

# ORGAN DONATION: IN SEARCH OF AUTONOMY

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## **Research Declaration**

I confirm that I have already submitted my Project Synopsis and Ethical Approval Form, which has been signed by my supervisor. I further confirm that this project is entirely my own work and that the research undertaken for the completion of this project was based entirely on secondary material or data already in the public domain (case law, journal articles, published surveys etc). It did not involve people in data collection through empirical research (eg, interviews, questionnaires or observation).

**Signed:**

**Dated:** 12<sup>th</sup> April 2018

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## INTRODUCTION

Organs have been transplanted from the dead into the living for almost 70 years. During this time advances in immunosuppression<sup>1</sup> have made the practice almost common-place. The demand for replacement organs has always outstripped supply; a problem which has spawned heated ethical debate amongst physicians and philosophers regarding the relative rights of the dying, dead and living. In England, at least, the Human Tissue Act 2004 is the primary source of transplant legislation but offers very little by way of direct guidance; delegating much of its powers to the Human Tissue Authority (HTA). The HTA, in turn, delegates much of its authority to various professional organisations such as NHS Blood and Transfusion (NHSBT) who oversee deceased organ transplantation.

Medical law and ethics have changed significantly since transplantation began in earnest in the 1970s. This essay contends that current transplantation practice is frequently unethical and bends the constrained laws to which it subscribes to their very limits. Since death is a pre-requisite to deceased organ donation it requires some certainty. However, the definition of death differs in both time and place. By constructively avoiding donor consent the concept of donor autonomy is granted second place to the needs of the recipients.

The law needs to change in order to reflect the ethics of the society it serves. Renewed interest in the concept of autonomy demands a review of the current ethical and legal constructs. There is sufficient scope within current statute and common-law to reconstruct transplantation rules so that the rights of the dying, the dead, and their families, are properly respected whilst still affording life-saving and life-changing donations to those whom require them. In addition to tort, such law may be found in property and equity.

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<sup>1</sup> Immunosuppression is the process by which the body's natural tendency to reject any foreign bio-material is attenuated. This also leads to a reduced ability to fight infection; bacteria and viruses are foreign bio-materials in much the same way as a donor heart or kidney.

## CHAPTER 1

### DYING AND DEATH

A discussion regarding deceased solid organ donation requires a working definition of 'dying' and 'death'. None of the definitions offered are without controversy.<sup>2</sup>

#### 1.1. Dying

The Oxford dictionary and thesaurus offers:

*Adjective.* On the point of death. Terminally ill, at death's door, on one's deathbed, in the jaws of death, on the point of death, near death, passing away, fading fast, sinking fast, expiring, moribund, breathing one's last, not long for this world; in *extremis*.<sup>3</sup>

Clearly, the temporal element of dying ranges from immediate (on the point of death) to possibly months or years (terminally ill). The context in which the word is used is key. This is not something the law, in its search for certainty, finds easy to deal with; it is open to misinterpretation and so is usually explained. Numerous respected judgments use 'dying' but the context is set by the individual case and the words surrounding the adjective.<sup>4</sup> For instance, in *Bland* 'dying' is contrasted to 'living', 'healthy', and 'curable', all of which conjure a different meaning depending on the broader context.<sup>5</sup> It is clearly possible to be living and dying at the same time or have an incurable cancer but be otherwise healthy. The Olympic rower, Sir Steve

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<sup>2</sup> IH Kerridge *et al* 'Death, dying and donation: organ transplantation and the diagnosis of death' (2002) 28 *Journal of Medical Ethics* 89; C Ronco 'Defining death in non-heart beating organ donors' (2003) 29 *Journal of Medical Ethics* 182; S Burns 'Human rights: How certain is death?' (2009) 159 *New Law Journal* 459; D Gardiner 'International perspective on the diagnosis of death' (2012) 108 *British Journal of Anaesthesia* 14; Gary Belkin *Death before dying* (1<sup>st</sup> edition, Oxford University Press 2014).

<sup>3</sup> Oxford online dictionary and thesaurus <<https://en.oxforddictionaries.com/thesaurus/dying>> accessed 28<sup>th</sup> March 2018.

<sup>4</sup> *R (Burke) v General Medical Council* [2005] EWCA Civ 1003, [2006] QB 273 [311]

<sup>5</sup> *Airedale NHS Trust v Bland* [1993] 2 WLR 316 [1993] AC 789. 'Dying' is contrasted to 'living' [822], 'healthy' [835] and 'curable' [810].

Redgrave has inflammatory bowel disease and diabetes.<sup>6</sup> Both are incurable but to describe him as ‘dying’ would be advancing an unqualified definition too far.

## 1.2. Death

The Human Tissue Act 2004 makes reference to death but does not define it. Instead it empowers the Human Tissue Authority (HTA) to give the definition.<sup>7</sup> The HTA avoid any definition by saying the ‘[d]iagnosis of death is a matter for clinicians providing end-of-life care.’<sup>8</sup> The medical profession, representing those clinicians, currently have two definitions of death.

The standard ‘circulatory’ definition allows any registered medical practitioner to diagnose death. To be dead, the person must have lost all function of the heart, lungs and brain. Simply, the patient has no heart beat and so no palpable pulse, does not breathe and does not react to any stimulus. The case notes would usually state: ‘no heart sounds, breath sounds or major pulse, no response to painful stimuli and fixed, dilated pupils. Mrs. Blogs is dead, rest in peace’. Observations would usually continue for five minutes, or longer if the clinician harbours doubts.<sup>9</sup> The heart has stopped, the lungs no longer inflate and the brain has ceased to function. This is the syndrome of death which accords with most people’s idea of death; currently and throughout history.<sup>10</sup> Without modern organ support the complete failure of either heart, lung or brain rapidly leads to the cessation of function of the remaining two.

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<sup>6</sup> S Mott ‘A tummy bug nearly cost me Olympic gold: Steve Redgrave on the misery of colitis’ Mail Online 20 December 2011 <[www.dailymail.co.uk/health/article-2076304/Steve-Redgrave-misery-colitis.html](http://www.dailymail.co.uk/health/article-2076304/Steve-Redgrave-misery-colitis.html)> accessed 29<sup>th</sup> March 2018.

<sup>7</sup> S.26(2)(d) Human Tissue Act 2004

<sup>8</sup> Human Tissue Authority, *Donation of solid organs and tissue for transplantation: Code of practice* (April 2017) 112

<sup>9</sup> Hypothermia and hypothyroidism are often cited as causes of deep coma masquerading as death. Usually, in a hospital setting, the difference between life and death is very obvious, having observed the patient in both states within a relatively short period of time.

<sup>10</sup> David DeGrazia, ‘The Definition of Death’ in Edward Zalta (ed), *The Stanford Encyclopedia of Philosophy* (2017) <<https://plato.stanford.edu/archives/spr2017/entries/death-definition/>> accessed 27<sup>th</sup> March 2018; D Schafer ‘What

Since the development of modern organ support there has been another definition of death; death according to brain-death criteria.<sup>11</sup> Here, the brain has failed but the heart and lungs are kept alive artificially, thus suspending circulatory death by an increasing length of time dependent on technological advances. This new definition opened up a line of argument between physiologists and philosophers; when are humans actually dead? Is it when all the cells in their body have ceased to function (complete biological death) or when they can no longer interact with the environment (social death). Practically, they need to be dead in order to remove organs, the procurement of which would otherwise be fatal. This much is dictated by the so-called 'dead donor rule'.<sup>12</sup> Miller and Truog take the view that a person can donate when either neurologically devastated or imminently dying without first being declared dead (social death).<sup>13</sup> This is an ethical argument, with considerable merit but without current English legal endorsement. Counter to this we have Veatch, whilst yielding much to Truog's argument, nevertheless entitles his reply 'killing by organ procurement';<sup>14</sup> a title destined to make even the calmest reader raise an ethical eyebrow. Verheijde contends that both circulatory and brain-death criteria occur too early in the dying process of the human person to be described as markers of death and that actual death in such patients is physician-assisted.<sup>15</sup>

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is death? Definitions and diagnoses from 2500 years of natural philosophy and medicine' (2013) 138 *Deutsche Medizinische Wochenschrift* 2671 (English version)

<sup>11</sup> Ad Hoc Committee of the Harvard Medical School 'A definition of irreversible coma' (1968) 205 *Journal of the American Medical Association* 337

<sup>12</sup> RM Veatch 'Killing by Organ Procurement: Brain-Based Death and Legal Fictions' (2015) 40(3) *The Journal of Medicine and Philosophy* 289; RD Truog 'Role of brain death and the dead-donor rule in the ethics of organ transplantation' (2003) 31(9) *Critical Care Medicine* 2391

<sup>13</sup> RD Truog 'Role of brain death and the dead-donor rule in the ethics of organ transplantation' (2003) 31(9) *Critical Care Medicine* 2391; RD Truog, FG Miller 'The Dead Donor Rule and Organ Transplantation' (2008) 359 *New England Journal of Medicine* 674

<sup>14</sup> RM Veatch 'Killing by Organ Procurement: Brain-Based Death and Legal Fictions' (2015) 40(3) *The Journal of Medicine and Philosophy* 289

<sup>15</sup> JL Verheijde *et al* 'Brain death, states of impaired consciousness, and physician-assisted death for end of life organ donation and transplantation' (2009) 12 *Medical Health Care and Philosophy* 409

The current English definition of death from the Academy of Medical Royal Colleges (AMRC) is:

Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person and, thus, the definition of death should be regarded as the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe.<sup>16</sup>

The document goes on to say:

The irreversible cessation of brain-stem function ... will produce this clinical state and therefore irreversible cessation of the integrative function of the brain-stem equates with the death of the individual and allows the medical practitioner to diagnose death.

In short, while there are some ways in which parts of the body may continue to show signs of biological activity after a diagnosis of irreversible cessation of brain-stem function, these have no moral relevance to the declaration of death for the purpose of the immediate withdrawal of all forms of supportive therapy. It is for this reason that patients with such activity can no longer benefit from supportive treatment and legal certification of their death is appropriate.<sup>17</sup>

Several aspects of this statement generate searching questions.

First, why create a second set of diagnostic criteria and complicate matters?

By 1968 there were severely brain-injured patients being kept in intensive care units attached to ventilators (a recent development) with no prospect of ever regaining the capacity for consciousness or the ability to breathe without mechanical support. The act of withdrawing ventilatory support would potentially amount to murder; a hitherto untested ethical and legal position. This was clearly an unsatisfactory state of affairs. The concept of 'brain death' meaning 'death' allowed such patients to be taken off their ventilators (because they were legally dead) and undergo a 'standard'

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<sup>16</sup> Academy of the Medical Royal Colleges, *A code of practice for the definition and confirmation of death* (2008)

<sup>17</sup> Academy of the Medical Royal Colleges, *A code of practice for the definition and confirmation of death* (2008) 11



cardio-respiratory death within minutes. Hence, it was a mechanism whereby clinicians could avoid prosecution for only doing what any reasonable person would see as morally acceptable. The 1993 case of *Bland* created a similar legal sleight of hand to allow clinicians to withdraw therapy on patients in a permanent vegetative state (PVS) without fear of criminal sanction; withdrawal of support being declared legally the same as not starting it in the first place.<sup>18</sup> The other obvious advantage of a brain death definition of death was that non-brain organs were still very much alive, even though the 'human person' had deceased. The AMRC notion that in 'some ways ... parts of the body may continue to show signs of biological activity' is arguably disingenuous; with the exception of the brain the whole of the rest of the body is quite obviously alive.<sup>19</sup> Henderson, Miller and Truog go to considerable lengths to refute the idea that brain death equates to a biological death.<sup>20</sup> Nevertheless, the removal of living organs from the dead allowed the development of transplant medicine; dead organs from a dead person being useless and living organs from a living person being illegal.<sup>21</sup> Whether the 1968 legal 'sleight of hand' *intentionally* brought about the birth of transplant medicine, rather than being a side-effect of allowing the withdrawal of therapy from permanently unconscious patients, is moot point.<sup>22</sup> A clear line had been drawn which has provided a degree of certainty as to the legality of subsequent actions on the (newly defined) cadaver. The debate between Browne and Pallis captures very well the tension between

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<sup>18</sup> *Airedale NHS Trust v Bland* [1993] 2 WLR 316, [1993] AC 789

<sup>19</sup> Drawing on the work of Shewmon, Miller and Truog list many of the bodily functions almost unaltered by brain death. FG Miller RD Truog *Death, Dying and Organ Transplantation* (Oxford, 2012) 64, DA Shewmon 'The brain and somatic integration: Insights into the standard biological rationale for equating "brain death" with death (2001) 26 *Journal of Medicine and Philosophy* 457

<sup>20</sup> DS Henderson, *Death and Donation* (Pickwick, 2011); FG Miller, RD Truog, *Death, Dying and Organ Transplantation* (Oxford, 2012)

<sup>21</sup> The obvious exception to this is the 'living related donor' but this does not usually result in the cardio-respiratory death of the donor.

<sup>22</sup> Martin Pernick, 'Brain death in cultural context: the reconstruction of death 1968-81' in SJ Younger *et al* (eds), *The definition of death; contemporary controversies* (John Hopkins University Press 1999)

philosophical and physiological reasoning regarding human death as equating to irreversible unconsciousness combined with the inability to breathe.<sup>23</sup> Both agree that humans die, the point of death is, self-evidently, debateable but the need to bury, cremate, harvest, display or otherwise interfere with a dead body, legally, is predicated on knowing dead from alive. At least, that is the case whilst it remains unlawful to fatally remove organs from those not legally dead.

Second, what is the evidence that ‘irreversible cessation of brain-stem function’ is the same as brain death?

The brain-stem is a primitive part of the human brain from which the twelve pairs of cranial nerves originate to control basic bodily functions such as breathing, coughing, swallowing, hearing, seeing and keeping balance. It is also a narrow conduit through which most of the nervous traffic to and from the brain passes. The higher brain, or cortex, is the part that gives us our exclusively human characteristics; speech, thought, emotion, intelligence, humour etc. Damage to the brain-stem has profound effects. Discrete lesions can lead to ‘locked-in syndrome’ in which victims are fully conscious but unable to move or communicate at all.<sup>24</sup> Damage to the high spinal cord can result in respiratory paralysis and a dependence on mechanical ventilation.<sup>25</sup> Anaesthesia can produce a comatose state clinically indistinguishable from brain-stem death; although the patient can be restored to completely normal function within a few minutes. Metabolic coma and poisonings can also create a quasi-brain-stem dead state. Often, however, the brain-stem is damaged as part of a catastrophic injury to the rest of the brain; either through direct

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<sup>23</sup> A Browne ‘Whole-brain death reconsidered’ (1983) 9 *Journal of Medical Ethics* 28; C Pallis ‘Whole-brain death reconsidered - physiological facts and philosophy’ (1983) 9 *Journal of Medical Ethics* 32

<sup>24</sup> E Smith, M Delargy ‘Locked-in syndrome’ (2005) 330 *British Medical Journal* 405

<sup>25</sup> A Chierigato ‘High Cervical Spinal Cord Complete Transection’ (2008) 65(8) *Archives of Neurology* 1126

trauma, ruptured blood vessels or profound hypoxia (following cardiac arrest).<sup>26</sup> To diagnose brain-stem death the clinician needs to be certain of the cause of coma, exclude anything which may be reversible and then comprehensively test the brain-stem. The current iteration of the diagnostic criteria embraces the AMRC 2008 definition of death and is embedded in the 2014 document 'Form for the diagnosis of death using neurological criteria'.<sup>27</sup>

In the UK, it is usually assumed that if the brain-stem is dead then the whole brain is dead. Provided the circumstances surrounding the brain-stem injury are in keeping with such an assumption the function of the rest of the brain is seldom actually tested in the UK. Evidence from other countries with different criteria for diagnosing brain death bears scrutiny. Of seventy countries surveyed in the 2002 publication by Wijdicks, twenty-eight of them required further tests to determine the status of the cortex.<sup>28</sup> Whilst there are very few reports of residual cortical function with a non-functioning brain-stem, they do exist.<sup>29</sup> The fact that some countries mandate testing the cortex as well as the stem suggests that whilst brain-stem death is strongly *associated* with brain death, the two are not synonymous. The AMRC 2008 document acknowledges the difference between brain-stem death and whole brain death stating 'the diagnosis of death, because of cessation of brain-stem function, does not entail the cessation of all neurological activity in the brain.'<sup>30</sup> The document then goes on to juxtapose this scientific fact with what is a philosophical argument: 'none

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<sup>26</sup> The brain requires a supply of blood containing oxygen in order to survive. Removal results in brain damage after only a few minutes. A brain haemorrhage results in a lack of blood supply and swelling of the damaged part of the brain. A cardiac arrest interrupts the blood supply to the whole brain which may then swell and die.

