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University College Cork, Ireland
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PALLIATIVE CARE FOR THE PERSON WITH DEMENTIA

GUIDANCE DOCUMENT 6

Ethical decision making in end-of-life care and the person with dementia



UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

The Irish Hospice Foundation
Striving for the best care at end of life for all

Palliative Care for the Person with Dementia

Guidance Document 6: Ethical Decision Making

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This guidance was developed after careful consideration of the evidence available at time of publication. Whilst every effort has been made by the authors to ensure the accuracy of the information and material contained in this document, errors or omissions may occur in the content.

This is a guidance document provided for information and educational purposes only. It has been designed to assist healthcare providers by providing an evidence-based framework for decision-making strategies.

This guidance document is not intended as a sole source of guidance for ethical decision making in dementia palliative care and healthcare professionals should also refer to professional codes of ethics, relevant national policies and laws.

This guidance is not intended to replace ethical and clinical judgment or to establish a protocol for all individuals with this condition. Guidance documents do not purport to be a legal standard of care. The guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or family. Adherence to this guidance will not ensure successful patient outcomes in every situation.

The Irish Hospice Foundation, 2016.

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Contents

1.	**Background**	**3**
2.	**Introduction to this guidance document**	**4**
3.	**Themes from the literature review**	**6**
4.	**Ethical decision making**	**7**
5.	**Guidance and resources**	**13**
	1. Promoting autonomy and the capacity of the individual to consent or refuse treatment and care	15
	2. Meeting the ethical goals of treatment and care – Do Not Attempt Resuscitation (DNAR)	25
	3. Disputing the ethical goals of treatment and care – clinically assisted nutrition and hydration	34
6.	**Additional Resources**	**42**
	6.1 Understanding the progression of dementia	42
	6.2 Alternative ethical decision making frameworks	43
	6.3 Approaches to care	46
	6.4 Dementia, palliative care and intellectual disability	47
	Factsheets to accompany this document	49
7.	**Conclusion**	**53**
	Glossary	54
	Appendix 1 – Steering and project group membership	55
	Appendix 2 – Methodology	56
	References	60
	Additional reading	63

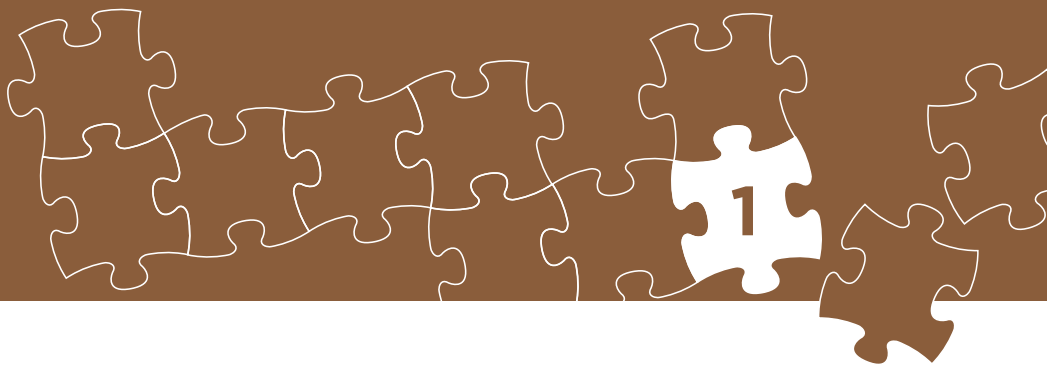
WHAT IS PALLIATIVE CARE?

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.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO (2016) Definition of Palliative Care http://www.who.int/cancer/palliative/definition/en/



BACKGROUND

Dementia is an umbrella term used to describe a condition which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function including; decline in memory, reasoning, communication skills and in the ability to carry out daily activities[1]. The number of people living with dementia in Ireland today is estimated to be around 48,000 and this number is set to treble by 2045[2]. Dementia is a chronic, life limiting condition[3–5].

People with dementia have a unique set of care needs which include: a progressive cognitive impairment; diminishing capacity; communication difficulties; possible responsive behaviours and a prolonged illness trajectory leading to uncertainty in relation to prognosis[1,6]. People dying with and/or from dementia require staff to have knowledge, skills, competence and confidence in both dementia and palliative care[7]. Palliative dementia care involves supporting the person with dementia and their family to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to participate in making decisions about future care needs[8]. Providing this care and comfort presents services with a significant challenge as each person's journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia[5,9]. This is often compounded by staff lacking basic knowledge, awareness and skills in supporting people with dementia[1,4]. It is recommended that palliative care principles are introduced in the person's care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care[3,8,9].

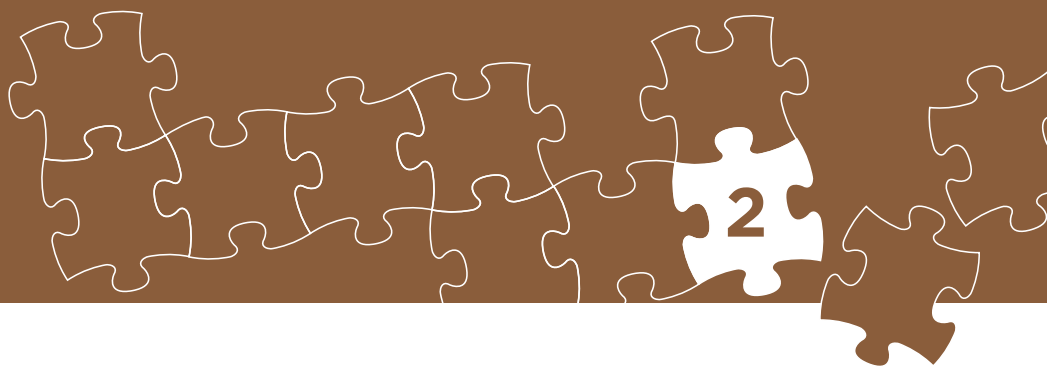
As illustrated, there has been growing recognition of the complexities involved in providing end-of-life care for people with dementia in the literature; however, there is a notable void of practice guidelines to support healthcare staff in delivering excellence in end-of-life care for people with dementia. In order to support staff in meeting the palliative care needs of people with dementia, there was a call for the development of practice guidelines for the Irish context [8,10,11,12].

A series of guidance documents was commissioned as part of The Irish Hospice Foundation's Changing Minds Programme:

1. Facilitating discussions about end-of-life care with the person with dementia
2. Advance healthcare directives and advance care planning
3. Loss and grief in dementia
4. Hydration and nutrition
5. Pain assessment and management
6. Ethical decision making
7. Medication management

Irish Hospice Foundation (IHF) have taken the lead for the development of guidance documents 1 – 3 with assistance from relevant experts. University College Cork (UCC) successfully tendered for the development of the guidance documents 4-7.

The steering group and project team overseeing the development of this guidance document are listed in Appendix 1.



INTRODUCTION TO THIS GUIDANCE DOCUMENT

'It is clearly imperative that key elements of the palliative care approach – in particular the focus on caring for the 'whole person', the importance of advance planning, the provision of adequate pain relief, the avoidance of inappropriate treatment, and support for family – should be made available in an appropriate way to people who are dying with dementia.'

(Nuffield Council 2009, p.55[13])

Dementia is associated with borderline capacity, dependence and behavioural changes and it prompts profound ethical questions about individual autonomy, selfhood and relationship. Specific ethical challenges that arise in relation to the care of individuals with dementia include: respecting autonomy and assessing capacity to consent to treatment, truth-telling and covert administration of medication, ensuring the overall well-being of individuals as well as their family/carers, making decisions about pain management and withholding and withdrawing treatment. These concerns are all the more pressing at the end of life where they may arise in tense and emotionally fraught circumstances and serve as a source of stress, for health professionals, care providers and families, who report feeling isolated and unsupported in making ethical decisions[13-16].

Many of the well-known ethical and legal cases involving end-of-life decision-making and questions about capacity concern patients in a persistent vegetative state, e.g. Karen Quinlan[17] and Nancy Cruzan[18] in the US, Tony Bland[19] in the UK and In re Ward of Court[20] in Ireland. However, ethical challenges that arise in relation to individuals with dementia have unique features that need to be taken into account. Authors such as Golan[21] and Jaworska[22] draw attention to the following distinctive dimensions of dementia:

1. Dementia involves a slow deterioration and irreversible decline of cognitive capacities – as distinct from a sudden loss of consciousness and transformation of a previously competent person to a permanently incompetent person. During the transformation, the person may have periods during which they are able to communicate their wishes regarding their treatment.
2. Developments in neuroscience and neuropsychology research indicate that individuals with dementia retain emotional and practical abilities long after they have suffered severe cognitive losses. This means that they may continue to hold values which should be respected and they may continue to have an interest in the continuation of their lives.
3. The person with dementia undergoes a long process of personality change – so much so that the validity and applicability of their prior wishes and advance directives may be in doubt.
4. The final stage of the dementia process is sometimes associated with difficulties in swallowing and this often prompts consideration of administering Clinically-Assisted Nutrition and Hydration (CANH).

A guidance document can provide a framework to support ethical decision-making in relation to dementia care but will not tell a caregiver exactly what to do. It is important to acknowledge that there is rarely one over-arching ethical principle or value that can be used to solve an ethical problem. Critical judgment is required based on the individual's rights and interests, the situation, the risks and the context in which the decision is made. There is rarely a single right solution for what should be done, and in fact reasonable disagreement can be expected and should even be encouraged. An approach to decision-making where solutions emerge in the course of dialogue, disagreement and negotiation often works best[15,16,23,24].

The aim of this guidance document is to provide caregivers of people with dementia, regardless of care setting, with a framework to support ethical decision making involving people living with dementia at the end of life.

Scope of Guidance Document

This guidance document will:

- Explain core ethical principles as they apply to individuals with dementia at the end of life
- Provide a decision-making tool that supports ethical decision making involving individuals with dementia at the end of life
- Offer guidance on key ethical challenges that arise in dementia care at the end of life.

Development of Guidance Document

This guidance document was developed by a project team and overseen by a steering committee *(please see Appendix 1 for membership of both groups)* using the process below.

1. Completion of scoping review.
2. Collation of key review themes to inform the ethical principles and decision-making tool.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
4. Preparation of Draft 2 for external consultation.
5. Assimilation of feedback from external consultation to final draft.
6. Final version published.

Structure of Guidance Document

The guidance provided in this document focuses on core ethical principles and values, a decision-making tool and three key ethical topics, based on the key themes emerging from the scoping review which were considered most beneficial for caregivers. These areas are examined in detail in the following sections. Where applicable, we have signposted available resources and tools to guide ethical decision making involving people with dementia.

THEMES FROM THE LITERATURE REVIEW

A scoping study was undertaken to inform the development of this specific guidance document (see Appendix B for overview of associated methodology). It found that ethical concerns in relation to dementia are inconsistently addressed in national dementia guidelines around the world[24-27]

Knuppel[25] identified a need for further research to specify how detailed ethical issues and related recommendations can and should be addressed in dementia guidelines. Knuppel's[25] systematic review of dementia guidelines in general indicates that Ireland does not have any such guidance, nor does it have any specific guidance on ethical challenges that arise in relation to dementia at the end of life.

Given the dearth of research in this area, a literature review identified the following three themes:

1. Common ethical and legal principles and values underpinning ethical decision-making for dementia care at the end of life.
2. Existing ethical decision-making frameworks for dementia care at the end of life.
3. Specific concerns that arise in end-of-life dementia care, e.g. advance care planning, truth-telling, assessment of capacity to consent or refuse treatment, enabling and protecting the person with dementia, withholding/withdrawing life sustaining treatment.

Drawing on the key themes, the Project Team agreed a set of Ethical Principles that inform an Ethical Decision Making Tool. The Decision Making Tool is, in turn, applied to three specific ethical challenges that arise in relation to the care of individuals with dementia at the end of life.

Three Areas for Ethical Guidance

1. **Promoting Autonomy and the Capacity of the Individual to Consent or Refuse Treatment and Care.**
2. **Meeting the Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR).**
3. **Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration (CANH).**



ETHICAL DECISION MAKING

Persons with dementia have the same rights as all persons, e.g. the right to life, autonomy, dignity, bodily integrity, freedom from inhuman and degrading treatment as well as the right to information, to consent and to confidentiality.[28-31].

To ensure that these rights are respected and protected, the project team has agreed that the following core ethical principles should underpin any decision-making process in dementia care at the end of life (Figure 1).

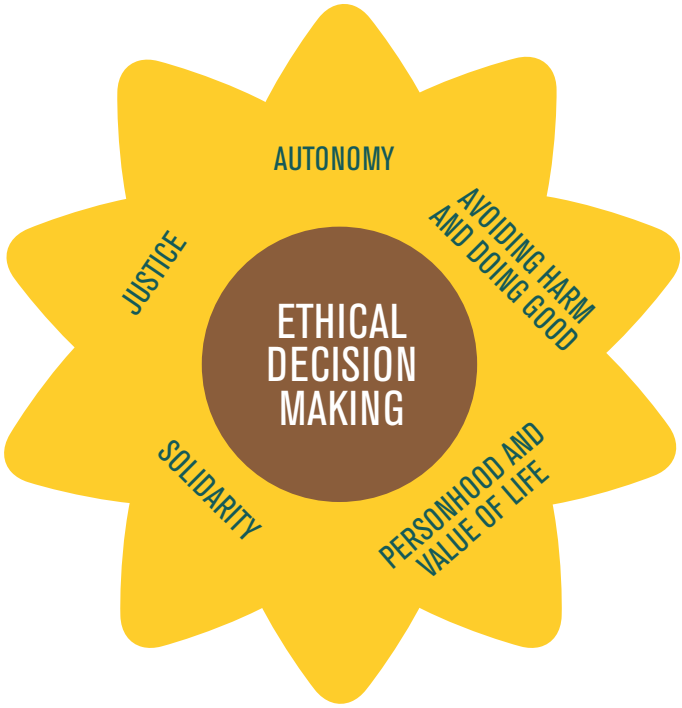


Figure 1: Core ethical principles underpinning any decision making process in dementia care at the end of life.

