



Presumed consent to organ donation

By Philippa Taylor

Introduction

Over the past 100 years or so advances in medical sciences have allowed for the successful transplantation of several different organs and tissues. Despite historical controversy over organ transplantation there is now near-universal acceptance that organ donation and transplantation is a positive social good, enhancing and saving the lives of recipients. However, there is an imbalance between supply and demand. Numbers of donors have risen, so that in 2017-18 the highest number of donors in the UK was recorded (1,574), but at the same time 6,044 patients were waiting for a transplant, from either living or deceased donors.¹

Continued demand for donors, along with improvements in surgical technique and intensive care, has generated debate about the best way to increase further the number of donors. Jurisdictions around the world have implemented different systems to try and solve this shortfall. Some systems and policies set up to encourage organ supply are uncontroversial such as public awareness campaigns. However, there is more controversy around other strategies such as incentives, preferential donations, mandated choice,² xenotransplantation and legislation that effectively 'presumes' consent to organ donation on death.³ This File focuses on this last, controversial and topical strategy of presumed consent and considers whether it is ethical and biblical.

A 2008 CMF File on Organ Transplantation considered some of the practical, biblical and ethical issues with transplantation more generally, so these will not be covered again here.⁴

'Presumed consent', also known as 'opt out', 'deemed consent' or 'deemed authorisation' to organ donation, presumes that after death any organs from all adults are automatically available for transplant, unless the individual had specifically expressed their objection, usually by signing a register. Some options allow the views of close relatives to the deceased to be taken into account (the 'soft' option) while others do not (the 'hard' version).

The most common alternative to the presumed consent system is the 'opt-in' system, usually indicated by the possession of a donor card and/or joining an **Organ Donor Register (ODR)**, which enables adults specifically to instruct that their organs be removed for transplantation after death, while the organs from those who have not left instructions to that effect cannot automatically be removed. A smaller proportion of people sign the opt-out ODR.⁵ If the deceased has left no explicit evidence of consent or dissent to organ donation then the views of close relatives will usually determine whether donation may take place.

Drivers for presumed consent

The concept of presumed consent for organ donation probably dates to an idea first raised in 1968 by Dukeminier and Sanders.⁶ They reasoned that no harm can be done by salvaging organs from human cadavers, so it is morally justifiable routinely to take viable body parts without the formal permission of the dying or their families. More lives would be saved, and none would be lost. They realised the importance of the law in this: 'By recognising the claims of persons to cadaver organs, the law can either help or hinder the creation of an adequate supply of organs for transplantation.' A controversial article by Professor Ian Kennedy in *The Lancet* in 1998 argued for presumed consent as a way of increasing the supply of urgently needed organs.⁷ Kennedy claimed that: 'a contracting-out system has a moral benefit

of relieving grieving relatives of the burden of deciding about donation at a time of great psychological stress.'

John Fabre of the British Transplantation Society countered: 'How it is that the state's relieving relatives of this burden has any moral value is hard to see. The reverse is rather the case; to have such decisions taken out of one's hands is morally degrading.'⁸

An Organ Donation Taskforce in 2008 was sympathetic to introducing presumed consent, but after reviewing the evidence reached a clear consensus that it would undermine donation as a gift, would not increase the number of donated organs, and would be costly to implement. Instead, they recommended an improved opt-in system.⁹

Since debating a motion at their Annual Representative Meeting in 1999, the BMA has endorsed and actively campaigned for presumed consent for organ donation in the UK.¹⁰

By 2018 in the UK, 24.9 million people (38% of the population) were on the ODR: a large increase from the 16.1 million in 2009.¹¹ Surveys suggest that around 80% of people support donation in principle.¹² This

indicates that inertia and apathy may play a part in the lower numbers signed up to the ODR. So, a key driver for legislation to presume consent is that it would: '*bridge the gap between a good intention (to donate one's organs) and the effort needed to implement that intention into practice (psychological barriers)*'.¹³

It would more accurately reflect the actual wishes of the population and lead to an increase in the number of available organs for transplantation. It would also send a signal to potential donors and their families that organ donation is a socially preferred choice, or 'good', and is recommended by policymakers.

