

Respecting wishes and avoiding conflict: understanding the ethical basis for organ donation and retrieval

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Editor's key points

- The ethical aspects of consent to organ donation after death differ from those related to live donation or other situations.
- Uncertainty about a potential donor's wishes in life impedes successful donation.
- There is often uncertainty over consent and the information required about procedures before or after death.
- An alternative, more descriptive approach to donor consent is needed.

Summary. Many people care deeply about what happens to their own and their loved ones' bodies after death. It is therefore important to capture individuals' wishes and ensure that they are respected as far as practically possible. At the same time, healthcare professionals need to feel confident that they are morally entitled to do what they need to do to ensure that someone's wishes are fulfilled. This article explores the decision to donate one's organs after death. It attempts to reconcile the way in which people are required to express their wish to donate organs with the need to reassure and support the professionals, who will care for them if they become potential donors. Current donor registration processes leave some professionals feeling that donors have not consented in the usual manner to procedures, which might be necessary before death. It is suggested that this issue could be addressed without imposing information overload on prospective donors, by changing the way in which the wish to donate is understood and expressed.

Keywords: ethics; informed consent; intensive care; organ donation; organ procurement; personal autonomy

Treatment of the human body

Ethicists can, if they choose, have the luxury of exploring ethical issues pertaining to the body, and the donation of bodily organs, unhindered by the finer details of the legal framework under which they fall. Instead, the ethical starting point is the premise that in our society, people care about what is done to human bodies, both during life and after death, and as such it is an issue of ethical concern. This was the commonsense approach adopted by Dame Mary Warnock who chaired the committee charged with establishing a sound basis for the regulation of medical and scientific interventions involving the treatment and use of human embryos.¹ It was also clearly the view of parents, who believed that they and their children had been seriously wronged by events at Alder Hey and Bristol Hospitals, which in part entailed the retention of children's organs after death without the knowledge or consent of their parents. Similarly, the recent Nuffield Council of Bioethics report on 'Human Bodies: Donation for Medicine and Research' acknowledges that whatever the potential benefits, the human body needs to be treated in a manner commensurate with the public's concerns.²

The nature of the concerns, which individuals have around their bodies, might shift over time and differ across cultures; some people will distinguish clearly between what is done to a body before or after death. However, for most people, it matters (in life and death) that bodies are treated with respect, and a constructive approach to organ donation

and transplantation must acknowledge and act in accordance with this fact.

Personal autonomy and other considerations

There are several possible explanations when looking to establish the basis for this concern for human bodies. For some, it is a matter of faith, the body being created by and in the image of a deity, and in order to live a life governed by the articles of that faith. Conversely, in a secular and politically liberal society, having control over one's body can be seen as an expression of freedom. As such any unwanted incursion upon or restriction of the ability to use one's body as one wishes will be seen as morally regrettable—unless it can be justified in terms of preventing a harm or sometimes promoting a greater good.

'Some professionals (feel) that donors have not consented in the usual manner to procedures that might be necessary before death'

The fundamental importance of bodily freedom is demonstrated by the fact that society still feels uncomfortable about the restraint of people who lack capacity, such as the patient with dementia found wandering from their home or place of care, even though it is known that their safety is at risk. In most cases, freedom of movement is acknowledged as a fundamental feature of a decent life.

It can be argued that retaining control over what is done to one's body goes beyond the claim that an individual should be free from unwanted incursions or restrictions.

'The approach to donation must be seen to balance the needs of recipients with those of people who want to help them and with those of people who do not'

Having a clear view of appropriate behaviour towards one's own and others bodies could be seen as an expression of personal autonomy. In turn, acknowledging and where possible acting in accordance with a person's wishes regarding treatment of their body signals respect for that autonomy, whereas failing to do so shows a lack thereof. So, in the case of the patient with dementia, society allows them maximum freedom of movement and uses forms of containment that do not directly restrain them, thereby respecting the remaining remnants of their autonomy and the autonomous person they once were.