4.1 Ethical principles

A. Autonomy

Autonomy is the capacity for self-determination; a person's ability to make choices about their own life based on their values and beliefs about what is important. The principle of respect for autonomy requires recognising the unique values, priorities and preferences of individuals and supporting them to participate as fully as possible in decisions about their care.

An autonomy-centred perspective obliges health professionals to:

- **focus on the experiences of the person receiving care and on what matters most to them**
- **be attuned to the way in which people make sense or meaning out of the world**
- **help the person to express themselves**
- **meet the person where they are in themselves and in their environment of care**
- **enable and foster relationships that are important to the person**
- **recognise and meet the needs of carers**

It should not be presumed that, simply because a person lacks the capacity to make a specific decision about a particular medical treatment or care, they do not have the capacity to make other decisions. In any case, their views should not simply be disregarded. Their autonomy can still be promoted through adherence to their advance plans/directives and by showing continued respect for their current wishes where possible.

Individuals with dementia may well lose their understanding of who they are and the connection between their past and future, but nevertheless retain core preferences and ethical values[32].

To provide active support, the caregiver must try to understand what the person with dementia is currently feeling, wanting and experiencing, whilst enabling and maintaining relationships and interests which are of importance to that person[13].

B. Avoiding harm and doing good

Promoting the well-being of the person with dementia

Avoiding harm and doing good can be applied to all interactions with a person who has dementia. This can range from very ordinary and everyday interactions – e.g. simply doing good by saying 'Hello' to someone with dementia, or sitting with them – to helping a person to make complex decisions, or to try to arrive at the most appropriate decision on a person's behalf.

When making decisions for individuals who lack capacity to make any decisions about their medical treatment or care, in the absence of any advance plan or directive, caregivers should act to promote the person's overall well-being, e.g. attention should be paid to pain and symptom management and to the avoidance of unnecessary suffering as well as the creation of opportunities for positive experiences and joy.

Promoting a person's well-being goes beyond weighing the burdens and benefits of proposed actions: it also involves taking the person's past and current wishes and preferences into account where possible.

A balance must be struck between enabling a person with dementia to live their life in the way they wish, promoting their well-being, ensuring their safety and protecting the safety and interests of others.

C. Personhood and value of life

The life of a person with dementia should be valued just as much as that of a person without dementia, with a particular focus on the person's capabilities, rather than on presumed deficits.

Given proper individualised, holistic and respectful care, the quality of a person's life with dementia can be positive. This holistic approach emphasises the following[33,34]

- Recognising the human value and dignity of people with dementia, regardless of age or cognitive impairment.
- Respecting the individuality of people with dementia, their unique personality, life stories, experiences, familial and social relationships.

Treatment and care should meet the physical, psychological, spiritual and social needs of each individual throughout the course of their illness.

D. Solidarity

Our interdependence as human beings means that any of us may be touched by dementia and all of us will certainly be touched by end-of-life issues. As such, we are 'fellow travellers' who have faced, or will at some point face, dependency in our lives.[13] This understanding prompts an empathic response:

The quality of care provided should reflect the standard of care we would expect for ourselves and the people we love.

This interconnectedness is reflected in the relationship between the person with dementia, their caregivers and healthcare professionals, all of whose interests should be considered. On this view, our dependency on each other is the norm, not the exception.

> ***'Our dependency is not …. an exceptional circumstance. To view it as such reflects an outlook that dismisses the importance of human interconnectedness, not only for purposes of survival, but for the development of culture itself.'*** (Kittay 1999[35])

E. Justice

Distributive Justice

In healthcare, distributive justice involves the fair or equitable distribution of finite resources. Problems of distributive justice arise when there is a scarcity or shortage of resources within a society. Advances in health technologies and care practices raise expectations that result in ever-increasing demands on the health allocation of a state's budget. This increased demand may lead to allegations of injustice when these limited resources are not equally accessible to all who might benefit from them.

> ***Access to treatment and care, while constrained by the availability of resources, should not be restricted on the basis of age, disability, psychological or intellectual impairment.***
>
> (Syrett, 2014[36])

Resource allocation in dementia care becomes particularly challenging at the end of life. Uncertainty about when a person with dementia enters the dying phase raises questions about the need for hospitalisation and the appropriateness of providing potentially burdensome life-prolonging treatment.

Social Justice

- recognises that different groups in society may be advantaged/disadvantaged on the basis of socio-economic status, gender or ethnicity, and that this leads to diminished health and well-being.
- requires that particular attention be paid to the way in which group differences can place individuals and families at a disadvantage, and to the need to develop strategies / processes / practices to ameliorate inequities.

These five principles; Autonomy, Avoiding Harm and Doing Good, Personhood and Value of Life, Solidarity and Justice encompass the key features of an emerging and significant theme in healthcare and in dementia care in particular – Person-Centered Care (PCC). PCC requires recognition of the dignity and uniqueness of each person and of what is important to them. It obliges health professionals and carers to form and foster therapeutic relationships that put the person with dementia – their needs, wishes, experiences and personalities – at the centre of concern.[32-34]

Conclusion

The principles employed in this Guidance Document are secular in origin and support a view of what is good or worthwhile from an intersubjective perspective. For example, we can agree that the idea of promoting a person's well-being is a good thing, although we may disagree about what 'well-being' might mean in a given context.

Justifying an action by appealing to ethical principles means having to defend that choice of action over others in a manner which goes beyond one's own perspective, bias, values and interests. By choosing an action based on principles, we remove our own partial viewpoint from the decision and appeal to a more general sense of what is the right thing to do.



4.2 Ethical decision making tool

Drawing on existing frameworks[37-40] and mindful of the five core ethical principles that we have adopted above, we have developed an ethical decision-making tool for addressing ethical challenges involving persons with dementia:

Actions	Responsibilities
1. Articulate the ethical problem(s) and identify relevant facts	Be ethically sensitive and communicate clearly
2. Identify stakeholders' interests, needs, values	Be respectful and inclusive
3. Weigh the merits and demerits of available courses of action	Be informed and fair
4. Select the action which can best be supported by ethical principles	Be impartial and transparent
5. Review	Check: Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?

Campbell and McCarthy[41]



Actions and Responsibilities

1. Articulate the ethical problem(s) and identify relevant facts

- Make an initial assessment of the situation in order to identify the main ethical issue(s) and the facts deemed relevant to the decision which needs to be made.
- Although the issue(s) may also have legal, clinical or organisational aspects, be sensitive to and focus on the ethical dimensions of the problem – identify the ethical values that are at risk.
- Clarify the ethical issue(s) in question in order to identify the interests and values of those who are affected by the decision and bring into focus the perceived harms and benefits associated with making a decision.

2. Identify stakeholders' interests, needs, values

- Ensure that all persons who have a stake or interest in the decision being made are consulted or represented and their needs and values identified. Inclusiveness is a vital part of good decision-making, so no person affected by the decision should be excluded from the decision-making process without adequate justification. Those who are affected by the decision must have an opportunity to give voice to what is important to them.

3. Weigh the merits and demerits of available courses of action

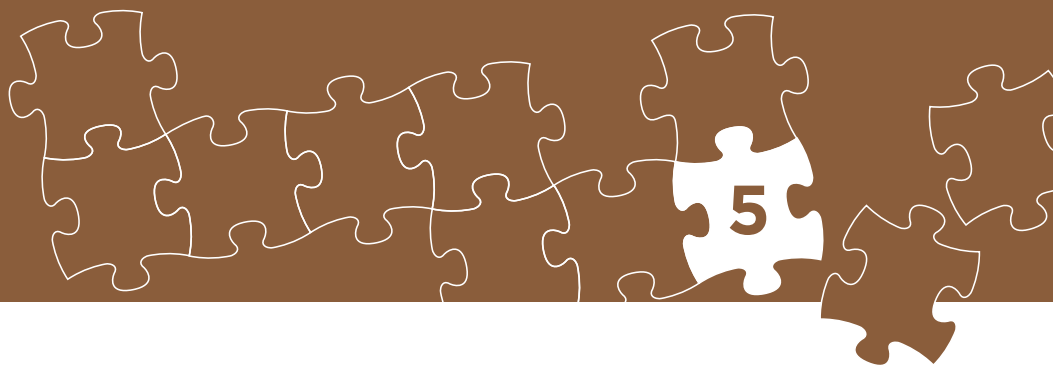
- Explore available options and their foreseeable consequences and compare their relative merits and demerits fairly. Consider the perceived harms and benefits associated with each available course of action from the perspectives of all stakeholders.
- Make any underlying values, assumptions, motivations explicit and promote clarity, fairness and transparency in the decision-making process.

4. Select the action which can best be supported by ethical principles

- Defend your choice of action over other possible choices by appealing to ethical principles which have applicability beyond your own perspective, values and interests. The recommended action should be based on a more general sense of what is the right thing to do in the context of the choices available. Different principles, e.g. autonomy, justice, solidarity etc., may be more or less relevant and applicable in different situations.

5. Review

- A decision which is ethically sound is one which is sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent.



GUIDANCE AND RESOURCES

The three areas that healthcare professionals, carers and people with dementia would benefit from guidance with regard to ethical decision making are introduced below and are outlined in further detail in subsequent sections of this document. These are as follows:

5.1 Guidance Area 1

Promoting Aautonomy and the Capacity of the Individual to Consent or Refuse Treatment and Care.

The autonomy of the person with dementia may be promoted and enhanced by engaging in a process of Advance Care Planning (ACP) while the person still has the capacity to make decisions about future treatment. Even if an Advance Care Plan or an Advance Healthcare Directive is in place, an autonomy-centred approach requires that healthcare professionals pay attention to what the experience of their condition means to the person who is now living with dementia and their carers. It requires that healthcare professionals and carers actively support the person with dementia so that they are encouraged to retain and express their sense of self and maintain the relationships that are important to them, rather than simply being protected from harm.

5.2 Guidance Area 2

Meeting the Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR)

Meeting the ethical goals of treatment and care may sometimes require limiting medical treatment in cases where individuals have refused it or in situations where it offers no overall benefit. Omitting to administer a particular treatment such as CPR for a particular patient is generally viewed as morally justified if it is considered futile (ineffective/without benefit) or unnecessarily burdensome. When discussing judgments of futility, it should be made clear that it is not people's lives that are judged futile. A judgment of futility is not a value judgment about the significance or worth of this person's life or that a life with dementia is not worth living. Rather, the judgment relates to the expectation that the treatment will not provide any benefit for this particular person at this stage of their dementia and/or related illnesses.

5.3 Guidance Area 3

Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration

As persons with dementia approach the end of their lives, the body's increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty in swallowing. However, food has an emotional, symbolic and social importance which should not be underestimated. Assisting to feed someone who is sick is a 'powerful instinctive act' and the human contact provided by the act of feeding assistance may be of therapeutic benefit.

Deciding whether or not the administration or continuation of Clinically Assisted Nutrition and Hydration (CANH) is clinically indicated requires careful consideration of its burdens and benefits in the context of the specific goals of care for the person with dementia. Such considerations include the person's illness trajectory, the potential impact of the intervention on the person's condition, the expected clinical outcomes, the impact of a potential inpatient admission on the person, and the preferences/values of the person with dementia[42].

Readers are advised to also refer to Guidance Document No 4 in this series, focusing on hydration and nutrition.



5.1 Guidance Area 1

Promoting Autonomy and the Capacity of the Individual to Consent or Refuse Treatment and Care

The autonomy of the person with dementia may be promoted and enhanced by engaging in a process of Advance Care Planning (ACP) while the person still has the capacity to make decisions about future treatment. The Advance Care Plan might include an advance statement of wishes and preferences (Advance Healthcare Directive) about treatment and care in a predefined future situation. The ACP may also include the appointment of a designated healthcare representative who will have the authority to interpret the stated will and preferences of a patient and consent to or refuse treatment on their behalf if they lose capacity (See Guidance Document No. 2 for further explanation and discussion of Advance Care Planning. See also the provisions of the Assisted Decision Making (Capacity) Act 2015[43]).

Even if an ACP is in place, an autonomy-centred approach requires that healthcare professionals pay attention to what the experience of their condition means to the person now living with dementia and their carers. It requires that they actively support the person with dementia so that they can be encouraged to retain and express their sense of self and maintain the relationships that are important to them, rather than simply being protected from harm.[13]

This approach obliges health professionals and organisations to create the conditions that foster capacity including the development of relational skills and practices:

> ***'[T]he capacity to communicate, to engage in meaning-sending and meaning receiving relationships… with others, and to evince understanding and evaluation of such communication.' e.g. touch, gesture, facial expression, posture, eye contact, sitting together, may endure long after speech, memory, functional capacities for daily living are compromised (Jennings 200[44]).***

One of the most pressing ethical challenges that arises in caring for people with dementia is the fact that their understanding of their situation and ability to make decisions is affected by their illness. Depending on the nature and stage of their illness, their capacity may fluctuate or be seriously compromised.

Assessing Capacity

Every adult is presumed to have capacity to make decisions about their own healthcare. Rather than signalling that they lack capacity, the fact that the person with dementia may currently not have sufficient understanding or appreciation in respect of a particular decision should in the first instance signal a requirement for the provision of supports to enhance their decision-making capacity to the greatest degree possible (adapted from National Consent Policy 2014; Section 5.5[45]).

Where a person with dementia, having been given all appropriate help and support:

- is unable to communicate a clear and consistent choice or
- is obviously unable to understand and use the information and choices provided,

the possibility of incapacity and the need to assess capacity formally should be considered (National Consent Policy 2014, 5.4[45]).

Assessing whether a patient has capacity can be complex, difficult and uncertain. A responsible capacity assessment should prevent two possible mistakes: *"first, the unjustifiable overruling of patient autonomy in order to safeguard patient well-being; and second, the unjustifiable respecting of patient autonomy at the cost of the patient's well-being"*[46].

