

# **The British Legal Framework on Organ Donation and Transplantation**

## **Introduction**

From the first heart transplant carried out in the United Kingdom ('UK') in 1968 to the scandals of Alder Hey and the Bristol Royal Infirmary in the 1990s, the UK's history of organ donation is characterised by a tension between furthering medical development and tackling novel bioethical questions. In this paper, I address two current pressing legal issues – the shift to an opt-out system of donation and the application of the best interest test to incapacitated adults in the organ donation context. First, in relation to the opt-out system, I explore the role of the family in donation decisions, the scope of the organs included within the system and public awareness of the shift. Secondly, I evaluate the principles of relationality and altruism in best interest decisions.

## **The Opt-Out System**

### **Legal Framework**

Organ donation in the UK currently operates as an 'opt-out' system. Wales was the first country to implement this system with the Human Transplantation (Wales) Act 2013 and the Human Transplantation (Excluded Relevant Material) (Wales) Regulations 2015.<sup>1</sup> England followed with the Organ Donation (Deemed Consent) Act 2019, which amended the Human Tissue Act 2004, and the Human Tissue (Permitted Material: Exceptions) (England)

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<sup>1</sup>Williams et al, 'Presumed Dissent? Opt-Out Organ Donation and the Exclusion of Organs and Tissues' (2022) 30 Med L Rev 268, 282

Regulations 2020.<sup>2</sup> Scotland implemented the Human Tissue (Authorisation) Scotland Act 2019 and Human Tissue (Excepted Body Parts) (Scotland) Regulations 2020.<sup>3</sup> Each regulation sets out organs which are excluded from the system.

In England, certain groups of adults are also excluded from this system: those who have not been ordinarily resident in England for at least 12 months immediately before dying and those who lacked capacity to understand the effect of an opt-out system for a significant period before death.<sup>4</sup> Wales' legislation states the same.<sup>5</sup> Similarly in Scotland, excluded adults are those who had an opt-out declaration in place immediately before their death, those who were not ordinarily resident in Scotland for at least 12 months prior to their death and those incapable of understanding deemed consent.<sup>6</sup>

A family member, or individual with a 'qualifying relationship' to the deceased, can provide information 'that would lead a reasonable person to conclude that the person concerned would not have consented' to organ donation which can prevent donation from proceeding in England, despite the existence of 'appropriate consent'.<sup>7</sup> A 'qualifying relationship' is either a specified family member or friend of long standing.<sup>8</sup> A similar provision is provided in Welsh legislation, whereby a 'relative or friend of long standing' may voice an objection.<sup>9</sup> In Scotland, no such relationship is specified; the Human Tissue (Scotland) Act 2006 section 6D(2)(d) states that 'a person' is sufficient to provide an objection. I will use the word 'family' when discussing all of these specified relationships.

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<sup>2</sup> Ibid

<sup>3</sup> Ibid

<sup>4</sup> Human Tissue Act 2004 section 3(9) and (10)

<sup>5</sup> Human Transplantation (Wales) Act 2013 section 5

<sup>6</sup> Human Tissue (Authorisation) (Scotland) Act 2019 sections 6D(1)(b), 6D(2)(a) and 6D(2)(b)

<sup>7</sup> Organ Donation (Deemed Consent) Act 2019 sections 1(4) and Human Tissue (Authorisation) (Scotland) Act 2019 section 6D(2)(d)

<sup>8</sup> Human Tissue Authority, 'Qualifying Relationships' (1 March 2022) <https://www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem/qualifying-relationships> accessed 15 July 2022

<sup>9</sup> Human Transplantation (Wales) Act 2013 section 4(4)

From 2023, Northern Ireland will move to an opt-out system.<sup>10</sup>

### The Role of the Family

The UK's opt-out system is described as a 'soft' opt-out system; there is a residual role for the family of the deceased in making the final donation decision. The Human Tissue Authority's guidance, Code F, states that the position is that 'the existence of appropriate consent permits an activity to proceed but does not mandate that it must'.<sup>11</sup> Specifically, Code F sets out that the role of the family can be decisive: 'the final decision about whether to proceed rests with the [Specialist Nurses] and the medical practitioners caring for the patient, in conversation with the family'.<sup>12</sup> The Government have further justified the shift as being compatible with the European Convention on Human Rights ('ECHR'). It is the Government's position that consulting 'close relatives' prior to donation renders the likelihood of an interference with Article 3 of the ECHR lower.<sup>13</sup> The family thus play an important role.