Safeguards enable those who feel strongly about not being a donor to opt-out by signing up to a register. So, it is argued presumed consent maintains the principle of individual choice for objectors to organ

donation because they can choose to opt out. Although objectors to donating their organs have actively to sign an opt-out, it is argued that such individuals should rightly be burdened with the task of registering because organ donation is, presumptively, socially desirable. Therefore, the burden of communicating objection should be placed on objectors to organ donation.

Moreover, if organ donation is regarded as socially desirable, utilitarian thinking argues that the greater benefit to society by organ donation should outweigh any possible harm to the donor. Indeed, the dead cannot be harmed by the removal of their organs, while the living (and society in general) stand to benefit from them.

From a deontological perspective, it can be argued that an individual has a duty to promote the good of society, which includes the duty to donate, particularly if they want the right to be a recipient (if in need) of a transplant.¹⁴

Ownership of the body

These arguments rely in part on the assumption that any mistaken removal (where the deceased objected to organ donation but had not opted-out) cannot violate a dead body. Society already (generally) accepts unconsented interference with bodies after death through post-mortem examinations, in greater numbers than from organ transplantation.

Taken to its logical conclusion, dead bodies may be treated simply as material to be used, just as other natural resources are used, for the benefit of others. Under a presumed consent system, the assumption about ownership of the deceased's body begins to move from family ownership to State. Logically, based on utilitarian thinking and without safeguards to protect the rights of those seeking to opt-out, this could ultimately lead to compulsory donation.

The gift of donation and informed consent

Underlying the reason many people have donor cards or sign the ODR is the view that organ donation is a personal gift: *'The state is never going to own my body. It's mine to do with as I choose. Donating organs is a gift and an intensely personal one.'*¹⁵

There is also evidence that most recipients wish to be certain that donated

organs have been freely given by donors and their families as gifts.¹⁶ It can be argued that what is not volunteered is not a gift. Presumed consent is no substitute for expressed consent and if organs are removed for transplantation without *express* or *explicit* consent there is no gift or 'donation'; there is only taking without asking. Organ donation and organ requisition are entirely different. Even more, the act of presuming consent is the act of another person – or the State – and not of the person themselves.

Organ retrieval under presumed consent systems is thus no longer a 'gift' from the donor but a 'take' by the State.¹⁷

The argument for presumed consent rests upon the assumption that every single person knows and understands that their consent will be presumed. So, if a person has not opted out, their consent can reasonably be assumed. *'There is no deceit because the climate of presumption is clear – unless opt-out has been exercised, organs will be used if suitable.'*¹⁸

The problem with this argument is that it is virtually impossible, even with public awareness campaigns, to be sure that everyone has access to the message, hears or sees it, understands it, can weigh the information and has made an active decision not to opt-out. It is doubtful that consent can truly be presumed from those who are disorganised, apathetic, disabled, less well-educated or informed, isolated, lacking full capacity, of limited language ability, suffering from (temporary) mental illness, dependent, or from those who change their minds. Costly public information campaigns would need to continue for many years to maintain awareness and even then, their penetration would be incomplete.

Across Europe, surveys have shown poor understanding of existing donor registration policies.¹⁹ Fewer than 50% of the participants in the default opt-in countries, and only 19% from the default opt-out countries have correctly identified the organ donation legislative system in their country.²⁰

Shortly after the presumed consent law came into force in Wales, awareness of it peaked at 82% of the eligible population – no doubt helped by public and media debate about the new law. However, within two years, this had

dropped to 70% with no sign the decline in awareness was levelling off.²¹

In the light of these figures, the assumption that silence equals consent would not be ethical. McKellar says that when a presumed consent system uses a person's ignorance of the scheme to increase the number of organs for transplantation, this can be considered a form of deceit.²²

A weakness of the presumed consent system is that consent is (presumed) given by 'doing nothing'. This may, for some people, reflect a deliberate decision and expression of consent to donate on death. However, others will unintentionally have 'done nothing' and their genuine consent will be lacking though presumed. It runs counter to other areas of law and medicine, where informed consent requires a *positive* action. Obtaining written consent is required by law for medical treatment to ensure consent is valid and that people have thought about the implications. Consent in law involves several components: it must be voluntary, fully informed and the information understood and used to make an informed decision; none of which is guaranteed under a presumed consent system.²³

This makes presumed consent ethically problematic because it uses the law to say that people who have done nothing (neither signed an ODR, nor signed the opt-out register) have actually done something.