<sup>27</sup> D Gardiner 'Form for the Diagnosis of Death using Neurological Criteria' <<https://ficm.ac.uk/sites/default/files/Form%20for%20the%20Diagnosis%20of%20Death%20using%20Neurological%20Criteria%20-%20Full%20Version%20%282014%29.pdf>> accessed 28<sup>th</sup> November 2017.

<sup>28</sup> EFM Wijdicks 'Brain death worldwide: accepted fact but no global consensus in diagnostic criteria' (2002) 58 *Neurology* 20

<sup>29</sup> D Gardiner 'International perspective on the diagnosis of death' (2012) 108 *British Journal of Anaesthesia* 14, 19

<sup>30</sup> Academy of the Medical Royal Colleges, *A code of practice for the definition and confirmation of death* (2008) 11

of these potential activities indicates any form of consciousness associated with human life, particularly the ability to feel, to be aware of, or to do, anything.'

This leads to the third issue for consideration, by what authority does the AMRC state that the signs of life exhibited by brain-stem dead patients on intensive care have 'no moral relevance to the declaration of death'?

Legal death does not necessarily equate to biological death or social death. As described earlier, and as exhibited in children born without a cerebral cortex (anencephaly),<sup>31</sup> the rest of the human body can exist for months or even years with just a few grams of functioning brain tissue.<sup>32</sup> This is not biological death. The human person, the social entity, no longer exists but this can also be said of patients in a permanent vegetative state.<sup>33 34</sup> The AMRC distinguish the two by stating:

'First, the irreversible loss of the capacity for consciousness does not by itself entail individual death. Patients in the vegetative state have also lost this capacity. The difference between them and patients who are declared dead by virtue of irreversible cessation of brain-stem function is that the latter cannot continue to breathe unaided without respiratory support, along with other life-sustaining biological interventions.'<sup>35</sup>

Is the ability to breathe unaided all that separates a 'human person' from a dead body? It may well be the case but this is, surely, a philosophical argument and not one that the AMRC, with the greatest of respect, is at liberty to dictate. Social death is not an issue that rests easy with the medical profession. In 1994 the American

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<sup>31</sup> DA Stumpf *et al* 'The infant with anencephaly' (1990) 322 *New England Journal of Medicine* 669

<sup>32</sup> DA Shewmon 'Chronic "brain death": Meta-analysis and conceptual consequences' (1998) 51 *Neurology* 1538

<sup>33</sup> J Kitinger, C Kitinger 'Causes and consequences of delays in treatment withdrawal from PVS patients: a case study of *Cumbria NHS Clinical Commissioning Group v Miss S and Ors* [2016] EW COP 32' (2017) 43 *Journal of Medical Ethics* 459

<sup>34</sup> MM Monti 'The vegetative state' (2010) 341 *British Medical Journal* 292

<sup>35</sup> Academy of the Medical Royal Colleges, *A code of practice for the definition and confirmation of death* (2008) 11

Medical Association supported the idea that babies born with anencephaly be offered for organ donation on the basis that they had no cortical function although they were brain-stem 'alive'.<sup>36</sup> If brain-stem death is accepted as death of the human person then absence of brain above the brain-stem should surely be conclusive. The AMRC are unequivocal in their rejection of this but offer no argument as to the 'moral relevance' of their position.

Fourth, why is there a pressing need for the 'immediate withdrawal of all forms of supportive therapy' once brain-stem death has occurred?<sup>37</sup> Certification of brain-stem death must occur promptly but the need to *immediately* withdraw support is less clear.

A 2016 publication by the AMRC states that it is 'appropriate to continue ventilating the patient in order to establish whether donation is consistent with the patient's wishes, values and beliefs, and if so, to consider donation an integral part of post-mortem care.'<sup>38</sup> Hence, delaying withdrawal of supportive therapy is appropriate to secure organs. Similarly, for the relatives of the organ donor '[o]nce the patient is dead, the concept of clinical harm can no longer be relevant. However, other potential harms remain, and include the risk of causing distress to the patient's family, which may be affected by ... their ability to spend time with their deceased loved one.'<sup>39</sup> The two contradictory publications seem to afford a level of compassion

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<sup>36</sup> Canadian Paediatric Society 'Use of anencephalic newborns as organ donors' (2005) 10(6) Paediatric Child Health 335, 336

<sup>37</sup> Academy of the Medical Royal Colleges, *A code of practice for the definition and confirmation of death* Academy of the Medical Royal Colleges (2008) 11

<sup>38</sup> UK donation ethics committee (UKDEC), *An ethical framework for donation after confirmation of death using neurological criteria (DBD)* Academy of the Medical Royal Colleges (2016) 13

<sup>39</sup> UK donation ethics committee (UKDEC), *An ethical framework for donation after confirmation of death using neurological criteria (DBD)* Academy of the Medical Royal Colleges (2016) 14

(in the form of time given by the bedside) to a donor's relatives which is denied the relatives of the non-donor.

The author's experience of brain-stem death is that families require an explanation as to how the diagnosis of death can possibly be made when their loved one is warm, pink, passing urine, defaecating and exhibiting all the features of an alive person save for being unconscious. It is counter-intuitive to assert that the person is dead simply because a series of complex tests performed twice by two senior doctors has determined that the brain-stem (and, probably, the whole brain) no longer functions. Their loved one is clearly biologically alive; explanation of brain-stem death allows them to appreciate that consciousness will never be regained and as a 'human person' they will never again exist; social death. Time is given to family members to say goodbye and pay their last respects. Withdrawal of support then proceeds (in the non-donor) and circulatory death is observed a few minutes later. Families usually see this as the moment of death even if the time of death is officially recorded as the conclusion of the first set of brain-stem tests. No less respect is given to the families of donors and non-donors.

### **1.2.1. The illusory disconnect between death and donation**

The coincidence of brain-stem death as a means by which support can be legally withdrawn and organs acquired has already been touched upon. The AMRC identify 'those who argue that the diagnosis of irreversible cessation of brain-stem function as a criterion for the diagnosis of death itself is irretrievably wedded to the desire to acquire organs for transplantation. The fact is that there is no logical relationship between them.'<sup>40</sup> History suggests that the two emerged side by side and logic dictates that without brain-stem death, transplantation medicine would

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<sup>40</sup> C Machado 'A definition of human death should not be related to organ transplants' (2003) 29(3) *Journal of Medical Ethics* 201. Endorsed by the AMRC in reference to the same statement: Academy of the Medical Royal Colleges, *A code of practice for the definition and confirmation of death* (2008) 9

not have evolved. It is unfortunate, but inescapable, that the two are related. Since *Bland* and in keeping with modern judgments on the vegetative state,<sup>41</sup> ‘best interests’ can readily serve to allow the withdrawal of all support from the permanently unconscious without the need for brain-stem death testing.<sup>42</sup> The patient’s perceived best interests lie at the heart of the 2018 statement on devastating brain injury from the Faculty of Intensive Care Medicine.<sup>43</sup> Where patients with severe brain injuries require invasive support to stay alive, best interests discussion with families often allow for treatment withdrawal (followed swiftly by circulatory death) without recourse to the Court of Protection.<sup>44</sup> The Mental Capacity Act, increasing respect for autonomy and a recognition that ‘social death’ is what matters to most people, negates the need for brain-stem death testing in all patients save those tiny few in whom outcome is genuinely unknown. This approach would have left transplantation medicine without the vast majority of its donors. Had this been the case it is possible the current controversies surrounding donation following circulatory death would have been addressed decades ago.

Death is only one factor to be considered when transplanting organs but it is a crucial one; a person cannot consent to a post-mortem activity if she is ignorant as to when she is regarded as dead. Whether dead or not, the actual removal of her organs can only proceed when ‘appropriate consent’ is acquired.<sup>45</sup> Consent, or what scant evidence of it that can be gleaned immediately post-mortem, is the subject of the next chapter.

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<sup>41</sup> *Cumbria NHS Clinical Commissioning Group v Miss S and Ors* [2016] EWCOP 32

<sup>42</sup> Mental Capacity Act 2005; *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2013] All ER (D) 339

<sup>43</sup> Faculty of Intensive Care Medicine, *Management of perceived devastating brain injury after hospital admission: a consensus statement* (2018) <[www.ficm.ac.uk/sites/default/files/dbi-consensus-statement-2018.pdf](http://www.ficm.ac.uk/sites/default/files/dbi-consensus-statement-2018.pdf)> accessed 2<sup>nd</sup> January 2018.

<sup>44</sup> A Manara ‘Bespoke End-of-Life Decision Making in ICU’ (2015) 43(4) *Critical Care Medicine* 909

<sup>45</sup> S.4 Human Tissue Act 2004

## CHAPTER 2

### CONSENT

In simplistic terms, the ethical pillars of good, harm, autonomy and justice serve as useful reference points for any debate attempting to resolve a conflict of interests. The law serves to define harm and delivers justice where ‘a harm’ is ameliorated by ‘a good’. Of autonomy, Mason and Laurie argue that:

In contemporary medical law and ethics, consent has come to be treated as being synonymous with autonomy – that is, the state of self-determination which imports the right to choose for oneself how to live one’s life. Seen in these terms, autonomy and consent are individualistic and atomistic notions, focusing on the individual person and the protection or furtherance of his or her interests. Consent is sought as the ultimate expression of self-determination ...<sup>46</sup>

In the context of trespass to the person and limited offences against the person, consent acts as a complete defence.<sup>47</sup> To be effective as a defence the offence must be one to which consent can operate; one cannot consent to removal of a kidney for sexual gratification<sup>48</sup> but it is possible to consent for removal for the purposes of donating it to someone with kidney failure.<sup>49</sup> In order to give legal consent the subject requires the mental capacity to understand the nature and purpose of the intended act, be provided with adequate information on the potential effects of the act and enter into the agreement voluntarily.<sup>50</sup>

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<sup>46</sup> JK Mason, GT Laurie ‘Consent or Property? Dealing with the Body and its Parts in the Shadow of Bristol and Alder Hey’ (2001) 64(5) *Modern Law Review* 710, 717

<sup>47</sup> *Collins v Wilcock* [1984] 3 All ER 374; *R v Brown* [1993] UKHL 19, [1994] 1 AC 212

<sup>48</sup> *R v Brown* [1993] UKHL 19, [1994] 1 AC 212

<sup>49</sup> S.33 Human Tissue Act 2004

<sup>50</sup> S.2 and S.3 Mental Capacity Act 2005; *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] 1 AC 1430



In England, there is a system of ‘opt-in’ for organ donation. That is to say, an individual must indicate a wish to become an organ donor; no indication equating to ambivalence. Other countries have an ‘opt-out’ system; one which assumes everyone wishes to become a donor unless they specifically indicate the contrary.<sup>51</sup> The latter system turns the ambivalent into presumed consenters and, theoretically, increases the donor pool. Three problems are common to either system; legal, ethical and practical.

## 2.1. Legal

Some regard it as ‘immoral to require consent for cadaver organ donation’<sup>52</sup> or take the stance that the needs of the living grossly outweigh any interest the deceased may have in their own corpse.<sup>53</sup> These positions lend unequivocal support to either an opt-out system or one in which even opt-out is not allowed. Others take an approach which requires the individual to express a wish to donate.<sup>54</sup> It is contested that in England and Wales neither system, irrespective of ethics, can claim either express or implied consent; both the current English opt-in system and Welsh opt-out system lack some or all of the legal characteristics of consent.

Supposing a 17-year old male decides to get a driving licence by completing the D1 form available from the Driver and Vehicle Licensing Agency (DVLA).<sup>55</sup> The form

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<sup>51</sup> Nations such as Spain, France, Italy and Belgium. AM Rosenblum *et al* ‘The authority of next of kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations’ (2012) 27 *Nephrology Dialysis Transplantation* 2533

<sup>52</sup> HE Emson ‘It is immoral to require consent for cadaver organ donation’ (2003) 29 *Journal of Medical Ethics* 125

<sup>53</sup> J Harris ‘Organ procurement: dead interests, living needs’ (2003) 29 *Journal of Medical Ethics* 125, 130

<sup>54</sup> Nations such as the United States, Canada, Australia, India and South Africa: Am Rosenblum *et al* ‘The authority of next of kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations’ (2012) 27 *Nephrology Dialysis Transplantation* 2533. As recently as 2008 the Organ Donation Task Force also advocated ‘opt-in’: BH Willis, M Quigley ‘Opt-out organ donation: on evidence and public policy’ (2014) 107(2) *Journal of the Royal Society of Medicine* 56

<sup>55</sup> DVLA website <[www.gov.uk/dvlaforms](http://www.gov.uk/dvlaforms)> accessed 29<sup>th</sup> January 2018.

includes a section on organ donation saying ‘I want to donate an organ to help someone else after my death. Please register me on the NHS Organ Donor Register as someone whose organs can be used for transplant’. There are then several boxes to tick depending on which organ(s) he wishes to donate.<sup>56</sup> There is no option to reject the offer and be registered as someone who does not want to donate.<sup>57</sup> There is no further information, whatsoever, provided to inform the choice. The original 2011 online form had three options “Yes, I would like to register”, “I do not wish to answer this question now”, and “I am already registered on the NHS Organ Donor Register”.<sup>58</sup> Again, no option to register a definite ‘no’ and no other information available to inform the choice. Whatever the ethics of making it very easy to be on the donor register and difficult to positively decline, this is not consent. If the applicant dies aged 40 the choice he made at 18 cannot be relied upon to be contemporaneous, especially if the definition of death changes interim.

