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RESEARCH ARTICLE

Disputing death: brain death in the courts

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Abstract

Death by neurological criteria (DNC) has remained controversial since its introduction over 50 years ago. Objections to the diagnosis of DNC have been coming before the courts in various jurisdictions, including at least seven recent challenges before the UK courts. In responding to these challenges, the UK courts have expressed no doubts as to the status of DNC and have affirmed that following a diagnosis of DNC, the matter of best interests is no longer relevant. Yet, the courts have also, tacitly, acknowledged that DNC is not quite the same as cardio-pulmonary death.

This paper begins by setting out the origins of DNC as a medico-legal construction, and its ongoing controversies. It then analyses the treatment of DNC, including authorisation of DNC testing, by the UK courts. It shows that the courts have been operating a form of ad hoc reasonable accommodation of different views of DNC but have done so without normative engagement. The paper argues that the courts should recognise that DNC disputes are not simply concerned with whether, as a matter of fact, DNC has been correctly diagnosed, but also raise profound questions about rights and interests, both of families and of the DNC dead.

Keywords: health law; DNC; brain stem death; best interests

Introduction

The moment of diagnosis of death by a medical practitioner denotes an irreversible change in the metaphysical and legal status of the individual. While the law remains engaged in various ways,[1] under orthodox legal approaches there is no longer a person with rights or interests to protect. A lot then hinges on the diagnosis being both sound and correct. In a review article, Dale Gardiner et al outline three sets of criteria according to which human death can be diagnosed: 'somatic (features visible on external inspection of the corpse such as rigor mortis or decapitation), circulatory, [or] neurological'.[2] For Gardiner el al, these 'represent a diagnostic standard in which the medical profession and the public can have complete confidence'.[3]

Despite this assurance of certainty, the last condition – death by neurological criteria (DNC), more commonly referred to as brain death, or in the UK and Ireland, brain stem death[4] – has remained controversial since its introduction over 50 years ago. Highlighting the ongoing debate at the turn of this century, Alexander Capron described the status of brain death as simultaneously 'well settled

[1]These include coronial, inheritance, and insurance processes, and the disposition of the corpse: see generally, H Conway *The Law and the Dead* (Abingdon: Routledge, 2016).

[2]D Gardiner et al 'International perspectives on the diagnosis of death' (2012) 108 (suppl_1) British Journal of Anaesthesia i14.

[3]Ibid.

[4]Unless referring to specific statements/contexts, the paper adopts the generic term DNC.

yet persistently unresolved'.[5] It is 'well settled' because both the equivalence of DNC with the death of the whole person, and the consequent construction of DNC as legal death, have been accepted in almost all jurisdictions.[6] Yet, it remains 'unresolved' due to the persistence, and amplification, of reservations about the cogency, validity and security of a diagnosis of DNC.[7]

Objections to the diagnosis of DNC have started to come before the courts in various jurisdictions[8] as 'the slow simmer of an academic debate has now begun to boil over into a legal conflagration'.[9] Since 2015, at least seven challenges have come before the UK courts,[10] each case emerging from a personal tragedy for the litigants.[11] In responding to these challenges, the courts have expressed no doubts as to the axiomatic correctness of the status quo. Yet, the courts have also, tacitly, acknowledged that DNC is not quite the same as cardio-pulmonary death. Thus, a distinct jurisprudence regarding DNC is emerging.

This paper analyses this jurisprudence, showing that the courts operate a tacit and ad hoc reasonable accommodation of alternative views of DNC. This has worked relatively well but has some important shortcomings, especially a lack of satisfactory engagement with the normative elements of DNC. It is argued here that such analysis is necessary if the courts are to deal appropriately with emerging challenges.

In order to contextualise current jurisprudence, and the normative issues at stake, this paper begins by briefly setting out the origins of DNC as a medico-legal construction, and its ongoing controversies. It then analyses the treatment of DNC by the UK courts to date, including judicial responses to the challenges posed by authorisation of DNC testing. The final part of the paper separates out the normative elements of DNC that have not been attended to by the courts, and argues that the current legal framework will need to evolve in order to satisfactorily address these matters.

1. DNC: origin and controversies

DNC is a medico-legal construction, originating from the deliberations of the 1968 Ad Hoc Committee of the Harvard Medical School.[12] The Committee was convened to address two ethical challenges: the first posed by the development of mechanical ventilation which allowed cardio-pulmonary death to be indefinitely postponed; and the second by the emerging science of organ

[5]A Capron 'Brain death – well settled yet persistently unresolved' (2001) 344(16) New England Journal of Medicine 1244.

[6]See T Pope 'Brain death forsaken: growing conflict and new legal challenges' (2017) 37(3–4) Journal of Legal Medicine 265 at 269; J Bernat 'The definition and criterion of death' (2013) 419 Handbook of Clinical Neurology 431.

[7]From the substantial body of literature see eg DA Shewmon '"Recovery from brain death": a neurologist's apologia' (1997) 64(1) Linacre Quarterly 30; DA Shewmon 'Brain stem death, brain death and death: a critical reevaluation of the purported equivalence' (2007) 14 Issues in Law & Medicine 125; F Miller and R Truog *Death, Dying and Organ Transplantation: Reconstructing Medical Ethics at the End of Life* (New York: Oxford University Press, 2008); M Nair-Collins 'Death, brain death and the limits of science: why the whole-brain concept of death is flawed public policy' (2010) 38 Journal of Law, Medicine & Ethics 667.

[8]See eg Canada: *McKitty v Hayani* [2019] ONCA 805; *Ouanounou v Humber River Hospital and Others* [2018] ONSC 6511; United States: *In re Lawson*, No CL16-2358 (City of Richmond Cir Ct (VA), May 23, 2016); *Stinson v UC Davis Children's Hospital*, Kaiser Permanente Roseville, No S-CV-0037673 (Placer Cnty Sup Ct (CA), April 29, 2016); *McMath v California*, No 15-cv-06042-HSG, 2016 US Dist. LEXIS 171534 (ND Cal Dec 12, 2016).

[9]Pope, above n 6, at 268. There also appears to be a rise in challenges which do not result in litigation: see Pope, ibid, at 283–284.

[10]Although, for convenience, we refer to the UK here, it should be noted that DNC has not been considered by the UK Supreme Court and that the relevant case law has emerged only from England and Wales and Northern Ireland.

[11]See *Re A (A Child)* [2015] EWHC 443 (Fam); *Oxford University Hospital Trust v AB and Another* [2019] EWHC 3516 (Fam); *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164; *North West Anglia NHS Foundation Trust v BN* [2022] EWHC 663 (Fam); *A Health and Social Care Trust v RL* [2022] NIFam 17; *Barts Health NHS Trust v Dance and Battersbee* [2022] EWCA Civ 935; *Guys and St Thomas NHS Foundation Trust v A, B and C* [2022] EWHC 2422 (Fam).

[12]H Beecher et al 'A definition of irreversible coma: report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death' (1968) 205(6) JAMA 337.

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transplantation.[13] The Committee found that 'an organ, brain or other, that no longer functions and has no possibility of functioning again is for all practical purposes dead', and set out a series of clinical tests to determine this.[14] Eight years later, the United Kingdom Academy of Medical Royal Colleges (AMRC) issued a Statement indicating their view that permanent functional death of the brain stem constituted brain death and that once this had occurred artificial support was fruitless and should be withdrawn.[15]

The legal component of the construction emerged first in the US, where clinicians were increasingly nervous of relying on a consensus report in a changing medico-legal landscape.[16] In 1978, the US Congress referred the status of DNC for consideration by the newly established President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The Commission concluded that DNC should be recognised as legal death, finding that death occurs when 'the body's physiological system ceases to constitute an integrated whole'.[17] A model law drafted by the Commission defined death as occurring following either the 'irreversible cessation of circulatory and respiratory function' or the 'irreversible cessation of all functions of the entire brain, including the brain stem'.[18] The model law became the Uniform Determination of Death Act (UDDA), which was widely adopted by individual states, albeit with divergence in respect of diagnostic requirements,[19] and provisions to allow for 'reasonable accommodation' of religious differences.[20] In the UK, as set out below, the jurisprudence of DNC emerged more slowly through the courts.

