courts to interpret and apply 'any statutory provision or rule of law … in a manner compatible with the State's obligations under the Convention provisions.'[29] The scope of Section 2 depends on the interpretation of the term 'statutory provision' as the interpretative obligation extends to 'any statutory provision'. The *ECHR Act 2003* defines a 'statutory provision' as:

> any provision of an Act of the Oireachtas or of any order, regulation, rule, licence, bye-law or other like document made, issued or otherwise created thereunder or any statute, order, regulation, rule, licence, bye-law or other like document made, issued or otherwise created under a statute which continued in force by virtue of Article 50 of the Constitution.[30]

This is a broad interpretation of the term 'statutory provision' and demonstrates that it not limited to primary legislation, as seen in *The Law Society of Ireland v The Competition Authority*.[31]

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[27] European Convention on Human Rights, Article 8.
[28] European Convention on Human Rights, Article 3.
[29] European Convention on Human Rights Act 2003, s 2(1).
[30] European Convention on Human Rights Act 2003, s 1.
[31] *The Law Society of Ireland v The Competition Authority* [2006] 2 IR 262.

An issue in *The Law Society of Ireland v The Competition Authority* was whether Section 5 of the *ECHR Act 2003* could apply to a notice published by the Competition Authority which related to the 'legal representation of persons attending before the competition authority'.[32] Section 5 of the *ECHR Act 2003* addresses the possible role of the High Court or the Supreme Court in making a declaration of incompatibility which means that 'a statutory provision or rule of law is incompatible with the State's obligations under the Convention provisions.'[33] It was argued by the Competition Authority that the notice was not a 'statutory provision' as defined by Section 1(1) of the *ECHR Act 2003*.[34] However, O'Neill J held that 'the prohibition on multiple representation contained in the notice is a "rule" within that definition and in addition falls comfortably within the meaning of "other like documents", as set out in the definition.'[35] As a result, the notice could be the subject of a declaration under Section 5 of the *ECHR Act 2003*. On this basis, it can be argued that standards and guidance published by bodies such as the Health Information and Quality Authority, the Irish Medical Council, An Bord Altranais, and the Health Service Executive are capable of coming within the meaning of 'statutory provision'. This would require courts to interpret and apply them in 'a manner compatible with the State's obligations under the Convention provisions',[36] as required by Section 3 of the *ECHR Act 2003*.

Section 3 of the *ECHR Act 2003* requires that 'every organ of the State shall perform its functions in a manner compatible with the State's obligations under the Convention provisions.'[37] Again, the scope of this section greatly depends on the interpretation of a term, namely 'organ of the State'. This term was described by the *ECHR Act 2003* as including:

> a tribunal or any other body (other than the President or the Oireachtas or either House of the Oireachtas or a Committee of either such House or a

[32] *The Law Society of Ireland v The Competition Authority* [2006] 2 IR 262, 262.
[33] European Convention on Human Rights Act 2003, s 5(1).
[34] *The Law Society of Ireland v The Competition Authority* [2006] 2 IR 262, 271 'It was submitted that the essence of the material to be published under s. 30(1)(d) would be guideline material, with the necessary implication that the persons to whom the notice might be addressed, were not be bound in law to follow the guideline and could choose an alternative way, if one was available, to achieve compliance with the Act.'
[35] *The Law Society of Ireland v The Competition Authority* [2006] 2 IR 262, 286.
[36] European Convention on Human Rights Act 2003, s 2(1).
[37] European Convention on Human Rights Act 2003, s 3(1).

> Joint Committee of both such Houses or a court) which is established by law or through which any of the legislative, executive or judicial powers of the State are exercised[38]

On this basis, an organ of the State must be a body established by law or a body 'through which any of the legislative, executive or judicial powers of the State are exercised'.[39] This would include bodies such as the Health Information and Quality Authority,[40] the Irish Medical Council,[41] An Bord Altranais,[42] and the Health Service Executive.[43] These bodies must therefore carry out their functions in a way which is compatible with the obligations placed on the State. In this respect, it is not a defence before the ECtHR to argue that the actions of an organ of the State were authorised by statute.[44] In circumstances where the issue relates to domestic legislation then it is a declaration of incompatibility which is the solution set out by the *ECHR Act 2003*.[45] In any case, it has been suggested by de Londras and Kelly that organs of the State should not be passive but 'should take measures to ensure compliance with the Convention, rather than simply waiting for a negative court decision against them.'[46] This would mean that bodies such as the Irish Medical Council and An Bord Altranais should take active steps to ensure their standards and guidance, including those on specialist palliative care, protects and vindicates the human rights contained in the ECHR.

Section 4 of the *ECHR Act 2003* outlines authorities to be considered by the courts when examining the Convention. This includes a wide range of decisions and opinions from the ECtHR, the European Commission of Human Rights, and the Committee of

[38] European Convention on Human Rights Act 2003, s 1.
[39] European Convention on Human Rights Act 2003, s 1.
[40] Established by the Health Act 2007.
[41] Established by the Medical Practitioners Act 1978.
[42] Established by the Nurses Act 1950.
[43] Established by the Health Act 2004.
[44] Fiona de Londras and Cliona Kelly, *European Convention on Human Rights Act* (Round Hall 2010) 127.
[45] European Convention on Human Rights Act 2003, s 5; de Londras (n44) 13 Such a declaration does not impact on the '"validity, continuing operation or enforcement of the statutory provision or rule of law in respect of which it is made"' and it will not have any impact on the proceedings before the court or on the legal position of the applicant who sought the declaration.'
[46] de Londras (n44) 97 'At the very least these bodies would be expected to "proof" their policies, strategies and decision making processes so as to ensure compatibility with the Convention'.

Ministers.[47] Courts are also required to take account of 'the principles laid down by those declarations, decisions, advisory opinions, opinions and judgments.'[48] This is a wide range of authorities on which to draw but there is also a margin of appreciation enjoyed by the States in applying the human rights set out in the ECHR. The basis of this margin of appreciation is that authorities in a State 'are in a better position than an international judge when weighing competing public and individual interests.'[49] However, this is not to say that courts are provided an unrestricted margin of appreciation. In contrast to this, certain rights such as the right to be free from torture and inhuman or degrading treatment have a very narrow margin of appreciation as there can be no limitation placed on this right.[50]

The EU Charter of Fundamental Rights

The European Union has drafted a number of treaties on human rights, including the European Union Charter of Fundamental Rights. This was largely a codification of human rights. For example, de Búrca wrote that the Charter of Fundamental Rights 'sets out in a single text, for the first time in the EU's history, a wide range of civil, political, economic and social rights of European citizens and of all persons resident in the EU.'[51] The Charter of Fundamental Rights did not have full effect until the Lisbon Treaty entered into force on the 1st December 2009. The European Union is

[47] European Convention on Human Rights Act, s 4. Judicial notice shall be taken of the Convention provisions and of—
(a) any declaration, decision, advisory opinion or judgment of the European Court of Human Rights established under the Convention on any question in respect of which that Court has jurisdiction,
(b) any decision or opinion of the European Commission of Human Rights so established on any question in respect of which it had jurisdiction,
(c) any decision of the Committee of Ministers established under the Statute of the Council of Europe on any question in respect of which it has jurisdiction,
and a court shall, when interpreting and applying the Convention provisions, take due account of the principles laid down by those declarations, decisions, advisory opinions, opinions and judgments.

[48] European Convention on Human Rights Act, s 4.

[49] Evana Kirrane, 'Human Rights in the Irish Constitution and in the European Convention on Human Rights - A Comparative Study' (2003) 21 Irish Law Times 7, 10; *Powell and Rayner v the United Kingdom* App No 9310/81 (ECtHR, 21 February 1990) [44] 'It is certainly not for the Commission or the Court to substitute for the assessment of the national authorities any other assessment of what might be the best policy in this difficult social and technical sphere. This is an area where the Contracting States are to be recognised as enjoying a wide margin of appreciation.'; See also *Hatton and Others v the United Kingdom* App No 36022/97 (ECtHR, 8 July 2003) [100].

[50] Gerhard Van Der Schyff, 'Interpreting the protection guaranteed by two-stage rights in the European Convention on Human Rights: the case for wide interpretation' in Eva Brems and Janneke Gerards (eds), *Shaping Rights in the ECHR: The Role of the European Court of Human Rights in Determining the Scope of Human Rights* (Cambridge University Press 2014) 68.

[51] Gráinne de Búrca, 'The Domestic Impact of the EU Charter of Fundamental Rights' (2013) The Irish Jurist 49, 49.

required to act and legislate in line with the Charter. The Charter of Fundamental Rights is applicable to Institutions of the European Union and Member States when implementing EU law; it does not serve to extend the competences of the European Union. However, the Charter of Fundamental Rights will be referred to sparingly in this thesis as the Charter is not applicable to 'the Member State's actions in purely national situations'.[52] Nonetheless, the Charter of Fundamental Freedoms highlights rights which ought to be protected and serves to encourage a culture of rights protection.

The impact of the Charter is that it 'strengthens the protection of fundamental rights by making those rights more visible and more explicit for citizens.'[53] Of particular relevance to palliative care is the recognition in the Charter of Fundamental Rights of rights such as a right to human dignity,[54] the right to the integrity of the person,[55] the prohibition of torture and inhuman or degrading treatment,[56] the respect for private and family life,[57] the rights of the elderly,[58] and the right to healthcare.[59] Article 52 of the Charter of Fundamental Rights addresses the scope and interpretation of rights and principles. It sets out that the Charter of Fundamental Rights overlaps with and is to be aligned with the meaning of those rights also contained within the ECHR.[60] As such, the Charter will be cited along with the ECHR in this Chapter but will be drawn on sparingly due to its limited enforceability. In addition to the Charter, reference will also be made to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine,[61] and the European Charter of Patients' Rights.[62]

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[52] ibid 52.
[53] 'EU Charter of Fundamental Rights' (European Commission, 25 July 2013) <http://ec.europa.eu/justice/fundamental-rights/charter/> accessed 20 June 2014.
[54] Charter of Fundamental Rights of the European Union, Preamble and Article 1.
[55] Charter of Fundamental Rights of the European Union, Article 3.
[56] Charter of Fundamental Rights of the European Union, Article 4.
[57] Charter of Fundamental Rights of the European Union, Article 7.
[58] Charter of Fundamental Rights of the European Union, Article 25.
[59] Charter of Fundamental Rights of the European Union, Article 35.
[60] Charter of Fundamental Rights of the European Union, Article 52(3) 'In so far as this Charter contains rights which correspond to rights guaranteed by the Convention for the Protection of Human Rights and Fundamental Freedoms, the meaning and scope of those rights shall be the same as those laid down by the said Convention. This provision shall not prevent Union law providing more extensive protection.'
[61] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention) 1997.
[62] European Charter of Patients' Rights 2002.

The United Nations

The United Nations has also addressed the protection of human rights. This is demonstrated by Universal Declaration of Human Rights which is the foundation for the International Covenant on Civil and Political Rights [hereinafter 'ICCPR'] and the International Covenant on Economic, Social and Cultural Rights [hereinafter 'ICESCR']. The ICCPR is monitored by the United Nations Human Rights Committee, to which States normally report every four years. A number of rights set out in the ICCPR overlap with those contained in the Irish Constitution and the ECHR[63] but due to enforceability these rights will generally be examined by reference to Irish courts and the ECtHR. The ICESCR can be said to 'list standards towards which parties to the Covenant are obliged to work.'[64] It has been suggested that the ICESCR contains one of the most extensive articles on the right to health in human rights law.[65] In this regard, Article 12.1 of the Covenant provides for the 'right of everyone to the enjoyment of the highest attainable standard of physical and mental health.'[66] The steps to be taken in protecting this right are set out in Article 12.2 of the ICESCR.[67] However, the limited discussion of the right to health in case law means this Chapter will focus on more established rights, such as the right to bodily integrity.

The Right to Bodily Integrity

The right to bodily integrity has been recognised in the Irish Constitution, the European Convention on Human Rights, and the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, and the Charter of Fundamental Rights of the European Union. Furthermore, the right to bodily integrity is protected through the criminal and tort law on assault. In Ireland,

[63] Overlapping rights include the right to life, the prohibition of torture, and the right to privacy.
[64] Mangan (n12) 56.
[65] ibid.
[66] International Covenant on Economic, Social and Cultural Rights (1966), Article 12.1.
[67] International Covenant on Economic, Social and Cultural Rights (1966), Article 12.2.
The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
(b) The improvement of all aspects of environmental and industrial hygiene;
(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

the right to bodily integrity was recognised in *Ryan v Attorney General*[68] as an unenumerated right under Article 40.3.1˚ of the Irish Constitution.[69] The plaintiff in this case objected to the addition of fluorine to the water supply and argued that this amounted to 'an infringement of her own personal integrity.'[70] The Court followed this in recognising a right to bodily integrity as part of the personal rights protected by the Constitution. In the High Court, Kenny J defined the right to bodily integrity as meaning:

> that no mutilation of the body or any of its members may be carried out on any citizen under authority of the law except for the good of the whole body and that no process which is or may, as a matter of probability, be dangerous or harmful to the life or health of the citizens or any of them may be imposed (in the sense of being made compulsory) by an Act of the Oireachtas.[71]

Counsel for the plaintiff argued that this interpretation was 'too narrow'.[72] It is submitted that linking the right to bodily integrity to protection from 'an Act of the Oireachtas'[73] makes it difficult to enforce in many situations. For example, the absence of legislation which expressly addresses specialist palliative care would make the enforcement of this right particularly challenging in this area of healthcare.

The Supreme Court in *Ryan v Attorney General* did not clarify the meaning of the right to bodily integrity as the Court did not consider it necessary to pronounce upon the definition of Kenny J. Although the Court recognised a right to bodily integrity it was found that there was no violation of this right.[74] Subsequent case law resulted in the expansion of this right 'into a more general right not to have one's health endangered by the actions of the State'.[75] By extension, this would mean that specialist palliative care should be provided in a manner which does not further endanger the

[68] *Ryan v Attorney General* [1965] IR 294.
[69] Bunreacht na hÉireann Article 40.3.1˚ states that '[t]he State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen.'
[70] *Ryan v Attorney General* [1965] IR 294, 296.
[71] *Ryan v Attorney General* [1965] IR 294, 313-314.
[72] *Ryan v Attorney General* [1965] IR 294, 332.
[73] *Ryan v Attorney General* [1965] IR 294, 313-314.
[74] *Ryan v Attorney General* [1965] IR 294, 295.
[75] Gerard Hogan and Gerry Whyte, *Kelly: The Irish Constitution* (4th edn, Butterworths 2003) 1420.

health of the patient. The expansion of the right to bodily integrity has been demonstrated in cases such as *The State (C) v Frawley*.[76]

The applicant for habeas corpus in *The State (C) v Frawley* had a 'severe sociopathic disorder which led him to commit violent acts injurious in the main to himself'.[77] The medical attention needed was of a 'highly specialised'[78] type and was not available in Ireland. Finlay P held that it was not the obligation of the State 'to build, equip and staff the very specialised unit'[79] which would be needed in these circumstances. Nevertheless, Finlay P stated that 'I see no reason why the principle … should not also operate to prevent an act or omission of the Executive which, without justification, would expose the health of a person to risk or danger'.[80] As such, the right to bodily integrity is not limited to protection from legislation which has potentially harmful effects but is of broader applicability. On this basis, this right could be drawn on to encourage the Executive to take steps to ensure that appropriate palliative care can be accessed by terminally ill patients.

The nature of the right to bodily integrity in relation to medical treatment was further clarified in the case of *The State (McDonagh) v Frawley*[81] in which a prisoner with backache argued that he was not receiving appropriate treatment. The prisoner applied for habeas corpus on the basis of an alleged breach of the right to bodily integrity. Both the High Court and Supreme Court accepted that 'lack of medical attention might amount to such a breach, but found that his complaint had not been substantiated'.[82] On this basis, a lack of appropriate medical treatment is capable of breaching the right to bodily integrity. The lack of appropriate treatment is a very real possibility in the context of palliative care. For example, in Chapter Two the surveys on the provision of palliative care conducted by O'Leary and Tiernan,[83] and Hospice Friendly Hospitals[84] were highlighted.

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[76] *The State (C) v Frawley* [1976] IR 365.
[77] Hogan (n75) 1420.
[78] *The State (C) v Frawley* [1976] IR 365, 372.
[79] *The State (C) v Frawley* [1976] IR 365, 372.
[80] *The State (C) v Frawley* [1976] IR 365, 372.
[81] *The State (McDonagh) v Frawley* [1978] IR 131.
[82] Hogan (n75) 1421.
[83] Norma O'Leary and Eoin Tiernan, 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers' (2008) Palliative Medicine 77.
[84] McKeown (n2).

In the survey conducted by O'Leary and Tiernan it was demonstrated that 24% of specialist palliative care services restricted care for noncancer patients in some manner.[85] In a similar vein, the Hospital Friendly Hospitals report revealed considerable differences between doctors and nurses with regard to whether a patient had actually received specialist palliative care. Doctors believed 22% of patients had received specialist palliative care compared to the nurse's response of 32%.[86] The difference of 10% is a substantial figure and suggests that there is no harmonious understanding between these professions as to what constitutes specialist palliative care. This is problematic as doctors and nurses work closely in the care of the patient. These surveys suggest that not all patients in need of specialist palliative care can avail of or are provided with specialist palliative care. The cumulative effect of these surveys and the case law discussed is to suggest that the right to bodily integrity is likely to be infringed if appropriate palliative care is not provided. Although, it must also be shown that such care is necessary for the patient. However, it is necessary to recognise that a more limited interpretation of the right to bodily integrity may exist.

The cases of *The State (c) v Frawley* and *The State (McDonagh) v Frawley* both concerned the interpretation of the right to bodily integrity in the context of prisoners. There is no case law which grounds an equivalent right to bodily integrity in the context of healthcare for the general population. This point was highlighted by Hogan and Whyte in stating that 'given the very special circumstances of penal imprisonment, it is not the case that the right, as so stated, can be relied on in every other set of circumstances as well.'[87] Economic concerns alongside resource implications may hamper a broader application of this right. There would appear to be a certain reluctance among the judiciary in expanding access to socio-economic rights which may result in significant implications for the allocation of public resources. This point is evidenced by the approach of the Supreme Court in *TD v Minister for Education*[88] and in *Sinnott v Minister for Education*.[89]

[85] O'Leary (n83) 77.
[86] McKeown (n2) 33.
[87] Gerard Hogan and Gerry Whyte, *Kelly: The Irish Constitution* (4th edn, Butterworths 2003) 1420.
[88] *TD v Minister for Education and Science* [2001] 4 IR 259.
[89] *Sinnott v Minister for Education* [2001] 2 IR 545.

Consequently, the likelihood that the right to bodily integrity would be recognised by the courts as grounding an individual right to healthcare provision in the context of palliative care may come down to the associated economic cost. This is a factor to be aware of but does not necessarily mean that the right to bodily integrity would not be recognised and protected in the context of palliative care provision. Palliative care is not limited to a certain group in society, not limited to a particular illness, and it signals a shift from aiming to cure to aiming to minimise pain experienced near the end of life. As such, in many instances palliative care reflects a shift in the allocation of resources.

Palliative care does not require the provision of expensive experimental drugs, and can be provided in the existing healthcare infrastructure. However, in order for appropriate palliative care to be provided it must not be hampered by an ineffective legal framework. In this respect, ensuring clarity in the legal framework for specialist palliative care cannot be said to raise the same concerns about the allocation of scare public resources as seen in the cases of *TD v Minister for Education* and in *Sinnott v Minister for Education*. On this basis, it can be argued that the courts may be more open to recognising circumstances in which there is a breach of the right to bodily integrity in the context of palliative care. However, it must be recognised that the definition of bodily integrity set out by Kenny J in *Ryan v Attorney General* speaks of the imposition of a process which be 'dangerous or harmful to the life or health of the citizens'[90] In this regard, palliative care would not amount to the imposition of such a process but would instead be a demand for a form of healthcare; a demand for what would be classed as a socio-economic right.

There is no explicit recognition of a right to health in the Irish Constitution or in legislation in this jurisdiction. Despite this, in the Supreme Court case of *Heeney v Dublin Corporation*,[91] it was stated by O'Flaherty J that '[i]t is beyond debate that there is a hierarchy of constitutional rights and at the top of the list is the right to life, followed by the right to health and with that the right to the integrity of one's dwellinghouse.'[92] In contrast to this is the case of *Re Article 26 and the Health*

[90] *Ryan v Attorney General* [1965] IR 294, 313-314.
[91] *Heeney v Dublin Corporation* [1998] IESC 26.
[92] *Heeney v Dublin Corporation* [1998] IESC 26, [16]

(Amendment) (No. 2) Bill 2004 in which it was argued that a right to healthcare could be identified as part of 'the right to life, the right to bodily integrity and the right to human dignity of the person.'[93] The Supreme Court did not accept this argument and held that 'a requirement to pay charges of the nature provided for prospectively in the Bill could not be considered as an infringement of the constitutional right to life and the right to bodily integrity as derived from Article 40.3 of the Constitution.'[94] It is clear, therefore, that in Ireland the right to bodily integrity has not been interpreted by the courts as including socio-economic rights. There is a considerable degree of judicial resistance to the recognition or expansion of this type of right which would make it especially challenging to rely on in this context.

This section has, up to this point, concentrated on Irish case law but it is necessary to also consider the impact of the ECHR and the approach of the ECtHR to the right to bodily integrity. The ECtHR has, in several cases, highlighted the importance of an appropriate legal framework in order to protect the right to physical integrity. In this respect, the ECtHR adds an enhanced recognition of positive rights as well as adding to constitutional jurisprudence in a substantial manner.

Identifying a Right to Physical Integrity in the ECHR

A right to physical integrity has been interpreted as being a part of Article 3 and Article 8 of the ECHR.[95] Article 3 of the ECHR establishes a prohibition on torture and inhuman or degrading treatment and Article 8 of the ECHR sets out the right to respect for private and family life. There is an overlap in the interpretation of these Articles but their application is distinguished based on the seriousness of the interference with the rights of the individual. Article 3 of the ECHR is applied for particularly grave interferences with an individual's right to physical integrity while Article 8 of the ECHR is applied at a lower threshold. Both Article 3 and Article 8 of the ECHR place a positive obligation on States to protect the physical integrity of citizens.

[93] *Re Article 26 and the Health (Amendment) (No. 2) Bill 2004* [2005] 1 IR 105, 111.
[94] *Re Article 26 and the Health (Amendment) (No. 2) Bill 2004* [2005] 1 IR 105, 106; Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 272 'Rights to health-related resources will likely always have severe limits'.
[95] *Pretty v United Kingdom* (2002) 35 EHRR 1.

X & Y v Netherlands[96] demonstrates the existence of positive obligations stemming from Article 8 of the ECHR. In this case the ECtHR held that the Netherlands was under an obligation to protect the applicant from an infringement of her Article 8 rights. As stated in this case, the concept of a 'private life' under Article 8 of the ECHR includes the physical and psychological integrity of the individual.[97] The case of *X & Y v Netherlands* was subsequently cited in *Pretty v United Kingdom*.[98] The ECtHR in *Pretty v United Kingdom* recognised a right to physical integrity under both Article 3 and Article 8 of the ECHR. In relation to Article 3 it was stated that it 'obliges them to respect the physical and human integrity of such individuals.'[99] The ECtHR in *Pretty* also set out that '[a]s the Court has had previous occasion to remark, the concept of "private life" is a broad term not susceptible to exhaustive definition. It covers the physical and psychological integrity of a person'.[100] This has been the approach of the ECtHR in several cases but this does little to actually clarify the meaning of the right to physical integrity under the ECHR.[101] Greater guidance on the right to physical integrity can be found in *Glass v United Kingdom*,[102] and *Tysiąc v Poland*.[103]

In *Glass v United Kingdom* it was argued by the applicants that 'certain decisions taken by a hospital authority and its doctors with respect to the treatment of the first applicant interfered with the latter's right to respect for personal integrity.'[104] David Glass had an operation to 'alleviate an upper respiratory tract obstruction.'[105] There were a number of subsequent complications which led to him becoming critically ill. Hospital staff were of the opinion that he was dying but the patient's family were not satisfied by this opinion. David's condition fluctuated several times leading to discharge and readmission to the hospital. The doctors discussed the use of morphine with David's

[96] *X & Y v Netherlands* (1986) 8 EHRR 235.
[97] *X & Y v Netherlands* (1986) 8 EHRR 235, [22] '[t]here was no dispute as to the applicability of Article 8 (art. 8): the facts underlying the application to the Commission concern a matter of "private life", a concept which covers the physical and moral integrity of the person, including his or her sexual life.'
[98] *Pretty v United Kingdom* (2002) 35 EHRR 1.
[99] *Pretty v United Kingdom* (2002) 35 EHRR 1, [13].
[100] *Pretty v United Kingdom* (2002) 35 EHRR 1, [61].
[101] *Tysiąc v Poland* (2007) 45 EHRR 42, [107]; *YF v Turkey* (2004) 39 EHRR 34, [33].
[102] *Glass v United Kingdom* (2004) 39 EHRR 15.
[103] *Tysiąc v Poland* (2007) 45 EHRR 42.
[104] *Glass v United Kingdom* (2004) 39 EHRR 15, [3]; *Glass v United Kingdom* (2004) 39 EHRR 15, [7] The first applicant is David Glass who is 'a severely mentally and physically disabled child who requires twenty-four hour attention.' The second applicant is David Glass' mother.
[105] *Glass v United Kingdom* (2004) 39 EHRR 15, [9].

mother during one of his readmissions.[106] However, she was opposed to the administration of morphine. Regardless of this, diamorphine was prescribed for David during a subsequent readmission to the hospital. The family strongly objected to this treatment and so David's care was transferred to his general practitioner. This alternate care proved to be much more beneficial and David's condition improved. The applicants exhausted all possible legal remedies in the UK and brought the case before the ECtHR.

It was not contested in *Glass v United Kingdom* that 'the hospital was a public institution and that the acts and omissions of its medical staff were capable of engaging the responsibility of the respondent State under the Convention.'[107] This demonstrates the applicability of the ECHR to the provision of specialist palliative care in a hospital in this jurisdiction. Several allegations were put before the ECtHR and the Court found there to be a violation of Article 8 of the ECHR. On this point, the ECtHR set out that:

> the decision to impose treatment on the first applicant in defiance of the second applicant's objections gave rise to an interference with the first applicant's right to respect for his private life, and in particular his right to physical integrity.[108]

This demonstrates a close link between respect for the private life of the patient and their right to bodily integrity. In the judgment of the ECtHR it was also recognised that 'the regulatory framework in the respondent State is firmly predicated on the duty to preserve the life of a patient, save in exceptional circumstances.'[109] This point was considered in Chapter Three[110] and will be explored further in this Chapter in the context of the right of autonomy.[111]

The impact of the fragmented regulatory framework was also raised in *Glass v United Kingdom*. On this point, the ECtHR commented that 'it does not accept the view that the many sources from which the rules, regulations and standards are derived only

[106] *Glass v United Kingdom* (2004) 39 EHRR 15, [12].
[107] *Glass v United Kingdom* (2004) 39 EHRR 15, [71].
[108] *Glass v United Kingdom* (2004) 39 EHRR 15, [70].
[109] *Glass v United Kingdom* (2004) 39 EHRR 15, [75].
[110] Text to n58 in Chapter Three.
[111] See p137.

contribute to unpredictability and an excess of discretion in this area at the level of application.'[112] The focus should not be the origin of various rules but should instead be on whether the substance of the 'rules, regulations and standards'[113] combine to provide a predictable and consistent system in which healthcare professionals can practice, and thereby protect rights such as the right to physical integrity. In effect, this is the type of approach which is adopted in this thesis in relation to the legal framework in Ireland for specialist palliative care as it also draws from a wide range of sources.

A legal framework for any area of healthcare must, by its nature, draw from a variety of sources to ensure it reflects and encourages best medical practice in the care of the patient. However, the legal framework should not be so diffuse as to 'contribute to unpredictability and an excess of discretion'.[114] Overall, the ECtHR held that 'the decision of the authorities to override the second applicant's objection to the proposed treatment in the absence of authorisation by a court resulted in a breach of Article 8 of the Convention.'[115] In short, this case demonstrates that the provision of palliative care clearly engages the rights set out in the ECHR, including the right to physical integrity. Additionally, the protection of these rights in practice often requires positive action on the part of the State.

Positive Obligations arising from the ECHR

Mowbray suggests that judicial recognition of positive obligations serves to ensure that the human rights set out by the ECHR are 'practical and effective'.[116] A positive right can be understood as establishing 'a right to receive a particular good or service from others'[117] and can be 'grounded in principles of beneficence and justice.'[118] Steps may need to be taken by the State or organs of the State to ensure that human rights are actually protected and are therefore not illusory. In this regard, the importance of

[112] *Glass v United Kingdom* (2004) 39 EHRR 15, [75].
[113] *Glass v United Kingdom* (2004) 39 EHRR 15, [75].
[114] *Glass v United Kingdom* (2004) 39 EHRR 15, [75].
[115] *Glass v United Kingdom* (2004) 39 EHRR 15, [83].
[116] Alistair Mowbray, *The Development of Positive Obligations Under the European Convention on Human Rights by the European Court of Human Rights* (Hart Publishing 2004) 221.
[117] Beauchamp (n9) 370.
[118] ibid.

an appropriate legal framework along with the right to physical integrity was discussed in *Tysiąc v Poland*.[119] In this case the applicant alleged that:

> Her right to due respect for her private life and her physical and moral integrity had been violated both substantively, by failing to provide her with a legal therapeutic abortion, and as regards the State's positive obligations, by the absence of a comprehensive legal framework to guarantee her rights.[120]

The legal framework in Poland for abortion lacked a basic decision-making procedure. This served to narrowly constrain cases in which an abortion could be performed.

The applicant in *Tysiąc v Poland* argued that 'the process in her case had not been fair and had not afforded due respect for her private life and her physical and moral integrity.'[121] The applicant in this case suffered from severe myopia. She became pregnant with her third child but was worried that her retina might detach due to the pregnancy. She was examined by three ophthalmologists who 'concluded that, due to pathological changes in the applicant's retina, the pregnancy and delivery constituted a risk to her eyesight.'[122] Despite this, they were not willing to issue a certificate to allow for the pregnancy to be terminated. Further medical advice was subsequently sought by the applicant and a general practitioner issued a certificate stating that the pregnancy amounted to a threat to the health of the applicant. Nonetheless, the applicant's request for an abortion was refused by the Head of the Gynaecology and Obstetrics Department in the State hospital. The applicant gave birth by Caesarean section and six weeks later her eyesight had further deteriorated.

The ECtHR noted that a decision-making framework for this area should be 'timely',[123] 'fair'[124] and should not be framed in such a way as to limit its

[119] *Tysiąc v Poland* (2007) 45 EHRR 42.
[120] *Tysiąc v Poland* (2007) 45 EHRR 42, [67].
[121] *Tysiąc v Poland* (2007) 45 EHRR 42, [83].
[122] *Tysiąc v Poland* (2007) 45 EHRR 42, [9].
[123] *Tysiąc v Poland* (2007) 45 EHRR 42, [118] 'The procedures in place should therefore ensure that such decisions are timely so as to limit or prevent damage to a woman's health which might be occasioned by a late abortion.'
[124] *Tysiąc v Poland* (2007) 45 EHRR 42, [113].

application.[125] These points were made in the context of abortion but it can be argued that these principles are relevant for any area of healthcare which is especially time sensitive such as specialist palliative care. The Court concluded that there was a lack of an appropriate legal framework to assist in identifying whether a lawful abortion could be obtained.[126] This resulted in the applicant experiencing 'severe distress and anguish when contemplating the possible negative consequences of her pregnancy and upcoming delivery for her health.'[127] The importance of a legal framework to protect a person's rights under Article 8 of the ECHR was also raised in *A, B, and C v Ireland*.[128]

There were three applicants in *A, B, and C v Ireland* but it is the discussion of the third applicant which is of most relevance to this thesis.[129] This woman travelled to England for an abortion as she believed she would not have been able to 'establish her right to an abortion in Ireland.'[130] She had previously received chemotherapy over the course of three years and it was not clear what impact a pregnancy would have on her illness. Although, it was understood that 'it would be dangerous for the foetus if she were to have chemotherapy during the first trimester.'[131] The applicant subsequently became pregnant but was not aware of this when 'she underwent a series of tests for cancer'.[132] She researched the health risks raised and due to the lack of clarity she travelled to England to have an abortion.[133] There were complications stemming from this procedure such as 'prolonged bleeding and infection.'[134] These facts led the applicant

[125] *Tysiąc v Poland* (2007) 45 EHRR 42, [116].
[126] *Tysiąc v Poland* (2007) 45 EHRR 42, [124].
[127] *Tysiąc v Poland* (2007) 45 EHRR 42, [124].
[128] *A, B, and C v Ireland* (2010) ECHR 2032, [167] 'The first and second applicants complained under Article 8 about the restrictions on lawful abortion in Ireland which meant that they could not obtain an abortion for health and/or well-being reasons in Ireland and the third applicant complained under the same Article about the absence of any legislative implementation of Article 40.3.3 of the Constitution.'; Sonya Donnelly, 'A, B and C v Ireland: A Commentary' (2011) 11(2) Medico-Legal Journal of Ireland 43; Sheelagh McGuinness, 'A, B, and C Leads to D (for delegation!)' (2011) 19(3) Medical Law Review 476; Jennifer Schweppe, 'Taking Responsibility for the "Abortion Issue": Some Thoughts on Legislative Reform in the Aftermath of A, B and C' (2011) 2 Irish Journal of Family Law 50.
[129] *A, B, and C v Ireland* (2010) ECHR 2032, [242] 'It concludes that there has been no violation of Article 8 of the Convention as regards the first and second applicants.'
[130] *A, B, and C v Ireland* (2010) ECHR 2032, [22].
[131] *A, B, and C v Ireland* (2010) ECHR 2032, [23].
[132] *A, B, and C v Ireland* (2010) ECHR 2032, [24].
[133] *A, B, and C v Ireland* (2010) ECHR 2032, [24] 'She alleged that, as a result of the chilling effect of the Irish legal framework, she received insufficient information as to the impact of the pregnancy on her health and life and of her prior tests for cancer on the foetus.'
[134] *A, B, and C v Ireland* (2010) ECHR 2032, [26].

to complain on the basis of Article 8 of the ECHR and 'the alleged failure to implement the constitutional right to an abortion in Ireland in the case of a risk to the life of the woman.'[135]

The ECtHR recognised the lack of a suitable decision-making framework in Ireland for abortion and highlighted the absence of any procedure for resolving a situation where there are differing opinions between the parties involved.[136] The use of medical consultation or litigation options as set out by the Irish Government was viewed as ineffective in such circumstances by the ECtHR.[137] On this basis, the Court concluded that:

> the authorities failed to comply with their positive obligation to secure to the third applicant effective respect for her private life by reason of the absence of any implementing legislative or regulatory regime providing an accessible and effective procedure by which the third applicant could have established whether she qualified for a lawful abortion in Ireland in accordance with Article 40.3.3 of the Constitution.[138]

The discussion of *A, B, and C v Ireland* moved the focus slightly away from the right to physical integrity in this section but it demonstrated the importance of complying with the positive obligations raised by Article 8 of the ECHR.[139] In particular, the case of *A, B, and C v Ireland* further demonstrated the importance of an appropriate decision-making framework for the legally and ethically challenging aspects of healthcare.

In applying this reasoning to specialist palliative care it is evident that there needs to be a decision-making framework in place which makes it clear for both the patient and

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[135] *A, B, and C v Ireland* (2010) ECHR 2032, [3].
[136] *A, B, and C v Ireland* (2010) ECHR 2032, [253]. 'Furthermore, there is no framework whereby any difference of opinion between the woman and her doctor or between different doctors consulted, or whereby an understandable hesitancy on the part of a woman or doctor, could be examined and resolved through a decision which would establish as a matter of law whether a particular case presented a qualifying risk to a woman's life such that a lawful abortion might be performed.'
[137] *A, B, and C v Ireland* (2010) ECHR 2032, [263].
[138] *A, B, and C v Ireland* (2010) ECHR 2032, [267].
[139] See p170. The breadth of positive obligations under Article 8 and their role in developing the legal framework will be drawn on in Chapter Five when examining the professional standards and guidelines in Ireland for specialist palliative care.

the healthcare professional when palliative sedation can be administered and whether artificial nutrition and hydration can be withdrawn. In this regard, the ECtHR in *Tysiąc v Poland* made it clear that such a framework needs to be 'timely',[140] 'fair'[141] and should not be framed in such a way as to limit its application.[142] Adopting such an approach helps ensure that rights such as the right to bodily integrity can be effectively protected and vindicated. Closely related to the right to bodily integrity is the right to be protected from inhuman or degrading treatment.[143] The precise meaning of this right will be explored in the next section.

Protection from Inhuman or Degrading Treatment

The right to be protected from torture and inhuman or degrading treatment has been set out in the ECHR,[144] the Charter of Fundamental Rights,[145] the ICCPR,[146] the United Nations Convention against Torture,[147] and the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment.[148] Protection from inhuman or degrading treatment was recognised in the *State (C) v Frawley*[149] as an unenumerated right guaranteed by Article 40 of the Irish Constitution. In this case Finlay P set out that:

> If the unspecified personal rights guaranteed by Article 40 follow in part or in whole from the Christian and democratic nature of the State, it is

[140] *Tysiąc v Poland* (2007) 45 EHRR 42, [118].
[141] *Tysiąc v Poland* (2007) 45 EHRR 42, [113].
[142] *Tysiąc v Poland* (2007) 45 EHRR 42, [116].
[143] Hogan (n75) 1422 'An obvious corollary of the right to bodily integrity is the right to freedom from torture, or inhuman or degrading treatment.'; *The State (C) v Frawley* [1976] IR 365, 374 'If the unspecified personal rights guaranteed by Article 40 follow in part or in whole from the Christian and democratic nature of the State, it is surely beyond argument that they include freedom from torture, and from inhuman or degrading treatment and punishment.'
[144] European Convention on Human Rights, Article 3.
[145] Charter of Fundamental Rights of the European Union, Article 4 'No one shall be subjected to torture or to inhuman or degrading treatment or punishment.'
[146] International Covenant on Civil and Political Rights (1966), Article 7.
[147] Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984).
[148] European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Strasbourg, 26.XI.1987 Text amended according to the provisions of Protocols No. 1 (ETS No. 151) and No. 2 (ETS No. 152), which entered into force on 1 March 2002.
[149] *The State (C) v Frawley* [1976] IR 365.