It is important to choose the best time and best circumstances for assessing a person's capacity. Consideration should be given to the person's environment and the method of communication used. See Guidance Document 1 in this series for more about communication skills.

Legal decision-making capacity refers to a specific decision to be made about a particular medical treatment at a particular time. A person with capacity:

- understands in broad terms the reasons for, and nature of, the decision to be made and is able to retain this knowledge long enough to make a voluntary choice.
- has sufficient understanding of the principal benefits and risks of a medical intervention and relevant alternative options, after these have been explained to them in a manner and in a language appropriate to their individual level of cognitive functioning.
- can communicate their choice (sometimes with the support of augmentative communication strategies [See Guidance 1]).

According to the Assisted Decision Making (Capacity) Act 2015, a person lacks capacity to make a decision to consent or refuse medical treatment if they are unable to –

(a) understand the information relevant to the decision;
(b) retain the information long enough to make a free choice;
(c) weigh the information as part of the decision-making process;
(d) communicate their decision



Guidance Area 1:

Promoting Autonomy and Assessing Capacity to Consent or Refuse Treatment and Care

Plan for end-of-life care: Encourage individuals to plan for end-of-life care while they have the capacity to do so. Good communication and (appropriate) reassurance is essential to ensuring that people with dementia can make decisions which are informed and which represent their considered views. (See Guidance Document Nos 1 and 2).

Presume capacity: When in doubt, the process of assessing capacity should be fair and free from prejudices based on age, mental illness, dementia or intellectual disability.

Provide supports: Ensure that the decision-making capacity of the person with dementia is enhanced to the greatest degree possible. Seek to support people who have borderline capacity in making decisions for themselves insofar as this is possible. Listen for what matters to them, attend to the relationships that are important to them and talk to the person with dementia in a way that they can understand. Use augmentative communication strategies (see Guidance Document No. 1).

Inform yourself and seek advice: Be familiar with the legal criteria for capacity, as this is the relevant test for determining whether or not a person has legal authority to make decisions. If in doubt, seek a second opinion from another colleague with expertise in the area of capacity assessment (e.g. a psychologist or geriatrician). This is especially important in the event of disputes between family members or between professionals and family members, where health care professionals have difficulty dealing with the expressed wishes of people with dementia and the expectations of their loved ones.

Consider the context: Choose the best time and best circumstances for assessing a person's capacity.

Respect the person's values: Where a person is considered to lack legal capacity in relation to specific decisions about their medical treatment and care, any decisions made should, where possible, be informed by an understanding of, and respect for, what is of value and importance to an individual. Therefore, when engaging with persons with dementia:

> ***Instead of asking****: 'Can this person reason and come to a rational decision?'* and *'Can this person grasp what is best for their life as a whole?'*
>
> ***We might ask***: *'Does this person still value and can they live in accordance with their values?'* (Jaworska 1999)[47].

CASE STUDY 1

Karolina Husarek is a 55-year old woman who has Down Syndrome and a mild intellectual disability. Karolina was diagnosed with Alzheimer's disease just over three years ago. Prior to her recent admission to the local community nursing home she lived independently in a supported living environment. She was independent in all activities of daily living with access to support services if required.

Recently, Karolina has developed epilepsy and had initially agreed to take her anticonvulsant medication. Despite this, her epilepsy is not fully controlled and she continues to have some seizures although the duration and frequency of her seizures has significantly reduced. However, Karolina has begun to refuse to take her anticonvulsants as she feels she is taking too much medication. Owing to her intellectual disability and Alzheimer's diagnosis, some staff are of the opinion that Karolina lacks insight into her condition and the importance of taking her medication. Despite staff having discussed this at length with Karolina, she is adamant that she is not going to take *'all those tablets'.* She has informed staff that, since the anticonvulsants have not stopped her seizures, *'those tablets are no good'.*

In the past month, Karolina also began to appear to be hypersensitive to auditory and visual stimuli. She complained of severe headaches and was observed holding her head in her hands and appeared to be in considerable pain. A CT scan revealed a large mass, which was diagnosed as an inoperable brain tumour. A number of palliative options have been prescribed, including analgesics and steroids. Palliative radiotherapy has also been discussed. It is clear that the decline in Karolina's health is accelerating at pace. Staff are concerned that she will continue to refuse to take any more medications which will impact on symptom management as part of her palliative care. They are considering other options such as telling her that the oral medication is a health supplement, because in the past she has taken vitamin supplements.

Consider the case by applying the Ethical Decision-Making Tool

1. Articulate the ethical problem(s) and identify relevant facts

Ethical problem(s)

Nursing staff are unclear as to the impact of Alzheimer's disease on Karolina and are unsure of her ability to participate in decision-making about her treatment and care. A decision needs to be made about Karolina's immediate and long term care given her refusal to take the medication prescribed for her. Some staff are of the opinion that Karolina's decision to refuse medication and other therapeutic interventions should be respected. Other staff are unsure if Karolina has the capacity to fully understand the implications of her decision. These staff are of the opinion that the administration of her medication in a disguised form (covert medication) is justified to manage the symptoms she is experiencing (See examples of international guidelines relating to the use of covert medication in vulnerable populations in Additional Resources and Guidance Document 7 on the administration of covert medication)

Relevant facts

Karolina is diagnosed with Alzheimer's disease, which is progressing rapidly. She also has a mild intellectual disability and Down Syndrome.

A decision needs to be made about Karolina's refusal to take medication or avail of other therapeutic interventions prescribed for her. These are considered essential to minimise the symptoms which Karolina is currently experiencing and will experience as her health deteriorates in the future.

Karolina's medical condition has further deteriorated since she developed epilepsy and was diagnosed with an inoperable brain tumour.

Karolina strongly believes that she should not take her medication as she feels the medication is not doing her any good.

Karolina has been living independently, predominately without supports. As such, a strong therapeutic relationship has not been established between her and the nursing staff.

Nursing staff are committed to supporting Karolina to remain within the supported accommodation setting within her community. However, they feel under pressure to act and they are concerned that her refusal to take medication and other therapeutic interventions will compromise their ability to support her in this setting.

There is no end-of-life policy in the support service that addresses situations like this.

2. Identify stakeholders' interests, needs, values

Karolina Husarek

Karolina's independence is vital to her quality of life; to maintain this to the greatest extent possible, she needs to remain in her current supported living accommodation **(quality of life, autonomy, solidarity).**

Karolina's own views should be central to how this situation is addressed **(autonomy).**

Karolina's health and continued well-being depends on good medication management and symptom control **(doing good, avoiding harm).**

Nursing Staff

Nurses are morally obligated to support Karolina to live in accordance with her own beliefs and values and to help her to maintain the relationships that are important to her **(autonomy).**

They are also obligated to avoid harming Karolina and to act in ways that benefit her **(avoiding harm, doing good).**

Nurses may experience moral distress when unable to fulfill their obligations to Karolina, for example if they are unable to continue to support her to stay in her home **(avoiding harm, personhood, solidarity).**

Nurses may experience moral distress when faced with a situation in which respecting Karolina's wishes impacts on their ability to provide good quality patient care and symptom management **(doing good, avoiding harm, solidarity).**

Organisation

Nursing home management and health services are obligated to put in place policies and procedures to ensure that safe, respectful, quality care is provided to service users **(doing good, avoiding harm).**

Organisations are obligated to provide quality services which respect the human rights of service users and ensures their needs are met **(autonomy, doing good, avoiding harm, solidarity).**

Organisations are obligated to ensure staff are supported and empowered to deliver that care **(doing good, avoiding harm, justice, solidarity).**

Organisations are obligated to work closely together to ensure the best quality care and to conserve scarce resources **(justice).**

3. Weigh the merits and demerits of available courses of action:

1. Respect Karolina's decision to refuse to take medication and potentially avail of other therapeutic interventions.

Merits

Respecting Karolina's wishes may reduce her distress and anxiety given the changes in her circumstances. It may support the development of a therapeutic relationship between Karolina and nursing staff.

Demerits

Exposes Karolina to the risk of accelerated deterioration of her condition. Respecting Karolina's wishes at this point may compromise her autonomy in the future, should her condition deteriorate more rapidly without medication. It may also impact negatively on her living situation.

2. Respect Karolina's decision while continuing to discuss her refusal to take medication and potentially avail of other therapeutic interventions with her.

Merits

Respects Karolina's wishes without abandoning her to harms which she may not fully understand or appreciate. It may reduce her distress and anxiety given the changes in her circumstances. Facilitates the development of a therapeutic relationship between Karolina and nursing staff.

Demerits

Delays the anticipated benefits of taking the medication. Exposes Karolina to the risk of accelerated deterioration of her condition. Respecting Karolina's wishes at this point may compromise her autonomy in the future should her condition deteriorate more rapidly without medication.

3. Administer medication in the form of 'covert medication' informing Karolina they are vitamin tablets

Merits

Immediate administration of medication will clinically benefit Karolina. Overriding Karolina's wishes at this time may afford nurses the opportunity to promote her autonomy at a later date as the situation progresses.

Demerits

Deceiving Karolina violates her right to autonomy and dignity. Subterfuge undermines the therapeutic relationship.

Administering the medication covertly may not be clinically appropriate and staff worry that doing so may contravene best practice guidelines.

4. Select the option which can best be supported by ethical principles

Respect Karolina's decision while continuing to discuss her refusal to take medication and potentially avail of other therapeutic interventions with her.

Karolina's capacity to participate in decisions about her care may be formally assessed. If she has capacity to make her own decision regarding medication, her reasons for refusing medication should be explored. Health professionals supporting Karolina are obligated to communicate honestly with her in relation to their clinical concerns and the possible impact of her decision on her living situation. However, advice should not be allowed to become manipulative. Options should be clearly stated, Caroline's own views should be elicited and encouraged and she should not be in any doubt that decisions are hers to make. If, following discussion, she continues to indicate that she does not want to take medication, her wishes should be respected.

If an assessment reveals that Karolina lacks the capacity to make a decision about taking her medication, Karolina should be supported to participate in the decision-making process, taking

cognisance of her level of intellectual ability and the co-existing diagnosis of Alzheimer's disease.

When engaging with Karolina, nursing staff must first identify what is of importance and of value to her. Karolina's values should be central to decisions made about her care. Her refusal to take medication may be informed by a number of factors and these should be explored. It is also important to explore her understanding of different concepts, such as serious illness, death and her understanding of time. It would also be important to explore how Karolina links concepts together, i.e. linking serious illness to dying.

There is no moral pressure to satisfy whimsical wishes (unless to do so comforts and reassures). However, consistent and unwavering wishes are to be given respect. Karolina has consistently stated she wishes to remain within her supported living accommodation and this request must be respected also.

Communicate clearly and sensitively

Continued efforts should be made to develop a therapeutic relationship with Karolina, to facilitate open, respectful communication. Appropriate communication can alleviate a person's concerns and can sometimes prevent confrontational situations developing between the individual involved and health professionals. Efforts should be made to maintain open lines of communication with Karolina and to continue to explore her reasons for refusing medication. It would also be important to have such a discussion each time there is a change in her health status, i.e. if she experiences an increase in pain or nausea.

Make reasonable adjustments

Reasonable adjustment requires that health professionals within the health services are prepared to adapt and/or revise their usual or routine practices in order to ensure that those with an intellectual disability are not disadvantaged. These adjustments should reflect a reasonable effort to accommodate the specific needs of those with disabilities. Karolina may require access to easy read material and medical jargon should be avoided. Providing longer appointment times and follow up appointments to address queries will also facilitate good communication. Since Karolina does not appear to have any next of kin, an independent advocate, friend or key worker from her supported living accommodation might be in a position to support her.

5. Review

Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?

Additional resources

Resources for Healthcare Professionals/Family Caregivers

In many cases, there will be clear continuity between the way people with dementia approach their life now and in the past[13]. However, in the event that there is a divergence, the Nuffield report[13] advises that

> ***"neither past nor present can automatically take precedence, but that the relative strength of the person's wishes, the degree of importance of the decision, and the amount of distress being caused should all be important factors to consider".***

There are arguments in favour of prioritising the person's past or present preferences, based on the assumptions made about the person's beliefs, values and behaviour. Nuffield[13] recommend that the following factors are considered:

- How important is the issue at stake? For example, maintaining a person's religious practice or moral beliefs (e.g. with regard to what they eat) is likely to have been much more important to them than issues of aesthetics, taste, or smartness of dress.
- How much distress or pleasure is it causing now? If maintaining a past belief is causing major distress, then it is likely that the person's current well-being and not their previous autonomy interests should take precedence.
- Consider the underlying values or beliefs on which the earlier preferences were based. Have they genuinely changed or can they be interpreted in a new light? It may be the case that the person is expressing 'old' views or preferences in a different way.
- Explore whether the apparent changes in preferences or values result from psychosocial factors (such as fear) or directly from the dementia (such as sexually disinhibited behaviour), or whether on the other hand they are linked with a genuine pleasure in doing things differently?
- Early (and continuing) discussions on these issues shortly after diagnosis will clearly help caregivers to obtain a greater understanding of the strengths of the beliefs and values held by the person with dementia at that time. This will enable an appropriate balance to be made between potentially conflicting interests if this later becomes necessary.

Alzheimer Europe (2015) Dementia in Europe Ethics Report: Ethical dilemmas faced by health and social care professionals providing dementia care in care homes and hospital settings. Available at: http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/Ethical-dilemmas-faced-by-professionals-providing-dementia-care-in-care-homes-and-hospitals

McCarthy J, Donnelly M, Dooley D, Campbell L and Smith D (2011) Ethical Framework for End of Life Care. Cork: Cork University Press.
Amazon Kindle http://amzn.to/1KnaCyH
Apple ibooks http://itunes.apple.com/us/book/isbn9781782050223

McCarthy J, Donnelly M, Dooley D, Campbell L and Smith D (2011) Ethical Framework for End of Life Care (8 Modules and 8 Study Sessions).
Available to download at: http://hospicefoundation.ie/publications/ethics/

Nuffield Council on Bioethics (2009). Dementia: Ethical Issues. Nuffield Council on Bioethics. Available at: http://nuffieldbioethics.org/project/dementia/

Covert Medication (See Guidance Document 7)

The resources listed below are some examples of national and international guidelines relating to the use of covert medication in vulnerable populations.