Of course, autonomy has to be about more than simple liberty. If we understand autonomy as involving the claim to live one's life in accordance with one's values, beliefs, goals, and projects, it becomes a fundamental form of self-governance, which might also extend to the idea of control over one's body.³ Choice over what an individual does with their own body (plus what society permits to be done to it) can be seen as an important component of how an autonomous individual wants to live their life or die their death.

Clinicians' concerns

In a society that places a high premium on personal autonomy, it nonetheless needs to be acknowledged that social and cultural factors will in part determine the extent to which people choose, or are able, to exercise their autonomy in the ways we most value. It is also needed to be understood that post-mortem donation will become an issue at the point in life where someone can no longer exercise their autonomy or object in any way to what is done to their body. Therefore, in order to retain faith and public trust,⁴ the approach to donation must be seen to balance the needs of recipients, with those of people who want to help them and with those of people who do not.

This issue is familiar to those working in an intensive care setting, who have frequently highlighted the potential for a conflict of interest (real or perceived), when caring for dying patients who have also been identified as potential donors. Practitioners describe their concerns regarding what can justifiably be done to a patient once further active treatment is not considered to be in their medical best interests. There are concerns about the acceptability of acting when an intervention or change of standard practice would not be of direct medical benefit to the patient but could, or would, make donation more likely, or improve the quality of the organs donated.

This is a further illustration of the fact that people care about what is done to human bodies, particularly when there is no direct benefit to the person whose body is subjected to an intervention. In this case, the person who cares what happens is not the person whose body is acted upon, but rather the person required to conduct the intervention. Therefore, one of the things we need to clarify is whether there is any simple way of explaining how the patient's agreement to become a donor provides doctors with the necessary permissions, which would spare the clinician this sense of conflict. Without such reassurance, there are likely to be lost opportunities for donation.

Those who wish not to donate

The person who acknowledges and articulates their autonomous self, and sees their life as grounded in values or bounded by a faith that they wish to be reflected in their actions, is very helpful to those involved in identifying and caring for prospective donors. This is particularly true when that person takes the trouble to express and record their wishes pertaining to the end of their life—whatever they might be. The reason for this is that one of the biggest obstacles to successful organ donation is uncertainty; it needs to be known what people want to do or not to do.

Consider the person who does *not* wish to donate. At present, these people remain largely invisible unless they choose to express their views to significant others, or very unusually include donation refusal in an Advance Decision or written statement of what they do *not* wish to be done to them once they lose capacity.

'The autonomous individual is not required to provide reasons for their choices'

In a sense the autonomous person who does *not* wish to donate is not required to take responsibility for that decision, and it is most commonly expressed on their behalf by a family member, if and only if the issue of donation is raised, when they have lost capacity at the time of their death.

In the UK, a competent person is entitled to say that they do not want to be treated, even if they will suffer as a result and maybe even die. As long as they are deemed to have capacity, they are not required to give any reason for their decision, nor can their decision to refuse a treatment be overridden because the reason they choose to give is eccentric or challenging to a healthcare professional.⁵ Clearly, the right not to be a donor could be seen as an extension of this right not to be treated, and should be respected as such.

Tolerance of a person's choice not to donate (that is respecting and supporting their wish despite thinking that they might be morally wrong, mistaken, or both) might be a challenge to those who are supportive of donation. Some resent the fact that the current situation, in which no one is required to record their objections to donation, allows for the possibility that a person who has been opposed to

donation all their life could nonetheless benefit from another's donation—the so-called free-rider problem. However, it can be argued that the important issue, from basic principles, is that a person should be free to choose and that they should be supported in their choice. Once they have chosen, it is always preferable to know their wishes because of the problems that uncertainty causes for families and clinicians.

