On the Ethics of Organ Transplantation: A Catholic Perspective

The report of a working party
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Foreword

In the words of Pope John Paul II, ‘We should rejoice that medicine, in its service of life, has found in organ transplantation a new way of serving the human family.’ The Catholic Church is clear that, in itself it is a good and meritorious thing to donate our organs after we are dead. Even while we are alive, actions such as giving blood can be a powerful expression of human solidarity and of Christian charity. Such actions can help build a culture of life, a culture in which life is cherished.

At the same time, organ transplantation involves a complex set of practices. These raise ethical questions that require both technical scientific knowledge and careful philosophical and theological analysis. One example, explored in this Report, is the question of how to diagnose death and, more deeply, what we mean by human death. When can we say with moral certainty that the soul has departed, that the person is no more, and what remains is no longer a living human body?

The Church is a sure guide on matters of faith and morals, but to apply this faith in practice we also need knowledge of the world. It is a challenge for each new generation to apply the unchanging truth of the Gospel to the changing world in which we live. This Report has been compiled by theologians, philosophers, and Catholic clinicians. It is a valuable contribution to contemporary Catholic reflection on the ethics of organ transplantation. The Report focuses particularly on the practice of organ donation as it occurs in Britain and Ireland, but many of the issues it raises seem to be of general application. It is a strength of the working group that it included members from the United States, Australia, and Spain as well as from the United Kingdom.

I welcome this report as a source of reflection to help Catholics, and men and women of good will, to examine the ethical issues that surround organ transplantation so they come to an informed choice. I hope it will also be of use to healthcare professionals in reflecting on their practice, to practice ethically in the service of the human family. The value of the Report is as much in the questions it asks as in the answers it gives, and I would encourage readers to consider these questions seriously and then to follow their own best judgements.

The donation of our organs is not something that can be presumed, for then it would no longer be donation, but something for each person to consider and to discuss with those close to them. It is part of the Catholic tradition to be mindful of death and to prepare for it. Part of this preparation is to think about what will happen afterwards and what effect our death may have on others (not leaving unresolved conflicts, making a will, the disposal of our remains). In a world where people avoid serious discussion of death part of the Church’s contribution is to encourage and enable such discussions.

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Introduction

The Catholic Church has played a significant role in the rise and maintenance of consensus on the ethical character of organ transplantation. The highest rates of organ donation in the world occur in European countries with a strong Catholic heritage and Catholicism seems to be positively associated with rates of donation, especially among those who are aware of the Church’s teaching in this area. Support and encouragement for the practice of organ donation has been expressed repeatedly by popes and also by national hierarchies. This teaching is also expressed in the Catechism of the Catholic Church, especially the revised edition of 1997:

‘Organ transplants are in conformity with the moral law if the physical and psychological dangers and risks to the donor are proportionate to the good that is sought for the recipient. Organ donation after death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity’.

At the same time the Church has been insistent that, as with other practices which are capable of being performed in a way that is ethical, respectful of human dignity and beneficial for the common good, care must be taken that organ transplantation is in fact performed ethically. Ethical and ecclesial support for practices and institutions is never a ‘blank cheque’ but is always conditional on the upholding of ethical standards.

This report is the work of an international group of clinicians, philosophers, and theologians, convened by the Anscombe Bioethics Centre, Oxford. Most of the drafting was done by Prof David Albert Jones and Prof Nicholas Tonti-Filippini with further comments, suggestions, and corrections from other working group members. The aim of the report is to set out the ethical requirements which must be met if transplant medicine is to achieve its true end, and merit the support of Catholics and, more generally, of men and women of good will. It also addresses some new concerns which have arisen, within the Church and within society, about the ethical practice of transplantation, and in particular the criteria for diagnosing death and the issue of presumed consent.

It is hoped that this report will be a contribution to reflection on the practice of organ transplantation, not only by the Catholic community in the United Kingdom and Ireland, but by men and women of good will throughout the world.
On the Ethics of Organ Transplantation: A Catholic Perspective

I. Live donation

1. Current practice, legal structure and professional guidance in the United Kingdom and Ireland

By far the most common form of live solid-organ donation is kidney transplant. In the Republic of Ireland in 2012 there were 32 live kidney donations, which is seven per million population (pmp). This compares with 1,009 live kidney donations in the United Kingdom (15.8 pmp) between 1 April 2011 and 31 March 2012. In part the greater number in the UK (greater proportionate to the population, not only in absolute terms) is because of the pressure generated by the lower percentage of post mortem donation in the United Kingdom. Whereas in Ireland fewer than one in five kidney donations are from a live donor, in the United Kingdom this figure is greater than one in three.

The legal and regulatory structure is different in the United Kingdom and the Republic of Ireland. Nevertheless, there are similarities across these countries, not least in that both must now conform to European legislation, most specifically the EU Directive on Organ Donation and Transplantation 2010. This directive aims to bring all EU countries up to the same quality and safety standards and also to help facilitate transfer of suitable organs across Europe. Legislation in the United Kingdom and Ireland must now be harmonised with this directive.

In terms of national legal frameworks, the key legislation in England, Wales and Northern Ireland is the Human Tissue Act, 2004. This established the Human Tissue Authority (which is technically an Executive Non-Departmental Public Body sponsored by the Department of Health) which regulates organ, bone marrow and body donations through Codes of Practice, policies and position statements, and a system of licensing and inspection. Of the nine Codes of Practice, the two key Codes for live organ donation are Code of Practice 1: Consent and Code of Practice 2: Donation of solid organs for transplantation (which covers both live and post mortem donation). Code of Practice 2 was revised in March 2013 and these amendments will be considered for Parliamentary approval in 2014. The law in Scotland is covered by separate legislation, The Human Tissue (Scotland) Act 2006. Nevertheless, in order to maintain a United Kingdom-wide consistency on live-donation, this activity in Scotland is also regulated by the Human Tissue Authority.

In relation to the co-ordination and encouragement of organ donation (as opposed to its regulation), the key body in the United Kingdom is ‘NHS Blood and Transplant’. This was founded in October 2005 through an amalgamation of UK Transplant, the National Blood Service and Bio Products Laboratory. NHS Blood and Transplant is an NHS Special Health Authority responsible for optimising the supply of blood and organs and the quality and efficiency of transplant services.

In the Republic of Ireland the legal structure is somewhat similar to that which existed in the United Kingdom prior to the passing of the Human Tissue Act. As of July 2013 the Blood & Organs Policy Unit within the Department of Health is working towards drafting a Human Tissue Bill. Formerly the National Organ Procurement Service for the Republic of Ireland, which has played an analogous role to that of NHS Blood and Transplant in the United Kingdom, had

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6 http://www.organdonation.ie/facts
7 http://www.organdonation.nhs.uk/statistics/
been co-ordinated through the Organ Procurement Office at Beaumont Hospital. From 2011, the Health Service Executive (HSE) has established a National Office for Organ Donation and Transplantation charged with creating a formal National Procurement Organisation. There are, therefore, developing structures in the Republic of Ireland to support organ donation closely analogous to those in the United Kingdom, and under the influence of the 2010 EU Directive, it is likely that similarities in these analogous structures will further increase.

2. **Ethical issues**

   i. **The goods of transplant medicine**

   Transplant medicine aims to use knowledge and skill to save life, to restore health and to alleviate suffering. In its aim and rationale it therefore conforms to the fundamental aims of medicine as understood in the Hippocratic tradition of ethical medicine.\(^9\)

   Considered as medicine, established techniques such as kidney transplantation are very successful and no more risky than other forms of surgery. They have transformed the lives, or saved the lives, of many sick people.

   In addition to the good aims and good consequences of transplant medicine for those who are sick, organ donation has a further benefit in that it is a visible expression of human solidarity. The free donation of organs expresses and helps support an ethos of giving, even of sacrifice, and has been characterised by Pope John Paul II as an expression of the culture of life. ‘We should rejoice that medicine, in its service to life, has found in organ transplantation a new way of serving the human family, precisely by safeguarding that fundamental good of the person’.\(^10\)

   Though kidney transplantation is well established, there are other areas of live-donor transplantation that raise some difficult questions in relation to the level of risk for the donor. It is now possible to transplant a lobe of a liver or a lobe of lung. However, partial liver procurement has a significant mortality rate for the donor. The mortality rate for lung lobe procurement is not well established, but is also thought to be significant.

   Other new issues include a trend toward accepting donors who have existing health complications. The latter has implications for both recipients and donors, and may alter the overall mortality and morbidity figures for living donation. The payment of donors has emerged as an issue, with pressure being applied to not only pay for expenses incurred, but also to pay recompense for the time involved, including time away from paid employment. This could blur the line between being a donor and being a vendor. Each of these issues is explored further below.

   ii. **Is it in principle acceptable?**

   Yes, organ donation from a living person can be morally acceptable. It is acceptable precisely as a voluntary act of charity, provided that it does not involve a serious loss of function for the donor. Pope John Paul II praised blood and organ donors for such a ‘noble

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and meritorious act as donating your own blood or an organ to those of your brothers and sisters who have need of it.\(^\text{11}\) Just as the Christian life involves a willingness to suffer for the sake of others, and to risk life and health in the service of others, so undergoing the risk of surgery for the sake of someone in need is a profoundly Christ-like act.

iii. Limits to acceptability

In the first place it is clear that organ donation is justified only as an act of charity and not through a subordination of the individual to the greater good of society. In 1956 Pius XII condemned the view that organs could be taken from one person for another for the reason that each person relates to ‘humanity’ as a part to a whole. Against such a utilitarian attitude, Pius XII insisted that doctors should seek to protect or restore the health and bodily integrity of each person, for ‘in ‘humanity’ each individual is a value in himself, although related to others’.\(^\text{12}\) Here he followed his predecessor Pius XI who had condemned eugenic sterilisation as an illegitimate attempt of the State to exercise power over the bodily integrity of its citizens.\(^\text{13}\)

In the second place, while free donation of an organ can be ethical, there are limits to what a person can donate: ‘a person can only donate that of which he can deprive himself without serious danger or harm to his own life or personal identity, and for a just and proportionate reason. It is obvious that vital organs can only be donated after death’.\(^\text{14}\)

The traditional Catholic understanding is thus that it is acceptable to take reasonable risks with one’s health, but not to ask a doctor seriously to harm the functional integrity of the body. This raises two questions: what constitutes reasonable risk? And what constitutes serious harm to functional integrity? For example, partial liver and lung lobe transplants both involve significant risk to the life of the donor. Lung lobe donation does involve some loss of function. Arguably, a small degree of diminishment of function is not equivalent to harm to functional integrity – but what degree would be equivalent? Even if someone wished to, it would be wrong to seek to donate a second kidney, or a functioning eye or hand even to restore function in another, and a still greater wrong for a doctor to subject a healthy patient to an operation which would be very likely to end in death or serious loss of function.

In cases of significant risk or predictable loss of function, informed consent is not enough. When two parents each donate a lung lobe to a child with cystic fibrosis, the procedure has a chance of being a triple mortality. One of the problems in this area is that there may be no limit to what parents may be prepared to do for the sake of their child and the medical team may be unwilling or unable to decide where the limit should be. There can be ‘heroic virtue’ in risking one’s life for someone, but if there is no realistic prospect of benefit, risking life would be folly. It is like the scenario of a fireman stopping a parent from rushing into a collapsing burning building to rescue a child. It requires practical wisdom to know what is right in such situations, and in practical and political terms, an ethical outcome is helped by consulting widely in the construction of general guidelines and constituting a group of conscientious people as an ethics committee to advise on particular difficult cases.

\(^\text{11}\) Address to blood and organ donors 2 August 1984.
\(^\text{13}\) *Casti Connubii* (1930), 22-23.
\(^\text{14}\) Address to Society for Organ Sharing 20 June 1991.
iv. Payment, remuneration, and exploitation

In 1956, Pope Pius XII warned of the dangers of remuneration for organ donation: ‘it cannot be doubted that grave abuses could occur if a payment is demanded’. Nevertheless, while he was concerned about the dangers of exploitation from a trade in organs, he did not think that all forms of remuneration were necessarily wrong in themselves: ‘it would be going too far to declare immoral every acceptance or every demand of payment’.  

In contrast, Pope John Paul II in 1991 argued that it is only the act of free donation that justifies the taking of organs from the body and that any exchange of human organs for money would be a failure to respect the inherent dignity of the body: ‘Nor can (the body’s) organs and tissues ever be used as items for sale or exchange. Such a reductive materialist conception would lead to a merely instrumental use of the body, and therefore of the person. In such a perspective, organ transplantation and the grafting of tissue would no longer correspond to an act of donation but would amount to the dispossession or plundering of a body.’

