Feeding Decisions at the End-of-Life: Law, Ethics and Emotions

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I. Introduction

The act of feeding holds considerable emotional sentiment. It is symbolic in expressing love, compassion, and nurture. Feeding is essential to our existence, not just as a means of physical sustenance, but also because of our social need to nurture and feed others. Medical interventions can frustrate these needs. This was demonstrated in 2013, when the British Dietetics Association (BDA) made a policy regarding the use of home-made liquidised food for tube-fed patients. There had been a rise in requests for advice, which was partly attributed to carers seeing it as a way to "reconnect with caring".[1] The BDA advised against home-made food because it increases the likelihood of feeding tube blockages and gastric infections.[2]

Medical advances in clinically assisted nutrition and hydration have created ethical dilemmas about what its role should be at the end-of-life. Many families see clinically assisted nutrition and hydration as a means of improving their loved

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1 The British Dietetic Association, 'Policy Statement: Use of Liquidised Food with Enteral Feeding Tubes' (2013) 2 <www.bda.uk.com/improvinghealth/healthprofessionals/policystatement_liquidisedfood> accessed 15 August 2017.

2 ibid 3.

one's comfort at the end-of-life, despite contrary medical evidence and opinion.[3] This has sometimes been permitted, as it is acknowledged that "symbolic feeding" serves the family's means of fulfilling their duty to nourish, despite having little or no benefit to the patient.[4] These observations confirm the important emotional component of feeding. This calls for further investigation of the role of emotions in legal decisions regarding feeding.

Two key areas of law where this issue arises are end-of-life decisions in the context of prolonged disorder of consciousness (PDCs) and anorexia nervosa (hereinafter, "anorexia"). This article uses an analysis of legislation and cases in these two areas of law to explore how emotion is manifested, and what influence it may have had on judicial reasoning. I will consider specific cases, but also reflect on trends since the landmark rulings of *Airedale NHS Trust v Bland* in relation to PDCs,[5] and *Re E* in relation to anorexia.[6] Anthony 'Tony' Bland was eighteen years old when he was crushed in the Hillsborough disaster, inflicting him with a prolonged disorder affecting his consciousness, Airedale NHS Trust made a request to withdraw feeding. 'E' was a 32-year-old woman with severe anorexia, who was under palliative care as she refused all nutrition. Her local authority sought judicial review from the Court of Protection to determine if she should be 'force-fed'.

Case law since *Bland* and *Re E* concerning the withdrawal of clinically assisted nutrition and hydration in patients with a PDC, and the refusal of feeding in anorexia cases, continues to raise legal and ethical questions.[7] This has focused primarily on a discussion of autonomy, rights, and the value of life. However, these issues will not be the focus of the discussion in this article. Instead, I will focus on the emotional responses and reasoning found in relevant areas of law. I will consider the extent to which emotion has influenced case law and legislation, and whether it has informed moral reasoning in this area, to develop a position on what role emotion *should* play in end-of-life decisions.

In the background of these practical questions is a more fundamental debate about the role of emotion in morality, and this is where the article begins. Both Kantian and utilitarian traditions in moral theory promote reasoning as the

3 Natasja Raijmakers and others, 'Variation in attitudes towards artificial hydration at the end of life: a systematic literature review' (2011) 5(3) Current Opinion in Supportive & Palliative Care 265, 265.

4 Steven Miles, 'Futile Feeding at the End of Life: Family Virtues and Treatment Decisions' (1987) 8 Theoretical Medicine 293, 295.

5 *Airedale NHS Trust v Bland* [1993] AC 789 (HL), [1993] 2 WLR 316.

6 *A Local Authority, E (by her Litigation Friend the Official Solicitor) v A Health Authority, E's Parents (also known as "Re E")* [2012] EWHC 1639 (COP), [2012] HRLR 29.

7 *Bland* (n 5), *Re E* (n 6).

principle method of determining what we are morally required to do. These theories portray emotion as a negative influence on one's ability to reason, and do not consider it to be part of rational decision-making. However, I argue that a theory of emotion is essential to our understanding of not just how we respond to moral questions, but how we reason and make moral decisions. I posit that emotions are fundamental to how we develop our moral framework, and also provide the means by which we put moral reasoning into practice. Together with the legal analysis, this ethical analysis will be used to defend the view that there should be greater recognition of the crucial role emotion plays in end-of-life legal decision-making.

II. Emotions and Moral Reasoning

The role of emotion in moral reasoning is a long-standing point of contention. For instance, some traditional and ancient ethical theories advocated moral systems that are impartial and objective. Emotions are considered as a partiality that lead to irrational decision-making. It is still claimed by some philosophers, such as Peter Singer, that emotions corrupt rational moral reasoning, and should be controlled.[8] However, other philosophers have contested this claim. In this Part, I shall consider the claims against the role of emotions made by Kantian and utilitarian theorists. Singer, who has a utilitarian perspective, continues to disregard the role of emotion in moral reasoning. In response, the philosophical arguments which justify the role of emotion in moral reasoning, will be set out, in support of my position. I shall conclude that there is a central position for emotion in moral reasoning. This will provide the foundation for the legal analysis of cases involving feeding decisions at the end-of-life, which will be explored in Parts III to V.

A. Kantian ethics

Immanuel Kant discussed the role of emotion in his theory of morality. Kantian ethics takes a deontological approach. Deontology in a normative theory that states that morality is determined by the "rightness" of our actions, and not by their outcome.[9] The right choice conforms to moral norms and moral law.[10] Kant termed moral law the "categorical imperative"; which he claimed imposed duties on the agent.[11] He believed that conduct only had moral worth when it is

[8] Peter Singer, The Expanding Circle (Clarendon Press 1981) 93.

[9] Larry Alexander and Michael Moore, 'Deontological Ethics' (Stanford Encyclopedia of Philosophy, 17 October 2016) <https://plato.stanford.edu/archives/win2016/entries/ethics-deontological/> accessed 20 August 2017.

[10] ibid.

[11] Julia Driver, Ethics: The Fundamentals (Blackwell Publishing 2007) 80.

driven by duty, in compliance with the categorical imperative. In his consideration of emotions, which he termed "inclinations", he claimed that though they are not necessarily a negative force, they have no moral worth.[12] Kant's views were in reaction to David Hume, who stated that "reason is, and ought only to be the slave of the passions, and can never pretend to be any other office than to serve and obey them".[13] Hume argued that "the passions" (or emotions) are the only motivation to human action. Reason can never motivate action, but is employed to reach the goals set by our emotions.[14] Kant refuted this as he believed inclinations to be too fickle as motivators of action. Reason, he believed, provided moral motivation and rational judgements about what we should do.[15] Kant went so far as to say that, when love is commanded out of duty, it is more morally significant than when it is motivated by a desire to do good.[16]

Stocker has argued that the traditional theorists such as Kant failed to appreciate the importance of motivational and emotional drivers of rational morality. Stocker argued that a life lead by duties and obligations is not fulfilling, nor does it evoke "moral goodness".[17] He posits that the conceptual disassociation of motivations from reasoned judgement is not applicable in the real world. He claims that to value something one must have a motive, and that "motive and reason must be in harmony for the values to be realised".[18] Stocker stated that this is a failure of not just Kant's deontological ethics, but also of utilitarianism and egoism.[19] These theories failed to consider value of the relationship between the subject and object of affection.[20] Stocker demonstrates this by considering love; he argues that without the commitment of an interdependent relationship, acting for the sake of duty will not be sufficient motivation to maintain the act.[21] The divide between the reason and motive becomes incomprehensible in real life situations and has pragmatic failings. Stocker goes so far as to say that without valuing the motivations, we dehumanise relationships, and fail to acknowledge what makes "a human life worth living".[22]

[12] ibid 86.
[13] David Hume, A Treatise of Human Nature (Dover Publications 2003) 295.
[14] Driver (n 11) 82.
[15] ibid 84.
[16] Immanuel Kant, Grounding for the Metaphysics of Morals on a Supposed Right to Lie because of Philanthropic Concerns (James Ellington tr, 3rd edn, Hackett 1981) 12.
[17] Michael Stocker, 'The Schizophrenia of Modern Ethical Theories' (1976) 73(14) The Journal of Philosophy 455.
[18] ibid.
[19] ibid 459.
[20] ibid.
[21] ibid 458.
[22] ibid 460.