If it is assumed that people care about what happens to their bodies, then the staff caring for such patients need to create space for those who want nothing done to their bodies, save what is required by their chosen rituals around death, dying, and burial/cremation. However, given the value of donation at a public level, policy makers might choose not to create specific opportunities for expressing a wish not to donate. Consider the recent change to the UK driving licence, which requires people to record whether they wish to donate and want to be registered, that they are already registered, or that they do not want to decide at this point. The process does not give them the specific opportunity to decline to donate.⁶

Those who propose and support an opt-out approach to donation emphasize the duty of people, who do not wish to donate to make their wishes known. If this is done they feel comfortable to assume, that in the absence of a registered objection, donation can proceed. In the 'hard' forms of this approach, donation would proceed irrespective of the views of family members who may be uncertain of their loved one's unrecorded wishes. The 'softer' approach would pay heed to a family's claims that the person would not have wanted to donate. For such a system to work, society would have to ensure that people would feel safe to record their objections and that they would take the trouble to do so, because in the absence of objectors making themselves known, the system would do little to remove uncertainty and might place families in an even more difficult position than now.

Those who wish to donate

Currently, the autonomous person who wishes to donate organs has a number of options. They can register directly with the organ donation register, they can carry an organ donor card, fill in the form on the back of their driving licence and/or as campaigns have requested 'tell a loved one'. An expressed statement of intention to donate is clearly a helpful point from which to proceed, as it suggests that donation is consistent with the person's views on what should and should not be done to their body after death. It might also suggest that the act of donation is consistent with the type of person they aimed to be in life and after death.

For some, donation will be consistent with a lack of concern for their body after death, an example perhaps of the recycle and reuse philosophy they adopted in other areas of their life. For them, in the face of the need for transplanted organs, it would be wrong to waste their bodily parts when they could be used for the benefit of others. For

another person, the act of donation might be seen as a positive act of altruism imbued with a strong sense of wanting to help one's neighbour, in life and after death. For those who wish to donate, to be unable to do so robs them of a valued opportunity to do good. They could consider this to be just as harmful to their interests as their organs being retrieved in a situation where their views were unclear or unknown.

This matter aside, the person who chooses to donate and expresses the wish to do so removes the barrier of uncertainty and places family and healthcare professionals in a firmer position from which to proceed. However, having decided to be a donor, it is worth asking whether someone signs up for whatever that entails or whether they can refuse parts of the treatment necessary to enable them to become one. If someone rejects medical treatment for themselves, then clearly they will (normally) be the one who suffers any costs associated with non-intervention, and the choice to refuse is in an important sense 'their own business'. If a potential donor (or their family) refuses treatment where that treatment would secure or benefit a transplantable organ, the cost is borne by those who receive an inferior organ, or maybe by those who lose out completely if the organ is thereby lost to transplant. This is regrettable and possibly inconsistent, given that it undermines the original intention to donate, but it is defensible given the overriding right to refuse treatment.

This review began with the idea that people care about what happens to their bodies. For some people, this will amount to a concern that donation should *not* proceed after their death, for others, it will translate into a wish that it should. In some senses, the reasons why people want or do not want to donate are irrelevant, although clinicians will want to be sure as far as possible that the decisions people come to are not based on misinformation or unduly influenced by others. However, some would go further than this and say that in committing to donation, a person must understand what they are consenting to, and if this is the case, staff will need to question whether the forms of expression listed above are recognizable forms of consent. If forced to conclude that they are not, then it is arguable that the moral (and legal) basis for donation has been undermined.

The problem of consent

It will be argued here that consent to donation after death does not display all the characteristics demanded of a morally robust expression of consent to living donation, but does nonetheless provide an adequate basis on which to proceed. In living donation, the need for fully informed consent is clear, the patient agrees to donate and then needs to consent to the medical procedures that will facilitate that wish to help another. They will live to experience the consequences of that choice, and healthcare professionals are charged with the responsibility of ensuring that they understand the risks and possible consequences of

that choice and are prepared for any interventions that they might consciously experience.⁷ The role of the doctor in this case is to help the individual in their wish to donate, but importantly, they must also identify, communicate, and minimize the risks associated with fulfilling that wish.