> surely beyond argument that they include freedom from torture, and from inhuman or degrading treatment and punishment.[150]

Despite recognising an unenumerated right to protection from torture and inhuman or degrading treatment, the Court in *Frawley* held that this right had not been breached. Finlay P associated this right with 'revenge, retaliation, the creation of fear or improper interrogation.'[151] In the opinion of Finlay P, this right was not to be associated with the 'discharge of a duty to prevent self-injury or self-destruction.'[152] Linking this right to ideas of revenge and retaliation begins to demonstrate the challenge of successfully relying on this right, particularly in the context of specialist palliative care. However, it is to be questioned whether Irish courts would still take such a narrow interpretation of the right to be protected from torture and inhuman or degrading treatment, particularly in light of ECtHR jurisprudence.

Protection from inhuman or degrading treatment is provided by Article 3 of the ECHR which sets out that, 'No one shall be subjected to torture or to inhuman or degrading treatment or punishment.'[153] This is an absolute right under the ECHR to which no derogations are permitted. *Ireland v UK*[154] demonstrated the distinction between torture and inhuman or degrading treatment. In this regard, the ECtHR took the view that 'this distinction derives principally from a difference in the intensity of the suffering inflicted.'[155] Torture is a much higher threshold and the focus will be placed on inhuman and degrading treatment in this section. Article 3 of the ECHR imposes both positive[156] and negative obligations[157] on States. The negative obligation imposed by the State is absolute in that it states that 'no one shall be subject' to the prohibited forms of treatment. In contrast to this, the positive obligation is not absolute and has

[150] *The State (C) v Frawley* [1976] IR 365, 374 'Such a conclusion would appear to me to be inescapable even if there had never been a European Convention on Human Rights, or if Ireland had never been a party to it.'
[151] *The State (C) v Frawley* [1976] IR 365, 374.
[152] *The State (C) v Frawley* [1976] IR 365, 374.
[153] European Convention on Human Rights, Article 3.
[154] *Ireland v United Kingdom* (1978) ECHR 1.
[155] *Ireland v United Kingdom* (1978) ECHR 1, [167].
[156] *Z and Others v the United Kingdom* (2001) 34 EHRR 3.
[157] *Pretty v United Kingdom* (2002) 35 EHRR 1, [50] 'It may be described in general terms as imposing a primarily negative obligation on States to refrain from inflicting serious harm on persons within their jurisdiction.'

largely 'been developed through the Convention jurisprudence.'[158] This may impose a variety of obligations such as

> an obligation on states to pass criminal laws outlawing and punishing ill-treatment amounting to torture or inhuman or degrading treatment; an obligation to investigate arguable breaches of art 3; and an obligation to take reasonable steps to prevent real and immediate risks of torture or inhuman or degrading treatment at the hands of non-state agents.[159]

As stated earlier, there is a high threshold for successfully relying on Article 3 of the ECHR which has had the effect of limiting its use. In discussing this right it is necessary to consider the distinction between 'inhuman treatment' and 'degrading treatment' as well as what constitutes inhuman or degrading treatment. The difference between degrading treatment and inhuman treatment is based on the 'degree of suffering caused, whether physical or mental'.[160] Nonetheless, cases such as *II v Bulgaria*[161] have demonstrated that the ECtHR does not always 'draw a sharp distinction and use qualifications such as 'inhuman *and* degrading treatment'.'[162]

Inhuman treatment was defined in the *Greek* case as causing 'severe suffering, mental or physical, in the particular situation'.[163] Degrading treatment was also defined in that case as treatment which 'grossly humiliates him before others or drives him to act against his will or conscience'.[164] In *Pretty v the United Kingdom*, degrading treatment was described by the ECtHR as treatment which 'humiliates or debases an individual showing a lack of respect for, or diminishing, his or her dignity or arouses feelings of fear, anguish or inferiority capable of breaking a person's moral and physical

[158] Javan Herberg and David Pievsky, 'Article 3: Prohibition of torture and of inhuman or degrading treatment' in Lord Lester Herne Hill, David Pannick, and Javan Herberg (eds), *Human Rights Law and Practice* (2nd edn, LexisNexis 2004) 138.
[159] ibid.
[160] David Feldman, 'Human dignity as a legal value: Part 1' (1999) Public Law 682, 691.
[161] *Il v Bulgaria* App 44082/98, (9 June 2005); See also *Mayzit v Russia* (App. 63378/00), (20 January 2005).
[162] Pieter van Dijk and GJH van Hoof, *Theory and Practice of the European Convention on Human Rights* (3rd edn, Martinus Nijhoff 1998) 310 (emphasis in original).
[163] Report of November 5, 1969, Yearbook of the European Convention on Human Rights, Vol. XII (1969) 186.
[164] Report of November 5, 1969, Yearbook of the European Convention on Human Rights, Vol. XII (1969) 186.

resistance'.[165] The reference to 'dignity' reflects its status in the ECHR.[166] It has been described as 'the very essence' of Article 3 of the ECHR and the characterisation of dignity will be discussed later in this Chapter.[167] The above definition of degrading treatment is more detailed than that set out in the *Greek* case and demonstrates how the focus is on the consequences of the actions rather than the intention behind the action. This is in contrast to the interpretation of Finlay P in *State (C) v Frawley*.[168] Of particular importance is that there must be actual bodily injury or 'intense physical or mental suffering'.[169] This does not need to be the result of physical violence but may take the form of a naturally occurring illness as demonstrated by the cases of *D v United Kingdom*,[170] *Keenan v United Kingdom*,[171] and *Bensaid v United Kingdom*.[172] The applicant in *D v United Kingdom* was found to be in possession of a quantity of cocaine upon arriving at Gatwick Airport in London. He served his prison sentence in England and was to be removed to his home country of St. Kitts upon release. While serving his sentence, the applicant was diagnosed as suffering from AIDS. The applicant sought to remain in the UK 'on compassionate grounds since his removal to St Kitts would entail the loss of the medical treatment which he was currently receiving, thereby shortening his life expectancy'[173] The Chief Immigration Officer

[165] *Pretty v United Kingdom* (2002) 35 EHRR 1, [52]; See also *Price v the United Kingdom*, App no 33394/96, (ECtHR, 10 July 2001); *Valašinas v Lithuania*, App no 44558/98, (24 July 2001).
[166] Christopher McCrudden, 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19(4) The European Journal of International Law 655, 687 'the ECtHR has increasingly resorted to the use of dignity language in interpreting Article 3.'
[167] *Selmouni v. France* App no 25803/94 (ECtHR, 28 July 1999) [99] 'in respect of a person deprived of his liberty, recourse to physical force which has not been made strictly necessary by his own conduct diminishes human dignity and is in principle an infringement of the right set forth in Article 3'; *Ireland v United Kingdom* (1978) ECHR 1, [27] Note the separate opinion of Judge Sir Gerald Fitzmaurice. In relation to degrading treatment under Article 3 ECHR it was stated that, '[i]n the present context it can be assumed that it is, or should be, intended to denote something seriously humiliating, lowering as to human dignity, or disparaging, like having one's head shaved, being tarred and feathered, smeared with filth, pelted with muck, paraded naked in front of strangers, forced to eat excreta, deface the portrait of one's sovereign or head of State, or dress up in a way calculated to provoke ridicule or contempt'.
[168] Text to n148.
[169] *Ireland v United Kingdom* (1978) ECHR 1, [167].
[170] *D v United Kingdom* (1997) 24 EHRR 423.
[171] *Keenan v United Kingdom* (2001) EHRR 913.
[172] *Bensaid v United Kingdom* (2001) ECHR 82, [46] 'Not every act or measure which adversely affects moral or physical integrity will interfere with the right to respect to private life guaranteed by Article 8. However, the Court's case-law does not exclude that treatment which does not reach the severity of Article 3 treatment may nonetheless breach Article 8 in its private-life aspect where there are sufficiently adverse effects on physical and moral integrity.'; See also Stephanie Palmer, 'AIDs, expulsion and Article 3 of the European Convention on Human Rights' (2005) 5 European Human Rights Law Review 533.
[173] *D v United Kingdom* (1997) 24 EHRR 423, [11]; *D v United Kingdom* (1997) 24 EHRR 423, [52] 'The Commission also noted that it has not 'been shown whether the applicant would be guaranteed a bed in either of the hospitals on the island which, according to the Government, care for AIDS patients.'

refused this request. The risk to the applicant's health was accepted by the Commission and 'concluded that the removal of the applicant to St Kitts would engage the responsibility of the respondent State under Article 3'.[174] The cumulative effect of these conditions led to the Commission deciding that 'to remove him to St Kitts would amount to inhuman treatment by the respondent State in violation of Article 3'.[175]

The decision in *D v United Kingdom* demonstrates that the potential of being denied appropriate medical care was sufficient in this case to engage Article 3 of the ECHR.[176] This position was summarised in *L v Lithuania*[177] where the ECtHR stated that:

> Article 3 entails a positive obligation on the part of the State to protect the individual from acute ill-treatment, whether physical or mental, whatever its source. Thus if the source is a naturally occurring illness, the treatment for which could involve the responsibility of the State but is not forthcoming or is patently inadequate, an issue may arise under this provision.[178]

This quote demonstrates the relevance of Article 3 of the ECHR to the provision of specialist palliative care as the treatment and care must be available and needs to be adequate for the naturally occurring illness. Nevertheless, it is to be emphasised that the key facts in *D v United Kingdom* are that the patient was already terminally ill and there was no real prospect of appropriate medical care if he were to be extradited. In effect, the case of *D v United Kingdom* did not serve to establish Article 3 as 'promoting a general social right to medical care for individuals facing expulsion from the state.'[179] Instead it appears that a complete lack of medical care or inadequate medical care would be required to give rise to a breach of Article 3 of the ECHR.

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[174] *D v United Kingdom* (1997) 24 EHRR 423, [45].
[175] *D v United Kingdom* (1997) 24 EHRR 423, [53].
[176] See also *Tanko v Finland* App no 23634/94 (Commission Decision, 19 May 1994) 1 'The Commission does not exclude that a lack of proper care in a case where someone is suffering from a serious illness could in certain circumstances amount to treatment contrary to Article 3 (Art. 3).'
[177] *L v Lithuania* (2008) 46 EHRR 22.
[178] *L v Lithuania* (2008) 46 EHRR 22, [46].
[179] Palmer (n172) 537; Exceptional circumstances not clarified in cases of *BB v France*, App no 30930/96 (ECtHR, 7 September 1998) or *Tatete v Switzerland*, App no 41874/98 (ECtHR, 6 July 2000).

A further way in which a person may be degraded is 'to impose medical treatment on him or her without his or her consent.'[180] Such treatment was at issue in the ECtHR case of *Herczegfalvy v Austria*.[181] The person at the centre of this case was a 'compulsorily detained psychiatric patient.'[182] The patient was force fed and sedated without his consent, isolated and restraints were used to control his movement. The patient complained that this amounted to a violation of Article 3 of the ECHR. The ECtHR identified two necessary elements for successfully invoking the protection offered by Article 3 of the ECHR. The first point is that 'the treatment must reach a minimum level of severity in terms of degradation and humiliation.'[183] This threshold will depend on the circumstances of the individual case.[184] For example, in *Kudla v Poland*[185] it was stated that, 'the Court has consistently stressed that the suffering and humiliation involved must in any event go beyond that inevitable element of suffering or humiliation connected with a given form of legitimate treatment or punishment'[186] In deciding whether this threshold is met a number of factors must be considered.

The factors to be considered include the form of treatment and its physical impact on the individual, the manner in which such treatment is provided, and the use of physical restraint.[187] In *Keenan v United Kingdom*[188] the Court recognised that factors to be considered include 'the duration of the treatment, its physical and/or mental effects and, in some cases, the sex, age and state of health of the victim.'[189] The weight to be given to each of these factors is not clear but they demonstrate the range of factors

[180] Feldman (n160) 693.
[181] *Herczegfalvy v Austria* (1992) 15 EHRR 437.
[182] Feldman (n160) 693.
[183] Mary Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2010) 215.
[184] ibid.
[185] *Kudla v Poland* (2000) 35 EHRR 198.
[186] *Kudla v Poland* (2000) 35 EHRR 198, [92].
[187] Donnelly (n183) 215.
[188] *Keenan v United Kingdom* (2001) 33 EHRR 913.
[189] *Keenan v United Kingdom* (2001) 33 EHRR 913, [109]; *Keenan v United Kingdom* (2001) 33 EHRR 913, [110] 'In considering whether a punishment or treatment is "degrading" within the meaning of Article 3, the Court will also have regard to whether its object is to humiliate and debase the person concerned and whether, as far as the consequences are concerned, it adversely affected his or her personality in a manner incompatible with Article 3.(see, for example, Raninen v. Finland, judgment of 16 December 1997, Reports 1997-VIII, pp. 2821-22, § 55). This has also been described as involving treatment such as to arouse feelings of fear, anguish and inferiority capable of humiliating or debasing the victim and possibly breaking their physical or moral resistance (see Ireland v. the United Kingdom, judgment of 18 January 1978, Series A no. 25, p. 66, § 167), or as driving the victim to act against his will or conscience (see, for example, the Commission's opinion in the Greek Case, Chapter IV, Yearbook 12, p. 186).'

which the ECtHR can draw on to identify treatment as being inhuman or degrading. The second point is that there will be no breach of Article 3 if the treatment is demonstrated to be therapeutically necessary.[190] In *Herczegfalvy v Austria*, the ECtHR held that there had been no violation of Article 3 as 'medical necessity justified the treatment in issue.'[191] The issue of what is therapeutically necessary is not always clear in specialist palliative care. This was demonstrated in Chapter Two in relation to the withdrawal of artificial nutrition and hydration along with the decision to administer palliative sedation.[192] In circumstances where the interference with the patient does satisfy the criteria for Article 3 of the ECHR then the right to private life 'comes into play'.[193]

Further guidance on Article 3 of the ECHR can be found in the case of *R(on the application of N) v Doctor M and Others*.[194] In *R(on the application of N) v Doctor M and Others* it was accepted by Dyson LJ that as long as the minimum severity threshold is met and in the absence of consent it must be shown that the treatment was in line with the best interests of the patient and was therapeutically necessary. Donnelly suggests that on this basis it appears that 'Article 3 adds a new element to the decision-making process (in cases where the minimum severity threshold is reached).'[195] However, this severity threshold may be a more fluid test. This is demonstrated by the case of *Selmouni v France*.[196]

In *Selmouni v France*, the ECtHR were of the opinion that 'the increasingly high standard being required in the protection of human rights and fundamental liberties correspondingly and inevitably requires greater firmness in assessing breaches of the fundamental values of democratic societies'.'[197] The opinion of the ECtHR in *Selmouni v France* demonstrates that what constitutes inhuman or degrading treatment

[190] *Herczegfalvy v Austria* (1992) 15 EHRR 437, [82].
[191] *Herczegfalvy v Austria* (1992) 15 EHRR 437, [83].
[192] Text to n188 and n189 in Chapter Two.
[193] ECHR Online, 'Protection of physical and psychological integrity under article 8 ECHR' <http://echr-online.com/art-8-echr/private-life/physical-integrity> accessed 20 June 2014 'the right to private life comes into play when the interference does not reach the threshold required to qualify it as torture or inhuman treatment.' The right to private life is protected by Article 8 of the ECHR and will be considered over the course of the next section.
[194] *R(on the application of N) v Doctor M and Others* (2002) EWCA Civ 1789.
[195] Donnelly (n183) 216.
[196] *Selmouni v France* (2000) 29 EHRR 403.
[197] Donnelly (n183) 217.

will change over time and a stricter standard may be seen in future. It is to be remembered that the rights set out in the ECHR provide 'a floor of rights protection rather than a ceiling'.[198] This position has been set out by Grosz, Beatson, and Duffy who state:

> There is no imperative that parties to the Convention should adopt a uniform approach, only that they should not fall below a irreducible minimum, which will be monitored by the Strasbourg institutions. It is therefore open to national courts to develop a domestic jurisprudence under the Convention which may be more generous to applicants than that dispensed in Strasbourg, while remaining broadly consistent with it.[199]

On this basis, Irish courts are not prevented from applying a more stringent approach to human rights protection. The ECHR has always been treated as a living instrument and its scope has been greatly expanded by the ECtHR over the years, especially on moral issues. Despite this, there remains a relatively high threshold for successfully relying on Article 3 of the ECHR which has limited its use.

Palliative care in Ireland has developed considerably in recent years but the possibility of insufficient care at the end-of-life remains a possibility. In Chapter Two and earlier in this chapter, research on the provision of palliative care conducted by O'Leary and Tiernan,[200] and Hospice Friendly Hospitals[201] was highlighted. The disparity of care available to people suffering from illnesses other than cancer was identified in these surveys.[202] In addition, it was shown that there was a degree of confusion about whether specialist palliative care was provided or whether it would even have been beneficial to certain patients.[203] Consequently, these surveys demonstrate that there are cases where terminally ill patients do not receive specialist palliative care or the

[198] Palmer (n172) 539.
[199] Stephen Grosz, Jack Beatson, and Peter Duffy, *Human Rights: The 1998 Act and the European Convention* (Sweet and Maxwell 2000) 20.
[200] O'Leary (n83).
[201] McKeown (n2).
[202] O'Leary (n83) 77 'Twenty four percent of services limited availability for noncancer patients in some way. Of those services available for noncancer patients, the type of care provided to them was the same as for cancer patients in 81% of services.'
[203] McKeown (n2) 32 in over a quarter of cases it is not clear whether specialist palliative care would have been of benefit to the patient.

care provided is inadequate. In effect, these types of cases could give rise to a breach of Article 3 of the ECHR.

The protection from inhuman or degrading treatment is an important facet of the legal framework for specialist palliative care and must be protected in practice. Whether this right is or is not provided for in professional standards and guidelines will be examined in Chapter Five. Although the right to be protected from inhuman or degrading treatment is significant in the context of specialist palliative care, it has been suggested that it is Article 8 of the ECHR which has resulted in 'more helpful jurisprudence'.[204]

The Right to Autonomy

The term autonomy is derived from the Greek words 'autos' meaning self and 'nomos' meaning rule or law.[205] The concept of autonomy is a difficult concept to adequately define due to the range of competing definitions.[206] It can be summarised as an individual's freedom to make their own decisions. Patient involvement in end-of-life care is particularly important. A reason for this is that 'Pain is always subjective'.[207] In effect, it is only the patient who knows and feels their own pain. The right of autonomy is most at issue when the decision of an individual conflicts with that of another as regards what is best for the patient.[208] In relation to palliative care, this

[204] Donnelly (n183) 214.
[205] JT Pring, *The Oxford Dictionary of Modern Greek: Greek-English and English-Greek* (Doubleday 1986) [self-] 281; JT Pring, *The Oxford Dictionary of Modern Greek: Greek-English and English-Greek* (Doubleday 1986) [law] 180.
[206] Beauchamp (n9) 101 'At a minimum, personal autonomy encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding.'; Bryan A Garner, *Black's Law Dictionary* (9th edn, Thompson/West 2009) 154 'An individual's capacity for self-determination.'; Isaiah Berlin, *Four Essays on Liberty* (Oxford University Press 1969) 171 Berlin's positive liberty can be equated with autonomy – positive liberty focuses on '[w]hat, or who, is the source of control or interference that can determine someone to do, or be, this rather than that?'; Richard Lindley, *Autonomy* (MacMillan Education 1986) 6 'An autonomous person has a will of her or his own, and is able to act in pursuit of self-chosen goals.'; Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1998) 6 'freedom of the will', 'independence', 'critical reflection'; Denis A Cusack, 'Patient Autonomy: Perpetual Myth or Achievable Reality?' (1999) 5(1) Medico-Legal Journal of Ireland 2, 2 'The very concept of autonomy is not one for which there is a uniform definition.' Also defines autonomy as 'the right to self-govern, or the right to partial self-government, or the right to self-determination.'; Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 22 'self-mastery; choosing freely; choosing one's own moral position and accepting responsibility for one's choice'.
[207] International Association for the Study of Pain cited in World Health Organization, *Cancer Pain Relief* (World Health Organization 1986).
[208] Mary Donnelly, 'The right of autonomy in Irish law' (2008) 14 Medico-Legal Journal of Ireland 34, 34. 'when situations of conflict arise.'

illustrates the need to carefully balance the autonomy of the patient with the autonomy of the healthcare professional.[209] The competing rights of autonomy between the healthcare professional and patient should not be framed in such a way as to deprive a patient of care they need or force a doctor to provide care which he/she considers not to be in the best interests of a patient.[210] This is a difficult balance to achieve but it must be addressed in the legal framework for specialist palliative care if the framework is to promote clarity, consistency, and the protection of human rights in this jurisdiction.

Autonomy gives rise to both negative and positive obligations and the treatment of these obligations in case law will be outlined in this section.[211] This approach has been favoured as it demonstrates how autonomy is actually being interpreted and applied in practice and therefore, facilitates the identification of the existing legal framework for specialist palliative care practices.

The ethical concept that is autonomy has been recognised and protected in common law, constitutional provisions, the ECHR, and the Charter of Fundamental Rights.[212] Legal protection of such an ethical concept does not automatically ensure that autonomy will be protected but its value lies in the fact that 'legal endorsement does provide a means for patients to make ethical principles enforceable in their individual situations.'[213] Moreover, the importance attached to autonomy is demonstrated by Madden who suggests that 'Respect for the principle of individual autonomy is now

[209] Patrick Hanafin, *Last Rights: Death, Dying and the Law in Ireland* (Cork University Press 1997) 1 'In resolving any particular dilemma one must decide how much importance to give, on the one hand, to the autonomy of the individual patient and, on the other, to the freedom of the medical professional to intervene.'
[210] Deirdre Madden, *Medicine, Ethics and the Law* (2nd edn, Bloomsbury 2011) 365 "McCall Smith criticizes the prioritization of autonomy as the 'passive acceptance of a one-dimensional perspective' and questions the 'liberal individualist consensus' which dominates the debate. He says that 'the assertion that patient autonomy is a firm rule restricts discretion and places physicians in a straitjacket.'
[211] Beauchamp (n9) 107 (emphasis in original) 'The principle of respect for autonomy can be stated as both a negative obligation and a positive obligation. As a *negative* obligation, the principle requires that autonomous actions not be subjected to controlling constraints by others.' 'As a *positive* obligation, the principle requires both respectful treatment in disclosing information and actions that foster autonomous decision making.'
[212] Charter of Fundamental Rights of the European Union, Article 7 'Everyone has the right to respect for his or her private and family life, home and communications.'
[213] Donnelly (n208) 34.

regarded as central to healthcare decision-making.'[214] The status attached to autonomy in palliative care can be said to demonstrate:

> the fact that dying is no longer, in many cases, a natural occurrence, but is heavily influenced by medical decisions and usually takes place in medical facilities. Medically prolonged life can be prolonged suffering, and many people may seek to avoid it by demanding active euthanasia or making living wills, in which they specifically forego treatment.[215]

The legality of living wills will be discussed later in this Chapter but this quote underlines the necessity of taking account of the wishes of the patient in order to provide appropriate healthcare. In relation to specialist palliative care it must be asked what the right of autonomy actually means for the terminally ill patient, in what circumstances is the right of autonomy engaged, who has a duty to ensure the right of autonomy is protected, and does the application of this right highlight gaps or shortcomings in the legal framework for specialist palliative care.

Common Law Recognition of Autonomy

In *Re a Ward of Court* Denham J set out the importance of consent in medical treatment. This requires a person to be able to make an autonomous decision. Denham J set out that this 'arises out of civil, criminal and constitutional law.'[216] The absence of consent to medical treatment may result in 'trespass against the person in civil law, a battery in criminal law, and a breach of the individual's constitutional rights.'[217] However, a person's autonomous decision must be respected even if it is not necessarily in the patient's best interests from a purely medical perspective. Denham J highlighted this point and set out that 'medical treatment may be refused for other than medical reasons, or reasons most citizens would regard as rational, but the person of full age and capacity may make the decision for their own reasons.'[218] There is

[214] Madden (n210) 365.
[215] Council of Europe, 'Palliative care: a model for innovative health and social policies' Doc.11758, [4].
[216] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 156.
[217] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 156.
[218] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 156; John Stuart Mill, *On Liberty* (Oxford University Press 2008) 9 Mill interprets the concept of autonomy in a broad manner but this is subject to 'all the persons concerned being of full age, and the ordinary amount of understanding.'; Dan W Brock, 'Medical Decisions at the End of Life' in Helga Kuhse and Peter Singer, *A Companion to Bioethics*, (Blackwell Publishing 1998) 232-233 'there is no objectively correct point

considerable respect given to a person's autonomous decision even if it is not necessarily in the person's best interests. Donnelly commented that the approach of Denham J 'followed a well-established line of jurisprudence in both England and Wales and the United States where the common law right of autonomy has been held to allow a capable patient to refuse medical treatment even if this will lead to his or her death.'[219]

One of the main cases to demonstrate the common law right of autonomy is *Re T (Adult: Refusal of Medical Treatment).*[220] This case involved the refusal of a blood transfusion by a person who was raised as a Jehovah's Witness although she was not practicing her religion prior to this decision. In this case, Lord Donaldson MR commented that:

> An adult patient who, like Miss T., suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered. This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.[221]

This demonstrates that the right of autonomy requires a person to have sufficient mental capacity and the person's choice is limited to the treatment options proposed by the healthcare professional. Despite these limits, the right of autonomy does provide the patient with a considerable degree of control over medical decisions affecting them. Moreover, it is necessary that a clear test for assessing the mental capacity of a patient forms part of the legal framework for specialist palliative care and that patients are involved in decisions which impact on their medical care. The test for capacity and ways of giving effect to a patient's wishes will be discussed later in this section. In addition to common law protection, the right of autonomy has also been protected by the Irish Constitution and the ECHR.

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for all persons at which further treatment and the life it sustains are no longer a benefit, but are instead a burden and without value of meaning. There are only the decisions of different competent patients about that point.'

[219] Donnelly (n208) 35.

[220] *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 649, [1992] EWCA Civ 18.

[221] *Re T (Adult: Refusal of Medical Treatment)* [1992] EWCA Civ 18 [3].

Constitutional Protection of the Right of Autonomy

The right of autonomy was recognised as an unenumerated right protected by Article 40.3.1˚ of the Irish Constitution in the Supreme Court case of *Re a Ward of Court*.[222] In this case autonomy was viewed as part of the right to privacy by Hamilton CJ. However Denham J took the view that the right of autonomy was a separate constitutional right.[223] Despite this, the Court merely listed the relevant rights and did not engage in a discussion as to how these rights actually operate or how they are to be protected.[224] This was a surprising case to recognise a constitutional right of autonomy as the woman at the centre of *Re a Ward of Court* was in a near persistent vegetative state and could not indicate whether she wanted treatment withdrawn. In a separate case the right of autonomy has been seen as distinct from privacy and was 'affirmed *obiter* by two members of the Supreme Court in *North Western Health Board v HW and CW*.'[225] The case law on autonomy has continued to expand and the right of autonomy has been recognised as a basis for treatment refusal as seen in *JM v Board of Management of St Vincent's Hospital*.[226]

Donnelly suggests that *JM v Board of Management of St Vincent's Hospital* marked the 'first significant judicial engagement with the right' in Ireland.[227] This case involved a refusal of a blood transfusion in advance by a Jehovah's Witness who then lost consciousness. Patient autonomy was not to be the deciding factor in this case as the patient was admitted to wardship and it was ordered that treatment be administered. In making this decision the court relied on its parens patriae jurisdiction and suggested that if the patient were competent to refuse treatment then such a decision would be allowed. Finnegan P held that the patient had not made 'a clear final decision as the notice party was pre-occupied with her husband and his religious beliefs rather than her own welfare and whether or not to have treatment.'[228] As a consequence of this, the Court did not consider the decision of the patient to be real and was therefore not

[222] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79; Declan Costello, 'The Terminally Ill – The Law's Concerns' (1986) The Irish Jurist 35.
[223] *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79, 167.
[224] Donnelly (n208) 35 'little exploration of what the right meant and how it should be protected.'
[225] ibid 35.
[226] *JM v Board of Management of St Vincent's Hospital* [2003] 1 IR 321.
[227] Donnelly (n208) 35.
[228] *JM v Board of Management of St. Vincent's Hospital* [2003] 1 IR 321, 321.

an autonomous decision. This meant that the advance refusal of a blood transfusion was not upheld in this case.

The right of autonomy was also relied on by the applicant in *Fleming v Ireland & Ors*.[229] In this case it was submitted that a freedom to end a person's own life existed on the basis of the right to autonomy, right to bodily integrity, and self-determination. However, the Court noted that 'In the social order contemplated by the Constitution, and the values reflected in it, that would be the antithesis of the right rather than the logical consequence of it.'[230] This case demonstrates that the right of autonomy does not extend so far as to provide for a right to assisted suicide. The effect of this is that a person makes decisions as part of a society and decisions are constrained by values contained in the Constitution and the need to ensure decisions do not negatively affect other people.

While these cases recognised a right of autonomy they do little to demonstrate how the right can be utilised by the individual. As Donnelly noted, the 'majority of patients who seek to exercise their right of autonomy are restricted from doing so, not because of any general limit but because, in their particular circumstances, the right does not arise.'[231] For this reason, better guidance on the exercise of the right of autonomy can be found in ECtHR case law.

Protection of the Right of Autonomy under the ECHR

The ECHR contains provisions protecting autonomy but they do not expand past relevant constitutional provisions. Article 8 of the ECHR sets out that 'Everyone has the right to respect for his private and family life, his home and his correspondence.'[232] The first step in a case which raises Article 8 of the ECHR is to consider whether the complaint actually comes within the remit of Article 8. Unlike Article 3 of the ECHR, there is no minimum severity threshold for the application of Article 8. If answered in the positive, the second step is to then consider whether there has been an interference

[229] *Fleming v Ireland & Ors* [2013] IEHC 2, [2013] IESC 19.
[230] *Fleming v Ireland & Ors* [2013] IESC 19, [113].
[231] Donnelly (n208) 38.
[232] European Convention on Human Rights, Article 8(1).

with Article 8, and whether such interference is in accordance with the law, whether it pursues a legitimate aim, or if it is necessary in a democratic society.[233]

The right of autonomy as protected by Article 8 of the ECHR was the focus of *Pretty v United Kingdom*.[234] This case further serves to identify the limits which may be placed on a person's autonomy. It was alleged by the applicant in *Pretty v United Kingdom* that her rights under Articles 2, 3, 8, 9 and 14 of the ECHR were infringed as the Director of Public Prosecutions would not grant immunity to her husband for assisting in her suicide, in addition to the prohibition on assisted suicide set out in the Suicide Act 1961.[235]

The House of Lords did not consider that Article 8 of the ECHR had any relevance for the ending of life as with Mrs Pretty. This point is demonstrated by the view that although Article 8 'offered protection to autonomy during life, it did not say anything about the right of individuals to autonomy over their deaths.'[236] However, the relevance of the right of autonomy in relation to treatment refusal which would result in a patient's death was subsequently accepted by the ECtHR.[237]

The ECtHR held that the rights provided by Article 8 of the ECHR were engaged.[238] *Pretty v United Kingdom* demonstrates the issues to be considered in limiting a person's autonomy. In particular, under Article 8(2) the necessity of an interference with the right of autonomy was to be examined. Article 8(2) can be said to set out a three step test for limiting the right to respect for private life. For instance, Article 8(2) sets out that:

> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in

[233] European Convention on Human Rights, Article 8(2).
[234] *Pretty v United Kingdom* (2002) 35 EHRR 1.
[235] *Pretty v United Kingdom* (2002) 35 EHRR 1, [3] 'the refusal of the Director of Public Prosecutions to grant an immunity from prosecution to her husband if he assisted her in committing suicide and the prohibition in domestic law on assisting suicide infringed her rights under Articles 2, 3, 8, 9 and 14 of the Convention.'
[236] Dan Morris, 'Assisted suicide under the European Convention on Human Rights: a critique' (2003) European Human Rights Law Review 65, 78.
[237] *I v UK* [2002] ECHR 2979, [70]; *Goodwin v UK* [2002] ECHR 2978/02, [90].
[238] *Pretty v United Kingdom* (2002) 35 EHRR 1, [86].

> a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.[239]

This demonstrates that an interference with a person's private life is permissible under Article 8 provided it is necessary in a democratic society and the interference must be based on a listed purpose. In deciding on whether an interference is required in a democratic society, the Court considers the margin of appreciation enjoyed by the State. This margin of appreciation 'will vary in accordance with the nature of the issues and the importance of the interests at stake.'[240] As such, the ECtHR set out that 'The more serious the harm involved the more heavily will weigh in the balance considerations of public health and safety against the countervailing principle of personal autonomy.'[241] In this regard, the ECtHR in *Pretty* accepted that the interference was necessary and Article 8 of the ECHR had not been violated. Nevertheless on the basis of both ECtHR and Irish case law it is difficult to see how the refusal of treatment by a terminally ill patient could come within Article 8(2) of the ECHR. It is challenging to see how limiting autonomy in situations where there is a refusal of treatment could be necessary in a democratic society or what a listed purpose in this regard might entail. For example, in the case of *Re a Ward of Court*, Denham J set out that potential limitations on a person's autonomy arise 'in regard to contagious diseases or in a medical emergency where the patient is unable to communicate.'[242] There is no suggestion to support a broader set of limits.

The right to autonomy under the ECHR may give rise to positive obligations as demonstrated by the case of *R*(*Burke) v General Medical Council*.[243] The patient in *Burke* had spino-cerebellar ataxia which would eventually lead to his death. He

[239] European Convention on Human Rights, Article 8(2).
[240] *Pretty v United Kingdom* (2002) 35 EHRR 1, [70].
[241] *Pretty v United Kingdom* (2002) 35 EHRR 1, [74]; The limits on positive obligations was further demonstrated in the case of *Haas v Switzerland* App no 31322/07 (ECtHR, 20 January 2011) where the European Court of Human Rights did not accept that Article 8 of the ECHR contained a positive obligation for States to facilitate access to medication which would allow people to commit suicide. It was suggested by the applicant that suicide was the only way in which he could die in a dignified manner.
[242] Donnelly (n208) 36.
[243] *R*(*Burke) v General Medical Council* [2006] QB 273, [2005] 3 WLR 1132, [2005] EWCA Civ 1003.

challenged the guidance issued by the General Medical Council that artificial nutrition and hydration would be withdrawn from the patient in certain circumstances.[244] This case did not establish a right to request any course of treatment but instead it recognised a 'right to be protected from … a lack of treatment in such cases'.[245] The case was heard by Munby J and was subsequently appealed by the General Medical Council.

Munby J held that the patient had a right to have the treatment continued and that the guidance of the General Medical Council was incompatible with Articles 2, 3 and 8 of the ECHR.[246] Additionally, Munby J relied on autonomy, self-determination, dignity and the patient's best interests. Although it would appear that Munby J recognised a broad right of autonomy, the patient cannot request any treatment they want but is limited to choose from the possible treatment options as outlined by the doctor.[247] In this respect, the Court of Appeal emphasised the autonomy of the medical practitioner. The Court of Appeal allowed the appeal and held that:

> once a patient was accepted into hospital the medical staff came under a positive common law duty to care for him, a fundamental aspect of which was a duty to take reasonable steps to keep the patient alive; … that deliberately to bring about the death of a competent patient by withdrawing life-prolonging treatment contrary to the patient's wishes would infringe the patient's rights under articles 2, 3 and 8 of the Convention[248]

Based on the Irish case law on autonomy it appears that a similar approach which emphasises the freedom to choose from the medical options presented would be

[244] The General Medical Council is 'the independent regulator for doctors in the UK.' General Medical Council, 'Our role' <http://www.gmc-uk.org/about/role.asp> accessed 19 June 2014.
[245] *R(Burke) v General Medical Council* [2004] EWHC 1879 (Admin) [213]; David Gurnham, 'Losing the Wood for the Trees: Burke and the Court of Appeal' (2006) 14(2) Medical Law Review 253.
[246] European Convention on Human Rights, Article 2 Right to Life; European Convention on Human Rights, Article 3 Prohibition of Torture; European Convention on Human Rights, Article 8 Right to Respect for Private and Family Life.
[247] *R(Burke) v General Medical Council* [2006] QB 273, [51] 'In truth the right to choose is no more than a reflection of the fact that it is the doctor's duty to provide a treatment that he considers to be in the interests of the patient and that the patient is prepared to accept.'; See also *R(Burke) v General Medical Council* [2006] QB 273, 277-278 'To give a patient a right to require treatment of a particular form could also result in doctors (or trusts) being legally required to provide treatment which in their view would be contrary to that patient's best interests.'
[248] *R(Burke) v General Medical Council* [2006] QB 273, 273-274.

followed rather than a general freedom to request any form of medical treatment. Nevertheless, this approach to autonomy would require a patient to be presented with all relevant medical options. If there is a lack of a clear decision-making framework for specialist palliative care then a patient may not always be presented with all relevant medical options. Furthermore, this is not a particularly pro-active approach to protecting a patient's right to autonomy. For example, a terminally ill patient may lack capacity by the time decisions about the withdrawal of artificial nutrition and hydration are to be made. The absence of a framework for discussing specialist palliative care decisions with a terminally ill patient in a timely manner would render these rights largely ineffective and would result in an ad-hoc approach to decision-making. Despite this, it is necessary to clarify the test for capacity in this jurisdiction and examine forthcoming legislation which will impact on this area.