B. Utilitarian ethics

Emotion in decision-making is fundamentally opposed to utilitarian ethics. Utilitarian ethics claim that the morally right decision is the one that maximises overall happiness and therefore, the greatest good is that which benefits the greatest number.[23] Those who argue in support of utilitarian ethics consider emotions to be a barrier to objective reasoning in determining the greatest good. Singer states that ethics evolved out of our capacity to reason.[24] Reasoning, he claims, is only acceptable when the agent is "disinterested" in their own or other's interests.[25] He states that one's interests are no more important than those of others, and that equal weight should be given to the interests of all.[26] Therefore, interests are partialities which should not motivate decision-making, as this will not be accepted as valid by other reasoned beings.[27] Personal relationships and emotions provide a typical example of a potential partiality, which should not influence the determination of the greatest good. He disapproves of charitable contributions motivated by emotional responses, and instead endorses a rational consideration of where one's donation would do the most good.[28] Though Singer has denied criticisms that he wants to divorce emotion from charitable behaviour, he still views it as a potentially corrupting influence. He claims that reason alone should determine the ethical direction of what to do.[29] Emotion leads to impulsive reactions, and if we are partial our actions will not be motivated to do the most good.[30]

The impartiality advocated by Singer has pragmatic failings, and raises questions as to whether we have greater moral obligations to those closest to us. For example, the decision to prioritise caring for one's own elderly parents, over other elderly and equally needy persons, is a result of the greater compassion one feels for their own parents. This clearly contradicts utilitarian principles, where "a decision must give equal weight to the interests of all affected by it".[31]

[23] Julia Driver, 'The History of Utilitarianism' (The Stanford Encyclopedia of Philosophy, 22 September 2014) <https://plato.stanford.edu/archives/win2014/entries/utilitarianism-history/> accessed 2 August 2017.

[24] Singer (n 8) 111.

[25] ibid 93.

[26] ibid 111.

[27] ibid 93.

[28] Peter Singer, 'Precis: The Most Good You Can Do' (2016) 12(2) Journal of Global Ethics 132, 132.

[29] Anne Maclean, The Elimination of Morality: Reflections on Utilitarianism and Bioethics (Routledge 1993) 53–54.

[30] Peter Singer, 'Altruism and Emotion' The New York Times (New York, 10 December 2015). <www.nytimes.com/2015/12/11/opinion/peter-singer-on-altruism-and-emotion> accessed 2 August 2017.

[31] Singer, The Expanding Circle (n 8) 79.

Maclean has contested Singer's argument for impartiality. Instead, she submits that the recognition of special rights and obligations one has, such as those to one's own parents, is not a moral failing.[32] She states that avoiding partiality does not necessarily improve moral decision-making.[33] For example, it would seem morally wrong if one were to choose to donate all their money to a charity that helped needy people, and neglected the needs of their elderly parents. Maclean denounces Singer's separation of moral reasoning and human nature, stating that "there is no gap between the emotional and the rational components of human nature".[34] This argument poses that our emotional life is a precursor to rationality, rather than an obstacle.

Taylor's thesis sees emotional responses as normative, and connected to our evaluation of situations or events. Taylor disputes the claim that emotions are irrational, but goes further in saying that a deficiency of appropriate emotional responses is an indication of "moral failing or human short-coming".[35] An emotional reaction is justified when firstly the belief, of which the reaction is based, is well-founded; and secondly, that the reaction is appropriate to the situation. For example, if one saw a snake, believing it to be poisonous, it would be appropriate to feel fear. Furthermore, the reaction must be proportional to the stimulus. So, if one were to happen upon a poisonous snake in the wild, it might be appropriate to jump, scream, or run away. However, if one were to see a poisonous snake in a zoo, behind a glass screen, this response would be excessive, and therefore unjustified.[36] Taylor is not just saying that emotions are rational, but further, that their rationality is morally relevant.

The counter arguments posed by Stocker, Maclean and Taylor make a strong case for emotion as an essential component of our reasoning. They view the relationship between emotion, reasoning and morality, as much more co-dependant than the Kantian or utilitarian claims imply. Novel theories of morality have served to re-frame the debate, giving emotion a central role in our understanding of morality.

C. A new perspective: feminist ethics and the value of caring

Feminist ethics came about as a reaction to traditional theories, which were considered gender-biased, and dismissed typically female qualities as being morally

[32] Maclean (n 29) 59.
[33] ibid 61.
[34] ibid 69.
[35] Gabriele Taylor, 'Justifying the Emotions' (1975) 84(335) Mind 390, 390.
[36] ibid 392–393.

deficient.[37] Feminist philosophers disputed the entire framework of traditional theories which claimed women to be too emotional, personal, and "incapable of reason".[38] Female qualities assigned to women by essentialist theory further devalued and subordinated the woman's perspective. This extended to typically female 'activities' such as caring and mothering. Though these activities were praised, and even idealised, the undercurrent placed them as secondary to more 'important' male activities.[39] In response, novel moral systems have been formulated that advocate female qualities and activities, and incorporate the role of emotions in moral reasoning.

Fischer has written about the philosophical 'turn to affect' that occurred in the mid-1990s.[40] She describes the movement as a "paradigm shift in critical theorising", which brought the discussion of emotion and feeling to the forefront of the debate.[41] Progressive feminist theorists, such as Gilligan and Noddings, have posited an emotional, rather than the traditional rational, basis for morality.[42] Gilligan provided the basis for the care approach, and Noddings developed the normative ethical theory in her book *Caring*. Gilligan proposed that girls think differently to boys about moral issues and problems. She examined the work of Lawrence Kohlberg, and highlighted a fundamental gender-bias in his theory of moral development.[43] Kohlberg's understanding of morality was based on rules, principles, and justice; and derived from Kant and John Rawls.[44] He identified six stages of moral development, and formulated a test which he carried out on children. He found that girls tended to lag behind boys and claimed girls had a less developed sense of morality than boys.[45] Gilligan observed that though the boys tended to use logic or law to mediate situations, girls responded with communication through relationships. Gilligan disputed the claim that moral reasoning based on

[37] Jean Grimshaw, 'The Idea of Female Ethics' in Peter Singer (ed), A Companion to Ethics (Wiley 2013) 502.

[38] ibid.

[39] ibid.

[40] Clara Fischer, 'Feminist Philosophy, Pragmatism, and the "Turn to Affect": A Genealogical Critique' (2016) 31(4) Hypatia 810, 810.

[41] ibid 811.

[42] ibid 814.

[43] Carol Gilligan, In a Different Voice (Harvard University Press 1982) 100.

[44] Grimshaw (n 37) 503.

[45] Lawrence J Walker, 'Gender and Morality' in Melanie Killen and Judith Smetana (eds), Handbook of Moral Development (LEA 2006) 97.

relationships should be interpreted as being inferior to male patterns of moral reasoning.[46]

Noddings' ethical theory posed a new approach in moral reasoning. She saw traditional theories, such as Kantianism and utilitarianism, as having been discussed in "the language of the father: in principles and propositions, in terms such as justification, fairness and justice".[47] Instead she argued that the basis of human ethics is "caring".[48] She critiqued traditional theories for simplifying moral dilemmas to rules, which did not resemble real situations. When faced with a moral question, she posited that women typically need more information to come to a decision. Such as, the thoughts and feelings of all those involved. Female reasons, she stated, are based on "feelings, needs, impressions and a sense of personal ideal".[49] Which in turn had been judged unfairly as an inferior rationale than that of men.[50] Emotion is at the heart of her ethical theory and is based on the principle that all ethical behaviour stems from a universal "caring attitude".[51] She denied that justification is the principle measure of ethical conduct, advocating motivation instead. She refuted theories that claimed moral judgements could be tested in the same way as facts: that there is a definitive right or wrong. Instead she posed that moral judgements are not truths, but derive from a rational, caring attitude. Emotions in the context of a caring attitude are both responses and appraisals of a situation.[52] She further suggests that emotion does not necessarily require action to be complete; it can serve reflective purposes that restore the agent to a less stressful state.[53]

The feminist perspective has clearly laid out a place for emotion in reasoning and morality. The difficulty with removing emotion from rational thinking is hypothetical, as our emotional lives are intertwined with the cognitive processes required for reasoning. This poses a strong argument against the theories that claim: firstly, that emotions are irrational and illogical; and secondly, that emotions are not conducive to moral reasoning or appropriate moral action. In response to

[46] Gilligan (n 43).
[47] Nel Noddings, Caring: A Feminine Approach to Ethics & Moral Education (2nd edn, University of California Press 2013) 1.
[48] ibid.
[49] ibid 3.
[50] ibid.
[51] ibid 92.
[52] ibid 142.
[53] ibid 142–143.

these views emotion theorists have formed different approaches to explain how and why emotions influence our decision-making.

The moral decisions made in court can have the gravest consequences, and involve highly emotive situations. I argue that cases involving end-of-life feeding decisions are especially emotive. This is due to the concept of food being a basic and essential requirement. However, these concepts are tested when feeding is no longer sustaining but prolonging life, as is the case for patients with a PDC; or when food is viewed by the patient as detrimental to their existence, as is the case with anorexia. I have argued that there is a central role for emotion in moral reasoning. Therefore, the role of emotion in judicial reasoning in these cases will be particularly important. To explore this further, the legislation and case law will be set out and critiqued, to determine whether the decisions made in court are truly appreciative of the emotions; and further, to what extent do they influence judicial reasoning and the outcome of cases.

III. Prolonged Disorders Of Consciousness

Medical advances have developed treatments that allow recovery from even the most catastrophic brain damage; but this is not the case for everyone. Those who do not recover can be maintained in a state of perpetual limbo; suspended between life and death. The legislation and jurisdiction that apply to cases of PDC shall be described. Then, the specific emotions that have manifested in case law and its influence on legislation will be considered.