HIQA (2015). Medicines Management Guidance.
https://www.hiqa.ie/system/files/Medicines-Management-Guidance.pdf

NICE Guidelines (2015). Managing Medicines in Care Homes National Institute for Health and Care Excellence. http://www.nice.org.uk/guidance/qs85/chapter/quality-statement-6-covert-medicines-administration (Interactive guidelines)

Mental Welfare Commission (2013). Good Practice Guide Covert Medication.
Edinburgh,Scotland: Mental Welfare Commission.
http://www.mwcscot.org.uk/media/140485/covert_medication_finalnov_13.pdf

Mental Welfare Commission (2013). Covert Medication Care Pathway. Edinburgh, Scotland: Mental Welfare Commission.
http://www.wihb.scot.nhs.uk/LD/AWIA%20Disc/6.Medication/6.1_Covert_medication_care_pathway.pdf



5.2 Guidance Area 2

Meeting Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR)

If healthcare decision making is to be truly respectful of a person's wishes, then the goals of care must be clarified. Determining the goals of care entails considering the stage of a person's disease or prognosis and uncertainties related to this. The goals of care for any person are not set in stone. They are dynamic and can change rather quickly. On-going reassessment of goals and on-going documentation is necessary to ensure quality of care that is clinically judged feasible and in keeping with the particular person's preferences.

Meeting the ethical goals of treatment and care may sometimes require limiting medical treatment where individuals have refused it or in situations where it offers no overall benefit. Withholding or withdrawing life-sustaining treatments such as cardiopulmonary resuscitation (CPR), ventilators or dialysis machines, are ethically and legally accepted practices that should ideally be specified in advance care plans or directives (See Guidance Document No. 2).

The National Consent Policy (2014)[45] discusses CPR/DNAR in detail. It makes the following three points in relation to CPR:

1. A presumption in favour of CPR

'As a general rule, if no advance decision not to perform CPR has been made, and the wishes of the individual are unknown and cannot be ascertained, there is a presumption in favour of providing CPR, and healthcare professionals should make all appropriate efforts to resuscitate him/her. In these circumstances, the extent and/or duration of the CPR attempt should be based on the clinical circumstances of the arrest, the progress of the resuscitation attempt and balancing the risks and benefits of continuing CPR.'

2. When CPR should be stopped

'In some instances where CPR has been started, additional information may subsequently become available which makes continued CPR inappropriate, for example clinical information which indicates that CPR is unlikely to be successful, or information regarding the individual's preferences. […]'

3. When CPR should not be started

'[T]here will be some individuals for whom no formal DNAR decision has been made, but where attempting CPR is clearly inappropriate because death is imminent and unavoidable, for example, in the final stages of a terminal illness. In these circumstances, it is reasonable for healthcare professionals not to commence CPR.'

(National Consent Policy, Part 4, Section 5[45])

In general, according to the National Consent Policy[45], the most senior healthcare professional is responsible for making decisions about CPR in crisis situations. However, it is acknowledged that:

> ***'Situations may arise where a decision regarding CPR has to be made quickly and the most senior healthcare professional is unavailable. In such circumstances, decision making responsibility can be delegated to other less senior healthcare professionals, who should notify and discuss with their senior colleague as soon as possible'***
>
> (National Consent Policy, Part 4, Section 3.6[44])

Omitting to administer a particular treatment such as CPR for a particular person is generally viewed as morally justified if it is considered futile (ineffective/without benefit) or unnecessarily burdensome. In discussing judgments of futility, it should be made clear that it is not people's lives that are judged futile. A judgment of futility is not a value judgment about the significance or worth of this person's life or that a life with dementia is not worth living. Rather, the judgment relates to the benefit or otherwise of the treatment for this particular person at this stage of their dementia and/or related illnesses. It is vital to stress this point to family members in situations in which a DNAR has been signed.

> ***'Decisions about CPR must always be made on the basis of an individual assessment of each case and not, for example, on the basis of age, disability, the subjective views of healthcare professionals regarding the individual's quality of life or whether he/she lives in the community or in long term care. The individual's own views and values are centrally important.'***
>
> (National Consent Policy, Part 4, 3.2[45])

When people with dementia and their families are consulted, decisions about attempting CPR may raise sensitive and potentially distressing issues for people with dementia and those emotionally close to them. Initially it is most important to determine the capacity of people with dementia who are deciding on DNAR or CPR.

According to the Assisted Decision Making (Capacity) Act (2015) if a patient currently lacks the capacity to make a particular healthcare decision (e.g. to consent to or refuse CPR or other life sustaining treatments), treatment decisions should be based on their previously expressed wishes and/or any existing Advance Healthcare Directive. Where there is an Advance Healthcare Directive but there is ambiguity as to its meaning or application, then health professionals should consult the person's designated healthcare representative (if any) or those who are significant in the person's life who may be able to interpret the Advance Healthcare Directive and/or offer insights as to the person's values and beliefs. Where ambiguity persists, the opinion of a second health professional should be sought. Throughout these deliberations the person with dementia should be the focus of concern:

> ***'[A]ct at all times in good faith and for the benefit of the relevant person.' (Assisted Decision Making (Capacity) Act 2015 Pr.2 S.8(7)(e))***

Documenting decisions carefully will ensure that they are understood and implemented, particularly if staff who are not familiar with the person are on duty when a crisis does arise. However, it should be clear to staff that the documentation process is secondary and gives effect to the decision; it is not the decision itself. A valid DNAR is one that is reached following an appropriate decision-making process.

Respect for the person's well-being and dignity also means that, if a person with dementia has a DNAR in their chart, they and, where appropriate, their family, need reassurance that all pain management and supportive physical, psychological, social and spiritual care will continue.

Unnecessary hospitalisation

The duty to respect the person's right to life must be balanced against the duty to protect the patient from inhuman or degrading treatment and the duty to respect the patient's right to dignity and bodily integrity. Sometimes ethical dilemmas concerning competing obligations – such as preserving human life and avoiding harm – can arise as a result of hospital admissions.

When a person with dementia is approaching the end of life, a palliative approach to care should be adopted and, where possible, acute episodic illness should be managed in the community.

> ***Current or previously-expressed preferences with regard to place of care should be honoured as a principle, but best interest, safety and family caregiver burden issues should also be given weight in decisions on place of care (van der Steen et al 2014: 200)[4].***

The most frequent causes of hospitalisation among people in the end stages of dementia are pneumonia and urinary tract infections, even though being in hospital is not necessary for optimal treatment[49]. People with dementia can deteriorate when they move to an unfamiliar environment and admissions are often distressing and disorientating for them[48]. A recent audit of dementia in acute care highlights that approximately 1 in 12 people admitted to an acute hospital with a diagnosis of dementia will die during that admission[49]. Unnecessary hospital admissions can be avoided through advance care planning and liaison with the medical team[50]. Generally most people with dementia and their families prefer to remain in their usual place of care, rather than be admitted to hospital. To maximise the potential for this to occur, it is important to recognise that:

- There is a need for knowledge and expertise in relation to end-of-life care in long term care settings.
- The duration of the end stage of dementia and the dying process can be uncertain and this can be difficult for families.
- There is a need for teams to anticipate needs and changes; best practice is not to bombard families with information.
- Advance care planning issues need to be addressed[12].

Where admission to hospital is unavoidable, staff working in acute settings should be familiar with best practice for the care of people with dementia in such an environment, as outlined in the Irish National Audit of Dementia Care in Hospitals 2014 report[49].

Guidance Area 2

Meeting Ethical Goals of Treatment and Care

Do Not Attempt Resuscitation (DNAR)

Make resuscitation status clear: DNAR decisions should be clearly and accurately documented, dated and signed by a health care professional in the individual's healthcare record. Information should be provided about:

1. The rationale for the decision, including whether or not there is an advance care directive or plan.
2. Who was involved in discussions about the decision, including any discussion with the person themselves.
3. Whether a DNAR decision is to continue indefinitely or will be subject to review for example within a particular time or in the event of clinical change.

(National Consent Policy 2014, Part 4[45])

Resuscitation status should be made clear to family members and the reason why a DNAR is considered appropriate should be made clear. The meaning and limits of a DNAR should be explained in full to family members.

Explain the risks and benefits: Many people, patients, families and even some health professionals have unrealistic expectations about the likely success and potential benefits of CPR for persons with dementia and lack detailed understanding of what is involved. In the clinician-patient and family conversation, it is important to find out whether they understand what is actually involved in CPR, what likely outcomes can be anticipated, and what possible suffering might be involved for the patient if it is attempted.

Be informed: Be aware of the national and local policies in relation to DNAR and its requirements as these apply to your professional role. Act in accordance with the policy with respect to the making, documentation, communication and implementation of DNAR decisions.

Put systems in place: Healthcare providers should have systems in place to ensure compliance with DNAR instructions, particularly to ensure that a DNAR decision is communicated to staff who may not always be familiar with the individual patient to ensure that it is complied with in the event of an emergency.

DNAR and other end-of-life decisions: A decision not to attempt CPR applies only to CPR. It does not apply to any other aspect of treatment and all other treatments and care that are appropriate for the individual should continue. However, many DNAR decisions and discussions will occur in a broader context of decisions and discussions about end-of-life care, and it is often appropriate that documentation should reflect that broader context and refer to any additional decisions.

CASE STUDY 2

Noel Dabrowski is a 78-year old widower who emigrated to Ireland from Poland many years ago and speaks very good English. He has been cared for in a nursing home for the past two years, since he suffers from the early stages of Alzheimer's and was not coping very well at home. In the past six months he has also been diagnosed with end stage chronic bronchitis and heart failure. Despite this condition, Noel is actively interested in what is happening around him. He has two sons and one daughter, who visit him frequently and take a keen interest in his care. His children have accepted that nothing more can be done for their dad though he is seen regularly by his GP for symptom management and monitoring.

Early one evening Noel's condition suddenly deteriorates and he is breathless and increasingly confused. The nursing staff feel that since his resuscitation status has not been discussed or determined, they have no choice but to begin resuscitation efforts, call an ambulance and his family and seek his admission to hospital. One of the nurses hesitates and asks her colleagues; *'Would Noel or his family want us to resuscitate him in these circumstances and move him to hospital? Will resuscitation and further treatment benefit Noel?'*

Consider the case by applying the Ethical Decision-Making Tool

1. Articulate the ethical problem(s) and identify relevant facts

Ethical problem

A decision needs to be made about resuscitating Noel and admitting him to hospital but there is no DNAR order, care plan or advance directive that could guide the nurses as to how to proceed.

Relevant facts

1. Noel seems to be in the final phases of his illness.
2. It is likely that CPR will be painful and burdensome and the move by ambulance from familiar to unfamiliar surroundings will cause discomfort. It also seems likely that these efforts will be futile i.e. that Noel will not survive the intervention.
3. It is unclear how much Noel understands about what is happening to him because of his Alzheimer's and his breathlessness.
4. Noel's family seem to have believed that their father was for palliative care only and they indicated that they had accepted this, but there was no documentation to support this understanding.
5. The nursing staff feel under pressure to make a decision due to perceived lack of time. In the absence of any clarity around Noel's resuscitation status, they feel compelled to provide CPR and to call the emergency services.
6. There is no end-of-life policy in the nursing home that addresses situations like this.

2. Identify stakeholders' interests, needs, values

Noel Dabrowski

1. Respect for Noel's overall interests, including his autonomy interests requires that his views should inform what happens to him. **(autonomy)**
2. Noel's life should be saved if possible. **(value of life)**
3. Noel should not be subjected to painful, futile, unnecessarily burdensome or undignified treatment. **(avoiding harm, personhood)**
4. If Noel is dying, he should be supported to die in comfort and dignity surrounded by those he loves. **(doing good)**

Noel's family

1. Noel's family have accepted that further treatment for Noel's overall condition would be futile. **(avoiding harm)**
2. They indicate that they want high quality care for Noel. **(doing good)**
3. They demonstrate that they are very close to Noel and would want to be with him in his final days and hours. **(solidarity)**

Nursing Staff

1. Nurses are morally, legally and professionally obligated to respect Noel's wishes and values if known and to support his family. **(autonomy)**
2. They are also obligated to avoid harming Noel and his family and to act in ways that benefit them. **(value of life, avoiding harm, doing good)**
3. Nurses are not obligated to provide futile and/or burdensome care to patients. **(avoiding harm)**
4. Nurses may experience moral distress when they are unable to fulfil these obligations. **(avoiding harm, solidarity)**

Organisation

1. The nursing home management and health services in the region are obligated to provide necessary policies and procedures to ensure safe, respectful, quality care is provided to patients and that staff are supported and empowered to deliver that care. **(value of life, avoiding harm, doing good, autonomy, justice, solidarity)**
2. They are also obligated to conserve scarce resources. **(justice)**

3. Weigh the merits and demerits of available courses of action

1. Transfer Noel to hospital

Merits:

Resuscitation efforts can be maximized and they may temporarily prolong Noel's life. The move reassures nurses that they are doing everything they can to save Noel's life and addresses any worries about their obligations under the law.

Demerits:

The move risks increasing Noel's discomfort and suffering. He may become disorientated and confused and the move may hasten his death. The move is likely to cause the nursing staff moral distress if they believe that resuscitation efforts are actually futile.

2. Telephone Noel's GP to clarify Noel's resuscitation status. Telephone Noel's family to seek their understanding of Noel's wishes for his end-of-life care.

Merits:

This ensures that any decision made is consistent with what Noel would want. It also provides the nurses with the ethical and legal reassurance to act.