Identifying Capacity

Due to the nature of specialist palliative care the capacity of a patient may be difficult to determine due to effects of the illness or the impact of sedative or pain-killing drugs. Donnelly highlighted the importance of capacity in stating that 'an understanding of capacity is essential in order to appreciate what the principle of autonomy means at a conceptual level and how it operates in individual cases.'[249] The role of capacity is demonstrated in the case of *Fitzpatrick and Another v K and Another*.[250] The woman in this case was a Jehovah Witness and refused a blood transfusion after the birth of her child. Instead, she suggested that she should be treated with coca cola and tomatoes. Due to concern about the woman's autonomy the Master of the hospital applied to the High Court for 'authority to transfuse Ms. K.'[251] This application was heard by Abbott J who ordered that the blood transfusion be administered due to the constitutional rights of Ms. K's infant son and Ms. K be restrained if necessary.[252] Ms. K subsequently recovered and argued that 'the *ex parte* order should not have been applied for and should not have been made and should be set aside'.[253] It was also

[249] Donnelly (n183) 90.
[250] *Fitzpatrick and Another v K and Another* [2008] IEHC 104, [2009] 2 IR 7.
[251] *Fitzpatrick and Another v K and Another* [2009] 2 IR 7, 14.
[252] *Fitzpatrick and Another v K and Another* [2008] IEHC 104, [I] 'It is ordered that the Plaintiff be authorised to administer to the Defendant including all appropriate steps by way of restraint or otherwise all appropriate medical treatment and other ancillary procedures including blood transfusion and clotting agents.'
[253] *Fitzpatrick and Another v K and Another* [2008] IEHC 104, [I].

argued on behalf of Ms. K that due to the time at which the transfusion was administered it was unlawful as it was not necessary for the preservation of her life, that her child's constitutional rights should not have been placed ahead of her autonomous decision, and that she 'was entitled to refuse all or any medical treatment proposed by the plaintiffs by virtue of Article 40.1, Article 40.3.1 and Article 40.3.2 and Article 44.2.1 of the Constitution and articles 8 and 9 of the Convention.'[254]
In the High Court, Laffoy J placed considerable emphasis on the issue of capacity. Ultimately the Court held that Ms K lacked capacity based on a number of factors including the fact that she had undergone:

> a long labour, a difficult delivery and a massive haemorrhage; the communications difficulties created by the fact that Ms. K's first language was not English; the fact that she was a young woman in a foreign country whom the Hospital personnel believed had no family members in the State to whom the Hospital could turn for some assurance or confirmation of her religion and her understanding of her need for a blood transfusion; … and that by her disclosure, after the haemorrhage, Ms. K told the Hospital personnel for the first time that she was a Jehovah's Witness and would not take blood, which was at variance with the Hospital's understanding that she was a Roman Catholic which was based on the information she gave when booking.[255]

In reaching this decision the Court utilised the reasoning in the English case of *Re C*.[256] This case set out a three stage test for capacity which requires the patient to comprehend and grasp the treatment as well as believing it and considering such information in making their ultimate decision[257] in order to hold that the patient has the requisite capacity.[258] This demonstrates a functional approach to assessing the capacity of a patient as the focus is placed on whether the patient can understand the

[254] *Fitzpatrick and Another v K and Another* [2008] IEHC 104, [I].
[255] *Fitzpatrick and Another v K and Another* [2008] IEHC 104, [VII].
[256] *Re C (Adult: Refusal of Treatment)* [1994] 1 All ER 819.
[257] *Fitzpatrick & Anor v K & Anor* [2008] IEHC 104.
[258] Donnelly (n208) 37 'Significantly, Laffoy J held that that a refusal of treatment which has potentially life threatening consequences must "reach a particularly high threshold before it can be considered a valid refusal."

decision at hand rather than determining their capacity in an abstract manner.[259] Nevertheless, in determining the capacity of a patient it is necessary to also take account of the seriousness of the decision. As such, a more rigorous analysis of capacity may occur when there are serious consequences attached to a decision.

Laffoy J commented that treatment refusal which could potentially result in shortening the patient's life must 'reach a particularly high threshold before it can be considered a valid refusal.'[260] The reason for establishing such criteria is that the refusal of treatment would amount to a patient waiving their right to life as protected by the Irish Constitution. However, in this decision Laffoy J did not take into consideration a patient with a terminal illness. A broader interpretation of the right of autonomy may have been applied were the patient terminally ill. Such an approach would be in line with the decision in *Re a Ward of Court*.[261]

These cases have largely dealt with people seeking to actively have their right of autonomy vindicated. However, the manner in which decisions are made for those lacking capacity must also be discussed. The approach of the courts in this area will demonstrate how the wishes of a patient are addressed when they no longer have sufficient decision-making capacity. The optimum approach should form part of the regulatory framework for specialist palliative care in order to promote clarity and consistency.

Best Interests/Substituted Judgment

In a situation where the patient lacks capacity there are a number of approaches which the court may use to determine which treatment option should be selected. In this section the traditional approaches utilised will be discussed but this is an area which is currently changing due to the *Assisted Decision-Making (Capacity) Bill 2013*. Setting out the traditional approaches in this section allows for later comparison against the changes being introduced by the *Assisted Decision-Making (Capacity) Bill 2013*.

[259] Assisted Decision-Making (Capacity) Bill 2013, s 3 This introduces a functional approach to determining a person's capacity.
[260] *Fitzpatrick and Another v K and Another* [2008] IEHC 104, [IV].
[261] Text to n242.

The traditional approaches include the best interests approach and the substituted judgment approach. The best interests approach involves balancing the positive and negative consequences of continuing treatment in order to arrive at a decision.[262] Such an approach does have certain shortcomings particularly its subjective nature in deciding what is in a patient's best interests.[263] As such, the best interests approach may be viewed as being paternalistic.[264] It has also been described as 'inescapably a quality-of-life criterion.'[265] The substituted judgment approach allows the surrogate decision maker to select 'the path which is more likely to be closest to the patient's own wishes.'[266] An advantage of this approach is that 'it purports to give effect to the previous wishes, values and preferences of the incompetent patient.'[267] This is supported by Kennedy and Grubb who argue that the substituted judgment approach provides greater protection for an individual's self-determination.[268] Despite this, Beauchamp and Childress describe it as 'a weak standard of autonomy'.[269] They suggest that this standard should only be used 'if reason exists to believe that the surrogate decision maker can make a judgment that the patient would have made.'[270] The appropriate test to be used was discussed in *Re a Ward of Court*. Ultimately, the Supreme Court in this case 'enshrined best interests principles in the context of decision-making on behalf of a person who was a Ward of Court.'[271]

Lynch J in *Re a Ward of Court* was of the opinion that:

> the proper and most satisfactory test to be applied by the Court in this case is the best interests test, i.e., whether it is in the best interests of the ward

[262] Beauchamp (n9) 228 'Under the best interests standard, a surrogate decision maker must then determine the highest probable net benefit among the available options, assigning different weights to interests the patient has in each option balanced against their inherent risks, burdens, or costs.'
[263] Law Reform Commission, *Report on Vulnerable Adults and the Law* (LRC 83-2006) 69 In the Commission's view, one of the major objections to a best interests test for intervention in the life of an adult who has been found to lack capacity is that its application may simply equate to what the decisionmaker subjectively thinks is best for the person.'
[264] ibid 68.
[265] Beauchamp (n9) 228.
[266] Emma Keane, 'Withdrawal of Life Support for Patients in PVS' (2011) 2 Medico-Legal Journal of Ireland 83, 84.
[267] ibid 84.
[268] Ian M Kennedy and Andrew Grubb, *Medical Law* (3rd edn, Oxford University Press 2000) 838.
[269] Beauchamp (n9) 227
[270] ibid 227.
[271] Law Reform Commission (n263) 68.

> that her life, such as it is at present, should be prolonged by the continuation of the abnormal artificial means of nourishment, or, whether she should be allowed to slip away naturally by the withdrawal of such abnormal artificial means which would happen[272]

In applying this approach it was evident that Lynch J recognised the challenge in deciding the case based on the best interests of the patient.[273] However, it could be suggested that the test actually applied by Lynch J was a hybrid test. For example, Lynch J set out that:

> Whilst the best interests of the ward is the acid test, I think that I can take into account what would be her own wishes if she could be granted a momentary lucid and articulate period in which to express them and if, despite what I have already said, I can form a view on the matter.[274]

On this basis it appears that the best interests test was to the fore in the High Court but was supplemented by the substituted judgment approach. Feenan described the approach of Lynch J as 'novel'.[275]

In contrast to the test applied by High Court, the Supreme Court 'tended more to applying a discrete "best interests" test rather than the hybrid' model applied by Lynch J.[276] In considering the substituted judgment approach O'Flaherty J commented that it was 'impossible to adapt the idea of a 'substituted judgment' to the circumstances of this case'.[277] Despite this O'Flaherty J recognised that the substituted judgment approach might be relevant 'where the person has had the foresight to provide for future eventualities.'[278] This provision for 'future eventualities' could possibly take

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[272] *Ward of Court (withholding medical treatment) (No 2), Re*, [1995] 2 ILRM 401, 418.
[273] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 98 'Thus it is suggested that it must be still more difficult for another person to decide whether a patient unable to communicate and dependant on artificial life support, would wish such support to be maintained or not, or to decide whether the maintenance or removal of the life support was in the true best interests of the patient.'
[274] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 98.
[275] Dermot Feenan, 'Death, Dying and The Law' (1996) 14 Irish Law Times 90, 92.
[276] Patrick Hanafin, 'The Legal and Ethical Dimensions of End-of-Life Decision-Making in Contemporary Ireland' in Stefani Negri (ed), *Self-Determination, Dignity and End-of-Life Care: Regulating Advance Directives in International and Comparative Perspective* (Martinus Nijhoff 2012) 211.
[277] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 133.
[278] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 133.

the form of an advance care directive. In this regard, the comments of O'Flaherty J suggest a certain level of judicial acceptance for the concept.

In adopting a similar approach Denham J was of the opinion that the court was required to consider 'Any previous views that were expressed by the ward that are relevant, and proved as a matter of fact on the balance of probabilities.'[279] As such, Denham J applied a broader best interests test which drew on elements of the substituted judgment approach. In total Denham J considered fifteen separate factors in order to arrive at a decision as to the patient's best interests. Among the factors were the current condition of the ward, the level of bodily invasion which the medical treatment would require, the likely impact of the medical treatment, and input from the family, carers and medical practitioners.[280] Hamilton CJ followed the approach of Lynch J in the High Court, referring to it as 'the proper test'.[281] It appears that Hamilton CJ was supportive of the best interests test rather than the hybrid test which could be identified. As such the majority of the Supreme Court 'decided to frame their approach as the best interests of the Ward.'[282] However, this is not a strict paternalistic interpretation of what is in the patient's best interests. In practice a more flexible approach appears to be used when determining the appropriate medical treatment for a person lacking capacity.

The more flexible approach is demonstrated in guidance of the Irish Medical Council. It was set out by the Irish Medical Council that in relation to a seriously ill patient 'you should consult with any person with legal authority to make decisions on behalf of the patient and the patient's family if possible.'[283] The guidance of the Irish Medical Council will be examined fully in Chapter Five. Overall, it appears that there is room for a greater degree of legal clarity on the test to be applied as *Re a Ward of Court* demonstrates a more widely framed best interests approach. The introduction of the *Assisted Decision-Making (Capacity) Bill 2013* may serve to provide a greater level

[279] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 167.
[280] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 167.
[281] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 127.
[282] Keane (n266) 85.
[283] Irish Medical Council, 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners' (7th edn, 2009) 40.

of clarity as to who should be consulted in such instances and it is likely to have a substantial impact on the legal framework in Ireland for specialist palliative care.

Assisted Decision-Making (Capacity) Bill 2013

The Irish Government set out in its Programme for Government a commitment to introduce a capacity bill which 'is in line with the UN Convention on the Rights of Persons with Disabilities.'[284] On this basis, the *Assisted Decision-Making (Capacity) Bill 2013* is to satisfy Ireland's obligations under Article 12 of the UN Convention on the Rights of Persons with Disabilities. Article 12 of the Convention requires equal recognition before the law for people with disabilities. Consequently, the *Assisted Decision-Making (Capacity) Bill 2013* is intended to 'to reform the law and to provide a modern statutory framework that supports decision-making by adults and enables them to retain the greatest amount of autonomy possible in situations where they lack or may shortly lack capacity.'[285] This Bill would allow terminally ill patients to take active steps to better protect their autonomy and ensure they receive the end-of-life care they would want. In this respect, the Bill provides for the introduction of a statutory framework for the appointment of a decision-making assistant or a co-decision maker for an individual whose capacity is in question, or may soon be in question. Additionally, the Bill provides for the Office of the Public Guardian to be established. This statutory office will 'supervise decision-making assistants, co-decisionmakers, decision-making representatives and persons holding enduring powers of attorney.'[286] In this section, the guiding principles of the Bill will be outlined and the establishment of a decision-making assistant and co-decision maker will be examined for how these roles could potentially impact on specialist palliative care. Furthermore, a Draft General Scheme for Advanced Healthcare Directives to be incorporated into the *Assisted Decision-Making (Capacity) Bill 2013* has recently been published. The proposed legislation contained in this Draft General Scheme will also be examined in this section.

[284] Department of the Taoiseach, 'Programme for Government 2011-2016' 37.
[285] Assisted Decision-Making (Capacity) Bill 2013, explanatory memorandum.
[286] Assisted Decision-Making (Capacity) Bill 2013, explanatory memorandum.

The guiding principles of the *Assisted Decision-Making (Capacity) Bill 2013* set out that the capacity of an individual is presumed unless the contrary is shown.[287] The term 'guiding principles' signals a shift away from the use of the term 'best interests'. In this regard, the Bill requires all 'practicable steps' to be taken in helping an individual to make a decision.[288] This demonstrates the importance this Bill places on the autonomy of an individual. In circumstances where an intervention does have to be made it should minimise 'the restriction of the relevant person's rights',[289] 'the restriction of the relevant person's freedom of action'[290] and the intervention is to 'have due regard to the need to respect the right of the relevant person to his or her dignity, bodily integrity, privacy and autonomy.'[291] The importance of these concerns for specialist palliative care has been demonstrated throughout this Chapter. Section 8(7) of the Bill outlines the duties of an intervener in situations where an intervention is to occur. Among the factors to be considered by an intervener include the views of 'any person named by the relevant person as a person to be consulted on the matter concerned or any similar matter'[292] along with 'any decision-making assistant, co-decision-maker, decision-making representative or attorney for the relevant person'.[293] The role of the decision-making assistant and the co-decision maker must be examined as they have significant potential to support and define the healthcare decisions of an individual.

Assisted Decision-Making

A decision-making assistant is a person who is appointed by a person to assist them in making decisions about their personal welfare, property, and affairs.[294] A decision-making assistant would be appointed by an individual whose capacity is in question, or may soon be in question and is appointed by way of a decision-making assistance agreement.[295] The role and scope of authority for decision-making assistants is set out in Section 11 of the *Assisted Decision-Making (Capacity) Bill 2013*. This section sets out that a decision-making assistant is:

[287] Assisted Decision-Making (Capacity) Bill 2013, s 8(2).
[288] Assisted Decision-Making (Capacity) Bill 2013, s 8(3).
[289] Assisted Decision-Making (Capacity) Bill 2013, s 8(6)(a)(i).
[290] Assisted Decision-Making (Capacity) Bill 2013, s 8(6)(a)(ii).
[291] Assisted Decision-Making (Capacity) Bill 2013, s 8(6)(b).
[292] Assisted Decision-Making (Capacity) Bill 2013, s 8(7)(d)(i).
[293] Assisted Decision-Making (Capacity) Bill 2013, s 8(7)(d)(ii).
[294] Assisted Decision-Making (Capacity) Bill 2013, s 9.
[295] Assisted Decision-Making (Capacity) Bill 2013, s 9.

(*a*) to advise the appointer by explaining relevant information and considerations relating to a relevant decision,

(*b*) to ascertain the will and preferences of the appointer on a matter the subject or to be the subject of a relevant decision and to assist the appointer to communicate them,

(*c*) to assist the appointer to obtain any information or personal records (in this section referred to as "relevant information") that the appointer is entitled to and that is or are required in relation to a relevant decision,

(*d*) to assist the appointer to make and express a relevant decision, and

(*e*) to endeavour to ensure that the appointer's relevant decisions are implemented.[296]

In order to undertake these functions there are several criteria which need to be met by a potential decision-making assistant. Persons who cannot be appointed as a decision-making assistant include: those under the age of 18, people who have been convicted of an offence against the person or property of the proposed appointer or a child of the proposed appointer, or where there is a safety or a barring order made against the individual in respect of the proposed appointer or a child of the proposed appointer.[297]

The introduction of decision-making assistants would have a significant impact for specialist palliative care in terms of the legal framework and in the manner in which healthcare decisions are made at a practical level. A decision-making assistant could assist in ensuring that the patient has an appropriate understanding of the consequences of their decisions. This would ensure that a patient's autonomous decision is respected and implemented in practice. The professional standards and guidance will need to reflect this more complex approach to decision-making for vulnerable patients. The manner in which the current professional standards and guidance address decision-making will be discussed in Chapter Five. In addition to decision-making assistants the Bill also provides for the recognition of co-decision makers.

[296] Assisted Decision-Making (Capacity) Bill 2013, s 11.
[297] Assisted Decision-Making (Capacity) Bill 2013, s 12.

Co-Decision Making

A co-decision maker can be appointed by a person to make decisions jointly with them in relation to personal welfare, property, and affairs.[298] A co-decision making agreement has no effect except when a co-decision making order has been granted by the court. Such an order can be varied or discharged by the court and the order is subject to periodic review.[299] The Bill also provides for who can be appointed as a co-decision maker. Section 18 of the Bill sets out a co-decision maker should be 'a relative or friend of the proposed appointer who has had such personal contact with the proposed appointer over such period of time that a relationship of trust exists between them',[300] and the person must be 'capable of effectively performing the functions'[301] of a co-decision maker.

The functions of a co-decision maker are set out in Section 21 of the Bill. A co-decision maker is to advise the appointer and explain 'relevant information and considerations relating to a relevant decision.'[302] In addition to this, a co-decision maker will 'ascertain the will and preferences of the appointer',[303] 'assist the appointer to obtain any information or personal records that the appointer is entitled to and that is or are required in relation to a relevant decision',[304] 'assist the appointer to make and express a relevant decision',[305] and 'endeavour to ensure that the appointer's relevant decisions are implemented.'[306] These functions allow a co-decision maker to broadly assist the appointer in not only making a decision but also ensuring that effect is given to these decisions.

The introduction of decision-making assistants and co-decision makers is likely to have a substantial impact on the legal framework for specialist palliative care in Ireland. In particular, it will require professional standards and guidance to take account of these new roles as well as reflecting on the manner in which these professions approach and assess the capacity of terminally ill patients. These positions

[298] Assisted Decision-Making (Capacity) Bill 2013, s 16.
[299] Assisted Decision-Making (Capacity) Bill 2013, s 17(7).
[300] Assisted Decision-Making (Capacity) Bill 2013, s 18(2)(a).
[301] Assisted Decision-Making (Capacity) Bill 2013, s 18(2)(b).
[302] Assisted Decision-Making (Capacity) Bill 2013, s 21(3)(a).
[303] Assisted Decision-Making (Capacity) Bill 2013, s 21(3)(b).
[304] Assisted Decision-Making (Capacity) Bill 2013, s 21(3)(c).
[305] Assisted Decision-Making (Capacity) Bill 2013, s 21(3)(d).
[306] Assisted Decision-Making (Capacity) Bill 2013, s 21(3)(e).

serve to augment the process of healthcare decision-making and may require more detailed guidance from professional bodies, if not already in place. A further point to consider in relation to the *Assisted Decision-Making (Capacity) Bill 2013* is the impact which it may have on advance healthcare directives.

Advance Healthcare Directives

It has been proposed that the *Assisted Decision-Making (Capacity) Bill 2013* will legislate for the use of advance healthcare directives in Ireland. In this regard, a Draft General Scheme for Advance Healthcare Directives has been published for incorporation into the *Assisted Decision-Making (Capacity) Bill 2013*. The advance healthcare directive was first proposed by Kutner in 1969.[307] The advance healthcare directive can be defined as:

> a statement made by a competent adult relating to the type and extent of medical treatments she or he would or would not want to undergo in the future should he/she be unable to express consent or dissent at that time.[308]

Madden suggests that the development of the advance care directive had three purposes; 'it relieved the patient's family of the burden of decision-making',[309] it enabled participation of the patient in decision-making, and it signalled a shift away from medical paternalism towards patient autonomy and self-determination. Despite these potential advantages, there is currently no legislation in Ireland for advance healthcare directives.[310] However, it was suggested, *obiter*, by O'Flaherty J in *Re a*

[307] Luis Kutner, 'Due Process of Euthanasia: The Living Wills, A Proposal' (1969) 44 Indiana Law Journal 539, 551 'The patient may not have had, however, the opportunity to give his consent at any point before treatment. He may have become the victim of a sudden accident or a stroke or coronary. Therefore, the suggested solution is that the individual, while fully in control of his faculties and his ability to express himself, indicate to what extent he would consent to treatment. The document indicating such consent may be referred to as 'a living will,' 'a declaration determining the termination of life,' 'testament permitting death,' 'declaration for bodily autonomy,' 'declaration for ending treatment,' 'body trust,' or other similar reference.'

[308] Irish Council on Bioethics, 'Is it time for Advance Healthcare Directives?' (Irish Council for Bioethics 2007) 90; See also Alexander Morgan Capron, 'Advance Directives' in Helga Kuhse and Peter Singer, *A Companion to Bioethics* (Blackwell Publishing 1998) 299; Elizabeth Campbell, 'The Case for Living Wills' (2006) 12(1) Medico-Legal Journal of Ireland 5; Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 2 '"advance healthcare directive" means an advance written expression of will and preferences made by a person with capacity, in accordance with Heads 4 and 5, concerning treatment decisions that may arise in the event that the person subsequently loses capacity'

[309] Madden (n210) 507; O'Shea (n2) 74.

[310] Law Reform Commission, *Report on Bioethics: Advance Care Directives* (LRC 94-2009); See also European Convention on Human Rights and Biomedicine 1997, Article 9 'The previously expressed

Ward of Court that had the patient set out her treatment preferences in advance then the Court could have drawn guidance from it.[311] This suggestion has been supported by subsequent cases such as *JM v The Board of Management of St Vincent's Hospital*[312] and *Fitzpatrick v FK (No.2).*[313] As it stands, the approach in Ireland to advance healthcare directives has been significantly influenced by the approach taken in England and Wales. Therefore, the criteria set out in England and Wales for advance healthcare directives will be set out prior to outlining the criteria in the Draft General Scheme for Advanced Healthcare Directives. This will allow for the current informal approach in this jurisdiction to also be outlined before being contrasted against the proposed legislative changes.

The guidelines for advance care directives in England and Wales were set out in the case of *Re AK (Adult patient) (Medical Treatment)*[314] prior to the introduction of the *Mental Capacity Act 2005*.[315] The patient in this case wished to have treatment withdrawn which would result in his death when he was no longer able to communicate. The requirements set out by the court in this case for a valid advance care directive were that; 'doctors must be satisfied that the patient is of full capacity',[316] there must be a voluntary refusal of treatment, and 'it must be clear that the directive must have specifically envisaged the particular situation that has now arisen.'[317] The interpretation of the right of autonomy by Irish courts suggests that a similar set of criteria would be required for a valid advance care directive in Ireland. As such, it would require capacity at the time of drafting the directive, there should be no undue influence, and the directive should relate to the circumstances which arise in the patient's care. This is supported by the National Council on Ageing and Older People who suggest that where such requirements are met it is likely that 'our legal system would be supportive of such action.'[318]

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wishes relating to medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account'.

[311] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 132-133.

[312] *JM v The Board of Management of St Vincent's Hospital* [2002] 1 IR 321.

[313] *Fitzpatrick v FK (No.2)* [2008] IEHC 104, [2009] 2 IR 7.

[314] *Re AK (Adult patient) (Medical Treatment)* [2001] 1 FLR 129.

[315] Mental Capacity Act 2005.

[316] Madden (n210) 509.

[317] ibid.

[318] O'Shea (n2) 78.

The Law Reform Commission stated in its 'Report on Bioethics: Advance Care Directives'[319] that it was aware that many hospitals have developed guidelines and protocols to deal with advance care directives in line with best practice models from the United Kingdom. This reflects the guidance of professional medical bodies in Ireland. For example, the potential role of advance care directives has been acknowledged in the Irish Medical Council's Guide to Professional Conduct and Ethics. This sets out that the doctor should respect a patient's advance healthcare plan.[320] The limits to the implementation of the advance care directive are also set out in the Guide to Professional Conduct and Ethics. In particular it is recognised that the decision of the patient must be an informed choice, the patient should not have changed their mind and 'the decision covers the situation that has arisen'.[321] In considering the validity of advance care directives the guide states that '[a]n advance treatment plan has the same ethical status as a decision by a patient at the actual time of an illness and should be respected'.[322] The Guide to Professional Conduct and Ethics also provides for situations where these criteria are not met or where there is uncertainty as to the existence of an advance directive. In this regard, the guidance states that:

> If there is doubt about the existence of an advance treatment plan, the patient's capacity at the time of making the treatment plan or whether it still applies in the present circumstances, you should make treatment decisions based on the patient's best interests. In making such a decision, you should consult with any person with legal authority to make decisions on behalf of the patient and the patient's family if possible.[323]

This reflects the role of the best interests approach although it does appear that the best interests are not identified in isolation as the guidance encourages wider consultation with the patient's family. Based on the points set out so far it appears that while advance care directives have not been provided for in Irish legislation the weight of

[319] Law Reform Commission (n310) 27.
[320] Irish Medical Council (n283) 39.
[321] ibid.
[322] ibid.
[323] ibid 40.

opinion suggests that they would be respected regardless.[324] Consequently, the move towards introducing legislation in this jurisdiction for advanced healthcare directives is a welcome step.

The Draft General Scheme for Advanced Healthcare Directives has generally followed the criteria set out above. In this regard, the Draft General Scheme sets out that an advance healthcare directive can be made by 'Any person who has reached the age of 18 and who has capacity within the meaning of this Act may make an advance healthcare directive.'[325] The advance healthcare directive for a treatment refusal is to be followed provided that:

> (a) the treatment to be refused is clearly specified, and
> (b) the circumstances in which the treatment refusal is intended to apply are clearly outlined, and
> (c) at the time the advance healthcare directive is to be followed the person who made the directive lacks capacity to consent to the treatment in question.[326]

The Draft General Scheme also sets out requirements in relation to the form of the advance healthcare plan. For example, it must be a written directive[327] and must contain details about the person making the advance healthcare directive[328] along with details of the person's general practitioner[329] and 'any nominated patient-designated healthcare representative and/or any attorney appointed through an enduring power of attorney.'[330] Other heads of the Draft General Scheme include sections on the validity

[324] Irish Medical Council (n283) 22; Madden (n210) 531 'In terms of the likelihood of the advance directive or living will being legally valid in Ireland, it can be surmised from judicial statements that such a decision by a patient would be recognised as legally valid if the patient was competent and informed when the directive was made, and that it was clear and specific to the patient's current situation. As long as the directive was lawful, the courts would uphold its validity.'
[325] Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 4(1).
[326] Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 4(2).
[327] Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 4(4)(a).
[328] Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 4(4)(b)(i).
[329] Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 4(4)(b)(ii).
[330] Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 4(4)(b)(iii).

and effect of advance healthcare directives, the role of a patient-designated healthcare representative, enduring powers of attorney, and the role of the courts. As it stands, the Draft General Scheme for Advanced Healthcare Directives is a positive step in further protecting and respecting patient autonomy in healthcare.[331] Nevertheless, it must be recognised that advance care directives are not a perfect solution to ensuring that a patient's right of autonomy endures. On this point, Beauchamp and Childress have suggested that advance healthcare directives have the potential to 'generate practical and moral problems.'[332]

Criticism of advance care directives stem from the difference in time between the drafting and ultimate reliance on an advance care directive.[333] This is based on the argument that a person cannot tell for certain what decision they would make unless they were in that situation at the time. Keane highlights a number of problems in relation to advance care directives. For instance, Keane suggests that advance care directives are 'often nebulous, sometimes so much so that they are rendered useless.'[334] However, it has also been argued that the use of an advance care directive would 'facilitate easier decision-making regarding selective non-treatment'.[335] An area of non-treatment which is of particular significance for specialist palliative care practices is the do not resuscitate order. This is generally made outside the advance care directive and it is necessary to consider the background to the making of such an order due to its considerable relevance for patients receiving specialist palliative care.

Do Not Resuscitate Orders

A do not resuscitate order [hereinafter 'DNR'] can be defined as 'a doctor's written order not to attempt cardiopulmonary resuscitation (CPR) on a particular patient.'[336] As such, other forms of treatment such as the administration of antibiotics may carry

[331] Beauchamp (n9) 14 'Substantive rules. Rules of truth telling, confidentiality, privacy, forgoing treatment, informed consent, and rationing health care provide more specific guides to action than do abstract principles. An example of a rule that sharpens the requirements of the principle of respect for autonomy in certain contexts is "Follow an incompetent patient's advance directive whenever it is clear and relevant."'
[332] ibid 189.
[333] Eoin Tiernan, 'Moving Points in Palliative Care – Advance Directives' (1995) 1(1) Medico-Legal Journal of Ireland 37.
[334] Keane (n266) 89.
[335] Hazel Biggs, 'Euthanasia and death with dignity: still poised on the fulcrum of homicide' (1996) Criminal Law Review 878, 887.
[336] Madden (n210) 513.

on in the interim. Madden highlighted that 'there is no legislative authority or judicial precedent upholding their legality.'[337] The status of DNRs was examined by the Law Reform Commission's Report on Advance Directives.[338] The absence of a legal framework for DNR's was recognised by the Law Reform Commission as was the lack of a clear system for doctors to address this issue. The Law Reform Commission recommended that the proposed Code of Practice on Advance Care Directives should:

> contain guidelines on the process of putting in place a DNR order. The Commission also recommends that the guidelines should provide that before a DNR order is made there is a consultative process, that this is documented on the patient's chart and that it is made by the most senior available member of the healthcare team.[339]

The development of such guidelines would provide increased clarity and greater certainty in this area. The inclusion of a clear consultative process also provides a way for ensuring that patient's wishes are addressed and respected. As it stands, it appears that the practice is for the medical practitioner to consult with the medical and nursing team in addition to the patient's family in order to ascertain whether a DNR should be recorded and therefore, to potentially avoid a subsequent challenge of the decision.[340] However, DNRs still do not have a legislative basis in Ireland and this complicates the use of DNRs to guide the work of healthcare professionals in this jurisdiction.

Dignity in Palliative Care

In this section it will be demonstrated that the status of dignity is not particularly clear and its precise meaning has not been clarified by Irish courts or by the ECtHR.[341] Nevertheless, it is important to draw out what is meant by dignity as well as to

[337] ibid 516.
[338] Law Reform Commission (n310).
[339] ibid 65.
[340] Madden (n210) 513.
[341] Leon R Kass, *Life, Liberty and the Defense of Dignity* (Encounter Books 2002); Ruth Macklin, 'Dignity Is a Useless Concept' (2003) 327 British Medical Journal 1419, 1419 'dignity seems to mean nothing other than respect for autonomy.'; Feldman (n160); Mette Lebech, 'What is Human Dignity?' (2004) Maynooth Philosophical Papers 59; Andrew Clapham, *Human Rights Obligations of Non-State Actors* (Oxford University Press 2006); Doris Schroeder, 'Dignity: Two Riddles and Four Concepts' (2008) 17(2) Cambridge Quarterly of Healthcare Ethics 230; Suzy Killmister, 'Dignity: not such a useless concept' (2010) 36 Journal of Medical Ethics 160; Dignity as reducible to autonomy see Deryck Beyleveld and Roger Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford University Press 2001).

underline the problems raised by the idea of a right of dignity. This importance is due to the status given to dignity in professional standards and guidance, as will be demonstrated in Chapter Five.[342] This section will first outline the principle of dignity as set out in various treaties and conventions. Second, the interpretation of dignity by the courts will be examined.[343] Dignity raises challenges for this approach due to its amorphous nature which defies simple categorisation. In order to demonstrate how such an issue will impact on the use of the term 'dignity' in professional standards and guidance it is necessary to draw on more academic commentary which examines the status and meaning of dignity. It will be argued in this section that the principle of dignity has been poorly defined by courts and is so closely linked to human rights which have a substantial body of jurisprudence associated with them that the use of the term 'dignity' only serves to generate confusion. In effect, using a principle such as 'dignity' which lacks a clear meaning undermines consistency and clarity in the professional standards and guidance in which it is used.

An Underlying Principle or a Right?

Despite the importance placed on dignity, it is a nebulous principle which defies simple definition.[344] For example, Feldman wrote that the meaning of the right to dignity is problematic to 'pin down.'[345] In this vein Binchy commented that 'Its meaning depends greatly on the philosophical premises of those who invoke it; the range of such premises is so broad that 'dignity' can have completely opposing connotations.'[346] Human dignity has been described as 'the central value underpinning

[342] Text to n57 and n139 in Chapter Five.

[343] The focus is on the law in practice rather than the theoretical underpinnings of rights.

[344] Stephen W Smith, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying Process* (Cambridge University Press 2012) 128 'It can never be more than one of a number of values, principles and policies which pull decision-makers in different directions.'; David Feldman, 'Human dignity as a legal value: Part 2' (2000) Public Law 61, 75 'The content of its central core is not clear, making it an uncertain guide.'; Macklin (n341) 1419 'A close inspection of leading examples shows that appeals to dignity are either vague restatements of other, more precise, notions or mere slogans that add nothing to an understanding of the topic.'; Conor O'Mahony, 'There is no such thing as a right to dignity' (2012) 10 International Journal of Constitutional Law 551.

[345] David Feldman (n160) 682.

[346] William Binchy, 'Dignity as a Constitutional Concept' in Eoin Carolan and Oran Doyle (eds), *The Irish Constitution: Governance and Values* (Round Hall 2008) 308; O'Mahony (n344) 551 'in spite of this voluminous and often erudite body of literature, there is little or no consensus as to what the concept of human dignity demands of law makers and adjudicators. Indeed, for all the importance and emphasis placed on human dignity in the text of international conventions, domestic constitutions, and court decisions, the elusive nature of the concept has led many commentators to argue that it is, at best, meaningless or unhelpful, and at worst, potentially damaging to the protection of fundamental human rights.'

the entirety of international human rights law.'[347] The term is contained in the Universal Declaration of Human Rights,[348] the International Covenant on Civil and Political Rights,[349] the International Covenant on Economic, Social and Cultural Rights,[350] the Charter of Fundamental Rights,[351] and in the Preamble to the Irish Constitution[352] as well as other treaties and conventions.[353] Although it is not explicitly referred to in the ECHR it has been acknowledged by the ECtHR that the protection of dignity and human freedom is 'the very essence of the ECHR'[354] This quote from *S.W. v the United Kingdom* begins to demonstrate a significant challenge to the characterisation of dignity, namely that dignity may be something other than a right and might instead be interpreted and applied as a principle or value. As such, dignity may function as an overarching principle or value rather than something tangible to be expressly protected.

The differing interpretations of dignity which exist mean that a phrase such as 'death with dignity' could be interpreted in a variety of ways. On this basis, if professional standards and guidance refer to the dignity of the patient it is important that a broader framework be in place to deliver on what professional bodies understand as 'dignity'. In effect, the reference to 'dignity' must be expanded on to ensure specialist palliative care is provided in a consistent manner across healthcare providers. This demonstrates the importance of clarifying the position of dignity in this jurisdiction and demarcating its role within the legal framework for specialist palliative care.

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[347] O'Mahony (n344) 552.

[348] Universal Declaration of Human Rights, Article 1, Article 25; Christopher McCrudden, 'Human Dignity and Judicial Interpretation of Human Rights' (2008) 19 European Journal of International Law 655, 678. McCrudden in discussing the status of dignity in the UDHR and the UN Charter of Fundamental Rights noted that '[i]ts utility was to enable those participating in the debate to insert their own theory [of human rights]. Everyone could agree that human dignity was central, but not why or how.'

[349] International Covenant on Civil and Political Rights (1966), Preamble, Article 10.

[350] International Covenant on Economic, Social and Cultural Rights (1966), Preamble.

[351] Charter of Fundamental Rights of the European Union, Article 1.

[352] Bunreacht na hÉireann, Preamble 'We, the people of Éire, […] seeking to promote the common good, with due observance of Prudence, Justice and Charity, so that the dignity and freedom of the individual may be assured, […] [d]o hereby adopt, enact, and give to ourselves this Constitution.'

[353] UN Convention on the Elimination of All Forms of Racial Discrimination; UN Convention on the Elimination of All Forms of Discrimination against Women; Vienna Declaration made at the World Conference on Human Rights in 1993.

[354] *S.W. v the United Kingdom* App no 20166/92 (ECtHR, 22 November 1995) [44]; See also *McDonald v United Kingdom* [2014] ECHR 492.