Disorders of consciousness (DCs) refer to states where a patient has wakefulness, but absent or reduced awareness of their surroundings. DCs result from brain injury where the brain-stem remains intact but areas of the cerebral cortex, which regulate awareness and higher-level brain functions, is profoundly damaged. DCs can be transient or permanent: they include coma, vegetative state and minimally conscious state. If a DC persists for more than four weeks it can be said to be a PDC and will be diagnosed as either a vegetative state or a minimally conscious state.[54]

In a vegetative state there is wakefulness with complete absence of environmental awareness, and in a minimally conscious state there is wakefulness with minimal awareness. A minimally conscious state presents with "inconsistent, but reproducible" behavioural evidence of awareness, which is greater than reflexive or automatic responses.[55] In 2015, the incidence of patients in a vegetative state

[54] Royal College of Physicians, Prolonged disorders of consciousness: National clinical guidelines (Royal College of Physicians 2015) 1.

[55] ibid 3.

in the UK was between 4,000 and 16,000; and three times as many were thought to be in minimally conscious state.[56] If consciousness has not been regained after one to two years the likelihood of regaining consciousness is very low, and those who do are likely to be left with profound disabilities.[57] The body is maintained with clinically assisted nutrition and hydration, and patients will require 24-hour specialist care and equipment to prevent complications.[58] In 2013, the cost of treating someone in a PDC was estimated at £7,500 per month.[59]

A. The law applied to prolonged disorders of consciousness

A patient with capacity has the right to refuse any medical treatment.[60] Medical law is built on the principle that treatment can only be given to a competent adult if they give their consent. To provide treatment where the risks outweigh the benefits is malpractice.[61] However, those in a PDC lack the mental capacity to make a decision and their wishes are scarcely known. For those lacking capacity, we need to consider the Mental Capacity Act 2005 (MCA 2005) which came into force in 2007. It serves as the legal framework to determine capacity and provides safeguards such as the patient's best interests checklist, advance decisions, and creating a lasting power of attorney.

B. Advance decisions

An Advanced Decision to Refuse Treatment (ADRT) can be made by a competent adult over 18 to specify what treatments they would accept or refuse if they were to lose decision-making capacity.[62] An ADRT can be cancelled or amended by the competent individual at any time.[63] If the ADRT refuses life-sustaining treatment it must be in writing, signed and witnessed, and state that the

[56] Sarah Bunn and Zoë Fritz, 'Vegetative and Minimally Conscious States' (Houses of Parliament, Parliamentary Office of Science & Technology 2015) 1 <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-489#fullreport> accessed 2 August 2017.

[57] Royal College of Physicians (n 54) 9.

[58] ibid 3.

[59] ibid.

[60] Department for Constitutional Affairs, 'Mental Capacity Act 2005 Code of Practice: Issued by the Lord Chancellor on 23 April 2007 in accordance with sections 42 and 43 of the Act' (published by The Stationery Office on behalf of the Department for Constitutional Affairs 2007) 20 <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf> accessed 2 August 2017.

[61] *F v West Berkshire HA* [1991] UKHL 1, 1.

[62] Mental Capacity Act 2005 Code of Practice (n 60) 159.

[63] ibid.

person is aware that the consequences, if actioned, could be life-threatening.[64] "A valid and applicable advanced decision to refuse treatment has the same force as a contemporaneous decision", and when applicable it must be followed by clinicians or they could face criminal prosecution or civil liability.[65]

If an ADRT has not been written correctly, or is not applicable to the decision that needs to be made, it is not binding but may be considered as part of a best interests decision. In *Re D*, 'D' had put his wishes into a letter stating that he refused invasive treatments that would prolong a reduced quality of life.[66] D was in vegetative state, but as his signature had not been witnessed the ADRT was not valid. Nonetheless, the court came to the same decision in his best interests, and clinically assisted nutrition and hydration was withdrawn. This highlights an issue with ADRT: without legal advice, the layperson may be unaware of the stipulations to producing a legitimate ADRT. It will also be invalid if it was withdrawn by the individual before they lost capacity; if it does not specify what treatment they are refusing; if there is conflict with a subsequent ADRT or a lasting power of attorney; or if there are reasonable grounds to believe that the ADRT no longer represents the patient's decision.[67] On this final point, it has been applied to circumstances where there have been advances in medications or treatments since the time the ADRT was written up. In these circumstances, it is deemed that the patient would have been unaware of the anticipated better outcome; therefore, the ADRT is no longer deemed valid.[68] Secondly, this applies where there is reasonable belief that the ADRT no longer represents the patient's beliefs or values. In *HE v A Hospital Trust;* 'AE' was a 24-year-old woman who was born Muslim before becoming a Jehovah's Witness and writing an advance decision to refuse blood transfusions. Later, was engaged to a Muslim man and stopped attending Jehovah's Witness meetings and services. When she lost capacity, her father sought a declaration from the court that the ADRT was no longer applicable. Munby J granted this after stating that decisions should favour the preservation of life when there were doubts to the validity of an ADRT.[69]

There are several practical difficulties in using an ADRT to protect one's wishes. First, to ensure its validity, legal advice will be required when writing it up. Secondly, medical advice may be desirable to understand the range of treatments and circumstances one might find themselves in when incapacitated, to ensure the ADRT is suitably specific. Thirdly, once produced it needs to be proven to be up-to-date or revised when wishes or circumstances change. Finally, one needs to

[64] ibid.
[65] ibid para 9.1, 9.2.
[66] *Re D; An NHS Trust v D* [2012] EWHC 886 (COP) [15].
[67] Explanatory notes to the MCA 2005, s 25.
[68] ibid, para 88.
[69] *HE v A Hospital Trust* [2003] EWHC 1017 (Fam) [49], [50].

put in place a process for ensuring that if one loses capacity the ADRT will be shown to the decision-makers. If all these difficulties are accounted for, the ADRT will provide a robust safeguard. However, the barriers are apparent, in 2015 it was reported that only 4% of the population produced an ADRT.[70] The MCA 2005 provides an alternative safeguard: appointing a proxy decision-maker, with the hope that some of these obstacles would be overcome.

C. Proxy decision-makers

The only form of proxy decision-maker who, if authorised, can make decisions to withdraw or withhold life-sustaining treatment on behalf of an incapacitated adult is a lasting power of attorney. This power, introduced by the MCA 2005, allows a patient to grant a person lasting power of attorney (hereinafter referred to as the "LPA") to make medical decisions on their behalf, if they were to lose capacity in the future.[71] The power can be exercised to make the decision to withdraw life-sustaining treatment if the patient specifically expressed this in the documentation.[72] The patient can appoint one or more LPAs, who either work jointly or severally.[73] The LPA's powers are restricted in that they cannot override an applicable and valid ADRT, nor can they make a decision that is not deemed to be in the patient's 'best interests'.[74] This is where the LPA's powers do not equate to a competent person's refusal. The LPA still has to apply the best interests checklist when making decisions and must not be motivated in any way by the desire to bring about the donor's death.[75] This is contentious: the patient may appoint an LPA to act on their behalf in unforeseen circumstances. Yet the LPA's influence may be no greater than any other next-of-kin in the medical team's determination of a best interests decision. As with the legal conditions required of an ADRT, the consequences of the MCA 2005 stipulations may not be fully understood by the patient when appointing an LPA. Therefore, they may also find themselves receiving treatment they would never have consented to.

D. Best interests

If the patient does not have an applicable and valid ADRT and they lose capacity, the medical team must make a best interests decision on their behalf.[76] The

[70] Bunn and Fritz (n 56) 3.
[71] Mental Capacity Act 2005, s 9(1)(a).
[72] Explanatory Notes to the Mental Capacity Act 2005, para 58.
[73] Mental Capacity Act 2005, s 10(4).
[74] Mental Capacity Act 2005 Code of Practice (n 60) para 7.24.
[75] Mental Capacity Act 2005, s 4(8)(a).
[76] ibid s 4.

points for consideration in determining a best interests decision are listed in section 4 of the MCA 2005. This includes ensuring that no presumptions are made about what the patient would think to be in their best interests;[77] and that the views of those close to the patient, such as the next-of-kin or LPA, are taken into account.[78] The patient's wishes, feelings, beliefs, and values, must also be ascertained where possible.[79] In decisions relating to life-sustaining treatment, the decision-maker must not "be motivated by a desire to bring about his death".[80] There are, however, difficulties and uncertainties about how the test should be applied: namely, there is no indication of what weight should be given to the different factors, and this is left to the decision-maker to determine. Though it allows flexibility in its application, it may also lead to inconsistency and insufficient regard for the patient's wishes and feelings. This has led to calls to reform the best interest test to comply with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which was ratified by the UK in 2009.[81] Though recent case law is placing greater emphasis the patient's wishes and feelings in determining best interests, though this has yet to be formalised.[82]

The determination of best interests starts with the assumption that life should continue. However, when treatment is deemed "futile, overly burdensome or intolerable for the patient or where there is no prospect of recovery", the decision to withdraw treatment is deemed justifiably in the patient's best interests.[83] This follows from Lord Keith's statement in *Bland* that "existence in a vegetative state with no prospect of recovery is by that opinion regarded as not being a benefit, and that, if not unarguably correct, at least forms a proper basis for the decision to discontinue treatment and care".[84] It is therefore difficult to reason how continuation of treatment in this instance could ever be viewed as being in the patient's best interests. If the diagnosis is indicative of no prospect of recovery, then the continued treatment could be argued to be at least malpractice, or at worst assault. The court's decision therefore hinges on the diagnosis. The first request to withdraw clinically assisted nutrition and hydration from a patient with a minimally conscious state diagnosis was in *W v M*,[85] but the application was