The teaching of Pope John Paul II coheres with what he says in other places on the significance of the body and self-giving in marriage, and also with his understanding of organ donation as Eucharistic – as a gift in and through the body. Payment for organs, for Pope John Paul II, thus becomes like simony. It is trafficking in sacred objects, seeking to buy or profit from something that should only be given freely. The theological account of donation propounded by Pope John Paul II is appealing, but it is not defined doctrine, and Catholics are still free to hold, with Pope Pius XII, that remuneration is not wrong in principle. Nevertheless, in practice both popes agree, as have many governments and international bodies who have repeatedly condemned and sought to prohibit the trade in human tissues and organs as dangerous and potentially exploitative.

A question does arise in relation to reimbursement of expenses and recompense for time, risk, or inconvenience, and from time away from paid employment. The reimbursement of expenses is not problematic provided that they are expenses that can be verified as having been necessary expenditure in relation to obtaining organs and tissue.

The recompense for time, including time away from paid employment, is problematic. First, there is the issue of the rate that should be paid. If that is based on what the person would have earned, then this might discourage health authorities from seeking donors among people who are of higher income, who would require more remuneration. If remuneration were set at some kind of flat rate, this could be a more significant inducement for someone who is on a low income. For such a person, recompense for their time may be indistinguishable from payment for the organs or tissues. If recompense is to be provided, it should not exceed lost income or at least not by such an amount as to constitute a significant inducement.

In addition to the issue of payment for donation, there are several further issues involved in permitting trade in human tissue after it has been separated from the body. First, there is the commodification of the human body in the sense in which that indicates a lack of respect for the person. Second, the establishment of blood banks, bone marrow banks, eye banks and solid organ transplantation on the basis of altruism indicates a significant level

15 Address to Eye Specialists 14 May 1956.  
16 Address to Society for Organ Sharing 20 June 1991.
of ‘social capital’.

If trade in tissue were permitted it would undermine that social capital and the substantial practices that depend upon it. Why would someone donate when they can sell? Third, trading human tissue would foster the development of perverse incentives, such that those in receipt of benefits would act in ways that they would not otherwise act. For instance, a donor who had an at-risk lifestyle, or who was already known to be infected, might decide to withhold information in order to be accepted as a tissue vendor. Fourth, the current altruistic practices permit organs and tissues to be made available on the basis of medical need, urgency and likely outcome. If trade is permitted then that equity of access could become subject to the ability of a potential recipient to pay. Trade may also increase the financial burden on the health care system, if the health care system is to meet the extra costs of paying tissue vendors. Either way there would be a loss of access and of equity of access. Fifth, where trade in tissue exists, the majority of vendors are financially and socially disadvantaged. That raises questions about the freedom of such a choice and the coercive nature of economic disadvantage. Finally, where there has been trade in tissue, the procurement teams have been less inclined to make provision for the ongoing monitoring and medical support of the vendors. It seems that the nature of the relationship between doctor and patient is reduced from a fiduciary to a contractual relationship and, implicitly, that vendors are expected to use the funds they received to take care of themselves. Vendors are therefore at much greater risk of harm, and less notice will be taken of that harm, than is the case for altruistic donors.

More will be said below on the application of this idea to cell lines and biotech products derived from human tissue.

v. Is live donation ever a duty?

It follows from the teaching of Pope John Paul II that organ donation, and especially live donation, cannot be a general or objective duty, in the sense of something that others have a right to demand. There is no-one who has more right to my kidney than I do. This needs to be emphasised because, as organ transplantation becomes more effective and more widespread, there is a danger that the act of generosity it presupposes could be taken for granted. A clear example of this is where a relative is pressurised into becoming a donor, especially where the patient needing the organ is a child. It is the responsibility of healthcare professionals to ensure that donation is free of such external pressure, and that the potential donor is given space to withdraw from a procedure to which he or she is not truly committed.

While there is no general duty to donate, such actions can be celebrated and encouraged precisely as acts of uncompelled generosity. Furthermore, as donation is archetypally an act of charity, so it is that the Holy Spirit may be calling a particular person to become a donor, and if the person recognises this, then it becomes a duty in charity for him or for her to consider doing so. In this sense donation may be a duty and unwillingness to donate may be a failure of duty. However, this is precisely in relation to the calling that each person has, and the degree to which we have each discerned it. It is not for others to decide, and still less to pressurise someone into an action which, by that coercion, fails to be an act of donation at all, and becomes a kind of familial conscription.

17 Social capital is a term used to refer to the value of social networks, the collaboration they make possible, and the cooperative dispositions they engender.

Taking organs and tissues from children

The taking of organs from children and others who are not able to make a competent and independent decision is usually not appropriate as they cannot make an altruistic choice, and no-one can make an altruistic choice on another’s behalf. Consent on behalf of another person must always be in their interests, and taking organs or tissue would violate their bodily integrity.

There can, however, be circumstances in which a child or other incompetent person may express a wish to donate and organ or tissue donation may be in his or her interests, such as when the potential donor is closely related to the recipient and dependent upon him or her for care, or emotionally or financially, so that the interests of donor and recipient are closely linked. In these circumstances the parents are so close to the situation that their judgement may be compromised and not necessarily reflect the interests of both people. However it has been argued that such a donation may be acceptable under strict conditions. For example, the Australian National Health and Medical Research Council held that it would be permissible in circumstances in which:

- there is minimal risk to the child;
- the recipient is an intimate relative;
- all other reasonably available options have been exhausted and the procedure is a last resort;
- the procedure is of proven efficacy;
- there is an independent decision that donation is in the child’s best interests;
- the parents consent;
- the child is old enough to understand and does not protest the procedure; and
- the legal requirements are met (Court or tribunal authority approves).19

This is a complex issue and there are differences between jurisdictions in responding to proposals to take organs from a person who is incompetent and in a dependant relationship. On the one hand, there is the person’s right to bodily integrity, and strong opinions are expressed that the human body should be regarded as sacrosanct and simply not available to be exploited in this way. On the other hand, there is the reality that the person may stand to gain significantly if the health of the relative is maintained. The latter raises some complex questions. If a person has been the recipient of a kidney from a developmentally disabled relative or a child on the grounds that it is in the interests of that person to donate the kidney because the donor is dependent on the care of the recipient, would there therefore be grounds to seek some kind of compensation if the recipient deserted the donor or otherwise failed to provide the expected support? The situation could of course be complicated by illness in the recipient. It might also be complicated if the recipient subsequently entered into a relationship and had children whose claim upon the recipient’s time and resources precluded also caring for the donor.20

In England, Wales or Northern Ireland, any proposal to remove a solid organ from a child or from an adult who lacks capacity must be referred to the Human Tissue Authority,21 and

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19 Australian National Health and Medical Research Council Organ and Tissue Donation by Living Donors: Guidelines for Ethical Practice for Health Professionals (Australian Government, 2007), 27.
in the case of a child a Court order must be obtained before such a referral. The Scottish legislation is slightly different, for example the age of majority is 16 rather than 18 years, but it is still the case that decisions with respect to donation by a minor will be referred to the Human Tissue Authority.

Finally, when looked at from the perspective of there being recipient obligations as a result of the transaction, then the whole process looks much more like trade in human tissue rather than altruism and charity. The donor, or others acting for him or her, provides or ‘sells’ his or her kidney for the services to be provided for the donor by the recipient.

There is thus reason to feel uneasy about deciding to take an organ or tissue from someone who is unable to make that choice freely for themselves. However, it is not clear that the practice should be completely outlawed. What would seem to make a difference would be the nature of the relationship between donor and recipient and the strength of the familial connectedness. The option should only be a last resort. It should be noticed that if the child is too young to express any wish then he or she cannot be a ‘donor’ properly speaking, but only one from whom something is taken. The language of donation should be used honestly and is only applicable where there is a relationship of giving, not only of taking.

Finally, the decision about organ donation being in the interests of the one from whom the organ is taken should be supported by an independent arbiter. The problem for a family is the potential for a conflict of interests between the needs of the one from whom the organ is taken and the needs of the recipient.

vii. Altruistic donation

In many countries, including the United Kingdom, live donation is ordinarily limited to those with a close relationship to the recipient, or else donor and recipient are paired with another donor and recipient in such a way that as they donate anonymously someone else donates to their close friend or relation. Special permission is needed for someone to give altruistically without any close relationship to the person. The practical reason for this is to counter the danger of payments, overt or hidden, to ‘altruistic’ donors. This danger is especially clear if the unrelated donor is from one country and the recipient from another.

Nevertheless, while for practical reasons healthcare professionals are right to be wary of live donation from an unrelated donor, this in fact represents the purist form of donation, understood as an act of generosity. Furthermore, as mentioned above, the existence of a close relationship provides no guarantee that payment and/or pressure have not occurred. It is right therefore that people who hear the call to do so are enabled to act as altruistic donors, at the same time as safeguards are maintained, such as psychiatric assessment by an independent doctor and anonymity of both parties.

viii. Paired and pooled donation and donation with restricted use

The practice of paired donation is rare, but has been facilitated by legislative changes in some jurisdictions. Paired donation happens usually when a relative wishes to be a donor but is of a different blood type to the person who needs the organ, so that the organ would be rejected. In those circumstances another donor and recipient combination may be found to match the first pair, so that the donor in the first pair is matched to and gives a kidney to

22 Human Tissue Authority Code of Practice 2: Donation of solid organs for transplantation, §49, 54-57.
23 Tonti-Filippini Nicholas, Ibid.
the recipient in the second pair, and the donor in the second pair is matched to and gives a kidney to the recipient in the first pair.

The arrangements can be quite difficult and there may be a risk that one donation and transplant will go through but not the second. Some also see this as a kind of trade in human tissue.

There is also a relatively new practice of list exchange in which a person who is not well-matched to their relative in renal failure donates to the national cadaveric system in exchange for receiving a well-matched organ for the relative from a cadaveric donor. In effect they enable the relative to queue jump by donating an organ where their own organ is not well-matched.

Some reject the practice for the unfairness of allowing someone to jump the queue ahead of someone else who may have been waiting longer, or who may be deserving of being given priority on other grounds. Some see this as a form of trade in human organs and to be rejected in principle. Others support the practice because it makes more organs available for transplant.

Restricted use (by stipulating the kind of recipient) may be motivated by concern for particular conditions with which someone is familiar, just as people donate financially to particular charities, and this need not imply discrimination. The particularity of generosity does not contradict justice. On the other hand, restricted use could express a discriminatory attitude against certain people and, in practice, would prevent healthcare services simply allocating on the basis of need. Hence, while paired and pooled donations are sometimes facilitated, no jurisdiction allows organ donors to restrict the kind of recipient by age, sex, race or disease. Such restrictions would carry too great a danger of expressing and reinforcing prejudice.

It should be noted that, in the typical case of live donation, the organ is ‘directed’ to a known individual, and is given for his or her benefit. Anonymous altruistic live donation is very much the exception. Hence the wish to donate is already in a sense conditional and disproportionately benefits those who have matched relatives willing to donate. Paired and pooled donation extends a practice that is already partial and interested rather than impartial and disinterested. The difference here seems a matter of distance and degree. A key question is whether the further extension of the practice of directed donation to paired and pooled donation undermines the ethos of donation. This must be decided by prudence which will look for defensible lines to protect the medical and social goods at stake.

ix. Domino donation

The term ‘domino donation’ refers to the donation of an organ which has been removed incidentally as part of a prior transplant procedure. There are two main examples.

First, for practical reasons it is more effective to transplant lungs and heart together than lungs alone. This means that a recipient of a lung transplant may be given a new heart even though their own heart was healthy. This healthy heart can then be given to a second recipient. Again, sometimes a transplant is done because of a progressive congenital condition but before the organ has failed. The organ which is removed, though imperfect, might offer some temporary benefit to a patient who is in danger of imminent organ failure. The ‘domino’ donation is anomalous in that it seems to contradict the usual rules.
for live donation – it is the donation of a vital organ (even the heart) from a live donor! It is also unusual in that the organ is removed as part of treatment and its subsequent use is unrelated to the reason for its removal. In this way it is different from both standard live donation and donation after death.

The domino donor is both a recipient and a donor. It would seem churlish of someone to receive an organ and refuse to allow the organ which has been taken out of them to be donated, but consent for this further use is still needed if it is to merit the name ‘donation’. Nevertheless, because the organ is removed as part of treatment it does not need the safeguards which should generally accompany live donation. In England and Wales domino donation requires consent but is not subject to the same regulatory (Human Tissue Authority) requirements as other types of living donation. The donor does not undertake any medical risk in donating and the reasons for needing consent are more closely analogous to the reasons for consent in donation after death (for example, the human significance of the body and the wider societal benefits of a system of donation).

