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RESPECTING THE LIVING MEANS RESPECTING THE DEAD TOO

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ABSTRACT

Why should we respect the wishes which individuals may have about how their body is treated after death? Reflecting on how and why the law respects the bodies of the living, we argue that we must also respect the ‘dead’. We contest the relevance of the argument ‘the dead have no interests’, rather we think that the pertinent argument is ‘the living have interests in what happens to their dead bodies’. And, we advance arguments why we should also respect the wishes of the relatives of the deceased regarding what happens to the bodies of their loved ones. In our analysis, we use objections to organ and tissue donation for conscientious reasons (often presented as religious reasons) to show why the living can have interests in their dead bodies, and those of their dead relatives, and why these interests should be respected.
INTRODUCTION

One day, sooner or later, our bodies will be burned, or eaten by worms. Given that inevitable fate, how can it be argued that the individual during her life, or her family after her death, have interests in what happens to the corpse prior to its ‘decent disposal’? If a liver from a corpse will save someone else’s life, if retaining the heart will enable cardiac surgeons to refine their surgical skills, why should any impediment stand in the way? How can the ‘dead’ command respect? John Harris puts his case forcefully:

…the complaints of those who object to actions that violate the physical integrity of the corpse are scarcely rational. Illusions are fine, but whether the State and the Courts should give judicial or official support to these illusions is more doubtful, particularly when to do so might deprive others of life saving therapies.¹

We beg to disagree. We contend that laws should acknowledge that some of the same considerations which require us to respect the bodily integrity of the living also demand that we respect the wishes of the individual about what happens to her corpse. Nor should we ride roughshod over the interests of bereaved relatives. Objections to organ donation and/or to removal of tissue for education or research should not be dismissed as irrelevant because the dead have no interests. They are not irrelevant. And attempts to dismiss ‘the dead’ as of no importance may backfire, however laudable the motives of those who seek to increase the supply of organs and tissue for transplantation, education or research. We argue that the values held by the deceased in life (and in particular religious and conscientious
values) cannot simply be discounted to justify removing his organs without consent after his death. Nor in some instances can those same values adhered to by bereaved families be dismissed as of no account.

WHY BODIES MATTER

Passionate concern about the fate of the body has a lengthy history. In 1834, the playwright, William Cobbett attacked two new Acts of Parliament – the dreaded Poor Law of 1834 and the Anatomy Act of 1832.

I’d rather die than see her begging a morsel of bread from the flint-hearted overseer…hear of her dying perhaps and of her body being cut to pieces like the carcass of a dead horse at the dog kennel.²

In 2008, were the benefit system to be re-organised to consign all citizens unable to support themselves to the workhouse, where they would be forcibly separated from their families, fed minimal rations and forced to work until they dropped, we would all agree that such inhumane treatment fails to respect the living. Our nineteenth century ancestors rightly feared the workhouse. Yet as Ruth Richardson has elegantly demonstrated, they feared the anatomy school more.³ However, even in 1834, workhouse masters could not literally ‘sell’ inmates’ bodies for dog meat. Unclaimed pauper bodies were made available to the anatomy schools to train medical students in dissection. Dissection offered an understanding of the human body that helped develop scientific medicine. Raymond Tallis says that:
Of all the clinical disciplines, pathology is the one which most directly reflects the
demystification of the human body that has made scientific medicine so effective
and humane.\textsuperscript{4}

So why in the nineteenth century and twentieth century did pathology become
demonised? Why did revelations that pathologists had retained organs and tissue
for medical research and training create such controversy?\textsuperscript{5} Why do so many
bereaved families still refuse consent to organ donation?\textsuperscript{6} Whatever use is made of
a dead body or tissue excised from the living, no-one suffers physical pain or
injury. No person appears to be harmed. We want to explore the notion of respect
for bodies, beginning with the living before moving to the dead.

**TISSUE FROM THE LIVING**

The law assigns a high value to bodily integrity. Touch me, and you trespass on my
person. Intrude on a living body without due authorisation and you violate Article 8
of the European Convention on Human Rights.\textsuperscript{7} So it seems heretical even to ask
why our bodily integrity should be respected? We may claim respect by virtue of
our virtues, if any. But what are the claims of our bodies? Imagine that deep in our
DNA is buried information crucial to the health of our families, or even the
community at large.\textsuperscript{8} As we sleep, someone (a researcher) gently scrapes away a
skin cell and thus our miraculous DNA becomes accessible. We feel no pain. We
will not notice the loss of one flake of skin. Yet an assault has occurred, and
section 45 of the Human Tissue Act 2004 is violated.\textsuperscript{9} The law condemns the
disrespect, but what harm has been done? One obvious answer is that our
autonomy has been violated. We have been robbed of the choice about helping our families, or helping medicine. But perhaps the ‘thief’ knows what uncharitable individuals we are and that we would have said no. Whatever the good motives, does that exacerbate the offence? What if he simply finds the cell shed on a scarf that we have borrowed? Still he commits an offence. He has no claim to presume our consent. He still violates section 45 of the 2004 Act, even if in strict law he may not be a ‘thief’.10

Bodily material has several values. The origins of the common law’s absolutist stance to bodily integrity probably lies in the difficulty of drawing a line elsewhere than condemning the ‘least touching of another’.11 If someone can scrape a single skin cell, why could they not garner a slide full of skin cells? Today, any bodily material has other more quantifiable values. We may be content for our hairdresser to chuck away our shorn locks, but would not want agents of our insurers, or employers, or the state collecting them for analysis. Imagine our DNA has commercial value. We might be content to give it away, but might feel very different about someone selling it to the Medical School, or the Medical School selling it on to a biotechnology company.12 We could elaborate, but do we have to? Few people would dissent from the view that no-one should interfere with our living bodies without our consent, regardless of whether the ‘victim’ suffers any hurt or tangible harm.13
Does agreeing to surgery alter the picture? The Nuffield Council Report on Human Tissue in 1995 suggested that, in agreeing to surgery, the patient abandoned any interest in excised tissue.\textsuperscript{14} Mason and Laurie comment that:

To assert …that patients be deemed to abandon their tissue is to ignore the potential value which those very patients may well hold in retaining control over that material.\textsuperscript{15}

If we have a cyst from an eyelid excised, it is a fair bet we will not have a strong interest in its fate.\textsuperscript{16} Some patients however, may be concerned to safeguard their genetic privacy. And what if viable ovaries are removed? Could you assume that the woman was content to allow any ripe ova to be used in IVF, or allow her ovaries to be used in research? A devout Sikh might retain an interest in even the smallest scrap of bodily material. Orthodox Jews seek means to store amputated limbs to be buried with them when they die. A small boy might simply want his appendix back to keep in a jar and exhibit to his friends. A host of reasons may describe why a particular individual may ascribe value to bodily material from the living which most people might dismiss as ludicrous. Different kinds of explanations are advanced to justify why we should respect individuals’ claims to rights over ‘their’ bodily material, be it attached or detached from the body. Privacy, bodily integrity, dignity, property are all given their day in court.\textsuperscript{17} No theory fully explains a claim to control over all bodily material. Mason and Laurie come closest in suggesting a harm that ‘…can include the ‘harm’ of disrespect for the dignity of the human organism’.\textsuperscript{18} Whatever its source, some kind of claim to
control of our bodily material while still living is endorsed in law. There is no balancing exercise. Weighing respect for the ‘human organism’ against the good our bodily material could do for others is not even essayed. We cannot be required to donate blood (trivial though any ‘cost’ to us may be). Nor may excess blood taken from us for therapeutic purposes be given to others without our consent even if our blood might save their lives.

In translating principle into practice, English law acknowledges that many people have little concern about the use of excised bodily material. And so the Human Tissue Act 2004 adopts a compromise. Consent to retention of ‘material’ lawfully removed in the course of surgery is presumed for purposes of audit, medical education or public health surveillance. Explicit appropriate consent is always required for transplantation. Explicit appropriate consent will usually be required for research unless the study is approved by a Research Ethics Committee and the material is anonymised.

TISSUE FROM THE DEAD
Whatever the reasons advanced for respecting the bodily integrity of the living, and bodily material from the living, the dead are another species, some would say, or no species at all, hence Harris’s objections that actions that violate the physical integrity of the corpse are ‘scarcely rational’. ‘Illusions’ cannot be allowed to ‘deprive others [living people] of life saving therapies’. 
The tendentious nature of Harris’s language is evidenced in his description of all beliefs that endorse respecting the corpse as illusions. This is a statement that ignores much of the history and culture of the society in which we live. If this is a description that is particularly aimed at religious beliefs then it is certainly far from being proved. Illusions are beliefs that are objectively false - Harris’s rejection of the basis of these types of belief is not something that applies to those who hold them. He can not show that they are objectively false. However carefully Harris argues his case, ultimately he can only assert it. He is unlikely to convince those whose beliefs he rejects, as Thompson explains:

As Mill said, in order to know that the premises are true one has already to know that the conclusion is true- so if I am in doubt about the conclusion, and want to be given a reason for accepting it, it will do no good to offer me what I must regard as at least as doubtful as the conclusion.

For those who hold the beliefs that Harris rejects as irrational, it is perfectly reasonable to want the body to remain intact for the afterlife. Religious beliefs form an internally coherent belief system. However even if we accept what Harris says, it is unclear whether we should live in a society that will not indulge ‘illusions’ of this type. We tend to agree with the argument of Bernard Williams:

…at the limit, the argument will be heard that coercive force can be justified to prevent the formation of inappropriate desires or to encourage the formation of appropriate ones, so that people, as Rousseau put it, can be forced to be free.
Freedom of conscience and freedom of religion are considered important features of most liberal democracies. They are important because they allow us to be the authors of our own lives, a point which we will later address more fully. If we want to take steps to curtail individual freedoms, we must move cautiously, even if we believe that the overall benefit will be large. There are certain types of beliefs that can be shown to be true or false objectively. There are other types of belief of which we can be less sure. When these beliefs are the strongly held conscientious beliefs of an individual then liberalism demands that we should let them live as they choose, we should respect their beliefs.  

Objections to the use of corpses are often said to derive from religion. We address these later. We consider some other objections first.

In the wake of almost unprecedented public controversy generated by revelations that organs and tissue had routinely been retained by pathologists (without consent) after the completion of post-mortem examinations, the Department of Health set up the NHS Retained Organs Commission chaired by the second named author. In the course of over three years, the Commission met thousands of relatives deeply aggrieved by their discovery that they had buried or cremated only part of their relative’s body. The heart or the brain was missing. In some rarer cases virtually all internal organs had been removed and retained. Yet very few families stated that in no circumstances would they have consented to retention of their relative’s organs – other than those who objected on grounds of religion. A number had
asked if their relatives’ organs could be donated for transplant purposes. The Redfern Report says of one such case.

Until recently both parents had carried organ donor cards for many years. They would have donated their daughters’ organs to another child. They would have considered the organs being used for research if they were asked but they were never asked. The right to decide the fate of their daughter’s organs was taken away from them.29

What many families objected to was covert conscription, and what they saw as an abuse of both their dead relative and themselves. Those who dismiss any objection to retention and beneficial use of bodily material might then advance two arguments:

• The majority were simply complaining of a breach of etiquette.