(a) Criticisms of DNC as legal death

Criticisms of DNC fall broadly into two categories: clinical and biological/metaphysical. Clinical concerns have been raised about the absence of a universal definition and globally agreed criteria for DNC diagnosis. The whole brain formulation ('irreversible cessation of all functions of the entire brain') applies in North America, most European countries, and Australia and New Zealand. Under the brain stem formulation set out by the AMRC Code of Practice (2008) and applied in the UK and Ireland, death is described as 'the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe'.[21] This standard does not require that all neurological activities in the brain have ceased; rather, what follows from this diagnosis is that 'none of these potential activities indicates any form of consciousness associated with human life, particularly the ability to feel, to be aware of, or to do, anything'.[22]

There are also 'major international differences' in the way in which DNC is diagnosed.[23] The working standard for contemporary diagnosis of whole brain death is the American Academy of Neurology (AAN) *Position Statement on Brain Death Determination* (2018),[24] although deviation from these practice guide-

[13]See D Rothman *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision-Making* (New York: Basic Books, 1991) pp 148–160.

[14]Beecher et al, above n 12.

[15]Statement issued by the honorary secretary of the Conference of Medical Royal Colleges and their Faculties in the United Kingdom on 11 October 1976 'Diagnosis of brain death' (1976) BMJ 1187 (13 November 1976), updated by Memorandum issued by the honorary secretary of Conference of Medical Royal Colleges and their Faculties in the United Kingdom on 15 January 1979 'Diagnosis of death' (1979) British Medical Journal 332.

[16]See Pope, above n 6, at 270–271; Rothman, above n 13.

[17]President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research *Defining Death: Medical, Legal and Ethics Issues in the Determination of Death* (1981) p 33.

[18]Ibid, p 73.

[19]Only 36 states adopted the precise language of the UDDA into their legislation.

[20]On these, see text following n 83 below.

[21]Academy of Medical Royal Colleges *A Code of Practice for the Diagnosis and Confirmation of Death* (RCPCH, 2008) p 11.

[22]Ibid.

[23]M Smith 'Brain death: time for an international consensus' (2012) 108(S1) British Journal of Anaesthesia i6 at i8.

[24]JA Russell et al 'Brain death, the determination of brain death, and member guidance for brain death accommodation requests: AAN position statement' (2019) 92(5) Neurology 228.

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lines appears relatively widespread.[25] For brain stem death, the operative guidance is provided by the AMRC Code of Practice[26] and, for infants under two months, the Guidance of the Royal Colleges of Paediatrics and Child Health.[27] The variation in diagnostic standards led the World Brain Death Project (WBDP) to set out a series of recommendations for the diagnosis of DNC.[28] However, it is notable that in 2008 the President's Commission rejected the brain stem death standard as (in their view) it could not outrule the persistence of higher cognitive functioning. At the same time, the AMRC re-endorsed the brain stem death standard. The WBDP has not resolved this issue, and it seems that global consensus remains elusive.

The core of the biological challenge to DNC is usefully summarised by Franklin Miller and Robert Truog as follows:

> All neurological conceptions of death suffer from two, closely related, fatal flaws. First, they fail to capture a critical feature of what we mean by 'death' – that is, a dead human body is a corpse. Second, they fail to explain cogently and coherently why a being that is determined to be dead by neurological, but not cardiopulmonary, criteria is dead and should be seen as a corpse.[29]

Unlike a corpse, where the body becomes cold and rigid and quickly begins to disintegrate and decompose, with DNC, assuming ongoing artificial respiration and nutrition, the heart often continues to beat, the vital organs continue to function, the body remain warm, and hormonal balance and the ability to fight infections are maintained.[30] Moreover, growth and sexual maturation in children, and gestation in pregnancy, can continue for several months.[31]

This difference raises fundamental questions about our understanding of the biological, metaphysical, religious and social divide between life and death. Inevitably, such questions give rise to diverse responses. For Miller and Truog, while it is defined by biological status, death should not be seen as morally determinative.[32] Thus, they reject the 'dead donor rule' (ie organs may be taken for transplantation only following a declaration of death), arguing instead that the morally relevant question is whether or not the donor will be harmed by the removal of the organ/s.[33] The philosopher John Lizza posits that death should be understood as 'the irreversible loss of the psychophysical integration of the human being or human person', but also proposes that 'it is a mistake to think that decisions about the definition and criteria for determining human death are simply matters for biology and can be made independent of philosophical, axiological, and cultural considerations'.[34]

Some adherents of the major world religions, while agreeing with this last statement, proffer a very different perspective on DNC. Objections to DNC have been grounded in elements of Buddhism,

[25]DM Greer et al 'Variability of brain death determination guidelines in leading US neurologic institutions' (2008) 70 Neurology 284; S Wahlster et al 'Brain death declaration: practices and perceptions worldwide' (2015) 84 Neurology 1870.

[26]Academy of Medical Royal Colleges, above n 21, p 11.

[27]*The Diagnosis of Death by Neurological Criteria in Infants less than Two Months Old* (RCPCH, April 2015). There are ongoing questions regarding the reliability of testing for this population: see *Guys and St Thomas NHS Foundation Trust v A, B and C* [2022] EWHC 2422 (Fam).

[28]D Greer et al 'Determination of brain death/death by neurological criteria' (2020) 324(11) JAMA 1078.

[29]'The incoherence of determining death by neurological criteria: a commentary on controversies in the determination of death' (2009) 19(2) Kennedy Institute of Ethics Journal 185 at 190.

[30]See Millar and Truog, above n 7; M Nair-Collins et al 'Hypothalamic-pituitary function in brain-death: a review' (2016) 31(1) Journal of Intensive Care Medicine 41; M Nair-Collins 'We die when entropy overwhelms homeostasis' in M Cholbi and T Timmermann (eds) *Exploring the Philosophy of Death and Dying: Classical and Contemporary Perspective* (New York: Routledge, 2021). Note that this is not true of every patient with a diagnosis of DNC. Sometimes such patients exhibit profound cardiovascular instability and cannot be somatically sustained despite intervention.

[31]M Esmaeilzadeh et al 'One life ends, another begins: management of a brain dead pregnant mother – a systematic review' (2010) 8 BMC Medicine 74, identified 12 cases where viable infants were born following DNC with a mean gestational duration of 38.3 days (with a range from 2 days to 107 days).

[32]Miller and Truog, above n 7, p 173.

[33]Ibid, p 135.

[34]J Lizza 'Defining death: beyond biology' (2018) 55 Diametros 1 at 4. For elaboration see J Lizza *Persons, Humanity and the Definition of Death* (Baltimore: John Hopkins University Press, 2006).

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Catholicism/Christianity, Islam, and Judaism, as well as in Japanese Shinto and Native American beliefs.[35] Although derived from very different religious underpinnings, these beliefs largely share the view that a person's spirit, soul or essence continues until their heart stops beating. From this perspective a diagnosis of DNC does not indicate death, and cannot justify the removal of somatic supports.

There are also aesthetic and emotional reactions at play in responses to DNC which are especially significant in the fraught and tragic circumstances in which such diagnoses are made. DNC patients in an intensive care unit will often look like every other critically ill patient – not dead. This appearance of biological persistence presents a primal challenge to understandings of death and requires traumatised family members to make extraordinarily difficult choices in respect of withdrawal of somatic support or organ retrieval.[36]

Even from the brief discussion above, we can see that the concept of DNC raises questions around religious, philosophical, social and cultural beliefs that lack societal consensus.[37] Bearing this in mind, we turn now to the ways in which this complex landscape has been navigated in the UK courts.

2. DNC in the UK courts

Issues relating to DNC have been coming before the UK courts for over four decades, although the last couple of years have seen a significant acceleration. In these cases, the courts have unequivocally confirmed DNC as legal death and, more problematically, have affirmed that questions of best interests are irrelevant following DNC. Yet, they have also, implicitly, recognised that DNC is somehow not the same as cardio-pulmonary death and have operated on the basis that some form of informal 'reasonable accommodation' of alternative beliefs is appropriate. In some respects, this approach appears to have worked reasonably well. Cases are resolved, generally without an appeal. However, its ad hoc nature comes at a cost in terms of certainty and scope.

(a) DNC as legal death

DNC was first recognised as legal death in the UK in *Re A (A Minor)*,[38] a case concerning a 19 month-old child. Johnson J showed no evident awareness of the significance of the diagnosis of DNC and, with perfunctory analysis, found that A was dead 'for all legal, as well as, medical purposes'. He then affirmed that the medical professionals could lawfully disconnect A from the ventilator which had been providing somatic support.[39] *Re A* was quickly followed by the equally understated Northern Ireland case of *Re TC (A Minor)*.[40]

Although these cases hardly provide sturdy foundations for the re-writing of legal death, the matter was placed on a somewhat firmer footing in *Airedale NHS Trust v Bland*.[41] Several members of the Judicial Committee noted that Tony Bland was not brain stem dead and that therefore the matter

[35]See Pope, above n 6, at 291; from the considerable literature see D Van Drunen *Bioethics and the Christian Life: A Guide to Making Difficult Decisions* (Wheaton, IL: Crossway, 2009); D Nguyen *The New Definition of Death for Organ Donation: A Multidisciplinary Perspective from the Perspective of Christian Ethics* (Bern: Peter Lang, 2018); M Munir 'Islamic juridical discourse on death: is brain death a modern criterion of death' (2018) 57 (3–4) Islamic Studies 187; E Gabbay and J Fins 'Go in peace: brain death, reasonable accommodation and Jewish mourning rituals' (2019) 58 Journal of Religion and Health 1672.