77 ibid s 4(1)(b).
78 ibid s 4(7).
79 ibid s 4(6).
80 ibid s 4(5).
81 Law Commission, Mental Capacity and Deprivation of Liberty (Law Com No. 372, 2017) 161.
82 *Briggs v Briggs* [2016] EWCOP 53, [2017] 4 WLR 37 [7].
83 *Re C* [2010] EWHC 3448 (COP) [59].
84 *Bland* (n 5) 859.
85 *W v M* [2011] EWHC 2443 (Fam), [2012] 1 WLR 1653.

not granted as withdrawal was not deemed to be in her best interests. Newton J came to a similar conclusion in *St George's Healthcare NHS Trust v P&Q*, but in this case the determination of the patient's wishes and feelings formed a significant role in the ruling.[86] the patient's religious beliefs, his family's disagreement with the medical team, and his diagnosis favoured the continuation of life-sustaining treatment. In determining best interests, the court's role has historically been one of scrutinising the diagnosis and acting accordingly. However, as greater weight is placed on wishes, feelings, beliefs and values, the emphasis falls on a determination how the patient would view that decision.[87] This has marked the most significant change in the legal jurisprudence in these cases: the removal of the requirement for judicial approval when withdrawal is unanimously deemed to be in the patient's best interests.

E. Judicial approval

2017 saw three landmark cases that questioned and held that there is no longer a requirement for clinicians to seek court approval, when there is no dispute that withdrawal is in the patient's best interests.[88] Up until last year, approval from the Court of Protection was advised in all incidences.[89] This specification had been heavily criticised, as it incurred significant time delays and costs.[90] The requirement originated from the recommendation made by Lord Goff in 1993: in *Bland,* he stated that judicial approval would be "desirable" for the reassurance of families and the public.[91] However, he also stated that once a "body of experience and practice has been built up" the need for an application would not be necessary in every case.[92] Yet this has taken two and a half decades to be realised, notably

86 *St George's Healthcare NHS Trust v P&Q* [2015] EWCOP 42.

87 British Medical Association, Decisions to withdraw clinically-assisted nutrition and hydration (CANH) from patients in permanent vegetative state (PVS) or minimally conscious state (MCS) following sudden-onset profound brain injury: Interim guidance for health professionals in England and Wales (British Medical Association 2017) 2.

88 *NHS Trust v Mr Y and Mrs Y* [2017] EWHC 2866 (QB), *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169, *M v A Hospital* [2017] EWCOP 19.

89 Court of Protection, Practice Direction 9E: Applications relating to serious medical treatment (Courts and Tribunals Judiciary 2015) para 5(a).

90 Adam Formby, Richard Cookson and Simon Halliday, 'Cost Analysis of the Legal Declaratory Relief Requirement for Withdrawing Clinically Assisted Nutrition and Hydration (CANH) from Patients in the Permanent Vegetative State (PVS) in England and Wales' (2015) CHE Research Paper 108, iii <https://www.york.ac.uk/media/che/documents/papers/researchpapers/CHERP108_cost_analysis_CANH_PVS_declaratory_relief.pdf> accessed 3 August 2017.

91 *Bland* (n 5) 815–816.

92 ibid.

because the recommendation was established in legislation, such as the MCA 2005 Code of Practice and Court of Protection Rules.[93] The British Medical Association guidance acknowledged that this instruction was not intended to be immutable, and hoped that court review would not be required indefinitely.[94] They noted that there is often little practical difference between clinically assisted nutrition and hydration withdrawal in these circumstances, and other equally serious situations where it is not seen as a benefit.[95] The original purpose of judicial approval was to reassure families, yet research found the effect to be the contrary.[96]

These changes will certainly be welcomed by many. In recent years there has been mounting support for reform of the law,[97] though others may call to question why this reform took so long to come, and why so many judges were unwilling to question its necessity. It has been commented that the judges' language in these cases perpetually reinforced it as "a decision for the courts".[98] Lord Goff's recommendation undoubtedly was an attempt to quell concerns that the ruling would lead to euthanasia by the back door. Yet, I also posit that the nature of feeding as an act of providing nourishment, and the abhorrence of starvation as a means of death, also explains why reform took so long to come.

F. Feelings about life and feelings about food

There are two principle issues that provoke emotional response in PDC cases: these are the feelings one has about what it is to have a meaningful life, and concerns about imposing one's own standards on the incapacitated. The other is the emotion roused by the idea of withdrawing nutrition and hydration. The emotional response and reasoning of these issues are complex and may vary depending on the subject's relation to the patient. The discussion here will focus on

[93] Mental Capacity Act 2005 Code of Practice (n 60) para 8.18; The Court of Protection Rules 2017, SI 2017/1035.

[94] British Medical Association, Withholding and Withdrawing Life Prolonging Medical Treatment: Guidance for Decision Making (3rd edn, Blackwell Publishing 2007) para 30.2.

[95] ibid.

[96] Celia Kitzinger and Jenny Kitzinger, 'Court Applications for Withdrawal of Artificial Nutrition and Hydration from Patients in a Permanent Vegetative State: Family Experiences' (2016) 42(1) Journal of Medical Ethics 11.

[97] Simon Halliday, Adam Formby and Richard Cookson, 'An Assessment of the Court's Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State' (2015) 23(4) Med L Rev 556, 587.

[98] Richard Huxtable and Giles Birchley, 'Seeking Certainty? Judicial Approaches to the (Non-)Treatment of Minimally Conscious Patients' (2017) 25(3) Med L Rev 428, 438.

the latter, but there is a complex interaction between the two, and it is not possible to consider one wholly in isolation.

The greatest emotional burden in these cases falls on the relatives. Kitzinger and Kitzinger found that two thirds of relatives believed that the patient would rather be dead than sustained in their condition.[99] Feelings about the use of feeding tubes are mixed. Some see it as a non-negotiable basic act of nurturance, whereas others consider it to be an "unnatural act of heroic medicine and a technological means of denying death".[100] Nonetheless, even those who believe the patient would not want to be alive, find the prospect of allowing starvation too cruel and barbaric to even contemplate.[101] Families long for a peaceful death where nature takes its course; and death by withdrawal of clinically assisted nutrition and hydration is often not perceived this way.[102] Kitzinger and Kitzinger reflect that "failing to feed… is a highly emotive issue with deep cultural resonance".[103] There are two reasons why death by starvation is viewed this way. First, the death is slow, it can take three weeks or longer. The prospect of watching their loved one waste away for that time is often unbearable. It also provides a long period of time to regret and reconsider their decision. Secondly, starvation is considered a 'painful' death. The assurance that they can no longer feel pain, or will be provided with pain relief, does little to alleviate their concern. Everyone has experienced hunger pains, and is equally aware of how easily they are remedied after eating. Ian Miller has commented that western societies find the idea of hunger particularly "unacceptable".[104] The difference in court rulings for those in a vegetative state and minimally conscious state may be influenced by the idea of starvation pain. The decision to deny withdrawal in *W v M*, who had a minimally conscious state diagnosis, could be viewed as a reaction to the abhorrence of starvation.[105] It could be argued that this decision was influenced by the patient's increased consciousness and therefore perceived ability to feel pain, with the reasoning that starvation is unacceptable for those able to experience it.

The emotional response to starvation is not just due to the means of death, it is also related to the carer's perception of their caregiving responsibilities. In *Re C,* the staff at the unit opposed the application for withdrawal because it "is against

[99] Kitzinger and Kitzinger (n 96) 158.

[100] Sharon Kaufman, And a Time to Die: How American Hospitals Shape the End of Life (University of Chicago Press 2006) 188.

[101] Kitzinger and Kitzinger (n 96) 159.

[102] ibid.

[103] ibid.

[104] Ian Miller, 'Starving to death in medical care: Ethics, food, emotions and dying in Britain and America, 1970s–1990s' (2017) 12(1) BioSocieties 89, 93.