In Ireland there has been a lack of clarity as to whether dignity is a right or a value to be recognised by the courts. It has been suggested that 'It is possible that our late and incomplete recognition of the importance of dignity in the area of healthcare has stymied its proper acceptance as a core human right.'[355] Dignity has been referred to in a number of Irish cases,[356] most notably in *Re a Ward of Court*, and *Fleming v Ireland & Ors*.

In *Re a Ward of Court* Denham J stated that 'An unspecified right under the Constitution to all persons as human persons is dignity—to be treated with dignity … As long as a person is alive they have this right.'[357] This suggests a judicial willingness to recognise a right to dignity but there is little explanation for what such recognition would entail. In contrast to this, the Supreme Court in *Fleming v Ireland & Ors* referred to dignity as being a constitutional value which is recognised and respected by 'the rights protected'[358] in the Irish Constitution. The Court also referred to dignity as a 'principle under the Constitution'.[359] This approach to dignity clearly categorises it as a value or principle rather than a right in this jurisdiction. In particular, the approach of the Supreme Court in *Fleming v Ireland & Ors* suggests that the dignity of a patient can be upheld by protecting and vindicating the constitutional rights of the patient which would include the right to bodily integrity, protection from inhuman or degrading treatment, and the right to autonomy. This understanding of dignity clearly

[355] Shane O'Hanlon and Jennifer Schweppe, 'Health, Dignity and Human Rights' (2010) 11(2) Medico-Legal Journal of Ireland 97, 97.
[356] *Re Article 26 and the Offences Against the State (Amendment) Bill 1940*, [1940] 1 IR 470, 478-479 'In dealing with the Preamble counsel laid great stress on the words "dignity and freedom of the individual" and focussed their attention upon those words exclusively. This does not seem to us to be the correct method of arriving at the true meaning and effect of the Preamble. The main object aimed at is the promotion of the common good, which, it is contemplated, will assure the dignity and freedom of the individual, the attainment of social order, the restoration of the unity of our country and the establishment of concord with other nations. Apart from the grammatical construction of the words of the Preamble, it seems to us difficult to understand how the dignity and freedom of the individual member of a State can be attained unless social order is maintained in that State'; *Re Philip Clarke* [1950] IR 235; *Attorney General v Southern Industrial Trust* (1957) 94 ILTR 161; *Norris v Attorney General* [1984] IR 36, 71 per Henchy J 'there is necessarily given to the citizen, within the required social, political and moral framework, such a range of personal freedoms or immunities as are necessary to ensure his dignity and freedom as an individual in the type of society envisaged.'; *I O'T v B* [1998] 2 IR 321, 373 Keane J considered there to be a link between the right to privacy and the concept of dignity as set out in the preamble to the Irish Constitution. 'I find it difficult to imagine an aspect of human experience which falls more clearly into the constitutional area of privacy, as thus defined, than the circumstances of the natural mothers in the present case.'
[357] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79, 163.
[358] *Fleming v Ireland & Ors* [2013] IESC 19, [110].
[359] *Fleming v Ireland & Ors* [2013] IESC 19, [138].

places it as a value to be achieved through the protection of enumerated and unenumerated rights in this jurisdiction.

Feldman identifies two conceptions of dignity, namely, subjective and objective conceptions. The subjective conception of dignity is 'concerned with one's sense of self-worth, which is usually associated with forms of behaviour which communicate that sense to others.'[360] Whereas the objective conception of dignity is 'concerned with the state's and other people's attitudes to an individual or group, usually in the light of social norms or expectations.'[361] Donnelly states that 'People who lack the capacity for dignity in the subjective sense may still enjoy dignity in the objective sense.'[362] This is particularly important in the context of palliative and specialist palliative care practices where a patient may be heavily sedated. Such a point was also recognised by Feldman who suggested that:

> patients in a persistent vegetative state can be regarded as having intrinsic human dignity in this objective sense, in that responsible beings owe a moral, and often a legal, duty to have regard to their interests and rights when making decisions affecting their welfare.[363]

This is bound up in the previous examination of the right of autonomy and reflects the close relationship between the right to life, right of autonomy and dignity.

Regardless of an objective or subjective conception of dignity it can be noted that dignity is 'not an end in itself, or even a means to an end.'[364] This can be said to demonstrate the fundamental and inherent nature of dignity. As such the principle of dignity may come within the scope of a variety of rights although there are certain rights which have a 'particularly prominent role in upholding human dignity'.[365] On this point Feldman included 'the right to be free of inhuman or degrading treatment, the right to respect for private and family life, the right to freedom of conscience and

[360] Feldman (n160) 685.
[361] ibid 686.
[362] Donnelly (n183) 212-213.
[363] Feldman (n160) 686.
[364] ibid 687.
[365] ibid 690.

belief … and the right to be free of discriminatory treatment.'[366] This wide range of rights demonstrates the broad relevance and impact of the principle of dignity. It demonstrates that in applying the right to life and right of autonomy in the context of specialist palliative care practices it is also necessary to consider how decisions and actions impact on the dignity of the patient.

The principle of dignity can be said to establish certain limits. This is illustrated by Feldman's comment that it is accepted by many that 'certain things that cannot be done even to unconscious or dependent people without violating their dignity and denying them the respect that is due to them'.[367] In relation to healthcare, Jacobson has suggested that the breach of a patient's dignity could lead them to experience 'degradation, humiliation, disempowerment and loss of self-worth'[368] as well as an overall decline in their health.[369] In addition to this, a lack of respect for the dignity of a patient could result in adverse outcomes including 'denial of access to appropriate treatment, subjection to inappropriate clinical interventions or unwarranted long-term institutionalisation.'[370] Consequently, there must be a clear explanation of what is meant by dignity when this principle is referred to in the regulatory framework for specialist palliative care. For example, Foster sets out that dignity must have a clear meaning if it is to be useful and there must also exist a framework for its use.[371]

This section has demonstrated that there is no clear meaning as to what dignity entails or requires. It has also been argued that it may be incorrect to categorise dignity as a right. As such, reference to dignity in professional standards or guidance is not capable of being linked with a right to dignity or case law which describes its meaning. Instead dignity can be viewed as a principle or value. A considerable difficulty is the multiple theoretical frameworks which exist for explaining and defining what this value means in practice. If professional bodies do not clearly define their interpretation of dignity

[366] ibid 690; Jay Woogara, 'Patients' rights to privacy and dignity in the NHS' (2005) 19(18) Nursing Standard 33 In this article it is noted that the terms 'dignity' and 'privacy' are closely linked.
[367] Feldman (n160) 687.
[368] Nora Jacobson, "A taxonomy of dignity: a grounded theory study" (2009) 9(3) BMC International Health and Human Rights cited in O'Hanlon (n345) 97.
[369] ibid 97.
[370] Writing Group for the Consortium for Health and Human Rights, 'A Call to Action on the 50th Anniversary of the Universal Declaration of Human Rights. Health and Human Rights' (1998) 3(2) Health and Human Rights cited in O'Hanlon (n355) 97.
[371] Charles Foster, *Human Dignity in Bioethics and Law* (Hart Publishing 2011) 1.

then it will be left to individual healthcare professionals to use their best judgment. However, as it stands dignity appears to be more of an aspiration; something which is easier recognised in the breach rather than in the provision. Nonetheless, dignity appears to be a principle which can be realised through protecting and vindicating a patient's human rights. The achievement of this in specialist palliative care will depend to a considerable degree on the professional standards and guidance in place for doctors and nurses practising in Ireland.[372]

Conclusion

The aim of this chapter was to outline and examine the human rights framework for specialist palliative care. It is clear from the preceding analysis that human rights have a vital role in the provision of specialist palliative care and form a central part of the legal framework for this area. This chapter demonstrated that the right to bodily integrity and the right to be free from inhuman or degrading treatment are closely related and give rise to positive obligations on the State. The right to bodily integrity is not limited to protection from legislation but can be drawn on in a variety of circumstances. Ensuring that this right is adequately protected may require steps to be taken on the part of the State to address failings in the legal framework which hamper the protection of the right to bodily integrity. The cases discussed on this point had obvious applicability to the area of specialist palliative care due to their focus on issues in healthcare. The protection from inhuman or degrading treatment was also shown to be of significance to the provision of specialist palliative care. This right may be engaged in circumstances where the patient experiences severe mental or physical suffering. The cases discussed in this Chapter demonstrated that the possibility of being denied appropriate medical care was sufficient to engage Article 3 of the ECHR. Furthermore, reference to research by O'Leary and Tiernan, and Hospice Friendly Hospitals demonstrated the potential infringement of this right in Ireland in the context of specialist palliative care.

This Chapter also highlighted how the right of autonomy provides the patient with a degree of control over medical decisions which impact directly on them. This right has been protected and recognised in common law, in the Irish Constitution, and in the

[372] See Chapter Five.

ECHR. The effective protection and accessibility of this right, along with other rights discussed, is essential for patients who are at one of the most vulnerable stages in their life. The role of this right in practice will be considered in the next Chapter which focuses on the professional standards and guidelines in place for specialist palliative care. In particular, the right of autonomy needs to be protected in any decision-making procedure set out by professional standards or guidance. Moreover, it emerged from this Chapter that the status of dignity is not particularly clear. In this respect, recent case law in Ireland appears to have characterised dignity as a constitutional value as opposed to a human right. This underlines the nebulous nature of dignity; a principle which has many meanings, especially in end-of-life care, depending on the theoretical framework being employed. Nevertheless, the breach of a patient's dignity clearly signals greater human rights concerns in the care of the patient due to its close links with well-established human rights. Consequently, the role of dignity within professional standards and guidance will be examined in Chapter Five. Overall, this Chapter demonstrated the complexity of the rights framework in Ireland for specialist palliative care. This is a key part in the broader legal framework for specialist palliative care and any suggestions for reform set out in later chapters will need to take account of the scope of these rights and how they interact in practice.

THE REGULATORY FRAMEWORK IN IRELAND FOR SPECIALIST PALLIATIVE CARE

Introduction

The legal framework in Ireland for specialist palliative care is not easily delineated. Part of this framework was highlighted in the previous chapters which demonstrated the role and impact of human rights and principles which serve to promote the care of the terminally ill patient. These included the right to life, right to bodily integrity, protection from inhuman or degrading treatment, right of autonomy, and the principle of dignity. These must be given effect throughout the legal framework for specialist palliative care. In this regard, the legal framework is composed of human rights, professional standards and guidelines, and policies drafted at the local level. The absence of legislation dealing expressly with specialist palliative care practices places a greater burden on professional standards and local policy to protect the human rights of a patient while also striking a balance with the need for healthcare professionals to be given sufficient autonomy in caring for the patient. This requires a delicate balance and it highlights how a fragmented and inadequate regulatory framework has the potential to hamper the protection of a patient's human rights. On this basis, the regulatory framework is a significant aspect of the overall legal framework for specialist palliative care.

The aim of this Chapter is to outline and examine the regulatory framework in Ireland which is directly applicable to doctors and nurses. The requirements imposed by professional standards are particularly important due to the combination of different palliative care providers and the legally and ethically complex decisions which have to be made in specialist palliative care.[1] Consequently, professional standards and local policy will be examined for to how they address palliative sedation, artificial nutrition and hydration, the decision-making framework for these practices, patient rights, and how they encompass the four principles of autonomy, beneficence, nonmaleficence, and justice set out by Beauchamp and Childress.

[1] See p43 and p49.

Professional standards and guidance should be clear and consistent both independently and across healthcare professions. In effect, healthcare professionals should have a clear understanding of the limits of the care which can be provided, as well as being supported by a comprehensive decision-making framework to assist in deciding what level of palliative care may be required and what steps should be taken when commencing certain practices. In Chapter Four it was highlighted that the decision-making framework needs to be 'timely',[2] 'fair'[3] and should not be framed in such a way as to limit its application.[4] The framework should be structured in a manner which minimises the possibility of breaching a patient's human rights.[5] As such, it is necessary that legal and ethical issues are dealt with comprehensively in professional standards and guidance so as to ensure that patients can receive optimum care. The guidelines will also to be examined for consistency. The issue of consistency has previously been identified as a failing in the provision of palliative care in Ireland.[6] This may relate to consistency in standards within and across professions in healthcare. In this Chapter it will be questioned whether such criticisms are justified and the source of any such failing will be highlighted with the aim of identifying a solution in subsequent chapters.

The arguments in this Chapter are advanced over the course of three main sections. The first section examines the standards and guidance published by the regulators of the medical professions in Ireland, namely the Irish Medical Council and An Bord Altranais. The standards and guidance of these regulatory bodies shape the manner in which doctors and nurses provide specialist palliative care in this jurisdiction.

The second section addresses the function of the Health Information and Quality Authority and the standards they have set for end-of-life care in Ireland. In particular, the standard on end-of-life care contained in the 'National Quality Standards for Residential Care Settings for Older People in Ireland' will be considered.[7] Meeting

[2] *Tysiąc v Poland* (2007) 45 EHRR 42, [118]; Text to n119 in Chapter Four.
[3] *Tysiąc v Poland* (2007) 45 EHRR 42, [113].
[4] *Tysiąc v Poland* (2007) 45 EHRR 42, [116].
[5] See Chapter Four.
[6] Department of Health and Children, 'Report of the National Advisory Committee on Palliative Care' (Department of Health and Children 2001) 23.
[7] Health Information and Quality Authority, 'National Quality Standards for Residential Care Settings for Older People in Ireland (February 2009).

this standard requires local policy to be developed which sets out how care at the end of life is to be provided.

The third section of this Chapter considers the guidance of representative bodies and non-governmental organisations. In particular, the papers and recommended frameworks on specialist palliative care published by the Irish Association of Palliative Care and European Association of Palliative Care will be examined. The work of these bodies is not directly enforceable but serves to inform local policy and assist in defining best practice in this area. In short, these three sections allow for a substantial proportion of the regulatory framework in Ireland for specialist palliative care to be identified and examined for how it protects patients and for whether it provides a clear and consistent framework under which healthcare professionals can practice. Overall, it will emerge from this chapter that the current legal framework in Ireland for specialist palliative care is inadequate and consequently a more appropriate legal framework needs to be identified.

Professional Conduct and Ethics in Irish Healthcare

Doctors, nurses, and allied healthcare professionals work together in providing palliative care.[8] However, it is the doctor and nurse who are most closely involved in the provision of specialist palliative care. These professions have a substantial impact on the care of the terminally ill patient due to their involvement in treatment decisions, in the provision of palliative sedation, and the withdrawal of artificial nutrition and hydration. This underlines the need to focus on the professional standards and guidance applicable to these professions. The professional standards and guidance are set out by the professional bodies with responsibility for regulating these professions, namely the Irish Medical Council [hereinafter 'IMC'] and An Bord Altranais.

The Role of the Irish Medical Council

The IMC was established by the *Medical Practitioners Act 1978*.[9] It is the regulator of the medical profession in Ireland and is currently governed by the *Medical Practitioners Act 2007*.[10] Consequently, the IMC is an 'organ of the State' under the

[8] See p48.
[9] Medical Practitioners Act 1978.
[10] Medical Practitioners Act 2007.

European Convention on Human Rights Act 2003.[11] This requires the IMC to carry out its functions in a way which is compatible with the obligations placed on the State by the European Convention on Human Rights and Fundamental Freedoms. The purpose of the IMC is set out by the *Medical Practitioners Act 2007* as 'to protect the public by promoting and better ensuring high standards of professional conduct and professional education, training and competence among registered medical practitioners.'[12] This underlines how the protection of the public is closely tied to the professional conduct and competence on the part of the medical practitioner. In line with this, the IMC is required to set out appropriate standards of practice for doctors including 'the establishment, publication, maintenance and review of appropriate guidance on all matters related to professional conduct and ethics for registered medical practitioners'.[13] As such, a significant function of the IMC is to establish and maintain professional standards and guidance for medical practitioners in Ireland.

This section will examine the standards of practice and the guidance issued by the IMC which are relevant to specialist palliative care. The standards of practice which will be examined range from the first Guide to Ethical Conduct and Behaviour and to Fitness to Practise,[14] to the most recent edition of this guide, i.e. the Guide to Professional Conduct and Ethics for Registered Medical Practitioners [hereinafter 'Guide to Professional Conduct and Ethics'].[15] This is the main guidance on conduct and ethics published by the IMC. Examining different editions of the guide allows for the understanding of and attitude to palliative care over the years to be drawn out and it provides greater context for the examination of the current Guide to Professional Conduct and Ethics. The discussion of previous editions of the guide will be concise and will focus on highlighting the most salient points for specialist palliative care. It is the current, seventh edition of the Guide to Professional Conduct and Ethics, which will be given the greatest attention and it will be examined in a broader manner than

[11] Text to n37 in Chapter Four.
[12] Medical Practitioners Act 2007, s 6; Simon Mills, *Clinical Practice and the law* (Bloomsbury Professional 2007) 19-20.
[13] Medical Practitioners Act 2007, s 7(2)(i).
[14] The Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (Dublin 1981).
[15] Irish Medical Council, 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners' (7th edn, Dublin 2009).

other editions of the guide for how it impacts on the provision of specialist palliative care.

Legal Status of the Guide to Professional Conduct and Ethics

The Guide to Professional Conduct and Ethics has no 'binding force in law'[16] but is relevant for the 'internal regulation of the profession and it lays down what is ethical medical practice in Ireland.'[17] In effect, the Guide has no formal legal status in Ireland. However, Madden suggests that the professional standards could potentially be 'indirectly incorporated into law through case law'.[18] The situation envisaged by Madden is one in which a patient argues that they 'had a legitimate expectation that the guide would be adhered to by the doctor and that this formed an implied term of the contract with the doctor.'[19] On this basis, professional standards can be seen as forming part of the broader legal framework in Ireland for specialist palliative care. Despite this, the Guide does not contain comprehensive guidelines but establishes principles which are to be drawn on by doctors in connection with 'their judgment, experience, knowledge and skills in each situation.'[20] This underlines the subjective nature of complying with the Guide to Professional Conduct and Ethics and highlights the challenge of enforcing these guidelines. The failure of a doctor to comply with the Guide can have severe professional consequences for the doctor and this illustrates the significance of examining the Guide to Professional Conduct and Ethics.[21]

Guide to Ethical Conduct and Behaviour and to Fitness to Practise

The first IMC professional standards were published in 1981[22] and were titled Guide to Ethical Conduct and Behaviour and to Fitness to Practise.[23] Ethical conduct was addressed under four headings which were: 'responsibility to patients',[24] 'responsibility to colleagues',[25] 'responsibility to the community',[26] and 'professional

[16] Deirdre Madden, *Medicine, Ethics and the Law* (2nd edn, Bloomsbury 2011) 74.
[17] ibid.
[18] ibid.
[19] ibid.
[20] ibid.
[21] Text to n102.
[22] This followed the establishment of the Irish Medical Council by the Medical Practitioners Act 1978.
[23] Guide to Ethical Conduct and Behaviour and to Fitness to Practise (n14).
[24] ibid 11.
[25] ibid 13.
[26] ibid 14.

standards'.[27] Guidance on end-of-life care was addressed under 'responsibility to the community' rather than being included as part of 'responsibility to patients' or 'professional standards'. This categorisation suggests that end-of-life care was not being considered primarily from the patient's perspective. Moreover, the relevant guidance was set out under the heading of 'euthanasia'.[28]

The use of the term 'euthanasia' reflects the point made in Chapter Two that palliative care in Ireland was only beginning to develop in the 1980's.[29] Nevertheless, this does demonstrate that the primary concern of the IMC was the need to emphasise the illegality of euthanasia rather than addressing end-of-life care in detail. Regardless of the terminology used, the Guide to Ethical Conduct and Behaviour and to Fitness to Practise set out that 'Where death is imminent it is the doctor's responsibility to take care that a patient dies with dignity and as little suffering as possible.'[30] There is no explanation in the 'Guide to Ethical Conduct and Behaviour and to Fitness to Practise' as to what dignity entails or requires. The effect of this is to leave the interpretation of dignity to the subjective interpretation of individual medical practitioners. This issue will be returned to when considering the current edition of the Guide to Professional Conduct and Ethics.[31]

The second,[32] third[33] and fourth edition[34] of the IMC Guide to Ethical Conduct and Behaviour continued to address end-of-life care under the heading of 'euthanasia'. In addition to this, no change was made to the substantive content of the guidance. The lack of change in the third edition of the Guide to Ethical Conduct and Behaviour is notable as this comes after the position of consultant physician in palliative medicine

[27] ibid 16.
[28] ibid 15.
[29] Text to n21 in Chapter Two.
[30] The Medical Council (n14) 15.
[31] Text to n56.
[32] Irish Medical Council, 'Constitution and Functions: A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (2nd edn, Dublin 1984) 22 The same headings were used in both the 1981 and 1984 guide, i.e. '[r]esponsibility to [p]aients', '[r]esponsibility to [c]olleagues', '[r]esponsibility to the [c]ommunity', '[p]rofessional [s]tandards'.
[33] Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (3rd edn, Dublin 1989) 33-34. This was broadly similar to the 1981 and 1984 guidance in that it contains guidance on responsibility to patients and responsibility to the community but was expanded in certain respects. For example a section on professional responsibilities was added to the Guide.
[34] Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (4th edn, Dublin 1994) 43.01.

was created[35] and after the establishment of the Irish Hospice Foundation.[36] The Irish Association of Palliative Care was established in the time between the third and fourth edition, yet no change was made to the Guide to Ethical Conduct and Behaviour. As such, there was a clear cultural and professional shift in Ireland at this time in relation to palliative care which was not reflected in the professional standards developed by the IMC. The next substantial event in the development of end-of-life care in Ireland was the case of *Re a Ward of Court*.[37]

The IMC issued a statement after *Re a Ward of Court*. In this statement it was set out that:

> It is the view of the Council that access to nutrition and hydration is one of the basic needs of human beings. This remains so even when, from time to time, this need can only be fulfilled by means of long established methods such as naso gastric and gastrostomy tube feeding.[38]

This statement reaffirmed the Guide to Ethical Conduct and Behaviour and to Fitness to Practise in place at the time and cited the Principles of Medical Ethics in Europe[39] in support of their position.

Based on this statement it appears that the IMC categorised artificial nutrition and hydration as medical care rather than medical treatment. For example, the IMC statement considered nutrition and hydration to be 'one of the basic needs of human beings.'[40] This categorisation would have restricted the approach the courts have taken on this issue based on the difficulty of justifying the withdrawal of care rather than

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[35] Text to n23 in Chapter Two.
[36] Text to n24 in Chapter Two.
[37] *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.
[38] Medical Council Statement, 'Statements of the Medical Council and An Bord Altranais on the Ward case' (1995) 1(2) Medico- Legal Journal of Ireland 60.
[39] ibid Appendix J (Principles of Medical Ethics in Europe) of 'Guide to Ethical Conduct and Behaviour and to Fitness to Practise'. Article 2 'In the course of his professional practice a doctor undertakes to give priority to the medical interest of the patient. The doctor may use his professional knowledge only to improve or maintain the health of those who place their trust in him; in no circumstances may he act to their detriment'.
Article 4 …. The doctor must not substitute his own definition of the quality of life for that of his patient.
[40] ibid.

treatment.[41] The IMC also set out that 'The Council sees no need to alter its Ethical Guide.'[42] No changes were made at the time of this statement but the next edition of the Guide to Ethical Conduct and Behaviour was updated in certain respects. Changes in the fifth edition of the Guide to Ethical Conduct and Behaviour demonstrate the evolving legal framework for palliative care in Ireland.[43]

The fifth edition of the Guide to Ethical Conduct and Behaviour made a number of changes to the guidance on end-of-life care.[44] For instance, the heading titled 'euthanasia' was replaced with the term 'the dying patient'.[45] This move away from the term 'euthanasia' to the more ethically neutral phrase 'the dying patient' suggested a shift in the attitude of the IMC towards palliative care. It signalled a more open approach to caring for the patient at this point in their life. A number of small changes were also made to the text of this guidance. The revised section set out that:

> Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible. Deliberately causing the death of a patient is professional misconduct.[46]

Changes introduced by this edition of the Guide include the use of the term 'sick person' instead of 'patient', reference to the comfort of the individual, and the term 'euthanasia' is completely removed from this section. This edition of the Guide also refers to the dignity of a person without clarifying what this means or requires from the doctor. The cumulative effect of these changes was to signal a more open attitude to end-of-life care on the part of the IMC but there was little detail on how the human rights of a patient were to be protected in practice.

The guidance of the IMC developed further when the sixth edition of the Guide to Ethical Conduct and Behaviour was published in 2004. This was the first IMC Guide

[41] See pp97-104.
[42] Medical Council Statement (n38).
[43] Madden (n16) 74 The Guide was published in 1998 which was in line with the timing between previous editions.
[44] Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour' (5th edn, Dublin 1998) 38. The contents of the guide were expanded from the previous edition with more headings and more detail.
[45] ibid.
[46] ibid.

to Ethical Conduct and Behaviour to refer directly to the treatment provided to the person near the end of life. In this regard, the sixth edition of the Guide to Ethical Conduct and Behaviour added the guidance that when death is imminent 'a doctor is not obliged to initiate or maintain a treatment which is futile or disproportionately burdensome.'[47] The IMC did not expand on when treatment could be considered 'futile'[48] or what was to be considered 'disproportionately burdensome'.[49] This clearly requires the doctor to make the decision based on 'their judgment, experience, knowledge and skills in each situation.'[50] This provides a wide ranging autonomy to doctors but an appropriate regulatory framework requires more than this. Such a framework must provide sufficient structure and clarity to ensure a consistent standard of healthcare across providers of palliative care and thereby consistently protect the right to life, right to bodily integrity, right of autonomy, and protect the patient from inhuman or degrading treatment. These are all relevant concerns for examining the seventh edition of the Guide to Professional Conduct and Ethics.

Seventh Edition of the Guide to Professional Conduct and Ethics

The IMC Guide to Professional Conduct and Ethics is currently in its seventh edition and this provides the most detailed guidance on end-of-life care of any IMC Guide to date. Consequently, while the discussion of previous IMC Guides was narrow in focus, it is necessary to consider the seventh edition of the Guide to Professional Conduct and Ethics in a more holistic manner. Sections addressing the dignity of the patient,[51] nutrition and hydration,[52] end-of-life care,[53] consent to medical treatment,[54] and advance healthcare planning[55] will be examined. It is to be questioned whether the current Guide to Professional Conduct and Ethics adequately specifies the four principles along with protecting the human rights of the patient. In this context, the first aspect of the Guide to Professional Conduct and Ethics to be considered is Section 22 on 'End of life care'[56]

[47] Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour' (6th edn, Dublin 2004) 34.
[48] ibid.
[49] ibid.
[50] Madden (n16) 74.
[51] Irish Medical Council (n15) 14.
[52] ibid 20.
[53] ibid 22.
[54] ibid 33.
[55] ibid 39.
[56] ibid 22.

End-of-Life Care

Section 22 of the Guide to Professional Conduct and Ethics sets out guidance on end-of-life care over the course of several sub-sections. The guidance contained in these sub-sections is a considerable expansion from previous editions of the Guide and reflects the established role of palliative care in Ireland.

Section 22.1 of the Guide underlines the importance of ensuring that the patient 'dies with dignity, in comfort and with as little suffering as possible.'[57] The principle of dignity has been a constant through all editions of the Guide to Professional Conduct and Ethics. However, reference to this principle is not linked to any treaty or convention nor is it explicitly grounded in any particular theoretical framework. This approach to dignity results in each medical practitioner relying on a subjective understanding of dignity to guide their approach to the care of the patient. This undermines consistency in specialist palliative care across healthcare providers and does not provide clarity for the patient in terms of the type of care they are likely to receive.

Section 22.1 is not the only section in the Guide to Professional Conduct and Ethics which addresses the dignity of the patient. Section 5 of the Guide to Professional Conduct and Ethics sets out that 'All patients must always be treated with respect for their dignity.'[58] Unfortunately, the concept of dignity is not defined by Section 5 either. Dignity clearly occupies a central role in the Guide to Professional Conduct and Ethics but the lack of a clear meaning is problematic. This reflects the challenges raised by dignity which were highlighted in Chapter Four[59] and suggests the existence of a fragmented legal framework for specialist palliative care in Ireland as it is necessary to look beyond the Guide to Professional Conduct and Ethics to understand what dignity may mean.[60]

Section 22.2 of the Guide to Professional Conduct and Ethics addresses the provision and withdrawal of treatment. This section sets out that:

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[57] ibid.

[58] ibid 14 The remainder of this section concentrates on respecting the dignity of patients with disabilities.

[59] Text to n341 in Chapter Four.

[60] Text to n346 in Chapter Four.

> There is no obligation on you to start or continue a treatment, or artificial nutrition and hydration, that is futile or disproportionately burdensome, even if such treatment may prolong life. You should carefully consider when to start and when to stop attempts to prolong life, while ensuring that patients receive appropriate pain management and relief from distress.[61]

The use of the term 'prolong' rather than a term such as 'sustain' underlines the element of futility which is to be present in making the decision to withdraw artificial nutrition and hydration.[62] As McGlade et al. wrote, 'Advances in medical technology make it possible to prolong life in terminally ill patients, possibly not extending life, but prolonging the dying process.'[63] Identifying when further treatment is futile is a complex decision which medical practitioners regularly have to take and is loaded with a range of broader concerns. These concerns include the wishes of the patient if they are known and the importance of identifying what constitutes an appropriate time for the withdrawal of artificial nutrition and hydration. These are issues which need to be addressed by professional standards in order to ensure that treatment decisions are made in a clear and consistent fashion across providers of palliative care. On this point, Section 19 of the Guide to Professional Conduct and Ethics does serve to highlight some of the issues which medical practitioners should take account of when making treatment decisions around the nutrition and hydration of a patient.

In Section 19 it is set out that, 'If a patient is unable to take sufficient nutrition and hydration orally, you should assess what alternative forms are possible and appropriate in the circumstances.'[64] As such, this Section focuses on the factors to be considered in deciding on whether artificial nutrition and hydration should be commenced. In deciding what treatment option to pursue the medical practitioner is to consider 'the

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[61] Irish Medical Council (n15) 22.
[62] Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 169 'Physicians have no obligation to provide pointless, futile, or contraindicated treatment.' Although it is recognised that '[p]alliative interventions may still be continued.'; Beauchamp (n62) 170 'Our conclusion is that a genuinely futile medical intervention – one that has no chance of being efficacious in relation to accepted goals – is morally optional and in many cases ought not be introduced or continued.'; *Airedale N.H.S. v Bland* [1993] AC 789, 837; *Ward of Court (withholding medical treatment) (No 2), Re,* [1996] 2 IR 79.
[63] Ciara McGlade, William Molloy and Suzanne Timmons, 'Decision-Making in Incompetent Older Adults: Clinical, Social and Legal Issues' (2011) 2 Medico-Legal Journal of Ireland 70, 74.
[64] Irish Medical Council (n15) 20.

burden or risks to the patient, the patient's wishes if known, and the overall benefit to be achieved.'[65] These considerations engage the patient's right of autonomy, as well as the right to bodily integrity, and protection from inhuman or degrading treatment. The factors the medical practitioner is to bear in mind will be drawn out in greater detail later in this Chapter when examining the decision-making framework and the protection of the patient's right of autonomy in the Guide to Professional Conduct and Ethics.[66]

The last line of Section 22.2 of the Guide to Professional Conduct and Ethics requires the medical practitioner to identify what constitutes 'appropriate pain management'.[67] This type of decision requires a substantial balancing of principles such as nonmaleficence and beneficence. Therefore, there is a need for these principles to be appropriately specified for the medical practitioner. Chapters Two and Three highlighted the importance of having a clear framework for decisions around pain management especially due to suggestions that palliative sedation closely resembles euthanasia.[68] This Section does little to strengthen the distinction between these practices and allows the medical practitioner a substantial degree of autonomy in making decisions on appropriate pain management. Nevertheless, there are other sections in the Guide to Professional Conduct and Ethics which might provide clarity on these decisions and these will be outlined in due course.

Protection of the Right of Autonomy

Chapter Four demonstrated the significant role which the right of autonomy has in specialist palliative care. The right of autonomy impacts on decisions to withdraw treatment or to request that a particular course of treatment be followed. The protection of this right emphasises the subjective nature of pain and that the terminally ill patient should be given the opportunity to be actively involved in making decisions which impact on their healthcare. It is positive that Section 22.3 of the Guide to Professional

[65] ibid.
[66] See p179.
[67] Irish Medical Council (n15) 22.
[68] J Andrew Billings and Susan D Block, 'Slow euthanasia' (1996) 12 Journal of Palliative Care 21; B Mount, 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts' (1996) 12 Journal of Palliative Care 31; H Brody, 'Commentary on Billings and Blocks "Slow Euthanasia"' (1996) 12 Journal of Palliative Care 38; James Gilbert, 'Palliative medicine: a new specialty changes an old debate' (1996) 52(2) British Medical Bulletin 296, 297; J Kenyon Mason and Graeme T Laurie, *Mason & McCall Smith's Law & Medical Ethics* (9th edn, Oxford University Press 2013) 615.

Conduct and Ethics addresses a patient's right of autonomy in relation to treatment decisions. This Section sets out that 'You should respect the right of patients to refuse medical treatment or to request the withdrawal of medical treatment.'[69] The refusal of treatment is also addressed by Section 40.1 of the Guide to Professional Conduct and Ethics which sets out that:

> Every adult with capacity is entitled to refuse medical treatment. You must respect a patient's decision to refuse treatment, even if you disagree with that decision. In these circumstances, you should clearly explain to the patient the possible consequences of refusing treatment and offer the patient the opportunity to receive a second medical opinion if possible.[70]

Section 40.1 demonstrates that there are a number of points to be addressed in order to protect and vindicate the right of autonomy. For instance, it is important that issues of capacity and communication be addressed appropriately both by the medical practitioner in practice and in the Guide to Professional Conduct and Ethics. If the right of autonomy is not to be illusory then it is necessary that requirements for its protection and vindication in practice are clearly set out.

Section 22.4 of the Guide to Professional Conduct and Ethics outlines issues relating to communication with the patient and their families. Communication is vital for ensuring the patient is able to make informed decisions in relation to their healthcare. The Guide to Professional Conduct and Ethics requires medical practitioners to:

> take care to communicate effectively and sensitively with patients and their families so that they have a clear understanding of what can and cannot be achieved. You should offer advice on other treatment or palliative care options that may be available to them.[71]

This is a positive step in promoting effective palliative care and delivering on the right of autonomy. In communicating 'effectively and sensitively with patients'[72] the medical practitioner is also ensuring that the patient is sufficiently informed to make

[69] Irish Medical Council (n15) 22; See also *Herczegfalvy v Austria* (1992) 15 EHRR 437.
[70] Irish Medical Council (n15) 38-39.
[71] ibid 22.
[72] ibid.

decisions about their healthcare. In this regard, greater detail on respecting the right of autonomy and healthcare decision-making in general is set out in Section D of the Guide to Professional Conduct and Ethics which is titled 'Consent to Medical Treatment'.[73]

Section 33 of the Guide to Professional Conduct and Ethics addresses the general principles of Section D. The general principles set out by Section 33 emphasise the importance of obtaining informed consent prior to medical treatment being carried out and it underlines the importance of the patient's right of autonomy.[74] For instance, 'The ethical and legal rationale behind this is to respect the patient's autonomy and their right to control their own life.'[75] In order for a patient to exercise their capacity, the medical practitioner is to ensure that they have been given appropriate information,[76] along with 'appropriate help and support'.[77] In circumstances where a patient does not have capacity the patient is 'still entitled to the same respect for their human dignity and personal integrity as any person with full capacity.'[78] The Guide to Professional Conduct and Ethics also adopts a functional approach to the assessment of a person's capacity.[79] If a patient does not have sufficient capacity to make a particular decision this does not mean that they are not capable of making other decisions or will not be capable of making this type of decision in the future.[80]

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[73] ibid 33.
[74] ibid 34; Beauchamp (n62) 124 Informed consent as a vital element in respecting the principle of autonomy.
[75] Irish Medical Council (n15) 34.
[76] ibid 'Every adult patient is presumed to have the capacity to make decisions about their own healthcare. As their doctor, you have a duty to help your patients to make decisions for themselves by giving them information in a clear and comprehensible manner and by ensuring that they have appropriate help and support. The patient is also entitled to be accompanied during any such discussion by an advocate of their own choice.'
[77] ibid; Assisted Decision-Making (Capacity) Bill 2013, s 8(3) 'A relevant person who falls within *paragraph (a)* of the definition of "relevant person" in *section* 2(1) shall not be considered as unable to make a decision in respect of the matter concerned unless all practicable steps have been taken, without success, to help him or her to do so.'
[78] Irish Medical Council (n15) 34; Assisted Decision-Making (Capacity) Bill 2013, s 8(6)(b) 'have due regard to the need to respect the right of the relevant person to his or her dignity, bodily integrity, privacy and autonomy.'
[79] Irish Medical Council (n15) 34-35 'A functional approach should be taken when assessing an individual's capacity. This approach assesses the individual's ability to make the relevant choice depending on: their level of understanding and retention on the information they have been given, and their ability to apply the information to their own personal circumstances and come to a decision.'; *Fitzpatrick and Another v K and Another* [2008] IEHC 104; Assisted Decision-Making (Capacity) Bill 2013, s 3.
[80] ibid 35.

It was set out in Chapter Four that the *Assisted Decision-Making Capacity Bill 2013* provides for assisted decision making and co-decision makers where the capacity of the patient was in doubt. Despite the seventh edition of the Guide to Professional Conduct and Ethics pre-dating this Bill, it suggests that other people may have the 'legal authority to make decisions on the patient's behalf.'[81] However, in circumstances where a medical practitioner is to make a decision on behalf of a patient who lacks capacity they are to consider factors such as:

> which treatment option would provide the best clinical benefit for the patient,
> the patient's past and present wishes if they are known,
> whether the patient's capacity is likely to increase,
> the views of other people close to the patient who may be familiar with the patient's preferences, beliefs and values, and
> the views of other health professionals involved in the patient's care.[82]

This is a broad range of factors to consider but in terms of accuracy it cannot match the direct reliance on patient autonomy; a significant aspect of which is informed consent.