[36]S Shah et al 'A narrative review of the empirical evidence on public attitudes on brain death and vital organ transplantation: the need for better data to inform policy' (2015) 41(4) Journal of Medical Ethics 291; M Shildrick *Visceral Prosthesis: Somatechnics and Posthuman Embodiment* (London: Bloomsbury, 2022) pp 179–180.

[37]LF Ross 'Respecting choice in definitions of death' in *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death Special Report* (2018) 48(6) Hastings Center Report S53.

[38][1992] 3 Med LR 303; see commentary [1993] 1 Medical Law Review 98.

[39][1992] 3 Med LR 303.

[40]Unreported High Court of Justice in Northern Ireland (Family Division); MacDemott J; 30 November 1993; case commentary [1994] 2 Medical Law Review 376.

[41][1993] AC 789.

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could not be disposed of on this basis.[42] The legal status of brain stem death was accepted rather than analysed. Lord Browne-Wilkinson remarked that it was 'now apparently possible, with the use of a ventilator, to sustain a beating heart, even though the brain stem and therefore in medical terms the patient, is dead; the "ventilated corpse"'.[43] Thus, he noted that '[t]he physical state known as death has changed. In many cases, the time and manner of death is no longer determined by nature but can be determined by human decisions'.[44] His Lordship was clear that this required legislative intervention, noting that 'judges' function in this area of the law should be to apply the principles which society, through the democratic process, adopts, not to impose their standards on society'.[45] It was for Parliament to 'lay down principles of law generally applicable to the withdrawal of life support systems'.[46]

(i) Contemporary affirmation

Parliament did not act, and so the status of DNC in the UK continues to be grounded in the common law. There is, however, no doubt that DNC constitutes legal death. This was categorically affirmed by the Court of Appeal in *Re M (Declaration of Death of Child)*.[47] The case (on appeal from the High Court decision in *Manchester University NHS Foundation Trust v Midrar Namiq and Others*)[48] concerned an infant who, because of oxygen deprivation during labour, had no detectable heartbeat at birth. He was resuscitated and ventilated in the neonatal intensive care unit. Various tests, including an MRI scan, showed 'global brain injury affecting the entire cortex'.[49] Two weeks after his birth, following further testing, Midrar was diagnosed DNC dead. Both of Midrar's parents were strongly opposed to the withdrawal of ventilation, both before and after the diagnosis of DNC. In the High Court, Lieven J granted the declaration sought by the Trust that it was lawful for them to make arrangements to withdraw ventilation and to allow him a 'kind and dignified death'.[50]

On appeal, McFarlane P quoted in detail from the AMRC Code of Practice, emphasising the 'extensive consultation' process involved in its development and its endorsement by the then Chief Medical Officer.[51] Turning to the legal context, he found that in *Bland* 'the medical consensus that death was to be diagnosed by an absence of brain stem function was expressly endorsed'.[52] It was, he said, not 'open to this court to contemplate a different test'.[53] In light of this, McFarlane P upheld Lieven J's finding that a best interests assessment was not required and found that Francis J had been in error in *Oxford University Hospital Trust v AB and Another* in holding it was in AB's best interests to have somatic support withdrawn.[54] Thus, he concluded that 'where a person is dead, the question of best interests is, tragically, no longer relevant'.[55]

(ii) Scope of the legal process

Given that the diagnosis of DNC is a matter for medical professionals, the role of the court is to ensure that this has been properly carried out in accordance with the AMRC Code of Practice.[56] In *Namiq*,

[42] [1993] AC 789, at 856 per Lord Keith; 863 per Lord Goff; 878 per Lord Browne-Wilkinson.
[43] Ibid.
[44] Ibid.
[45] Ibid, at 879.
[46] Ibid, at 880.
[47] [2020] EWCA Civ 164 (hereafter *Re M*).
[48] [2020] EWHC 180 (Fam) (hereafter *Namiq*).
[49] Ibid, at [9].
[50] Ibid, at [61].
[51] [2020] EWCA Civ 164, at [25].
[52] Ibid, at [39].
[53] Ibid, at [91].
[54] [2020] EWCA Civ 164, at [49].
[55] Ibid.
[56] See eg the application of the Code of Practice in *North West Anglia NHS Foundation Trust v BN* [2022] EWHC 663 (Fam). The definitive role of the Code of Practice was affirmed by the Court of Appeal in *Barts Health NHS Trust v*

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Lieven J found that the burden of proof in confirming DNC lies with the party asserting this and that the court should 'apply anxious scrutiny to the evidence'.[57] This statement was not considered by the Court of Appeal, possibly because the evidence that Midrar was DNC dead was overwhelming. The Court did, however, affirm that the decision is made on the balance of probabilities.[58] In the Northern Irish case of *A Health and Social Care Trust v RL*, McFarland J felt the need to explain that this standard did not mean that 'the court will proceed on the basis that the patient is more likely than not to be dead, or to put it in perhaps the starkest terms, there is a 51% chance that the patient is dead'.[59] The choice before the court is binary: the person is dead or not dead.[60] He explained that the court 'must seek out cogent evidence to overcome the unlikelihood that [RL] is dead'[61] and also noted that the Code of Practice operates on a binary and not a balance of probabilities. Thus, where the Code is used, it is difficult to see that the balance of probabilities plays any role in deliberation.

Where a court has concluded on DNC, the appropriate declaration, as identified by the Court of Appeal in *Re M*, is that the individual died at a particular time and date (the time at which DNC was diagnosed) and that it is lawful for ventilation and other clinical interventions to be withdrawn.[62] Notably, in approving this declaration (the wording of which was drawn from the decision of Hayden J in *Re A (A Child)*),[63] the Court of Appeal identified as 'particularly apt' Hayden J's description of the purpose of the declaration being to afford the individual who had died 'dignity in death'.[64]

(b) The same but different

Notwithstanding repeated affirmations of DNC as legal death, the courts have also reflected a view that DNC is not quite the same as cardio-pulmonary death. In the early case of *Re TC (A Minor)*, MacDermott LJ found that while 'death in the usual sense, of course, terminates wardship', in a DNC case such as the one before him where the patient is a ward, it was preferable that a court application be brought before ventilation is removed.[65] Critiquing this response, Ian Kennedy argued that 'MacDermott LJ seemed to think that he was dealing with some other kind of death; one which the court in wardship had better keep an eye on'.[66] For Kennedy, the view that there were 'various forms of death' was 'nonsense' and MacDermott LJ had 'unnecessarily introduce[d] an element of confusion where none is justified'.[67]

(i) Some other kind of death

Notwithstanding Kennedy's criticism, it has emerged in later jurisprudence that the courts do regard themselves as dealing with 'some other kind of death'. This is perhaps most clearly reflected in *Re A (A*

Dance and Battersbee [2022] EWCA Civ 935, at [37]. Here, the Court of Appeal overturned the High Court decision [2022] EWHC 1435 (Fam) where Arbuthnot J had made a declaration of DNC death notwithstanding that it had not been possible for the clinicians to conduct the apnoea test in accordance with the Code. The Court did not make a formal finding in this regard because all three parties during the appeal hearing had agreed that it would have been better for the judge to proceed to consider best interests once it was clear that it was not possible to declare DNC in compliance with the Code; however, the Court [2022] EWCA Civ 935, at [37] 'strongly caution[ed] judges in future cases of this kind from being drawn into attempting to declare death on a basis outside the Code where none of the medical witnesses has themselves made a diagnosis of death'.

[57][2020] EWHC 180 (Fam), at [35].

[58][2020] EWCA Civ 164, at [96].

[59]*A Health and Social Care Trust v RL* [2022] NIFam 17, [30] (hereafter *RL*).

[60]Ibid, at [31].

[61]Ibid, at [33].

[62][2020] EWCA Civ 164, at [111].

[63][2015] EWHC 443 (Fam).

[64][2020] EWCA Civ 164, at [60].

[65]Unreported High Court of Justice in Northern Ireland (Family Division); MacDemott J; 30 November 1993; case commentary (1994) 2 Medical Law Review 376.