Demerits:

Any delay may risk Noel's life. Staff may experience moral distress if they believe that they are doing the wrong thing in delaying treatment for Noel. They may also worry about their legal obligations.

4. Select the option which can best be supported by ethical principles:

Contact Noel's GP and family

The attempt to avoid the perceived risk of litigation should not take priority over what is best for Noel. If the nursing staff are unable to reach Noel's GP and his family, and they are in doubt about their ethical and legal obligations, they should seek advice from senior staff in the nursing home. Currently, the section on DNAR orders of the Irish National Consent Policy (2014) supports the nursing staff to make whatever decision (1. or 2.) they believe respects Noel's wishes and will benefit him. The Assisted Decision Making (Capacity) Act 2015 also supports health professionals who, in the absence of a clear advance directive, act in good faith and for the benefit of patients.

Noel has a right to life. The right to life is one of the most fundamental rights and it is protected by the Irish Constitution, the European Convention on Human Rights as well as under United Nations human rights instruments. Noel cannot be deprived of his right to life because he may lack capacity to make a decision. It would be both unlawful and unethical to deny treatment to anyone on this basis.

Yet, the right to life is not absolute. It is generally accepted that treatment is not required where treatment would be futile because it offers no reasonable hope of benefit or because, even though it does, the expected benefit would be outweighed by burdens such as excessive pain and discomfort.

Noel has a right to dignity, a right to freedom from inhuman and degrading treatment and a right to bodily integrity. If resuscitation involves severe trauma such as cracking of his ribs, this would be an invasion of Noel's bodily integrity that would not be justified if it is unlikely to benefit Noel. Noel's right to dignity would also be compromised because his last moments of life would be spent in this way.

Telephoning the GP is supported by the principle of beneficence.

Nursing staff caring for Noel may have had an opportunity to discuss his care with him during periods when he was most lucid. Where possible, every effort should continue to be made to explain to Noel what is happening.

Any indications from Noel as to what he wanted prior to the incident can inform their decision-making process.

This case also arose in part because the resuscitation process was neither clarified nor documented on the ward and the family's understanding of Noel's wishes or their expectations were not documented. Ongoing communication with Noel's family maximizes the chances of agreement and appropriate resolution of difficult situations and it ensures that, even if the participants fail to reach agreement, the discussion takes place in the best possible way for the patient, the family and the health professionals. Patients are members of families and, given Noel's relationship with his children, it is right that they should be consulted. Respect for Noel's rights requires family involvement.

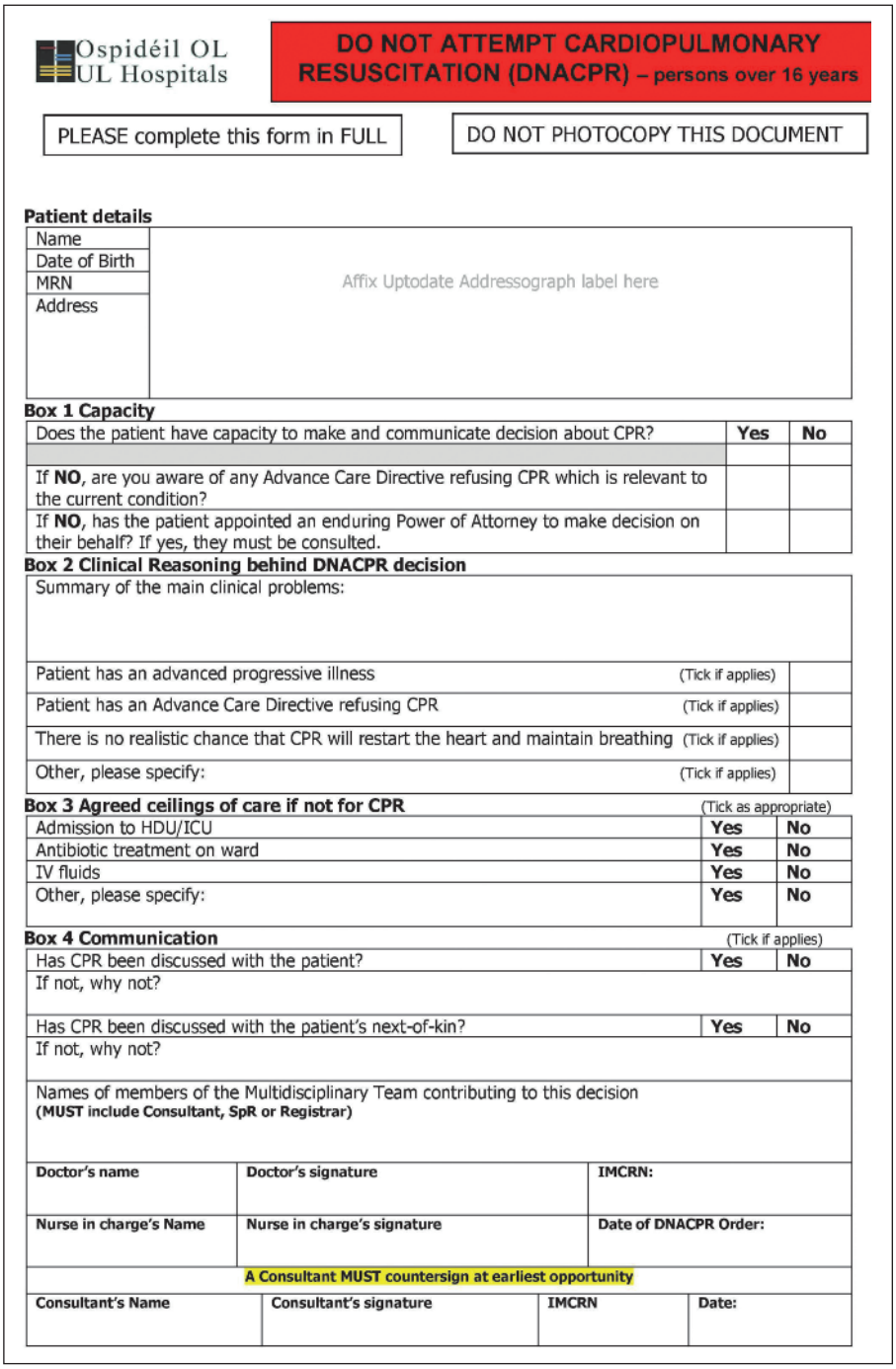
5. Review

Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?

Additional resources

1. **National Consent Policy, Part 4 (2014)**
   Available at:
   http://www.hse.ie/eng/about/Who/qualityandpatientsafety/qpsfocuson/consentfocuson.html

2. An example of a DNACPR form (Twomey, F. and Casey, D. (2016) Pilot of DNACPR Form at University Hospital Limerick, Poster at National HFH Conference).



Ospidéil OL
UL Hospitals

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) – persons over 16 years

PLEASE complete this form in FULL

DO NOT PHOTOCOPY THIS DOCUMENT

Patient details

Name	Affix Uptodate Addressograph label here
Date of Birth	
MRN	
Address	

Box 1 Capacity

Does the patient have capacity to make and communicate decision about CPR?	Yes	No
If **NO**, are you aware of any Advance Care Directive refusing CPR which is relevant to the current condition?		
If **NO**, has the patient appointed an enduring Power of Attorney to make decision on their behalf? If yes, they must be consulted.		

Box 2 Clinical Reasoning behind DNACPR decision

Summary of the main clinical problems:	
Patient has an advanced progressive illness (Tick if applies)	
Patient has an Advance Care Directive refusing CPR (Tick if applies)	
There is no realistic chance that CPR will restart the heart and maintain breathing (Tick if applies)	
Other, please specify: (Tick if applies)	

Box 3 Agreed ceilings of care if not for CPR (Tick as appropriate)

	Yes	No
Admission to HDU/ICU	Yes	No
Antibiotic treatment on ward	Yes	No
IV fluids	Yes	No
Other, please specify:	Yes	No

Box 4 Communication (Tick if applies)

Has CPR been discussed with the patient?	Yes	No
If not, why not?		
Has CPR been discussed with the patient's next-of-kin?	Yes	No
If not, why not?		

Names of members of the Multidisciplinary Team contributing to this decision
(MUST include Consultant, SpR or Registrar)

Doctor's name	**Doctor's signature**	**IMCRN:**
Nurse in charge's Name	**Nurse in charge's signature**	**Date of DNACPR Order:**

A Consultant MUST countersign at earliest opportunity

Consultant's Name	**Consultant's signature**	**IMCRN**	**Date:**

5.3 Guidance Area 3

Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration

Poor appetite and weight loss are often associated with dementia[51]. Difficulties with eating experienced by people with dementia may be caused by physiological problems associated with the disease or by psychological problems, such as depression. It may also be the case that a person's routine has been disrupted or that their food preferences are simply not met[52]. In situations in which people with dementia are no longer able or willing to take food orally, the option of administering clinically-assisted nutrition and hydration (CANH) must be carefully considered (See Guidance Document 4).

Food has an emotional, symbolic and social importance which should not be underestimated; offering feeding assistance* to someone who is sick is a 'powerful instinctive act' and the human contact provided by the act of assisting someone to eat and drink may be of therapeutic benefit[52]. CANH is a medical treatment[53,54], and, like other medical treatments, it is associated with both burdens and benefits, depending on an individual person's circumstances.

> ***'Deciding whether or not the administration or continuation of CANH is clinically indicated requires careful consideration of its burdens and benefits in the context of the specific goals of care for the patient. Such considerations include the patient's illness trajectory, the potential impact of the intervention on the patient's condition, the expected clinical outcomes and the preferences/ values of the patient or proxy decision-maker.'***
>
> (ASPEN, 2014[42])

CANH may be very useful in providing nutrition and hydration to people who are temporarily unable to swallow or have dysfunctional gastrointestinal tracts. It may also benefit people with chronic disabling conditions who value their quality of life[55]. However, there is insufficient evidence to suggest that CANH can provide meaningful clinical benefit to people who are terminally ill or approaching the end of their lives.

In people with dementia, CANH most commonly takes the form of feeding assistance via a PEG tube. Supposed benefits of PEG feeding include prolonged survival, prevention of malnutrition and weight loss, reducing the incidence of aspiration pneumonia and reducing the development of pressure ulcers[56]. However, existing evidence suggests that tube feeding rarely achieves its intended clinical goals in people with advanced dementia[57], and it does not establish that tube feeding (enteral nutrition) is effective in terms of prolonging survival, improving quality of life, providing better nourishment or decreasing the risk of pressure sores[51,56,58].

Rather than preventing suffering, tube feeding may actually cause it in a person with dementia[53,57]. NG tube feeding is associated with numerous complications, including diarrhoea, nausea, vomiting and oesophagal perforation. Intravenous feeding is associated with risk of infection, phlebitis and electrolyte imbalances[59], while the burdens of PEG feeding (enteral nutrition) include risk of infection around the site of PEG and increased risk of aspiration pneumonia in advanced dementia[42].

* NB: The term feeding assistance is used in this guidance document to describe assistance with eating and drinking for a person with dementia. The term 'feeding' alone contributes to a negative connotations associated with ageing and stereotypes older persons.

When tube feeding replaces oral feeding on a long-term basis, people are deprived of the taste of food and the opportunity for contact with caregivers while eating[57,58]. Although healthcare professionals may be aware of the risks associated with tube feeding, they may feel compelled by institutional, societal or legal pressures to intervene[51,56].

As people with dementia approach the end of their lives, decreased interest in food is normal[53]. The body's increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty swallowing[58,59]. However, the body adapts physiologically at the end of life and this prevents people from suffering as a result of the absence of food[54]. Terminal dehydration in people who are close to death is beneficial in the sense that it reduces respiratory and gastrointestinal secretions[58].

Decisions about whether or not to assist people with hydration or nutrition may be better managed by reframing the discussion in terms of 'comfort feeding only' or 'tastes for comfort' and devising an individualised care plan which focuses on the person's treatment goals. Careful assistance by hand is the least invasive and potentially most satisfying way of maintaining nutrition for the person with dementia[56].

Health professionals should set aside ample time early in the process of end-of-life care planning to discuss treatment options with people with dementia and family members - including the possibility of foregoing CANH – rather than waiting until the person is at the end of his or her life[60].

Where a person is at a moderate – advanced stage in their illness and admission to acute hospital is required for the purposes of administering CANH, this should be considered with regard to the potential benefit for the person. As indicated in Guidance Area 2, evidence suggests that acute admission can cause significant (and often avoidable) distress at the time to people with dementia and their carers: there is also evidence to suggest that the disorientation and distress that people with dementia often experience in hospital have a long-term and sometimes permanent effect on the person's cognitive abilities and capacity to continue coping on their own[61]. Indeed, a hospital admission will often be a 'trigger' for admission into residential care, thus forcing the person with dementia and those close to them to make important decisions about the future at a point of crisis, instead of in their own time.

Guidance Area 3

Disputing the Ethical Goals of Treatment and Care

Clinically Assisted Nutrition and Hydration

CANH is a medical treatment with benefits and burdens: In situations in which people with dementia are no longer able or willing to take food orally, the option of administering clinically-assisted nutrition and hydration (CANH) must be carefully considered. CANH is a medical treatment, and, like other medical treatments, it is associated with both burdens and benefits, depending on an individual person's circumstances. While it may help some people with dementia, there is insufficient evidence to suggest that CANH can provide meaningful clinical benefit to people who are terminally ill or approaching the end of their lives.

Consider the goals of care: Deciding whether or not the administration or continuation of CANH is clinically indicated requires considering the nature and severity of the person's illness, the specific goals of care for the person, the expected impact of the intervention, the person's current preferences or previously expressed will and preferences, if available, and the views of any designated healthcare representative, or other family members and carers, about what the person with dementia would have wanted if they no longer have capacity to make a decision about CANH.

Devise an individualized care plan: As people with dementia approach the end of their lives, the body's increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty swallowing. However, the body adapts physiologically at the end of life and this prevents people from suffering as a result of the absence of food. An individualized care plan which focuses on the person's treatment goals, including the option of comfort feeding assistance, may allow better management of decisions about whether or not to provide feeding assistance to people with advanced dementia.