The importance of informed consent is recognised in Section 35 of the Guide to Professional Conduct and Ethics.[83] As part of this, informed consent requires the medical practitioner to 'explain the process in such a way as to ensure that patients do not feel that their consent is simply a formality or a signature on a page.'[84] This requires the medical practitioner to provide the patient with 'sufficient information, in a way that they can understand'.[85] The Guide to Professional Conduct and Ethics goes into considerable detail in relation to ensuring the patient is given the information necessary to exercise their right of autonomy. For instance, the Guide to Professional

[81] ibid.
[82] ibid 35-36.
[83] ibid 36.
[84] ibid; Beauchamp (n62) 122 The first meaning of informed consent is that it is 'an individual's autonomous authorization of a medical intervention or of participation in research. In this first sense, a person must do more than express agreement or comply with a proposal.'
[85] Irish Medical Council (n15) 36 'As part of the informed consent process, patients must receive sufficient information, in a way that they can understand to enable them to exercise their right to make informed decisions about their care. This refers to the disclosure of all significant risks or substantial risks of grave adverse consequences.'

Conduct and Ethics sets out that 'the medical practitioner is to 'take appropriate steps to find out what patients want to know about their condition and what they ought to know about their condition, its investigation and treatment.'[86] This demonstrates that the level of information to be provided may fluctuate based on a number of factors which the Guide to Professional Conduct and Ethics also outlines.[87] In addition to this, the medical practitioner is required to take account of a patient's individual needs and priorities as well as the 'patients' beliefs, culture, occupation or other factors'[88] which may impact on the 'information they need to reach a decision.'[89] The medical practitioner is also required to answer questions raised by the patient in an open manner.[90]

Due to the nature of informed consent, these are ongoing issues for the medical practitioner in the care of the patient.[91] Furthermore, in seeking the consent of the patient it is necessary that the information be communicated in adequate time, e.g. 'Where possible, you should explain risks well in advance of an intervention.'[92] Moreover, the effect of sedation on the patient is recognised and it is suggested that the medical practitioner should not 'seek consent when a patient may be stressed, sedated or in pain and therefore less likely to make a calm and reasoned decision.'[93] On this basis, it should be recognised that in specialist palliative care the discussions need to take place at an appropriate time based on the patient's disease trajectory. For example, it could be argued that decisions about artificial nutrition and hydration need

[86] ibid.
[87] ibid 36-37 'The amount of information given to individual patients will vary according to factors such as the nature of the condition, the mode of investigation, the complexity of the treatment, the risks associated with the treatment or procedure and the patient's own wishes. For example, patients may need more information to make an informed decision about a procedure that carries a high risk of failure or adverse side effects or about an investigation for a condition that, if found to be present, could have serious consequences for the patient's employment, social or personal life. See also Appendix A.'
[88] ibid 37.
[89] ibid 'You should ask your patient whether they have understood the information they have received and if they would like more information before making a decision.'
[90] ibid 'You must answer any questions the patient raises as fully as the patient wishes. You must not withhold from a patient any information necessary for decision making unless disclosure would cause the patient serious harm. In this context 'serious harm' does not mean the patient would become upset or decide to refuse treatment.'
[91] ibid 'Obtaining informed consent cannot be an isolated event. It involves a continuing process of keeping patients up to date with any changes in their condition and the treatments or investigation proposed. Whenever possible, you should discuss treatment options at a time when the patient is best able to understand and retain the information.'
[92] ibid.
[93] ibid.

to be made prior to decisions about sedation so that the patient has the opportunity to be fully involved in the decision-making process.[94] Moreover, as these standards are applicable to all medical practitioners it is suggested that a more structured approach may need to be set out in order to give full effect to these standards in a palliative care setting. The sections discussed so far are supported by Appendix A of the Guide to Professional Conduct and Ethics.

Appendix A addresses the 'Information for patients prior to giving consent'.[95] Information to be given prior to consent and which is particularly relevant to specialist palliative care includes: 'details of the diagnosis, and prognosis, and the likely prognosis if the condition is left untreated',[96] 'options for treatment or management of the condition, including the option not to treat',[97] 'details of the procedures or therapies involved, including methods of pain relief',[98] 'information about how and when the patient's condition and any side effects will be monitored or re-assessed',[99] and 'a reminder that patients have a right to seek a second opinion'.[100] Unfortunately, the approach to decision-making and the factors to be considered are spread out across the Guide to Professional Conduct and Ethics. This makes it more difficult to ensure that care is provided in a consistent manner. Despite this, it has been shown that the decision-making framework in the Guide to Professional Conduct and Ethics is relatively detailed and is supportive of patient autonomy.

Overall, it is necessary that medical professionals have a clear understanding of the care to be provided and the standards they are to meet. The current IMC Guide to Professional Conduct and Ethics demonstrates a clear normative shift in the guidelines. In this regard, there is more detail in this Guide on standards relevant to specialist palliative care but certain weaknesses persist. This reflects the fact that there are limits in terms of what can be achieved by the Guide to Professional Conduct and Ethics as it does not contain comprehensive guidelines but establishes principles

[94] Text to n119 in Chapter Six; *Tysiąc v Poland* (2007) 45 EHRR 42 The decision-making framework needs to be 'timely', 'fair' and should not be framed in such a way as to limit its application.
[95] Irish Medical Council (n15) 59.
[96] ibid 60.
[97] ibid.
[98] ibid.
[99] ibid 61.
[100] ibid.

which are to be drawn on by doctors. Despite this, the manner in which the Guide has developed demonstrates a move towards establishing more detailed guidance for the medical profession in Ireland. It may be necessary that separate guidelines be developed by the IMC which address the area of specialist palliative care in detail. This approach would still come within the role of the IMC as set out by the *Medical Practitioners Act 2007*.[101] The decision-making framework set out in the Guide to Professional Conduct and Ethics in terms of supporting the right of autonomy is strong however there is no assistance in recognising when treatment is futile, when appropriate pain management is needed, or what conversations around palliative care should entail. In other respects, the Guide to Professional Conduct and Ethics demonstrates the potential of professional standards. For example, it does not have the rigidity of legislation and can be updated easily to reflect advances in medical knowledge. The Guide to Professional Conduct and Ethics has clear strengths in protecting the human rights of a patient but in the specific context of specialist palliative care it is evident that there are issues of clarity and consistency which need to be addressed. In order to draw out these points fully it is necessary to also examine the manner in which the Guide to Professional Conduct and Ethics is enforced. This provides a view of the IMC Guide in practice and demonstrates the concerns relevant to the enforcement of the Guide to Professional Conduct and Ethics.

Enforcement of the Guide to Professional Conduct and Ethics

Medical practitioners who fail to comply with the Guide to Professional Conduct and Ethics may be the subject of a complaint. This is provided for by section 57 of the *Medical Practitioners Act 2007*.[102] Complaints relating to treatment and care provided

[101] Medical Practitioners Act 2007, s 6 'to protect the public by promoting and better ensuring high standards of professional conduct and professional education, training and competence among registered medical practitioners.'

[102] Medical Practitioners Act 2007, s 57(1) A person (including the Council) may make a complaint to the Preliminary Proceedings Committee concerning a registered medical practitioner on one or more than one of the grounds of—
(a) professional misconduct,
(b) poor professional performance,
(c) a relevant medical disability,
(d) a failure to comply with a relevant condition,
(e) a failure to comply with an undertaking or to take any action specified in a consent given in response to a request under section 67(1),
(f) a contravention of a provision of this Act (including a provision of any regulations or rules made under this Act), or

during specialist palliative care are most likely to come within section 57(1)(a) and (b) of the *Medical Practitioners Act 2007* which relate to professional misconduct and poor professional performance.

The Preliminary Proceedings Committee is the first stage in the investigation of a complaint and is to make a decision on the appropriate action to be taken. In cases where the Preliminary Proceedings Committee are of the opinion that further action is required then the complaint may be referred to a Fitness to Practise Committee. On this point, it is necessary to consider how the grounds of professional misconduct and poor professional performance are interpreted.

Professional Misconduct

Professional misconduct is defined in the Guide to Professional Conduct and Ethics as:

> Conduct which doctors of experience, competence and good repute consider disgraceful or dishonourable; and/or Conduct connected with his or her profession in which the doctor concerned has seriously fallen short by omission or commission of the standards of conduct expected among doctors.[103]

This demonstrates that professional misconduct may occur by way of an act or omission of the doctor. Greater guidance on the interpretation of professional misconduct can be found in the case of *O'Laoire v The Medical Council*[104] which was taken under the *Medical Practitioners Act 1978*.

In *O'Laoire v The Medical Council*, the court described indicators of professional misconduct as;

> (a) Conduct which is 'infamous' or 'disgraceful' in a professional respect is professional misconduct;

(g) a conviction in the State for an offence triable on indictment or a conviction outside the State for an offence consisting of acts or omissions that, if done or made in the State, would constitute an offence triable on indictment.

[103] Irish Medical Council (n15) 11.

[104] *O'Laoire v The Medical Council* (High Court, 27 January 1995).

(b) Conduct which would not be 'infamous' or 'disgraceful' in any other person, if done by a medical practitioner in relation to his/her profession, may be considered as 'infamous' or 'disgraceful' in a professional respect;
(c) 'Infamous' or 'disgraceful' conduct is conduct involving some degree of moral turpitude, fraud or dishonesty;
(d) The fact that a person wrongly but honestly forms a particular opinion cannot of itself amount to infamous or disgraceful conduct in a professional sense; and
(e) Conduct which could not be properly characterised as 'infamous' or disgraceful' and which does not involve any degree of moral turpitude, fraud or dishonesty may still constitute professional misconduct, if it is conduct connected with the profession in which the medical practitioner concerned has seriously fallen short, by omission or commission, of the standards of conduct expected amongst medical practitioners.[105]

According to Keane J, these tests are to be read in conjunction with the definition of professional misconduct as contained in the IMC Guide. Tests one to four are known as the 'moral turpitude test', while the fifth test is referred to as 'the expected standards test.'[106] These tests have been followed in a number of cases such as *An Bord Altranais v O'Ceallaigh*;[107] *Millett-Johnson v Medical Council*;[108] and *Cahill v Dental Council*.[109] The case of *O'Laoire v The Medical Council* also set the standard of proof as the criminal standard. In effect, it is to be proved beyond reasonable doubt that there was professional misconduct.

Poor Professional Performance

Poor professional performance is defined by the Guide to Professional Conduct and Ethics as:

[105] *O'Laoire v The Medical Council* (High Court, 27 January 1995) quoted in Madden (n16) 61-62; *McCandless v General Medical Council* (1995) 30 BMLR 53, [1995] 1 WLR 169 It was held that the words serious professional misconduct are intended to have the same meaning as 'infamous conduct in a professional respect'. The extension of potential penalties such as suspension and the imposition of conditions suggested that the term is intended to cover serious instances of negligence.
[106] Madden (n16) 62.
[107] *An Bord Altranais v O'Ceallaigh* [2000] IR 412, [2011] IESC 50.
[108] *Millett-Johnson v Medical Council* (High Court, 12 January 2001).
[109] *Cahill v Dental Council* [2001] IEHC 97.

> a failure by the practitioner to meet the standards of competence (whether in knowledge and skill or the application of knowledge and skill or both) that can reasonably be expected of medical practitioners practising medicine of the kind practised by the practitioner.[110]

This includes 'poor communication' on the part of the medical practitioner.[111] The definition of poor professional performance suggests that standards of competence in specialist palliative care are to be compared against the standards of other specialist palliative care providers.[112] This is a difficult level to identify due to the lack of comprehensive guidelines. The term 'poor professional performance' involves distinct considerations from those which apply to misconduct allegations. This distinction may be based on a medical practitioner falling short of the skills and knowledge expected among medical practitioners.[113] Although such a failing must be significant for poor professional performance it would not amount to a severe falling short.

Section 77 of the *Medical Practitioners Act 2007* provides further guidance for the courts in determining professional misconduct as well as poor professional performance as it allows the court to 'admit and have regard to the evidence of any person of good standing in the medical profession as to what constitutes professional misconduct or poor professional performance in relation to the practice of that profession.'[114] However, this is only of relevance if the doctor is sanctioned. The imposition of sanctions by the Medical Council depends on the report of the Fitness to Practice Committee. The sanctions are set out by section 71 of the *Medical Practitioners Act* 2007 and may include;

> (a) an advice or admonishment, or a censure, in writing;
> (b) a censure in writing and a fine not exceeding €5,000;

[110] Irish Medical Council (n15) 11.
[111] ibid.
[112] Shipman Inquiry, 'The Shipman Inquiry – Fifth Report' (The Stationery Office 2004) [24.10] Competence describes the knowledge and skills of the doctor. Performance sets out what the doctor does in practice.
[113] Irish Medical Council (n15) 11.
[114] Medical Practitioners Act 2007, s 77(1).

(c) the attachment of conditions to the practitioner's registration, including restrictions on the practice of medicine that may be engaged in by the practitioner;
(d) the transfer of the practitioner's registration to another division of the register;
(e) the suspension of the practitioner's registration for a specified period;
(f) the cancellation of the practitioner's registration;
(g) a prohibition from applying for a specified period for the restoration of the practitioner's registration.[115]

As such, being the subject of a sanction can have serious consequences for the medical practitioner. In 2010 there were 160 complaints against doctors practising in the general division, 212 complaints against doctors practising in the specialist division, and 12 practising in the trainee specialist division.[116] Medical practitioners in the specialist division are clearly at a higher risk of complaint than their colleagues in the general division. This underlines the importance for both the medical practitioner and the patient of ensuring that appropriate standards and guidance are in place for specialist palliative care. The focus so far has been on the role of the medical practitioner but as Chapter Two highlighted, a range of professions are involved in the provision of specialist palliative care. On this basis, it is essential to also consider the guidance issued by An Bord Altranais as it is vital that nurses also have clear professional standards within which to work.

The Role of An Bord Altranais

An Bord Altranais was established by the *Nurses Act 1950*.[117] It is the regulatory body of the nursing profession in Ireland and is currently governed by the *Nurses and Midwives Act 2011*.[118] The purpose of An Bord Altranais is the 'promotion of high standards of professional education, training and practice and professional conduct among nurses'.[119] In line with this, An Bord Altranais has published 'The Code of

[115] Medical Practitioners Act 2007, s 71.
[116] Irish Medical Council, 'Statistics 2010' <http://www.medicalcouncil.ie/News-and-Publications/Publications/Annual-Reports-Statistics-/Statistics/Statistics-2010/Statistics-2010.html> accessed 24 June 2014.
[117] Nurses Act 1950.
[118] Nurses Act 1985.
[119] Nurses and Midwives Act 2011, s 8.

Professional Conduct for each Nurse and Midwife'[120] [hereinafter 'Code of Professional Conduct']. In addition to this, An Bord Altranais have published a revised draft of the Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives,[121] guidelines for nurse prescribers,[122] and guidance for nurses working with older people.[123] These will be addressed in turn over the course of this section.

The Code of Professional Conduct for each Nurse and Midwife

The function of the Code of Professional Conduct is to support the nurse in making 'professional decisions, to carry out his/her responsibilities and to promote high standards of professional conduct.'[124] The Code of Professional Conduct makes no clear reference to specialist palliative care but does mention end-of-life care. In this regard, the Code of Professional Conduct sets out that:

> The nurse must at all times maintain the principle that ever [sic] effort should be made to preserve human life, both born and unborn. When death is imminent, care should be taken to ensure that the patient dies with dignity.[125]

Dignity is again a guiding concept in the care of the patient but no detail is provided on how it is to be interpreted. This is a failing which overlaps with the current IMC Guide to Professional Conduct and Ethics.[126]

The Code of Professional Conduct does not provide guidance on communication or specialist palliative care practices such as the provision of palliative sedation or the withdrawal of artificial nutrition and hydration. In effect, the Code of Professional Conduct is vague in how best to care for the terminally ill patient. However, the statement issued by An Bord Altranais after the case of *Re a Ward of Court* provides

[120] An Bord Altranais, 'The Code of Professional Conduct for each Nurse and Midwife' April 2000.
[121] Nursing and Midwifery Board of Ireland, 'Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives' (October 2013).
[122] An Bord Altranais, 'Collaborative practice agreement for nurses and midwives with prescriptive authority' (2nd edn, December 2007); An Bord Altranais, 'Practice Standards for Nurses and Midwives with Prescriptive Authority' *(*September 2010).
[123] An Bord Altranais, 'Professional Guidance for Nurses Working with Older People' (April 2009).
[124] An Bord Altranais (n120) 4.
[125] ibid 8.
[126] Text to n57.

insight into their attitude towards the withdrawal of artificial nutrition and hydration. This is supported by the point that the An Bord Altranais Code of Professional Conduct at the time of *Re a Ward of Court* contained the same guidance on end-of-life care as the current Code of Professional Conduct. The An Bord Altranais statement set out that:

> so long as there remains a means of nutrition and hydration of this patient it is the duty of the nurse to act in accordance with the Code and to provide nutrition and hydration. In this specific case, a nurse may not participate in the withdrawal and termination of the means of nutrition and hydration by tube. In the event of the withdrawal and termination of the means of nutrition and hydration by tube the nurse's role will be to provide all nursing care.[127]

It is not clear from the An Bord Altranais statement whether it is the patient's lack of capacity or some other factor which resulted in An Bord Altranais expressing reservations about the outcome of this case. Nonetheless, An Bord Altranais made their position clear in this statement when they commented that they saw 'no reason to change the code following consideration of this judgment.'[128] Despite this, the withdrawal of artificial nutrition and hydration continues to occur in this jurisdiction. This places nurses in a difficult legal position due to the lack of clarity from An Bord Altranais on the circumstances, if any, for when artificial nutrition and hydration can be withdrawn from the patient. Furthermore, the lack of clarity makes developing a harmonious understanding of specialist palliative care practices among healthcare professionals even more challenging and hampers consistency in the provision of specialist palliative care. It was only in October 2013 that An Bord Altranais published a new draft Code of Professional Conduct. The contents of this Code will be compared with the current Code of Professional Conduct for how it protects human rights and the guidance it provides for nurses engaged in the provision of specialist palliative care in Ireland.

[127] An Bord Altranais Statement, 'Statements of the Medical Council and An Bord Altranais on the Ward case' (1995) 1(2) Medico- Legal Journal of Ireland 60, 60.
[128] ibid.

Draft Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives

The draft Code recognises that nurses draw on more than the Code of Professional Conduct in practise. For example, the draft Code sets out that 'Professional accountability, competency and the quality of professional practice are based on this structure in tandem with other supporting guidance and standards frameworks.'[129] The Code 'supports ethical and clinical decision-making, on-going reflection and professional self-development',[130] 'informs the general public about the professional care they can expect from nurses and midwives',[131] and 'sets standards for the regulation, monitoring and enforcement of professional conduct.'[132] These points are important to address for specialist palliative care and they also reflect the fact that a code of professional conduct sets standards which patients expect will be met.

Underpinning the draft Code of Professional Conduct and Ethics are five principles, i.e. 'Respect for the dignity of the person',[133] 'Professional responsibility and accountability',[134] 'Trust and confidentiality',[135] 'Quality of practice',[136] and 'Collaboration with others'.[137] These principles serve to guide the interaction between the nursing profession, patients, and other healthcare professionals.[138] The draft Code of Professional Conduct and Ethics underlines how the Code is not only for the registered nurse but also the general public. For example, the draft Code of Professional Conduct and Ethics sets out that, 'The standards of conduct and professional practice follow from the ethical values and show the attitudes and behaviours that members of the public have the right to expect from nurses and midwives.'[139] This demonstrates that professional standards not only clarify practice for the healthcare professional but also serve to better inform the patient as to the standard of care and manner in which treatment decisions are to be made. Of the

[129] Nursing and Midwifery Board of Ireland (n121) 4.
[130] ibid 5.
[131] ibid.
[132] ibid.
[133] ibid 6.
[134] ibid.
[135] ibid.
[136] ibid.
[137] ibid.
[138] ibid 'guide the various relationships between nurses, midwives, service users and colleagues.'
[139] ibid.

principles which underpin the draft Code of Professional Conduct and Ethics it is the 'Respect for the dignity of the person' which is of most relevance to palliative care due to the values and standards of conduct it requires of the nurse.

Respect for the Dignity of the Person

The draft Code of Professional Conduct and Ethics sets out the basis for dignity in the Code. This is a welcome step which was not taken in the previous edition of the Code of Professional Conduct or in the IMC Guide to Professional Conduct and Ethics. The draft Code of Professional Conduct and Ethics sets out that the principle comes from the Universal Declaration of Human Rights. Furthermore, the European Convention on Human Rights, the Irish Constitution, and the Equal Status Acts[140] are drawn on as sources 'for the values and standards established for respecting the dignity of the person.'[141] This recognises that the care of the patient is underpinned by a broad range of human rights which impact on the manner in which care is to be provided to the patient. As such, the Code provides detail on values, standards of conduct, and supporting guidance in relation to respecting the dignity of the patient.

Values relating to dignity include the point that nurses are to respect every person 'as a unique individual',[142] and to 'respect and defend the dignity of every stage of human life'.[143] As part of this nurses are to 'respect each person's right to self-determination as a basic human right.'[144] In relation to self-determination, the draft Code sets out that:

> It is presumed that all adults have capacity to make health care decisions. In respecting the right of self-determination, informed consent is key. Where a person does not have capacity, nurses and midwives with others, consider the person's best interests when making health care decisions.[145]

[140] Equal Status Act 2000.
[141] Nursing and Midwifery Board of Ireland (n121) 7.
[142] ibid.
[143] ibid.
[144] ibid.
[145] ibid 7.

This is an area which is likely to change in certain respects given the *Assisted Decision Making (Capacity) Bill 2013*. Nonetheless, the detail contained in this draft Code is a substantial improvement over previous standards issued by An Bord Altranais.

The standards of conduct for respecting the dignity of the person also reflect the values set out in the draft Code of Professional Conduct and Ethics. The standards of conduct set out that 'In end-of-life care, you should support the person to die with dignity and comfort. You should seek to understand how the person views dignity and provide care that tries to meet their needs.'[146] There are two points which can be made in relation to this standard. First, it suggests that dignity is inherent in the individual and is not something to be provided to the patient but is instead something which is protected by the broader actions of the healthcare professional. For example, once the meaning of dignity is ascertained the nurse is to 'provide care that tries to meet their needs.'[147] The second point in relation to this standard is the challenge of its application in practice. The concept of dignity is not particularly easy to define[148] but the nurse is to 'seek to understand how the person views dignity'.[149] In the context of palliative care, this is not an easy step for either the nurse or a terminally ill patient. It would clearly involve the nurse drawing on past experience in order to understand the concept of dignity. However, a broader framework for the legal and ethical issues arising in specialist palliative care practices could provide the nurse with greater structure and clarity in practice.

Advance healthcare plans are also addressed as part of the standards of conduct in relation to dignity. For instance, 'You should respect an individual's advance care directive or plan, if known.'[150] The supporting guidance on dignity further concentrates on advance healthcare plans. The absence of a legal framework in this area at present is recognised in the draft Code of Professional Conduct and Ethics.[151] However, it sets out that 'guidance from health care regulators and others may help to

[146] ibid 8.
[147] ibid.
[148] Text to n334 in Chapter Four.
[149] Nursing and Midwifery Board of Ireland (n121) 8.
[150] ibid; Beauchamp (n62) 14 'An example of a rule that sharpens the requirements of the principle of respect for autonomy in certain contexts is "Follow an incompetent patient's advance directive whenever it is clear and relevant."'
[151] Nursing and Midwifery Board of Ireland (n121) 9; Draft General Scheme of Legislative Provisions to Provide for the Making of Advance Healthcare Directives, Head 4(2).

inform you about best practice regarding the ethical and professional issues associated with advance care directives or plans.'[152] Similar to the IMC, An Bord Altranais sets out that an advance healthcare plan should be respected provided 'the service user made an informed choice regarding their decisions',[153] 'the decision covers the situation that has occurred',[154] and 'there is no indication that the service user has changed their mind since the advanced care directive or plan was made.'[155] Protecting the right of autonomy through advance healthcare plans serves as another way in which the dignity of an individual can be respected. The autonomy of a patient is also directly referred to as part of the standards of conduct for dignity.

The nurse is required to 'protect and promote autonomy of service users',[156] as well as recognising the importance of a patient's consent.[157] The draft Code sets out that that the level of information and discussion in each case will fluctuate and depends on issues such as 'the complexity, nature and level of risk associated with the intervention.'[158] However, a basic level of information which should be provided is not set out in the draft Code. On this basis, a subjective approach will be required from the nurse in determining the information and the nature of the discussion with the patient to take place. Nonetheless, the draft Code of Professional Conduct and Ethics is a positive step in providing greater guidance for nurses practising in Ireland. The draft Code addresses a number of failings in the previous Code of Professional Conduct and demonstrates more engagement with the broader legal framework. In addition to the Code of Professional Conduct, it can be noted that An Bord Altranais publishes further guidelines for nurses which serve to provide greater detail in caring for certain areas of the patient population. For instance, aspects of the 'Professional Guidance for Nurses Working for Older People' are of relevance for the provision of specialist palliative care.

[152] ibid.
[153] ibid.
[154] ibid.
[155] ibid.
[156] ibid 8.
[157] ibid; ibid 9 'If a service user is not able to give informed consent for care, you must make sure that you act in the person's best interests. This includes: taking into account the person's previous directions and wishes, if known, discussing with family members or carers as appropriate, discussing with other members of the health care team.'
[158] ibid 10.

Professional Guidance for Nurses Working for Older People

The objectives of this guidance include providing 'professional guidance and direction for nurses caring for older people across all healthcare settings'[159] and providing 'a nursing framework for end of life care that embraces living and dying as part of the normal care structure and processes in all care settings'.[160] A significant motivating factor in the development of this guidance was the 'progressive increase in the older population, and the intensity of quality of care required to meet their complex needs'.[161] This point was set out in Chapter One as a main factor in the need to examine and identify an appropriate legal framework for specialist palliative care in this jurisdiction.[162]

The 'Professional Guidance for Nurses Working with Older People' sets out standards on 'person-centred holistic care',[163] 'therapeutic relationship',[164] 'care environment',[165] 'quality of care',[166] 'professional development',[167] and 'end-of-life care'.[168] The rationale for the standard on end-of-life care is that 'Older people may feel disempowered in their decision-making at this time. In order to protect their rights, it is important to be guided by, and work within, a legal framework.'[169] The importance of a clear legal framework for specialist palliative care is central to this thesis and has been recognised and highlighted by several stakeholders in patient care.[170] In this respect, it is positive that An Bord Altranais recognises the role and impact which an appropriate legal framework can have for both the healthcare professional and the patient.

[159] An Bord Altranais (n123) 4.
[160] ibid.
[161] ibid 3.
[162] Text to n46 in Chapter One.
[163] An Bord Altranais (n123) 10.
[164] ibid 11.
[165] ibid 12.
[166] ibid 14.
[167] ibid 15.
[168] ibid 13.
[169] ibid 13; Eamon O' Shea and others, 'End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland' (Hospice Friendly Hospitals Programme and National Council on Ageing and Older People 2008) 60.
[170] Norma O'Leary and Eoin Tiernan, 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers' (2008) Palliative Medicine 77; Kieran McKeown, Trutz Haase and Shelagh Twomey, 'Dying in Hospital in Ireland: Nurse and Doctor Perspectives, Report 2' (Irish Hospice Foundation 2010).

Standard 4 on end-of-life care requires that 'The older person receives comprehensive, compassionate end of life care that is person-centred and responds to the older person's unique needs and respect for his/her wishes.'[171] The guidance also acknowledges the expanded role of palliative care as well as its potential for use earlier in the disease trajectory. On this point, the guidance sets out that 'End of life care is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.'[172] This demonstrates a recognition of general palliative care, the palliative care approach, and specialist palliative care in the care of the older person. Despite this, the guidance refrains from addressing the complex issues of palliative sedation and the withdrawal of artificial nutrition and hydration. These are practices which remain without clearly defined professional standards for nurses and therefore lack an appropriate legal framework. This is especially significant due to changes in professional competencies. In particular, An Bord Altranais has recently established guidelines for nurses with prescriptive authority.

Nurses with Prescriptive Authority

It is a relatively recent development that certain nurses have taken on the responsibility of prescribing medication. The basis of a nurse's prescriptive authority is based on 'a dual framework of medicines legislation and professional regulation.'[173] The main legislation providing for nurses prescriptive authority is the *Irish Medicines Board (Miscellaneous Provisions) Act 2006,*[174] the *Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations 2007*[175] and the *Misuse of Drugs (Amendment) Regulations 2007*.[176] These set out requirements for the nurse to be able to prescribe and the conditions for prescribing. An Bord Altranais has also issued guidelines for nurse prescribers, namely the 'Practice Standards for Nurses and

[171] An Bord Altranais (n123) 13.
[172] ibid.
[173] An Bord Altranais, 'Practice Standards for Nurses and Midwives with Prescriptive Authority' (September 2010).
[174] Irish Medicines Board (Miscellaneous Provisions) Act 2006.
[175] Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations 2007, S.I. 201 of 2007.
[176] Misuse of Drugs (Amendment) Regulations 2007, S.I. 200 of 2007.

Midwives with Prescriptive Authority'[177] as well as the 'Collaborative Practice Agreement for Nurses and Midwives with Prescriptive Authority'.[178]

The 'Practice Standards for Nurses and Midwives with Prescriptive Authority' sets out standards which the nurse prescriber is to meet. These include standards on clinical decision-making, communication and history taking, documentation, continuing professional development and continued competency. The standards recognise that the nurse prescriber may prescribe drugs for end-of-life care but merely lists the types of drug suitable for palliative care and their route of administration.[179] There is no guidance addressing specialist palliative care practices such as appropriate levels of sedation or the practice of withdrawing artificial nutrition and hydration. The overall effect is that in the specialist palliative care setting the nurse prescriber has an increased role which is complicated by the lack of clear guidelines.

Overall, the current guidance issued by An Bord Altranais does not effectively address specialist palliative care practices. In addition to this, the human rights framework has not been adequately integrated into the current Code of Professional Conduct. The lack of detail in the Code of Professional Conduct and other guidelines published by An Bord Altranais may lead to inconsistency between nurses and doctors due to the subjective interpretation of these standards. Nevertheless, forthcoming guidance is beginning to demonstrate a shift in the way palliative care is addressed by the regulatory body for nurses in Ireland, and appears to acknowledge the importance of an appropriate legal framework to guide the nurse in their day-to-day activities. In any case, changes will need to be made to future professional standards and guidance in order to take account of measures being introduced by the *Assisted Decision Making (Capacity) Bill 2013*.

[177] An Bord Altranais (n173).
[178] An Bord Altranais, 'Collaborative practice agreement for nurses and midwives with prescriptive authority' (December 2007).
[179] An Bord Altranais (n173) 29.

Health Information and Quality Authority Standards

The Health Information and Quality Authority [hereinafter 'HIQA'] was established by the *Health Act 2007*.[180] HIQA is an independent body whose role is 'to promote quality and safety in the provision of health and personal social services for the benefit of the health and welfare of the public.'[181] The main way in which HIQA achieves this is through the development of standards of care which health care institutions are obliged to implement through local policies.[182] The standards of care are designed to: 'place patients at the heart of the care process',[183] 'be a benchmark for change for safety',[184] 'give patients a clear expectation of the standard of care they can expect to receive',[185] 'ensure services will be clear on what is expected of them',[186] and 'provide a strategic approach to improving safety, quality and reliability in our health service.'[187] HIQA monitors compliance with these standards and undertakes investigations of care providers when required. Consequently, HIQA does not actually draft guidelines but instead sets standards for the provision of care.

The standards established by HIQA are 'applicable to services provided by or on behalf of the Health Service Executive (HSE) as well as services provided by a nursing home.'[188] On this basis, hospices are not currently subject to HIQA standards or inspection. This is problematic given the legally sensitive nature of specialist palliative care. The position of HIQA on the inspection of hospices was made clear by the Minister for Health at the time, Mary Harney,[189] in a debate of the Select Committee

[180] Health Act 2007. The Health Act 2007 created a system for registering and inspecting residential care settings for the older person. This is also applicable to both private and public sector nursing homes; Department of Health and Children, 'Quality and Fairness – A Health System for You' (Department of Health and Children 2001); Jody Corcoran, 'Early death still "a major health issue"' *Irish Independent* (Dublin, 25 November 2001); Eithne Donnellan, 'Leas Cross findings "grave" – expert' *The Irish Times* (Dublin, 9 September 2006) 5; HIQA was originally proposed in 2001 by the National Health Strategy but was not established until the controversy in nursing home care, particularly the controversy surrounding Leas Cross nursing home.

[181] Health Information and Quality Authority, 'About us' <http://www.hiqa.ie/about-us> accessed 4 March 2014.

[182] Health Act 2007, s 8.

[183] Health Information and Quality Authority, 'Safer Better Healthcare' <http://www.hiqa.ie/standards/health/safer-better-healthcare> accessed 4 March 2014.

[184] ibid.

[185] ibid.

[186] ibid.

[187] ibid.

[188] ibid.

[189] Select Committee on Health and Children Deb 7 March 2007 <http://debates.oireachtas.ie/HES/2007/03/07/00004.asp> accessed 4 March 2014.

on Health and Children. During the debate the Minister for Health stated that 'We are not providing for an inspectorate of the acute and palliative care sectors for the very good reason that these areas require a different form of expertise.'[190] This serves to demonstrate that palliative care is an area with its own particular challenges which have not yet been adequately addressed in this jurisdiction. Despite this, Chapter Two set out that palliative care is not only provided in the hospice but is provided in a variety of locations such as in acute general hospitals, 'the patient's own home, in a local community hospital, in a nursing home or any other setting in the community.'[191] Therefore, palliative care is not only a concern for hospices but is provided across the healthcare system in Ireland. Nonetheless, HIQA has included requirements for end-of-life care in the standards on 'Residential Care Settings for Older People in Ireland'.

National Quality Standards for Residential Care Settings for Older People in Ireland

These standards focus on the care of the patient in a residential care setting such as a nursing home. HIQA standards are 'developed based on legislation, research findings and best practice.'[192] As a result, it would be expected that the standards for end-of-life care in a residential care setting should have a great deal of overlap with end-of-life care requirements in other locations. The end-of-life care standard in the 'National Quality Standards for Residential Care Settings for Older People in Ireland' addresses a variety of issues commonly raised by palliative care such as assessment of the patient's needs, documentation and review of these needs. The standard references autonomy in that it set out that, '[t]he resident's wishes and choices regarding end of life care are discussed and documented'.[193] Furthermore, this standard directly refers to 'preferred religious, spiritual and cultural practices'[194] yet neglects any mention of sedation or artificial nutrition and hydration. The end-of-life care standard requires the residential care setting to have suitable facilities in place for end-of-life care so 'that the resident is not unnecessarily transferred to an acute setting except for specific medical reasons, and in accordance with his/her wishes.'[195] Unfortunately, this

[190] ibid.
[191] Department of Health and Children (n6) 34.
[192] Health Information and Quality Authority, 'Older people' <http://www.hiqa.ie/standards/social/older-people> accessed 4 March 2014.
[193] Health Information and Quality Authority (n7) 23.
[194] ibid.
[195] ibid.

standard makes no reference to what these facilities may be. A clearer picture of what is required by this standard will largely be achieved by residential care settings failing to meet the standard and receiving greater instruction from HIQA. A system which seeks to encourage consistent high standards could avoid many failures and weaknesses in the first instance by simply setting out in more detail what is required.

Linked to the HIQA National Quality Standards for Residential Care Settings for Older People in Ireland is the *Health Act 2007 (Care and Welfare Of Residents in Designated Centres for Older People) Regulations 2009*.[196] The purpose of these regulations is to underpin HIQA National Quality Standards for Residential Care Settings for Older People in Ireland. Section 14(1) of the *Health Act 2007 (Care And Welfare Of Residents In Designated Centres For Older People) Regulations 2009* requires that '[t]he registered provider shall ensure that the designated centre has written operational policies and protocols for end of life care.'[197] The effect of this is to continue the creation of policy at local level. Other sections in the Regulations refer to principles such as dignity[198] and the comfort of the resident[199] without providing guidance on how these can be achieved or can be incorporated in local policy. As a result of this, guidance on these points may come from publications issued by groups involved in the promotion of palliative care.

Guidance of Representative Bodies and NGO's

This section examines the guidance issued by representative bodies, namely the Irish Association of Palliative Care [hereinafter 'IAPC'], and the European Association of Palliative Care [hereinafter 'EAPC']. The guidance issued by these groups is drawn on in examining the legal framework for specialist palliative care for several reasons. First, the IAPC and EAPC have been selected as they have had a considerable role in shaping the development of palliative care in Ireland and Europe respectively. Second, as much of the regulatory framework is reliant on policy developed at the local level

[196] Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009.
[197] Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009, s 14(1).
[198] Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009, s 10.
[199] Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009, s 14.

it is likely that the reports and guidance issued by these bodies will have an influence on both the doctors and nurses providing specialist palliative care. The third reason for considering the publications of the IAPC and the EAPC is the fact that they have examined and provided guidelines and frameworks for the specialist palliative care practices which are the focus of this thesis. However, it is to be underlined that these are guidelines and frameworks published by representative bodies and therefore are not directly enforceable in this jurisdiction. Nevertheless, they provide a valuable insight into developing guidelines for specialist palliative care.