[66]Case commentary (1994) 2 Medical Law Review 376.

[67]Ibid, at 377.

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Child).[68] Child A was declared DNC dead on 10 February 2014 and, in accordance with the applicable protocol, the Senior Coroner for Manchester was informed.[69] Child A's parents, who were Muslim, did not agree to the removal of ventilation and sought to have Child A moved to Saudi Arabia, where he would be maintained on somatic support. The consultant paediatrician responsible for Child A's care engaged with the parents to see if it was possible to facilitate their request. This delayed the removal of ventilation and, after 48 hours, the Senior Coroner for Manchester wrote to the Trust's Director, stating that he had assumed jurisdiction over the body and that it was 'wholly inappropriate for a deceased body to be intubated and ventilated when this is futile and, to my mind, unethical'.[70] Accordingly the Senior Coroner asked that the body be extubated, allowing the parents a 'short but reasonable time' with the body before extubation, and then moved to the mortuary to be returned to the parents. The Central Manchester NHS Foundation Trust sought the guidance of the High Court.

Hayden J granted a declaration that ventilation should be removed 'to allow Child A, who died on 10th February, dignity in death'.[71] However, he recognised that 'in a multi-cultural society there has to be recognition that people, particularly those with strong religious beliefs, may differ with medical professionals as to when death occurs',[72] and that it was 'hardly difficult to understand why the still breathing body is regarded as alive, even though 'breath may be entirely delivered by machine'.[73] For this reason, he strongly rejected the Senior Coroner's assertion of authority to order the removal of the body. While he accepted that a such a statutory power existed,[74] he found that '[a]n insistence on a legally precise definition of death to trigger the involvement of the Coroner, in such challenging circumstances is, in my judgment, so obviously wrong as to be redundant of any contrary argument'.[75] Referring to the formal communication issued by the Senior Coroner, he suggested that the Senior Coroner 'might well reflect now whether that kind of language was suitable in such sensitive circumstances'.[76]

Hayden J's approach was approved in *Re M* as providing 'the correct structure for dealing with sensitive applications of this nature'.[77] The Court of Appeal also emphasised the role of the court in resolving DNC disputes. McFarlane P noted the four-month delay between the time between the diagnosis of DNC and the time that the judgment was delivered and recognised that this was, in part, due to ongoing efforts by the Trust to reach a resolution of the dispute. While not criticising the Trust's decision to 'exhaust options one-by-one', McFarlane P encouraged the use of the courts as part of this process. It should not, he said 'be thought that the mere issue of an application to the court is such a negative step as to compromise other attempts to resolve the matter by way of second opinion, further tests or mediation'.[78] In fact, 'the court itself might direct and facilitate reasonable further testing and may encourage mediation'.[79]

This approach to mediation can be seen in operation in Celia Kitzinger's helpful unofficial transcript[80] of the hearing in *North West Anglia NHS Foundation Trust v BN*, a case concerning a previously healthy woman in her mid-forties who suffered a subarachnoid haemorrhage and was

[68][2015] EWHC 443 (Fam).

[69]Now the Notification of Deaths Regulations 2019, SI 2019/ 2111; see reg 3 for circumstances in which the duty arises.

[70][2015] EWHC 443 (Fam), at [19].

[71]Ibid, at [26].

[72]Ibid, at [24].

[73]Ibid, at [24].

[74]The Coroner's Act 2009, s 15 states that a senior coroner who is responsible for conducting an investigation into a person's death or needs to request a post-mortem examination into whether the death is one into which the coroner has a duty to conduct an investigation may order the body to be removed to any suitable place.

[75][2015] EWHC 443 (Fam), at [24].

[76]Ibid, at [20].

[77][2020] EWCA Civ 164, at [42].

[78]Ibid, at [108].

[79]Ibid.

[80]'Withdrawing Treatment after Brain Stem Death: A Case in the Family Division', https://openjusticecourtofprotection.org/2022/03/16/withdrawing-treatment-after-brain-stem-death-a-case-in-the-family-division/ (accessed 14 December 2022).

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subsequently declared DNC dead.[81] Here, we see Sir Jonathan Cohen mediating a solution between BN's foster mother, PS, who opposed the proposed withdrawal of somatic support, and the Trust, who had applied for a declaration affirming brain stem death and authorising the withdrawal. During the hearing, it became clear that PS would accept this ruling but she wanted some time for both herself and other family members to say goodbye to BN. The clinician expressed his concerns about the proposed time frame (PS requested a seven-day period) which he described as 'totally unacceptable – from my professional perspective', and suggested twenty-four hours. Kitzinger's transcript indicates that Sir Jonathan recognised that he was stepping outside of his judicial role to effectively mediate between PS's 'understandable and proper request' and the clinician's preference. Eventually, it was agreed that somatic support would be withdrawn in two days.[82]

(ii) Reasonable accommodation

What we are seeing in these cases is an ad hoc form of 'reasonable accommodation' of alternative views of DNC, a concept which first emerged in US legislation giving effect to the UDDA at State level.[83] The most extreme example is the New Jersey Declaration of Death Act[84] which provides that a person should not be declared DNC dead where 'the licensed physician authorized to declare death has reason to believe … that such a declaration would violate the personal religious beliefs of the individual'. Several other states provide for lesser measures of accommodation.[85] In New York, for example, hospitals are required to establish written procedures for the reasonable accommodation of the individual's religious or moral objections to the use of the DNC standard.[86] The policies, accommodations and time periods differ.[87] Thaddeus Pope indicates that one New York hospital operates a 72-hour delay, while also citing two New York cases where the courts restrained the hospital from removing somatic support from young children in order to afford the parents a chance to find an alternative facility.[88]

The possibility of a reasonable accommodation requirement in the absence of a statutory scheme was identified by the Court of Appeal for Ontario in *McKitty v Hayani*.[89] Ms McKitty had been declared DNC dead. Her parents, acting as her substitute decision-makers, had objected to the declaration on religious grounds, relying on the Canadian Charter of Rights and Freedoms in this regard. The Court of Appeal approached the case based on a presumption that Ms McKitty was a holder of Charter rights.[90] The Court then indicated that if a breach of Ms McKitty's Charter rights could be established (discussed further below), the next element in the analysis would be to consider whether 'some regime of reasonable accommodation, as is found in the legislation of some American states, could potentially remedy an unjustified limitation'.[91]

While the UK courts have never used the term 'reasonable accommodation', we would suggest that the UK courts are in fact operating a form of reasonable accommodation in practice. However, the absence of an accompanying rights/interests analysis has resulted in a problematic situation where neither a normative foundation nor a clear indication of boundaries are identified. This presents practical challenges, leaving senior coroners, families and clinicians in a difficult place. Under the Coroners and

[81][2022] EWHC 663 (Fam) (hereafter *BN*).

[82][2022] EWHC 663 (Fam), [22].

[83]See generally Pope, above n 6, at 278–282.

[84]NJ Rev Stat § 26:6A-5.

[85]See eg California: Cal Health & Safety Code § 1254.4(a) (2012)); Illinois: Ill Pub Act No 095–0181 (2008); New York: 10 NYCRR § 400.16 (1987).

[86]New York State Department of Health and New York State Task Force on Life and the Law *Guidelines for Determining Brain Death* (2011) p 4 available at https://www.health.ny.gov/professionals/hospital_administrator/letters/2011/brain_death_guidelines.pdf (accessed 14 December 2022).

[87]Ibid.

[88]See Pope, above n 6, at 279.

[89][2019] ONCA 805.

[90][2019] ONCA 805, at [47].

[91]Ibid, at [82].

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Justice Act 2009, senior coroners are obliged to conduct an investigation 'as soon as practicable' into certain statutorily designated deaths.[92] Following *Re A (A Child)*, it is clear that certain actions cannot be taken by senior coroners but it is less obvious what actions should be taken, and when/whether the coroner should insist on court referral.[93]

For families and clinicians, too, there is no clear pathway for action and no indication regarding the point at which court referral becomes appropriate or necessary. McFarlane P's encouragement of the early involvement of the court in *Re M*[94] suggests a prompt application should be made, and subsequent cases appear to have come to court more quickly.[95] The early involvement of the courts inevitably formalises the encounter. This may have positive elements, including providing family members with a space to articulate their concerns and requiring clinicians to listen to these.[96] However, it also has negative elements; referrals to court may add to the trauma which families are already experiencing, and potentially workable negotiated solutions are necessarily jettisoned as the matter becomes part of a formal legal process.[97]

There is also a lack of clarity as regards what a court might do in terms of reasonable accommodation. To date, the accommodation afforded by the UK courts has been allowing families time to say goodbye before removal of somatic support. While this does impact on the use of ICU resources, it is largely manageable even without too close an examination of the normative underpinnings. However, a more significant (and contentious) form of accommodation would be the facilitation of a transfer to a facility which provides somatic support to those diagnosed DNC.