It takes our most personal property – our organs – and makes them accessible through a pre-ticked box. Conversely, it is hard to argue that registering on the ODR or carrying a donor card is always an act of 'informed consent', as the term is more broadly understood, but it is clearly intended as an act of authorisation.

Under both frameworks, the views of close relatives to the deceased are considered, except under the 'hard' version of presumed consent. So, it can be argued this negates concerns about informed consent because both frameworks usually allow for families to override or veto. In practice, therefore, under a (soft) presumed consent system, an absence of an opt-out decision by the deceased means that the family will have the final say, usually (but not always) inferred from what they consider the deceased would have wanted. So, they could still refuse permission to

donate organs even though the deceased did not exercise his/her opt-out and may have wanted to donate.

The role of the family

The family therefore plays an important part in the debate around presumed consent. Although most organ donation systems allow the final decision to be made by family members, this may actually undermine the consent of the deceased. Yet if requests of the family are ignored, or overruled, this implies the State really owns the body on death.

Although there is no legal owner of a dead human body, it is the family that in common law is generally expected to take custody and assume responsibility for cremation or burial. It is generally accepted that close relatives are best placed to know how the deceased would have felt about donation and this moves the responsibility for decision-making towards them. In the relatively uncommon – and often traumatic – situation where someone dies unexpectedly, and has organs suitable for donation, is free of transmissible agents, and is in the ‘right’ place (ideally an ICU), then medical staff and/or transplant coordinators will hope to broker an agreement with relatives, but the final decision is the family’s to take. Leaving aside ethics, from a practical perspective, requiring clinicians to retrieve organs against the stated wishes of the family would put them in an invidious position and wise clinicians would not press ahead with retrieval where in their judgment it would cause overwhelming distress to the family.

The care of the family will be their concern, along with the care of those needing a transplant. Families are not usually asked to give a reason for vetoing donation, so we must be careful in ascribing cause without clear evidence. The fact that there is distress and refusal should be sufficient reason to be wary of attempts to override the family’s wishes. Nonetheless, both opt-in and soft opt-out systems allow for a family to override a (now deceased) person’s autonomy, which could be argued as being morally wrong.

Practically however, if the deceased had made their preferences unambiguously known, then families are highly likely to honour this. Research has found that a decision made under opt-in systems is

perceived by families to be clearer and stronger and less ambiguous, because it involves an active decision: ‘affirming one’s personal agency in the choices one makes.’

Lead researcher, Magda Osman, concludes: ‘...presumed consent acts as a weaker signal of underlying preference to donate, and may lead to sustained or higher family refusal rates than active choice to donate.’²⁴

Autonomy

Respect for autonomy is regarded as one of the cornerstones of modern medical practice. Acting in accordance with a deceased person’s prior wishes regarding organ donation signals respect for their autonomy. However, as already noted, neither system guarantees that a person’s autonomy is not violated: whether under a presumed consent system by removing organs from a person who objected to donation but did not have the preference recorded, or under an opt-in system by not removing organs from a person who wanted to donate but did not record their preference on a register. Autonomy is undermined whether it involves a mistaken removal or a mistaken non-removal.

Under a presumed consent system some will consciously choose to donate their organs and give effect to this decision by doing nothing. However, in doing ‘nothing’ others really will have done ‘nothing’ and genuine informed consent will have been bypassed. Presumed consent offers less protection against the risk of collecting organs from persons who have reservations about organ donation. Veatch calculates that: ‘*procuring organs on the basis of a presumption of consent will violate that right at least 30% of the time*’.²⁵

Is a mistaken removal or a mistaken non-removal morally the same? Veatch says that removal of organs without explicit consent constitutes a blatant violation of bodily integrity (and thus autonomy), whereas failure to remove organs when it may have been desired, is ‘merely’ an unfortunate failure to help bring about a desired outcome.²⁶ Utilitarian arguments would justify a *mistaken removal* in a presumed consent system as a moral mistake that saves other lives, whereas an equivalent mistaken *non-removal* under an opt-in system costs lives.