• The minority of absolute objectors should be overruled in the public interest.

We reject both arguments. The first fails because it fails to recognise that death of the body is not the end of the biographical person. When a parent dies, in the context of a bereavement we must all expect to face, we do not cease to regard her as mother. We do not in common parlance now speak of ‘the deceased’ – or ‘the corpse’ or ‘the ashes’. While she no longer enjoys the attributes of personhood, she
remains a person in the minds of those attached to her. Reflect on this telling paragraph in the Bristol Interim Report:

For the parents of a deceased child, human material, certainly substantial specimens such as organs and parts of organs, and even smaller parts are still thought about as an integral part of the child's body and thus are still the child. For the pathologists and clinicians the material is regarded as a specimen or object. It is dehumanised.\textsuperscript{30}

The focus on retention of children’s organs by the media obscured the evidence that organs were retained from people of all ages, to the anger of some families who resented the apparently exclusive focus on children.\textsuperscript{31} Nonetheless, the especial anger generated by organ retention involving children should engage us here for a moment. In some cases, the baby was only a few days or a few weeks old or even stillborn. The death of a child before her parents is a reversal of the natural order, even when the child is 30 and the parents are in their sixties. The death of a baby has become so rare that for most of us it is unimaginable. When an adult or an older child dies, the family share a set of memories of what that person did and said. The physical memory remains, but is supplemented by other kinds of recollection. With the baby or small child, that physical memory may be all that there is. The body is the baby. And for many years the parents’ relationship with the child is bound up in contact, touch, cuddles and washing and dressing the child.

In his address to the congregation at the memorial service for children whose organs were retained at Alder Hey Hospital, the Bishop of Liverpool spoke
eloquently of the human importance of contact.\textsuperscript{32} Death removes the possibility of that warm connection ever again. Sudden, untimely death, often leaves the survivors with feelings of guilt. Revering the body is the final service you can render your child, wife or father. Revering the body may take many forms. Donation of organs and tissue may be one such form. But the person whose body now lies in the mortuary is still (whatever the law or philosophers or anyone else may say) perceived as \textit{yours}, not material to be harvested by others. That does not mean that families should always be perceived as likely to adopt a negative attitude to requests to retain parts of the deceased’s body for transplant or other purposes. The central claim is that the body of the dead child (or adult) and the family’s interest in the final disposition of that body should be respected.\textsuperscript{33} The Redfern Inquiry concluded:

On the evidence we feel that many more parents would be willing to consider consenting to their children’s organs or tissue being retained for the purposes of medical education and research, if the matter were dealt with more openly and respectfully.\textsuperscript{34}

Individuals themselves may be as concerned with the treatment of their body after death as they are in life. They may decide that they want certain things to be carried out after they die, and they may wish for their bodies to be treated in a certain way. They may have a preference for whole body burial over cremation. Their reasons may be based on religious beliefs, cultural practices, other conscientious beliefs, or even have no basis. They may be content to donate all
their organs, or just some of their organs. They may be adamantly opposed to any ‘interference’ with their corpse. How best should we respect these wishes in death? Should we respect them at all?

DEATH – OF PERSONS AND TRANSITION

Those who argue that the dead (and their bereaved families) have no interests fail to reflect on the nature of death. Death is not akin to a switch that once “off” means that the dead person ceases to matter at all. Death is described by some as, and can traditionally be seen to be, a socially constructed event. Death rituals have formed an important part of the grieving process. Throughout history there has been an expectation that in death the body will be respected as a symbol of the living person. Death of someone close to you is difficult to accept. We struggle to adjust to an understanding that the person is gone. Identifying with the dead is so hard that we think of the dead body as a symbol of the pre-mortem person.

The dead infant, the wife succumbing to breast cancer at 35, the elderly father dying suddenly of a heart attack, do not change their nature for their mother, husband or daughter. They remain Susannah, Lucy and Dad.

They are not simply things. How families lets go of their lost relatives differs.

In the hyper-medicalized West, death, like many other life events, has become a medical event, more so when it takes place in a busy hospital setting. Death is feared and medically heroic efforts may be taken in order to avoid it. Thus the use
of the bodies of the recently dead, through organ or tissue donation, represents a point of collision between life and death. The lives of some become reliant on the death of others. This practical reality is often conflated with the view that the interests of the living must thus be pitted against the no longer existent interests of the deceased. Simply phrasing such a conflict in this manner immediately tips the balance towards the living. We contend that this is too simplistic an approach.

RELIGION IN THE BALANCE?

One commonly cited objection to organ donation, or any other retention of bodily material from the dead, is religion. Consent to organ donation is refused because the family members argue that their faith requires burial or cremation of an intact body. As we shall see, there is little evidence that any of the major world religions holds an absolute objection to organ donation although there may be objection to other forms of interference with the corpse, and/or restrictions on the manner and form of donation. Faith based objections are much discussed perhaps because such objections are sometimes seen as at least ‘reasoned’ if not endorsed as rational. Other objections such as ‘I can’t bear to think of my baby without her heart’ – or- ‘we can’t stomach the thought of removing mum’s eyes’ may seem to carry less weight. So, although it may at times appear that we place too much emphasis on religious beliefs, we discuss them here to illustrate a strong category of conscientious objection and to begin to show how it is important to respect individual beliefs, even if to many they seem objectively irrational. Conscientious beliefs and practices have been described by Ellis as:
… beliefs and practices, which are not merely important to people, but important because, in light of their content, they are regarded as somehow demanded of them. This would extend to moral, political and, perhaps, some aesthetic beliefs as well as religious ones.\textsuperscript{42}