(iii) Transfer as reasonable accommodation?

Although the requirement to facilitate a transfer is not explicitly mentioned in any of the statutory provisions on reasonable accommodation in the US, it has been approved by the courts in several states. Pope argues that it might be seen as falling within the category of 'reasonable' action under relevant statutes.[98] The case of Jahi McMath, a 13-year-old girl who was diagnosed DNC dead following a cardiac arrest after a routine tonsillectomy, is the most well-known example of how such transfers can operate. Jahi's mother, disagreeing with the diagnosis of DNC, initiated legal proceedings to have it overturned.[99] When this failed, she sought court orders to facilitate a transfer to a sub-acute facility where somatic support would continue to be provided. This required that somatic support continue until the transfer and that a tracheostomy and percutaneous endoscopic gastrostomy (PEG) insertion be performed prior to the transfer (a requirement of the transfer facility). The District Court for the Northern District of California declined to order these procedures to be performed.[100] A settlement was eventually reached whereby Jahi was transferred without the tracheostomy but with ongoing

[92]Coroners and Justice Act 2009, s 1(1). These are where the senior coroner has reason to suspect that the deceased has died a violent or unnatural death; the cause of death is unknown; or the deceased died in custody or otherwise in state detention: s 1(2).

[93]The matter is not addressed in any of the Guidance notes provided by the Chief Coroner: see https://www.judiciary.uk/related-offices-and-bodies/office-chief-coroner/guidance-law-sheets/coroners-guidance/ (accessed 14 December 2022). Notably, *Re A (A Child)* [2015] EWHC 443 (Fam) is not one of the Key Cases listed on the Chief Coroner's website: https://www.judiciary.uk/related-offices-and-bodies/office-chief-coroner/key-cases/ (accessed 14 December 2022).

[94][2020] EWCA Civ 164, at [108].

[95]In *North West Anglia NHS Foundation Trust v BN* [2022] EWHC 663 (Fam), BN was declared DNC dead on 10 March 2022 and the application for a judicial declaration was lodged on 11 March; in *A Health and Social Care Trust v RL* [2022] NIFam 17, RL was declared DNC dead on 20 April 2022 and the application for declaratory relief was made on 25 April.

[96]On the complex responses to formal legal involvement in end-of-life situations, see S Halliday et al 'Law in everyday life and death: a socio-legal study of chronic disorders of consciousness' (2015) 3(1) Legal Studies 55.

[97]See the suggestion by counsel in *Barts Health NHS Trust v Dance and Battersbee* [2022] EWHC 1435 (Fam), at [140] that mediation opportunity had been lost (mediation having initially been refused by the parents) by the matter being brought to Court.

[98]Pope, above n 6, at 281.

[99]For detail of the relevant hearings, see Pope, above n 6, at 302–306.

[100]*Winkfield v Children's Hospital Oakland* Case No C 13-5993 SBA (N D Cal 20 Dec 2013).

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ventilation, initially to a New Jersey Catholic hospital and ultimately to an apartment in New Jersey[101] where she continued to biologically exist with somatic support for five years.[102]

The possibility of transfer has been identified in two UK cases but a sustained argument on this basis has not yet been raised. In *Re A (A Child)*, Hayden J noted that Child A's parents had been trying to put together a package to move Child A to Saudi Arabia, something which the clinician in charge had explored 'perhaps somewhat improbably on reflection'.[103] A more concrete proposal for transfer was raised in the Northern Irish case of *RL*, which concerned a 21 year-old man diagnosed DNC dead on 20 April 2022 having suffered a cardiac arrest following anaphylaxis.[104] RL's parents had attempted to arrange for him to be transferred to either of two willing facilities, one of which was in the country in which RL's parents lived.[105] However, both required a tracheostomy and PEG insertion to be performed in advance, something which RL's medical team were very reluctant to do. As described by McFarland J '[a]lthough RL, whose life had been diagnosed as being extinct, would suffer no pain or discomfort through the surgical procedures, with no prospect of any recovery of consciousness, it was considered that exposure to these further invasive treatments to be unethical'.[106] It is difficult to imagine a circumstance in which the court could have required clinicians to provide the interventions contrary to their own ethical/moral standards and unsurprisingly, this was the end of the matter. McFarland J made an order affirming DNC and permitting the withdrawal of mechanical ventilation.[107] He also put a stay of 24 hours to allow RL's parents to appeal. This did not happen and RL was removed from ventilation in the presence of his parents. Notwithstanding the lack of an appeal, the case raises important questions about the role of clinician ethics in judicial deliberations on DNC.

(iv) Ethics in judicial deliberations about DNC

As described above, the clinicians in *RL* expressed a concern that subjecting RL to further invasive treatments would be unethical, effectively ending discussion of the matter. Clinical ethical concerns are also expressed in Kitzinger's account of the hearing in *BN*.[108] In response to a question by counsel for the Trust regarding whether he had ethical concerns about continuing treatment, the treating clinician stated 'Yes, it's not ethical to continue to ventilate a brain stem dead patient. It's not ethical for the family as well. And it's not ethical for the staff'.[109] In so far as can be determined from the material available, this is also the extent of the exploration of ethics in the case.

These clinicians may have been drawing on the AMRC Code of Practice, which states that once death has been diagnosed, '[t]he appropriate course of action is then to *consider* withdrawal of mechanical respiratory support, the ethical justification for which has passed, and to allow the heart to stop'.[110] This, however, is neither detailed nor definitive. There are, of course, ethical arguments which could be made. One concern of particular relevance in *BN* relates to distributive justice and the fair usage of finite resources; in this case an ICU bed.[111] Even if public resources are not being consumed because the person has been transferred to a private facility, ethical concerns may be raised about commercial operators profiting from traumatised and vulnerable families. Arguments could also

[101]Pope, above n 6, at 304.

[102]Although this duration of biological persistence is likely unusual, it is difficult to be definitive because, DNC diagnosis tends to be a self-fulfilling prophecy: see M Nair-Collins 'Clinical and ethical perspectives on brain death' (2015) 5 Medicolegal and Bioethics 69.

[103][2015] EWHC 443 (Fam), at [18].

[104][2022] NIFam 17.

[105]The other was a private clinic run by a Professor EF who gave evidence disputing DNC and and asserted he had awakened about 1000 people from 'cerebral coma': [2022] NIFam 17, at [12].

[106][2022] NIFam 17, at [11].

[107]Ibid.

[108][2022] EWHC 663 (Fam).

[109]Above n 80.

[110]Above n 21, p 13 (emphasis added).

[111]This is one element of the fourth of Beauchamp and Childress' four principles of medical ethics: see T Beachamp and J Childress *Principles of Biomedical Ethics* (New York: Oxford University Press, 8th edn, 2019).

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be made about futile treatment, although these in turn raise questions about how the concept of futility is to be understood in the contested metaphysical domain of DNC.[112]

For the discussion here, the relevant point is that an unexamined reference to ethics should not serve as a trump card in dealing with DNC. Although the courts have ceded factual decisions about the diagnosis of DNC to the medical profession acting in accordance with the applicable guidance, they have not, and should not, cede the authority of the court in its entirety. Thus, the fact that a clinician has identified an ethical concern should not, of itself, determine the legal outcome. Equally, where a clinician has been found who is prepared to provide a procedure (eg a tracheostomy) that would facilitate a transfer, this should not, of itself, be determinative. However, in the absence of a normative underpinning of judicial reasoning, there is a risk that one or other of these positions may become the case without consideration of the pertinent moral issues at stake. This is further explored in the final part of this paper, but first we turn to one further aspect of these cases, the role of authorisation for DNC testing.

(c) Authorisation for DNC testing

As outlined above, the legitimacy of a diagnosis of DNC depends on confirmatory clinical testing being carried out. This then raises the question of how (and indeed whether) such testing should be authorised. For children under the age of 18 years, this question turns on the role of parental consent. For adults, the relevant factor is whether the test is 'an act in connection with the care or treatment' of P which meets the criteria under s 5 of the Mental Capacity Act 2005. As elaborated upon below, for both adults and children, this ultimately comes back to an evaluation of best interests.