[105] *W v M* (n 85).

the unit's philosophy of care".[106] The nature of feeding in providing nurture and care is indisputable. Erde and Herring commented on nursing resistance to the introduction of pump-feeding to nursing homes in the 1980s (the pump provided a continuous feed, eliminating the need for nurses to provide bolus feeds by syringe).[107] Nurses equated the loss of feeding time with a "loss of nurturing time".[108] For healthcare professionals the idea of allowing preventable suffering is particularly intolerable, and goes against caring responsibilities. Not only does it oppose the staff's perception of their own duties, but there is societal opposition as it "clashes with expectations of medical care".[109]

The ruling in *Bland* has not alleviated the emotional dilemma faced by families and clinicians.[110] Though Hoffmann J made note of the "emotional symbolism of food" and its power to evoke "deeply intuitive feelings".[111] The redefinition of clinically assisted nutrition and hydration to "medical treatment" was an attempt to reclassify his death as "letting nature take its course".[112] However, as we have seen in the Kitzinger and Kitzinger study, it is not perceived to be doing anything of the sort. Though the court goes to great lengths to try to sympathise with the emotions of the family and clinicians, such as emphasising the tragic nature of the case, it has failed to appreciate how the means of death will impact the family's reasoning.[113] Discontinuing feeding is not perceived as a natural death. This is demonstrated in the words of Karen Quinlan's father (a prominent case in the United States), who when asked if they should stop clinically assisted nutrition and hydration as well as her ventilation said: "oh no, that is her nourishment".[114] The focus of withdrawal in these cases being an omission, rather than an act, is juxtaposed with the emotional experience of those involved. This accounts for why, when judicial approval was required, only a tiny proportion of cases are ever brought to court. Kitzinger and Kitzinger's study found that families were frustrated that the courts had put them in the position where withdrawing clinically assisted nutrition and hydration was the only "legal exit route", leading some to even consider murder as a better alternative.[115] The court concerns itself with trying to be objective and

[106] Re C (n 83) [31].
[107] Edmund Erde and Marvin Herring, 'A discussion of some moral issues in nutrition and feeding' (1985) Journal of Medical Humanities and Bioethics 5, 6.
[108] ibid 7.
[109] Miller (n 104) 90.
[110] *Bland* (n 5).
[111] ibid 832.
[112] ibid 445.
[113] Huxtable and Birchley (n 98) 435.
[114] Daniel Callahan, 'On Feeding the Dying' (1983) 13(5) The Hastings Center Report 22, 22.
[115] Kitzinger and Kitzinger (n 96) 160.

impartial, and judicial approval was a defence to avoid accusations of euthanasia at all costs. Though the issue that causes the greater emotional pain is that the only option for families is to allow their relative to starve to death. This has not been sufficiently discussed in the courts and will continue to be a principle cause of distress for relatives and clinicians.

There are specific issues that arise in PDC cases due to the minimal prospect of recovery and the patient's inability to consent; but these are not the issues for those with anorexia. Here, the patient can usually fully participate in the discussions, and their refusal of food is often seen as the only barrier to a full recovery. In anorexia cases, food remains central to the legal and ethical dilemmas, and provokes strong emotional reaction. For those in a PDC the question has been whether to withdraw feeding, for those with anorexia it is whether to forcibly impose feeding. To consider the role of emotion in moral reasoning, these different cases need to be described and compared, this will be tackled in Part V of this article. Next, the legislation and case law applicable to patients with anorexia will be described and appraised.

IV. Anorexia Nervosa

Anorexia is an eating disorder characterised by low body weight. Persons with anorexia control their weight by restricting calorie intake and the types of foods eaten. Sufferers of anorexia may also exercise excessively, purge by vomiting or using laxatives, or binge eat.[116] The physiological effects of starvation cause the body to become emaciated and every major organ system can be compromised.[117] Anorexia has one of the highest mortality rates of any psychiatric condition.[118] Treatment for anorexia combines psychotherapies with monitored weight gain. The National Institute of Clinical Excellence (NICE) recommend that people with anorexia should be treated in the community where possible; however, those with severe physical complications may require inpatient treatment.[119] The intense fear of weight gain, as well as the distorted perception of their own weight, may result in non-compliance or avoidance of treatment services. Treatment may then need to be carried out against the individual's wishes if their weight is dangerously low. It is in these circumstances that the courts have had to intervene to determine

[116] National Economic and Development Authority, 'Anorexia: Overview and Statistics' <https://www.nationaleatingdisorders.org/anorexia-nervosa> accessed 3 August 2017.

[117] American Psychiatric Association (APA), Diagnostic and Statistical Manual of Mental Disorders: DSM–5 (5th edn, APA 2013) 341.

[118] Royal College of Psychiatrists, MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa (2nd edn, Royal College of Psychiatrists 2014) 8.

[119] National Institute of Clinical Excellence, Eating disorders: recognition and treatment (NG69) (National Institute of Clinical Excellence 2017) paras 1.11.1, 1.11.3.

whether it is right to impose compulsory treatment in the form of 'force-feeding'. Force-feeding is typically administered through a nasogastric tube: a fine tube that is inserted into the nose, down the back of the throat and into the stomach. Liquid feed, fluids and medications can then be passed through it. Inserting the tube can be uncomfortable for the patient, particularly if they are resisting, but if the nasogastric tube is in the correct position and left undisturbed it should be quite comfortable.

A. The law applied to anorexia

A person with anorexia can be detained in hospital for treatment under the Mental Health Act 1983 (as amended in 2007) (MHA 1983), irrespective of whether they consent if the following three conditions are met.[120] First, the MHA 1983 can only be applied to treat 'mental disorders', which includes eating disorders.[121] A mental disorder is "any disorder or disability of the mind". [122] The European Convention on Human Rights (ECHR) uses the term "persons of unsound mind". Both legislations permit a broad interpretation and do not precisely define what this includes.[123] ECHR guidance states that some flexibility should be permitted in its interpretation because "psychiatry is an evolving field, both medically and in social attitudes".[124] This allows inclusion criteria to be adaptive, however it also risks being discriminative. In anorexia, this has been shown to implicate gender bias. It is portrayed as a female disorder, to the disadvantage of male sufferers. Assessments have been found to underscore men resulting in under-diagnosis. [125] Attempts to re-balance these issues include the use of more sex-neutral diagnostic

[120] Mental Health Act 1983, s 63.

[121] Department of Health, 'Mental Health Act 1983: Code of Practice: Presented to Parliament pursuant to section 118 of the Mental Health Act 1983' (published by The Stationery Office on behalf of the Department of Health 2015) 26 <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf> accessed 2 August 2017.

[122] Mental Health Act 1983, s 1(1).

[123] European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14, Article 5(1)(e).

[124] ECtHR, Guide on Article 5 of the Convention: Right to Liberty and Security (ECtHR, 2014) para 87.

[125] Alison Darcy and Iris Lin, 'Are we asking the right questions? A review of assessment of males with eating disorders' (2012) 20(5) Eating Disorders: The Journal of Treatment and Prevention 416, 417.

criteria in the DSM–5.[126] Nevertheless, there remain potential dangers in using social attitudes as a determining factor.

Secondly, the individual's health and safety must be sufficiently at risk to warrant hospital detention and treatment.[127] This could include a risk of suicide, or the physical effects of starvation and malnutrition being life-threatening. This is supported by NICE who advocate refeeding when physical health is severely compromised.[128]

Finally, appropriate treatment must be available. The administration of force-feeding as treatment for anorexia is controversial. Food is not normally considered to be medicine, however in *Bland*, it was agreed that clinically assisted nutrition and hydration is to be considered medical treatment and not basic care.[129] Treatment has since been broadened to include symptoms or manifestations that stem from the mental disorder.[130] *Riverside Mental Health NHS Trust v Fox* was the first anorexia case to authorise physical or pharmacological restraint as part of the treatment required to apply force-feeding.[131] The judge reasoned this by stating that in order to access therapy for her eating disorder she first needed to gain weight, and he concluded that force-feeding was therefore treatment for anorexia under section 145.[132] In *Re KB*, of the same year, the court held that NGT feeding was treatment for mental disorder for those with anorexia. The judge stated that "relieving symptoms is just as much a part of treatment as relieving the underlying cause".[133]

The MHA 1983 is typically required if the individual is competent but refusing treatment. The MHA 1983 would not be required if the patient were competent and consenting to treatment; in which case, the normal principles of medical law would apply. For a patient who lacked capacity, they could be treated in their best interests under the MCA 2005.[134] However, due to anorexia being termed a mental disorder, and the patient's likely refusal of treatment, the MHA 1983 is often applied. Furthermore, the courts have consistently ruled that persons

[126] APA (n 117) 338–345.
[127] Mental Health Act 1983, s 3(2).
[128] National Institute of Clinical Excellence (n 119) para 1.11.1.
[129] *Bland* (n 5).
[130] Mental Health Act 1983 Code of Practice (n 121) para 24.4.
[131] *Riverside Mental Health NHS Trust v Fox* [1994] 1 FLR 614.
[132] Mental Health Act 1983, s 145(4).
[133] *Re KB (adult) (mental patient: medical treatment)* [1994] 19 BMLR 144, 146.
[134] Jonathan Herring, Medical Law and Ethics (6th Edition, OUP 2016) 580.

with anorexia lack capacity. This is a contentious area of debate, as is the concept of force-feeding being in best interests.

B. Capacity

Adults with capacity, including those with mental illness, have the right to refuse any medical treatment for whatever reason, even if without it they will die.[135] The test of competence set out in *Re C*, formed the basis of the capacity assessment in the MCA 2005.[136] Capacity is determined using a functional and diagnostic test. The functional test assesses an individual's ability to understand, retain, use or weigh the relevant information and to communicate a decision.[137] The diagnostic test states that incapacity can only occur if it can be proven that there is an impairment or disturbance to the functioning of the mind or brain.[138] Capacity should be assumed unless proven otherwise.[139] Nevertheless, for those with anorexia, the courts have consistently ruled that the patient lacks the capacity to make a decision about refusing food. The patient's reasoning fails as they are not deemed to *believe* the information around risks.