This position is principally criticised for undermining patient autonomy. Shaw et al argue that 'ignoring the "dying wish" of a patient can be seen as dishonouring the deceased' and thereby violating their wishes.<sup>14</sup> The frequency of family vetoes is evidenced in the latest National Health Service ('NHS') Activity Report— for example, for bowel donations, there were 785

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<sup>10</sup> The Organ and Tissue Donation (Deemed Consent) Bill (Northern Ireland) 2022

<sup>11</sup> Human Tissue Authority, 'Code F: Donation of Solid Organs and Tissue for Transplantation' (2020) paragraph 75

<sup>12</sup> Ibid paragraph 118

<sup>13</sup> Organ Donation (Deemed Consent) Bill 2019 Explanatory Notes (2018) paragraph 39

<sup>14</sup> Shaw et al, 'Family Over Rules? An Ethical Analysis of Allowing Families to overrule Donation Intentions' (2017) 101 Transplantation 482, 484

organ donors and family permission was refused in 39 cases.<sup>15</sup> With the demand for organs vastly outweighing the supply, even a small number of refusals can have an impact. Williams et al highlight how increasing the number of organs available for donation was a UK-wide policy aim for the move to an opt-out system.<sup>16</sup> For example, in England, the Department of Health's 2018 Impact Assessment states that the policy objective of a move to an opt-out system is to 'increase the annual number and quality of organs transplanted so that everyone requiring a transplant stands the best chance of receiving one'.<sup>17</sup> The inclusion of the family veto arguably undermines this key aim by retaining families' ability to have the final say in certain circumstances where the deceased consented to donation.

Concerns regarding violating patient autonomy are compounded by the fact that a sizable number of families do not discuss organ donation with each other and therefore are unaware of each other's wishes. NHS Blood and Transplant research shows that 50% of survey respondents had not spoken to anyone about organ donation and 4% stated that they 'didn't know' whether they had spoken to anyone about their preferences.<sup>18</sup> Families' ignorance may therefore unintentionally violate donors' preferences.

The uniquely distressing position that families are placed in immediately after the deceased's death has been argued to be a factor in favour of removing the family veto. Shaw et al argue that making the donation decision 'places a considerable burden on families who may instinctively refuse donation because they are so upset'.<sup>19</sup> Families may make 'rash, highly

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<sup>15</sup>NHS Blood and Transplant, 'Organ and Tissue Donation and Transplantation Activity Report 2021/22' (2022) page 26

<sup>16</sup>Williams et al (n 1) 272

<sup>17</sup>Ibid and Department of Health, 'An Opt-Out System of Organ and Tissue Donation: Impact Assessment' (2018) page 1

<sup>18</sup>NHS Blood and Transplant, 'Families need to talk about organ donation, to give thousands waiting the chance of a "new beginning"' (5 September 2016) <https://www.organdonation.nhs.uk/get-involved/news/families-need-to-talk-about-organ-donation/> accessed 15 July 2022

<sup>19</sup>Shaw et al (n 14) 485

emotional' decisions as a result of their vulnerable state of mind, rather than one based on 'settled values'.<sup>20</sup> In fact, the NHS's organ donation website states that 'there may be cases where it would be inappropriate for donation to go ahead if donation would cause distress to your family'.<sup>21</sup> Affording primacy to views made in this context may be inappropriate as such views may fail to reflect the true wishes of the deceased and even the family.