In donating after death, the patient will not live to experience any consequences of their generosity—good or bad. It is something they wish to do and if the opportunity arises, they might hope that the healthcare team does whatever they can to help them to fulfil that wish. They (or more likely others) might seek certain reassurances, such as the promise that all steps were previously taken to keep them alive and work towards recovery, if that were ever a realistic goal. They might want to know how disruptive the procedure would be of normal post death rituals and might want to be told that nothing would happen until they were ‘really dead’. Or, they might not have any concerns other than wanting to know that having decided to donate, nothing will get in the way of that happening if the opportunity arises. Once again it is important to stress that the autonomous individual is not required to provide reasons for their choices, nor are they required to inform themselves more fully than they desire. While this is clearly problematic when someone is undertaking surgery the risks of which they could live to bear the cost of, it might be less so when the procedure occurs after death when as far as is known there is no experience.

Some will challenge this approach citing, in particular, the case of donation after circulatory death (DCD). In DCD, successful donation usually requires interventions *in life*, which will have consequences for the prospective donor in the short time before they die. Herein lies a great challenge—acquiring consent in advance for a range of unfamiliar procedures, which might become necessary when caring for a prospective DCD donor. This requires a balance between a commitment to inform those who wish to know and respect for the preferences of those who do not wish to know the details of what will be done to them in the interests of their wish to donate.

The question then arises as to whether in the case of donation after death (be it after brain stem death or circulatory death), it might be sufficient to make information available to people, rather than require them to access and absorb it. It can be argued that

‘in the case of donation after death people should be free to agree to donation on the basis of as much (or as little) information as they wish to receive’

This is because they are expressing a wish to donate, consistent with the sort of person they want to be and with their view of their body and what should and should not be done to it. Primarily, they are consenting to donation, not the medical processes necessary to facilitate it. These processes are only a means to an end with consequences they will not live to experience.

Consent processes

It is not difficult to see how and why a recognition that people care about their bodies and what is done to them usually translates into a strong requirement for consent in a medical setting. Nor should we be lax in defining what we mean by consent and including within the definition features such as being adequately informed, having time to deliberate, not being coerced, etc. By committing to a system where a clear expression of a wish to donate is retained, we acknowledge that people should, *if they choose*, treat donation in a relevantly similar way to any other form of medical intervention. For those who wish to be fully informed, the information should be available in an honest and straightforward form both directly from official sources and more widely through societal and educational routes. However, for those who see their wish to donate as being independent of any desire or need to know exactly what that entails, current forms of registration of their intention to donate might be sufficient. This is because we can justifiably interpret the consent as being attached primarily to the act of donation, as opposed to the procedures associated with it. The person is most concerned about doing something they consider to be acceptable or maybe even necessary because of the values they hold.

It is interesting to note that one way in which we have been hesitant to allow people to link donation of organs to their broader values and beliefs is with regard to the possibility of directed donation after death—that is, specifying to whom an organ should or should not be donated. Live donors most commonly donate to people they know well, and it will have been established that they are happy to donate to that particular person. Donation after death is akin to donating to an anonymous pool of potential recipients, who qualify on the basis of clinical need. Some now feel uncomfortable with the lack of opportunity to benefit significant others through directed donation after death, particularly if there had been an intention to do so in life, and the matter is being actively discussed. While one can see why a person might want to specifically bequeath an organ to a family member after death, one can also anticipate that some people might choose to dictate a preference for certain categories of recipient, for example, non-smokers, up-standing citizens, non-alcoholics with the consequent risk of discrimination and inequity of access to medical services. While some people would become donors if they could be sure that their organ would go to ‘the right sort of person’, we have to decide whether expanding the donor pool by allowing people to place conditions upon their donation is ethically acceptable, given that it could further restrict some people’s chance of acquiring an organ and override considerations of clinical need.