Make a plan in advance: Set aside ample time early in the process of end-of-life care planning to discuss the possibility of foregoing CANH, rather than waiting until the person with dementia is at the end of his or her life.

Listen to people with dementia and their families: Recognise the pressures which families can place on people in end-of-life contexts. While recognising the importance of communication and engagement with family members, professionals should make efforts to ensure that the person is not pressured into making decisions about end-of-life care which do not accord with what they want or need in order to keep family members happy.

Reassure both the person with dementia and the family that the primary duty is owed to the person with dementia. While this needs to be done sensitively, it is essential that this primary duty is maintained and that all parties involved are aware of it.

CASE STUDY 3

Mary is a 92-year-old woman who has been living in a residential care setting for older people, for the last 10 years. About two years ago, she fell out of bed and broke her hip. Since then, her health has been in gradual decline, with reduced mobility over time. A year ago, she was diagnosed with mild to moderate dementia.

When Mary broke her hip, her family was very angry, suggesting that this may have occurred due to a lack of supervision in the care setting. Since the fall, they have constantly questioned the care provided. Staff are concerned that the family may attempt to take legal action against the care centre and feel that the family no longer trust them.

A few weeks ago, Mary was diagnosed with a chest infection and was admitted to hospital at her family's request. She spent 24 hours in A&E and was admitted to a ward for one night and was then discharged back to the nursing home. Since then, Mary's health has declined and it is clear that she is now approaching the end of life.

Mary is weak and spends all of her time in bed. Six days ago, Mary refused to eat. Since then she has declined all food and drink, although on two occasions she requested egg white, which she was given when she asked for it. Staff have talked to Mary and she continues to communicate both verbally and non-verbally that she does not want to eat or drink anything. Previously Mary had said that she would not want to be admitted to hospital or to have any type of a feeding device inserted if she were at the end of her life.

Mary's family is very concerned. They question everything the nursing home staff do. They believe that, since Mary is requesting such nourishing food, she wants to live and is fighting for life. They want Mary to be taken to hospital to be fed artificially using a PEG tube.

Consider the case by applying the Ethical Decision-Making Tool

1. Articulate the ethical problem(s) and identify relevant facts

Ethical problems

A decision needs to be made about Mary's care, but this process is complicated by tensions in the relationship between Mary's family and those providing her care.

Mary has indicated her wishes but her family disagree with them.

Relevant facts

1. Mary's physical and mental health have declined over the course of the past two years; this decline has accelerated rapidly during the past month and she has lost interest in food, although she requests a small amount of food every couple of days.
2. Mary's family members want her to be taken to hospital and fed via a PEG or nasogastric tube.
3. Although Mary doesn't have an Advance Care Directive, there is clear documentation of her wish (consistent over time) not to be hospitalised or fed artificially.
4. As a result of Mary's fall and her subsequent decline, her family members have lost faith in the quality of care provided by staff in the nursing home.
5. Nursing home staff believe that members of Mary's family may be prepared to take legal action if their request to transfer Mary to hospital is not complied with.

2. Identify stakeholders' interests, needs, values

Mary

1. Mary is able to express her preferences on some level. She is refusing food for a reason and this needs to be explored. **(autonomy)**
2. Mary has explicitly stated on previous occasions that she does not want to go into hospital. Even if she no longer has capacity to make this decision, this expressed preference should be central to the decision-making process. **(autonomy, avoiding harm)**
3. Mary's capacity to understand the consequences of not eating should be assessed. **(autonomy, avoiding harm)**
4. Her nutrition status should be assessed and her needs determined in the context of promoting her autonomy and well-being **(autonomy, avoiding harm, doing good)**

Mary's family members

1. Mary's family value keeping her alive for as long as possible, and to this end they may not be able to appreciate that her own wishes must also be considered in this situation. **(avoiding harm, doing good, autonomy, solidarity)**

2. Because she is elderly and has dementia, Mary's family may see her refusal of food as the result of a lack of capacity and they may believe that her wishes should be overridden in the interests of keeping her alive. **(value of life)**
3. Mary's family may see food as symbolic of their love and attachment and possibly as the only thing they can still do for Mary, hence their insistence on the provision of artificial nutrition and hydration. **(avoiding harm, solidarity)**
4. Mary's family may believe that clinically-assisted nutrition and hydration may prolong Mary's life or improve its quality. **(value of life, avoiding harm, doing good)**

The healthcare professionals and staff caring for Mary

1. Healthcare professionals caring for Mary may not have reached a consensus about what is best for her. Some members of staff may be reluctant to transfer Mary to hospital against her express wishes; others may perceive withholding food as tantamount to allowing Mary to starve. **(autonomy, avoiding harm, doing good)**

2. While those caring for Mary may need an opportunity to explore the rationale underlying their own perspectives, the conversation between members of the care team should focus on devising appropriate goals of care for Mary, in the context of her own wishes, her illness and current clinical status. **(autonomy, avoiding harm, doing good)**

Nursing home management

1. The management team should be presumed to have put Mary's overall benefit at the centre of the decision-making process. **(avoiding harm, doing good, autonomy)**

2. However, because they may be concerned that Mary's family may take legal action against the nursing home or complain publicly, management may feel compelled to go along with the family's request for hospitalisation.

3. Weigh the merits and demerits of available courses of action

1. Continue to care for Mary in the nursing home, giving her food by mouth if and when she requests it.

Merits:

This course of action seems to be in accordance with Mary's wishes, and as such it prioritises her autonomy. Careful assistance with hand or comfort feeding assistance would allow Mary to taste small amounts of food and experience the social aspects of eating. Comfort feeding assistance accompanied by oral hydration may have a therapeutic benefit for Mary.

Demerits:

Mary may be malnourished and may be in need of more comprehensive nutrition support than oral intake can provide. Members of Mary's family may be concerned that she may be suffering from hunger and thirst or may feel that she is starving to death, even though the body naturally loses interest in food as death approaches. Mary may eventually become completely unable to eat, meaning that she is entering the dying phase.

2. Transfer Mary to hospital where clinically-assisted nutrition and hydration will be administered.

Merits:

CANH may improve Mary's nutritional status and may temporarily improve her quality of life.

Demerits:

This is against Mary's previously expressed wishes and her current preferences, and as such it violates her autonomy. If a capacity assessment indicates that Mary is capable of making a voluntary decision to stop eating and drinking, she has a legal right to do so; as such, administering CANH against her wishes violates this legal right and is akin to providing treatment without consent. If Mary's refusal of food is an indication that she is approaching the end of her life, prolonging the dying process may be burdensome for her. Mary may need to be restrained to prevent her resisting the insertion of, or pulling out, the gastrostomy tube; this is a direct violation of her autonomy.

4. Select the action which can best be supported by ethical principles

Promote Mary's ability to participate in decisions about her care.

Mary's capacity to participate in decisions about her care should be formally assessed. If she has the capacity to make her own decision about eating, her reasons for refusing food should be explored. If, after discussing her situation, she indicates that she does not want to be fed unless she requests food, her wishes should be respected.

If they can be elicited, Mary's values should be central to the decision-making process. Mary's refusal to eat may be prompted by a number of factors and these should be explored. Members of her family should also be encouraged to express their perspectives, but if Mary is found to have capacity in relation to the decision about assistance, her preferences must be prioritised.

Provide care which balances Mary's autonomy and her well-being.

If an assessment reveals that Mary's capacity to make healthcare decisions about CANH is in doubt, her ability to participate in decision-making at a level appropriate to her cognitive ability should be promoted and her wishes respected as far as possible. If she refuses to communicate or if she is judged to lack decision-making capacity completely, her previously expressed wishes should be taken into account in the decision-making process. Because a refusal to eat may be the result of a number of causes, Mary should be given a thorough medical assessment incorporating an examination of her mouth, teeth and/or dentures (including an analysis of her medication regimen for side-effects). Mary should also be screened for depression.

Explore the burdens and benefits associated with available treatment options.

Assess the benefits and burdens of administering CANH to Mary in accordance with the best available evidence.

Communicate clearly and sensitively.

Efforts should be made to open the lines of communication between those caring for Mary and her family. A meeting between all family members and staff caring for Mary should be arranged and the goals of care for Mary should be clearly established. The perspectives of the family members should be sensitively elicited and explored. The family members' reasons for requesting that Mary be hospitalized should be identified and the burdens and benefits of providing clinically assisted nutrition and hydration to Mary should be fully explained to them. Her family members may be experiencing emotions which are common when confronted with the ending of a loved one's life, such as anxiety, distress and possibly grief and guilt – emotions which are often masked by anger and mistrust. They may see giving Mary food as the one last thing they can do for her and may be unwilling to forego this. They may be unaware of the evidence indicating that enteral feeding does not benefit people at the end of life and may in fact cause harm.

Staff may need to revisit the fall incident and acknowledge the distress and anxiety experienced by Mary's family, if necessary acknowledging any systemic flaws responsible. The person who chairs the meeting should keep the conversation focused on the need to determine appropriate goals of care. Staff should make it explicit to Mary's family that they are giving Mary the best care they can and should emphasise the importance of focusing on their shared goal of respecting her wishes and doing what is best for her.

5. Review

Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?

Additional resources

National Institute for Clinical Excellence (UK)

Nutrition Support in Adults: https://www.nice.org.uk/guidance/cg32

Supporting People with Dementia and their Carers in Health and Social Care (2006; modified 2015): http://www.nice.org.uk/guidance/cg42

American Academy of Nutrition and Dietetics

Position and Practice papers on ethical and legal issues in assisted feeding and hydration (2008): http://www.eatrightpro.org/resource/practice/position-and-practice-papers/position-papers/ethical-and-legal-issues-in-feeding-and-hydration

American Society for Parenteral and Enteral Nutrition (ASPEN)

Ethics Position paper (2010): http://ncp.sagepub.com/content/25/6/672.full.pdf+html

ADDITIONAL RESOURCES

6.1 Understanding the progression of dementia

When considering ethical decision making involving a person with dementia, it is important to understand the progression of the condition and consider its effect on the person's memory, ability to make decisions and communicate.

Whilst many classification systems exist to grade the severity of the dementia (e.g. Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS)[62] (also known as the Reisberg Scale) and the FAST - Functional Assessment Staging)[63], the Clinical Dementia Rating (CDR) Scale[64,65] is considered to be the most widely used staging system in dementia research. Here, the person with suspected dementia is evaluated by a health professional in six areas: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care and one of five possible stages (0-3) of dementia is assigned (see below).

CDR-0	**No dementia**
CDR-0.5	**Mild** Memory problems are slight but consistent; some difficulties with time and problem solving; daily life slightly impaired
CDR-1	**Mild** Memory loss moderate, especially for recent events, and interferes with daily activities. Moderate difficulty with solving problems; cannot function independently at community affairs; difficulty with daily activities and hobbies, especially complex ones
CDR-2	**Moderate** More profound memory loss, only retaining highly learned material; disoriented with respect to time and place; lacking good judgment and difficulty handling problems; little or no independent function at home; can only do simple chores and has few interests.
CDR-3	**Severe** Severe memory loss; not oriented with respect to time or place; no judgment or problem solving abilities; cannot participate in community affairs outside the home; requires help with all tasks of daily living and requires help with most personal care. Often incontinent.

The Clinical Dementia Rating Scale[64,65]

Progression of Dementia

Three important influences on the life-span of dementia are the type of dementia, the stage of dementia, and whether the course of deterioration is rapid or slow.[66,67]

Life expectancy of the person with dementia

Although dementia is a progressive, life limiting and an incurable condition, it is not possible to clearly predict a person's life expectancy and this uncertainty can be very challenging for the person with dementia and their relatives/friends.

Although, specific life expectancy cannot be provided, there are some indicators below that healthcare staff can provide on the probable life expectancy of the person:

- 4.5 years post diagnosis is the average survival time for a person living with dementia[67]. However, some people can live for 20 years post diagnosis.
- Half of the people with late stage dementia will die within 1.3 years[66].

6.2 Alternative ethical decision making frameworks

The Nuffield Council on Bioethics[13] present a framework based on a number of core commitments:

- That individuals with dementia, with good care and support, can expect to have a good quality of life throughout their illness;
- That promoting both the interests of the person with dementia and those who care for them is important;
- That we need to act in solidarity with people with dementia, to acknowledge their citizenship and our mutual interdependence;
- That we should recognise the personhood, identity and value of people with dementia who remain the same equally valued persons throughout the course of their lives.

A Case Based Approach to Decision Making[13]

Nuffield[13] offers a three-step process to approach ethical decisions, taking the reader through case studies focusing on a number of key areas relevant to dementia care at the end of life.

1. **Identifying and clarifying the relevant factual considerations** *Carefully consider the background factors e.g. degree and duration of danger and distress to the person, the effect on the caregiver, what the person may have wanted before illness, what they are currently able to understand.*
2. **Interpreting and applying appropriate ethical values considering the person with dementia, caregivers and healthcare professionals**
3. **Comparing with other similar situations to find ethically relevant similarities or differences.**

The Nuffield[13] document presents a care pathway for people with dementia within which a person-centered, supportive and palliative approach to care is recommended at all stages of the illness trajectory. With regard to end of life and palliative care specifically for a person with dementia, the report notes the importance of the palliative philosophy of caring for the 'whole person', advance care planning, the provision of adequate pain relief, the avoidance of inappropriate treatment, and support for family. Considerable attention is given to decision making, an inevitable aspect of end of life care, focusing on when it may not be appropriate to provide a particular treatment for the dying person and how best to manage symptoms at the very end of life.