The question of parental consent first came before the UK courts in *Namiq*.[113] Relying on the decision of the European Court of Human Rights (ECtHR) in *Glass v United Kingdom*,[114] counsel for Midrar's parents argued that a DNC test could only be carried out if the parents had given fully informed consent and that evidence from any such tests would be invalid in the absence of such consent.[115] Lieven J dismissed this argument, finding that the parents in this case had been aware that the tests were going to be carried out, probably on the day in question; that they had been fully informed of the purpose of the tests and had not said that the tests should not go ahead.[116] She also found that there was no need for written consent to testing or for information in respect of the test to be written down.[117] Lieven J did not, however, offer a view on the more general question of whether informed consent to DNC testing was required, noting that it was not necessary for her to reach a conclusion on this point.[118] Although it generally upheld Lieven J's findings of fact,[119] the Court of Appeal did not comment specifically on this matter.

[112]This has been widely debated: see eg B Brody and A Halevy 'Is futility a futile concept?' (1995) 20 Journal of Medicine and Philosophy 123; P Helft et al 'The rise and fall of the futility movement' (2000) 343 New England Journal of Medicine 293; L Schneiderman and N Jecker *Wrong Medicine: Doctors, Medicine and Futile Treatment* (Baltimore: John Hopkins University Press, 2nd edn, 2011); M Nair-Collins 'Laying futility to rest' (2015) 40 Journal of Medicine and Philosophy 554; N Glover-Thomas 'Getting the balance right: medical futility, scientific advancement and the role of law' (2020) 28(3) Medical Law Review 573.

[113][2020] EWHC 180 (Fam). This question has come before state level US courts on several occasions and has had a mixed response. Courts in three states (California, Kansas and Montana) have found that informed parental consent is necessary for such testing: see Pope, above n 6, at 309–310, while courts in two other states (Georgia and Virginia) have found that parental consent to DNC testing is not required: Pope, ibid, at 311–313.

[114][2004] ECHR 103.

[115][2020] EWHC 180 (Fam), at [45].

[116]Ibid, at [45]. Lieven J also noted ibid that, even if the tests had taken place without parental informed consent, this would not mean that the results of the tests were inadmissible as evidence as to brain stem death.

[117]Ibid, at [45].

[118]Ibid.

[119]*Re M* [2020] EWCA Civ 164, at [68].

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The question of informed consent arose more directly in *Barts Health NHS Trust v Dance and Battersbee*.[120] The case concerned a 12-year-old boy, Archie Battersbee, who had suffered a cardiac arrest, having been found hanged by a dressing gown cord from the bannisters in his family home. Archie underwent repeated CT scans, EEGs, and an MRI, all of which indicated significant brain damage and possible DNC. The logical next step would be to carry out formal DNC testing, including the apnoea test, which involves removing the patient from ventilation to see if they can breathe unaided. Archie's family refused to consent to this test because of concerns that the test would risk Archie's suffering further brain damage.[121] The Trust applied under s 8 of the Children Act 1989 for a declaration that it was lawful and in Archie's best interests that DNC testing be carried out.[122] Archie was joined as a party to proceedings and a Guardian appointed.

Before turning to the substantive analysis, it should be noted that Arbuthnot J. operated on the basis that court referral is necessary in the absence of parental consent. Although she did not specifically comment on the matter, this would suggest an acceptance that parental informed consent to DNC testing is required. This approach is entirely consistent with that of the ECtHR in *Glass v United Kingdom* where the ECtHR was clear that end of life disputes of the kind before the court should be determined by the courts and not by individual clinicians.[123] This approach is also consistent with that taken in both *Re A (A Child)*[124] and *Re M*.[125] It is also worth noting that there is nothing in Arbuthnot J's judgment (or indeed in any of the DNC-related jurisprudence) to support a view, which Lieven J may or may not have intended to convey in *Namiq*, that lower information requirements or a less formal approach to informed consent applies in respect of DNC testing.

Arbuthnot's analysis in *Battersbee* appears to have been concerned primarily with the matter of risk. The expert medical witness, Dr Playfor, set out the risks of the apnoea test, which he described as a 'significant physiological challenge'.[126] However, for various reasons, including that he had already performed a two-minute informal apnoea test on Archie (it is not clear from the judgment whether Archie's parents had consented to this), he concluded that the risks of serious complications during the apnoea test were very small[127] and that alternative tests proposed by Archie's family would require Archie to be moved, which would pose a greater risk than the apnoea test.[128] Dr Playfor considered that 'it was in Archie's best interests to have formal brain stem testing, there was no reason to do anything other than that'.[129] Arbuthnot J found that the risks of apnoea testing were small, the procedure would be carried out with care, and that 'a step such as this will enable the family and those treating Archie to know whether he is dead or alive'.[130] Accordingly, she found apnoea testing to be in Archie's best interests.

The difficulty with this finding is that while the factors mentioned by Arbuthnot J are all perfectly good reasons why testing should take place, they are not evidence that testing would be in Archie's best interests. No attempt is made to establish the benefit for *Archie* in DNC testing and it is difficult to see what case might in fact have been made. Indeed, given that the effect of a DNC diagnosis would be that Archie no longer had interests to be protected, it might be argued that a diagnosis of DNC is decidedly not in Archie's best interests. This argument is potentially even stronger in respect of (some) adults. Here, the applicable standard as set out in s 4(6) of the Mental Capacity Act 2005 requires the assessor to take account of P's past and present wishes and feelings and in particular

[120][2022] EWHC 1165 (Fam).
[121]Ibid, at [17].
[122]Ibid, at [20].
[123][2004] ECHR 103, at para 83.
[124][2015] EWHC 443 (Fam).
[125][2020] EWCA Civ 164, at [42].
[126][2022] EWHC 1165 (Fam), at [44].
[127]Ibid, at [50].
[128]Ibid, at [88].
[129]Ibid, at [64].
[130][2022] EWHC 1165 (Fam) at [93].

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any relevant written statement made by P while s/he had capacity and of the beliefs and values that would be likely to influence P's decision if s/he had capacity. Where P had left clear instructions that they do not wish DNC testing to take place, it becomes difficult to justify such testing as being in P's best interests.

The point being made here is not that a court should not permit testing; there are good public interest reasons why DNC testing is appropriate, including the need to gather preliminary evidence in order to facilitate judicial consideration of the substantive matter. It is also plausible that a best interests argument could be made, perhaps in respect of dignity, but this would require considerably more attention to be paid to normative matters than in *Battersbee*.[131]

3. DNC: the normative dimension

With the exception of McFarlane P's statement that 'where a person is dead, the question of best interests is, tragically, no longer relevant',[132] the UK courts have assiduously avoided the normative dimension of DNC. At one level, this is unsurprising; these issues are complex and it is understandable that High Court judges in particular prefer to avoid delving too deeply. Yet, a contested diagnosis of DNC contains unavoidably normative elements. Below, we identify some of the issues at stake and the difficulties that may arise for courts in attempting to resolve these within the current legal framework.

(a) Parental/family rights

The role and scope of parental or family rights in the context of DNC has not been considered by either the UK courts or the ECtHR. There is, however, an established body of ECtHR jurisprudence which affirms parental (and family) rights in respect of the body of a deceased child or loved one.[133] These rights derive from the protection for private and family life under Art 8. As described by the ECtHR in *Solska and Rybicka v Poland*, the exhumation of the applicants' husbands' remains in spite of their objections 'could be regarded as impinging on their relational sphere in such a manner and to such a degree as to disclose an interference with their right to respect for their private and family life'.[134] If disputes about exhumation fit within an individual's 'relational sphere', it would seem reasonable that disputes about DNC would also fall within this sphere. It may further be argued that in some cases, parental rights to manifest their religion or belief as protected by Art 9 of the ECHR would be implicated. In this regard, it is important that while the ECtHR has found that in order to manifest a belief, the action must be intimately linked to the belief in question,[135] it has also held that it is not necessary to establish that a particular manifestation of belief is an essential tenet of the religion in question.[136] An Art 9 argument would presumably be stronger for parents of younger children, with the linkage with parental manifestation of belief likely to be found to reduce as a child matures.

Presuming that Art 8 and/or Art 9 were found to apply, the inquiry would then have to turn to whether these protections may be limited on the basis that this is 'necessary in a democratic society'.[137] As outlined by the ECtHR in *Pretty v United Kingdom*, 'the notion of necessity implies that the

[131]The issue of consent to testing was not part of the appeal and does not feature in any of the subsequent litigation in respect of Archie Battersbee.

[132]*Re M (Declaration of Death of Child)* [2020] EWCA (Civ) 164 at [24].

[133]See eg *Pannullo and Forte v France* Application No 37794/97, ECHR 30 January 2002; *Hadri-Vionett v Switzerland* Application No 55525/00, 2008; *Petrova v Latvia* Application No 4605/05, 24 June 2014; *Elberte v Latvia* Application No 61243/08, 13 January 2015; *Lozovyye v Russia* Application No 4587/09, 24 April 2018; *Solska and Rybicka v Poland* Application Nos 30491/17 and 31083/17, 20 September 2018.