At the bedside

Some encounters between patients and medical professionals arise from situations or processes which are not intrinsically medical but where some degree of medical

assistance is required. Examples include childbirth, termination of a pregnancy, and undergoing cosmetic surgery. The decision to proceed in these situations is a personal one, which will be made in accordance with individual values and motivations. There are legal requirements, which mean that the professionals involved must establish that the patient genuinely wishes to proceed and is aware of any associated risks. The clinician is also required in some sense to ensure that the patient has accounted for their future self-interests in making the decision, but the clinician's primary role is to assist the patient in achieving the intended goal or outcome, for example, successful childbirth, the ending of a pregnancy, or a newly sculpted body.

The decision to donate organs after death is perhaps unexpectedly similar. This is something an individual decides to do, either because they actively think it is a good thing to do or because they can come up with no morally powerful reason not to do it when faced with the fact of scarcity and growing demand for organs. It will only happen after death, and after it has been established that the medical profession can offer a person no other form of beneficial treatment. There is no future self to worry about, and the clinician's responsibility is focused on the present and past wishes of the donor. It is the donor's prerogative to choose whether or not to worry about the exact details of retrieval.

This may be illustrated using an analogy with childbirth. A woman can decide that she someday wishes to give birth even before she understands what is entailed in doing so. She can choose to become pregnant without acquiring any prior information on the details of childbirth. She may be advised along the way and told of the various options available, but similarly she can choose not to engage fully with this advice. At the time of the birth, it is hoped that a woman will be able to consent to any procedures required, but it is also accepted that decisions may need to be made in her best interest as required. It cannot be assumed that if she fails to give any such consent that this is because she had failed to educate herself about the part of the process involving medical intervention. Attending staff will do everything they can to help her give birth to a healthy baby but will refrain from doing anything she asks them not to do, even if this puts her and her baby at risk. They might regret her lack of engagement with what is entailed in having a child, while at the same time acknowledging that the important decision upon which she has reflected appropriately is the issue of becoming a parent and bringing a child into the world.

To use a different example, if someone chooses to terminate a pregnancy, they can take that decision without being forced to understand the full details of the procedure entailed. The risks will be explained and two doctors will need to agree that the request is within the law, but beyond this, it is a personal choice if the woman decides to protect herself from the details of what will be done. Staff should be wary of those who attempt to influence women by imposing upon them information they choose not to access for themselves.

These examples fail to highlight one crucial component of what some might see as an over-relaxed approach to consent. In deciding to become a mother and acknowledging that this will involve giving birth, the individual has a preconception of what that might entail, and will only be happy to accept any risks or harms involved that they would consider proportionate to their goal. Similarly when deciding to be a donor, a person might not seek to uncover the exact details of the processes and interventions entailed, but will probably make reasonable assumptions about the manner in which their body will be treated and the fact that their medical best interests will be considered at the same time as those of any potential recipients. If this is accepted to be the case, there are direct consequences for staff looking after potential donors. If prospective donors are allowed to decide for themselves how much information they need about the process of donation before agreeing to become a donor, then staff need to know which of the processes that will actually happen to the donor are within the bounds of what that individual would reasonably expect, accept, or both. To reintroduce the language of consent, staff need to be assured that what happens during donation is something that people hypothetically would have consented to had they chosen to become fully informed of the details. If it is preferred to avoid the language of consent, the same thing can be stated by requiring that potential donors can trust that what they are agreeing to is reasonable and proportionate to what they wish to achieve.

This will require that those caring for prospective donors strike a reasonable balance between ensuring that the person's wishes are fulfilled—which could require reconsideration of some of the procedures avoided in the past and what a person might reasonably have been expected to consent to. In turn, this might involve very careful consideration of some of the more challenging procedures proposed in the light of the persisting shortage of donor organs, particularly hearts.

Spreading the word

The Organ Donation Taskforce's plea that organ donation become usual as opposed to unusual is relevant here.⁸ The more that individuals witness the reality of post-mortem donation first hand or through the accounts of significant others, the more they will understand and accommodate the range of possible procedures entailed. In turn, doctors will be able to trust that someone, who has expressed a wish to donate, does so on the basis of a reasonable background understanding combined with the level of information they wished to receive. By sharing stories of donation, we can share the facts relating to procedures and the facts about the wish that has been fulfilled. Thus, the sharing of stories will inform those who wish to be informed, while still emphasizing the goal-oriented and wish-fulfilling nature of the interventions involved.