Secondly, domino donation also refers to a series of living donor transplants that allows the procedures to take place in a way that circumvents technical difficulties of suitable matching. The initial donor donates to a recipient on the waiting list instead of to his or her intended recipient. This allows another donor to give his kidney to an unrelated recipient. More than two recipients can be accommodated, although in practice the donors’ kidneys are not given to the related recipient. The altruistically donated organs are pooled amongst recipients with the added benefit of best possible matching – and moving others ‘up the waiting list’.

x. Less than ideal donors

In recent times there has been a trend toward accepting organs from donors who may have health risks such as diabetes, obesity or transmissible infection, an issue that has its own obvious complications. Basically the solution involves matching recipients and donors.

It used to be the case that people with an infectious disease such as Hepatitis B or C or HIV, or who had a cancer considered to be possibly related to a virus, could not be donors. Now their organs may be used, provided that the recipient also has the same disease or infection status. Similarly, transplant surgeons used to be reluctant to take a heart from an elderly cadaver, but now they simply match with an elderly recipient.

That does raise the question of what to say to the recipients. There are different views on this. Some argue that the recipient needs to be told the health condition of the donor. Others argue that if they have matched the recipient and the donor, all the recipient needs to know is that the organ is a healthy organ for them.

Anonymity is an issue that has arisen in this context when the donation is from a stranger. Anonymity is thought to be important to protect both donors and recipients from undue interference or unwanted relationships. However the donor’s identity risks being revealed in passing on information about the donor organ to the recipient in order to meet the need for information about the quality of the organ and likely outcome.

There are also concerns about taking organs from living donors who have a disease that would put them at increased risk, such as hypertension, obesity or diabetes. Taking a kidney

24 Human Tissue Authority Code of Practice 2: Donation of solid organs for transplantation, § 28.
from a person with diabetes, for example, involves increased risk to the donor because renal disease is often a result of diabetes and having only one kidney would put the person at much greater risk of renal failure. However, if someone is insistent that they want to take the risk to benefit a relative, then the transplant teams sometimes have been willing to accommodate them.\footnote{Ibid.} This could be understood as heroic virtue, which can be admired, but which is not to be expected or demanded.

xi. Consent for research on tissue in biobanks and possible commercialisation

Biobanks are a recent phenomenon, but have become an important part of research into disease processes at the molecular level. They are often established by pathology services and the goal is to have a significantly large number of samples maintained in culture so as to provide a service to researchers. New drugs can be tried against a large range of tissue types and genotypes, and epidemiological research can search for genotypes thought to be associated with particular diseases. In England and Wales UK Biobank recruited 500,000 people between 2006 and 2010 to provide blood, urine and saliva samples for future analysis. These recruits also agreed to have their health followed.\footnote{http://www.ukbiobank.ac.uk/about-biobank-uk/} In Scotland, Generation Scotland\footnote{http://www.generationscotland.org/index.php?option=com_content&view=article&id=4&Itemid=8} incorporates three research tissue banks which together have recruited over 30,000 people.

These tissue banks are designed to be available as a resource for a range of medical research. As the ethical issues of these projects are typically similar to one another, donors are asked for broad or general consent to the use of their tissues in medical research, and are told that they will not be re-contacted for specific consent for each project. For analogous reasons, UK Biobank obtained generic ethics committee approval to cover the majority of research using the resource. This approach would be acceptable for research that is not contentious or that does not have significant implications for the donor or research subject or for his or her family. In general, genetic research requires that it remain possible to contact the tissue donor or his or her family in relation to significant findings that may affect the family or the donor. The Australian \textit{National Statement On Ethical Conduct Of Human Research}, for instance, requires consent to be obtained for all human genetic research and a ‘defensible ethical plan’ in relation to contacting the donor and family members.\footnote{Accessed 19/8/2013 from http://www.nhmrc.gov.au/guidelines/publications/e72}

There are obvious questions about what can reasonably be covered by ‘general consent’ and what forms of research would require further specific consent. For example, in 2009 Generation Scotland and UK Biobank were asked directly whether they would allow the use of donated tissue to create human-non human admixed embryos without specific consent. Generation Scotland responded that it would not use the tissue for this purpose without specific consent, whereas UK Biobank was not willing to make any such undertaking.\footnote{Jones DA, MacKellar, C. ‘Consent for biobank tissue in somatic-cell nuclear transfer?’ \textit{Lancet} 374.9693 (12 September 2009): 861-863.} The creation of admixed embryos is unethical for a range of reasons, as will be discussed below. It is made worse by the use of tissue for this purpose without specific consent.

Another area that donors may not have considered before giving tissue is the use of research to develop biotech products which may or may not carry the genetic identity of the donor. In general all materials that contain an individual’s genetic code or a substantial part of it is...
potentially re-identifiable and cannot be treated as de-identified or anonymised, because tracing the individual directly or through a family member whose data is contained on a genetic data base, including one of the many proliferating private data and tissue banks, has become increasingly possible. It is no longer possible to consider an individual’s genetic information as not potentially identifiable. There have been a number of cases of people conceived through anonymous artificial insemination being able to identify their genetic father through either the man himself or a relative being included in a genetic data base. Once a relative had been identified it proved relatively easy to establish which member of the family might have donated sperm, given the known timing and circumstances.

The ethical difficulties are further complicated if the products which the tissue is used to create (directly or indirectly) are made available only on a commercial basis. Tissue banks may remain in existence for a considerable time, and may be subject to commercial pressures, or may be amalgamated with other collections, or may wish to engage in relationships of exchange with tissue banks that have a commercial basis. In these ways commercial activity not envisaged at the time of donation may become a possibility later. If donation was made to a public resource then it is arguable that the intentions of the donor are not respected if the benefit is restricted by commercial interest or if there is a windfall profit to be made because the tissue contains a value that is unique or relatively unique to that individual, their family or other grouping. Such profits could undermine the willingness of people to donate tissue altruistically.

Providing relevant information and obtaining consent should be fundamental to the exchange of custody of tissues and any future commercial use. Information and consent processes should therefore aim to ensure that tissue donors are informed of downstream uses and commercialisation possibilities. The commercial use of human tissue products has been distinguished in practice from the commercial use of human tissue. However, it is a difficult distinction to make. What, for instance, is the difference between a cell removed from a person’s body and cells that have been grown in culture from that cell, especially if the genomic information remains intact? In these and similar scenarios, it would often be helpful for an agreement to be drawn up and signed when human tissue is exchanged – something akin to a Materials Transfer Agreement (MTA) that is routinely used in research when cells or genes or other important reagents are given to another laboratory. The MTA specifies what can and cannot be done with the biological material.

‘Attenuation’ offers a useful concept in making ethical decisions about commercial applications of tissue products. A tissue product may be considered to be attenuated in a subjective sense when it has lost significance to the donor and donor family. Objectively a product may be considered to be attenuated when it has lost significant properties such as cellular or genomic properties or, more contentiously, where the reason for inclusion does not use these significant properties. However, even if one accepts that attenuation differentiates a human tissue product such that it may justifiably be made available for commercial purposes, this should only occur within ethical guidelines that protect the interests of donors and their families and the interests of the community.

31 Ibid.
32 Ibid.
II. Post mortem donation

1. Current practice, legal structure and professional guidance in the United Kingdom and Ireland

In the Republic of Ireland in 2012 there were 239 solid organ transplants of which 207 came from 78 deceased donors (population rates of 52 per million population, 45 pmp, and 20 pmp respectively). This compares with 3,960 organ transplants in the United Kingdom between 1 April 2011 and 31 March 2012, of which 2,951 were from 1,154 deceased donors (62.1 pmp, 46.3 pmp and 18.1 pmp respectively). Thus the United Kingdom had fewer deceased donors than the Republic of Ireland, relative to the size of its population, but conducted more transplant operations.

In the United Kingdom there is no statutory definition of death. In the Republic of Ireland the draft Human Tissue Bill (2009) proposes a definition of death in relation to neurological criteria as ‘the irreversible cessation of all functions of the entire brain, including the brain stem’, but this has not passed into law. Thus in both countries the diagnosis of death is a matter of established practice codified in professional guidelines. In the United Kingdom in 1995, after a review by a Working Group of the Royal College of Physicians of London, the Conference of Medical Royal Colleges adopted a new definition of death. Death was defined as the ‘irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe’. It was stated that the irreversible cessation of brain stem function will produce this state and that ‘therefore brain stem death is equivalent to the death of the individual’. The 1995 definition of death was reiterated in the 2008 Academy of Medical Royal Colleges Code of Practice for diagnosing death, which sets out both neurological and circulatory criteria. In the Republic of Ireland neurological criteria for diagnosing death are set out in the 2010 guidelines of the Intensive Care Society of Ireland.

The legal and regulatory structure for post mortem organisation in the Republic of Ireland reflects what was said about live donation. However, in the United Kingdom, the legal and regulatory structures for post mortem donation are complicated by two factors. In the first place the Human Tissue (Scotland) Act 2006 diverges from the Human Tissue Act 2004 in how it conceptualises permission for use of body parts. It uses the concept of authorisation rather than consent. Furthermore, the remit of the Human Tissue Authority does not cover Scotland for the purposes of post mortem donation, as it does for live donation. In July 2013 the Welsh Assembly passed the Human Transplantation (Wales) Bill, which is due to come into effect in 2015. This introduces a system of presumed (‘deemed’) consent for taking organs post mortem. To complicate matters further, the Welsh legislation will have to be harmonised with the Human Tissue Authority Codes of Practice, and with the activities of NHS Blood and Transplant. It remains to be seen what difference the legislation will make to medical practice in Wales.

In 2013, both in the Republic of Ireland and in Northern Ireland there have been discussions about enacting presumed consent legislation for post mortem transplantation, but as yet no concrete legislative proposals have been tabled.

33 http://www.organdonation.ie/facts
34 http://www.organdonation.nhs.uk/statistics/
35 Code of Practice for the Diagnosis and Confirmation of Death (London: Academy of Medical Royal Colleges, 2008).
The management of donors who donate after diagnosis of death by circulatory criteria requires some decisions to be made while the patient is still alive. In England and Wales these decisions are covered by the Mental Capacity Act 2005 and in Scotland by the Adults with Incapacity (Scotland) Act 2000. In Northern Ireland, the Department of Health, Social Services and Public Safety produced a document in March 2011 on Legal Issues Relevant to Donation after Circulatory Death (Non-Heart-Beating Organ Donation) in Northern Ireland. In the Republic of Ireland this area is not covered by statute law and it was only in 2011 that the Beaumont Hospital Clinical Ethics Forum proposed guidelines for ‘Non Heart Beating Organ Donation’. These were endorsed by the Intensive Care Society of Ireland in 2012.

2. Ethical and philosophical issues

i. Goods of transplant medicine

The benefits of post mortem organ donation are similar to those of live donation. This is a form of medicine that saves and transforms lives. Furthermore, there are some kinds of benefit that are only possible with post mortem donation, for example heart transplant (even though a heart may come from a live donor as part of domino donation, this will always presuppose a previous post mortem donation).

As with donation from the living, donation after a person’s death is an expression of generosity on the part of the donor and also on the part of those who are bereaved. The sacrifice on the part of those who are grieving, and thus the generosity when they allow the transplant to go ahead, should not be overlooked. Indeed, if it is done well, post mortem donation can also be a consolation for people in grief, in that the person can continue to help others even after he or she has died. The gift extends beyond death. However, the language of gift needs to be used cautiously because it can be received as coercive by families if their refusal to allow donation is seen as somehow ungenerous, or the latter is implied.

ii. Catholic teaching on the definition of death

According to Catholic teaching, the soul is the principle of life, and death is therefore understood as the separation of body and soul. It is defined doctrine that human beings, body and soul, are good by nature and are created by God, and furthermore that the soul does not pre-exist the body but is created instantly when the body comes to be, forming a unity with the body. More specifically, the Councils of Vienne and Lateran V condemn those who deny that ‘the rational or intellective soul truly and in itself is the form of the human body (forma corporis humani)’.

The doctrine that the human soul is the form of the living human body implies that each human being has one soul. The same soul is the source or principle of mental life and the source or principle of bodily life. This excludes the idea that the soul is something extra or alien added to a living body, or is imprisoned within a body (as Plato thought). The human being has different powers – mental, emotional, physical – but all these are powers of a single being who has life in virtue of his or her soul.