[134]Application Nos 30491/17 and 31083/17, 20 September 2018 at para 110.

[135]*Eweida and Others v United Kingdom* [2013] ECHR 37 at para 82.

[136]*SAS v France,* Application No 43835/11, 1 July 2014 at para 55.

[137]As set out in Art 8(2) and Art 9(2).

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interference corresponds to a pressing social need and, in particular that it is proportionate to the legitimate aim pursued'.[138] Both the social need for a clear definition of death, and the fair distribution of limited public (ICU) resources, would make it difficult to base an effective challenge to the diagnosis of DNC on family/parental objection, or to justify ongoing publicly funded somatic support of the DNC dead, on either Art 8 or Art 9 grounds. However, the case in respect of a transfer of someone who has been diagnosed DNC dead to a private facility where ongoing somatic support would be provided (and funded by family members[139]) is more finely balanced. Why should the parents of Child A, for example, not be facilitated to remove Child A to Saudi Arabia where he would receive ongoing somatic support? Here, the courts have a problem. Because the best interests (and implicitly the rights) of the DNC dead are specifically excluded from the analysis, any counterarguments based on these cannot be considered. Thus, we have the counter-intuitive proposition that the entity (to choose a neutral term) who could be transferred and provided with somatic support is legally excluded from the deliberative process. This brings us to the complex and contentious issue of the interests and rights of the DNC dead.

(b) Interests/rights and the DNC dead

As noted in the Introduction, legal orthodoxy dictates that the dead have neither rights nor interests.[140] In the words of the ECtHR, this is on the basis that 'the human quality is extinguished on death'.[141] There is, however, a notable dissonance between the orthodox legal position and the almost universal view (both historical and contemporary) that respect for the dead (and for human remains) is a fundamental societal value.[142] This dissonance has led to wide-ranging scholarly efforts to justify a claim for some form of recognition of posthumous rights or interests. Two broad lines of argument can be distinguished. The first, linked to the will or choice theory of interests, concerns instructions given by/promises made to the deceased while they were alive. Here, the argument is that where someone has taken steps during their lives to provide for some occurrence after their death (eg through a testamentary disposition or instructions regarding disposal of their body), they have an interest in ensuring that this occurrence takes place. This is sometimes justified as arising from the institution of promise-keeping[143] or from the persistence of critical interests.[144] The second line of argument is linked to the concept of posthumous harm. Here, the argument is that the dead can be harmed notwithstanding that they have no awareness of such harm and that, accordingly, the dead are holders of interests and also possibly rights.[145] Aspects of these arguments have received some support in the UK

[138][2002] ECHR 423 at para 70. See also *Solska and Rybicka v Poland* Application Nos 30491/17 and 31083/17, 20 September 2018, para 126.

[139]The picture would be more complex if charitable funding or crowd funding was involved although it could be argued that charities (or crowds) may choose which (lawful) enterprise they wish to support.

[140]This view is often traced to *Haynes' Case* [1614] 12 Co Rep 113 where the Court found that a corpse could not be said to own its winding sheets since it is 'but a lump of earth hath no capacity': see N Naffine '"But a lump of earth": the legal status of the corpse' in D Manderson (ed) *Courting Death: The Law of Mortality* (London: Pluto, 1999).

[141]*Akpinar and Altun v Turkey* [2007] ECHR 183, para 82. See also *The Estate of Kresten Filtenborg* Application No 1338/03, 2006 and *Elberte v Latvia* [2015] ECHR 1 and the comments of Peter Smith J in *Ibuna v Arroyo* [2012] EWHC 428 (Ch), at [50].

[142]This is evidenced in many social and cultural traditions, including ritualised burial of the dead: see W McCorkle *Ritualizing the Disposal of the Deceased: From Corpse to Concept* (New York: Peter Lang Publishing, 2010); T Laquer *The Work of the Dead: A Cultural History of Mortal Remains* (Princeton, NJ: Princeton University Press, 2015).

[143]See R Brecher 'Our obligation to the dead' (2002) 19 Journal of Applied Philosophy 109.

[144]See J Harris 'Law and regulation of retained organs: the ethical issues' (2002) 22(4) Legal Studies 527 at 534. Note that, for Harris, these are weak interests, subject to the public good.

[145]See eg B Levenbook 'Harming someone after his death' (1984) 94 Ethics 407; G Pitcher 'The misfortunes of the dead' (1984) 21(2) American Philosophical Quarterly 183; J Feinberg *The Moral Limits of the Criminal Law: Harm to Others* (New York: Oxford University Press, 1984); W Glannon 'Persons, lives and posthumous harms' (2001) 32(2) Journal of Social Philosophy 127; D Sperling *Posthumous Interests: Legal and Ethical Perspectives* (Cambridge: Cambridge University Press, 2008). For counter arguments, see Harris, above n 144; J Callahan 'On harming the dead' (1987) 97 Ethics 341.

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courts (especially in respect of a person's instructions regarding treatment of their body),[146] and in dissenting judgments of the ECtHR.[147] Thus, there is at least a possibility that closer scrutiny by the courts may result in some degree of refinement of the orthodox position.

Consideration of the rights/interests of the DNC dead is a subset of this broader debate. Any extension of rights to the dead would clearly encompass the DNC dead. However, DNC also gives rise to a separate question arising from the fact that, as outlined above, DNC is a medico-legal construction about which there is not complete societal consensus. Thus, it is at least arguable that, even if the dead do not have interests, this need not necessarily be the case for the DNC dead. This argument gains some support from *Barts Health NHS Trust v Dance and Battersbee*,[148] which throws into sharp relief the artificiality of a neat distinction in DNC cases between those who have interests and those who do not. Following (partial) DNC testing, the Trust returned to the High Court to apply for a declaration of DNC and if this was not granted a consideration of best interests in respect of ongoing ventilation.[149] Arbuthnot J granted the declaration of DNC. However, in deference to Archie's parents, she also undertook a best interests analysis as if she had not found Archie to be DNC dead. This led her to conclude that had she not found Archie to be DNC dead, she would have found that it was not in his best interests to continue to receive medical treatment, including ventilation.[150] Following the overturning of Arbuthnot J's finding of DNC death by the Court of Appeal, the question of best interests assumed a new significance. The Court found that because of Arbuthnot J's 'procedural mis-step', Archie's parents could not be expected to have confidence in her best interests evaluation and so a fresh evaluation was required.[151] This task was subsequently undertaken by Hayden J who found it to be in Archie's best interests that life-sustaining treatment be withdrawn.[152]

Looking beyond the UK, the neat categorisation of the DNC dead as non-interests or rights holders is further challenged by the decisions of the Irish High Court in *PP v Health Service Executive*[153] and of the Court of Appeal for Ontario in *McKitty v Hayani*.[154] *PP* concerned a 26-year-old woman (NP) who was diagnosed DNC dead on 3 December 2014.[155] NP's father, PP, having consulted family members and NP's fiancé, asked that ventilation should be withdrawn. However, a difficulty arose because NP was approximately 15 weeks pregnant, and at the time in question the Constitution of Ireland provided specific protection for the right to life of the 'unborn'.[156] Clinicians were therefore uncertain of the legal permissibility of acceding to PP's request and the matter was referred to the High Court. By the time the case was heard almost three weeks later, 'devastating' clinical testimony as to NP's condition was presented to the Court. NP's bodily functions had deteriorated substantially; her brain had begun to liquefy, brain tissue was extruding, and her body had become very swollen due to fluid overload. The Court accepted, without comment, that brain stem death had occurred on 3 December 2014, thus affirming, for the first time, the legal status of DNC in Ireland.

[146]See *Burrows v HM Coroner for Preston* [2008] EWHC 1387 (QB) and Cranston J's obiter comments in *Ghai v Newcastle City Council* [2009] EWHC 978 (Admin): see T Muinzer 'The law of the dead: a critical review of burial law, with a view to its development' (2014) 34(4) OJLS 791 at 801–804.

[147]See eg the dissenting judgments of Hedigan J (joined by Gyulumyan J) in *The Estate of Kresten Filtenborg* Application No 1338/03, 2006 and of Fura-Sandström J in *Akpinar and Altun v Turkey* [2007] ECHR 183.

[148][2022] EWHC 1435 (Fam).

[149]Ibid, at [2].

[150]Ibid, at [196].

[151][2022] EWCA Civ 935, at [41].