The courts consistency is persistent: in *Re E*, Jackson J stated "E's obsessive fear of weight gain makes her unable of weighing the advantages and disadvantages of eating in any meaningful way".[140] In *Re L*, King J found that Ms L understood that she was close to death "but she has no deep understanding of her position".[141] Similarly, the two expert assessments of Ms X agreed that she was unable to use and weigh up the information, as she was "unable to apply the information to herself or believe in the need for it"; Dr Glover went further by doubting Ms X's ability to understand or retain all the relevant information.[142] In another recent case, Hayden J said Z "never fully comprehended the consequences of her behaviour in relation to food or nutrition".[143] Though the diagnosis of a particular mental illness should not presume incapacity, anorexia could be argued as an exception to the rule.[144]

Anorexia is invariably deemed to impair the patient's ability to use or understand information around food, regardless of how eloquently the patient articulates their preferences or understanding. This premise has long persisted in

[135] *Re T (Adult: Refusal of Medical Treatment)* [1992] EWCA Civ 18 [3].
[136] *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290.
[137] Mental Capacity Act 2005, s 3(1).
[138] ibid s 2.
[139] ibid s 1(2).
[140] *Re E* (n 6) [49].
[141] *The NHS Trust v L* [2012] EWHC 2741 (COP) [49].
[142] *A Foundation Trust v Ms X* [2014] EWCOP 35 [27], [28].
[143] *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56 [5].
[144] Mental Capacity Act 2005 Code of Practice (n 60) para 4.48.

medical and legal thinking.[145] The 'absolute presumption' of incapacity has been criticised for only interpreting the decision to be in regards to nutrition, rather than the patient's wider understanding of their quality of life.[146] Frequently those with anorexia are deemed to have capacity regarding other areas of their life; for example Ms X could make decisions in regards to her alcoholism, and Ms L could consent to or refuse antibiotics for her pneumonia.[147] Though guidance states capacity assessments are decision specific, there also seems to be no consideration that the patient will be able to regain capacity in the future.[148] Munby J stated that believing information was essential in order to comprehend, understand and weigh that information.[149] However, the requirement of a 'belief component' has been contested: Coggon has argued that one does not need to believe in something to understand it, and has called for the removal of the belief requirement from mental capacity law.[150]

There are several reasons why the anorexic's lack of capacity is contentious. Firstly, there would be repercussions if a court deemed the patient to have capacity. This should not influence the judge's decision, but it is important to recognise the potential for bias. The capacitous patient has an absolute right to refuse medical treatment, and a court would find it very difficult to oppose a competent refusal. If the patient was found to have capacity this could raise concerns of the legality of the compulsory treatment carried out not just to that patient, but to other anorexia sufferers receiving compulsory treatment. Secondly, the MHA 1983 is a particularly paternal piece of legislation, and for those with anorexia this seems acutely apparent. All court cases have involved young women, many of whom developed anorexia before puberty, and have spent large parts of their lives in hospitals. In *Re E* (in which Jackson J ruled in favour of force-feeding); E's abilities and intelligence are mentioned multiple times.[151] Yet, these are not given as reasons to respect her autonomous decision, but a rationale for why she must be 'saved'. Lastly, there seems to be a strong reluctance to find the anorexic's decision unwise, but capacitous. I believe this is partly due to a misperception of what food and nutrition mean to different people. For those with a 'healthy' relationship to food; it not only provides sustenance, but also enjoyment and positive social interactions.

145 Ian Kennedy and Andrew Grubb, Medical Law: Text and Materials (2nd edn, Butterworths Law 1994) 143–144.

146 Daniel Wang, 'Mental Capacity Act, Anorexia Nervosa and the Choice Between Life-Prolonging Treatment and Palliative Care: *A NHS Foundation Trust v Ms X*' (2015) 78(5) Med L Rev 871, 871.

147 *Ms X* (n 142) [30], and *Re L* (n 141) [54].

148 Mental Capacity Act 2005 Code of Practice (n 60) para 4.4.

149 *X v MM and KM* [2007] EWHC 2003 (Fam) [81].

150 John Coggon, 'Alcohol dependence and anorexia nervosa: Individual autonomy and the jurisdiction of the Court of Protection' (2015) 23(4) Med L Rev 659, 667.

151 *Re E* (n 6) [5], [16], [75], [101], [132].

To question this fundamental truth for 'healthy' eaters appears to be so jarring that it cannot be conceived to be rational to think otherwise. For whatever the reason, the anorexic is yet to be found to have the capacity to decide for themselves, and it resides with others to make a decision on their behalf.

C. Best interests

The determination of best interests in anorexia cases has shown a marked change in judicial thinking. Force-feeding patients with anorexia has long been criticised by medical and legal commentators, yet it was only comparatively recently that the courts have become reluctant to impose invasive treatments. Force-feeding aims to relieve the physical symptoms that stem from the mental disorder. However, the irrevocable long-term damage caused by taking away control, "the anorexic's holy grail",[152] for short-term gain is considered by many to be contradictory. The landmark ruling in *Re L* was significant in that it handed power back to the anorexia sufferer, and allowed Ms L to decide for herself whether she would accept nutritional support.[153]

The legal jurisprudence in determining best interests in anorexia is similar to that described for those in a PDC.[154] However, the apparent difference is that those with anorexia can participate in the decision-making, yet this seems to create other difficulties for the courts. Courts are under increasing pressure to keep the person at the centre of the process as evidence shows that the patient's involvement improves outcomes.[155] Court of Protection judges have been motivated to meet the patient prior to the trial to gain a more holistic understanding of the person.[156] The MCA 2005 acknowledges the patient by requiring the consideration of past and present wishes, feelings, beliefs, and values.[157] The difficulty in applying the MCA 2005 to those with anorexia is that their primary and consistent wish is to be left alone. Yet the lack of hierarchy in determining the weight to be accorded to the patient's wishes and feelings has been criticised for being "unhelpfully vague".[158] Their wishes seem juxtaposed to the presumption that we should all value our

[152] Penney Lewis, 'Feeding Anorexic Patients Who Refuse Food' (1999) 7(1) Med L Rev 21, 32.

[153] *The NHS Trust v L* (n 141) [71].

[154] Mental Capacity Act 2005, s 4.

[155] Val Williams and others, Making Best Interests Decisions: People and Processes (Mental Health Foundation 2012) 83 <www.mentalhealth.org.uk/sites/default/files/BIDS_report_24-02-12_FINAL1.pdf> accessed 4 August 2017.

[156] See, for example, *CC v KK and STCC* [2012] EWCOP 2136, and *Wye Valley NHS Trust v B* [2015] EWCOP 60.

[157] Mental Capacity Act 2005, s 4(6)(a)(b).

[158] Nell Munro, 'Taking wishes and feelings seriously: the views of people lacking capacity in Court of Protection decision-making' (2014) 36(1) Journal of Social Welfare & Family Law 59, 62.

own lives. Clough has commented that there is a "persistence of value judgements about the agency of the person with anorexia".[159] Instead the courts take a "narrow, biomedical view" that often leans heavily on the opinion of the medical experts.[160] Clough goes on to say that even though the change in judicial approach could be interpreted as a greater understanding of the patient's will and preferences; she states that in neither *Re L* nor *Ms X* were the complexity of their views satisfactorily explored.[161] Munro criticised the judge in *Re E* for making no effort to engage with the subtleties and contradictions of E's views.[162]

D. A plea for control: the emotional response and reasoning

The central issue—forcing treatment upon someone who vehemently does not want to receive it—provokes intense emotional response. The emotions of the patient, the family, and clinicians may clash, and precede opposing interpretations of best interests. The involvement of the court at this time introduces a further stress for those involved, as well as the judge's own feelings and emotions. In this section, I shall explore the trends in the emotional responses of different participants. I will consider how this played into their reasoning and what influence this may have had on the outcome of the trial.