From this understanding it follows that, while definitions of death might refer to the loss of mental capacity and/or to the loss of integrated functioning of the body, these two

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elements must be understood as aspects of a single event. This is exactly how John Paul II defines death:

‘The death of the person is a single event, consisting in the total disintegration of that unitary and integrated whole that is the personal self. It results from the separation of the life-principle (or soul) from the corporal reality of the person’. 38

The practical problem is how to relate the notion that death is the separation of the soul from the body to the empirical observations that indicate that death has taken place. The notion that is contained within the doctrine proclaimed at Vienne, and reaffirmed many times since, is that the soul forms and informs the matter to be the unity that is the human body. This unity, brought about by the soul, is demonstrated empirically by the integration of the living body as a functioning whole of the human kind. As a consequence of this doctrine, the empirical determination of death occurs when it can be understood that the unity of the body, in the dynamic sense of the parts of the body continuing to be maintained as a unified human organism, has disintegrated.

Historically, prior to the advent of artificial ventilation, loss of all brain function resulted in loss of spontaneous breathing and the latter led rapidly to cardiac arrest and loss of circulation, and similarly loss of circulation resulted in both the death of the nervous system and also loss of the endocrine system, so there was no temporal distinction between the outcome of circulatory and neurological criteria for death. With the advent of ventilation and the use of drugs such as inotropes to assist heart function and vasopressors which act on the blood vessels, the circulation of blood could be maintained for a short time after loss of all brain function. This led to questions about diagnosing death while breathing and circulation were maintained artificially. Was such a diagnosis possible? The question to be asked is whether, for a body in this condition, there is empirical evidence of the unity of the body continuing in the sense of the parts of the body being in communication with one another to constitute an integrated human organism.

In recent times some have contested the diagnosis of death on neurological grounds because some organs and tissue remain in communication with one another in patients who satisfy the neurological criteria for death. However, others have countered that this observation does not necessarily imply integration in the required sense, which is the dynamic unity of the whole organism and not just between some parts and some other parts.

iii. Diagnosing death by neurological criteria

Pope John Paul II provided an authoritative Catholic understanding of neurological criteria for death in his address to the Transplantation Society in 2000:

‘Here it can be said that the criterion adopted in more recent times for ascertaining the fact of death, namely the complete and irreversible cessation of all brain activity, if rigorously applied, does not seem to conflict with the essential elements of a sound anthropology’. 39

According to Pope John Paul II, there does not seem to be conflict with Catholic anthropology because the loss of capacity for brain activity ‘is considered the sign that the individual organism has lost its integrative capacity’. 40

38 Address to 18th International Congress of the Transplantation Society 29 August 2000, §4.
39 Address to 18th International Congress of the Transplantation Society 29 August 2000, §5.
40 Ibid.
In contrast, the definition of death put forward in the United Kingdom by the Academy of Medical Royal Colleges is flawed. It defines death as ‘the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe’. By the capacity to breathe is meant the ability to breathe spontaneously. The problem is not only that this definition does not explicitly specify that brain damage must underlie both these irreversible losses, but also that it appears to combine just one specific and particular element of brain function, and one specific and particular element of brain-mediated bodily function. The selected elements are certainly important, and individuals meeting these criteria may well meet sounder and more comprehensive definitions of death; but the arguably arbitrary selection of two individual elements of function leaves this definition – in many ways, one of the most important definitions there can be in clinical medicine – open to challenge. For example, other functions of the brain that cause integration of the body as a dynamic whole may persist, even though the person can no longer breathe spontaneously or be conscious. Of significance are the endocrine and neurological systems that depend on some functions of the brain if they are to keep all parts of the body in dynamic relationship to each other.

This is not to imply that the human person can be identified with the brain, but rather that the brain has a role on which the systems of the body depend. In diagnosing death by circulatory criteria there is a similar dependency on heart function. The heart is not the person, but is usually needed for the circulation to be maintained and when the heart irreversibly stops it is usually assumed that death has occurred. Neither the heart nor the brain is a ‘super organ’ but their function is usually needed for the dynamic unity of the parts of the body to be maintained. Thus death can be diagnosed when either the loss of all brain function or the loss of circulation is irreversible.

In relation to the understanding of death set out by Pope John Paul II, the description of ‘complete and irreversible cessation of all brain activity’ should be understood as applying to all activity that is related to the integrated functioning of the organism. The undirected firing of neurones is not ‘activity’ in this sense. Similarly ‘integrative capacity’ should be understood as the integration of an organism as a substantial living whole of the human kind, and not merely as the relating of one part to another. Some capacity for reflex reactions may remain in a body after death.

The acceptance in principle of neurological criteria for death had also been affirmed by the German bishops in 1990, and by the Commission of the Bishops’ Conferences of the European Community in 2007. Nevertheless, Pope John Paul II was clear that ‘with regard to the parameters used today for ascertaining death – whether the ‘encephalic’ signs or the more traditional cardio-respiratory signs – the Church does not make technical decisions’, and in practice, the safe use of neurological criteria depends crucially on these technical decisions.

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41 Academy of Medical Royal Colleges Code of Practice for the Diagnosis and Confirmation of Death (London: Academy of Medical Royal Colleges, 2008), 11.
42 Organ transplantations: Joint Declaration by the German Bishops’ Conference and the Council of the German Protestant Church (31 August 1990).
45 Address to 18th International Congress of the Transplantation Society 29 August 2000, §5; see similar remarks by Pius XII (Address to an International Congress of Anesthesiologists (24 November 1957), in AAS, 49 (1957)).
It is important to note that the concept of integration that the Pope applied is based on the doctrine proclaimed at the Council of Vienne. That concept incorporates the notion that the soul forms and informs the matter that constitutes the unity that is the human body. Disintegration implies loss of communication between the parts of the body such that they no longer constitute the dynamic unity of a living organism which, by virtue of the kind of thing it is, possesses a rational nature. The judgement of Pope John Paul II also depended explicitly on the empirical judgement that the loss of all brain function means that necessarily the individual organism has lost its integrative capacity.

This empirical judgement remains a matter of dispute among Catholic clinicians and theologians in good faith. Nevertheless, at least some of these differences seem to depend on two factors: first, some have not applied the doctrine of Vienne to mean that the soul forms and informs the matter to be a dynamic unity between all the parts. For some, any communication between parts is ‘integration’. Second, in most English speaking countries, including the US and the UK, there has developed a trend, over the past thirty years, by which death by the neurological criteria may be diagnosed by clinical tests showing loss of brain stem reflexes and loss of spontaneous breathing, even though some brain functions, such as the functions of the midbrain, may continue.

Apparent evidence of continuing integrative functions such as maintaining homeostasis in ‘brain dead’ patients may simply reflect a less rigorous standard for diagnosing death. This appears to be part of the reason why a panel formed by the Pontifical Academy of Sciences rejected empirical claims by a prominent US clinician that integrative functions continue in some patients whose death has been diagnosed by neurological criteria. The European members of that committee would have been more familiar with diagnosis which included measurement of blood flow to the brain rather than with the US and UK standard of clinical tests for brain stem function alone.

Criteria for diagnosing death vary between countries. The criteria used in the UK and in the Republic of Ireland are less rigorous than in other jurisdictions and this is a cause of concern for those donating, accepting organs, or working in transplant medicine. Because the UK and Irish criteria are based upon loss of brain stem function only, which results in irreversible loss of consciousness and irreversible loss of spontaneous breathing, some clinicians argue that other brain functions may continue. As discussed above, the standard that John Paul II described is more rigorous, in that it requires loss of all brain function. In the Republic of Ireland, while the proposed Human Tissue Bill defines death as ‘the irreversible cessation


of all functions of the entire brain, including the brain stem’, it is not clear that this will affect the way death is diagnosed in practice, for the draft legislation also states that ‘determination of death must be made in accordance with accepted medical standards’. In the Republic of Ireland, as in the United Kingdom, ‘accepted medical standards’ only require clinical testing of brain stem function. The implications of this for potential donors and recipients and for healthcare professionals are explored below.

As with all diagnostic interventions, it is important that in testing for loss of brain function, the patient is not subjected to unnecessary or undue risk. In particular, it has been suggested that the apnoea test (for ability to breathe spontaneously) has itself the potential to cause brain damage in patients who, if not dead, are in a very vulnerable state. Inasmuch as this is so, this test should be confirmatory following the results of other less invasive tests. The ethical injunction not to cause harm has greater force where the test is not directly for the benefit of the patient but for the benefit of others (either in relation to organ donation or in relation to the limited availability of intensive care facilities).

In many European countries, the diagnosis of death by neurological criteria includes as standard a test to show loss of blood supply to the brain. Loss of blood supply can be demonstrated by an angiogram (by contrast injection or more reasonably CT angiography) or by Doppler ultrasound. An additional advantage of doing this kind of ancillary testing is that the family can see an image that shows loss of blood supply to the brain. That can be more compelling and more significant for their ongoing grief processes than the simple verbal assurance that clinical tests indicate loss of brain stem function. There is nothing observable for the family in relation to the latter. They are asked simply to accept the medical diagnosis. In the current circumstances of medical criteria based not on loss of all brain function, as the moral situation requires, but on loss of brain stem function, it has become problematic for donors, their families and recipients to rely on the medical claim without evidence.

iv. Elective ventilation

Elective ventilation is the term given to artificial ventilation of the lungs in a variety of situations and in the context of organ donation is sometimes used to mean initiating or continuing ventilation in a dying patient so that, if death were subsequently to occur, this would then happen in a context where it could be confirmed clinically by neurological criteria and organs could be harvested. The ethical issue with elective ventilation is that it seems to represent the provision of treatment that is not for the benefit of the patient being ventilated but for the benefit of the future recipients of the patient's organs. Elective ventilation in these circumstances is not of therapeutic benefit and should be evaluated in a similar way to live donation. If there is express consent and the ventilation does no significant harm, then it may be ethically justified. However, if there has been no specific consent then ventilation should only be initiated or maintained if it is in the patient's overall best interests.

48 Note that in Australia, the law in most State jurisdictions defines death by the neurological criteria as irreversible loss of all brain function, but the Australia and New Zealand Intensive Care Society adopts medical criteria that allow death to be diagnosed by the clinical tests for brain stem function alone (Australia and New Zealand Intensive Care Society (ANZICS) Statement on Death and Organ Donation 2008 p.11).

Some clinicians have voiced concern that ventilation may precipitate a state of persistent unconsciousness. From a Catholic perspective it is important to emphasise that this would not be a state worse than death. Nevertheless, the possibility of this outcome is one of which patients should be aware and this is a further reason why, as a general rule, non-therapeutic elective ventilation should not be initiated without express consent. In contrast it can be reasonable to allow a degree of flexibility in the timing of withdrawal of ventilation once it has been decided that ventilation is futile; for example, to allow conversation with relatives or to facilitate donation where this is what the patient would have wanted. Such flexibility may be essential if donation is to occur after diagnosis of death by circulatory criteria.

Consent to organ donation post mortem is not itself consent to elective ventilation or other methods of organ support unless the person was aware of this as a possibility, or at least was aware of the possibility of ante mortem procedures in general, and consented in the full knowledge of this.

However, it may be the case that a relative knew the views of the patient well enough that he or she could make a reasonable judgement that the patient would have wanted the non-therapeutic procedure of ventilation for the purpose of preserving organs for transplantation.

Consider the circumstance in which a patient had agreed to living kidney donation to his niece, but having done all the preliminaries, he had then become too sick with heart disease to be considered a living donor. His illness then progressed until he was no longer able to make decisions. A decision was made to withdraw ventilation when the question of the original decision for living donation was raised. In such a case it would be reasonable to assume that continuing ventilation to preserve his kidney would be consistent with his original desire for much more intrusive surgery to take one of his kidneys while alive.

v. Diagnosing death by circulatory criteria

In recent times, there has been a renewed interest in obtaining organs for transplantation after death as diagnosed by circulatory (cardiac) criteria. In the United Kingdom this has risen from 8% of post mortem donation in 2002-03 to over 40% in 2011-12.50

The reality, in relation to death by neurological criteria, is that only 2% of deaths occur in monitored environments and following loss of all brain function. Much more commonly, death occurs after loss of cardiac function. That may happen in monitored circumstances, and may happen as a result of withdrawing life support. Where it is thus predictable, arrangements may be made beforehand to have the surgical teams available to procure organs soon after cardiac function ceases. This would allow for the procurement of solid organs such as hearts, lungs, livers and kidneys, which would otherwise have deteriorated such as to be unusable, because of the time-gap between loss of cardiac function and the availability of the surgical team.