The Human Tissue Act (HTA) says ‘[w]here the person concerned is alive, “appropriate consent” means his consent.’<sup>59</sup> Furthermore, Schedule 1 (purposes requiring consent: general) refers specifically to ‘transplantation’ (paragraph 7). Even if he were to try and get information about his choice from the organ donation UK website he would struggle to discover the difference between brain-stem death donation (DBD or Heart Beating Donors) and circulatory-death donation (DCD or Non-Heart Beating Donors); the two types of patient are managed differently, not least because the former is legally dead but the latter is still alive. The brain-stem dead individual is transferred to theatre and organs harvested after the family have

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<sup>56</sup> Various websites allow the D1 form to be downloaded in pdf format for completion and postage: <[www.podatekangielski.pl/download/d1.pdf](http://www.podatekangielski.pl/download/d1.pdf)> accessed 28th January 2018.

<sup>57</sup> Opting out of becoming an organ donor is an option if registering via the organ donation website <[www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)> accessed 29<sup>th</sup> January 2018.

<sup>58</sup> UK Government website, *Driving up organ donations* <<https://www.gov.uk/government/news/driving-up-organ-donations>> accessed 3<sup>rd</sup> January 2018.

<sup>59</sup> S.3(2) Human Tissue Act 2004

paid their last respects. The alive individual, who is soon expected to be dead by circulatory-death criteria, is transferred to theatre and support withdrawn. Depending on how long the individual takes to die, if at all, after a period of 5 or more minutes following circulatory-death, organs are re-perfused and removed.<sup>60</sup> If, as occasionally happens, the patient does not die in a predicted fashion they are transferred back to the intensive care unit where, usually, they complete their dying over a period of hours or days. Occasionally, they do not die for several weeks. The website fails to draw any distinction between the two types of donation but instead offers a hyperlink within the text of '[l]earn more about what your consent to organ donation means'. This link yields a legally tenable description of consent:

If your decision to donate, or not to donate, is registered on the Organ Donor Register, then as long as no one forced you to make the decision, you were aware of your actions, and had the information you needed, your decision is legally valid.<sup>61</sup>

The essential elements of voluntariness, capacity and required information are correctly stated but from where does he get the information? One could argue that if he is so concerned about what happens when he is critically ill or dead he can find out for himself. However, such self-reliance is not a feature of consent to any other healthcare related activity. A surgeon cannot simply say 'there are elements of the proposed surgery which may put you off signing the consent form so I'm not going to tell you'. This is the paternalistic approach to consent endorsed in *Bolam*, severely

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<sup>60</sup> The period of 5 minutes is subject to heated debate. The longer the waiting period the greater the certainty of death but the poorer the condition of the organs to be removed: JL Verheijde *et al* 'Brain death, states of impaired consciousness, and physician-assisted death for end of life organ donation and transplantation' (2009) 12 Medical Health Care and Philosophy 409, 414

<sup>61</sup> Human Tissue Authority, *Your guide to consent and organ donation* (2015) <[https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1514/your\\_guide\\_to\\_consent\\_and\\_organ\\_donation.pdf](https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1514/your_guide_to_consent_and_organ_donation.pdf)> accessed 25<sup>th</sup> March 2017.

criticised by Lord Scarman in *Sidaway*, rejected (albeit indirectly) in *Chester* and finally laid to rest in *Montgomery*<sup>62</sup> :

The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.<sup>63</sup>

As far as best interests are concerned, 'doctor knows best' was ethically questionable in 1957 but legally acceptable; in 2018, it is ethically and legally bereft of credible support. Doctor only knows best when she can demonstrate a patient's lack of capacity and casts far and wide for 'best interest' corroboration of her own ideas on what is best for her patient:

[I]n considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense ... and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.<sup>64</sup>

Once dead, the consent which was not gained in life can be legally gathered from relatives;<sup>65</sup> this is what happens in reality. Relatives are afforded the information and discussion which was denied the donor. However, whilst this may just reach a legally defensible standard for brain-stem dead donors (since they are legally dead) this cannot be said for the alive, but expected to die, circulatory-death donor. The potential circulatory-death donor is denied the information required to make an informed decision in life; information which will determine the way in which his

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<sup>62</sup> *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582; *Sidaway v Bethlem Royal Hospital Governors* [1985] 1 All ER 643; *Chester v Afshar* [2002] EWCA Civ 724, [2002] 3 All ER 552; *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] 1 AC 1430

<sup>63</sup> *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] 1 AC 1430 [87] (Lord Kerr and Lord Reed)

<sup>64</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2013] All ER (D) 339 [39] (Lady Hale)

<sup>65</sup> S.3(6)(c) Human Tissue Act 2004

death is managed. There is no choice in the matter. It is not possible to opt-in to brain-stem death donation and out of circulatory death donation; either you are on the donor register, or you are not.

## 2.2. Ethical<sup>66</sup>

Emson and Harris contend, respectively, that 'the needs of the living outweigh the needs of the dead' and 'it is immoral to bury or burn a corpse when the organs can support the living'.<sup>67</sup> It can only be true that, after death, human persons have no future interests; unless the deceased have a sentient existence outside of their physical body capable of being aware of, or affected by, what happens to their corpse (and other personal effects).<sup>68</sup> This is not to say the living are 'not interested' in what happens to their body after death.<sup>69</sup> Disposal of the dead is common-place but cannot be likened to putting the bins out on a Tuesday evening; the cultural and social significance of death requires no explanation. The way in which the corpse is managed is of *significance* to the living even if it is hard to argue that they are *affected by* how they are treated once dead.<sup>70</sup> The terror of being dissected or gibbeted after death was not lost on the courts of the 18<sup>th</sup> century who used such post-mortem

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<sup>66</sup> The terms ethics and morals are often used interchangeably. For the purposes of this essay 'ethics' (with its Greek derivation, *ethikos*) refers to 'the principles of conduct governing an individual or a circumscribed group' and 'morals' (with its Latin derivation, *mos*) refers to the 'proper behaviour of a person in society'.

<sup>67</sup> HE Emson 'It is immoral to require consent for cadaver organ donation' (2003) 29 Journal of Medical Ethics 125; J Harris 'Organ procurement: dead interests, living needs' (2003) 29 Journal of Medical Ethics 125, 130

<sup>68</sup> Several faiths value the integrity of the dead body: M Brazier 'Retained organs: ethics and humanity' (2002) 22 Legal Studies 550, 558

<sup>69</sup> S McGuinness, M Brazier 'Respecting the living means respecting the dead too' (2008) 28(2) Oxford Journal of Legal Studies 297

<sup>70</sup> Hamer argues 'that it is at least plausible to say that the dead are harmed by events occurring after their deaths. If so, the removal of organs against the wishes of the deceased seems to be a definite case of posthumous harms.' CL Hamer, MM Rivlin 'A stronger policy of organ retrieval from cadaveric donors: some ethical considerations' (2003) 29 Journal of Medical Ethics 196, 198

practices to attempt to reduce the murder rate.<sup>71</sup> Savulescu's idea that 'any kind of afterlife (if there is one) cannot depend on what is done to the dead body' is a claim based on his personal reflections, not scientific fact or reasoned argument.<sup>72</sup> There are clearly those who believe in an after-life and the treatment of their corpse influences their after-life.<sup>73</sup> Beliefs are sometimes logical and rational and concur with scientific or reasoned argument; but not always. Where there is divergence it is usually a belief which will determine an action.<sup>74</sup> Emson recognises that for relatives seeing a corpse it is 'emotionally tremendously evocative, hallowed by individual experience and by centuries of belief and tradition' but goes on to say:

[T]heir only claim upon it is as a temporary memorial of a loved one, inevitably destined to decay or be burned in a very short time. To me, any such claim cannot morally be sustained in the face of what I regard as the overwhelming and pre-emptive need of the potential recipient.<sup>75</sup>

What *he* regards as the overwhelming needs of the potential recipient is the key point. As a pathologist used to seeing corpses Emson's ethical viewpoint is naturally going to be different to someone who has never seen a corpse, particularly the fresh corpse of their own son. For a mother, believing that death means 'cold, stiff and motionless' to volunteer her 'warm, flexible and moving' son for immediate organ removal might seem very wrong; certainly, discarding a belief in the appearance of death would require something more than a lecture on physiology, rationality or morals from a professional whose dual role in patient care and organ procurement

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<sup>71</sup> Gibbetting was the practice of publically exhibiting the executed body of a criminal in chains until disintegration. The now repealed Murder Act 1752 prescribed 'not only the usual judgment of death, but also ... the marks of infamy hereby directed for such offenders, in order to impress a just horror in the mind of the offender, and on the, minds of such as shall be present, of the heinous crime of murder.' Such marks of infamy included 'hanging in chains' or 'be[ing] dissected and anatomized by the ... surgeons.'

<sup>72</sup> J Savulescu 'Death, us and our bodies: personal reflections' (2003) 29 *Journal of Medical Ethics* 125, 128

<sup>73</sup> DG Jones, MI Whitaker *Speaking for the Dead: The Human Body in Biology and Medicine* (Ashgate 2009), 137

<sup>74</sup> S McGuinness, M Brazier 'Respecting the living means respecting the dead too' (2008) 28(2) *Oxford Journal of Legal Studies* 297, 317

<sup>75</sup> HE Emson 'It is immoral to require consent for cadaver organ donation' (2003) 29 *Journal of Medical Ethics* 125, 126

may seem conflicting.<sup>76</sup>

The management of the body of the deceased in some cultures, whether borne through a belief in a corporal after-life or simply as a token of respect, cannot be swept aside as simply irrational, illogical or even immoral if it doesn't yield an opportunity for the living to go on living. Morality, from its very root in Latin, refers to the usual practices of society.<sup>77</sup> Infanticide in classical times was not morally wrong at that time and in that place;<sup>78</sup> suicide is considered as unethical by some but has not been illegal in the UK since 1961 so could hardly be regarded as immoral.<sup>79</sup>

What Emson and Harris are really saying, surely, is that for a fully informed relative (accepting that death has occurred) to deny the prospect of life to another, by preferring the organs of the deceased to burn or decay, requires a belief which is either irrational or affords more respect to the dead than the living. It can only be regarded as immoral if the relative's refusal is deliberately harmful.

The organ donation website openly berates relatives who refuse donation where the deceased have put themselves, by design or accident, on the donor register.<sup>80</sup> Levelling such guilt on already bereaved relatives *is* arguably immoral unless NHS Blood and Transplant judge that the psychological harm caused to these relatives by such a publication is outweighed by an improvement in donation rates.

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<sup>76</sup> The (paid) clinical lead for organ donation (CLOD) is usually the intensive care consultant in charge of the patient's well-being whilst being looked after on intensive care.

<sup>77</sup> The Latin *moralis* refers to the proper behaviour of a person in society, literally 'pertaining to manners'. Coined by Cicero in his work '*De Fato*,' II.i.

<sup>78</sup> PM Dunn 'Aristotle (384–322 BC): philosopher and scientist of ancient Greece' (2006) 91 Archives of Disease in Childhood Fetal Neonatal Edition 75, 77

<sup>79</sup> S.1 Suicide Act 1961

<sup>80</sup> NHS Blood and Transplant 'Families saying no to donation results in missed transplant opportunities for UK patients' Friday, 15 Jan 2016. <[www.organdonation.nhs.uk/news-and-campaigns/news/families-saying-no-to-donation-results-in-missed-transplant-opportunities-for-uk-patients/](http://www.organdonation.nhs.uk/news-and-campaigns/news/families-saying-no-to-donation-results-in-missed-transplant-opportunities-for-uk-patients/)> accessed 24th January 2018.

### 2.2.1. Preparing the dying for donation

The ‘non-therapeutic elective ventilation’ period between 1990 and 1994 and the current position of non-heart beating donors (DCD)<sup>81</sup> merit brief scrutiny inasmuch that they highlight reasons why the public may legitimately question medical ethics as applied to organ donation.<sup>82 83</sup>

In an attempt to acquire more organs for transplantation, patients who would otherwise have been left to die (using circulatory criteria) were kept alive in the hope of delaying their death until their organs could be acquired in a more controlled fashion (using brain-stem death criteria). The so-called Exeter protocol, or non-therapeutic elective ventilation, was similar in intention to the American Pittsburgh protocol of 1992;<sup>84</sup> making hopelessly ill but nevertheless alive patients a source of organs. At that time, ‘best interests’ were viewed purely in the medical sense; any therapy which would not benefit the patient physically should not be introduced. This was articulated in *Bland* by Lord Browne-Wilkinson:

[I]f there comes a stage where the responsible doctor comes to the reasonable conclusion (which accords with the views of a responsible body of medical opinion) that further continuance of an intrusive life support system is not in the best interests of the patient, he can no longer lawfully continue that life support system: to do so would constitute the crime of battery and the tort of trespass to the person.<sup>85</sup>

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<sup>81</sup> Non-Heart Beating Donors (NHBD) are currently referred to as Donation after Circulatory Death donors (DCD) in contrast to Donation after Brain-stem Death donors (DBD).

<sup>82</sup> British Transplantation Society *Transplantation From Donors After Deceased Circulatory Death* (July 2015) <[http://bts.org.uk/wp-content/uploads/2016/09/15\\_BTS\\_Donors\\_DCD.pdf](http://bts.org.uk/wp-content/uploads/2016/09/15_BTS_Donors_DCD.pdf)> accessed 31<sup>st</sup> March 2018.

<sup>83</sup> TG Feest *et al* ‘Protocol for increasing organ donation after cerebrovascular deaths in a district general hospital. (1990) 335 *Lancet* 1133; Academy of Royal Colleges ‘Non-therapeutic elective ventilation: A discussion paper’ April 2016 <[www.aomrc.org.uk/wp-content/uploads/2016/07/Nontherapeutic\\_elective\\_ventilation\\_0416-2.pdf](http://www.aomrc.org.uk/wp-content/uploads/2016/07/Nontherapeutic_elective_ventilation_0416-2.pdf)> accessed 29<sup>th</sup> January 2018.

<sup>84</sup> MY Rady, JL Verheijde, *et al* ‘Organ Procurement After Cardio-circulatory Death: A Critical Analysis’ (2008) 23 (5) *Journal of Intensive Care Medicine* 303

<sup>85</sup> *Airedale NHS Trust v Bland* [1993] 2 WLR 316, [1993] AC 789 [884]



The corollary of this was that such medically futile support should not be instituted either. The medical risk to the patient was that invasive support might actually produce a permanent vegetative state; the re-perfused brain being unwittingly revitalised.<sup>86</sup> Such a condition could hardly be seen as more desirable than a natural death. Department of Health advice promptly stopped the practice. Since then, the concept of ‘best interests’ has broadened considerably to include a person’s non-medical interests.<sup>87</sup> Hence, an argument constructed around personal autonomy may easily allow such a practice to re-emerge if the individual expresses a wish to become a donor through an “Exeter protocol”, voluntarily accepting the very small risk of being left in a permanent vegetative state. Coggon and Price both offer support for this concept although informed donor consent is clearly of paramount importance.<sup>88</sup> Furthermore, honesty when dealing with individuals and the public is essential in gaining trust and, hence, informed consent.<sup>89</sup>

Death, according to circulatory criteria, as described earlier, is fairly uncontroversial in that the longer a corpse is left unattended the more certain that the diagnosis of death becomes. Problems arise when an activity involving the newly confirmed corpse is planned. ‘Warm ischaemic time’ refers to the time between cessation of the circulation and organ re-perfusion with cold fluid prior to implantation into the recipient. Kidneys start to deteriorate immediately but retain some valuable function with warm ischaemic times of up to a few hours. For the recipient, the sooner the kidney is removed the better will be its function. For a potential donor, managed on

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<sup>86</sup> UK Donation Ethics Committee (UKDEC), *Nontherapeutic elective ventilation: a discussion paper* Academy of the Medical Royal Colleges (April 2016).