The Role of the Irish Association of Palliative Care

The IAPC was established in 1993.[200] Members of the IAPC include professionals involved in all aspects of palliative care including 'doctors, nurses, social workers, psychologists, counsellors, pharmacists, physiotherapists, pastoral carers, dieticians, administrators, educators, academics'.[201] The purpose of the IAPC is the promotion of palliative care in Ireland and internationally by the use of 'education, publications, representation on national bodies and opportunities for networking.'[202] In addition to this the IAPC is involved in 'the development of national policy for patient-centred, equitable and accessible palliative care for all who need it.'[203] The drafting of guidelines on palliative care practices is not a responsibility or an aim of the IAPC but it has developed resources which provide an outline of how such services should be provided. In this respect, the IAPC has published a discussion paper on palliative sedation[204] and a position paper on artificial hydration[205] which will be discussed in this section.

IAPC Discussion Paper on Palliative Sedation

The IAPC Discussion Paper on Palliative Sedation was published in March 2011 and functioned to encourage wider discussion and feedback on this practice.[206] The discussion paper considers the decision-making process for commencing palliative

[200] Irish Association of Palliative Care, 'Who We Are' <http://www.iapc.ie/who-we-are.php> accessed 24 June 2014.
[201] Irish Association of Palliative Care, 'Membership' <http://www.iapc.ie/membership.php> accessed 24 June 2014.
[202] Irish Association of Palliative Care (n200).
[203] Irish Association of Palliative Care (n201).
[204] Irish Association of Palliative Care, 'Palliative Sedation' (March 2011).
[205] Irish Association of Palliative Care, 'Artificial Hydration in Terminally Ill Patients' (March 2011).
[206] Irish Association of Palliative Care (n204).

sedation, the decision to provide or withdraw artificial nutrition and hydration, and it provides an explanation of refractory symptoms. The presence of a refractory symptom is often an indication that palliative sedation can be administered to the patient.[207] Guidance on this point can greatly assist the medical practitioner and the patient in recognising the stage of illness and the steps to be taken in the care of the patient. A refractory symptom is defined in the discussion paper as, 'symptoms that are uncontrolled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness.'[208] In order to determine whether a symptom is refractory, the IAPC cite research which suggests that:

> the clinician must perceive that further invasive or non invasive interventions are either incapable of providing adequate relief, or that the therapy is associated with excessive and intolerable acute or chronic morbidity and is unlikely to provide relief within a tolerable time frame.[209]

The discussion paper also identifies physical or psychological symptoms which may require sedation. The psychological symptoms which may require sedation include 'existential, spiritual, emotional or psychological distress'.[210] As has been noted in Chapter Two, the administration of sedation for these psychological difficulties alone is a controversial issue and can blur the legitimacy of the distinction between specialist palliative care and euthanasia.[211] In this respect, the IAPC recognises the difficulty which this poses and suggests that respite sedation be used as part of the symptom management. Respite sedation is a form of short term sedation as it sedates the patient for 24-48 hours at which point the sedative drug is reduced to bring the patient back to consciousness. In effect, respite sedation can be utilised to give the patient relief from their psychological suffering while avoiding the complicated decisions of treatment withdrawal often associated with palliative sedation. Adopting such an approach is a positive step in addressing the issues posed by existential suffering near

[207] ibid 2.
[208] Nathan I Cherny and RK Portenoy 'Sedation in the management of refractory symptoms: guidelines for evaluation and treatment' (1994) 10 Journal of Palliative Care 31 quoted in Irish Association of Palliative Care (n204) 2.
[209] Paul Rousseau, 'The Ethical Validity and Clinical Experience of Palliative Sedation' (2000) 75(10) Mayo Clinic Proceedings 1064 quoted in Irish Association of Palliative Care (n204) 2.
[210] Irish Association of Palliative Care (n204) 2.
[211] Text to n148 in Chapter Two; Text to n71 in Chapter Six The Dutch Guideline for Palliative Sedation does not allow sedation for patients suffering from existential distress alone.

the end of life and in maintaining the distinction between specialist palliative care and euthanasia.

The discussion paper recognises the importance of patient autonomy in making decisions relating to his/her medical treatment and care. Guidance is provided on determining the capacity of a patient to make a decision and the potential role of an advance care plan is also recognised. In circumstances where the patient lacks the necessary capacity and no advance care plan has been drafted, the IAPC suggests that 'doctors discuss the situation with other members of the multi-disiplinary team, as well as considering the wishes and concerns of the patient's family.'[212] The clear process set out in this paper for deciding whether sedation should be administered needs to be highlighted. This process recognises that decisions are to be multi-disciplinary which is in line with the manner in which palliative care is provided. The discussion paper suggests reference should be made to the following as part of the decision-making process:

> the patient's general condition, including the cause of the intolerable distress, treatments that have been attempted, limitations of other options of care
> the rationale for the decision that palliative sedation is the only method available for achieving symptom relief within an acceptable time frame (i.e., the symptoms are truly refractory)
> the aims of sedation
> the method of sedation
> the anticipated effects of sedation, including degree of reduction in consciousness levels, communication and oral intake
> the potential uncommon risks such as paradoxical agitation, delayed or inadequate relief
> medical treatments and nursing care to be maintained during sedation: treatments and care to maximize the patient's comfort are continued
> the expected outcomes if palliative sedation is not performed, including other treatment options, degree of suffering likely to persist with each

[212] Irish Association of Palliative Care (n204) 2.

option and expected survival with each option

commitment to the patient's well being and provision of best possible care[213]

These are steps which medical practitioners may already take but by setting them out in such a manner it provides clarity to all people involved in the care of the patient and removes any 'ad hoc'[214] image of decision-making in palliative care.

The categorisation of artificial nutrition and hydration was discussed in Chapter Two, Chapter Three, and has been referred to in this chapter in the context of the IMC statement after *Re a Ward of Court*.[215] The discussion paper briefly considered this practice and recognised the distinction between artificial nutrition and hydration. The guidance of the IAPC is to make any decision on this issue 'following consideration of benefits and burdens of each treatment as relative to each individual patient.'[216] Subsequently, advice is given on medication management when palliative sedation is commenced. This discussion paper is only two pages long but is relatively comprehensive in the manner in which it addresses specialist palliative care. Furthermore, the paper concludes by outlining the 'Ethical Principles Involved'.[217] These principles include beneficence, nonmaleficence, and autonomy. The reference to these principles demonstrates the fact that it is possible to specify these principles for specialist palliative care and it underlines their value in guiding the work of the healthcare professional.[218] Nevertheless, the status of this discussion paper means it lacks enforceability and there is no guarantee that it forms part of local policy in health care facilities. Although reference was made to artificial nutrition and hydration in this paper, the IAPC has also issued a position paper on artificial hydration.

[213] Irish Association of Palliative Care (n204) 3.
[214] Department of Health and Children (n6) 23.
[215] Text to n40.
[216] Irish Association of Palliative Care (n204) 3.
[217] ibid.
[218] Edmund Pellegrino, 'The metamorphosis of medical ethics: A 30 years perspective' (1993) 269 Journal of the American Medical Association 1158 quoted in Roberto Andorno, 'Do Our Moral Judgments Need to be Guided by Principles?' (2012) 21 Cambridge Quarterly of Healthcare Ethics 457, 458 'critics of the so-called principlism as developed by Beauchamp and Childress have faulted this theory for being ''too abstract, too rationalistic, and too far removed from the psychological milieu in which moral choices are actually made.'''

IAPC Position Paper on Artificial Hydration in Terminally Ill Patients

This position paper was published in March 2011 and considers 'the ethical issues relating to the role of artificial hydration in terminally ill patients.'[219] The IAPC paper recognises the distinction in decisions between administering sedation and the provision of artificial nutrition and hydration. Furthermore, it distinguishes between artificial nutrition and artificial hydration. The position paper focuses on the principles behind the removal of hydration such as a patient's request for the withdrawal of artificial hydration and whether the treatment may be 'unduly burdensome'.[220] The position paper on artificial hydration addressed this practice in a clear and unbiased manner, as demonstrated in the section titled 'Relationship Between Hydration Status and Patient Comfort'.[221] Reference was made to a Cochrane Review on artificial hydration as well as the review conducted by Raijmakers et al, both of which were discussed in Chapter Two.[222] The overall conclusion of the IAPC is that 'artificial hydration in terminally ill patients who do not have a reversible cause for their clinical deterioration, is unlikely to confer significant benefit.'[223] However, this is a position paper and there is no requirement that these views influence the drafting of local end-of-life care policies. Different institutions will develop policy based on differing research which serves to undermine consistent provision of specialist palliative care. The IAPC guidance also serves to demonstrate the relative ease and clarity with which these practices could be addressed on a national level rather than allowing local policy to guide such issues.

The Role of the European Association of Palliative Care

The EAPC was established in 1988 and aims to 'develop and promote palliative care in Europe through information, education and research using multi-professional collaboration, while engaging with stakeholders at all levels.'[224] The work of the EAPC is often disseminated through publications which require initiatives at a national level to ensure they are implemented. As such, the recommendations of the EAPC are not directly enforceable in Ireland but may be drawn on in the development

[219] Irish Association of Palliative Care (n205) 2.
[220] ibid.
[221] ibid.
[222] Text to n198 and n199 in Chapter Two.
[223] Irish Association of Palliative Care (n205) 3.
[224] European Association of Palliative Care, 'Mission Statement' <http://www.eapcnet.eu/> accessed on 4 March 2014.

of local policy on specialist palliative care. The IAPC is a member of the EAPC; as are 45 other associations across 26 countries. EAPC publications have examined many different aspects of palliative care.[225] However, this section will concentrate on the EAPC recommended framework for the use of sedation in palliative care.[226]

EAPC recommended framework for the use of sedation in palliative care

The EAPC recommended framework for the use of sedation was published in 2009. Guidelines were described in this framework as:

> helpful to educate medical providers, set standards for best practice, promote optimal care and convey the important message to staff, patients and families that palliative sedation is an accepted, ethical practice when used in appropriate situations.[227]

This framework is not automatically incorporated by members of the EAPC but instead the EAPC framework provides that recommendations contained in it 'may be adopted in their current form or, preferably, modified to reflect local cultural or legal considerations or the specific needs of the context in which they will be used, be it in the home, hospital or hospice-based care.'[228] Of most relevance, to this Chapter is the '10-item framework that addresses the key clinical issues.'[229]

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[225] GW Hanks and others, 'Morphine and alternative opioids in cancer pain: the EAPC recommendations' (2001) 84(5) British Journal of Cancer 587; F Stiefel, 'Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association of Palliative Care' (2001) 9(7) Supportive Care in Cancer 477; C Ripamonti, 'Clinical-practice recommendations for the management of bowel obstruction in patients with end-stage cancer' (2001) 9(4) Supportive Care in Cancer 223; Nathan Cherney and others, 'Strategies to Manage the Adverse Effects of Oral Morphine: An Evidence-Based Report' (2001) 19(9) Journal of Clinical Oncology 25; A Caraceni and others, 'Pain measurement tools and methods in clinical research in palliative care: recommendations of an Expert Working Group of the European Association of Palliative Care' (2002) 23(3) Journal of Pain and Symptom Management 239; L Radbruch and others, 'Fatigue in palliative care patients – an EAPC approach' (2008) 22(1) Palliative Medicine 13; L Radbruch and others, 'White Paper on standards and norms for hospice and palliative care in Europe: part 1' (2009) 16(6) European Journal of Palliative Care 278.

[226] Nathan I Cherny, Lukas Radbruch and The Board of the European Association for Palliative Care, 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care' (2009) 23(7) Palliative Medicine 581.

[227] ibid 581.

[228] ibid 583.

[229] ibid The 10 item framework includes; recommending pre-emptive discussion of the potential role of sedation in end-of-life care and contingency planning, describing the indications in which sedation may or should be considered describing the necessary evaluation and consultation procedures, specifying consent requirements, indicating the need to discuss the decision-making process with the patient's family, direction for selection of the sedation method, directions for dose titration, patient monitoring and care, the care and informational needs of the patient's family, and care for the medical professionals.

The first item in the framework is 'pre-emptive discussion of the potential role of sedation in end-of-life care and contingency planning'.[230] This includes suggestions that the doctor discusses the patient's preferences for end-of-life care. The framework also recommends that explicit reference be made in certain cases to 'CPR, ventilator support, pressor support, comfort care, antibiotics and artificial hydration and nutrition.'[231] Guidance on what should be discussed can assist in ensuring that patient's decisions about their healthcare can be made in a fully informed manner. In contrast to this, the IMC Guide to Professional Conduct and Ethics set out that 'You should take care to communicate effectively and sensitively with patients and their families so that they have a clear understanding of what can and cannot be achieved.'[232] The lack of detail on what should be discussed may be an advantage as doctors can exercise discretion on a patient by patient basis. However, this lack of detail also serves to create inconsistency between the palliative care different patients receive. Setting out guidance on what should be communicated is not to take from the role of the doctor but should serve to set a base standard which could improve the overall care of the patient and ensure that communication is consistent and clear between the healthcare professional and patient.

Further recommendations contained in the EAPC framework focus on the provision of sedation. Recommendations are made on the identification of symptoms requiring sedation as well as the 'necessary evaluation and consultation procedures'.[233] The issues to be evaluated are also clearly set out including 'the patient's medical history',[234] 'all relevant investigations'[235] and a 'physical examination of the patient'.[236] In line with other guidelines, reversible symptoms are not to form part of the evaluation for considering sedation.[237] Nevertheless, this aspect of the guidance has been criticised as '[i]t is unclear what constitutes refractory symptoms and what the relationship is between refractory symptoms and intolerable suffering'.[238] A

[230] ibid.
[231] ibid 584.
[232] Irish Medical Council (n15) 22.
[233] Cherny (n226) 584.
[234] ibid.
[235] ibid.
[236] ibid.
[237] ibid.
[238] Niklas Juth and others, 'European Association for Palliative Care (EAPC) framework for palliative sedation: an ethical discussion' (2010) 13(9) BMC Palliative Care 20, 20.

clearer definition would remedy such issues and would benefit the provision of specialist palliative care.

The 10-item framework also provides guidance on the selection of an appropriate level of sedation and associated practices. The general guidance on the provision of sedation is that 'the level of sedation should be the lowest necessary to provide adequate relief of suffering.'[239] On this point, the titration of sedative drugs is set out as well as setting out the approach to beginning assessment, continuing assessment of the patient's pain management needs and checks on 'heart rate, blood pressure and oxygen saturation'.[240] The framework clearly sets out the procedure to be followed as well as guidance on associated practices such as 'hydration and nutrition and concomitant medications'.[241] This framework underlines the independence of the decisions on sedation and the provision of artificial nutrition and hydration but refrains from setting a definitive position on the withdrawal of artificial nutrition and hydration. Instead, the EAPC suggest that this is a decision for the patient while also weighing up the 'estimated benefits/harms in light of the treatment aim'.[242]

The EAPC framework highlights the potential problems raised by palliative sedation. It not only acknowledges potential problems for the patient such as 'hastening death'[243] but also recognises distress which families may experience as a result of sedation. The potential for abuse of sedation has been recognised within the framework. Such abuse may not only be an excessive provision of sedation but may also be exhibited by an insufficient level of sedation given to a patient. By educating all parties involved and clarifying the role of palliative sedation this framework can improve the practice of palliative sedation and allow for end-of-life care to be provided in a much clearer manner. This type of approach serves to improve consistency and allows the patient greater understanding and input to their care. Nevertheless, this is guidance which presently can only prove effective if implemented by local policy in this jurisdiction.

[239] Cherny (n226) 586.
[240] ibid.
[241] ibid 587.
[242] ibid.
[243] ibid 582.

Conclusion

A common feature of the specialist palliative care practices which have been discussed is the lack of clear guidance and regulation. Palliative care in Ireland grew from the hospice movement and lacked a central plan for its national development. In effect, palliative care developed independently and the regulatory framework developed in a similar manner. The Report of the National Advisory Committee on Palliative Care identified this as a potential problem in setting out that '[i]ssues of responsibility, reporting structures and funding may be of an ad-hoc nature'.[244] This chapter served to underline the lack of clarity and consistency on specialist palliative care practices in the professional standards of the Irish Medical Council and An Bord Altranais. Nevertheless, it is these professional standards which form a majority of the regulatory framework for specialist palliative care in Ireland.

The discussion of HIQA demonstrated the possibility of developing standards for the provision of health care across Ireland. Therefore, it should also be possible to develop clear national guidance on palliative care which could address the failings highlighted by this Chapter. This could detail best practice for all providers of palliative care including hospices, hospitals and nursing homes. In addition to HIQA, the work of the IAPC and the EAPC also provide potential models for development. At a minimum, the work of these bodies highlights the issues in specialist palliative care which need clarity on a national basis. In short, it is evident that the legal framework for specialist palliative care in Ireland is inadequate. Consequently, an alternative legal framework needs to be identified; a framework which takes account of the legal and ethical issues raised by palliative care practices as well as repeat criticism that specialist palliative care practices may amount to 'slow euthanasia'.[245] These are issues which have been addressed in the Netherlands and the approach to specialist palliative care adopted in that jurisdiction will be examined in Chapter Six with the aim of identifying potential suggestions for reform.

[244] Department of Health and Children (n6) 23; Conor Sullivan, 'Hospice chief urges reform of system' *The Irish Times* (Dublin, 14 August 2010) 7 'The chief executive of the Irish Hospice Foundation has hit out at the "postcode lottery" for those with terminal conditions. Eugene Murray said there were large differences between regions in the care that is available to people at the end of their lives and suffering from terminal cancer, heart or respiratory conditions.'
[245] Cherny (n226) 582.

THE REGULATORY FRAMEWORK IN THE NETHERLANDS FOR SPECIALIST PALLIATIVE CARE

Introduction

Herodotus set out that, 'if one were to offer men to choose out of all the customs in the world such as seemed to them the best, they would examine the whole number and end by preferring their own'.[1] Nevertheless, in Chapters Four and Five it has been established that there is a lack of detailed national guidance on specialist palliative care in Ireland. This encourages the creation of a fragmented legal framework and results in inconsistency across healthcare professionals and healthcare facilities. The existence of such a fragmented framework can also undermine the consistent protection of a patient's human rights.[2] In order to ensure clarity and consistency in the legal framework and protect patient's human rights there is a need for reform in Ireland. In this regard, comparative legal research serves to provide a broader perspective on the 'customs' which exist and the possibilities for reform. This Chapter will consider what shape this reform may take by examining the regulation of specialist palliative care in the Netherlands. In short, the Netherlands has established detailed professional standards for the provision of palliative care. The Dutch standards are aimed at the medical practitioner but recognise the importance of co-operation with nurses in providing specialist palliative care. This Chapter will address a central research question of this thesis, namely what alternative legal framework might exist for specialist palliative care.

In examining the Dutch system of palliative care it is important to recognise that the model of regulation cannot be 'completely disconnected from the social structure of Dutch society, the legal system and the cultural climate on the one hand, and the system of health care and insurance on the other.'[3] The Dutch approach to palliative care must

[1] David Braund, 'Herodotos on the Problematics of Reciprocity' in Christopher Gill, Norman Postlethwaite and Richard Seaford (eds), Reciprocity in Ancient Greece (Oxford University Press 1998) 173.

[2] Text to n103 in Chapter Four. *Glass v United Kingdom* (2004) 39 EHRR 15, [75] A fragmented legal framework in and of itself does not necessarily violate the human rights of a patient but it should not be so diffuse as to 'contribute to unpredictability and an excess of discretion'.

[3] Sjef Gevers, 'Euthanasia: law and practice in The Netherlands' (1996) 52(2) British Medical Bulletin 326, 333.

be discussed in light of these broader issues.[4] This Chapter will first outline the development of palliative care in the Netherlands and will highlight the types of healthcare facility which led the Netherlands in this regard. This gives a sense of the healthcare system in the Netherlands and explains why this jurisdiction is a useful comparator. The Dutch guidelines for palliative care will then be examined as will the background to these guidelines. In particular, the guidelines published by the Comprehensive Cancer Centre of the Netherlands and the Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association) [hereinafter 'KNMG'] will be discussed in detail. The introduction of these guidelines was strongly influenced by the need to distinguish specialist palliative care practices from euthanasia. The legitimacy of the distinction between specialist palliative care and euthanasia is a central research question for this thesis and has been partly addressed in Chapter Three. It will be examined further in this Chapter in the context of the Dutch guidelines. This allows for the distinction to be drawn out in professional standards as well as having examined the distinction in practice in Chapter Three. The combination of these chapters allows for a rounded approach to addressing the central research questions of this thesis.

The Development of Palliative Care in the Netherlands

Palliative care in the Netherlands has had a similar development trajectory to palliative care in Ireland. Moreover, both jurisdictions have a common understanding of what palliative care involves and how it is to be defined. For instance, the Dutch government policy paper titled 'Palliative Care for Terminally Ill Patients in the Netherlands'[5] cites the World Health Organization definition of palliative care.[6] This is the same definition

[4] See pp64-71 in Chapter Three which outlined the legal status of euthanasia in the Netherlands.
[5] Anneke L Francke, 'Palliative Care for Terminally Ill Patients in the Netherlands: Dutch Government Policy' (The Hague 2003).
[6] Cecilia Sepúlveda and others, 'Palliative Care: The World Health Organization's Global Perspective' (2002) 24(2) Journal of Pain and Symptom Management 91, 94 'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'; Rien JPA Janssens and Henk AMJ ten Have, 'The concept of palliative care in the Netherlands' (2001) 15 Palliative Medicine 481, 482 'Most definitions of palliative care in the Netherlands are based on that developed by the World Health Organization in 1990.'; Netherlands Programme for Palliative Care, 'NPTN: palliative care comes under the spotlight in the Netherlands' (2009) 16(3) European Journal of Palliative Care 15.

which has been used by Irish reports on palliative care.[7] The harmonious interpretation of palliative care in both jurisdictions serves to strengthen the choice of the Netherlands as a comparator. In addition to a common understanding of palliative care, both the Netherlands and Ireland began to develop palliative care services from around the same time.

In 1975 the Antonius-IJsselmonde nursing home began to focus on the provision of palliative care in an attempt to 'improve special care for the dying.'[8] This was the first healthcare provider in the Netherlands to adopt this type of focussed approach to end-of-life care. Aspects of care which the Antonius-IJsselmonde nursing home focused on developing included 'bereavement support, specialist nursing care, psycho-social and spiritual aspects of care, and the need to create a homely atmosphere.'[9] The time after 1975 signalled a considerable change in how end-of-life care was viewed and provided in the Netherlands. For example, Gronemeyer et al. suggested that 'After 1975, death and dying were decreasingly considered a taboo period and society started to acknowledge its duty to care for terminally ill people.'[10] In a similar vein, the developments after 1975 were described by Biesenbeek as 'a period of reversal; a period in which the dying process had been brought more into the open and in which society had started to acknowledge its duty to care for the terminally ill.'[11] As such, a number of healthcare providers in the Netherlands began to focus on the development of palliative care practices from this time.

A key point in the development of palliative care in the Netherlands was the establishment of a number of hospices in the early 1990's. The Johannes hospice in Vleuten was founded in 1991,[12] the Kuria hospice in Amsterdam was set up in 1992 and the Rozenheuvel hospice was established in 1994.[13] It has been suggested that by

[7] Health Service Executive, 'Palliative Care Services – Five Year/Medium Term Development Framework' (Health Service Executive 2009).
[8] Reimer Gronemeyer and others, *Helping People at the End of their Lives: Hospice and Palliative Care in Europe* (Lit Verlag 2005) 231.
[9] Janssens (n6) 482.
[10] Gronemeyer (n8) 231.
[11] Janssens (n6) 482.
[12] Bert Gordijn and Rien Janssens, 'Euthanasia and Palliative Care in the Netherlands: An Analysis of the Latest Developments' (2004) 12(3) Health Care Analysis 195, 199.
[13] ibid; Rien JPA Janssens, Henk AMJ ten Have and Zbigniew Zylicz, 'Hospice and euthanasia in the Netherlands: an ethical point of view' (1999) 25(5) Journal of Medical Ethics 408, 409 It is the

setting up these hospices, people were attempting to 'make a concrete statement in the euthanasia discussion as a counterbalance to the euthanasia movement.'[14] This signals a demarcation between the provision of palliative care and euthanasia. Additionally, the impact of hospice care in the Netherlands can be illustrated by the experience of Rozenheuvel hospice. 571 patients were admitted to Rozenheuvel in the four years after it opened.[15] A quarter of these patients had made a request for euthanasia should the pain become unbearable.[16] However, there were only two people from the 571 patients who actually went through with their request for euthanasia.[17] One interpretation of this is that palliative care is capable of providing appropriate pain management along with other support necessary for the care of the patient. However, these figures could also be interpreted in a manner which suggests that specialist palliative care practices function similarly to euthanasia and therefore requests for euthanasia were needless in such circumstances.

As discussed in Chapter Three, there is a clearly defined legal framework for euthanasia in the Netherlands. In contrast to this, palliative care in the Netherlands had no such framework until much later and was provided with fewer safeguards in place. The combination of these factors could be viewed as undermining the legitimacy of the distinction between specialist palliative care and euthanasia in the Netherlands at the time. The need to emphasise the distinction between specialist palliative care and euthanasia arose several years later and this was achieved through the development of professional standards. Nevertheless, hospice care continued to develop in the Netherlands. For example, there were 38 hospices in 1999 and this rose to 241 hospices in 2008.[18] This expansion in the provision of palliative care was accompanied by an increased government focus on this form of care from 1996 onwards.[19]

Rozenheuvel hospice which can be said to best reflect the English St. Christopher's Hospice model for palliative care.

[14] Gronemeyer (n8) 231; Arianne Brinkman and Jaap Gootjes, 'NPTN: palliative care comes under the spotlight in the Netherlands' (2009) 16(3) European Journal of Palliative Care 151, 151 'The debate about the practice of euthanasia also played an important role. For the Dutch hospice pioneers, the most important motivation was to provide better care for the dying.'

[15] Gordijn (n12) 202.

[16] ibid.

[17] ibid.

[18] Brinkman (n14) 151.

[19] Gordijn (n12) 199 Gordijn and Janssens suggested that it was the visit of the Dutch Queen and the Minister for Health to Rozenheuvel which 'instigated Members of Parliament to raise questions regarding the organization of palliative care in the Netherlands.'; Minister of Health, Welfare and Sport (Dr E Borst-Eilers), 'Standpunt op hoofdlijnen palliatieve zorg' [Outline position on palliative care]

A policy statement issued by the Dutch government in 1996 highlighted 'the need to further develop palliative care in the Netherlands.'[20] This increased focus was wound up with a number of other motivations. For instance, several members of the Dutch Parliament suggested that 'a further proliferation of hospices was likely to lead to a reduction of the number of euthanasia cases'.[21] This point is illustrated in a letter to the Dutch Parliament in which the Minister for Health set out that:

> It is certainly so that at times, in the context of extremely severe suffering, good palliative care, adequate pain treatment and a familiar surrounding can shift the borders for the request to have euthanasia carried out and can at times even prevent the request.[22]

This quote suggests that palliative care is viewed more favourably than euthanasia and was regarded as a more ethically acceptable practice. In this letter the Minister for Health also set out that a small amount of funding was to be made available for the development of palliative care.[23] The purpose of this funding was to develop palliative care 'in the context of already existing institutions such as home care services, nursing homes and hospitals.'[24] The reason for adopting this approach was a view that 'the quality of regular health care was high.'[25] On that basis there was no perceived need for an independent palliative care provider.[26] This funding led to a number of initiatives aimed at promoting palliative care.[27] These initiatives promoted research and strengthened cooperation among palliative care providers.

Letter to the Chair of the Second Chamber of the States General (Ministry of Health, Welfare and Sport, 20 December 2001); Minister of Health, Welfare and Sport (Dr E Borst-Eilers), 'Definitief standpunt palliatieve zorg' [Final position on palliative care] Letter to the Chair of the Second Chamber of the States General (Ministry of Health, Welfare and Sport, 11 March 2002); Minister of Health, Welfare and Sport (Dr E Borst-Eilers) 'Palliatieve zorg' [Palliative care] Letter to the Chair of the Second Chamber of the States General (Ministry of Health, Welfare and Sport, 6 May 2002).

[20] Gronemeyer (n8) 231.

[21] ibid 232; Janssens (n6) 483.

[22] Gordijn (n12) 201.

[23] Gordijn (n12) 199 Minister of Health 'promised to further develop palliative care making available 250,000 guilders ($120,000).'

[24] ibid.

[25] ibid.

[26] ibid.

[27] ibid Six centres for the development of palliative care (COPZ's) were established with the purpose of improving 'coordination in care giving, develop educational modules and increase expertise and carry out research activities.'; Netherlands Programme for Palliative Care, 'NPTN: palliative care comes under the spotlight in the Netherlands' (2009) 16(3) European Journal of Palliative Care 151; Francke (n5) 19 'This project group's most important task was to investigate possible ways to stimulate the integration of professionally staffed hospices, volunteer-run hospices and hospice units into regular

At present, palliative care in the Netherlands is provided by general practitioners,[28] nursing homes,[29] care homes,[30] independent and volunteer run hospices,[31] and hospitals.[32] In 2006, the final place of care for patients suffering from cancer or other chronic diseases in the Netherlands was the home (31%),[33] hospital (28%),[34] nursing home (25%)[35] and care home (11%).[36] 5% of patients died in another type of healthcare facility including independent hospices.[37] This broad range of palliative care providers is also reflected in Ireland.[38] This underlines the importance of high quality palliative care in the general healthcare system. Such an approach moves palliative care from the margins to a more central position in the care of a patient. In these locations the doctor has an essential role in ensuring the patient is provided with appropriate palliative care. As a result of this, the legal framework for specialist palliative care in the Netherlands largely concentrates on the general practitioner but also takes account of other professions which are closely involved in providing palliative care. This approach appears to have been followed in the guidelines published by the Koninklijke

health care.' In 1999 the Hospice Care Integration Project group was created. The primary aim of this group was the integration of hospice facilities into core healthcare facilities.; Gronemeyer (n8) 232.

[28] Francke (n5) 6 Research conducted by Francke demonstrated that the general practitioner 'has contact a total of 26 times with a cancer patient in the palliative phase' and this contact is normally initiated by the doctor.

[29] Brinkman (n14) 151 '[u]ntil the 1980s, most people with severe illness were treated in hospitals and nursing homes.'; Gronemeyer (n6) 237 'there are many options in the Netherlands for outpatient palliative care as well as inpatient care traditionally offered by nursing and care homes. This is why the number of Dutch citizens that die in an independent hospice is still relatively low with less than one percent.'

[30] Francke (n5) 9.

[31] Nederlandse vereniging voor professionele palliatieve zorg, 'Palliative care in the Netherlands' <http://www.palliactief.nl/PalliatieveZorg/PalliatievezorginNederland.aspx> accessed 2 March 2014 This type of hospice is also referred to as 'almost-at-home-houses' and is a form of 'low-care hospice'. The first Dutch 'almost-at-home-house' was established in 1986 in Nieuwkoop. It is mainly for patients who require psycho-social care instead of medical support; Francke (n5) 10 'Volunteer-run hospices are suitable primarily for looking after terminally ill patients who can no longer be cared for at home for social reasons rather than exclusively medical reasons.'

[32] Francke (n5) 11 Palliative care in a hospital is often provided as part of 'regional palliative care networks.' As such, hospitals are part of the broader system of palliative care in the Netherlands but do not tend to provide comprehensive palliative care facilities. While a number of nursing homes contained a hospice unit this rarely occurs in the hospital setting.

[33] Lud FJ van der Velden and others, 'Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data' (2009) 8 BMC Palliative Care 4.

[34] ibid.

[35] ibid.

[36] ibid.

[37] ibid 'In 5% the place of death was either another place than those mentioned before or unknown. It may be assumed that 'other' includes, for instance, non-acute deaths in institutions for the mentally handicapped, mental healthcare institutions or one the 230 independent hospices that exists nowadays in the Netherlands. Ten years ago, the number of independent hospices was only some 40.'

[38] See p43.

Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association) [hereinafter 'KNMG'].

Guidelines on Specialist Palliative Care in the Netherlands

The manner in which palliative care was regulated in the Netherlands received particular attention in light of comments made by the Dutch Attorney General, Joan de Wijkerslooth in 2003. It was suggested by de Wijkerslooth that 'if sedation goes hand in hand with a decision to withhold hydration, it would amount to euthanasia albeit in a slow manner.'[39] This led de Wijkerslooth to call for '"terminal sedation" to be covered by the same legal controls as euthanasia.'[40] Consequently, the regional commission for overseeing euthanasia and physician assisted suicide would have to be notified in circumstances where a patient is continuously sedated and hydration is withdrawn.[41] Such an approach would clearly place specialist palliative care in the realm of euthanasia. It should be noted that the term 'terminal sedation' will occasionally be used in this Chapter in order to reflect the terminology used in relation to specialist palliative care in the Netherlands. This practice has the same meaning as 'palliative sedation' which was defined in Chapter Two.[42]

The impetus for the Attorney General's suggestion was a Dutch study on end-of-life care which 'suggested that between 4% and 10% of all deaths … occurred following terminal sedation.'[43] However, these statistics do not suggest that terminal sedation ultimately caused the death of the patient. Nevertheless, it is understandable that the Attorney General began to question the categorisation of terminal sedation and its relationship to euthanasia based on these figures.

[39] Gordijn (n12) 204 Research by Van der Wal et al. suggested that terminal sedation was administered in '6% of all deaths in the Netherlands (8,500 times a year).' Additionally, hydration was withdrawn in two thirds of such cases; Gordijn (n12) 205 'For instance, the research study of Van der Wal et al. indicates that in 51% of the cases of terminal sedation, the shortening of the patient's life was either the explicit goal (5%), or one of the goals next to other goals (46%). Apparently, at least in 5% of the cases terminal sedation does seem to be analogous to what can be called slow euthanasia.'

[40] Tony Sheldon, '"Terminal sedation" different from euthanasia, Dutch ministers agree' (2003) 327(7413) British Medical Journal 465, 465.

[41] Gordijn (n12) 205 'need to be reported to the regional commission for euthanasia and PAS.'

[42] Text to n138 in Chapter Two.

[43] Sheldon (n40) 465.

The potential re-categorisation of terminal sedation was criticised by providers of palliative care who were of the opinion that if specialist palliative practices are carried out correctly then it is 'an ultimate form of pain or symptom control, a form of normal medical treatment about which doctors and patients decide.'[44] The Dutch Health Minister at the time described terminal sedation and the withdrawal of artificial nutrition and hydration as 'normal medical treatment'.[45] In addition to this, the KNMG described the suggestion of the Attorney General as a 'frightening prospect'.[46] Overall, the suggestion of the Attorney General was not supported by the Dutch government and they instead believed it necessary to introduce 'a national guideline with respect to terminal sedation.'[47] This was also an attempt to mitigate the need to introduce legislation on specialist palliative care practices. A range of professional guidelines were introduced around this time which sought to emphasise the point that specialist palliative care practices are a normal aspect of medical treatment.[48] In this respect, the professional guidelines appear to have been successful as, at the time of writing, there has been no legislation enacted in the Netherlands which is aimed at specialist palliative care practices.

This Chapter will largely concentrate on the guidelines issued by the KNMG in 2005 and in 2009 as these guidelines are closely linked to the physician's professional standards in the Netherlands. In addition to this, subsequent guidelines such as those drafted by the Vereniging Integrale Kankercentra (Association of Comprehensive Cancer Centres) were aligned with the KNMG professional guideline on palliative sedation. Further refinements were in line with updated guidelines issued by the KNMG. As it is the guidance of the KNMG which appears to be a cornerstone for the provision of palliative sedation it is important to examine the contents and impact of this guideline in detail.

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[44] Gordijn (n12) 205.
[45] Sheldon (n40) 465.
[46] ibid.
[47] Marian Verkerk and others, 'A National Guideline for Palliative Sedation in The Netherlands' (2007) 34(6) Journal of Pain and Symptom Management 666, 666-667.
[48] Rien Janssens, Johannes J M van Delden and Guy A M Widdershoven, 'Palliative sedation: not just normal medical practice. Ethical reflections on the Royal Dutch Medical Association's guideline on palliative sedation' (2012) 38 Journal of Medical Ethics 664, 664 'The main premise of the Royal Dutch Medical Association's (RDMA) guideline on palliative sedation is that palliative sedation, contrary to euthanasia, is normal medical practice.'

The KNMG Guideline for Palliative Sedation

The KNMG is the professional body for doctors in the Netherlands.[49] Activities of the KNMG include the development of guidelines and policies for doctors, and the 'regulation of vocational training and registration of specialists.'[50] The Guideline for Palliative Sedation was developed by a committee appointed by the KNMG. This allowed for a broad range of input as the committee included a Professor in the ethics of care, two oncologists, two nursing home physicians, an anaesthesiologist, two general practitioners, a medical law coordinator and a policy advisor.[51] The Guideline which the KNMG committee developed is 'now part of the physician's professional standard(s)'[52] which a physician is obliged to follow. The Guideline for Palliative Sedation addresses 'Indications and preconditions for palliative sedation',[53] the decision to begin sedation, the provision of hydration, respite sedation as well as wider issues such as 'Dealing with the patient's family'.[54] The need to distinguish specialist palliative care from euthanasia was recognised by the committee developing the Guideline.[55] In line with this it was necessary to emphasise that palliative sedation was a normal part of medical practice. This is largely demonstrated in the Guideline through the prognosis of the terminally ill patient and the intention of the doctor.[56] These points will be discussed over the course of this section.