The decision to cease life support should of course be made by physicians not linked to the organ transplant team, and should be made independently and on ethically acceptable grounds such as that the patient considered the treatment to be overly burdensome. It would only be after the decision had been made that the issue of obtaining organs for transplantation could be

addressed. Similarly it is important that decisions about how to withdraw treatment are not unduly influenced by considerations of organ donation. For example, in a particular case, optimum comfort of the patient might indicate that it was best to maintain ventilation of a patient and maintain adequate sedation while withdrawing inotropes and/or vasopressors. This would avoid the possibility of trauma or distress which might be caused by abrupt asphyxia brought on by pulling out the endotracheal tube. However, such a manner of death might extend the warm ischaemic time and adversely affect the usefulness of the organs for donation. From an ethical perspective, the manner of withdrawing treatment must never directly intend to accelerate the dying process and must give first consideration to the care of the dying patient rather than the use of the organs after death. It also needs to be the case that the decision to withdraw is legitimately based on the treatment being overly burdensome or futile, in the sense that it is ineffective, rather than being a decision to end life.

A second issue concerns how soon after cessation of cardiac function it may be permissible to declare death and remove the organs. There is some variability depending on circumstances as to when it can be declared that the loss of cardiac function is irreversible. For instance, neonates can survive a significant period without cardiac function, whereas for adults the period may be much shorter. There has been some attempt to specify a number of minutes, but that does not reflect the variability. It might be possible to declare loss of cardiac function to be irreversible within ten minutes (let us say) in an adult, given the particular circumstances, but a longer period may be required for a neonate. The cause of the loss of cardiac function is also relevant. An advancing disease process such as ischaemic heart disease or metastasized cancer resulting in loss of cardiac function is unlikely to be recoverable.

A study of out-of-hospital cardiac arrest in 1993 showed that the probability of successful resuscitation declined from 67% immediately after the arrest, to zero at around 12 minutes.\textsuperscript{51} Data from such studies is not necessarily applicable to guidance on the diagnosis of death by cardiac criteria, given that the disease process that leads to death has a bearing upon the irreversible nature of cessation of cardiac function. Nevertheless, if a patient could potentially be resuscitated successfully after ten minutes then clearly he or she should not be declared dead before that point. It is noteworthy that guidance on ‘stand-off time’ between cessation of cardiac activity and declaration of death (and subsequent organ retrieval) varies considerably. In Italy in 2010 the National Bioethics Committee advised against reducing the statutory requirement of 20 minutes without heartbeat for the determination of death, though they were of the opinion that a ‘ten minute period of absolute lack of cardiac activity – ascertained with certainty – is to be considered an element of high likelihood of the death of the human being’.\textsuperscript{52} The same report found that in Switzerland and Holland a ten minute stand-off time was observed whereas in Spain, France and the United Kingdom the time was five minutes and in some hospitals in the United States, only two minutes. In Australia, The National Protocol for Donation after Cardiac Death states, ‘Death should be determined on the basis of immobility, apnoea, absent skin perfusion and the absence of circulation for a period of not less than two minutes and not more than five minutes. The absence of circulation is ideally determined by clinical means supplemented with intra-


\textsuperscript{52} National Bioethics Committee of Italy (20 July 2010): \textit{The criteria for ascertaining death}, section 4.2.
arterial pressure monitoring if available.\textsuperscript{53} It should be noted that the adoption of the Australian standard was on the basis of excluding the possibility of spontaneous recovery and did not include the possibility of successful resuscitation after that time. There is a difference between saying that loss of cardiac function is \textit{irreversible}, even if resuscitation were attempted, and saying that loss of cardiac function is \textit{permanent} because a decision has been made that resuscitation will not be attempted. One cannot rightly claim that death has occurred if cardiac function could be restored, even if a decision has been made not to do so. Otherwise such a decision might be reversed after death had been diagnosed.

The current definition of death that applies to this context in the United Kingdom and other jurisdictions is \textit{irreversible} loss of circulation.\textsuperscript{54} A question arises when the loss of circulation follows withdrawal of life-support but it remains possible that resuscitation and restoration of life-support could restore circulation. The suggestion has been made that the law should be changed to accommodate those circumstances with the word ‘permanent’ replacing the word ‘irreversible’. Loss of circulation could be said to be permanent if there had been a decision not to resuscitate and not to restore life-support. In those circumstances loss of circulation would not be necessarily irreversible but it might be permanent in those terms. What ‘permanent’ would mean, in that case, is that cardiac function would not be restored spontaneously and not that it was irrecoverable.

It is premature to declare that death has occurred while it remains possible that heartbeat and circulation \textit{could be restored} by resuscitation. One could imagine a set of circumstances in which the decision to withdraw life support was challenged by a relative, with the result that life support was re-introduced after death had been declared. If intervention succeeded in restoring circulation (and the patient retained some brain function) then clearly he or she would not have been dead. Diagnosis of death should correspond to an irreversible physiological state, not to a reversible decision by others that it would be convenient to treat someone as \textit{though they were dead}. The suggestion that we refer to permanent loss of circulation rather than irreversible loss of circulation would not seem to be ethically acceptable. In determining moral certainty of irreversibility, the test should not be whether spontaneous resuscitation is no longer a realistic possibility, but when a judgement was made with moral certainty that attempts at resuscitation would not succeed.

There is a problem with legally or ethically specifying a minimum timeframe because the circumstances can vary so much. If a patient suffers an arrest from the progress of a known and predictable illness, such as stroke, ischaemic heart disease or cancer of the lung or airway, it can be the case that the treating team can be reasonably certain that there would neither be spontaneous recovery nor would attempts to resuscitate succeed. In those circumstances a much shorter time would be permissible than in those circumstances in which the cause of the arrest may not be so certain. Then there are the circumstances of children, especially neonates, who have been known to survive significant periods without circulation. Notoriously, hypothermia can also significantly extend the time beyond which successful resuscitation can still occur. It would seem more appropriate that the judgement as to whether resuscitation is achievable be a clinical decision at the time, perhaps with the requirement that it be a decision arrived at independently by two experienced practitioners.

\textsuperscript{53} http://www.donatelife.gov.au/Media/docs/DCD%20protocol%2020020311-0e4e2c3d-2ef5-4dff-b7ef-af63d0b6a8a-1.PDF
\textsuperscript{54} Academy of Medical Royal Colleges \textit{Code of Practice for the Diagnosis and Confirmation of Death} (London: Academy of Medical Royal Colleges, 2008),12.
vi. May hearts be transplanted after diagnosing death by circulatory criteria?

There is an obvious problem, at least conceptually, in donating a heart after diagnosing death on the basis of irreversible loss of circulation. Clearly if the heart could be transferred to someone else then it was still capable of functioning and this raises questions about the irreversible nature of the loss of circulation. If the heart can be restarted in another body, why not in its own body?

Of course, the loss of circulation might have been brought about by factors extrinsic to the heart itself and thus a heart which failed in one body may function properly in a different body. For the heart to function there does need to be stimulation of the heart muscle to continue beating. Thus for instance a person may be dependent upon chemical stimulus from inotropic drugs or even a pacemaker. The withdrawal of either of those could result in loss of cardiac function. There would be a question over whether that loss of cardiac function in this body was irreversible, however. There would also be a question about whether withdrawal of those forms of life-support would be justifiable. In Catholic teaching, treatment may be withdrawn if it is overly burdensome, or if it is futile, i.e. ineffective. Obviously if a treatment is capable of maintaining cardiac function, it is not futile, although it may be overly burdensome.

vii. Consent for ante mortem procedures

The management of donation after diagnosing death by circulatory criteria (conventionally referred to as ‘donation after cardiac death’, DCD) requires that preparation occur before the person is dead. Thus conversation and permission for donation must occur, either with the patient or with the family or another representative, while the person is still alive. Similarly, while the organs are only taken after death, the patient must be prepared for surgery and taken to theatre while still alive. Doctors may also wish to provide procedures to the patient not for the sake of the patient but to preserve the organs so they are more suitable for transplantation. Often it is proposed that large cannulae be inserted into the femoral arteries, and the patient may be given anticoagulants. But those treatments are non-therapeutic and that means that doctors may not act without the consent of the patient, unless the family or others can provide information to show that had the patient been adequately informed about what would be involved the patient would have wished it. Non-therapeutic treatment of someone who cannot currently consent can only be given with prior consent or when it is in the patient’s best interests.

These ante mortem procedures should be treated in the same way as we treat live donation and elective ventilation. They are non-therapeutic procedures and should only be performed if the person volunteers and if the procedures do not subject them to undue risk. One cannot make an altruistic choice on behalf of someone else. Consent to these procedures thus cannot be given on behalf of another and consent to post mortem donation is not consent to these procedures unless the person was previously adequately informed. Thus it may be the case that a patient has indicated a desire to be an organ donor and understood that that would involve ante mortem procedures. In those circumstances the family or the representative might have grounds for saying that the ante mortem procedures were in the patient’s best interests because the patient wanted to be an organ donor, understood what was involved, and was prepared to accept procedures that were not instituted for his or her sake but for the sake of the potential recipient.
viii. Diagnosing death in children

The diagnosis of irreversible loss of circulation in an infant is problematic because of the longer possible survival time following loss of circulation. The clinician diagnosing death needs to be confident that circulation could not be restored. Diagnosis of death in children by neurological criteria also poses a challenge because of the greater plasticity and developmental potential of the child’s brain. It is noteworthy that many of the exceptional cases collected by the neurologist Alan Shewmon, on the basis of which he has cast doubt on the reliability of neurological criteria for death, involved diagnosis of death in children. That children may recover after longer periods of loss of circulation than adults, and that the disease process leading to loss of circulation may result in different periods of possible recovery, indicates that it is unwise to specify a fixed time period. It would be better to stipulate that two independent experienced physicians make a clinical decision that in the circumstances it is morally certain that the loss of circulation is irreversible.

ix. Consequences in relation to different organs

This report has highlighted challenges in the determination of death prior to the removal of organs. These challenges are different for neurological criteria and circulatory criteria, different according to the regulatory regime of different countries and different according to whether the potential donor is an adult or a child. They also have different consequences in relation to donation of different organs.

Donation of corneas can occur some time after death at a time when concerns raised above in relation to the diagnosis of death are no longer relevant. On the other hand, heart transplants are completely reliant on the availability of criteria for death which can be applied with certainty either while the heart is still beating or within a few minutes of its cessation.

Kidneys both deteriorate less rapidly post mortem (than the heart) and also may be obtained ethically from the living, and hence a posteriori from one who seems to be dead but may in fact be living. On the other hand, the effectiveness of kidney donation is dependent on the length of time without oxygenated blood, and methods to preserve the condition of the kidney while in situ (for example, by cold perfusion) would require consent, if performed ante mortem. Hence, in relation to the actual conduct of the donation, clarity about determination of death is essential.

Lungs and the liver fall somewhere between kidneys and the heart. There are procedures by which a lobe of the lung or a lobe of the liver could be taken from a live donor. However, these are considerably more hazardous for the donor than harvesting a kidney and are hazardous also for the recipient. These procedures are also markedly different from whole lung or liver retrieval from dead donors. The rate of deterioration post mortem is also greater in the liver or lung than in the kidney. Of course, a whole lung or liver can only be taken from a donor who is certainly dead (except as an incidental element of domino donation).

x. Consequences for donors, recipients, and healthcare professionals

From the discussion so far, it is evident both that confidence in criteria for determination of death is essential to support for post mortem organ donation, and that serious concerns have been raised about these criteria. Concerns of slightly different kinds have been raised in relation to neurological criteria and in relation to circulatory criteria. Pope John Paul II provided clear teaching that endorses a theoretical basis for whole-brain related neurological criteria. However, this teaching does not show that the practice of diagnosing death by neurological criteria in the UK or in Ireland is in fact adequate, given that the established medical practice is based not on loss of all function of the brain, but on loss of brain stem function, while in practice the latter may be diagnosed on the basis of clinical tests alone. Furthermore, there are striking differences in practice internationally in relation to both neurological and circulatory criteria, both concerning what tests are required and what measure, magnitude and duration is deemed necessary. An obvious example is the duration of the stand-off time for determining death by circulatory criteria: is two minutes deemed adequate (as in the United States) or is ten minutes deemed inadequate (as in Italy), or should it be the case that this be left to a clinical judgement depending on the circumstances rather than stipulating a minimum legal or ethical timeframe?

Notwithstanding the common practice of organ transplantation among the medical profession internationally, its approval by legislation and regulatory bodies, and the support and encouragement that various popes have given to the practice, these reasonable concerns place on people a duty to inform themselves before making decisions to donate, or to accept, or to transplant organs.

In relation to donation after death, people should consider how death is determined and what the practice of organ retrieval involves (before and after death), before consenting to donate. They should also share their views with those close to them, for in practice organ retrieval is unlikely to go ahead without the support (or at least, lack of opposition) of the family.