However, a 'hard' opt-out system (where the family have no say in the matter) may backfire and ultimately reduce the number of patients who consent to donation. Fears around scenarios 'where organs are taken against the wishes of...loved ones'<sup>22</sup> and instances of doctors 'undertreat[ing] or withhold[ing] treatment to ensure that the patient does become an organ donor'<sup>23</sup> can lead would-be donors to refuse consent in the absence of the safety net of a family veto. A striking instance of this phenomenon occurred in Singapore in 2007 with the case of Sim Tee Hua. Despite Sim's family stating their objections, his kidneys and corneas were donated as Sim did not object to donation when he was alive. This resulted in 'a massive public outcry and...in a significant subsequent drop in potential donors'.<sup>24</sup>

Cases like this highlight the inherent emotional dimension of organ donation which necessitates recognition of the importance of public and familial trust in the system. This is particularly key when 'the potential donor's death is defined not by conventional criteria (the cold, blue, and stiff definition of death) but by a set of clinical criteria' that confirms brain stem death.<sup>25</sup> Fabre et al argue that in such instances, 'a high level of trust is needed for the

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<sup>20</sup>Ibid

<sup>21</sup>NHS Blood and Transplant 'Understanding Consent for Organ Donation' <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/consent/> accessed 15 July 2022

<sup>22</sup>Williams et al (n 1) 281

<sup>23</sup>Fabre et al, 'Presumed Consent is Unnecessary' (2010) 341 British Medical Journal 922, 923

<sup>24</sup>De Wispelaere and Stirton, 'Advance commitment: an alternative approach to the family veto problem in organ procurement' (2010) 36 J Med Ethics 180, 181

<sup>25</sup>Fabre et al (n 23) 923

family to accept that the patient really is dead'.<sup>26</sup> Research carried out by Davies and Randhawa demonstrates how family involvement prior to death can remedy trust concerns.<sup>27</sup>

When respondents were asked about whether they consented to donation, many 'needed more time to talk and debate the issues with family, friends, and experienced people about their fears or reservations if they were going to agree to donation'.<sup>28</sup> As such, this may indicate that family involvement from the beginning of making donation decisions is crucial to increasing the number of people who consent.

Family involvement is recognised by the Nuffield Council on Bioethics as being vital in ameliorating 'medical mistrust'.<sup>29</sup> They argue in favour of the option of a family veto on the basis that failing to take into account the 'meanings and associations that may be held in connection with the deceased bodies of loved ones' can 'jeopardise trust in the whole system'.<sup>30</sup> For example, the retention of deceased childrens' organs unbeknownst to their parents at the British Royal Infirmary caused public outcry. Instances like this highlight how trust can be eroded by hospitals failing to recognise the dissonance between clinical and non-clinical perspectives of a deceased body; while a heart can have significant personal value from a non-clinical view, from a 'scientific perspective a heart can be seen as a piece of machinery that has...no role in a dead [body]'.<sup>31</sup> Retaining family involvement can ease would-be donors' concerns about hospitals taking a purely clinical view in regard to donation decisions and thus ensure trust remains in the system as a whole.

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<sup>26</sup>Ibid

<sup>27</sup>Davies and Randhawa, "'Don't Know Enough about It!': Awareness and Attitudes Toward Organ Donation and Transplantation among the Black Caribbean and Black African Population in Lambeth, Southwark, and Lewisham, United Kingdom' (2004) 78 Transplantation 420

<sup>28</sup>Ibid 424

<sup>29</sup>Nuffield Council on Bioethics, 'Response to the Government's consultation on introducing 'optout' consent for organ and tissue donation in England' (March 2018) paragraph 15

<sup>30</sup>Ibid paragraph 17

<sup>31</sup>Nuffield Council on Bioethics, 'Human bodies: donation for medicine and research' (2011) 25