<sup>87</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2013] All ER (D) 339

<sup>88</sup> D Price ‘End of life treatment of potential organ donors: Paradigm shifts in emergency and intensive care’ (2011) *Medical Law Review* 86; J Coggon ‘Elective ventilation for organ donation: law, policy and public ethics’ (2013) 39 *Journal of Medical Ethics* 130

<sup>89</sup> ‘Transparent disclosure to the general public of the risks involved to both organ donors and recipients is essential for societal debate on the ethical acceptability of DCD.’ MY Rady, JL Verheijde *et al* ‘Organ Procurement After Cardio-circulatory Death: A Critical Analysis’ (2008) 23 (5) *Journal of Intensive Care Medicine* 303, 309

an intensive care unit but clearly unable to survive, there are two broad options: wait until death and then see what organs can be harvested or manage the death in a way that minimises warm ischaemic time. Ethically, it could be argued that provided slowing the dying process incurs no harm and the potential donor has consented to non-heart beating donation, the latter scenario is broadly acceptable. This position accords with both *Montgomery* and *Aintree*.<sup>90</sup> However, as we have seen, there is no consent; simply a tick box which falls far short of consent. Without consent or a definite statement against donation it may still be ethical, if unlawful, to control a death to maximise donor potential provided this incurs no harm to the patient.<sup>91 92</sup> Disturbingly, the British Transplantation Society consider that the 'organ donor register allows accurate determination of an individual's wish to donate their organs in the event of his/her death.'<sup>93</sup> This dubious expression of autonomy is used to justify the Society's endorsement of (ante-mortem) interventions, 'even those that may be painful or undignified - in order to fulfil his/her stated wish.'<sup>94</sup> This is stretching consent too far and can hardly be seen as respecting autonomy. The box ticked by a 17-year old on his driving licence is not reliable evidence of an autonomous decision to undergo painful and undignified procedures in order to preserve his organs for someone else when he is a dying 40-year old. Little wonder

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<sup>90</sup> *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] 1 AC 1430; *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2013] All ER (D) 339

<sup>91</sup> 'Maintenance of life-sustaining treatment may be considered to be in the best interests of someone who wanted to be a donor if it facilitates donation and does not cause them harm or distress, or place them at significant risk of experiencing harm or distress.' Department of Health, *Legal issues relevant to non-heart beating organ donation* (2009) 10

<sup>92</sup> 'Once a decision to withdraw treatment has been reached by the critical care consultant, the current level of support should continue until the time to withdraw treatment is agreed with the relatives. It is inappropriate to escalate current treatment, add new therapies ... or to undertake invasive interventions ... to improve organ viability.' S Ridley 'UK guidance for non-heart-beating donation' (2005) 95(5) *British Journal of Anaesthesia* 592, 594

<sup>93</sup> British Transplantation Society *Transplantation from deceased donors after circulatory death* (July 2013) 32 < [https://bts.org.uk/wp-content/uploads/2016/09/15\\_BTS\\_Donors\\_DCD-1.pdf](https://bts.org.uk/wp-content/uploads/2016/09/15_BTS_Donors_DCD-1.pdf)> accessed 25<sup>th</sup> January 2018.

<sup>94</sup> British Transplantation Society *Transplantation from deceased donors after circulatory death* (July 2013) 34 < [https://bts.org.uk/wp-content/uploads/2016/09/15\\_BTS\\_Donors\\_DCD-1.pdf](https://bts.org.uk/wp-content/uploads/2016/09/15_BTS_Donors_DCD-1.pdf)> accessed 25<sup>th</sup> January 2018.

that relatives are still consulted before such decisions are taken if the weight of evidence of consent from the donor is so flimsy. Little wonder too that the public are sceptical about the motives of healthcare staff. Not all countries with transplant programmes accept non-heart beating donors at all, not least because of the ethical strains of balancing the needs of two sets of dying persons; those who will die soon but who have salvageable organs and those who will die later because of unsalvageable organs.<sup>95</sup> The relatively recent ‘Papworth-protocol’ is clear evidence of the lengths NHSBT are prepared to go to in order to acquire organs. After 5 minutes of no heartbeat, the ‘death through cardio-respiratory criteria’ donor’s heart is restarted but the blood supply to the brain cut-off.<sup>96</sup> This effectively re-perfuses the rest of the body but ensures the brain continues to die. Officially already a corpse when the heart is restarted and the rest of the body re-animated, there is no legal requirement to mention this practice to those giving ‘appropriate consent’.

### 2.3. Practical

In addition to the legalities and the ethics of gaining consent there is still the practical hurdle of its actual acquisition. As already mentioned, there are two systems at play throughout the 65 nations with transplant programmes; those which require evidence of participation from the donors themselves (opt-in) and those which assume silence on the matter is consent (opt-out, presumed or implied consent).<sup>97</sup>

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<sup>95</sup> D Price ‘End-of-Life Treatment of Potential Organ Donors’ (2011) 19 *Medical Law Review* 86, 89; J Oram, P Murphy ‘Controlled Non-heart-beating Organ Donation: A Survey of UK Intensive Care Units, Research Abstracts’ (2007) 8(1) *Journal of the Intensive Care Society* 48; N Jousset *et al* ‘Organ Donation in France: Legislation, Epidemiology and Ethical Comments’ (2009) 49(3) *Medicine, Science and the Law* 191, 197

<sup>96</sup> A Page, S Large, *et al* ‘Heart transplantation from donation after circulatory determined death’ (2018) 7(1) *Annals of Cardiothoracic Surgery* 75

<sup>97</sup> Am Rosenblum *et al* ‘The authority of next of kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations’ (2012) 27 *Nephrology Dialysis Transplantation* 2533, 2534

Proponents of ‘opt-out’ allow for consent being actively denied; the living potential donor registering their refusal to donate after their death. Consent being actively denied is afforded legal weight but not opting-out is viewed as ‘presumed consent’. This is a convenient description and conveys some meaning in the vernacular but it is not consistent with consent in the modern legal sense. Presumed consent is consent only if done voluntarily, with information and capacity. In reality, presumed consent to donation means either ‘never really thought about it’ or ‘wasn’t bothered either way’; both of which may ethically permit donation but cannot be regarded as legal consent.<sup>98</sup> Presumed consent by participation, as a defence to being pushed in a crowd or tackled badly on a football field,<sup>99</sup> is different to giving up organs once dead. Participation in life *per se* is not consent to organs being removed in death any more than silence is acceptance of an offer in contract.<sup>100</sup>

What we actually have with ‘appropriate consent’, as coined in the Human Tissue Act, is simply a nod in one direction or the other. It is not consent in the modern medical or legal sense at all. Where ‘appropriate consent’ points to the wishes of the bereaved this is also seldom consent. Few transplant co-ordinators (SNODs) have ever gained meaningful consent from an immediately bereaved relative (in lieu of ‘consent’ from the deceased).<sup>101</sup> A brief look at the practicalities makes this point abundantly clear.

The typical brain-stem dead donor demographic is a formerly healthy 18 to 49-year-old male involved in a car crash or suffering a sub-arachnoid haemorrhage.<sup>102 103</sup> The

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<sup>98</sup> CA Erin, J Harris ‘Presumed consent or contracting out’ (1999) 25 *Journal of Medical Ethics* 365

<sup>99</sup> *R v Barnes* [2004] EWCA Crim 3246, [2005] 1 WLR 910

<sup>100</sup> *Felthouse v Bindley* [1862] EWHC CP J 35, [1862] 142 ER 1037

<sup>101</sup> Role of Specialist Nurse, Organ Donation and Transplant website <[www.odt.nhs.uk/odt-structures-and-standards/organ-donation-retrieval-and-transplantation-teams/role-of-specialist-nurse](http://www.odt.nhs.uk/odt-structures-and-standards/organ-donation-retrieval-and-transplantation-teams/role-of-specialist-nurse)> accessed 31<sup>st</sup> March 2018.

<sup>102</sup> A subarachnoid haemorrhage is a particularly severe form of stroke affecting the young.

wife, parents and children are generally ‘shocked’ by the news; such a shock ‘involves the sudden appreciation by sight or sound of a horrifying event, which violently agitates the mind’.<sup>104</sup> Combined with the proximate relationship, a normal fortitude and the suddenness of the event, a bereaved relative partially fulfils the requirements of a psychiatric injury claimant.<sup>105</sup> How can capacity be confidently assumed here? It is reasonable to assume that the immediately bereaved can only really consent to the most basic self-supporting acts.<sup>106</sup> Compassionate leave is given to the bereaved not simply to be kind; employers do not want highly distracted and poorly functioning staff making errors of judgment and costing the business. Sometimes bereaved relatives volunteer that their son or daughter were keen donors. This makes the process considerably easier by negating any need to market the idea of donation afresh and thus improves the Donor Conversion Rate.<sup>107 108</sup>

### 2.3.1. Conflicts

In the UK, and in many other countries, it remains the case that even where a person has registered an interest in becoming a donor once dead, the relatives are given

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<sup>103</sup> NHSBT *Organ Donation and Transplantation Activity Report* (2017) 17  
<[https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4657/activity\\_report\\_2016\\_17.pdf](https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4657/activity_report_2016_17.pdf)>  
accessed 31<sup>st</sup> March 2018.

<sup>104</sup> *Alcock v Chief Constable of South Yorkshire Police* [1991] UKHL 5, [1992] 1 AC 310, [402] (Lord Ackner)

<sup>105</sup> *Alcock v Chief Constable of South Yorkshire Police* [1991] UKHL 5, [1992] 1 AC 310

<sup>106</sup> Self-supporting acts would include accepting food and water and buying basic goods. It would not include signing important documents or making complex decisions.

<sup>107</sup> ‘Specialist Nurses for Organ Donation (SN-ODs) have received detailed training in communication and family support, this means they are able to recognise and to avoid factors that inadvertently and unnecessarily lead to a family refusal.’ The Organ Donation & Transplantation (ODT) directorate of NHS Blood and Transplant (NHSBT) <[www.odt.nhs.uk/odt-structures-and-standards/organ-donation-retrieval-and-transplantation-teams/role-of-specialist-nurse/](http://www.odt.nhs.uk/odt-structures-and-standards/organ-donation-retrieval-and-transplantation-teams/role-of-specialist-nurse/)> accessed 2<sup>nd</sup> January 2018

<sup>108</sup> E Sheehy, SL Conrad *et al* ‘Estimating the number of potential organ donors in the United States’ (2003) 349 *New England Journal of Medicine* 667; YJ de Groot, EFM Wijdicks *et al* ‘Donor conversion rates depend on the assessment tools used in the evaluation of potential organ donors’ (2011) 37 *Intensive Care Medicine* 665

leave to over-ride this decision.<sup>109</sup> The Organ Donation UK website states ‘while your family has no legal right to override your decision, in practice their support is always sought.’<sup>110</sup> Almost 12% of relatives override the indication made by the potential donor.<sup>111</sup> There is even a webpage devoted to lamenting this position.<sup>112</sup>

Organ Donation UK promote the donor register and the majority of the public are in favour of donation (even if they do not get around to registering).<sup>113</sup> If the deceased have registered, and the Human Tissue Act actually accepted this as consent, then the relatives would lack *locus standi*. There is no statutory position in the Act that even suggests that relatives can over-ride the consent of the deceased; the converse is arguably true.<sup>114</sup> NHSBT, however, regard registration as evidence of the deceased’s wishes when asking relatives for appropriate consent but accept the relatives opposing decision as being determinative.<sup>115</sup> This seems wholly irrational.

There are three reasons for this apparent irrationality.

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<sup>109</sup> Next of kin have considerable influence in organ procurement in opt-out and opt-in systems internationally. Am Rosenblum *et al* ‘The authority of next of kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations’ (2012) 27 *Nephrology Dialysis Transplantation* 2533

<sup>110</sup> Organ Donation UK (NHSBT approved) website <[www.organdonation.nhs.uk/supporting-my-decision/myth-busting/](http://www.organdonation.nhs.uk/supporting-my-decision/myth-busting/)> accessed 24th February 2018

<sup>111</sup> J Morgan *et al* ‘The Rule of Threes: three factors that triple the likelihood of families overriding first person consent for organ donation in the UK’ (2017) *Journal of the Intensive Care Society* 1

<sup>112</sup> NHS Blood and Transplant ‘Families saying no to donation results in missed transplant opportunities for UK patients’ Friday, 15 Jan 2016. <[www.organdonation.nhs.uk/news-and-campaigns/news/families-saying-no-to-donation-results-in-missed-transplant-opportunities-for-uk-patients/](http://www.organdonation.nhs.uk/news-and-campaigns/news/families-saying-no-to-donation-results-in-missed-transplant-opportunities-for-uk-patients/)> accessed 24th January 2018.

<sup>113</sup> 30% of the eligible population are registered on the organ donor register but 58% will actually donate: *Taking Organ Transplantation to 2020: A detailed strategy* (2013) 15

<sup>114</sup> Section 3(2) describes ‘appropriate consent’ as meaning ‘consent’ if given in life. Section 3(6)(c) relates to ‘appropriate consent’ from person in a qualifying relationship but only if consent in 3(2) is not evident.

<sup>115</sup> Organ Donation and Transplantation (NHSBT) *Legislative framework: In the context of consent and authorization* <[www.odt.nhs.uk/deceased-donation/best-practice-guidance/legislative-framework/](http://www.odt.nhs.uk/deceased-donation/best-practice-guidance/legislative-framework/)> accessed 1<sup>st</sup> April 2018.

First, ticking a box on a driving license is not consent as might have been envisaged by the draftsmen of S.3(2) Human Tissue Act or consent as understood by responsible clinicians post-*Montgomery*. Hence, the Act does not recognise organ donor registration as equating to consent.

Second, the need to placate relatives outweighs the need to acquire organs; a position the NHSBT has adopted presumably out of a desire to maintain positive public relations.

Third, NHSBT do not accommodate informed, donor consent. Their statement '[y]ou can consent to donating some or all of your organs and/or tissue by: ticking in the appropriate boxes on the NHS Organ Donor Register' is simply not true.<sup>116</sup> It is suggested that NHSBT do not seek donor consent because it is easier to get a legal mandate from relatives in the form of 'appropriate consent', post-mortem.

Clearly, the consent based model for organ acquisition fails, in practice, to fully respect the wishes of the dead. This is true whether there is opt-in or opt out; relatives are allowed to decide on donation irrespective of the potential donors wishes.<sup>117</sup> The predicted failure of an opt-out system, in isolation, to increase donations in Wales, is evidence of this.<sup>118</sup> The consent model simply acts as a waiver to donor rights and gives valid excuse for others to acquire organs.

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<sup>116</sup> Organ Donation UK (NHSBT hyperlinked) website <[www.organdonation.nhs.uk/faq/consent/](http://www.organdonation.nhs.uk/faq/consent/)> accessed 30<sup>th</sup> March 2018.