[152]*Barts Health NHS Trust v Dance and Battersbee* [2022] EWFC 80, at [46]. Leave to appeal this finding was denied by the Court of Appeal in *Dance and Battersbee v Barts Health NHS Trust* [2022] EWCA Civ 1055.

[153][2014] IEHC 622.

[154][2019] ONCA 805.

[155][2014] IEHC 622; see A Mulligan 'Maternal brain death and legal protection of the foetus in Ireland' (2015) 15 Med Law Int 182. Note that the judgment does not include paragraph numbering so accurate pinpointing is not possible: the judgment may be accessed at www.bailii.org or www.courts.ie.

[156]This protection was removed following a constitutional referendum in May 2018.

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Both NP and the unborn were legally represented before the Court. Counsel for NP drew on a will or choice view of NP's interests to argue that the court should infer NP's wishes in respect of the pregnancy and 'strive to have the unborn delivered as a testament to her and as a sibling to her other children'. The inference of NP's wishes appears to have derived solely from the fact that she has posted a picture of her pregnancy scan on her Facebook page and that she was proud of her pregnancy and had intended to continue it. Counsel for the unborn argued that 'given NP had died, the rights of the unborn child must take precedence over the understandable grief of the family of NP and her entitlement to a death with dignity'. In setting out the applicable constitutional framework, the High Court was clear that NP was a bearer of constitutional rights. The Court recognised NP's 'right to retain in death her dignity with proper respect for her autonomy'. It continued:

> Such an approach has been the hallmark of civilised societies from the dawn of time. It is a deeply ingrained part of our humanity and may be seen as necessary both for those who have died and also for the sake of those who remain living and who must go on. The Court therefore is unimpressed with any suggestion that considerations of the dignity of the mother are not engaged once she has passed away'.[157]

Although affirming the existence of NP's rights, the Court did not engage in analysis of these rights or of the tensions between the choice view of NP's interests put forward by her counsel and the harm view which is implicit in the idea of a death with dignity. The case was ultimately (and conveniently) disposed of on the basis that withdrawal of somatic support from NP was in the best interests of the 'unborn', thus averting the need to work though the delicate balancing of interests.[158] Although the constitutional context for *PP* was unique, the issue of whether, and on what basis, somatic support should be removed from someone who is pregnant and who has been diagnosed DNC dead applies outside of this context and it is difficult to see how this question can be resolved without normative engagement.[159]

The decision of the Court of Appeal for Ontario in *McKitty v Hayani*[160] provides a more directly applicable example of judicial reasoning on the role of rights in DNC deliberations. As described above, Ms McKitty's parents had relied on the Canadian Charter of Rights and Freedoms to object on behalf of their adult daughter to her DNC diagnosis.[161] At trial, the Ontario Superior Court of Justice found that Charter rights did not apply to 'those declared brain dead but whose body is physiologically functioning as a result of external supports such as mechanical ventilation'.[162] By the time the appeal was heard, Ms McKitty's heart had ceased beating and the appeal was moot. Nonetheless, the Court of Appeal agreed to the parties' request to hear the appeal because it considered it necessary to correct elements of the Superior Court decision.[163] The Court of Appeal began from a position which recognised the normative status of DNC, stating that determination of death was not simply, or even primarily, a medical or biological question'.[164] It found that, although informed by physiology, the question of 'who the law recognises as a human being' is not a question to be answered by medical

[157][2014] IEHC 622.

[158]On the basis of the medical evidence, the High Court made a finding of fact that the 'unborn child would not be born alive' and that, in addition to the ongoing trauma and suffering for NP's partner and family, continuing somatic support would 'cause distress to the unborn child' and that this would be 'a distressing exercise in futility for the unborn child'.

[159]R Heywood 'Live or let die? Fine margins between life and death in brain dead pregnancy' (2017) 25(4) Medical Law Review 628.

[160][2018] ONSC 4015, [2019] ONCA 805.

[161]Because of the nature of the dispute, Ms McKitty's parents were permitted to act as substitute decision-makers, initiating the action on her behalf rather than on behalf of her estate: [2018] ONSC 4015, at [188].

[162][2018] ONSC 4015, at [204]. In reaching this conclusion, the Court drew on the decision of the Supreme Court of Canada in *Tremblay v Daigle* [1989] 2 SCR 530 that a foetus was not a subject of Charter rights.

[163][2019] ONCA 805, at [9].

[164]Ibid, at [29].

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knowledge alone but rather is evaluative; a 'question of justice, informed but not ultimately determined by current medical practice, bioethics, moral philosophy and other disciplines'.[165] The Court of Appeal also found that the Superior Court had erred in finding that Charter rights did not apply to the DNC dead. Although the Court of Appeal did not make a finding that Charter rights did apply in the case in question,[166] it held that the appropriate methodological approach in a case such as this, where the outcome turned on the application of Charter rights, was to presume that the applicant fitted within the category of Charter rights holders.[167]

Having adopted this methodological approach, the Court of Appeal then considered whether Ms McKitty's Charter rights had been infringed. The relevant provision of the Charter is section 2(a) which protects freedom of conscience and religion, and the Court's reasoning in this regard is instructive in showing how an argument under Art 9 of the ECHR might proceed (were the DNC dead considered – or presumed – to be rights holders). Because the 'neurologic determination of death does not inhibit or prevent persons from holding the belief that death occurs when the heart stops beating', the Superior Court found no inconsistency with Charter values.[168] Following on from this, the appellant's claim was that there was a religious obligation to have life support maintained while she remained alive (ie until her heart stopped beating in accordance with her religious faith).[169]

The Court of Appeal accepted that there was sufficient evidence that the appellant's beliefs were sincerely held and that they had the required nexus with religion. The next question was whether the impugned conduct had interfered with the claimant's ability to manifest the belief in a way that is not trivial or insubstantial.[170] Because of a sparsity of evidence, the Court declined to offer a view on whether the common law definition of DNC constituted such an interference, leaving this question open for another time.[171] As noted above, it did indicate that if there had been interference, one appropriate way to address this would likely be reasonable accommodation.

Conclusion

Although it has been argued that '[d]eath is not a social construct [but] one of the inescapable biological facts that unite all life forms',[172] the reality is more complex. This paper has shown that DNC is a construction created through innovative engagement by the medical and legal systems to address emerging problems caused by technological advances. Given the sheer ambition of the project – essentially to rewrite the nature of death – it is no surprise that problems and challenges emerged. Yet, by and large, the construction has been successful and DNC is now widely recognised as legal death. Even for one of its leading critics, DNC is now 'too flawed to endure, too ingrained to abandon'.[173]

This paper has argued that the constructed nature of DNC should be recognised as relevant in judicial considerations of DNC disputes. These disputes are not simply concerned with whether, as a matter of fact, DNC has been correctly diagnosed, but also raise profound questions about rights and interests, both of families and of the DNC dead. We have argued that these questions call for a more nuanced engagement than a simple assertion that best interests do not apply once DNC is

[165]Ibid.

[166]This was because the constitutionality of the underpinning statute which required completion of the declaration of death had not been raised at trial and could not be raised *de novo* on appeal: ibid, at [53].

[167]Ibid, at [47]. In this, the Court of Appeal drew on the methodology established by the Privy Council in the *Persons Case: Edwards v Canada (Attorney General)* [1930] 1 DLR 98 (PC).

[168][2018] ONSC 4015, at [240].

[169][2019] ONCA 805, at [77].

[170]Ibid, at [78].

[171]Ibid, at [79].

[172]M Hayden 'Negotiating ambiguities in life and death' 2016 Henry K Beecher Prize in Medical Ethics (30 May 2016), available at https://bioethics.hms.harvard.edu/news/2016-henry-k-beecher-prize-medical-ethics-announcement (accessed 14 December 2022).

[173]RD Truog 'Brain death – too flawed to endure, too ingrained to abandon' (2007) 35 J Law Med Ethics 273.

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diagnosed. This is not simply of theoretical concern; as identified above, these questions have direct practical relevance to decisions about transfers to facilities which provide somatic support and about continuing pregnancy. We recognise that this asks a lot from the courts. DNC became part of the UK (and Irish) legal framework without close analysis of the implications of this significant development for the myriad legal and ethical questions which are now arising. In an ideal world, perhaps the legislature might now finally respond to Lord Browne-Wilkinson's call to 'lay down principles of law generally applicable to the withdrawal of life support systems'.[174] However, this seems unlikely and in the meantime the responsibility lies on the courts to expand their normative engagement with DNC disputes and to provide guidance for clinicians, parents and families about all aspects of the legal framework which applies in these tragic cases.

[174] *Airedale NHS Trust v Bland* [1993] AC 789, at 880.

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