Further, practical cooperation of the family is required for the success of organ donation. The family of the deceased are ‘an essential source of information regarding any recent illness or medications that might affect the likelihood of successful transplant’.<sup>32</sup> There is a risk that families may refuse to provide this vital information if their wishes are disregarded. It is notable that the NHS Blood and Transplant Activity Report 2020-21 highlights the ‘incredible family support for organ donation with record numbers of families agreeing to donation’.<sup>33</sup> In the 2020-21 period, the family authorisation rate was the ‘highest ever’ at 69%; a 1% increase from the previous year, and ‘the sixth consecutive year of continuous improvement’.<sup>34</sup> Reframing the role of the family as an integral element of the ‘donation team’ would better reflect the reality of this continuous rise in consent rates. A system which prioritises families’ donation preferences may therefore both increase consent levels by would-be donors and reduce the number of families who do in fact veto a donation decision by easing trust concerns.

### The Exclusion of Certain Organs

Regulations in England, Wales and Scotland provide for the exclusion of certain ‘experimental’ organs from the opt-out system. For example, faces, limbs and uteri are not deemed to constitute organs for ‘routine’ transplantations and are therefore not included in the system. The scope of the opt-out system exists because of the second key policy aim: to better reflect existing donation preferences.<sup>35</sup> This aim is stated explicitly in policy documents. In England, the Department of Health and Social Care’s consultation outcome on the move to an opt-out system states that such a move ‘better reflects the position of the

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<sup>32</sup> Shaw et al (n 14) 484

<sup>33</sup> NHS Blood and Transplant ‘Organ and Tissue Donation and Transplantation Activity Report 2020/21’ (2021) page 5

<sup>34</sup> Ibid

<sup>35</sup> Williams et al (n 1)

majority of people who would be happy to donate their organs and tissue when they die’.<sup>36</sup> Similarly, in Scotland, the move to an opt-out system is stated as being a way of potentially ‘tackl[ing] the problem of people “not getting around” to making their wishes known’.<sup>37</sup> This claim arises from the data cited in the English consultation; there is ‘widespread public support for organ donation’ with 80% of individuals stating that they are in favour of it ‘in principle’.<sup>38</sup> Yet only 39% had opted-in prior to the legislative change.<sup>39</sup> As such, reflecting donation preferences more accurately is a key justification for the shift.

Williams et al highlight how selective willingness to donate based on organ type is evidenced in various reports.<sup>40</sup> NHS Blood and Transplant’s 2020-21 Activity Report shows that ‘while 85% of registered donors are willing to donate kidneys, pancreases, hearts, lungs, livers and corneas post mortem, 15% of this group do selectively refuse to donate at least one of these, with 10% of all donors unwilling to donate their corneas’.<sup>41</sup> In addition, a survey carried out in Germany in 2018 found that 13% of individuals who consented to donation refused to consent for certain organs.<sup>42</sup> Of this 13%, 56% refused to consent to cornea donation.<sup>43</sup> This illustrates that willing donors exhibit organ selectivity and thus the principle of excluding certain organs from the opt-out system is welcome.

The reasoning behind this selectivity is illustrated by research into a general unwillingness to consent to cornea donation. In a study assessing donors’ reasons for selective refusal, Lawlor

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<sup>36</sup> Ibid and Department of Health and Social Care ‘Consultation outcome:

Consultation on introducing ‘opt-out’ consent for organ and tissue donation in England’ (5 August 2018)

<sup>37</sup> Williams et al (n 1) and Scottish Government, ‘Organ and Tissue Donation and Transplantation: A consultation on increasing numbers of successful donations’ (December 2016) page 9

<sup>38</sup> Department of Health and Social Care (n 36)

<sup>39</sup> Ibid

<sup>40</sup> Williams and Manson “‘Take my kidneys but not my corneas”—Selective preferences as a hidden problem for ‘opt out’ organ donation policy’ [2022] Bioethics 1

<sup>41</sup> Ibid and NHS Blood and Transplant (n 33)