Beliefs have a normative force. They compel us to act in certain ways. We can know certain things without believing them. Knowledge, in some ways, has a less motivating nature than belief. For individuals who hold certain beliefs, there is no choice in how to act. There is only one course of action available to them. Simply to tell these people that they are wrong is not enough, and it is arguable that it is also not appropriate. Therefore when we consider how conscientious beliefs are manifested another point that we should be aware of is that, for the individual who holds the beliefs, having to give those beliefs up, modify them in certain ways, or lose the freedom to exercise them may have very serious effects. Again we refer to Ellis:

For some purposes, conscientious beliefs and the practices that go with them may properly be regarded simply as preferences. But they are special preferences because of the sort of constraint they place on those who have them. It is not simply difficult for such people to abandon them, as it may be difficult for a pigeon-fancier to give up his hobby. The sacrifice involved is of quite a different sort, a sort that it is reasonable to wish were immune from normal process of weighing interests.\textsuperscript{43}
Ellis’s definition poses two immediate challenges for us. (1) Must such a conscientious belief or practice command ‘official’ sanction from faith leaders? (2) Can such a ‘belief’ outweigh the quantifiable harm that is suffered if a patient dies for want of an organ, or medical advance is impeded by shortage of tissue for research or teaching?

RELIigious Myth, NOT REALITY?

A conference convened by UK Transplant and the Church of England Hospital Chaplaincy Council in 2003 established that in Judaism, Buddhism, Islam, Sikhism and most Christian denominations, there is no settled and uniform objection to organ donation per se. Judaism and Islam emphasise the importance of treating the dead body with dignity and that the norm should be to bury the entire body as swiftly as possible. Jewish scholars disagree on whether the imperative to save a life via organ donation may derogate from usual religious duties relating to the bodies of the dead. Lamm declares that one ‘…may not do violence to the human form even when the breath of life has expired’. The former Chief Rabbi, Immanuel Jacobovitz disagreed. Sinclair notes:

…two recommendations for bridging the gap between halakah and the modern policy of encouraging organ donation are the adoption of a personal-choice approach (limited autonomy) to live organ donations…and the adoption of the direct and immediate life-saving justification for cadaver donations to the realities of modern medicine.
He warns, however, that we should not ‘…lose sight of the moral imperative to treat dead bodies with dignity’. Muslim doctors, Sheikh and Gatrad, cite the Islamic doctrine ‘necessity permits the prohibited’. Organ donation is thus in their view not outlawed in Islam. Within Christianity, most major denominations endorse organ donation as a religious ‘good’; a sacrifice conforming to Christian ideals. Only some numerically small groups such as the Brethren prohibit cadaver donation. Nonetheless, in Judaism, Islam and Christianity many individual believers and local ministers and community leaders disagree. ‘A substantial number of the faithful remain profoundly unconvinced’. In particular, beliefs about bodily resurrection and the imperative not to violate the body created in the image of their Creator result in numerous individuals believing that their faith prohibits donation. Randhawa quotes one of those interviewed to elicit their views on organ donation.

‘I’m not sure about life after death, but if there is life I want to go complete.’

How much weight (if any) should we give to individuals whose beliefs are at odds with the official line in their professed faith? Is it relevant that religious leaders do not appear to demand such beliefs? Does evidence that a belief is derived from individual conscience rather than settled doctrine dilute the force that should be attached to that belief? Religion is no longer authoritative in the sense that it was fifty years ago. The influence of the Christian church is in decline; it is no longer the moral authority it once was; it is increasingly diluted through individual conscience. As we have seen Sinclair endorses personal choice in Judaism.
Personal choice works both ways – to allow the individual to choose to donate against the mainstream of religious doctrine and to allow the individual to elect to prioritise the older tradition of entirety of the body. Conscientious beliefs based in religious ideologies are not necessarily embedded through official doctrinal teaching. As Morgan & Lawton describe, religion and culture are inextricably intertwined and religious traditions of the past shape present cultural practices:

The attitudes of single religions, such as Christianity in the U.K or Islam in Saudi Arabia, have sometimes permeated whole societies and influenced their laws on financial assistance and health care for those in need, and their attitudes to abortion and euthanasia.55

It is religion, embedded in culture, that has had a profound effect on attitudes to how we treat our dead. The believer perceives what happens to the corpse as of equal weight to what she does with her living body. The knowledge of what may be done to the body when we die may affect us during life. We may be more acutely affected if we believe that we need our bodies for some journey we make after this life. Within the Romany community the burial of the body intact and ritual surrounding death are of great importance. Romany objections to organ donation are not exclusively founded on religion but derive from cultural tradition about the journey to an after life.56 Such a tradition will be perceived as irrational to those who deny any interests to the dead. It is also worth considering how a policy which overrules the choices of already marginalised groups within society may affect these groups and lead to them being further marginalised. Neither of us
sees the notion of bodily resurrection as rational. Does this matter? We suggest not. Leiter asks:

*Why* does it promote human well being to protect liberty of conscience? Many of the arguments trade, at bottom, on a simple idea: namely, that *being able to choose what to believe and how to live* … makes life better. Being told what *you must believe and how you must live*, conversely, makes life worse.\(^{57}\)

**BELIEF VS REASON?**

Biomedical jurisprudence offers many examples of dilemmas where an individual seeks to prioritise what she perceives as eternal life over the prolonged existence of the physical body. Jehovah’s Witnesses will refuse blood, not wishing for death, but accepting divine ordinance. And the law will respect the wishes of the adult Witness regardless of any more general view that the basis for refusing blood is wholly irrational, or, in the judgment of other believers, based on a misinterpretation of scripture.\(^{58}\) In prioritising ‘life after death’, Witnesses are not alone. For many people with religious views (orthodox or unorthodox) life and death remain deeply rooted in theology; they see life and death not in medical or legal terms, but as intrinsically religious events. Extra-temporal consequences are features of many religions. To live according to God’s will, the believer needs to trust that in death his body will be treated as God requires even though, in many cases, the individual believer’s perception of God’s will is not mandated by any official dogma prohibiting organ or tissue donation. And there are numbers of people with no belief in a god or an afterlife who equally strongly oppose any
interference in the dead body. Elaborate rituals bring comfort. Daily or weekly visits to a child’s grave – a grave decorated with toys and items dear to the child in life are common. People plan their funerals with meticulous care. Yet none of the loving care lavished on these physical remains will do any good to the deceased.