In those jurisdictions, such as the UK and the Republic of Ireland, which use a less stringent standard for the diagnosis of death by neurological criteria than loss of all brain function, it has been suggested that the standard specified by Pope John Paul II is not necessarily met. The UK and Irish criteria derive from the proposition that loss of brain stem function is sufficient, in itself, to imply the loss of all brain function, and thus to fulfil the ‘whole brain’ standard. This may commonly be so; for example, if the circumstances are such that tests for brain stem function are a final step in assessing the extent of brain injury involving other parts of the brain, and confirms that the damage to the rest of the brain is such that it extends to include the brain stem. Such a determination depends on the location and nature of the injury. However, ‘commonly’ is not ‘necessarily’: it is possible that the brain stem may have been destroyed, but that other parts of the brain are still functionally intact, and in those circumstances the criterion that there be ‘loss of all function of the brain’ has not been fulfilled. It should be acknowledged that many jurisdictions internationally have rejected definitions of death based only on the brain stem, or criteria based only on such definitions.

If someone is in doubt whether the criteria used in his or her country provides moral certainty that death has occurred then that person should not place his or her name on the Organ Donor Register. However, even in these circumstances a potential donor might specify that organs and tissue may be taken if the family members are satisfied that there
is a loss of all brain function. This could happen if, for example, ancillary tests were done and the family were supplied with images that showed loss of blood supply to the brain, or alternatively, if the circulatory criteria for death were applied in a way that convinced the family that loss of circulation was indeed irreversible. Furthermore, even if the family were not confident of the diagnosis of death, this would not rule out all donation. Depending on the processes adopted, because tissues such as skin, blood, bone and corneas remain viable for a longer period without circulation, it may be possible for a family who did not feel able to consent to solid organ transplant to consent to those other tissues being taken a reasonable time after death has been diagnosed.

In relation to accepting an organ, a person should not accept an organ if he or she is in doubt as to whether the donor was or would be dead at the time. There is a difference between choosing to be a donor and choosing to accept an organ. Whereas someone may have knowledge about the circumstances in which they would be willing to donate, they may have no knowledge of how an organ was obtained. In general, the degree of moral certainty needed to accept an organ should be greater than that required to donate, because it would not be right to profit from harm or the risk of harm to another. Clearly to make these decisions well takes courage and honesty as well as prudence, for someone’s conclusion may be that it would not be right for them to accept an organ. This decision is more difficult still if the person has dependents, and the benefits or risks to others should also be considered before making a decision. However, no-one should accept an organ if they know it is likely to have been obtained in procedures that were commenced before there was moral certainty that the donor was in fact dead. Nonetheless, patients receiving an organ are unlikely to know the actual circumstances or the tests used to diagnose death and might simply make known their view that they would not want to receive an organ if there was any doubt about whether the patient had satisfied adequate criteria to establish irreversible loss of circulation or irreversible loss of all brain function.

There have been suggestions that a person should not be permitted to be a recipient of organ transplantation unless they or their relatives have previously consented to being donors themselves. With respect to requiring the family members to be registered donors, this is obviously unfair. A person cannot be held to be responsible for the decisions of their family members, nor should they be penalised for not having family members who could have consented to be donors. In relation to the consent to being a registered donor on the part of the potential recipient of organ transplantation, the matter may be made complex by the reasons for not registering, such as being concerned that close relatives may not understand what is involved or that the relatives have objections not shared by the potential recipient. Finally, the premise of such a requirement is based on the idea of trading registration of family members or of the individual for access to transplanted organs. All the concerns raised above about trade in human organs and tissue would apply even though what is involved here is not a matter of monetary exchange: it is still trade, with all the complications and the moral significance of trading in human organs as something that lacks respect for the person who has died and for their body.

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56 It is not the intention of this report to set out particular criteria for diagnosis of death or to argue that particular ancillary tests, as are used in other jurisdictions, are necessarily required for moral certainty of death in every case in the UK or Ireland. The point here is only that, from an ethical perspective, the donor and/or the donor’s relatives should only consent to donate unpaired vital organs where they have moral certainty of death. The example of further ancillary tests in this paragraph is given, not to lay down general requirements, but as an instance of evidence some people may need in order to be certain in the particular circumstances.
Healthcare professionals should make the life and health of their patient their first concern. Hence doctors and nurses should be involved with organ transplantation if and only if they are satisfied that this is ethical both at those stages of the process with which they are directly involved, and at those stages which are the prerequisites of the process as a whole. Individual clinicians must not remove vital organs unless they have moral certainty that the person is dead, or unless the removal of organs would be acceptable in the case of a living patient (for example the taking of one kidney, with informed consent).

One of the difficulties that a conscientious health professional may face is being expected to cooperate with organ harvesting procedures and transplantation in circumstances in which he or she is not certain that reliable criteria have applied in the diagnosis of death by colleagues. There may be a need to indicate conscientious objection and to do so in a timely manner so that those organising staffing schedules are able to make appropriate arrangements so that the health professional is not put in a position of being asked to cooperate in procedures about which he or she has moral concerns. Within a workplace, a person exercising a right to conscientious objection also needs to respect the consciences of others. Thus for instance it would be problematic for a health professional to go to the relatives of someone in whom death had been diagnosed by dubious but nonetheless accepted criteria, and to express doubts about that decision by colleagues. His or her own witness, in terms of recording a conscientious objection in relation to his or her own conduct in not wishing to cooperate, would seem to be all that is required. Of course, the health professional might choose to be involved in advocacy outside the institution to seek to change the current practices.

In general, all people of good will have a duty to inform themselves of the ongoing debate surrounding the diagnosis of death and organ transplantation. People must make a judgement in conscience about what they should do given their understanding of the current evidence. We need to bear in mind that the Church is by no means opposed to cadaveric organ transplantation in principle, nor to diagnosing death by ‘whole brain’ criteria. At the same time, we each need to recognise that our sincere judgements made in good faith at the present time may need to be re-appraised in the future in the face of any evolving evidence.

Consent and presumed or ‘deemed’ consent

As a matter of history, in times of plague, many European countries made bodies of the dead the property of the state to ensure that relatives could not stand in the way of disposal of the bodies for infection control reasons. Those laws are part of the background behind differences in relation to obtaining organs after death for transplantation. In modern times, if the body belongs to the State, then it is up to the State to authorise the removal of organs and tissues for transplant or other purposes. In those countries that had legislated in that way, consent to organ donation may be presumed. It is then up to the family to launch an objection to prevent organ procurement going ahead automatically (this is sometimes called an ‘opt-out’ system). In some countries the family is not even allowed an objection, and a valid objection can only come in advance from the deceased (this is called a ‘hard opt-out’ system, as opposed to a ‘soft opt-out’ where the family is able to object).

In English speaking jurisdictions, the law typically continues to recognise the need to obtain consent for procuring organs and tissues. Thus we have some jurisdictions, such
as France, Austria, Spain and Sweden, practising opt-out and some, such as the English speaking jurisdictions, where the law requires explicit consent i.e. opting-in. This difference is often alleged to be a reason for some countries having higher organ donation rates. However, the differences in donation rates do not uniformly reflect differences in relation to presumed consent. For instance, Sweden has a relatively low donation rate even though it has adopted presumed consent.

There would seem to be other factors that are important. For instance, in Spain, there has been a concerted effort to make approaches to people who have potentially terminal illnesses and to discuss the possibility of organ donation in the event of death; there have also been concerted public education campaigns on the issue. It is also the case that several of the countries, including Spain, that have comparatively higher donation rates also have stricter practices in relation to diagnosing death by the neurological criterion. Most countries with higher donation rates also require ancillary testing showing absence of blood flow to the brain, and do not rely on the clinical criteria for brain stem function alone. It may well be that there is greater public confidence in the diagnosis of death by health professionals in those countries, and that this has led to greater acceptance of organ donation.

Despite the differences that occur in the legal and regulatory structures in relation to consent, the differences in actual practice tend not to be so great. Where the law presumes consent to donation unless the ‘donor’ has opted out, it is often the case that specialist nurses, ICU doctors or transplant coordinators still seek to inform the relatives in much the same way and tend not to take organs if there is a negative reaction from relatives of the dead. The common medical approach thus seems to have regard to the needs of the relatives once the patient has died. There is a reluctance to confront family members at the time of death of a relative when there may be a difference of opinion amongst them over procuring organs or over the diagnosis of death. Even where the patient had given consent, the teams would be reluctant to override the wishes of relatives who expressed great difficulty accepting the decision. To some extent this is simply a matter of taking good care of the relatives pastorally and emotionally at a time of great grief. It may also be a practical matter in that acting without the patient’s prior consent may cause negative publicity and public hostility to organ donation when the practice so much depends on good will.

The practice of respecting the wishes of relatives does, however, raise ethical concerns about the wishes of the person who wants to donate being overridden. Should their wishes, in life, about their own body not override the wishes of a relative? On the other hand, after death, the donor is no longer in a position to adjust his or her view to accommodate the needs of the relative. It may also be the case that the relative may have concerns about the practice of which the donor was unaware at the time of donation, such as doubts about the diagnosis of death. It may be that the decision to donate was not in fact a fully informed choice, especially in relation to the diagnosis of death. The evidence suggests that many people are unaware that organs may be taken from what is, in reality, a beating heart donor, and many people who consented to donation of the organs of a relative after death, in responding to surveys, have indicated that they did not think that death had really occurred until the heart actually stopped beating in the operating theatre during the harvesting process. Many are unaware, at the time of consenting to their organs being taken, that this will mean that their relatives will be expected to make their farewells in the intensive care unit while the heart is still beating and their family member looks alive
and merely asleep, albeit maintained on a ventilator. The information campaigns about becoming an organ donor by signing the organ donor registry or completing a donor form seldom explain the loss that is involved in not being with someone in that quietness that occurs after death by loss of circulation, nor do they usually explain that death according to the brain criterion results in beating heart donation. What then happens in the intensive care unit can be quite a shock.

The latter scenario is quite likely, given how little information is available to potential donors at the time that they complete the kind of donor form that is available online or from the government. In particular, many people at that time have given little thought to what donation means and that the organs may be taken in circumstances in which the relatives may not be completely sure that they are dead. Little has been done to explain to people what is actually involved in diagnosing death by the different criteria or the differences of opinion that exist about such diagnosis. Few realise that organ donation may mean saying farewell while the heart still beats, and artificial ventilation continues. Few seem to expect donation after death to involve the concept of a ‘beating-heart cadaver’.

From an ethical perspective, the Catholic Church has insisted that explicit consent from the donor or the family of the donor is essential as a matter of respect for the person who has died. Without that consent, the practice becomes taking and getting rather than giving and receiving organs, and it involves a lack of respect for the person who has died for their body to be treated as a commodity in that way. The notion of altruism and of giving organs and tissues is important to preserving human dignity. Pope John Paul II wrote that allowing the body to be used as an ‘object’ is to violate the dignity of the human person. He went on to say:

This first point has an immediate consequence of great ethical import: the need for informed consent. The human ‘authenticity’ of such a decisive gesture requires that individuals be properly informed about the processes involved, in order to be in a position to consent or decline in a free and conscientious manner. The consent of relatives has its own ethical validity in the absence of a decision on the part of the donor. Naturally, an analogous consent should be given by the recipients of donated organs.

It is highly regrettable that in 2013 the Welsh Assembly took the decision to enact legislation to introduce a hard opt-out system in Wales. It is the ethical duty of healthcare professionals in Wales to be sensitive to the needs of relatives to whom they also owe a duty of care, notwithstanding this inhumane legislation.

xii. Consent in children and those with incapacity

A person who is a child and too immature to consent or an adult who is incapacitated such that he or she is unable to consent may still be able to provide an organ after death where someone in a requisite relationship to the person consents to the procurement of the tissue. This stretches the idea of ‘donation’, but where a child cannot consent it is the proper role of a parent to take decisions on their behalf, and the relationship of a carer to an incapacitated adult is somewhat analogous (though not in all respects). The consent of a parent or guardian, because of their interest in the represented person and their presumed

58 Address to 18th International Congress of the Transplantation Society 29 August 2000, §3.
love for them, preserves the notion of respect for the person who has died. Consent from a parent or carer is quite different from sequestration of bodies by the State without express consent of the deceased or of those who knew them best, in such a way that the bodies are seen as just a resource to be exploited by the State.

xiii. Payment and other incentives to donate

As discussed earlier in regard to live donation, trade in human tissue is not ethically permissible. If donation caused additional expenses, it would be reasonable to cover such costs. However, seeking to encourage donation after death with financial incentives, for example by paying for funeral expenses, raises the issue of treating the human body after death as a commodity and thus failing to respect the person who has died. Also it would disproportionately affect poorer people and could endanger the positive ethos of donation. Before including the social capital in existing systems based on altruistic donation, accessibility to transplant organs on an equitable basis, and avoiding perverse incentives, in the nineteenth century, bodies for medical training were often obtained from the destitute who could not afford funeral expenses. This association contributed to a strong cultural resistance to allowing bodies to be used in this way, which in turn fostered serious abuses including grave robbery and, occasionally, murder. There are clear social dangers with linking ‘donation’ to the inability to afford a decent funeral.

xiv. Is post mortem donation ever a duty?