The first edition of the Guideline for Palliative Sedation was published in 2005[57] and since that time the KNMG has actively monitored the Guideline. There was criticism of certain aspects of the Guideline for Palliative Sedation and the KNMG attempted to resolve these issues by publishing a revised Guideline for Palliative Sedation in 2009.[58]

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[49] 'The Royal Dutch Medical Association' <http://knmg.artsennet.nl/Over-KNMG/About-KNMG.htm> accessed 3 March 2014.
[50] ibid.
[51] Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2009) 64.
[52] Verkerk (n47) 667.
[53] Royal Dutch Medical Association (n51) 22.
[54] ibid 46.
[55] Janssens (n48) 664.
[56] ibid 'This message is founded on stipulating the following two conditions: the prognosis of the patient should be less than 2 weeks, and the aim of the physician should be to relieve suffering and not to shorten the patient's life. A third element follows from these conditions: if palliative sedation does not shorten life, expert consultation, mandatory as it is in euthanasia cases, is just optional in palliative sedation cases.'
[57] Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2005).
[58] Royal Dutch Medical Association (n51).

Aspects of the 2005 Guideline which were the subject of criticism will be highlighted in the course of this section. In this regard, the Guideline will be examined on a chapter by chapter basis with the main issues being the indications and preconditions for palliative sedation, the decision-making process for palliative sedation, and the administration of fluids and palliative sedation.

Chapter two of the revised Guideline for Palliative Sedation defines palliative sedation and clarifies its relationship to the provision of palliative care. Chapter two also set out empirical data on the provision of palliative sedation in the Netherlands which ranged from the main symptoms leading to palliative care,[59] to the frequency with which artificial nutrition and hydration is withdrawn.[60] These figures created a picture of the way palliative care is provided in the Netherlands and served to set up discussion of the substantive guidelines on issues such as the indications and preconditions for palliative sedation.

Indications and Preconditions for Terminal Sedation

The third chapter of the KNMG Guideline for Palliative Sedation sets out the 'Indications and preconditions for palliative care'.[61] A main indication is that that the patient should have refractory symptoms.[62] A symptom can be considered refractory if 'None of the conventional modes of treatment is effective or fast-acting enough, and/or if these modes of treatment are accompanied by unacceptable side-effects.'[63] In Chapter Five it was highlighted that the Irish Association of Palliative Care set out a definition of refractory symptoms but neither the Irish Medical Council or An Bord Altranais provided guidance on the meaning or identification of this type of symptom. Nonetheless, there is a considerable subjective element in recognising a refractory symptom. For example, what constitutes an unacceptable side effect is likely to change depending on the individual patient. In light of this, the Guideline recognises the importance of a patient's involvement in decisions on palliative care, e.g. 'It will often

[59] ibid 20 'The symptoms most commonly experienced by patients in the last stages or final week of life are fatigue (83%), dyspnoea (50%), pain (48%), confusion (36%), anxiety (31%), depression (28%) and nausea and vomiting (25%). Fatigue is perceived as the greatest burden, followed by pain, anxiety, dyspnoea, depression, nausea/vomiting and confusion, in that order'.
[60] ibid 21 'Continuous, deep sedation was administered together with the non-administration of food or fluids in 5.4% of all deaths.'
[61] ibid 22.
[62] ibid.
[63] ibid.

be appropriate for the physician and patient to decide together whether or not, on balance, a symptom is refractory.'[64] The decision as to whether a symptom is untreatable, and therefore refractory, is based largely on two factors, namely 'the expected effectiveness of the possible treatment'[65] and 'the discomfort or other side-effects associated with the possible treatment.'[66]

The Guideline sets out symptoms which commonly require palliative sedation but it must be shown 'beyond reasonable doubt'[67] that the symptoms are untreatable. In order to demonstrate this, it is necessary that 'reversible causes of suffering must be meticulously excluded before a decision is taken to administer palliative sedation.'[68] Nevertheless, the Guideline highlights the importance of 'the patient's feelings regarding issues such as the discomfort of further diagnostic tests'.[69] As such, the decision to label a symptom as refractory leaves a considerable degree of discretion to the doctor and patient but at the same time the guidance is not so broad as to be meaningless. For example, the Guideline includes a 'flow diagram' to assist in the identification of refractory symptoms.[70] This provides a clear reference for both the doctor and the patient as to whether a symptom is likely to be refractory and promotes a degree of certainty in the provision of palliative sedation. In addition to this, chapter three of the Guideline also highlights symptoms which raise difficult ethical and legal issues, namely sedation in the case of existential suffering.

Palliative Sedation for Existential Suffering

A challenging symptom for the Guideline for Palliative Sedation has been the provision of palliative sedation for existential or psychological suffering.[71] It is possible that this is 'among the refractory symptoms that go to make up unbearable suffering.'[72] Nonetheless, the identification of existential suffering is such that it also

[64] ibid.
[65] ibid.
[66] ibid.
[67] ibid 23.
[68] ibid.
[69] ibid.
[70] ibid 25.
[71] Non-somatic suffering has also raised challenging issues for euthanasia. Text to n40 and n45 in Chapter Three.
[72] Royal Dutch Medical Association (n51) 24. 'Existential suffering may be expressed as feelings of pointlessness, emptiness, existential distress, a desire not to experience death or the dying process

requires 'expertise in the areas of psycho-social and spiritual problems'.[73] The 2005 Guideline was criticised for not allowing palliative sedation for this type of suffering. This point was clarified by the 2009 Guideline which set out that if the patient was also experiencing refractory symptoms then sedation could be administered.[74] However, existential suffering alone does not justify the provision of palliative sedation.[75]

The position of the KNMG Guideline for Palliative Sedation on sedation in instances of existential suffering is similar to the approach set out by the Irish Association of Palliative Care [hereinafter 'IAPC'] discussion paper on palliative sedation. For instance, the IAPC discussion paper suggested that psychological symptoms such as 'existential, spiritual, emotional or psychological distress'[76] could be addressed through the use of respite sedation rather than palliative sedation. The manner in which existential distress is treated is essential in distinguishing specialist palliative care practices from euthanasia. For example, it was highlighted in Chapter Two that sedation for existential distress, in the absence of a refractory symptom, furthers suggestions that specialist palliative care is a form of euthanasia in disguise.

Requisite Prognosis for Palliative Sedation

Chapter three of the Guideline for Palliative Sedation establishes the precondition for the administration of palliative sedation. This requires that in addition to the presence of one or more than one refractory symptom, the patient is expected to die 'in the reasonably near future – that is, within one to two weeks'.[77] The basis for establishing this prognosis as a requirement is because 'a longer prognosis might imply that the patient dies as a consequence of dehydration, instead of the underlying disease.'[78] In the Netherlands it is common practice to withdraw hydration from the sedated patient.

consciously, psychosocial problems, spiritual problems, or for instance the desire to preserve one's dignity.'

[73] ibid.

[74] ibid 25 'However, there are patients who have no refractory symptoms but simply want palliative sedation as a way of avoiding consciously experiencing the end of life. The committee does not regard this as an acceptable indication.' The guidance on existential suffering may reflect the challenging cases which have arisen in case law on euthanasia in the Netherlands.

[75] ibid.

[76] Irish Association of Palliative Care, 'Palliative Sedation' (March 2011) 2.

[77] Royal Dutch Medical Association (n51) 25.

[78] Janssens (n48) 665; Royal Dutch Medical Association (n51) 26 'If the patient's life expectancy exceeded one to two weeks, the non-administration of fluids would cause dehydration and hasten the time of death.'

As such, withdrawing hydration from a patient with a longer prognosis blurs the distinction between specialist palliative care and euthanasia.[79]

The difficulty in determining the patient's life expectancy was recognised in the Guideline for Palliative Sedation and it was suggested that the guiding factor in this regard should be an observation for certain signs which demonstrate the patient's condition is worsening.[80] These signs include the patient ceasing to eat and drink, tiredness, drowsiness, and disorientation.[81] In this regard, the Guideline for Palliative Sedation recognises that there are different disease trajectories and palliative care must adapt for each patient's condition. For instance, certain conditions make it difficult to recognise 'whether the patient is actually in the final stages of life.'[82] On this basis, the Guideline for Palliative Sedation makes reference to the possibility of using 'temporary or intermittent sedation'[83] as a way of recognising the true condition of the patient. It also suggests that this form of sedation gives the doctor an opportunity 'to evaluate the situation with the patient and/or family and if necessary to review the management of the case.'[84] This demonstrates that the Dutch guideline aims to provide palliative care appropriate to each patient's needs. Such a patient-centred approach is further displayed by the fact that in these complicated situations the 'committee considers the advice of a consultant, preferably a palliative specialist, to be mandatory'.[85] The inclusion of such requirements serves to demonstrate the comprehensive nature of the Guideline for Palliative Sedation. It also begins to highlight the range of parties which

[79] M Vermeulen, 'Zachte dood komt soms te vroeg' De Volkskrant (23 may 2007) quoted in Janssens (n48) 665 'It is unprofessional to render a person with a long life expectancy asleep and refrain from hydration and nutrition. That's just euthanasia with other means, because without food and fluid everyone dies after a week.'

[80] Janssens (n48) 665 'Yet, estimating prognosis is often difficult and dependent on several characteristics of the dying phase.'

[81] Royal Dutch Medical Association (n51) 26 'But once a number of characteristics of the phase of dying have been observed, it can be assumed that the patient is approaching the point at which death is inevitable. The most characteristic feature is that patients virtually cease to eat and drink. In addition, they are frequently cachectic, tired and debilitated and bedridden. They may also be drowsy and disoriented. Such signs that a patient is dying, combined with the worsening symptoms of disease, guide the decision-making process.'

[82] ibid 27; ibid 26-27 'The committee is not thinking here of cancer patients, but of conditions such as muscular dystrophy, amyotrophic lateral sclerosis (ALS), or cardiac or respiratory insufficiency. In some cases of this kind, it is hard to be certain whether the patient is actually in the final stages of life. It is important to avoid the premature initiation of continuous sedation until the time of death.'

[83] ibid 27.

[84] ibid.

[85] ibid.

may be involved in the decision-making process for the administration of palliative sedation.

The Decision-Making Process for Palliative Sedation

The decision-making process is set out in the fourth chapter of the KNMG Guideline for Palliative Sedation. There are three steps to be taken in making the decision to administer palliative sedation. These stages are; 'the initial proposal',[86] 'determining whether indications for palliative sedation are present',[87] and 'consultation with the patient and/or his representative(s).'[88] These stages are not isolated and may need to be repeated in certain circumstances.[89] The process involved underlines the importance of taking account of all the parties involved in the provision of palliative care such as the nursing staff who have 'regular close contact with the patient'.[90] Information is also to be collected from the patient, other healthcare professionals and the patient's family in order to ascertain the most appropriate approach to the care of the patient. The value of information from healthcare staff involved in the care of the patient is recognised in the Guideline for Palliative Sedation which sets out that:

> The committee would emphasise that the continuity of cooperation, coordination, exchange of information and communication among the various carers is crucial. Poor cooperation and coordination can produce discrepancies in the information received by the various parties involved and these can cause anxiety for the patient, family and indeed staff.[91]

This decision-making process is required regardless of whether the patient is receiving palliative care in a hospital or whether they are being cared for in the home. It highlights the importance of 'clear agreements … between all concerned'.[92] This requires effective transfer of information between healthcare staff and means that they need to share a common understanding of specialist palliative care practices.[93] The

[86] ibid 28.
[87] ibid.
[88] ibid.
[89] ibid 28 'The committee wishes to make the general observation that these stages are not one-off activities or decisions. Far more frequently, they are steps in a longer journey of palliative and other care. Some of the steps in that journey will have to be repeated.'
[90] ibid 29.
[91] ibid.
[92] ibid.
[93] Text to n98 in Chapter Two.

final decision on palliative sedation is made by the attending physician. The Guideline for Palliative Sedation sets out that the decision is to 'specify the aim of sedation … , its nature … , the choice of drugs, and the dose to be administered.'[94] The possibility of requiring consultation with an expert in palliative care is also addressed in the Guideline.

Requirements for Consultation

The KNMG Guideline attempted to distinguish palliative sedation from euthanasia and this required establishing a distinct decision-making process. As part of this, the Guideline for Palliative Sedation sets out that:

> given the nature and content of palliative sedation and the medical indications set forth in this guideline, the committee sees no need to insist that an expert physician be consulted at all times before deciding to administer palliative sedation.[95]

Nevertheless, the Guideline suggests that if a doctor is uncertain about his own expertise or finds it challenging to balance the various considerations which are part of deciding whether to provide palliative sedation then 'it is standard professional practice to consult the appropriate expert in good time.'[96] As such, to seek the advice of a consultant in such an instance would be common practice but the Guideline does emphasise the serious consequences of palliative sedation and describes it as a 'radical medical procedure'.[97] In this regard, the Guideline strives to achieve a decision-making process which pays heed to the impact of palliative sedation on a patient while attempting to distinguish the decision-making process from that implemented under section 2 of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001*.

Research on the level of consultation which occurs suggests that the number of cases in which the opinion of an expert is sought is not high. In a 2008 study conducted by Rietjens et al. it was shown that 'in 9% of the cases of palliative sedation, palliative

[94] Royal Dutch Medical Association (n51) 30.
[95] ibid.
[96] ibid.
[97] ibid.

consultation was requested in the last month before death.'[98] It would be harmful to the care of the patient if consultation is largely avoided in an effort to emphasise that palliative sedation is a normal medical practice. At the heart of the decision-making process for both palliative sedation and the termination of life on request is the care of the patient. On this basis, a decision to avoid a consultation should not be driven by the desire to distinguish the decision-making framework in palliative sedation from that required for euthanasia. Instead, palliative sedation and the termination of life on request should be distinguishable in substance rather than needing to emphasise distinctions in the decision-making process.

The role of consultation in deciding to administer palliative sedation has also been demonstrated in research from de Graeff et al.[99] This research revealed that 'in 41% (47 out of 113) of the cases where the palliative consultation team of the Integral Cancer Center for Central Netherlands was consulted on palliative sedation, a negative advice was given.'[100] The reasons for such advice included symptoms not being considered refractory or that life expectancy exceeded two weeks. The high percentage of cases where palliative sedation was deemed inappropriate suggests that consultancy is an important safeguard in protecting a patient's human rights and assists in distinguishing palliative sedation from euthanasia. Nevertheless, these figures could be interpreted as suggesting that consultation was sought in complex situations which required the opinion of an expert in palliative care. Such an interpretation would suggest doctors are judicious about seeking consultation. Regardless of this, it is important to get the views of a range of people as part of the decision-making process. The views of the patient are particularly important due to the right of autonomy, and the discussion with the patient and/or their representative on the possibility of palliative sedation has been assigned guidelines detailing what issues are to be addressed over the course of several conversations.

[98] Judith Rietjens and others, 'Continuous deep sedation for patients nearing death in the Netherlands: descriptive study' (2008) 7648(336) British Medical Journal 810 cited in Janssens (n48) 666.
[99] A de Graeff, 'De rol van consultatie bij palliatieve sedatie in de region Middenederland' (2008) 152 Ned Tijdschr Geneesk 2346 quoted in Janssens (n48) 667.
[100] ibid.

Discussion with the Patient and/or his Representative

The informed consent of a patient is necessary for the administration of palliative sedation but if the patient is not capable of making an informed decision then a representative of the patient must be consulted. The possible representatives of the patient are set out by the *Medical Treatment Contracts Act* in the Netherlands.[101] This legislation serves to establish an order of eligibility for the representation of a patient. The Guideline for Palliative Sedation addresses the different situations which are likely to arise and provides guidance on the discussion which is to take place. In relation to discussion with the patient, the Guideline suggests that the consent of a patient should be 'sought while the patient is still lucid.'[102] Furthermore, discussion with the patient is to include an explanation of palliative sedation. This allows the patient to understand their prognosis and the impact which palliative sedation would have on them.[103] The second category for discussion involves the 'Specific wishes and views of the patient'.[104] This allows the patient to discuss their concerns or anxieties about the 'process of dying',[105] their views on organ donation, spiritual care, and physical care during palliative sedation.[106] Discussion on these points may serve to ease the anxiety of the patient and lessen the need for sedation once a patient's concerns are addressed. The third category to be discussed addresses issues such as the provision of 'support for the patient's family'.[107] This underlines the breadth of the decision-making process and the clarity in communication between doctor and patient which is required in the Netherlands.[108] These are important steps to take in respecting

[101] In order of eligibility: the patient's legal representative (a guardian or mentor appointed by the Court), if he has one; whom failing a personal representative; whom failing his spouse, partner or companion; whom failing a parent, child, brother or sister.; Text to n282 in Chapter Four for discussion of the Assisted Decision-Making (Capacity) Bill 2013.

[102] Royal Dutch Medical Association (n51) 31.

[103] ibid 32 The issues to be discussed include: 'The patient's condition, life expectancy and prospects', 'The indications for and purpose of palliative sedation', 'The options in the case of unbearable and untreatable suffering', and 'The consequences of palliative sedation.'

[104] ibid.

[105] ibid.

[106] ibid The medical practitioner is to discuss the wishes of the patient on subjects such as 'organ donation', 'physical care during palliative sedation', 'non-administration of artificial nutrition/hydration', and 'The desire of the patient to receive the support of a spiritual advisor or other individual in relation to religious or ethical matters.'

[107] ibid 32-33 There is to be discussion with the family in order to help them understand the condition of the patient and the care to be provided. In addition to this, the medical practitioner is to properly inform 'the patient's designated representative during palliative sedation', and to provide 'information about consultations with additional experts (if applicable).'

[108] Chapter Five demonstrated that such detail is not contained in the professional standards of the Irish Medical Council or An Bord Altranais.

the patient's right of autonomy. For example, Beauchamp and Childress set out that respect for autonomy in medical care 'requires much more than avoiding deception and coercion. It requires an attempt to instill relevant understanding, to avoid forms of manipulation, and to respect persons' rights.'[109]

The KNMG Guideline also provides for situations where the patient may lack the necessary capacity to make decisions relating to their healthcare. Depending on the condition of the patient it may be necessary that the discussion be had with the patient's representative instead of the patient. However, in such cases it is still necessary that the patient 'be involved in the decision-making process as far as possible.'[110] This discussion is based on the same issues as set out above and concentrates on the interests of the patient. In any case it appears that the doctor has the final say in the administration of palliative sedation and it is possible that the opinion of a representative be ignored and palliative sedation provided without consent if necessary. This is a troublesome aspect of the guidance and suggests a paternalistic element in the decision-making process. In this regard, Beauchamp and Childress set out that:

> If shared decision making is presented as a plea merely for patients to be allowed to participate in decision making about diagnostic and treatment procedures, it continues the legacy of medical paternalism by ignoring patients' rights to consent or to refuse those procedures.[111]

Nevertheless, the Guideline for Palliative Sedation sets out that:

> As a rule … it is extremely important that a consensus should be reached between medical staff and the patient's family about the aim of the treatment (to relieve suffering and not to shorten life), the procedure that is appropriate to achieve this, and the consequences that it is likely to have. Such agreement is in the interests both of the patient and his family.[112]

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[109] Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 121.
[110] Royal Dutch Medical Association (n51) 33.
[111] Beauchamp (n109) 122.
[112] Royal Dutch Medical Association (n51) 33.

Part of the procedure in relieving a patient's suffering may be the withdrawal of artificial nutrition and hydration. The legal and ethical issues this raises have been set out in several chapters of this thesis so far and the manner in which the Dutch Guideline address the administration of fluids is especially important in recognising and establishing the demarcation between specialist palliative care practices and euthanasia.

The Administration of Fluids in Palliative Care

Chapter five of the 2009 Guideline for Palliative Sedation addresses the administration of fluids in palliative care. The Guideline considers situations where the patient is able or unable to take fluids or 'Does not wish to take fluids or have them administered.'[113] The Guideline for Palliative Sedation sets out that for patients who are able to take fluids and wish to continue doing so then 'superficial, brief or intermittent palliative sedation is a possible alternative.'[114] This avoids the patient being deprived of hydration and is a step in distinguishing specialist palliative care from euthanasia. The Guideline set out a number of factors which are to be considered in deciding whether to withdraw hydration from a patient who is unable to take fluids. The general guidance on this issue is that when palliative sedation is being administered it is 'futile' to also provide fluids.[115] Treatment is considered futile in circumstances where 'the resources involved unreasonably outweigh the potential benefits of the treatment.'[116] On this point, the Guideline suggests that the provision of artificial hydration 'may even prolong suffering or exacerbate it by increasing oedema, ascites, bronchial secretions, urine production and incontinence.'[117] In contrast to this, the literature reviews cited in Chapter Two did not identify such a clear position on the withdrawal of artificial nutrition and hydration.[118]

The Guideline for Palliative Sedation underlines the distinction between decisions to provide sedation and to withdraw hydration, for example, 'The decision-making

[113] ibid 36.
[114] ibid.
[115] ibid 36; Jeroen GJ Hasselaar and others, 'Changed Patterns in Dutch Palliative Sedation Practices After the Introduction of a National Guideline' (2009) 169(5) Archives of Internal Medicine 430, 436 'The RDMA guideline does not recommend artificial hydration during sedation because parenteral hydration increases the risk of edema and incontinence.'
[116] Royal Dutch Medical Association (n51) 36.
[117] ibid.
[118] Text to n198 and n199 in Chapter Two.

regarding fluids is in all cases a separate decision, which precedes the decision to initiate continuous sedation.'[119] This approach seems to cloud the distinction between the practices which the Guideline seeks to emphasise; while they may be considered separate decisions they are closely linked. In effect, sedation cannot be administered until a decision on the withdrawal of hydration has been taken, i.e. 'The actual initiation of continuous sedation will therefore only take place once the patient has decided to refuse fluids, has shown consistency in this respect, *and* exhibits a refractory symptom.'[120] As such, the decision-making process for administering palliative sedation requires the question of withdrawing hydration from the patient to also be addressed. The KNMG appear to be distinguishing palliative sedation from euthanasia on very narrow ground in the Guideline. For example, the Guideline states that:

> The committee would emphasise that two distinct decisions are involved here, which are taken together, but where the key lies in the initial decision by the patient himself. The order in which the decisions are taken and the existence of an interval between the two separate decisions are crucial.[121]

The fact that these decisions are so closely related is problematic in fully demarcating the role of specialist palliative care. It can be said to leave room for accusations that specialist palliative care is a form of euthanasia in disguise.[122] However, the Guideline does recognise the problems these decisions raise and places a special emphasis on the correct decision-making process. This promotes consistency among healthcare professionals and among healthcare facilities which provide specialist palliative care. In effect, by recognising and addressing the complex decisions which doctors face on a day to day basis it is possible to remove the image of decisions being taken on an ad-hoc basis. This is an important step in protecting the rights of a patient, providing clarity to healthcare professionals, and distinguishing specialist palliative care from euthanasia. In line with this, the Guideline clearly categorises artificial hydration as a

[119] Royal Dutch Medical Association (n51) 36.
[120] ibid 37 (emphasis in original).
[121] ibid.
[122] J Andrew Billings and Susan D Block, 'Slow euthanasia' (1996) 12 Journal of Palliative Care 21; BM Mount, 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes' (1996) 12 Journal of Palliative Care 31; H Brody, 'Commentary on Billings and Block's 'Slow Euthanasia'' (1996) 12 Journal of Palliative Care 38; Sjef Gevers, 'Terminal Sedation: A New Legal Approach' (2003) 10 European Journal of Health Law 359, 360.

'medical procedure'[123] rather than a form of medical care. Further to the decision-making process around artificial hydration it is essential to consider the guidance on the administration of palliative sedation.

The Administration of Palliative Sedation

Chapter six of the 2009 Guideline for Palliative Sedation focuses on issues relating to the administration of palliative sedation such as 'the preparations to be made, the initiation of sedation, proportionality, the drugs to be used and the method of administration, morphine and sedation, and … accompanying measures.'[124] The Guideline for Palliative Sedation goes so far as to specify the type of drug which should be used in palliative sedation as well as providing detail on the amount which should be originally administered,[125] issues of timing and the approach to be taken for continuous sedation.[126] The preparations to be made include informing 'all the professionals involved in the case', and requires the doctor to 'establish plans for the initiation procedure and later stages of the treatment (including details of how, when and by whom sedation may be initiated or the dose increased).'[127] This demonstrates awareness that a variety of healthcare professionals are involved in the care of the terminally ill patient. In order to ensure continuity of care it is vital that healthcare professionals share a harmonious understanding of the type of care which can and should be provided. This was shown to be a failing in the provision of palliative care in this jurisdiction. For example, it was highlighted in Chapter Two that doctors and nurses in Ireland did not share the same interpretation of specialist palliative care.[128] Furthermore, the 'Practice Standards for Nurses and Midwives with Prescriptive Authority' in Ireland merely listed the types of drugs suitable for palliative care and their route of administration.[129] The juxtaposition of the Irish and Dutch guidance underlines the weaknesses in the Irish legal framework for specialist palliative care.

[123] Royal Dutch Medical Association (n51) 37.
[124] ibid 38.
[125] ibid 39 'Midazolam is currently regarded as the preferred drug. Arguments in its favour are its short half-life, which means that treatment can be rapidly adjusted, and the considerable experience already gained with it in cases of palliative sedation.'
[126] ibid 39-40.
[127] ibid 38.
[128] Text to n95 and n96 in Chapter Two.
[129] Text to n179 in Chapter Five.

The KNMG Guideline recognises the importance of a 'multidisciplinary approach'[130] to palliative care and states that 'Nursing staff can contribute important input for drawing up the indications, estimating whether the conditions have been met, and implementing palliative sedation.'[131] On this basis, it is important for the care of the patient that there is clear and effective communication between the doctor and the nurse. The Guideline recognises the challenges that may occur at the beginning of sedation and highlights the importance of co-operation between the healthcare professionals involved in the care of the patient. For example, the Guideline states that:

> Situations may arise in the initial stage in which the physician must be able to intervene (for example, the patient may become delirious or sedation may be too superficial, or indeed too deep). After this, the administration of sedation can be left in large measure to nurses and other carers. They should then be properly informed and instructed, in particular about when to consult the physician.[132]

This provides practical guidance and gives clarity to all parties involved in the care of the patient. Other issues dealt with in the guidelines include effective '[r]ecord-keeping and evaluation'[133] and guidelines on how to deal with the patient's family.[134] Nonetheless, the Guideline for Palliative Sedation is only effective if it is actually used by doctors in the Netherlands. On this basis, it is necessary to consider the actual impact the KNMG Guideline has had.

The Impact of the KNMG Guideline for Palliative Sedation

A comprehensive study on the impact of the 2005 Dutch national guidelines for palliative care was conducted by Hasselaar et al.[135] In conducting this survey a baseline measurement was taken between the 1st February 2003 and the 1st May 2005. This involved 492 physicians including medical specialists, general practitioners, and nursing home doctors. After the national guideline for palliative sedation was introduced a follow-up study was conducted between the 1st January 2007 and the 30th

[130] Royal Dutch Medical Association (n51) 38.
[131] ibid.
[132] ibid 39.
[133] ibid 42.
[134] ibid 46.
[135] Hasselaar (n115).

June 2007. The follow-up study was based on the 492 physicians in the baseline measurement. It asked these physicians to 'report on their last case of deep and continuous sedation in the past 12 months.'[136] It can be noted that the results in this study reflect the changes brought about by the original guidelines prior to the refinements introduced by the 2009 guidelines. As such, this research examined the practice of palliative sedation in the two years before and after the introduction of the 2005 guidelines.[137]

The results of the study by Hasselaar et al. demonstrated an 'increase in patient involvement in decision making'.[138] For example, patient involvement increased from 72.3% to 82.2% between the two periods.[139] Furthermore, discussion of sedation between patient and doctor rose from '40.1% in the first period to 49.3% in the second period'.[140] Although there has been an increase in patient involvement in decision-making there is still a considerable percentage of patients with whom no discussion took place. However, it appears that increased discussion may be having an impact on the number seeking euthanasia or physician assisted suicide. It has been suggested that the fear of pain often 'leads to suicide ideation or the request for euthanasia'[141] and encourages 'public support for assisted-suicide and euthanasia.'[142] This fear may be addressed through discussion with the patient so they understand the level of care they will receive, should they need it. For instance, since the introduction of the KNMG Guideline there was a decrease in patient's requests for euthanasia.[143]

In the first period, the figure requesting euthanasia amounted to 14.5% while in 2007 this figure had dropped to 6.3%.[144] As such, the clear guidelines and the required discussions on patient care may serve to ease many of the fears patients have near the

[136] ibid 430.
[137] ibid.
[138] ibid.
[139] ibid.
[140] ibid 432; ibid 432 'the proportion of physicians that did not discuss sedation with the patients who did receive it decreased from 27.6% to 17.8%.'
[141] Susan Anderson Fohr, 'The Double Effect of Pain Medication: Separating Myth from Reality' (1998) 4(1) Journal of Palliative Medicine 315, 326.
[142] ibid.
[143] Hasselaar (n115) 432 'Finally, patient requests for euthanasia before sedation occurred significantly less often in 2007 (6.3%) compared with the first period (14.5%)'.
[144] ibid.

end of life.[145] Hasselaar et al. also advanced the argument that this change in figures might simply represent a 'more straightforward patient preference for palliative sedation at the end of life.'[146] Research has shown that continuous deep sedation is being administered more often in 2010 than it had been in 2005.[147] In any case this underscores the importance of a clear legal framework to support the provision of specialist palliative care. The absence of a clear legal framework in Ireland means these practices are provided with less regulation and less oversight. The lack of an appropriate legal framework also furthers suggestions that specialist palliative care closely resembles the practice of euthanasia.

An aspect of the guidelines which was seen as problematic was the lack of a requirement for explicit consent for the administration of terminal sedation. Despite worries about this, the research by Hasselaar et al. actually demonstrated that 'sedation was initiated significantly less often without patient involvement in the decision-making process.'[148] As such, clear guidelines on palliative sedation appear to provide the patient with greater certainty as regards their care and allows for more open discussion between patient and physician of possible treatment choices in palliative care. In addition to this the doctor has clear guidelines within which to work and the system of involving specialist palliative care consultants ensures that palliative sedation is not administered in unsuitable cases. The research also demonstrated a significant increase in the use of benzodiazepines for sedation rather than use of morphine.[149] This is in line with recommendations contained in the Dutch

[145] The alternative interpretation of these figures is to suggest that doctors view specialist palliative care as being in some way more acceptable than euthanasia and that it is on this basis that specialist palliative care is favoured. Were such a criticism shown to be true it could have serious consequences for the distinction between specialist palliative care and physician assisted suicide.
[146] Hasselaar (n115) 436.
[147] Bregje D Onwuteaka-Philipsen and others, 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey' (2012) 380(9845) Lancet 908, 908 'Continuous deep sedation until death occurred more frequently in 2010 (12·3%) than in 2005 (8·2%). Of all deaths in 2010, 0·4% were the result of the patient's decision to stop eating and drinking to end life; in half of these cases the patient had made a euthanasia request that was not granted.'
[148] Hasselaar (n115) 435.
[149] ibid 433 'benzodiazepines were more often prescribed for continuous sedation after the introduction of the guideline than before (69.9% and 90.4%, respectively) … A similar use of benzodiazepine combined with morphine was prescribed before (51.9%) and after the introduction of the guideline (51.9%), whereas the use of benzodiazepine without morphine increased after the introduction of the guideline (from 30 [18.8%] to 58 [36.3%]) … However, in total, the application of symptom-directed treatment remained comparable during both periods (55.6% in the first period and 58.1% in the second period)'.

guidelines.[150] The reason for favouring benzodiazepines as a sedative is due to the 'unpredictable sedative and side effects'[151] of morphine. It appears that as of 2007 these guidelines were already having a significant impact on the provision of palliative care in the Netherlands.[152]

Further concrete evidence as to the impact of the guidelines is available in the form of statistics which suggest that the use of guidelines by medical practitioners in the Netherlands has increased in the past number of years. For example, 60.1% of doctors in 2007 referred to some form of guideline when sedating a patient.[153] Although this figure may appear low, it represents a doubling in the use of guidelines since 2003.[154] Of particular importance for this thesis is the fact that 78.1% of doctors who administered palliative sedation were 'familiar with the RDMA guideline'.[155] It is likely that this figure will continue to rise when it is recognised that a number of other guidelines on palliative care have emerged in the period since the drafting of the KNMG Guideline for Palliative Sedation such as those published by the Comprehensive Cancer Centre the Netherlands.

Oncoline Guidelines

The Integraal Kankercentrum Nederland (Comprehensive Cancer Centre the Netherlands) [hereinafter 'IKNL'] is an organisation which 'facilitates the development, implementation and evaluation of guidelines for oncological and palliative care in the Netherlands.'[156] As part of this, the IKNL operates an online database[157] through which it is possible to consult both national and regional clinical practice guidelines and practice guidelines for nursing care. The oncoline.nl database

[150] Royal Dutch Medical Association (n51) 40.
[151] Rietjens (n98) 6.
[152] Hasselaar (n115) 435.
[153] ibid 432.
[154] ibid.
[155] ibid Note that higher percentages do exist depending on the area of practice. 83.9% of medical specialists reported familiarity with the KNMG guideline while this figure stood at 67.2% for general practitioners and 90.3% for nursing home physicians. RDMA stands for Royal Dutch Medical Association.
[156] Cancer Clinical Practice Guidelines, 'What to Find on Oncoline' <http://www.oncoline.nl/index.php?language=en> accessed 2 March 2014.
[157] ibid.

contains a broad range of guidelines relevant to palliative care of the patient.[158] Each guideline has differing levels of applicability based on the organisation responsible for its drafting. Palliative care guidelines listed on the Oncoline site include guidelines on delirium,[159] dyspnoea,[160] nausea and vomiting,[161] pain,[162] and palliative sedation.[163] It is not possible to examine each of these guidelines individually in this chapter and for this reason it is necessary to be selective. Although the guideline on palliative sedation is one of the more relevant guidelines for this thesis, the content of this guideline largely resembles the KNMG Guideline for Palliative Sedation. As such, this section will focus on the guideline on pain as the identification, measurement, and treatment of pain is a primary concern in the provision of specialist palliative care.

Guideline on Pain

The subject of pain was first addressed in a 1996 guideline by the Comprehensive Cancer Centre Middle Netherlands. A 2005 revision of the guideline formed part of the Vereniging Integrale Kankercentra (Association of Comprehensive Cancer Centres) [hereinafter 'VIKC'] book on clinical practice guidelines.[164] Further revision to the guideline was made in 2008 and 2010. These new versions of the guideline incorporated 'recommendations from the CBO/VIKC guideline 'Diagnosis and treatment of pain in cancer patients''.[165] In terms of applicability, the guideline recognises that 'circumstances may arise'[166] where it will not be possible to accurately follow the guideline. In such cases, the medical practitioner must demonstrate that there was a good reason for such deviation. Overall, the medical practitioner is 'responsible for determining the applicability of the guideline and the application of the guideline itself.'[167] It is likely that this guideline forms a substantial part of

[158] Guidelines exist on cancer rehabilitation, cancer survivorship care, colon cancer, constipation, delirium, dyspnoea, gastric carcinoma, ovarian carcinoma, prostate cancer, rectal cancer, renal cell carcinoma, screening for psychosocial distress, spiritual care and thyroid carcinoma.
[159] M Bannink, A de Graeff and H Monster, 'Delirium' (Integraal Kankercentrum Nederland 2010).
[160] AAF Baas, Z Zylicz and GM Hesselmann, 'Dyspnoea' (Integraal Kankercentrum Nederland 2010).
[161] A de Graeff, CM Molenkamp and GM Hesselmann, 'Nausea and Vomiting' (Integraal Kankercentrum Nederland 2010).
[162] A de Graeff, TC Besse and RJA Krol, 'Pain' (Integraal Kankercentrum Nederland 2010).
[163] EH Verhagen and others, 'Palliative Sedation' (Integraal Kankercentrum Nederland 2009).
[164] Cancer Clinical Practice Guidelines, 'Oncoline' <http://oncoline.nl/index.php> accessed 3 March 2014.
[165] ibid; CBO stands for Centraal BegeleidingsOrgaan (Dutch Institute for Healthcare Improvement).
[166] de Graeff (n162) 57.
[167] ibid.

palliative care guidance in the Netherlands but unlike the KNMG guideline it does not automatically form part of the physician's professional standards.

The current guideline on pain is divided into a number of sections including introduction, epidemiology, pathophysiology, causes, diagnosis, management and treatment, and stepwise diagnosis and management system. The introduction to this guideline serves to outline and explain the nature of pain. The definition of pain as set out by the International Association for the Study of Pain is quoted[168] as is the definition set out by McCaffery which states that 'pain is what the person experiencing it says that it is and is present when he says that it is present'.[169] The use of this definition serves to underline the subjective nature of pain; a point which has been highlighted at several points in this thesis. In effect, each patient will have differing experiences of pain. The guideline goes into detail on the classification and types of pain which exist. These are divided into categories such as nociceptive versus neuropathic pain,[170] somatic versus visceral pain,[171] breakthrough pain,[172] opioid-induced hyperalgesia[173] and total pain.[174] The details included serve to assist in the identification and classification of pain which the patient may be experiencing. Further background on pain is provided in the epidemiology section of this guideline. This provides an indication of the incidence of pain in cancer patients, with '[m]oderate to severe pain'[175] occurring in 64% of cases.[176] The figure is further broken down by type

[168] International Association for the Study of Pain, 'IASP Taxonomy' <http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698&navItemNumber=576#Pain> accessed 3 March 2014 quoted in de Graeff (n162) 2 'pain is an unpleasant sensory or emotional experience associated with real or potential tissue damage or described in terms of such damage'

[169] Margo McCaffrey, *Nursing Practice Theories Related to Cognition, Bodily Pain, and Man-environment Interactions* (UCLA Students' Store 1968) quoted in de Graeff (n162) 2.