By respecting the wishes of those who refuse to allow bodily material from the dead to be used for the benefit of others do we succumb to irrationality? We (happily) do so with the living. Not a drop of blood may be taken from us, however great the benefits to another might be. We allow the Jehovah’s Witness, a widowed mother of seven children, to die refusing a blood transfusion, respecting her belief, not because we are indifferent to the harm to her children or the cost to society, but because of the greater value of allowing her to be the author of her own life and death. But some may claim that these sorts of views are irrational and should not be indulged lest they are encouraged.

This leads us to the question of why it is that we should protect freedom of conscience if this involves us having to protect irrational or unsuitable beliefs? Who is to say which beliefs are suitable and which are not? Why should we indulge people’s ‘illusions’? Where should we draw the line between allowing people to hold certain beliefs and allowing them to act in ways which manifest these beliefs? In what ways should we be allowed to shape our lives? Freedom of religion and freedom of conscience are common features of most societies. These freedoms are protected by Human Rights law.
Freedom to manifest one’s religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others.\(^61\)

But what these particular freedoms involve is not clear. Does freedom of religion involve simply the freedom to believe in any god(s) or none at all? Or does it involve something more, the freedom to practise openly and in public one’s chosen religion? Can refusal to donate organs be seen as a manifestation of religious beliefs? In *Hoffmann v. Austria* it seems to be accepted that refusal of blood is a legitimate manifestation of the beliefs of a Jehovah’s Witness.\(^62\) Whether refusal to donate organs would be granted the same respect is unclear. Refusal of blood is a central tenet of the Jehovah’s Witness faith. As we have seen, an absolute prohibition against organ donation is not a doctrinal obligation within any major faith. Yet it is devoutly held by many of the faithful as a core matter of individual belief. Consider Robbin's argument:

> For a state to concede individual freedom of beliefs (which is essentially an intra psychic modality) is really to concede very little. How would a government prevent a citizen from holding an inappropriate belief? ... Oliver Cromwell prohibited the catholic mass, but in doing so denied that he was infringing freedom of conscience.\(^63\)

If it is accepted, that by making decisions for ourselves, we exhibit self-rule and in doing so become the authors of our own lives, then should this not involve a
subjective account of the good? Or is freedom of conscience simply the freedom to live one’s life according to some objective standard of what constitutes the good?

What should be tolerated in society? - at what cost comes freedom? Most people accept that there are certain acceptable limits to what we can permissibly do in society. For instance, if we believed that our lives will be made better by killing all blonde haired people, most would accept that toleration does not demand that this should be allowed. Alternatively, if we think our lives will be made better by dying our hair blonde, most will accept that we should be allowed to die our hair blonde.

What is at issue here is harm - harms to others and harms to ourselves.

However, these examples both sit at the extremes. Respect for the dead, or, more accurately, respect for concerns about what happens to our bodies when we are dead, is a less clear case. Thus far we have sought to show that what will happen to us in death affects us in life. We wished to re-focus the question from not simply what interests can the dead have to what interests can the living have in what happens to them when they are dead? But what limits should we place on these interests? How we define which interests should demand our respect and which should not is a vexed question, but its difficulty should not lead us to ignore it. In assessing the quality of someone’s life, it is one thing to say that ‘quality’ is the sort of thing that we cannot know or articulate, and another to say that, because we cannot know or articulate it, it will count for nothing. We face similar difficulties when trying to assess which interests that contribute to this ‘quality’ should be protected or indulged. Acknowledging that we cannot know these interests need not bring us to the conclusion that we should ignore them or leave them out. If we
do take this approach then what we are saying is that our inability objectively to know or assess what is important to you means we will not count it at all. In doing this we commit an error, rather like that pointed out by Parfit in ‘Innumerate Ethics’: in this assessment we are not granting everyone’s interests the same value, rather we are granting some no value at all. 66

In our present case, where it is the interests of those in need of an organ and those who do not wish for organs to be donated, what this amounts to is saying that units of time must win out. That if all we can objectively know are these units of time (the years gained by the individual who receives the organ) which are to be assessed against the unquantifiable harms caused to the individual who does not wish to donate the organ, then these units are all we can take into account. It is a form of poor egalitarian levelling down; we cannot know what these interests are so we can only make crude assessments using some kind of vitalist reasoning. It is one thing to say ‘that we can not know what you care about’ and another to say ‘we don’t believe what you care about is legitimate’- what we must try to figure out is how to deal with this grey area.

We must also consider whether this is the sort of balancing exercise that we even want to enter into. There are some choices we may be reasonable in not wanting to make and which it is reasonable not to force others to make. Consider Ellis’s earlier point that there are some beliefs which are so important ‘it is reasonable to wish [they] were immune from normal process of weighing interests.’ 67 Also, is this simply a question of redistribution?
It is enough to consider different possible states of affairs, or outcomes, each involving the same set of people. We imagine that we know how well off, in these outcomes, these people would be. We then ask whether either outcome would be better, or would be the outcome that we ought to bring about. This subject we call the ethics of distribution.68

This passage highlights the fact that this is a discussion that presumes that organs are goods to be redistributed.69 It is also a discussion that presumes that those in need of an organ are more worthy than those who do not want to donate it. By this we mean that there is a presumption that the entitlement lies with those who have a physiological need for the organ and it is up to those who do not wish to give it to give (good) reason why. We often ignore the fact that neither of these premises is necessarily certain.