<sup>117</sup> Organ Donation UK (NHSBT hyperlinked) website <[www.organdonation.nhs.uk/supporting-my-decision/myth-busting/](http://www.organdonation.nhs.uk/supporting-my-decision/myth-busting/)> accessed 24<sup>th</sup> February 2018.

<sup>118</sup> M Quigley, M Brazier *et al* 'The organs crisis and the Spanish model: theoretical versus pragmatic considerations' (2008) 34 *Journal of Medical Ethics* 223; N Hawkes 'Welsh opt-out law fails to increase organ donations' (2017) 359 *British Medical Journal* 5659; Human Transplantation (Wales) Act 2013

Consent does not mandate any positive obligations since the dead cannot burden others with a legal duty to use their organs. An alternative to a consent based system is property based; the umbrella of 'proprietaryship' commands powers far broader and deeper. Could this secure greater autonomy for the deceased?



## CHAPTER 3

### PROPERTY

To the layperson, the idea that her body is not her property must seem odd. Both Marxist and liberal doctrines suggest that if she is not owned by anyone else (slavery) then she must, therefore, own herself.<sup>119</sup> Her body cannot be touched or confined without lawful excuse,<sup>120</sup> but she is free to defend herself or even kill herself if she chooses.<sup>121</sup> Her image, work and even her thoughts are hers and the state is burdened with a duty to protect her rights and freedoms.<sup>122</sup> Yet, she is still not property; neither hers' nor the states'. The 'great non-sequitur', as coined by Harris, is that not being owned by anyone else does not automatically mean that there is self-ownership; it is possible to be owned by no-one.<sup>123</sup>

The legal dogma that 'there is no property in a body' has origins as far back as Roman times with the phrase '*Dominus membrorum suorum nemo videtur*'.<sup>124</sup> Coke made reference to the cadaver having no owner in the 17<sup>th</sup> Century<sup>125</sup> but it wasn't

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<sup>119</sup> J Harris 'Who owns my body?' (1996) 16(1) Oxford Journal of Legal Studies 55, 68

<sup>120</sup> *Collins v Wilcock* [1984] 3 All ER 374; Offences Against the Person Act 1861; Sexual Offences Act 2003, amongst others.

<sup>121</sup> *R v Palmer* [1971] AC 814; *R v Beckford* [1988] AC 130; S.3(1) Criminal Law Act 1967; Suicide Act 1961

<sup>122</sup> European Convention on Human Rights and Fundamental Freedoms.

<sup>123</sup> J Harris 'Who owns my body?' (1996) 16(1) Oxford Journal of Legal Studies 55, 71

<sup>124</sup> '*Dominus membrorum suorum nemo videtur*' Ulpianus, Dig 9,2,13 translatable as "it appears that no one is the master of his own body parts" (JW Maskill, personal communication); William L Burdick, *The Principles of Roman Law and Their Relation to Modern Law* (The Lawbook Exchange, 2012)

<sup>125</sup> 'The buriall [sic] of the Cadaver (that is, *caro data vermibus*) is *nullius in bonis*' in JK Mason, GT Laurie 'Consent or Property? Dealing with the Body and its Parts in the Shadow of Bristol and Alder Hey' (2001) 64(5) *Modern Law Review* 710, 713. '*Caro data vermibus*' translates as 'flesh given to worms' (JW Maskill, personal communication).

until *Williams* that the modern English phrase came into common judicial use.<sup>126</sup> Since then, the maxim has been chiselled away at.<sup>127</sup> However, the remaining edifice remains prominent, not least for three reasons: the difficulty in applying property to humans, *stare decisis* and fears of immorality.<sup>128</sup> An understanding of what property is serves to highlight the first of these issues.

### 3.1. Unbundling property

The idea that there is a universal definition of property is to conflate property as an object with property as a collection of rules governing the relationship between that object and those with ownership of it. Quigley encapsulates this well:

Property can usefully and convincingly be identified as a set of rules governing the relations between persons with regards to certain objects and, as such, consists of a bundle of jural relations ... The locus of property and ownership lies in the rights of use and control (use-privileges and control-powers); it recognises and protects a particular way of controlling certain resources.<sup>129</sup>

This set of rules can be unbundled. Doing so reveals that there are degrees of ownership. Herring and Chau suggest that ‘full-blooded’ ownership includes possession, the right to use, destroy, exclude and convey to another.<sup>130</sup> A lesser form of ownership may involve only some of these rights. For instance, it is possible to own a gun (property) without having the right to use it in public. It is possible for several people to have an interest in a piece of land (realty) without any one of them

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<sup>126</sup> *Williams v Williams* [1882] 20 ChD 659. An executor has lawful possession of a corpse and is burdened with a duty to arrange its burial. However, since there is (currently) ‘no property in a corpse’ a person cannot convey it in his Will.

<sup>127</sup> M Quigley ‘Property in Human Biomaterials--Separating Persons and Things?’ (2012) 32(4) Oxford Journal of Legal Studies 659, 659

<sup>128</sup> ‘*Stare decisis et non quieta movere*’ which translates as ‘to stand by decisions and not to disturb settled matters’. (JW Maskill, personal communication).

<sup>129</sup> M Quigley ‘Property in Human Biomaterials--Separating Persons and Things?’ (2012) 32(4) Oxford Journal of Legal Studies 659, 668

<sup>130</sup> J Herring, PL Chau ‘My body, your body, our bodies’ (2007) 15 Medical Law Review 34, 40

having the right to sell it despite 'owning' it.<sup>131</sup> The attractiveness of seeing the body as being property, from a liberal perspective, is that the individual has much greater control over what happens to parts of their body once removed. Seeing a body as a piece of property enables not only control over what is done with the body-part while it is within the individual, but, more significantly, grants rights over the piece of property once it is removed from the person. This is in marked contrast to the prevalent integrity/privacy rights-based view of organs which relies on the narrower rules of dignity, consent, and respect. It was the latter perspective which prevailed when the influential Nuffield Council on Bioethics considered the issue of ownership of living body material.<sup>132</sup> It was also this stance that was taken by Parliament when the Human Tissue Bill was debated. Since the Act fails to clearly identify when there can be property in a body, or a body part, it can be assumed that it reinforced a person's right to control the use of their bodily materials from a consent based standpoint rather than property.<sup>133 134</sup>

This consent (integrity/privacy rights-based) model works well in some respects in that the automatic right to slavery, organ-trafficking, prostitution, corpse inheritance etc. bestowed on a person by 'full-blooded' ownership of their own bodies is avoided altogether. However, it has increasingly been found wanting in other scenarios. Equally, applying 'full-blooded' ownership has not been the answer. A right in property needs to be allocated, disposition rights defined, and the content of these rights delineated. Relatively recent case law illustrates how the law has turned to property law to solve these difficult scenarios but stopped short of granting 'full-blooded' ownership.

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<sup>131</sup> Restrictive covenants and easements can burden a property thus diminishing a proprietor's control over disposition.

<sup>132</sup> Nuffield Council on Bioethics, *Human Tissue: Ethical and Legal Issues* (April 1995)

<sup>133</sup> D Price 'The Human Tissue Act 2004' (2005) 68 *Modern Law Review* 798

<sup>134</sup> J Herring, PL Chau 'My body, your body, our bodies' (2007) 15 *Medical Law Review* 34, 39

### 3.1.1. Allocation of property rights

In 1976 John Moore underwent a splenectomy for leukaemia at the Medical Centre of the University of California at Los Angeles (UCLA).<sup>135</sup> Without his permission, the doctors used part of his spleen to develop a cell line that would generate considerable income for them as well as adding significant scientific knowledge to help others. The fact that he was not fully informed of the value of his spleen and the purpose to which it was to be used, made a finding of negligence relatively straightforward. What proved much more difficult, as reflected in the twenty-six years between splenectomy and the Supreme Court judgment, was Moore's 'ownership' of his own spleen. The starting point in all questions of allocation in property law, is the possession rule. According to this rule, whenever there is an ownerless object, or *res nullius*, a property right in the object is acquired by the person who takes possession of it.<sup>136</sup> The *Moore* court declined to accept that Moore owned his own spleen; in keeping with the 'no property in a person' maxim. It decided that the spleen became an object capable of being owned only once removed. Hence, even though the doctors of UCLA had acquired the spleen without informed consent, they did not steal it, since it was *res nullius*. Once in possession of the spleen a proprietary interest was allocated to them and they were free to exercise 'full-blooded' property rights over it. This is a position regarded as 'absurd' by some commentators.<sup>137</sup> However, the danger of allocating property rights in his own spleen to Moore, were voiced in the leading judgement:

[The] important policy consideration is that we do not threaten with disabling civil liability innocent parties who are engaged in socially useful activities, such as researchers who have no reason to believe that their use of a particular cell sample is, or may be, against a donor's wishes.<sup>138</sup>

<sup>135</sup> *Moore v Regents of University of California* (1990) 51 Cal 3d 120

<sup>136</sup> S Douglas 'Property in human biomaterials: A new methodology' (2016) 75 Cambridge Law Journal 478, 481

<sup>137</sup> RN Nwabueze 'Donated Organs, Property Rights and the Remedial Quagmire' (2008) 16(2) Medical Law Review 201, 222

<sup>138</sup> *Moore v Regents of University of California* (1990) 51 Cal 3d 120 [51] (Panelli J)

This line of reasoning has widespread support as a ‘policy’ decision protecting the interests of humankind as a whole; organs are a community resource, *res communis*, and such a policy prevents individuals gaining too much control over their own ‘parts’.<sup>139</sup> However, as a stand-alone judgement, it is hard to accept that Moore was entitled to none of the profits made from the spleen he carried whilst the doctors, who tortiously removed it, were enriched.

An alternative approach to the allocation of property rights was taken in the recent case of *Yearworth*.<sup>140</sup>

Here, six claimants, before undergoing fertility-affecting cancer treatment, gave sperm samples to the North Bristol Hospital to freeze for later use. The hospital negligently allowed the sperm to defrost thus rendering the men incapable of becoming fathers. Five of the six men claimed for psychiatric injury. However, since the sperm was no longer part of their body, a claim in personal injury was rejected. Imaginatively, their successful claim related to bailment, an arrangement whereby one person asks another to look after a thing and to return it at the first person’s request.<sup>141</sup> The men argued that they had made a bailment of their semen to the hospital on the understanding that it would be returned for use later. They had only to prove that the semen was capable of forming the subject matter of a property right; the court assumed, without debate, that the men were entitled to automatic allocation when in possession. There was, therefore, a bailment of the semen.

Of note is that whilst possession of a thing is required in order to be allocated a property right in it, possession does not *per se* prove ownership. A good example of

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<sup>139</sup> J Herring, PL Chau ‘My body, your body, our bodies’ (2007) 15 Medical Law Review 34

<sup>140</sup> *Yearworth and others v North Bristol NHS Trust* [2009] EWCA Civ 37, [2009] 2 All ER 986

<sup>141</sup> L Skene ‘The current approach of the courts’ (2014) 40 Journal of Medical Ethics 10

this is the lawful possession of a body that the hospital enjoys before a corpse comes into the possession of the executor. The hospital does not own the body; it has not been allocated that right. The court in *Yearworth*, by design or good fortune, sidestepped the question of allocation of a property right in the sperm by simply assuming the men had been allocated a right by virtue of possession alone.<sup>142</sup> This was not the case in *Moore*; the first possessors who were allocated a property right in the spleen were the doctors who removed it. In *Yearworth*, the suggestion is that the first possessor is actually the progenitor of the tissues/organs in question. When *Yearworth* is examined in this way, a kidney donor is in possession of their kidneys and, as progenitors, are automatically allocated a property right in them.

### 3.1.2. Disposition of property rights

The question of disposition was important in the American case of *Catalona*.<sup>143</sup> Dr Catalona had come into possession of a large collection of donated tissue samples over a number of years. When he moved from Washington State University he wanted to take them with him to his next University. Washington State University resisted his claim that the tissue samples were property and conveyed to him by donors who retained a proprietary interest in them. The court decided that the samples had been abandoned by the donors and that the owners were the University who had taken them as *res nullius*; Dr Catalona had merely taken possession of them on behalf of the University. Were the court to have accepted that the donors had been allocated a property right in possession, the donors may have still retained a proprietary interest when they conveyed their samples to Dr Catalona for research use. Given that the samples had been abandoned they could not be conveyed as property; abandonment renders a 'res' a 'res nullius'.

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<sup>142</sup> S Douglas 'Property in human biomaterials: A new methodology' (2016) 75 Cambridge Law Journal 478, 483

<sup>143</sup> *Washington University v Catalona* (2007) 490 F 3d 667

Of particular note is that *Catalona* was decided entirely in ‘property’; the consent model was not required.

### 3.2. *Stare decisis* and fears of immorality

In 1908, a challenge to the ‘no property in a body’ maxim was made in the distasteful case of *Doodeward*.<sup>144</sup> Essentially, for the best part of forty years the pickled remains of a two-headed still-born child had been exhibited for money. The claimant demanded that the police, who had confiscated the ‘curio’, return it. Setting aside issues of public decency, Griffith CJ said:

[A] human body, or a portion of a human body, is capable by law of becoming the subject of property ... when a person has by the lawful exercise of work or skill so dealt with a human body or part of a human body in his lawful possession that it has acquired some attributes differentiating it from a mere corpse awaiting burial, he acquires a right to retain possession of it, at least as against any person not entitled to have it delivered to him for the purpose of burial.<sup>145</sup>

*Doodeward* has been cited in many cases since, most notably in *Kelly*.<sup>146</sup> Kelly had taken several preserved human body parts from the Royal College of Surgeons in London for artistic use. He challenged his conviction for theft on the grounds that the body parts were not property and thus not subject to the Theft Act 1968. The Court decided that the body parts had been preserved and as such had undergone the requisite application of ‘work or skill’ demanded in *Doodeward* to render them property capable of being stolen. Of note is that in *Dobson*, the same court found that there was ‘nothing to suggest that the actual preservation of [a brain] after the post-mortem was on a par with stuffing or embalming a corpse or preserving an anatomical or pathological specimen for a scientific collection’.<sup>147</sup>

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<sup>144</sup> *Doodeward v Spence* [1908] 6 CLR 406

<sup>145</sup> *Doodeward v Spence* [1908] 6 CLR 406 [413]

<sup>146</sup> *R v Kelly* [1999] QB 621, [1998] 3 All ER 741

<sup>147</sup> *Dobson v North Tyneside Health Authority* [1996] 4 All ER 474 [479] (Gibson LJ)

In *Kelly*, the specimens were preserved in formalin which passed the ‘work or skill’ test and rendered them property. In *Dobson*, the specimen was preserved in paraffin which did not pass the ‘work or skill’ test; this is a contrived distinction but one that a Court was bound to make in order to remain faithful to legal precedent whilst still delivering justice. Legal reference to *Doodeward* is made all the more remarkable when one considers that Barton J’s description of the deceased conjoined twins in *Doodeward* included ‘it is an aberration of nature’, ‘a well-preserved specimen of nature’s freaks’, ‘a thing’, ‘a dead-born foetal monster’ and ‘a curiosity’ rendered incapable of being ‘associated with a Christian burial’.<sup>148</sup> The conjoined twins, Jodie and Mary, were not referred to in this derogatory and dehumanising way in *Re A*.<sup>149</sup> The language and subject matter of *Doodeward* was of its time and yet it dominates cases involving human body parts, in life and death, to this day.