In our current circumstances, in which some people have reasonable concerns regarding the diagnosis of death, either by neurological criteria or by circulatory criteria, one can hardly argue that organ donation could be a duty. There may also be legitimate concerns about the effect of ‘beating heart donation’ on family members and close friends. They lose the opportunity for attending their relative at the time when circulation stops and there is a peacefulness of the body after death. Organ procurement can be significantly disturbing.

Abstracting from concerns about diagnosis of death, while the donation of organs and tissues after death (properly diagnosed) does no harm to the dead (a point made long ago by St Augustine59), it may have a significant impact on family and friends.

As discussed, in the circumstances of death being diagnosed by the neurological criteria, the family say their goodbyes in the intensive care unit which, they might suppose, is keeping the patient alive: the heart still beats and breathing is maintained on a machine. In the case of circulatory criteria, death typically will occur in an operating theatre following withdrawal of life support measures, and again the family will be excluded. This is a significant sacrifice for them and should not be regarded as a duty. There are also often other cultural and religious factors that may affect the way in which the donor or the family regards organ donation. Some cultures do not find organ donation at all acceptable, especially if it interferes with the rituals that are designed to show respect for the dead and that are an important aspect of grieving. Some people will not accept death diagnosed by neurological criteria at all, no matter how it is diagnosed.

As with live donation, while there is no universal or objective duty to donate after death, there may be a duty in charity that may be recognised by the person and by their family.

As such duties cannot be presumed or generalised, it is important that people discuss donation while they are alive. If the family know that the deceased wished to donate, and that this wish was informed and had been discussed with relatives, then they have a *prima facie* duty to permit this to happen, provided that the relatives are satisfied that death has indeed occurred and the practice is morally acceptable.

**xv. Distribution of organs**

The distribution of organs should be based on the medical assessment of relative need, urgency and outcome, and how long a person has been on the waiting list. It is important to identify factors that should not be taken into account, such as:

a. race, nationality, religious belief, gender, marital status, sexual orientation, social status, disability or age (except where conditions associated with the patient’s age or gender directly determine the likelihood of a poorer outcome);

b. willingness of family members to be donors (after death);

c. need for a transplant arising from the patient’s past behaviour;

d. capacity to pay; or

e. willingness to participate in experimentation, except where it is a trial for a novel transplant procedure that requires follow-up and audit.  

There are differences of opinion about whether consideration should be given to a person who has dependants, such as a mother of young children. Saving her life or restoring her health so obviously has such a significant effect on the lives and health of those children: there is no substitute for a natural mother in the life of a child. However, there is no consensus on such matters.

**xvi. Use of fetal and embryonic tissue and cell lines**

A major difficulty with the use of fetal tissue is complicity with the practice of abortion. In order for the tissue to be usable, arrangements need to be made beforehand to perform the abortion in such a way, and procure and process the tissue in such a way, as to identify and obtain the specific tissue required, and to prevent its deterioration if left in a warm ischaemic state. That requires a connection between those performing abortions and those wanting to obtain the tissue for research or other medical or transplant purposes. The arrangements may mean using an abortion procedure that delivers the fetus intact to facilitate procuring particular organs or tissues, rather than by more usual methods that dismember the body, such as suction or other instrumental curettage.

The mother’s consent is required and that means informing her about the uses and obtaining her consent at a time when she could still change her mind about destroying her unborn child. The fact of informing her and obtaining consent to a useful outcome to assist others may have a significant effect on whether she continues her pregnancy. The fact that from a situation of moral and emotional difficulty a benefit to others may result could be very influential in motivating her to have that abortion.

The complicity of those obtaining the tissue with the abortionists and the women would render the usual circumstances of obtaining fetal tissue unacceptable. It does not appear
possible that the tissue could be obtained after the abortion without that complicity. For one thing, the woman’s consent would need to be obtained prior to abortion in order to make the procurement arrangements possible.

Even greater complicity in moral evil is involved in deliberately forming human embryos for the purpose of harvesting embryonic stem cell lines and thus destroying the embryos in the process. There are also issues involved in the potential exploitation of women to obtain their eggs to create embryos. This way of deriving stem cells contrasts with adult stem-cell technologies and with ‘induced pluripotent stem cell’ technologies, neither of which have the same inherent ethical problems, and both of which hold great scientific and therapeutic promise.

Suggestions have been made about obtaining embryonic stem cell lines from embryos left over as ‘surplus to requirements’ on in vitro fertilisation programmes. Worldwide there are literally hundreds of thousands of embryos that are in that predicament after their parents have achieved the family they want, or because the parents have left the programme such as for health reasons, financial reasons or because they have separated and both no longer consent to seeking to achieve a pregnancy using the embryos formed from the gametes of each.

Using embryos that are likely to be doomed to being withdrawn from storage and destroyed has been supported by some researchers as a practical solution and supported by some politicians. After all, the embryos will die in any case. The ethical parallel is with people who may be dying in an intensive care unit. The fact that someone is dying does not justify using them for non-therapeutic or destructive research. Until they die they are owed the same respect for their life and dignity. Similarly, dying embryos ought not to be treated as mere objects to be treated in a utilitarian way simply because they will or may soon die.

The Congregation for the Doctrine of the Faith (CDF) has clarified that the ‘criterion of independence’ is not sufficient to ensure that the person may use ‘biological material’ which others have obtained by means of that injustice. This is particularly the case when the system that gave rise to the injustice is ongoing. Hence ‘there is a duty to refuse to use such ‘biological material’ even when there is no close connection between the researcher and the actions of those who performed the artificial fertilization or the abortion’. Nevertheless, there can be exceptions to this: ‘Grave reasons may be morally proportionate to justify the use of such ‘biological material’. Thus, for example, danger to the health of children could permit parents to use a vaccine which was developed using cell lines of illicit origin, while keeping in mind that everyone has the duty to make known their disagreement and to ask that their healthcare system make other types of vaccines available.’

If treatments are developed using methods that involve the exploitation of human embryos, then this would pose significant difficulties, particularly for the parents of children. Distance in time from the original exploitative use, as is the case with some contemporary vaccines developed from aborted fetuses, reduces the element of cooperation with the original immoral practice, but still leaves some obligation to take into account the possibility of scandal in an implied acceptance of the practice. The recipients would need to give clear witness to their beliefs about the immorality of exploiting human embryos.

xvii. Consent, use of and payment for human tissue products

The issue of payment for use of products derived from cadaveric tissue is similar to the issues explained above in relation to biobanks.

xviii. Use of nonhuman and admixed tissue

The possibility of xenotransplantation (transplanting tissue from nonhuman animals) was already considered by Pope Pius XII in 1956. The Pope’s comment is worth quoting in full:

‘One cannot say that every kind of transplantation of tissue that is biologically possible between individuals of different species is to be morally condemned; but it is still less true to say that no kind of heterogeneous transplant biologically possible could be prohibited or could give rise to any objections. One must distinguish according to the case and see which tissue or which organ it is a question of transplanting. The transplantation of the sexual glands of animals into human beings is to be rejected as immoral; but, on the other hand, the transplantation of the cornea of a nonhuman organism into a human organism does not pose any moral difficulties, if it is biologically possible and medically indicated.’

It is striking that the pope did not regard such transplantation as absolutely excluded, but unfortunately he provided no principles to distinguish cases which are acceptable and those that are ethically problematic. The example he gave of reproductive tissue can be explained by reference to the dignity of human procreation. The procreation of new human life is not merely a biological activity but one with a human and indeed a sacred meaning. This has been expounded in many documents concerning assisted reproductive technologies. It would be a clear offence against the dignity of procreation for a human being to beget a nonhuman animal or a being about whom there was ambiguity as to its human identity.

An example of such an offence was the proposal in the United Kingdom in 2007 to create embryos by a form of cloning using the nucleus of a human cell and the ovum of a cow, pig or rabbit. The embryo so created is called a ‘cybrid’ or ‘hybrid clone’. The CDF commented on this proposal in 2008:

> From the ethical standpoint, such procedures represent an offence against the dignity of human beings on account of the admixture of human and animal genetic elements capable of disrupting the specific identity of man. The possible use of the stem cells, taken from these embryos, may also involve additional health risks, as yet unknown, due to the presence of animal genetic material in their cytoplasm. To consciously expose a human being to such risks is morally and ethically unacceptable.

> The reference to health risks is a major concern in relation to xenotransplantation. Governments have been very hesitant to permit the transplantation of pig hearts into human patients, in part because of a fear that viruses from the animal may infect the patient and result in novel disease to which human beings currently have no immunity. The possibility of rejection also seems much greater between species and, thus far, the few cases of large-organ transplantation have resulted in rapid rejection and the death

63 Address to Eye Specialists, 14 May 1956.
64 Dignitas Personae, §33.
of the recipient. On the other hand, the transplantation of small quantities of nonhuman biological material, such as heart valves, seems well tolerated, and does not seem contrary to respect for human dignity or other ethical principles.

Related to the issue of xenotransplantation is the technique known as ‘human animal transgenesis’ in which human genes are added to an animal embryo so that the adult animal-human hybrid may have organs that can be transplanted into a human being without rejection. As with hybrid cloning, or the formation of cybrids, there would be an admixture of human and animal genes. There would seem to be two issues involved. One is the question of the identity of the being formed with both an animal and a human genetic inheritance. At what stage would the being no longer be considered merely an animal, and is that a question of the proportion of human genetic inheritance? A second issue concerns whether the human genome should be regarded as sacred because it is an essential part of the generative capacity of a human being. Is it inappropriate, because a failure to respect the dignity of a human being, for a scientist to use the human genome and thus, the generative capacity, to form a human animal hybrid? Is this crossing over of human and animal genomes in the formation of a hybrid being a failure to respect the sacredness of the generative capacity?

xix. Transplantation of brain and generative tissue

In relation to xenotransplantation, Pope Pius XII referred to the problem of transplanting reproductive tissue, and the CDF referred to the ethical significance of ‘the specific identity of man’. As issues of procreation and identity are relevant in relation to the specific identity, so they are relevant in relation to individual identity. Transplantation is ethically problematic where it would confuse individual identity either in relation to parenthood and procreation, or in relation to personal (psychological) identity. For this reason transplantation may be ethically problematic where it involves reproductive tissue or neurological tissue, or where, as in the case of human-animal transgenesis, it involves the use of the generative capacity of the human genome or parts of it in the formation of an embryo.

The distinction between ordinary tissue and generative tissue such as testes, ovaries or gametes is well established. In most jurisdictions, generative tissue has been excluded from transplant practice on the grounds that it might be used reproductively. However, there have been some recent developments that have led some to question this distinction. First it has become possible to induce pluripotency in somatic cells and by that process to generate ova and sperm. It has been argued that forming a gamete from an ordinary cell blurs the distinction somewhat between somatic tissue and generative tissue. The difference between an ordinary cell and a gamete formed from it remains clear. It requires a distinct and complicated process to generate from an ordinary cell a gamete (which has half the genetic complement and significant epigenetic changes to activate the genes within it). No-one is in any danger of confusing the gamete thus formed with an ordinary cell. What would make a gamete formed in that way significant is the capacity that it would have gained for fertilization and thus reproduction.

Second, it has become a practice to freeze ovarian tissue for women undergoing cancer treatment, and then thaw the tissue and transplant it back to the patient. The practice raises the possibility, at least, of an ‘allograft’ of ovarian tissue; that is, a transplant from someone else. In principle at least, the same might be achieved by transplanting male testes to another man. The issues that would arise in those circumstances would be similar to the issues involved in heterologous in vitro fertilisation or artificial insemination by donor because, presumably, the ovarian tissue or the testes would generate gametes with the genetic inheritance of the donor. The donor would be the genetic parents of any children conceived by the recipient.

The reproductive organs and generative tissue generally are associated with reproductive identity. For those reasons it is impermissible to procure generative tissue for transplant to another person.