The availability of clear impartial information for those who want it is a sufficient basis upon which to base the

claim that those who wish to donate should be able to do so. This is so even if their statements of intent fall short of our usual understanding of consent, being detached as they are from confident first-hand knowledge of the information that has been accessed. The cost associated with this approach is that the clinicians who might ultimately care for a dying patient and prospective donor will not know for sure that they have gained consent (in the usual sense) for some of the procedures that might be required to ensure the best chance of a successful donation.

The question then arises as to whether this is an uncertainty we can continue to ask clinicians to work around, or whether any more can be done to make clinicians to feel confident to proceed, even though patients have been allowed to refrain from acquiring information they might neither want nor need.

Deciding to donate

Earlier in this article, scant enthusiasm was shown for an opt-out system on the basis that it did little to remove the uncertainty around a person's wishes, which should be considered an important goal, given the background assumption that people care about what is done to the human body. It was then argued that people can have a wish that is based on as much or as little information as they choose, especially if they are not going to live to bear the consequences of the subsequent procedures entailed in fulfilling their wish.

'Consent [is] attached primarily to the act of donation, rather than the procedures associated with it'

If the choice someone has made is considered more important than the reasons for which they made it, then one possibility would be to support a move to mandated choice, where one is required to record one's choices relating to donation.⁹ The advantages in terms of removing uncertainty are persuasive. If we are required to register our views on donation, then they will always be available and families and clinicians will be relieved of certain problems. However, it might still be important to know more about what a person believes themselves to be agreeing to, if we wish to retain their right to access only as much information as they choose.

One possibility might be to move to a statement of the following kind:

'I wish for my organs to be donated after death. I have found out what I would like to know about the process of donation and I have discussed the matter with those who need to know my wishes. Having done this, I would like those caring for me at the time of my death to act in accordance with my wishes and if possible ensure that my wish to donate can be fulfilled.'

Conclusions

Before proceeding to change the fundamental basis for consent to organ donation, it might be preferable to

explore the ways in which people can be helped to capture and share their views and intentions regarding this important life choice. This may require a move away from a legal dependency upon consent as commonly understood, towards a richer descriptive approach to expressing individuals' wishes. If we can enrich the process in this way, clinicians could feel more confident that they have a secure basis from which to proceed with the interventions required to secure a successful donation.

The goal must be to ensure that a person can agree to donation without necessarily burdening themselves with the details thereof, safe in the assumption that the people caring for them at the time of their death will be seeking to do what is in their best interests. At the forefront is the goal of fulfilling their wishes, which might entail procedures that are no longer in their strictly medical best interest, but at the same time, they need to be able to trust that they will be protected from harms (and wrongs) they would not have considered reasonable, even in pursuit of a wish to donate.

In taking on this responsibility, colleagues should be encouraged to engage in some well-designed research related to the views and preferences of prospective donors, because experience tells us that healthcare professionals can be more prone to caution and risk minimization than those they care for,¹⁰ and there is a great deal at stake—both the wishes of the donor and, of course, the needs of a growing number of potential recipients. Those caring for the potential donor, whose wishes are known, should also feel reassured that in facilitating donation they promote that person's best interest in the richest sense,¹¹ and in doing what is medically necessary to fulfil that wish they should feel fulfilled as opposed to conflicted.

Declaration of interests

B.F. is Professor of Clinical and Biomedical Ethics at Brighton and Sussex Medical School. She was a member of the Department of Health's Organ Donation Taskforce and now serves on the UK Donation Ethics Committee. She is a co-applicant on the NIHR-funded DonaTE study, which is considering how to increase donation rates within ethnic minority communities. She has extensive professional dealings with transplant practitioners and those who care for potential donors in a hospital setting. The views expressed in this paper are personal to the author.

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