When treating anorexia clinicians must appreciate the patient's tumultuous emotions: "appalling despair, disgust, upset, sadness about what one has 'done to oneself'".[163] Those cases that end up in court are the most serious, with the most persistent anorexia. Therapy in these cases has not been able to reconcile the deep-rooted feelings and emotions that underpin the patient's reasoning and emotional life. The control of nutritional intake has been the patient's means of managing their emotions. Lewis has observed that "force-feeding crushes the patient's will, destroying who the patient is".[164] This is demonstrated in the case law, such as Ms X's anorexia and alcoholism being described as "the very essence of her life".[165] The loss of identity was apparent in *Re E*, who 'sees her life as pointless'. The anorexic's reaction to their distress has been a plea to retain control over their own lives. Ms X "has repeatedly requested that we do not detain or forcibly feed her" and in expressing her own views in a letter stated that she had 'had enough of the

159 Beverley Clough, 'Anorexia, Capacity and Best Interests: Developments in the Court of Protection since the Mental Capacity Act 2005' (2016) 24(3) Med L Rev 434, 439.
160 ibid 439, 444.
161 ibid 443.
162 Munro (n 158) 66.
163 Susie Orbach, Hunger Strike (Faber and Faber 1986) 139.
164 Lewis (n 152) 33.
165 *Ms X* (n 142) [21].

continual pressure of mental health staff and services'.[166] Ms W similarly wrote "I have no control, things I would like I am being denied", and E "wants to be allowed to make her own choices".[167]

The anorexic rationalises her plea to be left alone from two perspectives. Firstly, that force-feeding is futile. It is difficult to contest the anorexic's perspective in this instance: in each case there have been long-histories of repeated, unsuccessful force-feeding; it is therefore understandable that they have little belief that further treatment will have any benefit. In the cases since *Re E*, clinical and judicial thinking appears to have been more appreciative of this line of reasoning, as shown by the rise of therapeutic jurisdiction. Secondly, that it is detrimental to the relationships they value. Ms X prioritised spending whatever time she had left with her grandfather; Z requested to be allowed to stay at home with her parents; and E felt like a burden to her family and wanted to protect their emotional wellbeing.[168] This is supported by research that found that what mattered most to those with anorexia was the nature of their relationship with their parents and health professionals.[169]

The parent's feelings are often expressed as those of helplessness, or a determination to advocate for their child. This was particularly poignant in *Re E* where E's parents made a statement describing their eighteen-year struggle to help their daughter. They movingly expressed their love and understanding of her torment, and advocated for her 'right to die', pleading that she could be granted "some control over what would be the last phase of her life".[170] The familial nature of anorexia has been described as a key feature of the condition. Giordano notes that experts regard it as a "systemic condition", which "involves the family in a profound and particular way".[171] She states that at the point where force-feeding is being considered, the family are morally entitled to be part of the decision and have their feelings considered.[172] The emphasis on relationships and emotion in the reasoning of the patient and their families accords with the moral theories promoted

[166] ibid [48], [51].

[167] *Re W (Medical Treatment: Anorexia)* [2016] EWCOP 13 [29], *Re E* (n 6) [5].

[168] *Ms X* (n 142) [5], *Cheshire v Z* (n 143) [14], *Re E* (n 6) [76].

[169] Jacinta Tan and others, 'Attitudes of patients with anorexia nervosa to compulsory treatment and coercion' (2010) 33 International Journal of Law and Psychiatry 13, 13.

[170] *Re E* (n 6) [80].

[171] Simona Giordano, 'Anorexia and Refusal of Life-Saving Treatment: The Moral Place of Competence, Suffering, and the Family' (2010) 17(2) PPP 143, 148.

[172] ibid.

by feminist theorists. Historically, courts acknowledged these relationships but did not give sufficient weight to them as core to moral reasoning.

The courts response has shown significant change since the controversial ruling in *Re E*. Peter Jackson J made frequent comments on E's intelligence and positive qualities, this seemed in stark contrast to E's evaluation of her own life as pointless.[173] Furthermore, Jackson J's decision to force-feed E was reasoned as a compassionate act to "protect her right to life under Article 2".[174] Yet, by repeatedly mentioning her intelligence he placed greater moral obligation on the court to save her life. This imposed meaning on her life that she, and her parents, did not recognise. This could also be viewed as an act of frustration, as her anorexia is perceived to be stifling her potential. Further, the feelings of the clinicians and her parents contradict. Though Dr Glover (the court-appointed expert) appreciated that E and her family were psychologically prepared for her death he still felt it to be in her best interests to be re-fed.[175] Cases since *Re E* have shown greater appreciation of the anorexic's feelings and reasoning. For example, King J went to great lengths to prioritise minimising Ms L's distress and understanding her views, and those of her family.[176]

The current trend towards therapeutic jurisdiction and away from force-feeding, demonstrates a change in legal reasoning. Though there may be other factors that can be attributed to this trend, the judgement in *Re E* gained considerable press attention and criticism.[177] The response has provoked courts to weigh factors differently, with the patient's emotional wellbeing at the heart of the decision. This demonstrates how cultural influences have impacted the reasoning and moral decision-making made in court. The degree to whether this influence can be said to be beneficial to the rationality and morality of the decision requires further exploration.

V. Are Emotions In Case Law Rational And Moral?

The case law discussed will now be considered in reference to the theories of emotion. To determine if they demonstrate that emotion can be rational and moral in these instances; I will consider whether the individuals in these cases can be said to be acting in accordance with moral emotions. If emotion is fundamental

173 *Re E* (n 6) [5], [75], [132].

174 ibid [141].

175 ibid [87].

176 *The NHS Trust v L* (n 141) [12].

177 Daniel Sokol, '"As hard as it gets": the case of anorexic E and the right to die' The Guardian (London, 19 June 2012) <www.theguardian.com/law/2012/jun/19/anorexia-e-right-to-die> accessed 15 August 2017.

to our moral reasoning, as previously argued, then I shall ask whether emotion is sufficiently considered in case law and legislation. Before tackling these questions, let us return to the concepts of rationality and morality, and apply them to medical law. By applying these concepts, I will determine the role for emotion in cases of PDC and anorexia.

Legal enterprise sets out rules to guide human conduct. Rationality provides the means of creating these rules, and by which they are held accountable.[178] Brownsword takes a morally-driven approach to law, and has stated that for it to be rational it must meet two principles; firstly, it must be consistent, and secondly, it should be instrumental in guiding action.[179] These principles derive from traditional theories of rationality and moral judgement that advocate impartiality and reject a role for emotion.[180] As has been discussed, the role of emotion in rationality and morality is argued to be implicit to our moral reasoning. In comparing Brownsword's view to the account of moral emotions set out by Gibbard, one can see similarities in their principles despite differing accounts of the role of emotion. Gibbard describes certain 'moral emotions', such as guilt and anger, that produce societal moral norms.[181] These may not be fully engaged when one makes a decision, but a complete awareness of them is nonetheless essential to act morally.[182] The comparison with Brownsword arises from the Gibbard's claim that 'feelings' are normative, and ought to serve the agent as a guide to promote good. He also states that they ought to be "put to work" when accepted to be guides. He expands by saying that they must be harnessed to promote good.[183] As Gibbard has described, the requirement for consistency could be argued not as a reason to reject emotion in moral decision-making, but as a promotion of the appropriate use of moral emotions. Furthermore, emotions can therefore act as a means of guiding moral action in law.

A. Regarding prolonged disorders of consciousness

Kantian ethics have been very influential in philosophy and law, and have put forward a different approach to how one should be guided to act morally. Kant

[178] Richard Huxtable, Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat? (Routledge 2013) 30.
[179] John Adams and Roger Brownsword, Key Issues in Contract (Butterworths 1995) 10.
[180] Huxtable (n 178) 26.
[181] Allan Gibbard, Wise Choices, Apt Feelings: A Theory of Normative Judgement (OUP 1990) 126–127.
[182] ibid.
[183] ibid 274.

would argue that a judge should only be motivated by duty. The judiciary have a responsibility to act in accordance to the law and morals. In this sense, their conduct follows a deontological ethic, as it is the permissibility of the act that is morally significant. For example, they have a duty to respect the sanctity of life and should not permit acts that contradict this principle. Kant would argue that their conduct should be in accordance with the categorical imperative. The principle formulation for which is as follows: "act only according to the maxim whereby you can at the same time will that it should become a universal law".[184] Therefore, to test whether a moral action is permissible, one must determine whether there would be a contradiction in conception if it were universalised. For example, it follows that it is wrong to make lying promises: if everyone were to make promises they would not keep, it would undermine the purpose of making a promise.[185] The historical requirement of judicial approval in withdrawal of clinically assisted nutrition and hydration in PDC cases can be viewed as an act that became standardised in law. For those in a vegetative state, the courts favoured withdrawal of life-sustaining treatment and thereby deemed this act to be morally permissible. This is due to the categorisation of withdrawal as an omission, rather than an act that breaches the sanctity of life principle. However, the failure here is that the strict adherence to deontological morality results in a disregard for the wider implications of this action. This includes consideration of the emotional implications, by which I mean the suffering of families who will still feel they have no humane means to end their loved one's suffering.

An alternative moral position to apply to PDC cases would be that of an ethic of caring. In applying Noddings' ethical theory, the position of a judge is one of 'caring-about' the patient. 'Caring-about' "involves a certain benign neglect", it is more public than personal, and does not call for the "engrossment, commitment, displacement of motivation" involved in caring for someone.[186] The 'one-caring' "involves a special regard for the 'cared-for', and "stepping out of one's own personal frame of reference into the other's".[187] The 'one-caring' has a much deeper sense of the patient's needs and point of view. The withdrawal of clinically assisted nutrition and hydration as the only means of death available neglects the 'one-caring'. This is shown by the views of families reported in the Kitzinger and Kitzinger study, and vast number of cases that were not taken to court prior to the recent legal developments. The court's reluctance to tackle the issue of the means

[184] Kant (n 16) 30.
[185] Driver, Ethics (n 11) 88.
[186] Noddings (n 47) 112.
[187] ibid 24.

of death demonstrates the disconnect between the emotional needs and reasoning of families, and the moral reasoning of the courts.[188] Reasoning in this instance requires a deep sense of compassion for those involved, the moral reasoning advocated by Kant cannot account for the deeply personal nature of these cases. Furthermore, the basis for moral permissibility attributed to withdrawal, rather than say lethal injection, has a deontological basis. Yet, on a caring basis the moral reasoning could be argued very differently. The emotional impact of watching the patient die from starvation on the 'one-caring' is evidently much greater than that of an instant death. The emotional repulsion may vary according to proximity; for example, a stranger may be horrified to hear of euthanasia, whereas those involved in the caring may view this as compassion. Nevertheless, a greater consideration of the emotions may give a different weight to the moral reasoning in these cases.