The arcane ‘work and skill’ argument even appears in the Human Tissue Act 2004<sup>150</sup> but it is not really a satisfactory principle that should determine whether a living biomaterial, such as a kidney, is capable of being property.<sup>151</sup> Without ceding any ground to the ‘no property in a human body’ mantra (save for this reference to *Doodeward*), the Act contains a whole section on the trafficking of organs.<sup>152</sup> The Act also sets out restrictions on what can be done with donated material.<sup>153</sup> Either the Act is endorsing a property model and protecting morality or it is conceding that the

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<sup>148</sup> *Doodeward v Spence* [1908] 6 CLR 406, (Barton J)

<sup>149</sup> *Re A (conjoined twins)* [2000] EWCA 254 Civ, [2001] 2 WLR 480

<sup>150</sup> S.32(9)(c) Human Tissue Act 2004

<sup>151</sup> M Quigley ‘Property in Human Biomaterials--Separating Persons and Things?’ (2012) 32(4) Oxford Journal of Legal Studies 659 [663]; M Brazier ‘Retained organs: ethics and humanity’ (2002) 22 Legal Studies 550, 563

<sup>152</sup> S.32 Human Tissue Act 2004

<sup>153</sup> S.8 Human Tissue Act 2004



consent model is also open to immoral purposes; boundaries must exist whichever paradigm is preferred.

Mason and Laurie see a wide-spread ambivalence about property in human material.

Property is a powerful control device for the bundle of rights that it confers. It also carries a particular message—one of the potential for commerce and trade; of market advantage and disadvantage. To recognise a ‘quasi-property’ claim to material is to support a normatively strong connection to that material and, accordingly, to establish a strong, justiciable legal interest; by the same token, these examples indicate that ‘full’ property rights will only be recognized where there is little or no prospect of exploitation or other harm, which can include the ‘harm’ of disrespect for the dignity of the human organism.<sup>154</sup>

Commentary, following the American case of *Colavito* encapsulates this ambivalence well.<sup>155</sup>

In order to live independently of a dialysis machine, Robert Colavito needed a donor kidney. On the death of his friend, Peter Lucia, Lucia's wife consented to both of her late husband's kidneys going to Covalito. The consent form included a clause allowing the organs to go to someone else in the event that Covalito was not a suitable match. The transplant team sent one kidney to Covalito, in Miami, and the other to someone else in New York. The kidney sent to Covalito was anatomically flawed and was not implantable. The other was successfully implanted into the New York recipient.

Colavito claimed in conversion against the New York Organ Donor Network (NYODN), arguing that, when Mrs. Lucia made the directed donation, the kidneys

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<sup>154</sup> JK Mason and GT Laurie, *Mason & McCall Smith's Law and Medical Ethics* (7th edition, Oxford University Press 2005) 514

<sup>155</sup> *Colavito v New York Organ Donor Network* (No. 4) (2007) 486 F.3d 78

became his property and, by sending one of them to someone else, NYODN had interfered with his right to possession of both. As it turned out, neither kidney would have been any use to him; he was incompatible with both.<sup>156</sup> However, Colavito wanted access to both kidneys as would have been his right if they were both his property. Unfortunately, for the purposes of furthering the property debate, his claim failed on the grounds that he was not entitled to possession of any organ to which he was incompatible. This allowed the court to sidestep the fundamental question of whether a person can be allocated a property right in an immunologically compatible organ.

Douglas speculates that had 'the court recognised Colavito as having property rights in both organs, then he would have been able to exclude others from organs that were useless to him.'<sup>157</sup> This makes the assumption that Colavito would have been allowed access to, and utilised, the full 'bundle of rights' that property in the kidneys would have given him. There's nothing to suggest that even if this situation had presented itself to Colavito, he would have actually insisted on both kidneys. It is highly unlikely that a transplant team would have implanted both kidneys, even if they were compatible. Douglas also states:

The law of property is neutral to the issue of exploitation: it neither protects an owner's right to use a thing nor restricts his ability to do so. Consequently, the concerns explored by many commentators about the potential to exploit human biomaterials will arise irrespective of whether or not property rights are recognised.<sup>158</sup>

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<sup>156</sup> In order to be compatible, the immune system of the potential recipient must be similar to that of the donor so as to preclude immediate rejection of the kidney. Immunosuppressant drugs can only prevent rejection up to a point.

<sup>157</sup> S Douglas 'Property in human biomaterials: A new methodology' (2016) 75 Cambridge Law Journal 478, 497

<sup>158</sup> S Douglas 'Property in human biomaterials: A new methodology' (2016) 75 Cambridge Law Journal 478, 489

As alluded to earlier, property rights are rights *in rem*, that is to say rights that attach to the property and are enforceable against the whole world.<sup>159</sup> When ‘full-blooded’ property rights are allocated, judges and commentators, quite reasonably, cite immoral behaviours as a reason to stick with the ‘no property in a body’ maxim.<sup>160</sup> This ignores the fact that several judgments have employed property principles to yield a satisfactory outcome; urine<sup>161</sup>, blood<sup>162</sup> and semen<sup>163</sup> have all been considered as property without unleashing chaos on the world.

### 3.3. Creating a ‘res’ from ‘res nullius’

It is apparent from the cases discussed above that body parts (be they tissues or whole organs), can sometimes be considered property, at least for the purposes of legal reasoning. Herring argues that ‘[o]ur bodies are not, in a straightforward sense, ‘ours’. They are interdependent, interconnected and intermingling with other bodies.’<sup>164</sup> He goes on to argue that:

[T]he law’s approach to organ donation should start by seeing it as a reflection of the natural interaction between bodies and the interdependence of bodies. As all of us have enjoyed and participated in such interactions during our lives and we can presume that it is something we would wish to continue to be involved in after death.<sup>165</sup>

Whilst it is hard to dispute the sentiment it does not provide any tangible answers. Given that there is potentially property in a body or body part, it is important to try to define when this emerges; when is the normative line between consent to

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<sup>159</sup> This is to be contrasted to rights *in personam* which bind only the litigants; such is the case with an integrity/privacy rights-based model of the human body and its parts.

<sup>160</sup> *Moore v Regents of University of California* (1990) 51 Cal 3d 120

<sup>161</sup> *R v Welsh* [1974] RTR 478

<sup>162</sup> *R v Rothery* [1976] 63 Cr App R 231

<sup>163</sup> *Yearworth and others v North Bristol NHS Trust* [2009] EWCA Civ 37, [2009] 2 All ER 986

<sup>164</sup> J Herring, PL Chau ‘My body, your body, our bodies’ (2007) 15 Medical Law Review 34, 45

<sup>165</sup> J Herring, PL Chau ‘My body, your body, our bodies’ (2007) 15 Medical Law Review 34, 59

property crossed? Quigley makes considerable progress in trying to define, in principle, when a body, or part of it, can actually become property; ‘*res nullius*’ to ‘*res*’.<sup>166</sup> She argues that ‘separability functions as a bright line that must be crossed as a prerequisite for the transformation to *res* to take place’ and ‘crossing the normative line seems to render human tissue capable of being governed by property considerations.’<sup>167</sup>

Using the kidney as an example, the thing that is a kidney is readily identifiable whether it exists within a living human, a dead human, an ice box pending delivery to a recipient or a pickling jar in a museum. This much is clear to anyone on first inspection. In *Bentham*, a case revolving around whether or not the defendant’s finger, used to imitate a firearm during the course of a robbery, possibly contrary to S.17(2) of the Firearms Act 1968, could be considered ‘a thing’, Lord Bingham said:

[O]ne cannot possess something which is not separate and distinct from oneself. An unsevered hand or finger is part of oneself. Therefore, one cannot possess it ...What is possessed must under definition be a thing. A person’s hand or fingers are not a thing’.<sup>168</sup>

Lord Bingham would presumably argue that, in a pickling jar, a kidney is a ‘thing’ but in a human, it is not a ‘thing’. The former is actually separate, the latter is merely separable. If separable, a kidney is capable of becoming a thing and thus capable of being the appropriate subject of property rights. Quigley concludes that separability alone is ‘not sufficient to assign proprietorship rights’.<sup>169</sup> She reaches this conclusion by looking at Penner’s and Hardcastle’s work on the consequences of separable

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<sup>166</sup> M Quigley ‘Property in Human Biomaterials-Separating Persons and Things?’ (2012) 32(4) Oxford Journal of Legal Studies 659

<sup>167</sup> M Quigley ‘Property in Human Biomaterials-Separating Persons and Things?’ (2012) 32(4) Oxford Journal of Legal Studies 659, 670

<sup>168</sup> *R v Bentham* [2005] UKHL 18, [2005] All ER (D) 161 [8]

<sup>169</sup> M Quigley ‘Property in Human Biomaterials-Separating Persons and Things?’ (2012) 32(4) Oxford Journal of Legal Studies 659, 683

things being automatically allocated property rights without regard for whether they should be allocated those rights.<sup>170</sup> This is a consequentialist view, the like of which would have led Darwin to reject his evolution hypothesis: separability, as a pre-requisite for property allocation, must be rejected because of the potential consequences. The deontological view, it is argued, is more progressive and suitable: separability renders a thing capable of being the subject of a property right if society chooses to allocate that right. Furthermore, 'full blooded' rights need not all be allocated, should society choose to limit the allocation.

However, Lord Bingham's principle argument was, surely, one of statutory interpretation, not separability at all. His was a literal and purposive interpretation of S.57(4) Firearms Act 1968. This Act defines 'imitation firearm' as 'any thing which has the appearance of being a firearm ... whether or not it is capable of discharging any shot, bullet or other missile.'<sup>171</sup> To decide that the defendant's finger was a 'thing' would have allowed it to be confiscated under S.143 Powers of Criminal Courts (Sentencing) Act 2000. Lord Bingham went on to say:

Parliament might have created an offence of falsely pretending to have a firearm (although not an imitation firearm). But it has not done so. And the appellant was not accused of falsely pretending to have a firearm but of possessing an imitation firearm.<sup>172</sup>

This was put in an alternative way by Spencer, who, commenting on the Appeal Court's overturned judgment, said:

The Court has read "possessing a pretend firearm" to include "pretending to possess a firearm", a form of misbehaviour that is different, and wider, and to which the words of the section do not naturally apply ... if fingers count as an "imitation firearm" for the purposes of the section 17(2) offence, they

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<sup>170</sup> JE Penner, *The Idea of Property in Law* (OUP 1997) 105; R Hardcastle, *Law and the Human Body: Property Rights, Ownership, and Control* (Hart 2007) 145

<sup>171</sup> S.57(4) Firearms Act 1968

<sup>172</sup> *R v Bentham* [2005] UKHL 18, [2005] All ER (D) 161 [9]

presumably do so for the offence under section 17(1) as well: using or attempting to use a firearm “or imitation firearm” to resist arrest. As resisting arrest carries a maximum penalty of two years, a person who resists arrest by putting his hand in his pocket and saying “Stick ‘em up!” instantly converts a two year offence into one that is punishable with life imprisonment. That this is potentially oppressive should be obvious.<sup>173</sup>

Whilst part of Bingham’s *dicta*, the ‘person’s finger is not a thing’ argument was unnecessary to decide the case and, by giving fresh succour to the ‘no property in a body’ dogma, the Supreme Court unnecessarily revitalized *Doodeward*. Judge CJ consequently referred to Lord Bingham in the later case of *Yearworth* saying ‘[t]he common law has always adopted the same principle: a living human body is incapable of being owned. An allied principle is that a person does not even ‘possess’ his body or any part of it.’<sup>174</sup> *Stare decisis*, perpetuating a principle of no modern relevance except for cases involving body parts in pickling jars.

To Judge CJ’s credit, he took the law somewhat further than 1908 by focussing attention on the legal position of ‘parts of a human corpse’ and ‘parts or products of a living human’.<sup>175</sup>

First, he said of *Doodeward*, ‘such ancestry does not commend it as a solid foundation ... a distinction between the capacity to own body parts or products which have, and which have not, been subject to the exercise of work or skill is not entirely logical.’<sup>176</sup>

Second, he referred positively to Rose LJ’s speech in *Kelly*:

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<sup>173</sup> JR Spencer ‘Is that a gun in your pocket, or are you purposively constructive?’ (2004) Cambridge Law Journal 543, 545

<sup>174</sup> *Yearworth and others v North Bristol NHS Trust* [2009] EWCA Civ 37, [2009] 2 All ER 986 [30]

<sup>175</sup> *Yearworth and others v North Bristol NHS Trust* [2009] EWCA Civ 37, [2009] 2 All ER 986 [34], [37]

<sup>176</sup> *Yearworth and others v North Bristol NHS Trust* [2009] EWCA Civ 37, [2009] 2 All ER 986 [36]

[T]he common law does not stand still. It may be that if, on some future occasion, the question arises, the courts will hold that human body parts are capable of being property for the purposes of s 4 [Theft Act 1968], even without the acquisition of different attributes, if they have a use or significance beyond their mere existence. This may be so if, for example, they are intended for use in an organ transplant operation ...<sup>177</sup>

Thus, it is possible at least, for parts of a dead human to be regarded as property.

Third, regarding parts of a living human, he came but a step away from saying the same. Using the Californian case of *Hecht*,<sup>178</sup> which concluded that donated sperm was capable of being property, Judge CJ said ‘it is hard to regard ownership of stored sperm ... as other than a step further than that which the men invite us to take in the present case.’<sup>179</sup> The eventual outcome of *Yearworth* is, therefore, not entirely clear despite the conclusion that ‘the men had ownership of [the sperm] for the purposes of their claims in tort ... [and] from that conclusion it follows, *a fortiori*, that the men had sufficient rights in relation to it as to render them capable of having been bailors of it’.<sup>180</sup> It is unsettled whether their sperm could be called their property, with rights *in rem*, or simply owned for the purposes of a claim against the defendants alone.<sup>181</sup>

Hence, *Yearworth* remains the closest English law has come to paving the way for the organs of the dying and the dead to be the suitable subjects for the allocation of property rights. In the next chapter, the argument in favour of limited property rights will be developed.

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<sup>177</sup> *R v Kelly* [1999] QB 621, [1998] 3 All ER 741 [749]

<sup>178</sup> *Hecht v Superior Court of Los Angeles County* (1993) 20 Cal Rptr 2d 275

<sup>179</sup> *Yearworth and others v North Bristol NHS Trust* [2009] EWCA Civ 37, [2009] 2 All ER 986 [40]

<sup>180</sup> *Yearworth and others v North Bristol NHS Trust* [2009] EWCA Civ 37, [2009] 2 All ER 986 [47]

<sup>181</sup> LD Rostill ‘The ownership that wasn’t meant to be: *Yearworth* and property rights in human tissue’ (2014) 40 *Journal of Medical Ethics* 14

## CHAPTER 4

### ALTERNATIVE CONSTRUCTS

Death marks the point at which it is lawful to remove an organ from a human body without regard for the well-being of the donor. The chapter on death and dying demonstrated that death is not a fixed point; it changes depending on the purpose for which the dead (or dying) human is to be next used. A corpse cannot be burned, buried or preserved in formalin for display whilst the heart is beating but it can have its liver and kidneys removed. Any consent based system, in order to fulfil the requirement of adequate information, must explain death to the potential donor. The system in use in England pointedly does not; ‘appropriate consent’ is taken from the relatives only once the donor lacks capacity, has died or is expected to die.<sup>182</sup> Since consent is integral to any system purportedly respecting autonomy, it is argued that NHSBT show limited respect for donor autonomy.