The Nuffield[13] report presents several case studies highlighting specific dilemmas in practice with a focus on decision-making, particularly with regard to nutritional support. The area of advance planning and proxy decision-making is discussed in detail, with reference to UK law, noting how a person's earlier wishes and decisions about their healthcare should be considered and balanced with any preferences conveyed (for example through behaviour or gesture) after the person has lost the legal capacity to make such decisions. The document makes it very clear, that by focusing on the value of the person with dementia, the importance of autonomy and quality of life, clinical decisions should be made based on the benefits and burdens for the individual. Considerable attention is given to ethics and dementia in a societal context and one of the key recommendations of the report is the need for training to be developed with an emphasis on skills and knowledge, to enable informed ethical decisions to be made.

The need for such education has also been recognised and addressed by McCarthy et al[15,16] with regard to ethics and end of life care specifically. The *Ethical Framework for End-of-Life Care*[15] is a set of educational resources that aims to foster and support ethically and legally sound clinical practice in end-of-life treatment and care in Irish hospitals, specifically, but can be adapted for use across other settings.

A Consensus Approach

Karlawish[23] offers the following core principles to plan the palliative care for people who lack the capacity to make decisions using a model of consensus based decision-making:

- Identify potential decision makers – these may be friends or family of the person with dementia or people who have been involved in the person's care over a period of time.
- Clarify the person with dementia's diagnosis and prognosis
- Determine whether the person has an advanced directive or other advanced planning documentation to outline their care preferences.
- Engage with the potential decision makers, asking them to describe how things have changed over time. The purpose of this dialogue is both to achieve a consensus among decision makers about the person's current disease state, prognosis, quality of life, and previously stated values and to hear and clarify where necessary, the meaning of emotionally charged terms, such as "starvation," "suffering," "quality of life," "feeding," and "dying."
- Teach the potential decision makers about the expected clinical course of the disease, providing guidance based on clinical data and experience.
- Advocate for the person's quality of life and dignity.
- Decisions should be based on:
  1) the person's preferences and
  2) a balance of the burdens and benefits of each option in terms of its ability to relieve suffering and maximise dignity and quality of life.
- Palliative care should be offered whether life-prolonging measures are initiated or the person with dementia is treated with comfort measures only.
- In the event that a consensus is not reached:
  - Postpone the decision-making where appropriate and recommend that the participants take time to think about and discuss key issues.
  - Understand and separate from each person's perspective the goals of medical care and the treatment choices to achieve these goals.
  - Invent new solutions (for example, a time-limited trial rather than an all-or-nothing solution).
  - Avoid power struggles or personalising the conflict.
  - Call in a third party (e.g. clergy, ethicist, palliative care as appropriate).

6.3 Approaches to care

PERSON-CENTRED CARE

The predominant philosophy of care for people with dementia in recent years has been person-centred care[4,34]. Brooker[68] has suggested the acronym **VIPS** to encapsulate the broader meaning of person-centred care: people with dementia and their carers must be **Valued**; they must be treated as **Individuals**; the **Perspective** of the person with dementia must inform our understanding; and the person's **Social** environment must be attended to because of the fundamental importance of relationships in sustaining personhood. Towards the end of his book, *Dementia Reconsidered*, Kitwood[34] (who conceived the notion of person-centred care in dementia) suggested a new culture of care which:

> ***'…brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured. It reinstates the emotions as the well-spring of human life, and enjoys the fact that we are embodied beings. It emphasizes the fact that our existence is essentially social' (Kitwood[34] p.135).***

Person-centred care is underpinned by a philosophy of personhood, which Kitwood characterised as follows:

> ***'It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood[34] p.8).***

The notion of person-centred care was born out of opposition to a narrow biomedical view ('the medical model') and it is firmly based on a psychosocial and spiritual paradigm. As articulated by Kitwood, person-centred care places little emphasis on the medical management of patients.

PALLIATIVE CARE

If dementia is a terminal condition, individuals with dementia should have access to a palliative approach from the time of diagnosis.

> ***'Dementia can realistically be regarded as a terminal condition. It can also be characterized as a chronic disease or in connection with particular aspects, as a geriatric problem. However, recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.'***
>
> (van der Steen et al 2014: 200)[4]

Key aspects of palliative care relevant to dementia care can be summarised thus:[4, 69-71]

- Life is affirmed: people should be encouraged to live as well as they can even whilst accepting the inevitability of death, which should neither be hastened nor postponed;
- Distressing symptoms of whatever sort should be actively treated whilst maintaining quality of life;
- Care must be holistic: biological, psychological, social and spiritual, which necessarily means the family and significant friends must be included and care must extend to bereavement.

6.4 Dementia, Palliative Care And Intellectual Disability

The resource listed below is an example of an international guideline relating to promotion of access to palliative care for people with an intellectual disability.

- Help the Hospices (2013). Towards excellence in hospice care. Widening access to palliative care for people with learning disabilities. Help the Hospices; London http://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/hth_learning_disabilities_doc_singles_06_lr.pdf

The resources listed below are some examples of national and international guidelines and empirical research relating to the accurate and comprehensive assessment of Alzheimer's disease in people with an Intellectual Disability.

- Burt DB & Aylward EH. (2000) Test battery for diagnosis of dementia in individuals with intellectual disability. Working group for the establishment of criteria for diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual Disability Research 44, (2), 175-180*
- College of Psychiatrists of Ireland (2014). *A Guidance Document on Dementia in Persons with Intellectual Disability.* Dublin. College of Psychiatrists of Ireland http://www.irishpsychiatry.ie/Libraries/External_Events_Documents/A_Guidance_Document_on_Dementia_in_Persons_with_Intellectual_Disability_2013_doc_final_for_web.sflb.ashx
- Esralew, L., Janicki, M.P., DiSipio, M., Jokinen, N., Keller, S.M. and Members of the National Task Group Section on Early Detection and Screening. (2013). *National Task Group Early Detection Screen for Dementia: Manual*. Available from http://aadmd.org/sites/default/files/NTGEDSDmanual-bangor%20version-e.pdf
- Esralew, L., Janicki, M.P., DiSipio, M., Jokinen, N., Keller, S.M. National Task Group Section on Early Detection and Screening (2013). *National Task Group Early Detection Screen for Dementia* (NTG:EDSD). http://aadmd.org/ntg/screening
- McCarron, M. Fahey-McCarthy, E. Connaire, K. McCallion, P. (2008) Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Intellectual Disability, Dementia and Palliative Care. Report. Dublin: School of Nursing and Midwifery, Trinity College Dublin. http://www.nursing-midwifery.tcd.ie/assets/publications/pdf/fusing-horizons-of-care.pdf
- Strydom A., Lee L.A. Jokinen, N et al. (2009) Dementia in older adults with intellectual disabilities. Report on the state of science on dementia in people with intellectual disabilities. IASSID Special Interest Research Group on Ageing and Intellectual Disabilities. https://www.iassidd.org/uploads/legacy/images/documents/Aging/state%20of%20the%20science%20dementia%202009.pdf

The resources listed below are some examples of international guidelines relating to the provision of community supports for people with an Intellectual Disability and Alzheimer's disease.

- Jokinen, N., Janicki, M.P., Keller, S., McCalin, P., Force, L and the National Task Group on Intellectual Disabilities and Dementia Practices (2013). *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia.* Albany NY: NTGIDDP & Centre for Excellence in Aging & Community Wellness. http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf
- National Task Group on Intellectual Disabilities and Dementia Practice (2012). '*My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports.* American Association on Intellectual and Developmental Disabilities. http://aadmd.org/sites/default/files/press-release-logoheader.pdf
- Watchman, K (2008). Changes in Accommodation Experienced by People with Down Syndrome and Dementia in the First Five Years after Diagnosis. *Journal of Policy and Practice in Intellectual Disabilities, vol.5, no.1, pp. 65-68.*
- Watchman, K (2014). People with a learning disability and dementia: reducing marginalisation. *Australian Journal of Dementia Care, vol.2, no.6, pp. 31-34.*

The resource listed below is an example of an international guideline which seeks to enable caregivers, whether family members or staff, to prepare for and advocate during health visits.

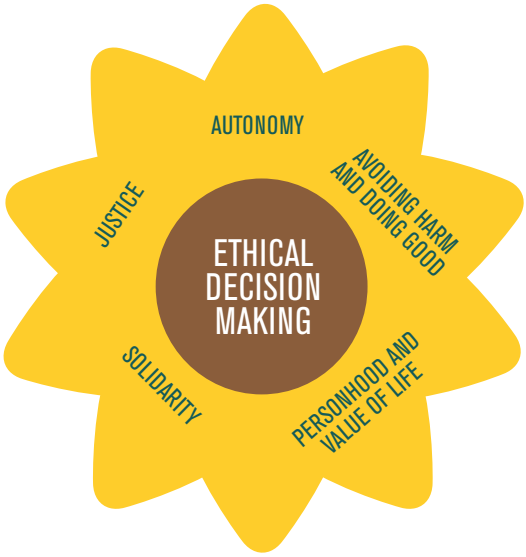
- Bishop, K.M., Hogan, M., Janicki, M.P., Keller, S.M., Lucchino, R., Mughal, D.T., Perkins, E.A., Singh, B.K., Service, K., Wolfson, S and the Health Planning Work Group of the National Task Group on Intellectual Disabilities and Dementia Practices (2014). *Guidelines for Dementia-Related Health Advocacy for Adults with Intellectual Disability and Dementia:* National Task Group on Intellectual Disabilities and Dementia Practices http://aadmd.org/sites/default/files/Bishop-document-web.pdf

FACT SHEET 6A 6B 6C 6D

Ethical decision making in end-of-life care and the person with dementia

Core ethical principles to underpin decision making

- Justifying an action by appealing to ethical principles means having to defend that choice of action over others in a manner which goes beyond our own perspective, bias, values and interests. By choosing an action based on principles, we remove our own partial viewpoint from the decision and appeal to a more general sense of what is the right thing to do.
- There is rarely one overarching ethical principle or value that can be used to solve an ethical problem. Critical judgment is required based on the individual's rights and interests, the situation, the risks and the context in which the decision is made.
- There is rarely a single right solution for what should be done, and in fact reasonable disagreement can be expected and even encouraged.
- An approach to decision-making where solutions emerge in the course of dialogue, disagreement and negotiation often works best.



Five Core Ethical Principles Underpin Ethical Decision Making in Dementia Palliative Care.

The Irish Hospice Foundation

This factsheet has been developed based on Irish Hospice Foundation Dementia Palliative Care Guidance Document No 6. Ethical Decision Making. Available from www.hospicefoundation.ie

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FACT SHEET 6A 6B 6C 6D

Core ethical decision making principles

Autonomy

- Focus on the experiences of the person and on what matters most to them
- Be attuned to the way in which they make sense or meaning out of the world
- Help the person to express themselves
- Meet the person where they are in themselves and in their environment of care
- Enable and foster relationships that are important to the person
- Recognise and meet the needs of carers

Avoiding Harm and Doing Good

- When making decisions for individuals who lack capacity to make any decisions about their medical treatment or care, in the absence of any advance plan or directive, caregivers should act to promote the person's overall well-being, e.g. attention should be paid to pain and symptom management and to the avoidance of unnecessary suffering as well as the creation of opportunities for positive experiences and joy.
- Promoting a person's well-being goes beyond weighing the burdens and benefits of proposed actions: it also involves taking the person's past and current wishes and preferences into account.

Personhood and Value of Life

- The life of a person with dementia should be valued just as much as that of a person without dementia, with a particular focus on the person's capabilities, rather than on presumed deficits.

Justice

- Requires that access to treatment and care should not be restricted on the basis of age, disability, psychological or intellectual impairment.
- Requires that attention be paid to the way in which group differences (e.g. gender, ethnicity) can place individuals and families at a disadvantage, and to the need to develop strategies/practices to ameliorate inequities.

Solidarity

- Our interdependence as human beings means that any of us may be touched by dementia and all of us will certainly be touched by end-of-life issues. The quality of care provided should reflect the standard of care we would expect for ourselves and the people we love.

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FACT SHEET 6A 6B 6C 6D

Ethical decision making in end-of-life care and the person with dementia

Ethical decision making tool

Articulate the ethical problem(s) and identify relevant facts

- Be ethically sensitive and communicate clearly

Identify stakeholders' interests, needs and values

- Be respectful and inclusive

Weigh up the merits and demerits of available courses of action

- Be informed and fair

Select the action best supported by ethical principles

- Be impartial and transparent

Review

- Check: Have I been sensitive, clear, respectful, inclusive, informed, fair, impartial and transparent?

See Guidance Document No 6 for more Information and Case Studies

Persons with dementia have the same rights as all persons

e.g. the right to life, autonomy, dignity, bodily integrity, freedom from inhuman and degrading treatment as well as the right to information, to consent and to confidentiality

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FACT SHEET 6A 6B 6C 6D

Ethical decision making in end-of-life care and the person with dementia



Guidance

Guidance Area 1

Promoting Autonomy and the Capacity of the Individual to Consent to or Refuse Treatment and Care

The autonomy of the person with dementia may be promoted and enhanced by engaging in a process of Advance Care Planning (ACP) while the person still has the capacity to make decisions about future treatment. Even if an Advance Care Plan or an Advance Healthcare Directive is in place, an autonomy-centred approach requires that healthcare professionals pay attention to what the experience of their condition means to the person who is now living with dementia and their carers. It requires that healthcare professionals and carers actively support the person with dementia so that they are encouraged to retain and express their sense of self and maintain the relationships that are important to them, rather than simply being protected from harm.

Guidance Area 2

Meeting the Ethical Goals of Treatment and Care – Do Not Attempt Resuscitation (DNAR)

Meeting the ethical goals of treatment and care may sometimes require limiting medical treatment in cases where individuals have refused it or in situations where it offers no overall benefit. Omitting to administer a particular treatment such as CPR for a particular person is generally viewed as morally justified if it is considered futile (ineffective/without benefit) or unnecessarily burdensome. When discussing judgments of futility, it should be made clear that it is not people's lives that are judged futile – judgments relate to the expectation that the treatment will not provide any benefit for this particular person at this stage of their dementia and/or related illnesses.