<sup>42</sup> Caille Brillet et al ‘Wissen, Einstellung und Verhalten der Allgemeinbevölkerung zur organ und gewebe spende: Ergebnisse der Repräsentativbefragung’ [2018] Bundeszentrale für gesundheitliche Aufklärung 23

<sup>43</sup> Ibid



and Kerridge found that respondents often blurred the concept of disfigurement in the symbolic and physical sense; concerns about the appearance of the deceased's body with an open casket viewing overlapped with concerns about changing the 'essence' or 'human element' of the deceased through removal of the eyes.<sup>44</sup> Lawlor and Kerridge further argue that the cultural significance of the eyes is another important factor in selective refusal, stating that 'vision is the most dominant of all the senses' as we live in a 'visual world' that attaches connotations of 'truth' to sight.<sup>45</sup> Again, this highlights the importance of clinicians understanding the social meaning behind donation beyond a purely clinical perspective of the body.

Public unawareness of which organs are scientifically able to be donated and transplanted provides further support for restricting the scope of the opt-out system to specified 'routine' organs. Williams et al argue that due to lower public awareness of the donation and transplantation possibilities of certain organs (such as faces), many individuals would 'never have considered the possibility of their donation at all'.<sup>46</sup> Such individuals would thus 'lack donation preferences altogether'.<sup>47</sup> Restricting the scope of the opt-out system to 'routine' organs therefore prevents donors from unwittingly consenting to donations that they had not considered.

Despite evidence in favour of the scope of the system being confined to certain organs as a general principle, questions arise as to which specific organs are included within the 'routine' and 'experimental' categories. Williams and Manson argue that in an opt-out system, the

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<sup>44</sup>Lawlor and Kerridge, 'Understanding Selective Refusal of Eye Donation Identity, Beauty, and Interpersonal Relationships' (2014) 11 Bioethical Inquiry 58, 59

<sup>45</sup>Lawlor and Kerridge, 'Anything but the Eyes: Culture, Identity, and the Selective Refusal of Corneal Donation' (2011) 92 Transplantation 1188, 1189

<sup>46</sup>Williams et al (n 1) 278

<sup>47</sup>Ibid

‘path to authorisation’ is compromised. In an opt-in system, ‘the provision of selective occasion is “built in” to the authorisation path when the donor selects the organs that they are willing to donate. For example, this can work by ticking a box for each organ; Williams and Manson describe this type of selection as ‘tightly “built in” to the process’ as the donor is reading the information and making a decision based on their understanding of it. By contrast, with an opt-out system, this selectivity is removed – ‘it is not as if the inaction of the donor on an opt out framework is triggered by, or bundled with, some kind of attention directing, information giving, preference signalling occasion’.<sup>48</sup> In fact, it has been argued that inaction cannot constitute valid consent at all – ‘presumed consent is a fiction. Without the actual consent of the individual, there is no consent’.<sup>49</sup> As such, while an opt-out system may reflect some individual’s preferences accurately, the process by which selection is expressed by individuals is crucially not a positive act.

This is particularly problematic when considering the original classifications of organs in the system. For example, in Wales, the ‘initial proposed lists were not evidenced based’.<sup>50</sup> Instead, the list was derived from the Government’s ‘anticipated beliefs’ about organ classification.<sup>51</sup> Williams et al note that this proposal may have ‘biased the consultation responses’.<sup>52</sup> As such, ‘appeals to donation preferences’ being used to ‘both motivate and legitimate shifts to opt-out frameworks’ lose validity if individual or public preferences did not determine the scope of the exclusions.<sup>53</sup>

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<sup>48</sup>Williams and Manson (n 40) 9

<sup>49</sup>Erin and Harris, ‘Presumed consent or contracting out’ (1995) 25 *Journal of Medical Ethics* 365, 365