Could autonomy express itself better in a property based system?

#### 4.1. Personal property

Harmon and Laurie may ‘deplore the extension of the property paradigm’<sup>183</sup> and question why existing legal doctrines cannot be used to provide appropriate individual protections and liberties, but the fact is, existing legal doctrines, in practice, do not provide individual protections and liberties.

On first inspection, there is clearly more scope for self-expression in a property model. Such unbridled proprietorship rights allow for sale, rental, co-ownership, auction, inheritance etc. Whilst it is precisely this allocation of ‘full-blooded’ rights

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<sup>182</sup> S.3(6)(c) Human Tissue Act 2004

<sup>183</sup> S Harmon, G Laurie ‘*Yearworth v North Bristol NHS Trust: Property, principles and paradigms*’ (2010) 69(3) Cambridge Law Journal 476, 493



that causes so many commentators to resile from the idea, the inheritable or tradable arguments do bare looking at.<sup>184 185</sup> For instance, Voo and Holm argue that ‘one social advantage of recognising ownership of organs ... would be to increase individual freedom and control over organs as transplant resources.’<sup>186</sup> The example of Iran’s regulated organ trading is cited as evidence of the success of a property model; sale is limited to a single kidney from a living donor with a second functioning kidney. Furthermore, whilst the idea that a family who inherit organs may want to sell them could seem revolting to the middle-class professional, there are families at the poverty level without such qualms. To the donor, the idea that the sale of their organs could maintain the welfare and integrity of their surviving family may be very attractive.<sup>187</sup>

Of course, trafficking is banned under the Human Tissue Act.<sup>188</sup> However, even in statute it is possible to find an element of practical, property-based realism. The Human Tissue Authority (HTA) is allowed to permit rewards and advertisements.<sup>189</sup> The trafficking section does not apply to gametes, embryos and ‘*Doodeward*-type’ material.<sup>190</sup> Rewards are only unlawful if conferring financial or material advantage; not expense related, and only if also construed as unlawful by the HTA.<sup>191</sup> Adverts, outside intensive care units, imploring relatives to consider agreeing to donation are common-place. The emotional rewards of agreeing to donation appear on television

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<sup>184</sup> JS Taylor ‘Organs tradable, but not necessarily inheritable’ (2014) 40 *Journal of Medical Ethics* 62

<sup>185</sup> TC Voo, S Holm ‘Organs as inheritable property?’ (2014) 40 *Journal of Medical Ethics* 57

<sup>186</sup> TC Voo, S Holm ‘Organs as inheritable property?’ (2014) 40 *Journal of Medical Ethics* 57, 59

<sup>187</sup> TC Voo, S Holm ‘Organs as inheritable property?’ (2014) 40 *Journal of Medical Ethics* 57, 60

<sup>188</sup> S.32 Human Tissue Act 2004

<sup>189</sup> S.32(3) Human Tissue Act 2004

<sup>190</sup> S.32(9) Human Tissue Act 2004

<sup>191</sup> S.32(1) Rewards; S.32 (2) Advertisements; Ss.32 (6) (7) and (11) defining permissible reimbursements.

almost every week. Given that the HTA have delegated authority to allow rewards for donation it would not even take a repeal of Section 32 to change the nature of donation; just a revised code of practice.

Allocating personal property rights naturally leads to the possibility of conditional and directed disposition of those rights.

#### 4.1.1. Conditional and directed donation

Directed donation describes the process whereby an organ is given to a specific individual whereas a conditional donation is made to a class of persons conforming to specified characteristics.<sup>192</sup> These characteristics are determined by the donor. NHS Blood and Transplant (NHSBT) dictate the conditions of acceptance based on the egalitarian principle that every person has an equal right to live.<sup>193</sup> Organs are ‘allocated to the person on the waiting list who is most in need and who is the best matched with the donor. This is regardless of gender, race, religion or any other factor.’<sup>194</sup> Whether or not NHSBT will facilitate a directed or conditional donation is a question of policy, not law.<sup>195</sup> The Human Tissue Act is silent on the matter.<sup>196</sup> Directed donation is now allowed, post-mortem, under the 2017 HTA ‘code of

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<sup>192</sup> AJ Cronin, JF Douglas ‘Directed and conditional deceased donor organ donations: Laws and misconceptions’ (2010) 18 *Medical Law Review* 275, 276

<sup>193</sup> G Pennings ‘Directed Organ Donation: Discrimination or Autonomy?’ (2008) 24 (1) *Journal of Applied Philosophy* 41, 43

<sup>194</sup> Human Tissue Authority Code of Practice *Donation of solid organs and tissue for transplantation*, 3<sup>rd</sup> April 2017 paragraph 23 states: ‘No organ should be transplanted under a form of consent which seeks to impose restrictions on the class of recipient of the organ’; S.4 Equality Act 2010; Article 14 European Convention on Human rights

<sup>195</sup> Until 2006, a group called LifeSharers, in the USA, provided a ‘club’ for potential organ donors to themselves be the object of a directed donation. The only condition of joining was to be a donor. See TF Murphy, RM Veatch ‘Members first: the ethics of donating organs and tissues to groups’ (2006) 15 *Cambridge Quarterly of Healthcare Ethics* 50

<sup>196</sup> AJ Cronin, JF Douglas ‘Directed and conditional deceased donor organ donations: Laws and misconceptions’ (2010) 18 *Medical Law Review* 275, 286

practice'.<sup>197</sup> Attaching conditions to a donation, a gift, is a prerogative of the donor; the autonomy of the potential donee allows her to refuse the gift. In the UK, NHSBT will decline any conditional donation on behalf of the potential recipient, even if this means their death.<sup>198</sup> <sup>199</sup> If NHSBT were to accept a donation and ignore the conditions attached, it would be in breach of Section 5 of the Human Tissue Act. Mclean argues that if the conditions themselves are 'illegitimate', then the gift can be used and the conditions ignored.<sup>200</sup> This may be legally true but this hardly accords with autonomy, irrespective of the ethical merits of the attached conditions.

The consent-based approach to conditional donation prohibits the expression of autonomy; one can only consent to an action if first presented with the possibility of the action occurring. It is a reactive model, not a pro-active one. In property, the owner can attach conditions freely; autonomy is respected. It is then the recipient (or agents acting on their behalf) who are burdened with refusing the donation. This may seem like a distinction without a difference but it is not. There is nothing in law which prevents conditional donation outside those characteristics protected by the Equality Act 2010 and Article 14 of the European Convention of Human Rights; there are simply no agents prepared to perform the task. A property model would allow potential donors the opportunity to tailor their donation to their own personal taste; a 'take it or leave it' position. The consent-based system, in practice, adopts a 'give it or keep it' position with NHSBT acting as agents for the whole population of

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<sup>197</sup> Human Tissue Authority Code of Practice *Donation of solid organs and tissue for transplantation*, (3<sup>rd</sup> April 2017) para 22 states: 'In law, individuals may also limit their consent by identifying a named recipient of an organ for transplantation, either as part of living donation, or for donation after their death. This is referred to as a directed donation.'

<sup>198</sup> L Beecham 'Donors and relatives must place no conditions on organ use' (2000) 320 *British Medical Journal* 534

<sup>199</sup> Directed donations are possible in the UK for blood and bone marrow, living related organ donation but not deceased organ donation; AJ Cronin, D Price 'Directed organ donation: is the donor the owner?' (2008) 3(3) *Clinical Ethics* 127

<sup>200</sup> A Maclean 'Organ Donation, Racism and the Race Relations Act' (1999) 149 *New Law Journal* 1250

potential recipients. Individual recipients may well be happy with the conditions set by the donor but their representative, NHSBT, will not act on their individual behalf.

Using a fictitious 'Jack' as an example, the next section develops the property model further by adding the idea of a representative as agent for the donor.

#### 4.2. Organs as property: examples

Supposing Jack has use of a number of organs, located in his body since before birth, and wishes to ensure that some of the best ones are used by others when he has finished with them.<sup>201</sup> The sole UK agency that he can approach for help is NHSBT. NHSBT will let him register an interest in donating his organs but will also allow his family to veto his wishes once he is dead.<sup>202</sup> He could make provision in his Will, relying on the executor to try and give his viable organs to someone else but by the time his Will is considered, none of his organs would be of any supportive value to a recipient. Jack is not happy about this.

Jack is a keen organ donor but doesn't like the idea of donating his liver to alcoholics or those not prepared to reciprocate. Jack was horrified when he found out that George Best was given a liver transplant and then continued to drink.<sup>203</sup> Jack is also of the opinion that if you are not prepared to give then you shouldn't be allowed to receive.<sup>204</sup> He knows that whilst he is alive he can donate one kidney and half of his liver to whomever he decides; provided, of course, the potential donee actually needs the gift and is a suitable match. On this basis, he quite rationally assumes that

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<sup>201</sup> Such a proposition is entirely compatible with both property and consent-based systems.

<sup>202</sup> Organ Donation and Transplantation (NHSBT) *Legislative framework: In the context of consent and authorization* <[www.odt.nhs.uk/deceased-donation/best-practice-guidance/legislative-framework/](http://www.odt.nhs.uk/deceased-donation/best-practice-guidance/legislative-framework/)> accessed 1<sup>st</sup> April 2018.

<sup>203</sup> The Guardian 'Alcohol abusers should not get transplants, says Best surgeon' <[www.theguardian.com/science/2005/oct/05/drugsandalcohol.medicineandhealth](http://www.theguardian.com/science/2005/oct/05/drugsandalcohol.medicineandhealth)> accessed 12<sup>th</sup> March 2018

<sup>204</sup> A belief in reciprocation falls foul of current NHSBT policy although this position may change. See NHS Blood and Transplant, *Taking Organ Transplantation to 2020 A detailed strategy* (2013) 15

his right to consent to *in vivo* removal of an organ, for the benefit of a specific recipient, will be afforded the same respect as in death. Jack also wants to be brain-stem dead before giving his organs. He found out from a friend that if he is merely dying and on the transplant register he may be taken to the operating theatre, allowed to be declared dead and then have his heart restarted but with the blood supply to his brain cut off.<sup>205</sup> He is concerned that this ‘Papworth-protocol’ is illegal in some countries.<sup>206</sup>

Jack is made aware that, in the UK, he can now direct his organs to a specific individual,<sup>207</sup> but he cannot impose conditions on the use of his organs once he is dead.<sup>208</sup> He is unaware that his liver would not be used for an alcoholic anyway; this condition is imposed by the transplant teams on the basis that alcoholics tend to continue drinking and damage their new liver.<sup>209 210</sup> He is also told that once on the organ donor register he cannot decline donation following circulatory-death but accept brain-stem death; it’s agree to both or none.

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<sup>205</sup> A Page, S Large *et al* ‘Heart transplantation from donation after circulatory determined death’ (2018) 7(1) *Annals of Cardiothoracic Surgery* 75

<sup>206</sup> A Page, S Large *et al* ‘Heart transplantation from donation after circulatory determined death’ (2018) 7(1) *Annals of Cardiothoracic Surgery* 75, 79

<sup>207</sup> Human Tissue Authority Code of Practice *Donation of solid organs and tissue for transplantation*, (3<sup>rd</sup> April 2017) para 22, as discussed earlier.

<sup>208</sup> Human Tissue Authority recommendation but not specifically barred by Statute, provided the condition does not breach S.4 Equality Act 2010 (protected characteristics) or Article 14 European Convention on Human Rights.

<sup>209</sup> Liver Transplant Unit, Leeds Teaching Hospitals NHS Trust, personal communication.

<sup>210</sup> By registering a condition, even one which would necessarily be adhered to anyway, the liver would be wasted. See also TM Wilkinson ‘What’s not wrong with conditional organ donation?’ (2003) 29 *Journal of Medical Ethics* 163

#### 4.2.1. Lasting Power of Attorney (LPA)

Jack only wants to go on the organ donor register if his interests are respected. Jack needs to nominate someone to act on his behalf. He inspects the Mental Capacity Act and finds the relevant section:

A lasting power of attorney is a power of attorney under which the donor (“P”) confers on the donee (or donees) authority to make decisions about all or any of the following –

(a) P’s personal welfare or specified matters concerning P’s personal welfare, and

(b) P’s property and affairs or specified matters concerning P’s property and affairs,

and which includes authority to make such decisions in circumstances where P no longer has capacity.<sup>211</sup>

Jack is aware that the powers he confers on an attorney can be specified. He only wants the issue of organ donation to be managed by this attorney when he is either dead, or incapacitated and dying, and specifies this in the deed of appointment.<sup>212</sup> Jack knows that the Human Tissue Act prioritises the attorney in its hierarchy of those capable of giving appropriate consent;<sup>213</sup> NHSBT even provide a nomination form to help with this.<sup>214</sup> However, Jack is also aware that if his attorney is not available at the appropriate time then his relatives will be asked instead.<sup>215</sup> His relatives are completely opposed to organ donation. Jack has donated power of attorney to his wife, in the event that he becomes incapacitated, but he doesn’t want her to have to deal with his organs; these he wants to be dealt with separately. He

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<sup>211</sup> S.9(1) Mental Capacity Act 2005

<sup>212</sup> Whether Jack should choose ‘personal welfare’ or ‘property and affairs’ goes to the heart of this chapter.

<sup>213</sup> S.3(6)(b)(ii) Human Tissue Act 2004

<sup>214</sup> NHSBT ‘Appointing a representative to make organ donation decisions on your behalf’ <<https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1050/appointing-a-representative.pdf>> accessed 1<sup>st</sup> April 2018

<sup>215</sup> S.3(8) Human Tissue Act 2004; Human Tissue Authority ‘Qualifying relationships’ <[www.hta.gov.uk/policies/qualifying-relationships](http://www.hta.gov.uk/policies/qualifying-relationships)> accessed 1<sup>st</sup> April 2018

decides that the LPA route is not entirely suited to his needs for the purposes of directing his organs when he is dead.

Jack investigates setting up a trust to keep his organs safe for the next users of them. He knows that property, not land (realty), held in trust, is beyond interference by either his attorney or executor.<sup>216</sup>

#### 4.2.2. Property held in trust

With its roots deeply set in equity, a trust has the potential to ensure all that is possible is done to fulfil the wishes of the settlor.<sup>217</sup> With a history going back to the Crusades, with knights trusting their property to friends pending their return from the Holy Land, the trustee is burdened with the responsibilities of a fiduciary. These responsibilities include trust, confidence, good faith, and honesty.<sup>218</sup> If Jack were to allocate himself property rights in the organs which he currently possesses, he could create a trust of those body parts. He decides to be the settlor of a trust, 'Jack's solid organs trust', with himself as trustee and his local hospital as a corporate co-trustee. Subject certainty is delivered by naming his transplantable organs and object certainty is delivered by reference to a class of beneficiaries consisting of those on the transplant register at the time of Jack's death who are neither suffering alcoholic liver disease and themselves are on the donor register.<sup>219</sup> Distribution to the beneficiaries should be administratively manageable since the size of the class of

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<sup>216</sup> S.36(6) Trustee Act 1925 as amended by the Mental Capacity Act 2005; S.22 (3) Law of Property Act 1925 as amended by S.9 (1) Trustee Delegation Act 1999

<sup>217</sup> S Farran, K Davies, *Equity and Trusts* (1<sup>st</sup> edition. Hall and Stott 2016)

<sup>218</sup> The judgements of Lord Millet in *Bristol and West Building Society v Mothew* [1996] EWCA Civ 533, and Lord Neuberger in *Sinclair Investments (UK) Ltd v Versailles Trade Finance Ltd* [2011] EWCA Civ 347 are well regarded descriptions of the high standards required of a fiduciary.