[170] de Graeff (n162) 57 Nociceptive pain is caused by tissue damage. Neuropathic pain may be defined as pain resulting from damage to the peripheral or central nervous system

[171] ibid Somatic pain is nociceptive pain that originates from the skin, connective tissue, muscle tissue or bone. Visceral pain is nociceptive pain that emanates from the internal organs of the thorax or abdomen.

[172] ibid Breakthrough pain is a suddenly occurring, temporary, often severe pain or an increase of pain that occurs in the presence of chronic pain.

[173] ibid 3 Opioid-induced hyperalgesia occurs when the administration of opioids results in hyperalgesia and increased pain.

[174] ibid Pain that is primarily somatic in nature may also be influenced to a large extent by psychosocial factors and/or life philosophy (see Causes). This universal concept of pain is also referred to as 'total pain'.

[175] ibid 4.

[176] ibid '64% of patients with an advanced stage of cancer.'

of cancer.[177] This guideline recognises the role of palliative care beyond cancer patients and to that effect it also provides data on pain caused by other illnesses.[178] This is helpful in encouraging a common understanding between healthcare professionals of the type of care which patients suffering from different illnesses may need.[179] In effect, this type of guideline can foster an improved knowledge of the decisions which need to be taken with the patient in relation to their care and can encourage wider palliative care provision at an appropriate time in the disease trajectory.

Under pathophysiology, the guideline examines dimensions of pain and highlights the impact of cultural factors on the communication of pain as well as broader social factors which may have a negative effect on the health of the patient. An awareness of such factors is vital for 'an integral, i.e. multidimensional, approach that may lead to a more effective treatment of pain.'[180] On this basis, the guideline is following the WHO definition of palliative care in that it is addressing the 'treatment of pain and other problems, physical, psychosocial and spiritual.'[181] Causes of pain are also addressed by this guideline. This facilitates the healthcare professionals understanding of the illness and allows for more focussed palliative care to be provided.

In relation to diagnosis, the guideline suggests that the patient should be given sufficient time 'to verbalise his pain, to discuss his concerns and anxieties, and to indicate to what extent the pain hinders him.'[182] This allows the patient to exercise their right of autonomy and it promotes patient involvement in the decision-making process. However, it does not provide the level of detail found in the KNMG Guideline for Palliative Sedation. In addition to this, the guideline also sets out what is required to establish 'a good pain history'.[183] This includes patient input, consideration of the

[177] ibid 'pancreas, oesophagus: more than 80% of patients', 'lung, stomach, prostate, breast, cervix, ovary: 70-80%', 'oropharynx, colon, brain, kidney, bladder: 60-70%', 'haematological malignancies (multiple myeloma, malignant lymphoma, leukaemia), soft tissue tumours: 50-60%'.
[178] ibid 'AIDS (40-50% of ambulant patients; 80% of hospitalised patients with advanced disease), ALS (60-70%), multiple sclerosis (50-60%), heart failure (41%), COPD (68%), severe renal failure (after withdrawal of dialysis) (40%)'.
[179] Text to n103 in Chapter Two.
[180] de Graeff (n162) 5.
[181] Cecilia Sepúlveda and others, 'Palliative Care: The World Health Organization's Global Perspective' (2002) 24(2) Journal of Pain and Symptom Management 91, 94.
[182] de Graeff (n162) 7.
[183] ibid.

'patient's environment',[184] as well as the need to examine each symptom of pain individually.[185] Guidance is also provided on how to provide care for different levels of pain as well as how to correctly identify the severity of pain.[186]

The measurement and treatment of pain is addressed under a number of sub-headings including; integral approach, treatment of the cause, non-pharmalogical symptomatic treatment, pharmacological symptomatic treatment, adjuvant pharmacological treatment and nervous system interventions. Guidance on pharmacological symptomatic treatment is split between basic pharmacological principles, treatment of nociceptive pain and neuropathic pain. In relation to basic pharmacological principles the guidance sets out the appropriate time frame for the provision of medication as well as the manner of its administration.[187] It can be noted that considerable guidance is provided under the headings of nociceptive pain and neuropathic pain. Under nociceptive pain a variety of medications are discussed.[188] This provides considerably more guidance than that contained in the KNMG Guideline for Palliative Sedation. The same can be said for guidance on neuropathic pain, adjuvant pharmacological treatment, and nervous system interventions. Although this guideline does not provide direct guidance on specialist palliative care it does equip the medical professional with the information necessary to make complicated decisions on end-of-life care due to its in-depth discussion on medicines used in palliative care.

The IKNL guidelines are complementary and serve to develop their own framework for palliative care. However, it becomes apparent in looking at the suite of guidelines on the oncoline site that regulation and guidance for specialist palliative care practices is just one aspect of caring for the terminally ill patient. Specialist palliative care practices are not provided in isolation but form the end stages of palliative care. As

[184] ibid.
[185] ibid.
[186] ibid The guideline suggests the use of a diary in which the patient records severity of pain twice a day. In assessing the score the medical practitioner is to take account of the circumstances in which the measurement is made. Furthermore, special observation scales are to be used when the patient does not have sufficient capacity.
[187] ibid 15 Instead of administering on an 'as required' basis a fixed schedule is used in which the time intervals are determined by the duration of effectiveness of the drug. 'If opioids are administered orally for maintenance treatment of pain then the opioids prescribed (morphine, oxycodone or hydromorphone) should be slow-release preparations.'
[188] ibid 16-22 Drugs discussed include: paracetamol, NSAIDs, opioids, morphine, fentanyl, oxycodone, hydromorphone, methadone, tramadol, buprenorphine.

such, specialist palliative care can be most effective when broader measures are in place which have the aim of establishing optimum care for the patient. At a minimum, clear guidelines on palliative sedation appear to provide the patient with greater certainty as regards their care and allows for more open discussion between the patient and physician of possible treatment choices in palliative care. In addition to this, the doctor has clear guidelines within which to work and the system of involving specialist palliative care consultants ensures that palliative sedation is not administered in unsuitable cases. The Dutch guidelines are well rounded by considering patient and doctor concerns as well as addressing areas of potential criticism.

Conclusion

Fohr has commented that uncertainty may ultimately have the severest impact on patients as it could be seen as 'directly contributing to the under treatment of suffering at the end of life.'[189] This not only relates to the level of sedative administered but in other cases it may mean that treatment is not provided in order to avoid subsequent decisions on treatment withdrawal.[190] This underlines the importance of a clear and consistent legal framework to support the provision of specialist palliative care. This chapter has highlighted an alternative legal framework for the regulation of specialist palliative care. In this regard it has demonstrated that the major difference between the Dutch and Irish system of palliative care is the existence of clear and comprehensive professional guidelines for specialist palliative care in the Netherlands. It was also established that clear guidelines can strengthen the distinction between specialist palliative care and euthanasia.

Palliative care in Ireland can be said to have developed in an ad hoc fashion as there was no central plan for its development and expansion. The result of this is that the provision of palliative care in Ireland can be seen as fragmented. The Netherlands shares a similar background to the development of palliative care but steps have been taken to encourage a uniform level of care across healthcare facilities. Such an approach is necessary to promote understanding and standards of care.

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[189] Fohr (n141) 326.

[190] Beauchamp (n109) 160 (emphasis in original) 'Giving priority to withholding over withdrawing treatment can lead to *overtreatment* in some cases, that is, the continuation of no longer beneficial or desirable treatment for the patient. Less obviously, the distinction can lead to *undertreatment*. Patients and families worry about being trapped by biomedical technology that, once begun, cannot be stopped.'

It would not be realistic or practical to attempt to draft legislation which would have a comparable effect to the KNMG Guideline for Palliative Sedation or the suite of guidelines accessible on the oncoline website. Medical knowledge on end-of-life care has developed considerably in the past number of decades and guidelines need to be able to quickly adapt and reflect advances in medicine. Furthermore, the KNMG Guideline for Palliative Sedation paid attention to the ongoing cooperation between doctors and nurses in providing palliative care. It is not sufficient for professional standards to largely ignore the role of other healthcare professionals and this is a point which must be addressed in a more detailed manner in Ireland. Overall, the legal framework for specialist palliative care in the Netherlands directly tackles the distinction between specialist palliative care and euthanasia and demonstrates that in order to advance the care of the terminally ill patient there can be no unanswered questions about the legitimacy of the practices involved.

CONCLUSION

The introduction to this thesis quoted the poet Philip Larkin who wrote that '[m]ost things may never happen: this one will'.[1] Although the inevitability of death is certain there is no reason why pain or suffering experienced by the patient at the end of life should go unaddressed. In this regard, specialist palliative care has a valuable role as a 'holistic and multidisciplinary approach to care'.[2] In order to fully achieve this role it is important that there is an appropriate legal framework in place which provides guidance on specialist palliative care practices for both the healthcare professional and the patient. Medical practice should not be unnecessarily hampered or further complicated due to the lack of an appropriate legal framework.

This thesis set out to advance the argument that the current legal framework in Ireland for specialist palliative care is inadequate and consequently a more appropriate legal framework which addresses the challenges raised in practice must be identified. This argument has been advanced over the course of the previous six chapters and has been drawn out through the three central research questions posed in this thesis. This concluding Chapter will first emphasise the factors around palliative care which illustrate the importance and necessity of this thesis. These factors include the limited legal analysis of specialist palliative care practices, the fragmented legal framework which currently exists in Ireland for specialist palliative care, and the legal concerns arising from the provision of palliative sedation and the withdrawal of artificial nutrition and hydration. Second, the central research questions which have formed the backbone of this research will be addressed individually. The substantive arguments stemming from the exploration of these central research questions will be outlined and the main findings, in respect of each, will be highlighted. Finally, drawing on the key findings of the thesis, the concluding section will suggest ways in which the legal framework in Ireland for specialist palliative care can develop so as to promote greater clarity, consistency, human rights protection, and respect for the four principles as set out by Beauchamp and Childress.

[1] Philip Larkin, 'Aubade' in Harold Pinter, Geoffrey Godbert and Anthony Astbury (eds) *100 Poems by 100 Poets* (Methuen 1986) 93.
[2] Irish Hospice Foundation, 'Primary Palliative Care in Ireland' (Dublin 2011) 3.

The Importance of Examining Palliative Care

As discussed in Chapter One and Two, the importance of examining the legal framework in Ireland for specialist palliative care is based on the fact that palliative care is an increasingly prevalent form of care provided to patients and it is likely that the number of patients receiving palliative care will increase in the coming years.[3] This is underlined by the expansion of palliative care providers,[4] the breadth of illnesses which palliative care addresses[5] and the development of specialist palliative care practices.[6] Despite the increasing significance of the legal framework, there has been limited legal analysis and policy discussion in Ireland on issues such as the decision-making framework needed for specialist palliative care practices,[7] or the controversial aspects of this form of care. Instead, the discussion of specialist palliative care has largely been from a medical perspective.

A fundamental matter in the legal framework for specialist palliative care is the need to distinguish specialist palliative care practices from euthanasia. The legitimacy of this distinction has often been questioned and is an issue which needed to be addressed in a sustained and extensive manner. The main challenges identified for administering palliative sedation include the difficulty of recognising the symptoms which may require palliative sedation,[8] and the difficulty in accurately judging an appropriate level of sedative drug which avoids toxicity and does not hasten the death of the patient. On the surface these appear to largely be medical concerns but there is a significant legal undercurrent to these decisions. This close relationship between medical and legal concerns persists in the decision to withdraw artificial nutrition and hydration from the patient. For example, questions arise in relation to the categorisation of artificial nutrition and hydration and the question of liability under the *Criminal Justice Act 1964* for withdrawing artificial nutrition and hydration.

The challenges stemming from the use of palliative sedation and the withdrawal of artificial nutrition and hydration emphasise the difficulty of identifying an appropriate

[3] Text to n46 in Chapter One.
[4] See p43.
[5] Text to n62 in Chapter One.
[6] Text to n16 in Chapter One.
[7] See pp11-12.
[8] Text to n139 in Chapter Two.

legal framework for specialist palliative care in Ireland. The legal framework must serve to protect the human rights of a patient, avoid unnecessarily constraining the decision making autonomy of the healthcare professional, and reflect the four principles espoused by Beauchamp and Childress. It should be remembered that the examination of the four principles was not the primary focus of this thesis but their function is to assist in the creation of more precise rules. As outlined in Chapter Two, the legal framework for specialist palliative care must also be clear and consistent in order to be effective. This point is supported by De Haan who recognised the potential role of regulation in stating that 'physicians are entitled to be "governed by rules which are fixed, knowable, and certain".'[9] On this basis, it was necessary to consider the legality of specialist palliative care practices under Irish law before the broader legal framework could be examined and any suggestions for reform be advanced.

The Legitimacy of the Distinction between Specialist Palliative Care Practices and Euthanasia

Specialist palliative care aims to tackle the pain experienced by the patient at the end of life and the manner in which this is achieved has led to suggestions that it is a form of euthanasia. The lack of clarity in the distinction between specialist palliative care practices and euthanasia was illustrated at the outset of Chapter Three which highlighted suggestions that 'morphine drips in such cases are a form of "slow euthanasia"'[10] and that 'palliative care is an alternative to permitting euthanasia on grounds of compassion'.[11] Despite this, the provision of palliative sedation has been justified by medical practitioners, ethicists, and lawyers on the basis of the doctrine of double effect.

Chapter Three set out recent interpretations of the doctrine of double effect and applied the criteria for double effect set out by Williams to palliative sedation. It was illustrated in Chapter Three that the criteria for double effect can be satisfied in instances where

[9] Joseph Raz, *The Authority of Law* (Oxford University Press 1979) 214-15 quoted in Jurriaan De Haan, 'The new Dutch law on euthanasia' (2002) Medical Law Review 57, 61.
[10] J Andrew Billings and Susan D Block, 'Slow euthanasia' (1996) 12 Journal of Palliative Care 21; B Mount, 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts' (1996) 12 Journal of Palliative Care 31; H Brody, 'Commentary on Billings and Blocks "Slow Euthanasia"' (1996) 12 Journal of Palliative Care 38.
[11] James Gilbert, 'Palliative medicine: a new specialty changes an old debate' (1996) 52(2) British Medical Bulletin 296, 297.

palliative sedation is provided. In this regard, it was argued that the administration of the sedative drug is morally good, the bad effect of hastening the patient's death is not a means of achieving the good effect, the intention in palliative care is directed towards the relief of suffering, and the relief of pain at the end-of-life is a sufficient reason to risk hastening the patient's death. As such, all four criteria for double effect, as set out by Williams, can be satisfied for the administration of palliative sedation. However, double effect can be interpreted from a variety of perspectives which are unlikely to lead to a homogenous interpretation of the role of double effect in cases of palliative sedation. As such, it was necessary to look beyond theory and examine the manner in which double effect has been considered by the courts.

Cases which raised the concept of double effect such as *R v Adams,*[12] *R v Cox,*[13] and *Moor*[14] were examined in Chapter Three. It was shown that these cases did not examine the application of the doctrine in a head-on or sustained manner.[15] In *Fleming v Ireland*, the role of double effect was indirectly referred to in evidence given by consultant physician in palliative medicine, Dr Tony O'Brien.[16] Furthermore, the doctrine of double effect was cited in the Irish Association of Palliative Care discussion paper on palliative sedation.[17] These references to double effect serve to demonstrate that the doctrine is recognised as part of the clinical practice of palliative medicine in Ireland.[18] Despite this, the doctrine has not yet been fully addressed by case law or legislation in this jurisdiction. Consequently, healthcare professionals are drawing on the doctrine of double effect despite there being no clear legal position on the doctrine or the necessary criteria for the successful application of the doctrine in this jurisdiction. The lack of a clear legal framework for double effect weakens its effectiveness in demonstrating the legitimacy of the distinction between palliative sedation and euthanasia. Much greater legal clarity is needed in distinguishing these

[12] *R v Adams* [1957] Crim LR 773.
[13] *R v Cox* (1992) 12 BMLR 38.
[14] *Moor*, The Times, 12 May 1999.
[15] Text to n208 in Chapter Three; Other cases which have discussed but not 'applied' the doctrine include *R(Pretty) v DPP* [2002] 1 All ER 1; *R(Nicklinson) v Ministry of Justice* [2012] EWHC 2381 (Admin).
[16] *Fleming v Ireland & Ors* [2013] IEHC 2, [38].
[17] Irish Association of Palliative Care, 'Palliative Sedation' (March 2011).
[18] *Fleming v Ireland* [2013] IEHC 2, [34].

practices so healthcare professionals have a clear legal framework in which to provide specialist palliative care.[19]

A further weakness with the doctrine of double effect is that it is of most relevance after the fact, i.e. after an act has occurred. It is not appropriate for healthcare professionals to be guided by a justification when providing palliative care. Instead, greater guidance is needed at an earlier stage in patient care. This guidance should, at a minimum, be clear on indications for palliative sedation, the decision-making framework for palliative sedation, and the practice of commencing palliative sedation. The lack of consistency in the application of the doctrine combined with the fact that it is a justification means that this area is in need of significant reform.

Closely tied to, albeit distinct from palliative sedation, is the practice of withdrawing artificial nutrition and hydration from the patient. The legality of withdrawing artificial nutrition and hydration is based to a substantial degree on whether it is categorised as a form of medical treatment or medical care. This is based on the reasoning that medical treatment can be withdrawn from a patient if it is futile and not in the best interests of the patient whereas medical care should continue to be provided. *Airedale N.H.S. v Bland*[20] and *Re a Ward of Court*[21] categorised the withdrawal of artificial nutrition and hydration as the withdrawal of medical treatment.[22] Therefore, once the treatment was withdrawn a patient would die from their original injuries rather than a lack of food and water. The line of reasoning adopted in these cases is not a particularly convincing approach to the withdrawal of artificial nutrition and hydration. In effect, it appears to have been employed with the pre-determined purpose of not placing liability on the healthcare professional. The weakness in this approach has been highlighted by Hanafin[23] and the President's Commission for the Study of Ethical

[19] John Keown, *The Law and Ethics of Medicine* (Oxford University Press 2012) 319-320 'Lord Joffe, explaining a clause in his Bill on assisted dying for the terminally ill, which would have entitled a terminally ill patient to request and receive such medication as may be necessary to keep him or her as free as possible from pain and distress, said that it was clear that some doctors were frightened of prosecution for using "double effect."'
[20] *Airedale N.H.S. v Bland* [1993] A.C. 789, [1993] 2 WLR. 350.
[21] *Ward of Court (withholding medical treatment) (No 2), Re*, [1995] IESC 1, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.
[22] See Chapter Three.
[23] Patrick Hanafin, *Last Rights*: *Death, Dying and the Law in Ireland* (Cork University Press 1997) 25.

Problems in Medicine and Biomedical and Behavioral Research.[24] All of this suggests that specialist palliative care requires a legal framework with a more substantial grounding in order to ensure that healthcare professionals and patients have certainty about the limits of care and the type of care which can be provided.[25]

Overall, the doctrine of double effect and the acts and omissions distinction serve to distinguish specialist palliative care practices from euthanasia but do not provide the clarity or certainty which is necessary for both the healthcare professional and the patient at the end of life. As stated in Chapter Three, these distinctions will continue to be seen as illusory until a more precise legal framework is introduced. Consequently, it is important that other parts of the legal framework provide a stronger base on which to provide specialist palliative care.

The Current Legal Framework for Specialist Palliative Care in Ireland

The second question asked by this thesis is what legal framework currently exists for specialist palliative care in Ireland. This question was addressed over the course of Chapters Three, Four, and Five. These Chapters discussed constitutional provisions, common law, legal instruments, the European Convention on Human Rights, and professional standards and guidance. This approach was taken so all aspects of the legal framework could be drawn out. This broad examination of the existing legal framework also had the benefit of identifying the foundations upon which an appropriate legal framework can be based.

Chapters Three and Four examined the right to life, right to bodily integrity, protection from inhuman or degrading treatment, the right of autonomy, and the concept of dignity in the context of palliative care. Any legal framework for specialist palliative

[24] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 'Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions' (1983) 61 cited by Glenys Williams, 'Acts and Omissions in Treatment Withdrawal: Conceptual Problems and Policy Decisions' (2008) 39 Cambrian Law Review 75, 87.

[25] Timothy E Quill, Bernard Lo and Dan W Brock, 'Palliative Options of Last Resort: A Comparison of Voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia' in Torbjőrn Tännsjő, *Terminal Sedation: Euthanasia in Disguise?* (Kluwer Academic Publishers 2004) 11 'However, hidden, ambiguous practices, inconsistent justifications, and failure to acknowledge the risks of accepted practices may also undermine the quality of terminal care and put patients at unwarranted risk.'

care has to respect the status human rights occupy in this jurisdiction. The case law on human rights not only demonstrates the necessity of protecting these rights but also the importance of ensuring that an appropriate framework is in place to give effect to these rights.[26]

The case of *A, B, and C v Ireland*[27] demonstrated the importance of an appropriate decision-making framework for the legally and ethically challenging aspects of healthcare. The ECtHR concluded that the authorities had failed to protect the third applicant's right to privacy due to the lack of 'any implementing legislative or regulatory regime providing an accessible and effective procedure by which the third applicant could have established whether she qualified for a lawful abortion in Ireland'.[28] In applying this reasoning to specialist palliative care it is evident that there needs to be a decision-making framework in place which makes it clear for both the patient and the healthcare professional when palliative sedation can be administered and whether artificial nutrition and hydration can be withdrawn.

The ECtHR in *Tysiąc v Poland* set out that such a decision-making framework needs to be 'timely',[29] 'fair'[30] and should not be framed in such a way as to limit its application.[31] Adopting such an approach helps ensure that the rights of the patient can be effectively protected and vindicated. As such, the rights of a patient should not be lessened by virtue of a terminal diagnosis. The existence of a clear framework by which to protect patient rights substantially aids the protection of the right to bodily integrity, protection from inhuman or degrading treatment, and the right of autonomy among others.

A substantial right in providing appropriate end-of-life care is the right of autonomy. This right has been recognised and protected in common law, constitutional provisions, the ECHR, and the Charter of Fundamental Rights. In *Re a Ward of Court* Denham J set out the importance of consent in medical treatment. This requires a

[26] Text to n91 in Chapter One.
[27] *A, B, and C v Ireland* (2010) ECHR 2032.
[28] *A, B, and C v Ireland* (2010) ECHR 2032, [267].
[29] *Tysiąc v Poland* (2007) 45 EHRR 42, [118].
[30] *Tysiąc v Poland* (2007) 45 EHRR 42, [113].
[31] *Tysiąc v Poland* (2007) 45 EHRR 42, [116].

person to be able to make an autonomous decision. The absence of a framework for discussing specialist palliative care decisions with a terminally ill patient in a 'timely' manner would render this right largely ineffective. It could also be viewed as symptomatic of an ad-hoc approach to communication and decision-making in specialist palliative care.

Chapter Four also demonstrated that the status of dignity is not particularly clear and its precise meaning has not been clarified by Irish courts or by the ECtHR. Dignity has been referred to in cases such as *Re a Ward of Court* and *Fleming v Attorney General*. In *Re a Ward of Court* Denham J suggested that there was a right to dignity but little detail was provided as to what the recognition of this right would entail. Despite this, the Supreme Court in *Fleming v Ireland* referred to dignity as being a constitutional value which is recognised and respected by 'the rights protected'[32] in the Irish Constitution. This approach to dignity appears to categorise it as a value or principle rather than as a right in this jurisdiction. The approach of the Supreme Court in *Fleming v Ireland* suggests that the dignity of a patient can be upheld by protecting and vindicating the constitutional rights of the patient. Nevertheless, dignity is a problematic and challenging principle to accurately define as evidenced by discussion of case law and academic commentary in Chapter Four.

It is clear from the preceding discussion that human rights have a vital role in the provision of specialist palliative care and form a central part of the legal framework for this area. Cases such as *A, B, and C v Ireland* and *Tysiąc v Poland* provide a signpost in terms of how human rights in healthcare are to be protected. Consequently, there needs to be clear process in place by which patients can have these rights protected and have their need for specialist palliative care assessed. Such a framework needs to be cognisant of and active in protecting human rights of particular significance to palliative care. Furthermore, there should be clarity as to what is meant in instances where the term 'dignity' is used.

These points were to the fore when examining the professional standards and guidance of the Irish Medical Council [hereinafter 'IMC'] and An Bord Altranais. The

[32] *Fleming v Ireland* [2013] IESC 19, [110].

professional standards of these bodies have begun to address a number of these issues but more work needs to be done in order to raise the professional standards to the level needed for healthcare professionals and patients in the area of palliative care. It was shown that the professional standards issued by bodies such as the IMC and An Bord Altranais are often vague and have a considerable subjective element. This can be explained by their role as guiding principles but the expansion of these professional standards over the years demonstrates that they have assumed a more substantial role in guiding medical practice in Ireland.

Guide to Professional Conduct and Ethics for Registered Medical Practitioners

The IMC Guide to Professional Conduct and Ethics contains sections addressing the dignity of the patient,[33] nutrition and hydration,[34] end-of-life care,[35] consent to medical treatment,[36] and advance healthcare planning.[37] As such, the IMC professional standards address many of the issues relevant to the provision of palliative care. Despite the increase in detail over previous editions of the IMC Guide there are certain weaknesses which persist. For example, the term 'dignity' is used in the Guide to Professional Conduct and Ethics but there is no guidance on how this is to be interpreted. Reference to this principle is not linked to any legal instrument nor is it explicitly grounded in any particular theoretical framework. In addition to this, there is no assistance in recognising when treatment is futile, when appropriate pain management is needed, or what conversations around palliative care should entail.

It is positive though that Section 22.3 of the IMC Guide to Professional Conduct and Ethics addresses a patient's right of autonomy in relation to treatment decisions. The importance of informed consent is also recognised in the Guide to Professional Conduct and Ethics as seen in Section 33[38] and Section 35.[39] However, Beauchamp and Childress set out that 'respect for autonomy in health care relationships requires more than avoiding deception and coercion. It requires an attempt to instill relevant

[33] Irish Medical Council, 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners' (7th edn, Dublin 2009) 14.
[34] ibid 20.
[35] ibid 22.
[36] ibid 33.
[37] ibid 39.
[38] ibid 34.
[39] ibid 36.

understanding, to avoid forms of manipulation, and to respect persons' rights.'[40] On this basis, there needs to be greater guidance around the issues in specialist palliative care which should be discussed with the patient. In addition to this, it is necessary that discussion with the patient occurs at a time when they are capable of communicating their wishes.

In other respects, the Guide to Professional Conduct and Ethics demonstrates the potential of professional standards. For example, it does not have the rigidity of legislation and can be updated easily and regularly to reflect advances in medical knowledge. The Guide to Professional Conduct and Ethics has clear strengths in protecting the human rights of a patient but in the specific context of specialist palliative care it is evident that there are issues of clarity and consistency which need to be improved. For example, much greater guidance is needed on co-operation with other healthcare professionals such as nurses.

An Bord Altranais Code of Professional Conduct

The Code of Professional Conduct does not provide guidance on communication or specialist palliative care practices such as the provision of palliative sedation or the withdrawal of artificial nutrition and hydration. In effect, the code is vague in how best to care for the terminally ill patient. It does little to advance the protection of human rights and due to the subjective nature of the Code of Professional Conduct it does not encourage consistency across the nursing profession.

Chapter Five highlighted that the Code of Professional Conduct has been reviewed by An Bord Altranais and a Draft Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives has been published.[41] In contrast to the current Code of Professional Conduct, this revised document defines how dignity is to be understood. This is a step which was not taken in the previous edition of the Code of Professional Conduct or by the IMC Guide to Professional Conduct and Ethics. The draft Code of Professional Conduct and Ethics sets out that the principle comes from

[40] Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 121.
[41] Nursing and Midwifery Board of Ireland, 'Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives' (October 2013).

the Universal Declaration of Human Rights. Furthermore, the European Convention on Human Rights, the Irish Constitution, and the Equal Status Acts are drawn on as sources 'for the values and standards established for respecting the dignity of the person.'[42] As such, the Code provides detail on values, standards of conduct, and supporting guidance in relation to respecting the dignity of the patient. This is a positive step in providing clarity, consistency and protecting the human rights framework applicable to specialist palliative care in Ireland. It demonstrates that weaknesses identified in other professional standards can be addressed and that they can be built upon to provide greater legal and ethical certainty for both the healthcare professional and the patient.

The professional standards issued by the IMC and An Bord Altranais, due to status and enforceability, provide a more solid foundation on which to improve the legal framework for specialist palliative care than the guidelines published by groups such as the Irish Association of Palliative Care [hereinafter 'IAPC'] and the European Association of Palliative Care [hereinafter 'EAPC']. It was argued in Chapter Five that the reports and guidance issued by bodies such as the IAPC and the EAPC may have a considerable influence on doctors and nurses providing specialist palliative care due to the reliance on local policy. There is a level of detail in the guidance issued by these groups which is not seen in the standards of the IMC and An Bord Altranais. However, the guidance issued by the IAPC and the EAPC are not directly enforceable in this jurisdiction. This severely hampers their potential in terms of delivering on clarity, consistency, and human rights protection across the providers of specialist palliative care in Ireland.

It has been commented that 'Ireland is at an embryonic stage in its embrace of matters medico-legal/ethical at a national and organised level.'[43] This thesis has demonstrated this point in outlining the failings in the current legal framework for specialist palliative care. Nonetheless, the current professional standards can provide the basis for further development. As a result of this it was necessary to examine a jurisdiction

[42] Nursing and Midwifery Board of Ireland, 'Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives' (October 2013) 7.
[43] Asim Sheikh and Cliona McGovern, 'Medicine, Medical Ethics and Law: Their Interplay and Future' (2002) 8 Medico-Legal Journal of Ireland 2, 5.

which sought to develop their professional standards in an attempt to ameliorate the level of specialist palliative care being provided. This approach illustrated the reality of adopting a legal framework with a substantial role for professional standards.

An Alternative Legal Framework for Specialist Palliative Care

The third central research question asked what alternative legal framework for specialist palliative care exists. In response to this, developments in the legal framework for specialist palliative care in the Netherlands were examined. Chapter Six highlighted that the major difference between the Dutch and Irish legal frameworks for specialist palliative care is the existence of clear and comprehensive guidelines in the Netherlands which form part of the physician's code of conduct. The reliance placed on professional standards in the Netherlands demonstrated a move away from a justification led approach to specialist palliative care and instead signalled a more active approach in defining this area of care and ensuring that it was provided in a manner which was legally and ethically sound for both the healthcare professional and the patient. Significant elements to emerge from the Dutch professional standards included the development of a clear decision-making framework for specialist palliative care, greater guidance in terms of clinical practice, and recognition of the constant co-operation between healthcare professions involved in delivering patient care.

The 'Guideline for Palliative Sedation' issued by the KNMG addresses '[i]ndications and preconditions for palliative sedation',[44] the decision to begin sedation, the provision of hydration, respite sedation as well as wider issues such as '[d]ealing with the patient's family'.[45] The third chapter of the KNMG 'Guideline for Palliative Sedation' sets out the '[i]ndications and preconditions for palliative care'.[46] A main indication is that that the patient should have 'refractory' symptoms.[47] The Guideline includes a 'flow diagram' to assist in the identification of refractory symptoms.[48] This provides a clear reference for both the doctor and the patient as to whether a symptom

[44] Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2009) 22.
[45] ibid 46.
[46] ibid 22.
[47] ibid.
[48] ibid 25.

is likely to be refractory and promotes a degree of certainty in the provision of palliative sedation. Chapter three of the 'Guideline for Palliative Sedation' also addresses symptoms which raise difficult ethical and legal issues, namely sedation in the case of existential suffering. It was shown in Chapter Two that non-somatic suffering such as existential distress is a complex symptom to treat appropriately and it is a symptom which needs to be adequately addressed in the legal framework in this jurisdiction in order to strengthen the distinction between specialist palliative care and euthanasia.

The decision-making process is set out in the fourth chapter of the KNMG 'Guideline for Palliative Sedation'. The steps in this process underline the importance of taking account of all the parties involved in the provision of palliative care such as the nursing staff who have 'regular close contact with the patient'.[49] This decision-making process is required regardless of whether the patient is receiving palliative care in a hospital of whether they are being cared for in the home. This broad applicability is positive in ensuring that terminally ill patients can receive the necessary care regardless of the location.

The administration of fluids in palliative care was addressed in chapter five of the 'Guideline for Palliative Sedation'. It set out a number of factors which are to be considered in deciding whether to withdraw hydration from a patient who is unable to take fluids. Chapter six of the 'Guideline for Palliative Sedation' focused on issues relating to the administration of palliative sedation such as 'the preparations to be made, the initiation of sedation, proportionality, the drugs to be used and the method of administration, morphine and sedation, and … accompanying measures.'[50] There is considerable detail contained in the Guide and it even specifies the type of drug which should be used in palliative sedation as well as providing detail on the amount which should be originally administered,[51] issues of timing and the approach to be taken for continuous sedation.[52] In addition to this, the 'Guideline for Palliative Sedation' acknowledges the importance of a 'multidisciplinary approach'[53] to palliative care and

[49] ibid 29.
[50] ibid 38.
[51] ibid 39.
[52] ibid 39-40.
[53] ibid 38.

states that 'Nursing staff can contribute important input for drawing up the indications, estimating whether the conditions have been met, and implementing palliative sedation.'[54] At present, the professional standards of the IMC and An Bord Altranais do not strengthen co-operation between these professions despite their close collaboration in practice.

The manner in which the Netherlands has addressed specialist palliative care has brought these practices more into the open. It is an approach which demonstrates the practicality of using professional standards to encourage decision-making in a 'timely'[55] and 'fair'[56] way. Importantly, it shifts the focus of the healthcare professional from a justification led approach to palliative care to one which promotes a 'holistic and multidisciplinary approach to care'.[57] The standards in the Netherlands took an important step in acknowledging the legal and ethical challenges which specialist palliative care raises and addressing these in a direct fashion. This was vital in distinguishing specialist palliative care from euthanasia, and promoting the care of the individual at a vulnerable stage in their life.

CONCLUSION: THE WAY FORWARD

Palliative care in Ireland can be said to have developed in an ad-hoc fashion as there was no central plan for its development and expansion.[58] Regardless of its origins, the clinical practice of palliative care in Ireland has been recognised internationally as being of a very high quality.[59] Developments in the legal framework for specialist palliative care need not stymie the progress of palliative care but should complement and provide a way of continuing the development and improvement of palliative care in this jurisdiction.

[54] ibid.
[55] *Tysiąc v Poland* (2007) 45 EHRR 42, [118].
[56] *Tysiąc v Poland* (2007) 45 EHRR 42, [113].
[57] Irish Hospice Foundation, 'Primary Palliative Care in Ireland' (Dublin 2011) 3.
[58] Department of Health and Children, 'Report of the National Advisory Committee on Palliative Care' (Department of Health and Children 2001) 23 'Palliative care services were established around the country due largely to the strong and concerted efforts of various voluntary organisations. This, however led to an ad-hoc development of services nationwide'.
[59] Economist Intelligence Unit, 'The quality of death: Ranking end-of-life care across the world' (Economist Intelligence Unit 2010) 11.

This thesis suggests that the most appropriate mechanism for providing clarity, consistency, protecting human rights, and the four principles as set out by Beauchamp and Childress is the continued development of the professional standards published by the IMC and An Bord Altranais.[60] The current reliance on local policy cannot adequately achieve what needs to be undertaken at a national level. In this regard, the population of the Netherlands is considerably higher than that of Ireland[61] and yet it was demonstrated that it was possible to draft national guidelines suitable for such a large and diverse population. In effect, Ireland's approach of leaving these issues largely to local policy only serves to create inconsistency and excessively complicates the provision of end-of-life care. National guidelines are not a panacea to the debates about end-of-life care but may assist in providing certainty to health care professionals working in this area as well as allowing for the voice of the patient to be clearly heard.

There are several arguments in favour of relying on professional standards to assist in the development and improvement of palliative care provision. These arguments have been outlined and substantiated throughout the course of this thesis. For instance, professional standards are directly enforceable in a way which local policy is not. The enforceability of professional standards means they can have a direct impact on the professionals most closely associated with the provision of palliative care in this jurisdiction. Moreover, professional standards are sufficiently flexible in that they are regularly updated to reflect developments in medical practice. Professional standards can therefore develop alongside updates in the provision of palliative care and would not restrict appropriate medical practice in end-of-life care. An additional positive aspect in relying on standards published by the Irish Medical Council and An Bord Altranais is that the standards do not need to be limited to general principles but can instead accord with the approach taken by the Royal Dutch Medical Association in the Netherlands. For instance, in recent years An Bord Altranais has published detailed guidance and standards applicable to particular aspects of medical care provided by the nursing profession in Ireland. The cumulative effect of these factors is to demonstrate that professional standards can support the role of the healthcare

[60] John Lombard, 'The Regulation of Palliative Care' (2012) Socio-Legal Studies Review 23.
[61] Central Statistics Office, 'Census of Population 2011: Preliminary Results' (Central Statistics Office 2011) Irish population 2011 – 4,581,269; The World Bank, 'Netherlands' (The World Bank 2012) <data.worldbank.org/country/netherlands> accessed 24 June 2014, Dutch population 2012 – 16,750,000.

professional while also ensuring that the care of the patient remains of paramount importance regardless of the location where they are being cared for.

While arguing that the most appropriate route to reform is revised and expanded professional standards, this is not to discount the role of legislation in respect of the broader healthcare system as it interacts with palliative care. For example, legislation is needed to formalise the status of advance care directives, do not resuscitate orders, and the approach to decision making for patients who lack capacity. Steps have been taken to address many of these issues as demonstrated by the *Assisted Decision-Making (Capacity) Bill 2013*. However, specialist palliative care practices require a legal framework which can be easily updated to reflect advancements in medical knowledge and ensure that the standard of healthcare continues to rise.

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