<sup>50</sup>Williams (n 1) 23

<sup>51</sup>Ibid

<sup>52</sup>Ibid

<sup>53</sup>Williams and Manson (n 40) 1

A further issue relating to the initial classification is that it was arguably influenced by a desire to ensure consistency between countries in the UK, rather than public preferences.<sup>54</sup> For example, the Welsh Government issued a consultation on the scope of organs in the opt-out system on the basis that ‘the list [of excluded organs] now needs further updating...to achieve parity across the UK wide system of organ donation.’<sup>55</sup> Williams et al argue that while this appears practically logical – NHS Blood and Transplant is the sole body responsible for organising donation and transplantation across the UK<sup>56</sup> – basing classification on a different principle (namely, consistency) similarly calls into question claims that the scope of the system is legitimised by the policy aim of reflecting public preferences.<sup>57</sup>

### Public Awareness

Public awareness of a shift from an opt-in to an opt-out system is key when consent is presumed from inaction. Parsons and Moorlock argue that clear communication to provide the public with awareness of what their inaction means in practice is key to respecting autonomy.<sup>58</sup> This means going beyond a superficial understanding of an opt-out system; instead providing ‘sufficient information’ to enable a would-be donor, or the donor’s family, to make an informed choice.<sup>59</sup> The importance of this is recognised by the Government, as they state that ‘if there is a lack of information about deemed consent then Article 8 [of the ECHR] may be interfered with’.<sup>60</sup>

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<sup>54</sup>Ibid 6

<sup>55</sup>Williams et al (n 1) and Welsh Government, ‘Human Transplantation (Excluded Relevant Material) (Wales) (Amendment) Regulations Consultation on draft regulations’ (2020) 6

<sup>56</sup>Williams et al (n 1) 288

<sup>57</sup>Williams and Manson (n 40)

<sup>58</sup>Parsons and Moorlock, ‘A global pandemic is not a good time to introduce ‘optout’ for organ donation’ (2020) 20 Medical Law International 155

<sup>59</sup>Ibid and Shaw, ‘Presumed evidence in deemed consent to organ donation’ (2018) 19 J Intensive Care Soc 2

<sup>60</sup>(n 13) paragraph 40

Parsons and Moorlock highlight how the ‘understanding’ requirement is ‘tacitly acknowledged in the DCA 2019 itself, whereby those who lack capacity to understand the impact of the Act are excluded from its reach’.<sup>61</sup> As the shift occurred during the height of the Covid-19 pandemic, it is questionable whether this level of understanding and awareness was achieved. One year after the introduction of the opt-out system in Wales was introduced, 26% of people were unable to describe the change to the system.<sup>62</sup> Shaw highlights how while this may appear to be low, it potentially means that over ‘1 in 20 “donors” are having their organs removed against their will’.<sup>63</sup> Insufficient public awareness therefore risks undermining trust in the system.

## **Incapacitated Adults and the Best Interest Test**

### **Legal Framework**

The application of the law on ‘live’ donations (the donation of regenerative tissue when the donor is alive) to adults lacking capacity is principally governed by the Mental Capacity Act 2005. The test applied in deciding whether donation can proceed is that of the ‘best interests’ of the incapacitated person, as set out in section 4 of the 2005 Act. Section 4(6) specifies three factors to be taken into account: (a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), (b) the beliefs and values that would be likely to influence his decision if he had capacity, and (c) the other factors that he would be likely to consider if he were able to do

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<sup>61</sup>Parsons and Moorlock (n 58) 160

<sup>62</sup>BBC News, ‘Half of organ transplants from deemed consent after new law’ <https://www.bbc.co.uk/news/uk-wales-politics-36520627> accessed 15 July 2022

<sup>63</sup>Shaw (n 59)

so. The best interest test is derived from *Re F (Mental Patient: Sterilisation)*.<sup>64</sup> Common law continues to provide guiding principles in addition to the three specified factors in the 2005 Act. In the context of organ donation, the Human Tissue Authority's guidance explicitly provides that donation in relation to incapacitated adults can be lawful.<sup>65</sup> In addition, the Mental Capacity Act 2005 Code of Practice confirms that 'such procedures may be in the person's overall best interests'.<sup>66</sup>