These arguments all assume that

autonomy is a relevant consideration. Where a person has not made their wishes known prior to death, Misselbrook argues that autonomy cannot properly be considered as a relevant consideration because there is no longer a person capable of self-determination. A person will still have interests (family, property) and their bodily remains should be respected, but autonomy no longer exists. So, it may be legitimate for others to take over possession of the body if there are strong reasons to do so.²⁷ However, there would still be many ‘mistaken removals’ and violations of consent, especially under a presumed consent system. Logically, this could lead to the coercive transfer of organs (from all who have not expressed a view) by the State to the sick for their ‘greater good’.

Biblical perspectives

The Bible does not provide specific instructions about how dead Christians should be disposed of, but it is clear that our bodies are important and what we do with them has significance. Jesus died to give resurrection life to our bodies and souls.²⁸ In life, the body is a temple for the Holy Spirit.²⁹ Even after death the body has significance – Paul tells the Philippians he hopes that Christ will be honoured in his body, whether by life or by death.³⁰ Indeed, death is ‘just’ a time of sleep, according to Paul.³¹

So, careful stewardship of the body is important. Hosier says: ‘*Care of the dead does indicate something about the Christian hope of resurrection – that it really is this body that will be raised to new life*’.^{32,33}

There are many biblical examples of people giving instructions about what was to happen with their bodies after death and these were respected by governing authorities.³⁴ Pharaoh gave permission to Joseph to bury his father Jacob in Canaan in the tomb of his fathers in accordance with Jacob’s wishes.³⁵ Joseph gave similar instructions about what was to be done with his own bones.³⁶ God buried Moses and Jesus was himself buried.³⁷

God places us in a network of supportive relationships, with families at the centre, but we are also in communities (the church) and nations.³⁸ As Christians we are not our own,³⁹ we were ‘bought with a price’ through Christ’s death and resurrection, so we belong to God.⁴⁰ But we also belong in a sense to our families and

communities who take responsibility (stewardship) for our bodies, as with Abraham, Isaac, Jacob and Joseph.

The giving of an organ to provide life or health to another person is a profoundly sacrificial act which could be said to resonate with the sacrificial love of Christ. Whilst being cautious about drawing exact parallels and reading more than is intended into biblical passages, in John's gospel we are told that: '*Greater love has no one than this: to lay down one's life for one's friends.*'⁴¹ The Christian obligation to love our neighbours as ourselves is an outworking of the Christian concept of grace; the unmerited favour that God showed us in Jesus Christ's self-giving death for us on the cross. He gave freely and sacrificially and asks the same of us.⁴²

Timothy reminds us that God richly provides us with everything to enjoy and we are to '*be rich in good works, to be generous and ready to share, thus storing up treasure for... a good foundation for the future.*'⁴³ And in the New Testament, the apostle Paul says, as a measure of the devotion and love of the Galatians for him, that they would have 'torn out their eyes and given them to him' to alleviate his painful eye condition.⁴⁴

The emphasis here is on giving and gifts. The altruistic gift aspect of donation (rather than a coercive procurement of organs) fulfils our Christian obligation to love our neighbours as ourselves. It could be argued that the opt-in system best reflects our desire to celebrate and support gracious gifts freely given. Yet, arguably, the presumed consent system could also be seen to reflect Christian concern for human solidarity in general, encouraging society to be sacrificial for others.

Conclusion

Practically, in jurisdictions with presumed consent schemes, outcomes do not consistently reflect higher rates of donation.⁴⁵ Countries with high retrieval rates generally employ other measures to increase the organ supply, namely: 'national and local initiatives, independent of presumed consent, designed to attenuate the organ shortage'. One of the most influential initiatives is investment in infrastructure and training clinicians or nurses to liaise with the families of potential donors.^{46 47}

The donation of an organ, with the intention of preserving the life or health of

another person is a sacrificial act consistent with biblical morality and stewardship. However, support for organ donation on death should be based on it being an altruistic gift, not undermined through any incentives or elements of felt duty. There is uncertainty about potential donors' wishes at the heart of both systems outlined in this paper, and Christians will disagree on the ethics of both. However, my concern is that a presumed consent system would be more likely to lead to removal of organs without the express permission of an individual before death.

Moreover, the basis of presumed consent in which the State in effect 'owns' the body, treating it as a disposable resource, and with the power to override family wishes, is arguably inconsistent with biblical teaching about personal and family ownership and careful stewardship of the body.

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