Guidance Area 3

Disputing the Ethical Goals of Treatment and Care – Clinically Assisted Nutrition and Hydration

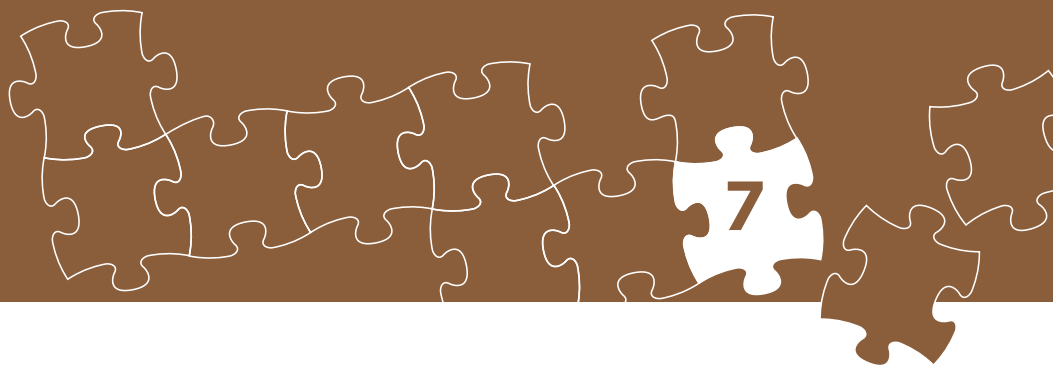
As a person with dementia approaches the end of their life, the body's increasing inability to absorb nutrients is often accompanied by loss of appetite and thirst and difficulty in swallowing. However, food has an emotional, symbolic and social importance which should not be underestimated. Offering feeding assistance to someone who is sick is a 'powerful instinctive act' and the human contact provided by the act of assisting someone to eat and drink may be of therapeutic benefit. Deciding whether or not the administration or continuation of Clinically Assisted Nutrition and Hydration (CANH) is clinically indicated requires careful consideration of its burdens and benefits in the context of the specific goals of care for the person with dementia. The evidence indicates that CANH does not offer clinical benefit in the long term and especially at the end of life. Any deliberations about CANH should include the person's illness trajectory, the potential impact of the intervention on the person's condition, the expected clinical outcomes, the impact of a potential inpatient admission on the person, and the preferences/values of the person.

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CONCLUSION

Individuals with dementia may well lose the thread of their lives as a whole, but still retain the ability to hold on to core moral values. Add to this, the fact that over the course of a slow deterioration, their cognitive capacity may fluctuate; it is imperative that individuals with dementia are viewed as subjects, not objects, of care and that focus is placed on their abilities to participate in decision-making and communication and not simply on the preservation of their comfort and safety. In addition, whether they have or lack memories or the capacity to communicate, they remain persons with unique life histories and relationships that we are obliged to honour and maintain.

The aim of this guidance document is to provide caregivers of people with dementia, regardless of care setting, with a framework to support ethical decision making for people living with dementia at the end of life. It:

- explains core Ethical Principles as they apply to individuals with dementia at the end of life
- provides a Decision Making Tool that supports ethical decision making for individuals with dementia at the end of life
- offers guidance on key ethical challenges that arise in dementia care at the end of life (preserving autonomy and decision-making and ethical goal setting in treatment and care [DNAR and CANH].

The case studies included all place emphasis on advance planning, individualized plans, the inclusion and support of loved ones where appropriate, and honest, ethical and evidence-based goal setting. They also prioritize the development of relational skills and practices in order to preserve an enabling environment within which individuals with dementia are consulted on factors that affect their lives and are supported to make meaningful choices in the face of their impairment. We believe that this kind of approach and these skills can best serve the needs of individuals with dementia at the end of their lives and, in turn, remind us all that even though we may be frail and dependent we may also hold on to our dignity and even flourish.

GLOSSARY

Advance Healthcare Directive: is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning treatment decisions in the context of an anticipated deterioration in their condition with loss of decision making capacity to make these decisions and communicate them to others. An advance healthcare directive is legally binding when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. An advance healthcare directive may also designate authority to a healthcare representative to interpret the will and preferences of the directive-maker and consent or refuse treatment based on their known will and preferences.

Advance care planning: refers to a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in a person's condition with loss of capacity to make decisions and communicate these to others.

Capacity: Legal decision-making capacity refers to a specific decision to be made about a particular medical treatment at a particular time. A person with capacity:

- understands in broad terms the reasons for, and nature of, the decision to be made and is able to retain this knowledge long enough to make a voluntary choice.
- has sufficient understanding of the principal benefits and risks of a medical intervention and relevant alternative options, after these have been explained to them in a manner and in a language appropriate to their individual level of cognitive functioning.
- can communicate their choice (sometimes with the support of augmentative communication strategies [See Guidance 1]).

According to the Assisted Decision Making (Capacity) Act 2015, a person lacks capacity to make a decision to consent or refuse medical treatment if they are unable to –

(a) understand the information relevant to the decision;
(b) retain the information long enough to make a free choice;
(c) weigh the information as part of the decision-making process;
(d) communicate their decision.

Cardiopulmonary resuscitation (CPR): is a group of treatments used when someone's heart and/or breathing stops. It was developed as a treatment intervention for cases of sudden unexpected cardiac or respiratory arrest. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing; chest compression, bag-and-mask positive-pressure ventilation, intubation and defibrillation. Drugs are also frequently used to stimulate the heart.

Do Not Attempt Resuscitation (DNAR): A DNAR order may generally be described as a request primarily written and signed by a medical practitioner but which could involve the patient, health care team and family, stating that in certain circumstances should the patient suffer from cardiopulmonary failure, cardiopulmonary resuscitation (CPR) should not be attempted. Such an order is only relevant to not attempting CPR and not to the withholding of any other treatment. This request should always be documented and kept in the patient's record.

Life Sustaining Treatment (LST): is any medical intervention, technology, procedure or medication that is administered to provide benefit for a patient and to forestall the moment of death. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation, haemodialysis, chemotherapy, or certain medications including antibiotics.

APPENDIX 1
STEERING AND PROJECT GROUP MEMBERSHIP

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Steering Committee
The outputs from the Project Group were overseen by a Steering Committee convenved by The Irish Hospice Foundation comprising of:

1. **Prof. Geraldine McCarthy** (Chair). Emeritus Professor, University College Cork and Chair South/South West Hospitals Group.
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3. **Ms. Marie Lynch**, Head of Healthcare Programmes, Irish Hospice Foundation.
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6. **Ms. Mary Mannix,** Clinical Nurse Specialist Dementia Care, Mercy University Hospital, Cork.
7. **Professor Philip Larkin,** Director of the Palliative Care Research Programme, School of Nursing and Midwifery, University Collge Dublin.
8. **Dr. Bernadette Brady,** Consultant in Palliative Medicine, Marymount Hospital & Hospice, Cork.

APPENDIX 2

METHODOLOGY

The process for developing this guidance document is outlined as follows:

1. The IHF project advisory group issued a tender for the development of a series of four guidance documents (No. 4-7). Dr Alice Coffey oversaw the development of all four guidance documents. A project team, led by Dr. Joan McCarthy, UCC, successfully tendered to develop this ethical decision making guidance document (See Appendix 1 for membership of the team). A Steering Committee was established by the IHF to oversee the development of this guidance document (See Appendix 1 for membership of the group). Drafts of the guidance document were reviewed by international/national subject experts (See Appendix 1 for details).

2. A literature review was conducted using scoping review methodology[72,73].

DATABASES SEARCHED

EBSCO Database

- Medline
- Academic Search Complete
- PsycINFO
- CINAHL Plus with Full Text
- Psychology and Behavioural Sciences Collection
- SocINDEX
- Social Sciences Full Text (H.W. Wilson)

Philosophers Index

SEARCH STRATEGY

The following key word strategy was agreed by the project team and used in EBSCO, adapted variations were developed for the other databases:

S1: TI (Belie* OR value* OR principle* OR ethic* OR moral* OR virtue*) OR AB (Belie* OR value* OR principle* OR ethic* OR moral* OR virtue*)

S2: TI (palliative OR dying OR "end of life" OR "end-of-life" OR hospice OR terminal* OR "end-stage" OR "end stage" OR chronic* OR "advanced illness" OR "advanced life limiting illness" OR "advanced life-limiting illness" OR "advanced life limited illness" OR "advanced life-limited illness" OR "late stage") OR AB (palliative OR dying OR "end of life" OR "end-of-life" OR hospice OR terminal* OR "end-stage" OR "end stage" OR chronic* OR "advanced illness" OR "advanced life limiting illness" OR "advanced life limited illness")

S3: TI (Dementia OR Alzheimer* OR demented) OR AB (Dementia OR Alzheimer* OR demented)

S4: TI (Guideline* OR guidance OR pathway* OR policy OR policies OR protocol* OR standard* OR framework) OR AB (Guideline* OR guidance OR pathway* OR policy OR policies OR protocol* OR standard* OR framework)

S5: S1 AND S2 AND S3 AND S4

References from relevant papers were scanned to identify additional papers as necessary.

INCLUSION CRITERIA

English language

Peer reviewed publications

Focus on adult populations (patients/family caregivers) with dementia

Book Chapters and Books

Thought pieces and reflective articles

EXCLUSION CRITERIA

Written in a language other than English

Conference abstracts, dissertations, book reviews.

Focus on populations under 18 years of age

Studies with a purely biochemical focus

Animal/lab based studies

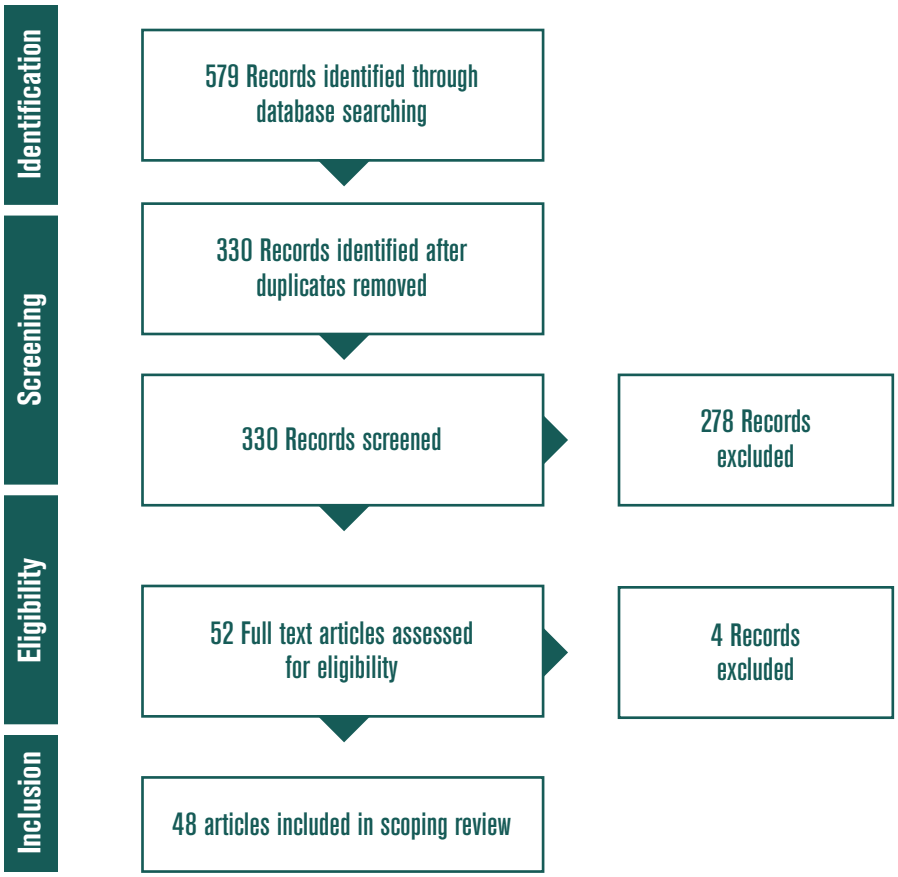
Papers generic to older people

Mixed Populations e.g. Parkinson's and Dementia

Not in English

Records retrieved were divided into three groups "Yes", "Maybe" and "Reject". A second and third screening of the "Yes" and "Maybe" folders was conducted to produce a final list for full-text review. Only papers satisfying the criteria above were included for data extraction. Where there was a disagreement regarding inclusion of a record, a third reviewer was consulted.

OUTCOME OF LITERATURE SEARCH



LITERATURE WAS REVIEWED TO CONSIDER

The volume of evidence available.

Theoretical models proposed.

Evidence specific to a variety of care settings.

Recommendations for practice.

Gaps in current knowledge, relevant research in progress and key emerging issues.

CLEARING HOUSES AND PROFESSIONAL BODIES

Searches of the following major clearing houses to identify pre-existing guidance documents, relevant to the domains above were also conducted:

Australian Government NHMRC
NHS Quality Improvement Scotland
Department of Health Australian Government
WHO
US: Institute of Medicine
Institute for Healthcare Improvement
United States National Guideline Clearinghouse
The Guidelines International Network
New Zealand Guidelines Group, NLH
National Library of Guidelines (UK) Includes NICE
Scottish Intercollegiate Guidelines Network
Health technology Assessment
NICE

3. Collation of key themes to inform the guidance by the Project Team.

LITERATURE REVIEW THEMES

1. **Common ethical and legal principles and values underpinning ethical decision making for dementia care at the end of life**
2. **Existing ethical decision making frameworks for dementia care at the end of life**
3. **Specific concerns that arise in end-of-life dementia care e.g. advance planning, truth-telling, assessment of capacity to consent or refuse treatment, enabling and protecting, withholding/withdrawing life sustaining treatment.**

4. Hand search of international and national policy and best practice guidelines - ongoing throughout the process in order to inform and populate the resources.

Limitations

The search was broad and highlighted key areas for guidance development. These areas e.g. hydration then required additional searches. Well known documents, e.g. Nuffield Report did not emerge from the academic search and were subsequently sourced online.

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