It is sometimes argued that it would be rational to choose to live in a world where there was less of a shortage of organs - this is undoubtedly true, if overall that world were a better place.70 However, what we are willing to sacrifice for this society is less clear. On reflection, it may be more rational to choose to live in a society where you have more chance of dying of organ failure, but more chance of being allowed to live your life in accordance with the views you hold to be most important. Or, to put it another way, we may choose to live in a world where we are more likely to die for lack of an organ, but where we have more opportunities to act as autonomous agents throughout our lives. Rawls describes this position as follows:
Equal liberty of conscience is the only principle that the persons in the original position can acknowledge. They cannot take chances with liberty by permitting the dominant religious or moral doctrine to persecute or suppress others if it wishes.31

In this situation, we are not making a judgment about which type of life is more valuable, rather we are considering the relative importance of two valuable worldviews. Desire to live in a world in which you have a greater access to certain types of healthcare, or a world in which you have greater capacity for freedom of conscience.

Some argue that the individual who will die is always going to be worse off. It is not clear whether this is always true. If we believe that removal of parts of our bodies will affect our chances of living extra-temporally, then we could assert that we are worse off. Indeed there seems to be strange cruelty in being born at all if this results in living a life where you believe you will be eternally damned. And for others who do not believe in extra-temporal consequences, but rather purely the distress which will be caused to them by their organs being donated - do we wish to set the threshold at life worth living? In order to justify why their wishes should be respected do they have to show that, by not respecting them, we make their lives not worth living, thus bringing them to a par with those who face dying?
In attempting to weigh the interests of the dead we once again resort to an easy case. There may be good reasons to object to using the bodies of the dead to make dog meat. The benefits of such an activity will not usually be seen to outweigh the harmful effects. The upset at the prospect of dead bodies being fed to dogs is stronger than the benefits of a plentiful supply of cheap dog food. The distress that would be caused to families and friends is likely to be seen as sufficient reason to object to a practice such as this. Organ and tissue donation are wholly different matters. There is a shortage of organs in this country. The suffering caused to individuals who will die for want of an organ is great. Many lives would possibly be saved if we had more organs. Many lives would possibly be saved if we could use post mortem tissue more readily in research. So would conscription of dead bodies for scientific research and organ donation be justified in a democratic society in the interests of public safety, for the protection of public order? Does prolonging life trump all other interests? Remember that we do not have an absolutist policy that encourages donation at all cost. We do not, for example, allow directed donation or the sale of organs; we have certain procedures in place to regulate the system of donation. Pennings suggests that this is a reflection of the fact that we do not believe that increased donation is a principle to be protected above everything else:

A person states a condition that conflicts with the procedures. By doing so, he or she renders the organs unfit for donation. As a consequence, the candidate donor, and not the transplant centre, is responsible for the waste of the organs… …
The cases presented above demonstrate that society does not want to maximize organs for transplantation at all costs; it wants to retrieve as many organs as possible within a procedure that fulfils a set of normative ethical rules. But must this all be placed in such oppositional terms one may ask? Must the interests of one group always be pitted against those of another? It could be argued that what is important here is respect in how we treat others. As has been mentioned, there are few religious groups who actively encourage their members not to donate their organs. The matter here is one of individual conscience and the fact that we are sometimes unclear about what this means does not mean we can just ignore it. An individual may have good reason to believe that she is justified in not allowing her tissue to be used for research, even if this means someone else may die. Similarly, individuals may have good reason to believe that their organs should not be removed from their bodies after their deaths.

**BENEFITING THE DEAD AND THE LIVING**

We have sought to show that at the least the dead are owed some degree of respect. If dead bodies were truly of no more account than say vegetables there would be no objection even to their use as dog meat. We have emphasised the value of choice, a value that studies of organ and tissue donation practice have endorsed. For many people the choice of whether to permit any or some use of their dead body, or the body of their relative, is crucially affected by how that choice is offered and what form that choice should take. Organ and tissue donation should not be seen as an all or nothing affair. So, for example, Muslim families with
concerns about the need to bury the entire body swiftly may be content to donate organs to promote the necessity of saving a life but not to donate a whole body to a medical school. Pragmatically the process by which the issues of organ and tissue donation are raised will be more important than legislative steps which over-rule choice. Sheik & Gatrad explain:

At a practical level we suggest that discussions concerning organ transplantation are initiated by the transplant team...allowing these concerns to be addressed accurately and sensitively. Such liaison workers may also have a key role to play in the aftermath of organ donation or transplant, exploring and allaying feelings of guilt that may ensue.

Sque et al have argued that more research needs to be carried out directly regarding tissue retention. While much work has been done to determine the views an individual may have regarding organ donation, less has been done in the area of tissue use. It is suggested that the ability to interchange human organs and tissue introduces a relatively unexplored dimension to grieving that requires specific attention.

The views of the family should be given serious consideration given the important role the body may have in the grieving process. We have mentioned how for the family the deceased remains a ‘person’ - this is so even when according to some accounts that ‘Person’ may no longer be there in any real sense.
Parents contrasted the very full information they received about the treatment of their children in life with the absence of information in death.\textsuperscript{78}

We should not presume that families will be against donation. The procedures that surround the manner in which the question of donation is raised will be all important. Pushing methods that over-rule or ignore people will not necessarily help to increase organ donation. As opposed to trying to deal with how individuals feel at the ‘moment of the decision’, methods like this ignore the issue, thus creating a system where the burden on the family of the deceased is increased. It can appear at times that there is much ‘propaganda’ in favour of organ donation. This could lead to individuals feeling guilty if they do not donate when it is simply a choice that not everyone can make. The social and cultural nature of death and death rituals is deeply ingrained. While it may be legitimate to claim that many of the beliefs surrounding the body in death, and the rituals we carry out in death, amount to little more than superstition, this does not change the fact that these ‘superstitions’ are pervasive. Changing the law surrounding donation so that it may in turn change these beliefs is a little naïve at best and at worst will make martyrs of many whose beliefs will not be changed.