A utilitarian would argue that the court's moral reasoning is right when it will result in the overall greatest happiness. Therefore, the unhappiness of families who cannot withdraw clinically assisted nutrition and hydration, due to the means of death, should be considered. However, the practicality of considering the views of persons whose voices have not been heard in court, questions its pragmatic validity. A judge will naturally be more emotionally invested in the case before them, rather than in those hypothetical cases. Where the well-being of other persons is not under scrutiny in the trial. Furthermore, courts are under increasing pressure to attribute greater weight to the wishes and feelings of incapacitated patients, in line with the approach taken by the UNCRPD. This will result in greater opportunity for the judge to understand the emotions of the patient and their families. Placing the wishes of the patient at the heart of best interests decision-making may result in a move away from utilitarian moral ideals. Prioritisation of the patient's wishes forces the judge to prioritise the 'happiness' of the patient over others. This was demonstrated in *Wye Valley NHS Trust v B,* a landmark case in its approach to best interests decision-making.[189] Mr B was a 73-year-old gentleman who suffered from schizophrenia and had a severely infected leg that required amputation to save his life. Mr B was adamant that he did not want his leg amputated, but he lacked capacity to make this decision. Peter Jackson J made the rare decision to meet Mr B himself, to gain a better understanding of his best interests. He refused to grant the application that it was in Mr B's best interests to amputate his foot, against the advice of expert evidence. Here we can see that the morally right outcome was deemed to be that which protected Mr B's autonomy, rather than supporting medical advice. The moral reasoning here is not demonstrated by a utilitarian or

[188] Kitzinger and Kitzinger (n 96).

[189] *Wye Valley NHS Trust v B* [2015] EWCOP 60.

Kantian approach, but morality that is derived from caring for Mr B's emotional wellbeing.

B. Regarding anorexia

The rise of therapeutic jurisdiction observed in anorexia cases can also be considered as a result of a deeper understanding of the patient's emotional reasoning. It is questionable whether this would be justified by Kantian ethics: one would need to consider whether it is permissible to stop enforced feeding on patients with anorexia. There may be patients for whom force-feeding is an important part of their recovery, and who would deteriorate without that treatment. Perhaps in this instance the utilitarian approach is better appeased. In *Re E* the decision to force-feed went against the reasoning of E, her parents, and the clinicians who had worked with her. Their collective happiness may have been greater if the outcome had been to respect E's wishes. However, it could be argued that the rise in therapeutic jurisdiction in anorexia cases following *Re E* may have other negative outcomes. Where there may be greater reluctance in the courts and hospitals to force-feed patients who would benefit. This could result in poorer outcomes for patients who do not end up in court and the overall net happiness would decrease. However, it would not be possible to foresee these consequences if one were attempting to act following a utilitarian ethic. I would argue that the moral permissibility of therapeutic jurisdiction is best reasoned under an ethic of care and emotion. The revulsion of forced treatment that is perceived to be futile is a key driver in the court's reasoning. Reasoning that tries to act 'objectively' and does not give weight to the emotions of those involved, as it was not deemed to be in accordance with judicial impartiality, seems to be out of step with wider changes in medical law.

Prinz defends the position that emotions are essential in moral theory.[190] He posits that "moral emotions promote or detect conduct that violates or conforms to a moral rule".[191] Reactive moral emotions, such as indignation at injustice, are central to our morality.[192] The emotional response to force-feeding is a moral response to the agent's detection of a rights violation. The right to bodily integrity and autonomy is threatened and the patient's response is to act in a way to defend themselves. Reflexive moral emotions, such as guilt, occur when one has violated the autonomy rule of a person one cares about.[193] By meeting the patient, the judge acts to raise the importance of the patient's wishes and feelings, but it will

[190] Jesse Prinz, The Emotional Construction of Morals (OUP 2007) 13.
[191] ibid 68.
[192] ibid 70.
[193] ibid 76.

also increase the judge's caring attitude. In Noddings' terms; this moves the judge from a 'caring-about' position closer to 'caring-for'. This in turn will result in a greater emotional response if one acts in a way that violates moral rules. Guilt can develop into shame, which arises when "cultures start to label certain acts as unnatural or deviant".[194] Societal changes that expect greater weight to be given to the patient's autonomy and aversion to paternal medical practices. The act of force-feeding has become increasingly more repulsive and morally impermissible.

The rise of therapeutic jurisdiction in anorexia cases demonstrates a change in how moral judgments are formulated. I have argued that our emotional response is core to our moral reasoning, and that societal emotional reactions guide our morality. This is best explained by an emotional and caring basis to human morality. The outcome of PDC trials also demonstrates how repulsion to starvation, the antithesis of the caring attitude, results in a preference for withdrawal in vegetative state but not minimally conscious state. The likelihood of neurological recovery in minimally conscious state cases is minimal. Yet the idea of starving a person with even a minimal level of consciousness provokes greater emotional repulsion, and I have argued that this is what underpins decisions to continue feeding.

VI. Conclusion

Utilitarian and Kantian rationalists will argue that moral judgements are made through reasoned decision-making. An impartial decision-maker considers all the information, then weighs and tests it according to moral principles. Nonetheless, what Kant and Singer failed to account for is how emotions are intrinsic to moral decision-making. Emotions not only help us to focus our attention on important matters, they help us to process information quickly, and are active in how we formulate our judgement. Moral decision-making is based on rules that we have learnt through our emotional experiences. Our emotions are a prerequisite to reasoning and provide a means of evaluating whether we have acted morally. When we feel injustice, we must learn how this should inform moral action to restore justice. Those who cared for Tony Bland felt outraged by his circumstances. They acted on his behalf to rectify the injustice that had befallen him. Reason without emotion cannot account for this. Reason alone might rationalise that we must preserve the sanctity of life and he was not actively suffering therefore should continue living, conversely reason could argue that he had no meaningful life therefore one should withdraw. However, it is our emotional evaluation of these

[194] ibid 78.

options that inform how we judge them. It is from this perspective that I have justified an internal role for emotion.

Cultural influences on how we interact with reasoning is also important to consider in these cases. These may change over time, and our emotions are responsive to these changes. For example, the Law Commission has recommended that greater weight be given to the patient's wishes and feelings in accordance with the Human Rights Act 1998 and UNCRPD.[195] Recent legal developments regarding the determination of best interests in both PDC and anorexia cases demonstrate a change in judicial reasoning to this effect. By giving greater weight to the patient's wishes and feelings the decision-maker is encouraged to show a greater understanding the emotional life of the individual. The turn to therapeutic jurisdiction in anorexia cases is not just a sign of a cultural shift towards autonomy, but also towards emotion. Although, the influence of emotion in PDC cases seems to be at odds with societal opinion. Families have reported they would support euthanasia, but not withdrawal of clinically assisted nutrition and hydration. The means of death provokes different emotions, and the moral reasoning in each eventuality is very different. The emotional response to murder is quite different to that of compassionate euthanasia. Perhaps if legal reasoning in these cases had been more informed by emotion, there would be greater agreement with societal and cultural influences.

Institutions impose their own specific arrangements that influence emotional reasoning. Institutions, such as courts and hospitals, differ in how they "model, direct, and constrain the psychological/emotional repertoire".[196] Some institutions may valorise some emotions, and stigmatise others. The cultural institutional differences require specific consideration in the feeding decisions discussed. The emotional response, reasoning, and morality, within a healthcare setting will be different to that of a court. Hospitals promote moral action based on caring and beneficence. Courts seek moral behaviour based on justice and evidence. Individuals entering these domains will in turn be influenced by the differing perspectives. *Re E* demonstrated a cultural difference in the emotional reasoning of E's clinicians and the court. These differences need to be recognised and analysed further, as this influences how moral decisions are reasoned and whether they are right.

In this article, I have defended emotions as assuming moral importance. Medical law concerning feeding decisions at the end-of-life have been described and examined. In applying the concepts of the philosophy of emotion to these legal

[195] Law Commission, Mental Capacity and Deprivation of Liberty (Law Com No. 372, 2017) para 14.12.

[196] Amélie Oksenberg Rorty, 'Enough already with "Theories of the Emotions"' in Robert Solomon (ed), *Thinking about Feeling: Contemporary Philosophers on Emotion* (OUP 2004) 277.

issues I have responded to my research question: Should emotion be a component of how we make decisions about feeding at the end-of-life? A better understanding of how emotions support our rationality and morality will help us to make better decisions. End-of-life feeding decisions are particularly emotive, and are at greater risk of being reasoned from a traditional rationalist perspective. The person's emotional response will vary according to the role and association to the case. Yet, without understanding the emotional forces in one's reasoning and morality, one cannot truly make a fully informed decision. This should inform medical law.