<sup>219</sup> Regarding the 'three certainties' (intention, object and subject) necessary for the creation of a valid trust: *Knight v Knight* [1840] 49 ER 58, *Green v Russell* [1959] 2 QB 226

potential beneficiaries is finite (at the time of death) and known (NHSBT register).<sup>220</sup> He is also very clear that brain-stem death is a pre-condition for donation. All of this is documented in the trust instrument, a copy of which is kept electronically on an NHS database for instant reference should it be required.

Jack's organs are his to use and his to donate once he has no need for them. By being his property he is free to dispose of them as he sees fit, provided the disposition is lawful and practical at the time of distribution. Whether NHSBT decide to respect his wishes, as agents delivering the practicality component, is a matter for NHSBT; they cannot be compelled to deal with Jack's property. However, NHSBT are not the only agents capable of distributing the assets of 'Jack's solid organs trust' to the beneficiaries. The actual removal and implantation is done by healthcare staff. Provided the healthcare staff act lawfully and within the guidelines set by their professional bodies, there is no reason why a private company couldn't help Jack achieve his wishes. The company would even be able to claim its expenses under the current rules.<sup>221</sup>

Jack has another idea. He knows that people on the kidney transplant list often have to visit a dialysis unit three times a week for the rest of their lives. He thinks this must be a miserable existence. It's also very expensive for the NHS; about £30,000 per patient per year.<sup>222</sup> Jack knows that his kidneys are still viable for up to an hour after circulatory-death.<sup>223</sup> His fears of not being fully dead after just 5 minutes of

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<sup>220</sup> *R v District Auditor Ex. Parte West Yorkshire Metropolitan County Council* [1986] RVR 24

<sup>221</sup> S.32 Human Tissue Act 2004

<sup>222</sup> National Kidney Federation <[www.kidney.org.uk/archives/news-archive-2/campaigns-transplantation-transcost-effect](http://www.kidney.org.uk/archives/news-archive-2/campaigns-transplantation-transcost-effect)> accessed 28<sup>th</sup> March 2018; M Kerr *et al* 'Estimating the financial cost of chronic kidney disease to the NHS in England' (2012) 27 *Nephrology Dialysis Transplantation* 73

<sup>223</sup> G Wong *et al* 'The Impact of Total Ischemic Time, Donor Age and the Pathway of Donor Death on Graft Outcomes After Deceased Donor Kidney Transplantation' (2017) 101(6) *Transplantation* 1152; K Dunne, P Doherty 'Donation after circulatory death' (2011) 11(3) *Continuing Education in Anaesthesia, Critical Care & Pain Journal* 82, 83



being without a pulse led him to insist on only being a donor after brain-stem death. He would be a bit more relaxed about donation after circulatory-death if the transplant team only take his kidneys and don't need to restart his heart. His family would have a bit more time with him once dead and he wouldn't need to die in an operating theatre; a private side-room on intensive care would be better. Jack also likes the idea that his kidneys have a tangible financial benefit; they can save the NHS money and gain some for his grieving family.

Jack acts as settlor for another trust, 'Jack's kidneys trust'. This trust has himself and the local hospital as co-trustees but, this time, his kidneys themselves are the subject of the trust. The beneficiary is his estate which will realise the sale value of the kidneys. Whilst he is trustee Jack can ensure that his kidneys are not sold prior to his death. Being held in trust he can also ensure that his wife, with power of attorney, cannot sell them either. Once he has died and he is automatically no longer a trustee, the remaining corporate trustee is responsible for selling the kidneys for the benefit of the estate.<sup>224</sup> A contract for £12,000 has already been agreed with the local clinical commissioning group (CCG) who need to ration their resources.<sup>225</sup>

#### **4.2.2.1. Trust: problems**

The fictitious examples above replace the egalitarian principles, which NHSBT abide by, with individual, autonomy driven principles. Property becomes embedded in the institution of a trust; ensuring that the maxims of equity prevail. This is a peculiarly English paradigm with few parallels in other European jurisdictions.<sup>226</sup> An 'organ

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<sup>224</sup> The corporate trustee could be an NHS body but it could be any organisation provided its representatives could act swiftly. An organisation would probably have a knowledge base superior to that of a specified person and would more likely be available, in any hospital, at the required time.

<sup>225</sup> Clinical Commissioning Groups (CCGs) were created following the Health and Social Care Act in 2012, and replaced Primary Care Trusts on 1 April 2013. They are clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area.

<sup>226</sup> S Farran, K Davies, *Equity and Trusts* (1<sup>st</sup> edition, Hall and Stott 2016) 12

trust' must be created legally otherwise the trust will fail as an instrument conveying benefit to the settlor's choice of recipients. The trust would fail if a sale of organs were specified in the trust instrument and then found to be an unlawful disposition. Similarly, if the corporate co-trustee were unwilling to be appointed because of ethical difficulties with the conditions put on the class of object, the trust would lack a trustee once the donor lost capacity or died. Since 'equity will not allow a trust to fail for want of a trustee' the executor of the donor's Will,<sup>227</sup> or a court appointed trustee could possibly become trustees.<sup>228</sup> The time element here (not even including probate) suggests that none of these options would actually save the trust. Under these circumstances either the organs would waste or relatives would be required to give 'appropriate consent', as is currently the case.

In the event of conflict, 'he who comes to equity must do equity'. A beneficiary could not, for instance, apply the precedent set in *Saunders* and demand a kidney from the donor prior to death.<sup>229</sup> Whilst in trust, the equitable owner of the kidney is the beneficiary, the intention of the settlor was that it should only become available post-mortem. Additionally, forced removal would amount to an offence against the person unless the donor also consented to removal.

Clearly, a 'property held in trust' system for organs does not lend itself to easy transition. However, the consent-system gives much less room for the expression of autonomy; a hybrid system could conceivably correct deficiencies whilst avoiding too many sharp edges. NHSBT remain as fiduciaries acting for recipients; an organ-donor trustee acts as fiduciary for the settlor.

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<sup>227</sup> S.36(4) Trustee Act 1925

<sup>228</sup> S.41 Trustee Act 1925

<sup>229</sup> *Saunders v Vautier* [1841] EWHC J82, [1841] 4 Beav 115

### 4.3. Consent-property hybrid

Whilst not maxim of equity, the idiom ‘if it aint broke don’t fix it’, is apposite here.<sup>230</sup> In life, the consent model works well and it is not suggested that this is altered. A defendant, having removed another living person’s kidney without consent can be charged with the crime of grievous bodily harm and sued for negligence; adding criminal damage and theft to the charge sheet would serve no purpose. However, in death, consent is decidedly out of place, whatever the prevailing definitions of death. There is little prospect of consent when dying, and definitely no prospect once dead. All that remains is the ‘appropriate consent’ of a bereaved relative based on a mere indication by the deceased, sometimes decades earlier; a situation somewhat mercilessly pursued by NHSBT.<sup>231</sup>

It is proposed that there is a hierarchy of legal constructs governing deceased solid organ transplantation:

First, a person who claims property in their organs will enjoy control over the disposition of their organs in death. The property is held in trust for beneficiaries either as organ recipients or recipients of the proceeds of the sale of those organs. The disposition is governed by the laws of property and equity. Whilst this method undoubtedly confers the greatest degree of autonomy it also creates new legal problems (as briefly exemplified above).

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<sup>230</sup> Attributed to Thomas Bertram Lance, Director of the Office of Management and Budget during Jimmy Carter's 1977 US Presidency. He was quoted in the newsletter of the US Chamber of Commerce, *Nation's Business*, May 1977: ‘Bert Lance believes he can save Uncle Sam billions if he can get the government to adopt a simple motto: "If it ain't broke, don't fix it."’

<sup>231</sup> ‘Specialist Nurses for Organ Donation have received detailed training ... this means they are able to recognise and to avoid factors that inadvertently and unnecessarily lead to a family refusal.’ The Organ Donation & Transplantation (ODT) directorate of NHS Blood and Transplant (NHSBT) <[www.odt.nhs.uk/odt-structures-and-standards/organ-donation-retrieval-and-transplantation-teams/role-of-specialist-nurse/](http://www.odt.nhs.uk/odt-structures-and-standards/organ-donation-retrieval-and-transplantation-teams/role-of-specialist-nurse/)> accessed 2<sup>nd</sup> January 2018; See also: I Black, L Forsberg ‘Would it be ethical to use motivational interviewing to increase family consent to deceased solid organ donation?’ (2014) 40 *Journal of Medical Ethics* 63

Second, a person without property in their organs is afforded the opportunity to consent to the manner of acquisition of their organs. The material difference between death by brain-stem criteria and death by circulatory criteria is too great to both deny the patient an informed choice and then burden the relatives with acquiescing at a time of maximum grief. Consent (with capacity)<sup>232</sup> or best interests (lacking capacity)<sup>233</sup>, provide the correct decision-making frameworks for the dying, not 'appropriate consent'.<sup>234</sup> 'Appropriate consent' should be restricted to post-mortem decision-making only. The current blurring of the lines lends support to Truog's argument that to avoid the 'increasingly contrived ways to extract functioning organs from people deemed to be dead ...' the 'dead donor rule' should be abandoned.<sup>235</sup> Miller agrees that the 'dead donor rule' 'is inconsistent with the legitimate life-saving practices of organ transplantation'. He suggests that informed consent provides 'a satisfactory rationale for vital organ donation from living donors'.<sup>236</sup> The clear message from both commentators is that if the patient is afforded the choice of donating vital organs whilst still alive, as part of life-support withdrawal, actual consent would be required. This mandates particular emphasis on the voluntary nature of the consent as well as the provision of relevant information. This line of reasoning also encompasses consented donation after circulatory-death following euthanasia, as seen in Belgium.<sup>237</sup> Having no use for their own organs, and not wishing to suffer the pain of surgery, it may well provide

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<sup>232</sup> S.2 and S.3 Mental Capacity Act 2005; S.3(2) Human Tissue Act 2004

<sup>233</sup> S.4 Mental Capacity Act 2005

<sup>234</sup> S.3(6)(c) Human Tissue Act 2004

<sup>235</sup> R Truog 'The price of our illusions and myths about the dead donor rule' (2016) 42 *Journal of Medical Ethics* 318, 318

<sup>236</sup> FG Miller *et al* 'The Dead Donor Rule: Can It Withstand Critical Scrutiny?' (2010) 35 *Journal of Medicine and Philosophy* 299, 302

<sup>237</sup> O Detry 'Organ Procurement and Transplantation in Belgium' (2017) 101 *Transplantation* 1953, 1954

significant comfort to a terminally ill person to know that someone else can benefit from their organs.<sup>238</sup>

Of course, this is currently unlawful in the UK but since it affords respect for autonomy and maximizes the potential for viable organs it is not beneath discussion. It could be argued that the doctrine of 'double effect', in the context of consent and wider best interest discussions, has a role to play.<sup>239</sup>

In *R v Adams*, Lord Devlin directed the jury as follows:

If the first purpose of medicine - the restoration of health - can no longer be achieved, there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if measures he takes may incidentally shorten life.<sup>240</sup>

It is perfectly normal to give anxiolytic and analgesic drugs to dying patients in the full knowledge that the comfort (the purpose) results in respiratory depression. Respiratory depression may incidentally shorten life (the side effect). The purpose of organ removal is to carry out what the patient wanted, and consented to, for the last hours of their life. The leap from one scenario to the other (and then to euthanasia and assisted suicide) is conceptually small although socially it is enormous.<sup>241</sup>

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<sup>238</sup> 'When death is very near, some patients may want to die in the process of helping others to live, even if that means altering the timing or manner of their death' R Truog *et al* 'The Dead-Donor Rule and the Future of Organ Donation' (2013) 369 *New England Journal of Medicine* 1287, 1289

<sup>239</sup> PR Ferguson 'Causing death or allowing to die? Developments in the law' (1997) 23 *Journal of Medical Ethics* 368; R Gillon 'The principle of double effect and medical ethics' (1986) 292 *British Medical Journal* 193; N Zamperetti, R Bellomo *et al* 'Defining death in non-heart beating organ donors' (2003) 29 *Journal of Medical Ethics* 182; R Huxtable 'Get out of jail free? The doctrine of double effect in English law' (2004) 18(1) *Palliative Medicine* 62

<sup>240</sup> *R v Adams* [1957] *Crim LR* 365

<sup>241</sup> Autonomy, as applied to assisted dying and euthanasia, is beyond the scope of this essay; A B Shaw 'Two challenges to the double effect doctrine: euthanasia and abortion' (2002) 28 *Journal of Medical Ethics* 102; TE Quill, B Lo *et al* 'Palliative Options of Last Resort A Comparison of Voluntarily Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia' (1997) 278(23) *Journal of the American Medical Association* 2099; M Klein 'Euthanasia and the doctrine of double effect' (2005) 24 *Wurzbürger Medizinhistorische Mitteilungen* 51 (English version)

Third, where there is no consent to circulatory-death donation, only brain-stem death donation should occur, provided 'appropriate consent' is gained from an attorney or reference to the hierarchy of relatives. Removing the possibility of circulatory-death donation without express consent would serve to encourage NHSBT to provide information and actively seek consent; not rely on grieving relatives for 'appropriate consent'.

## CONCLUSION

The consent-based system of organ donation in England fails on two fronts; there are more potential recipients than actual donors and donor autonomy is not respected. Deceased organ donation mandates an appreciation of what death is. There are several concurrent definitions of death, which renders informed consent difficult at best. Essentially, a person is dead when their doctor says they are; this is irrespective of the person's own opinion of which definition of death they subscribe to.

A potential donor has a legal right to consent to deceased organ donation but this is not encouraged by the organisation which acts on behalf of recipients, NHSBT. Instead, NHSBT rely on, and encourage, 'appropriate consent' from bereaved relatives. From an autonomy perspective, this is an inferior mandate.

The reluctance of the judiciary and legal commentators to permit the allocation of property rights in a person's own body stems partly from *stare decisis*, which loses its grip on anachronistic doctrines rather slowly, and revulsion at the idea of separable parts of persons being commodified. This position is only acceptable when the current paradigm delivers the results required; it does not. Either the consent model is renovated or a new system is entertained.

Granting limited property rights in parts of a human body to the possessor cedes ground to autonomy whilst leaving intact the prevailing integrity/privacy rights-based model of the human body (and its parts) where this functions effectively. The peculiarly English institution of the trust provides an equitable envelope for such proprietary interests to those who wish it.

The English view of organ donation might be favourably altered if the public were empowered to take control of their own body as well as their testamentary affairs.

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