A liberal democracy will wish to foster on the part of its citizens a serious reflective attitude to important matters of principle. It can hardly do this and at the same time accept that commitments reached in the light of such reflection may be submerged at any time in the calculus of interests on which decisions about the public good are normally based.\textsuperscript{79}
CONCLUSION

In this article, we hoped to show that when we commit to respecting the interests of the living we are also committing to respecting the dead. The concerns we may have with what is done with our bodies after death should not simply be dismissed as irrational. And, if they are, we have shown why concepts such as rational and irrational are to some extent fluid and can vary according to each individual’s perspective. To demand rationality in death is to some extent to misunderstand the nature of the processes involved, and at times places too much of a burden on those who should not have to bear it. Furthermore, proving the rationality/irrationality of fundamental beliefs will not necessarily be something that is objectively possible. Difficulties in defining what it is we mean when we speak about ‘conscientious’ or ‘important’ beliefs can not lead us to the conclusion that these difficulties can be overcome by ignoring them. It will be a disservice to the ends we may wish to promote to try and pursue arguments like this. We must to a certain extent ‘keep our eye on the prize’. The reason why we want to increase organ donation is to allow more people to enjoy their lives for longer. We should be wary of steps we take which may overall have a converse effect; those steps which reduce the enjoyment of life.

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1 J. Harris ‘Law and regulation of retained organs: the ethical issues’ (2002) 22 Legal Studies 527- 549 at 548. (our italics)
6 The rate of refusal has been found to be as high as 40%, and up to 70% in certain ‘non-white’ groups; see K. Barber, S. Falvey, C. Hamilton, D. Collett and C. Rudge ‘Potential for organ donation in the United Kingdom: audit of intensive care records’ (2006) 332 B.M.J. 1124-7; discussed in Sque, Payne and Macleod Clark ‘Gift of life or sacrifice? Key discourses for understanding decision-making by families and organ donors’ in M. Sque and S. Payne, above n 3 at 40-58.
7 Glass v United Kingdom [2004] 1 FCR 553.
8 See Brazier ‘Human(s) (as) Medicine(s)’ in S. MacLean (ed.) First Do No Harm (Aldershot, Ashgate, 2006) 187-202.
9 Section 45 of the Human Tissue Act 2004 extends to Scotland (see s. 59). The Human Tissue Act 2004 for the most part applies only in England, Wales and Northern Ireland. Section 45 makes it a criminal offence to possess bodily material for DNA analysis without qualifying consent or other lawful authority. ‘Excepted purposes’ constitute such lawful authority include medical diagnosis or treatment and the prevention or detection of crime. See J.K. Mason and G.T. Laurie Mason and McCall Smith’s Law and Medical Ethics (7th ed.) (Oxford, Oxford University Press, 2006) at 221.
11 Cole v Turner [1704] 6 Mod Rep 149.
12 See Moore v Regents of the University of California 793 p 2d 479 (Cal, 1990).
13 The difficulty the law has in dealing with metaphysical harms has been noted in J. Coggon, ‘Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Morality?’ (2007) 15:3 Health Care Analysis 235-255.
15 Mason and Laurie above n 9 at 520.
16 See M. Brazier ‘Human Tissue Retention’ (2004) 72 Medico-Legal Journal 39–52. (We may however have an interest in the cyst not being used to create a clone of you against your will, or to plant your DNA at a crime scene etc.).
17 See Herring and Chau above n 10.
18 Mason and Laurie above n 9.
21 Harris ‘Law and regulation of retained organs: the ethical issues’ n 1 above.
22 We don’t and can’t know if Harris or the Pope or anyone else is right. And at the end of it all, none of them can prove their case because it will be rooted in some metaphysical conviction that is (by definition) not empirically demonstrable.
25 Throughout this article religious beliefs will often be used as an example of a conscientious belief. However this itself can lead to problems as the official stance of most Religions does not prohibit organ donation. This could lead to the suggestion therefore, that if we really do wish to respect religious belief then this is one further reason to coerce people into donating
their organs; it is not an activity which ‘religion’ can protect them from. Indeed it would be peculiar for the law to single out one aspect of religious doctrine for enforcement. However for many people religious beliefs are as much a matter of personal or conscientious conviction as they are a matter of doctrine. In this article we argue that both doctrinal and personal religious beliefs and all other conscientious beliefs deserve strong consideration.

26 See The Bristol Inquiry n 5 above; The Redfern Report n 5 above ; Department of Health Report of a Census of Organs and Tissue Retained by Pathology Services in England (Department of Health, 2001). The then Secretary of State described the Redfern Report as the most shocking he had ever read; see The Times 29 January 2001. See also M. Brazier ‘Retained organs: ethics and humanity’ (2002) 22 Legal Studies 549-569. The Retained Organs Commission was set up to manage the process by which NHS trusts provided information to families about organ retention, oversee the process or organ return, act as an advocate for families and develop a new regulatory framework for organ and tissue retention.

27 See, for example, the summary relating to Stephen ‘buried ten years ago as a shell’; the Redfern Report above n 5 at 436.