### Relationality

Tension between relationality and an individualistic conceptualisation of autonomy is at the heart of the debate on the best interest test in the organ donation context. This was addressed in the first case to confirm that it could be lawful for an incapacitated adult to be an organ donor in the absence of a direct medical benefit arising from the procedure – *Re Y (Mental Incapacity: Bone Marrow Transplant)*.<sup>67</sup> This case concerned a 25 year old woman who lacked capacity. She had lived in a 'community home' since she was 17 years old. Her 36 year old sister required a bone marrow transplant as a result of pre-leukaemic bone marrow disorder. The court held that a bone marrow donation from Y was in her best interest in an emotional, psychological and socially beneficial way.<sup>68</sup>

The court took account of Y's wider interests in reaching this decision. In discussing the benefits of the procedure to Y, Connell J noted that Y 'benefits from the visits which she receives from her family and from her occasional involvement in family events' and that she

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<sup>64</sup>[1990] 2 AC 1 (HL)

<sup>65</sup>Human Tissue Authority, 'Code G: Donation of allogeneic bone marrow and peripheral blood stem cells for transplantation' (2017) paragraph 24

<sup>66</sup>Department for Constitutional Affairs, 'Mental Capacity Act 2005 Code of Practice' paragraph 8.20

<sup>67</sup>[1996] 2 FLR 787

<sup>68</sup>*Ibid* 794

has a close relationship with her mother.<sup>69</sup> Connell J held that if Y's sister were to die, her mother would be adversely affected and thereby so would the relationship between Y and her mother; Y's mother's 'ability to visit the defendant [Y] would be handicapped significantly, not only by a likely deterioration in her health, but also by the need which would then arise for her to look after her only grandchild, E.'<sup>70</sup> It was concluded therefore that the benefits of donation to Y included prolonging her relationship with her mother and improving her relationship with her mother and sister, as they both wished for donation to occur.<sup>71</sup>

The court's consideration of the relational benefits to Y is welcomed by Feenan. He argues that this approach is appropriate in the context of relationships characterized by dependency as it recognises 'the importance of emotional connection'.<sup>72</sup> Moving away from the 'privileging of the concepts of self-determination and autonomy' is a welcome shift from a feminist perspective.<sup>73</sup> Herring argues that these concepts can 'disadvantage women' by promoting 'the unattached unencumbered person as the norm', thus failing to reflect the reality of many women's lives.<sup>74</sup> In this sense, it is notable that the judgment features consideration of Y's mother's caring role for her grandchild as well as for Y. However, should relational values be promoted in this context as women are arguably disproportionately more likely to express an interest in organ donation?<sup>75</sup> For example, 52% of women were registered on the NHS Organ Donation Register, compared to 47% of men.<sup>76</sup>

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<sup>69</sup>Ibid 793

<sup>70</sup>Ibid

<sup>71</sup>Ibid

<sup>72</sup>Feenan, 'A good harvest? Re Y (Mental Incapacity: Bone Marrow Transplant)' (1997) 9 Child & Fam L Q 305, 307

<sup>73</sup>Ibid

<sup>74</sup>Herring, 'Relational Autonomy and Family Law' in Wallbank et al (eds), *Rights, Gender and Family Law* (Taylor and Francis Group 2010) 261

<sup>75</sup>Venter, 'A NHS Foundation Trust v MC [2020] EWCOP 33: Revisiting Best Interests and 'Altruistic' Incapacitous Stem Cell Donation' (2021) 29 Med Law Rev 337, 344-345

<sup>76</sup>NHS Blood and Transplant (n 13)132

Venter questions whether ‘altruistic behaviour in females should be further promoted in judicial reasoning’ as such a stance may contribute to a ‘gender imbalance’.<sup>77</sup>