29 See the Redfern Report above n 5 at 395.

30 See above n 5 at para. 33.

31 See (inter alia) The Investigation of Events that Followed the Death of Cyril Mark Isaacs (Department of Health, 2003).

32 ‘This is why the taking of our children’s organs and tissues has been such an offence to parents and families. When your child is sick and helpless, you hold them to yourself to let them feel the warmth and reassurance of your body. When they die, the memory you cherish is the warmth of that embrace body to body, flesh to flesh, heart to heart. The body— their body— weak and vulnerable, pressed against yours— strong and caring— hoping for a miracle.’ in Harrison, J et al. (eds.) Rebuilding Trust in Healthcare (Oxford, Radcliffe Publishing; 2003) 2.

33 We acknowledge that there may be conflict between the wishes of the family and those of the deceased. We do not, for reasons of space, discuss this issue here. For an analysis of this particular problem see H Conway ‘Dead, but not buried: bodies, burial and family conflicts’, (2003) 23 Legal Studies 423-452.

34 See the Redfern report above n 5 at 25.

35 For example, an individual may not be comfortable with their eyes being donated but may be happy to donate their heart or vice versa. G. Randhawa, ‘An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK.’ (1998) 13 Nephrol Dial Transplant 1949-1954 at 1952: ‘Of the people who would donate, some reticence was expressed by a few respondents only in donating their eyes. This was mainly related to how they would look before their burial…’.


37 See Richardson, above n 3 at 4-20.


39 See Brazier, above n 26 at 545.

40 See M. Sque “A dissonant loss: the bereavement of organ donor families” in Sque and Payne, above n 3 at 59-81.


43 Ibid at 240.


46 I. Jacobovitz Jewish Medical Ethics (Florida, Bloch, 1975) at 282-283.


48 Ibid.

“Jehovah's Witnesses are often assumed to be against donation because of their opposition to blood transfusions. However, this merely means that all blood must be removed from the organs and tissue before being transplanted.”


51 See Brazier, above n 26 at 559.


53 G. Randhawa above n 35 1952. It is interesting and important to note that one of the main bars to organ donation among this group was lack of information about the official stance of their religion towards donation. Many expressed the view that if their religion did allow donation then they do would be happy to donate their organs.

54 See Brazier, above n 26.


56 “Gypsies are a people of different ethnic groups without a formalized religion. They share common folk beliefs and tend to be opposed to organ and tissue donation. Their opposition is connected with their beliefs about the afterlife. Traditional belief contends that for one year after death, the soul retraces its steps. Thus, the body must remain intact because the soul maintains its physical shape.” http://www.transplantforlife.org/miracles/religion.html (Last accessed 28/08/07 at 18.25)

The Maoris and Pacific Islanders in New Zealand often hold similar beliefs and therefore have lower rates of donation than the general population:


58 Re T (Adult Refusal of Treatment) [1992] 4 All ER 649.

59 The use of a lower case ‘g’ is because ‘god’ in this instance is being used as a noun to describe a feature which most religions have without endorsing any one view of this feature.

60 This is not the situation in every jurisdiction. See Donnellan, E. ‘Woman in Court Transfusion case recovering in hospital’ The Irish Times, 22/09/06. “The judge directed the hospital to do everything in its power to save the life of the woman and said staff could restrain her if she physically attempted to stop doctors administering to her a life-saving transfusion. He said the interest of her newborn child, a boy, who he was told was "in good shape", was paramount and the baby could be left with no one in the State, as far as was known, to look after its welfare, if its mother passed away.”


61 European Convention on Human Rights, article 9(2).

62 Hoffmann v. Austria [Hoffmann c. Autriche], 17 E.H.R.R. 293, We acknowledge that not all religious and spiritual beliefs will be protected by article 9, we also accept that states will be afforded a margin of appreciation in how they protect these beliefs.


65 This refocusing fits well with the approach of the courts in Ashan v Universities Hospital Leicester [2006] EWHC 2624 (QB). In this case the courts recognised that it was in a woman’s interests to have her religious beliefs respected. This was regardless of the fact she would not directly experience this respect.


67 Ellis, A. above n 42 at 240.

A more detailed discussion of this point is beyond the scope of this paper. W. Glannon, 'Do the sick have a right to cadaveric organs?', (2003) 29, Journal of Medical Ethics, 153-156 is a useful introduction to this issue.

70 Harris ‘The Survival Lottery’ in John Harris (ed.), Bioethics above n 67 at 300-318.


73 Richardson provides an historical example which backs up this claim. She describes how Parliament instead of coming up with ways to improve consented donation passed the Anatomy Act 1832 which stated that all those who died in poverty and were too poor to pay for their funerals were liable to have their bodies taken and used for dissection. However this proved not to be as reliable a method for increasing the numbers of bodies available for dissection as the government had hoped for.

‘Fear of dying in the workhouse so terrified the Victorian poor and their children that they contributed vast profits to the big business insurance companies by paying in their millions for penny-a-week policies to cover funeral costs. The pauper funeral became the signature of social failure, and helps explain why a ‘decent’ funeral in Victorian and even early twentieth-century Britain provided so visible a public display, and why even in recent times, a pauper’s funeral was regarded as something to be avoided at all costs.’ Richardson, ‘Human Dissection and Organ Transplantation in Historical Context’ in M. Sque & S Payne (eds), above n 3 at 15.

74 A. Sheikh & R.A. Gatrad above n 49 at 107.

75 Sque & Payne ‘Closing thoughts and the future’ in M. Sque & S. Payne (eds ), above n 3 at 169-180.

76 Ibid.

77 We distinguish here between the everyday use of the word person in a descriptive sense and the morally normative use of the concept of ‘Persons’.

78 The Redfern Report above n 5 at 24.

79 See Ellis, above n 42 at 240.