A further limitation of a relational approach is that it is too speculative. Murphey highlights how ‘any acceptable evaluation of the preferences and emotional state of...an [incapacitated adult] has been argued to be extremely difficult to establish due to the limited mental capacity of the individual being evaluated.’<sup>78</sup> In *Re Y*, Y lacked the capacity to understand that her mother was in fact her mother. It is unclear how far courts are willing to go in determining what constitutes a sufficiently close relationship when a lack of understanding of arguably key features (namely, a biological connection) is not an issue. The inherently speculative nature of the assessment can thus give rise to an evidentiary issue. Lewis postulates a situation where the recipient of a donation no longer provides care to the incapacitated donor after the procedure.<sup>79</sup> Where no such guarantee exists, it can be risky to ground a best interest decision on an assumed previous and future relationship between the donor and another.

### Altruism

The role that altruism plays in the donation decision is central to the best interest test. The Nuffield Council on Bioethics recognises altruism as ‘underpinning important communal values’ which ‘expresses something very significant about the kind of society in which we wish to live’.<sup>80</sup> This value was considered in the best interest context in *A NHS Foundation Trust v MC*.<sup>81</sup> This case concerned an 18 year old woman who lacked capacity. Her mother had chronic leukaemia and required a peripheral blood stem cell donation. MC was the only

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<sup>77</sup>Venter (n 75) 345

<sup>78</sup> Murphey, ‘Minor Donor Consent to Transplant Surgery: A Review of the Law’ (1978) 62 Marquette Law Review 149, 160

<sup>79</sup>Lewis, ‘Procedures that are Against the Medical Interests of Incompetent Adults’ (2002) 22OJLS 575, 590

<sup>80</sup>Nuffield Council on Bioethics (n 31) 5

<sup>81</sup>[2020] EWCOP 33

family member who was a match. In considering MC's best interests, the court held that 'I also give some weight, although lesser weight, to the fact that MC may be seen by others positively by acting altruistically.'<sup>82</sup>Venter argues that taking altruism into account 'raises questions about whether an incapacitous donor has the ability to appreciate altruism and whether compelled altruism could still be regarded as a gift'.<sup>83</sup>This can further lead to a risk of exploitation. While the court emphasised that it only placed 'some weight' on altruism in *MC*, if this was to be taken as the 'sole benefit to the individual', it could lead to 'the patient's best interests being misconstrued', thereby 'represent[ing] the values of the decision-maker rather than the values of the individual required to undergo the process'.<sup>84</sup>As such, the speculative nature of such an assessment risks undermining the value of altruism. However, Herring and Foster argue that this interpretation of 'virtue' is too narrow. They question whether the ability to choose is necessary to be virtuous, highlighting how virtue can be ascertained from an individual's 'desires, attitudes, sensibilities or expectations', which those lacking capacity do have.<sup>85</sup> As such, it is argued that it would be 'wrong' to suggest that those lacking capacity can never be virtuous.<sup>86</sup>

## **Conclusion**

In this paper, I explored two current legal issues surrounding organ donation in the UK – the shift to an opt-out system of donation and the application of the best interest test to adults lacking capacity. In relation to the shift to an opt-out system, I addressed the role of the family, the exclusion of certain organs from the system and public awareness of the shift. In

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<sup>82</sup> Ibid [17]

<sup>83</sup> Venter (n 75) 344

<sup>84</sup> Brown, 'Autonomy, the Law, and Ante-Mortem Interventions to Facilitate Organ Donation' [2020] University of Manchester Thesis, 159

<sup>85</sup> Herring and Foster, 'Welfare means relationality, virtue and altruism' (2012) 32 Legal Studies 480, 487-488

<sup>86</sup> Ibid



relation to the best interest test, I evaluated the principles of relationality and altruism. While medical developments have ensured the growing success of organ donation and transplantation, the foregoing discussion highlights that bioethical debate in this area remains prevalent.