Similarly the brain is significantly determinative of personal identity and it has been considered impermissible to procure human brain tissue for transplant. This does not necessarily exclude all transplant of neurological tissue where there seems little or no likelihood of psychological characteristics being passed on (as there would not be in transplantation of peripheral nerves or of neural stem cells into the brain).

For similar reasons, the use of a person’s genome or part of it is significant because it contains the genetic or biological identity of the person and this is the means by which they may become a parent. Biological parenting is a process in which a child gains a genetic inheritance from each parent, and thus gains a human identity as a member of the human family with equal and inalienable rights.

xx. Donation of tissues other than for therapy

The cosmetic surgery industry is a significant consumer of human tissue, particularly products such as collagen, but also of bone and muscle. In recent times, those playing sport at elite levels have become consumers of cadaveric human tissue. For instance, it has become a practice to transplant intact tendons, rather than undertake repair of the person’s own tendon, because the recovery is likely to be much faster.

There has also developed a practice of using human tissue products in cosmetic consumables, such as face creams. There is a market for fetal tissue in that respect and the possibility of a market in embryonic stem cells. Biological products have also been used in the food industry, for example in the analysis and development of flavourings.

The use of human donated tissue for transplantation saves lives and restores health. An argument can be made for using donated human tissue for repair of people who have been damaged by accident, disease or medical or surgical treatment for disease. Other cosmetic uses, however, would stretch the understanding of those who donate tissue and may raise questions about respect for those who have died.
Other uses of the body post mortem include education and entertainment, for example the plastinated bodies in the *Body Worlds* exhibition or the shrunken heads (tsantsas) in the Pitt Rivers Museum in Oxford. Taking this further, body parts have sometimes been used for art or decoration (for example, the use of bones in ossuaries, of which the most famous is probably the Bone Church in Kutná Hora in the Czech Republic; or more recently the Australian artist who created a third ‘ear’ made from human cartilage which he had implanted into his forearm). In the past the display of body parts has also been an element of punishment (especially the display of bodies of the executed). Body parts have been employed for utilitarian purposes (especially the skin); they have also been used (and in some places still are) for purposes of ritual or magic. In this context one might also mention the practice of cannibalism in which parts of the human body are consumed. Human tissue may also be used for military purposes, for the development or testing of weapons, conventional or biological.

Some of these uses will be excluded because the activity itself is unethical or contrary to the faith (as is all use of body parts for magic or superstition). In other cases, such as the use of tissues in military contexts, care will be needed to ascertain whether or not the activity is acceptable (for example, is it an aspect of the development of weapons of mass destruction or is it an attempt to protect soldiers or citizens from potential future threats). There is also the question whether people have given consent for this use of their tissue: it cannot be presumed that people who have donated their bodies for medical training or their tissues for medical research have thereby consented to their use in a military context (even if that use is protective).

The question of the use of body parts in education is the most difficult. The use of the body for medical training is ethical (where the body has been donated with informed consent) and is one of the longest established uses of the body post mortem. In contrast, museums have often taken and displayed bodies without due concern for how the body was obtained. This is especially problematic where the relatives objected or would have objected to the use of the body, and where the body was obtained in circumstances of inequality, injustice or colonial exploitation. The lines between education, art, and entertainment are also difficult to draw clearly. In relation to artistic use it is more difficult to ensure respect for the dignity of the body, but such uses should not be ruled out absolutely. There is a significant cultural aspect to what constitutes the way in which respect may be paid to the body, and if this aspect is respected, then the use of the body even in art or entertainment could be ethical. Regardless of context, the display of body parts should always be done in a manner that respects the dignity of the human body.
III. Conclusion

This Report has demonstrated that organ donation, both from live donors, and post mortem, can be an ethical practice that is beneficial to the common good and fully in conformity with a Catholic understanding of anthropology and moral theology.

The Report has also identified a number of challenges that must be addressed if this practice is to be consistently, reliably and uniformly ethical in reality. First among these is the challenge of ensuring adequate diagnosis of death. It is certainly not the case that the Church in her authoritative teaching has rejected the current tests for death used in the UK or the Republic of Ireland. On the other hand, to make informed choices, Catholics, and men and women of good will, should be made aware (if they are not already) that diagnosis of death is a question that is disputed among scholars and, in relation to the technical details, one on which the Church does not have an authoritative view.

Church teaching in this area is concerned primarily with the theological and philosophical understanding of death. According to Pope John Paul II, ‘the death of the person is a single event, consisting in the total disintegration of that unitary and integrated whole that is the personal self. It results from the separation of the life-principle (or soul) from the corporal reality of the person’.

While the separation of the soul is not an empirically observable event, we can look for evidence that it has occurred such that ‘the individual organism has lost its integrative capacity’. The technical detail as to what constitutes that evidence for loss of ‘integrative capacity’ is not a matter about which the Church is expert and there is not a scientific consensus on the matter. Nor is there a theological or philosophical consensus as to the meaning of the ‘integrative capacity’ in relation to the ‘integrated whole that is the personal self’.

In promoting organ donation, therefore, people should be encouraged to examine the ethical issues for themselves, discuss donation with those close to them, and make an informed choice. Questions which people should consider include:66

- What sorts of live-donation procedures are compatible with respect for your body, for your life, and for your health?
- Is there anyone else who can legitimately give permission for organs to be taken except the person from whom they will be taken?
- What sorts of procedures are compatible with respecting the dead?
- What sorts of procedures are compatible with respecting the dying?
- What is the proper Catholic understanding of death?
- Can death be diagnosed reliably by neurological criteria?
- Can death be diagnosed reliably by circulatory criteria?
- How is death diagnosed in the country where you are living?
- Given the current practice in the country where you are living, are there procedures you should not consent to or otherwise be involved in?
- Given the current practice in the country where you are living, should you carry a donor card or be on the organ donation register?

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66 This list is adapted from Jones DA, Organ Transplants and the Definition of Death (London: CTS, 2001), p. 67.
• If you have decided to carry a donor card or to be listed on the organ donor register, have you discussed the implications of this with your family and those close to you, and do they understand the implications and what it may mean for them at the time of your dying, including the means by which death may be diagnosed and the reality of ‘beating-heart’ donation?
• How can organ donation be encouraged consistently with the duty to be honest about what it involves and the issues it raises?
• Can the positive elements of transplant medicine form the basis of a culture of life?
• Does the current transplant ethos need to be changed to bring this about?

An important strand through this Report is that the practice of organ donation and transplantation is not only an effective medical technique (or set of techniques); it is also an expression of human solidarity and a way in which we, as a society, express our understanding of the dignity of the human body. This is clear from the profound teaching of Pope John Paul II on the relationship between organ donation and the theology of the body. If transplant medicine ceases to express this human meaning, it becomes not simply morally indifferent but morally dangerous, not only to the well-being of patients and relatives, but to the integrity of society as a whole. For this reason, organ transplantation is a societal issue that demands the positive engagement of Catholics both as individuals (as citizens, patients, or professionals) and as an ecclesial community.
Glossary

Admixture: a combination of different sorts of thing, often used to refer to organisms which combine material from different species, for example human and animal genetic elements.

Adult stem-cell technologies: using versatile cells from an adult body (‘stem cells’) to make more specific cells (such as blood cells or nerve cells).

Allocution: a short talk or an address.

Allograft: transplant of living tissue from one place to another within the same person.

Altruistic donation: organ donation out of pure generosity without any close relationship with or knowledge of the recipient.

Angiogram: a picture of the inside of the blood vessels created by a medical imaging technique. It can be used to show the presence or absence of blood supply to the brain.

Ante mortem procedures: things done before death; in the context of organ donation, actions such as inserting a cannula so that, once death occurs, the organs can be flushed with a cool preserving fluid and kept in a good condition.

Attenuation: the loss of human significance when a tissue product is processed; for example, if its genetic properties are changed.

Body Worlds: an exhibition of preserved human bodies using a technique called plastination developed by the creator of the exhibition, Gunther von Hagens.

Biobank: a collection of tissue and/or blood samples donated by patients for use in medical research, diagnostically, or therapeutically.

Brain death: the state in which all brain functions are said to have ceased irreversibly, a term sometimes used to signify death as determined by neurological criteria. This document uses the phrase ‘death determined by neurological criteria’ because there is only one kind of death, but different ways of recognising it.

Brainstem: the lower part of the brain that regulates many systems of the body.

Brainstem death: the state in which all the brainstem functions are said to have ceased irreversibly. The term is sometimes used to signify death as determined by neurological criteria that are related only to brainstem function.

Beating-heart cadaver: someone who is determined to be dead by neurological criteria but whose heart is still beating.

Cadaver: a dead body.

Cadaveric donor: someone who donates parts of their body after their death.

Cannula: a tube inserted into the body, often into a blood vessel, for the delivery or removal of fluid.

Cardiac arrest: the cessation of normal circulation of the blood due to heart failure. It may be reversible and hence is distinct from ‘cardiac death’.
Cardiac death: a term sometimes used to signify death as determined by circulatory criteria.

Cardio-respiratory: concerning both the heart and breathing (‘respiration’).

Casti Connubii: an encyclical of Pope Pius XI on Christian marriage.

Catechism of the Catholic Church: the Catechism authorised by Pope John Paul II as the authentic and authoritative teaching of the Catholic Church in the light of the Second Vatican Council.

CDF (Congregation for the Doctrine of the Faith): a department of the Vatican responsible for upholding Catholic doctrine.

Cell lines: cells derived from a single original cell, and which have been cultured in the laboratory after being separated from their source.

Circulatory: related to the circulation of blood around the body.

Cloning: a process in which an embryo is produced that is genetically identical (or nearly identical) to another individual. This can be achieved by fusing an enucleated egg with an ordinary cell – the process that was famously used for the first time in the formation of Dolly the Sheep.

Commodification: turning something of inherent value into a commodity, an object to be bought, sold and traded.

Cornea: the strong, thin, transparent, topmost layer of the eyeball.

Council of Vienne: an Ecumenical Council of the Church held in Vienne in 1311.

Criterion of independence: the requirement that there be no close connection between researchers and any unethical actions by those who produced the material used for the research; for example those who develop cell lines by destroying human embryos.

Cystic fibrosis: an inherited disorder that affects the lungs in particular, and is sometimes treated by heart-lung transplantation.

DCD: donation after cardiac death: the donation of organs for transplantation after death has been determined by circulatory criteria.

Deemed consent: the term used for presumed consent in legislation passed by the Welsh Assembly in 2013.

Dilation and curettage: sometimes employed as a method of abortion by which the opening of the womb is widened and the lining of the womb, together with the unborn child, is scraped away.

Domino donation: the donation of an organ which has been removed incidentally as part of a previous transplant operation.

Donor: in the context of organ transplantation, a donor is someone who voluntarily gives an organ or tissue, whether during life or after death.

Doppler ultrasound: a technique that uses reflected sound waves to assess blood flow.
Ecumenical council: a solemn meeting of bishops and theologians convened to discuss matters of Church doctrine and practice and recognised by the Pope as having authority to settle questions of doctrine. Roman Catholic Church recognises twenty-one councils as ecumenical, the most recent being the Second Vatican Council (1962–1965).

Ecclesial: related to the Church.

Elective ventilation: artificial ventilation of the lungs; in the context of organ donation, initiating or continuing ventilation in a dying patient so that, if brain death were subsequently to occur, this would then happen in a context where it could be confirmed clinically and organs could be harvested.

Embryo: the first stage in the life of a developing organism; in human beings, from fertilization when the sperm and egg fuse to form a new single cell until the eighth week when the internal organs are fully formed. An embryo may also be formed by cloning.

Embryonic tissue: tissue in or from an embryo.

Embryonic stem cell: a pluripotent cell removed from a human embryo at or before the blastocyst stage of development.

Encephalic: concerning the brain (literally what is ‘inside the head’).

Encyclical: a letter written by a pope to the whole Church.

Eucharistic: related to the Eucharist, also called the Mass or Holy Communion, the Christian ritual in which the gift of Jesus’s body and blood is represented and made present.

Evangelium Vitae: an encyclical of Pope John Paul II on issues of life and death.

Fetal tissue: tissue in or from a fetus.

Fetus: a developing organism after the embryonic stage and before birth (in animals that give birth).

Gametes: the male and female reproductive cells (in humans, the sperm and egg) that combine to give rise to a new organism.

Generative tissue: the tissue that generates new life; that is, the gametes and those tissues that produces gametes (the ovaries and testes).

Generative faculty: the reproductive organs but also the capacity of the human genome to pass on human identity in the formation of an embryo.

Genome: the set of genes or chromosomes that are the genetic inheritance that determines the identity of a living being.

Genotype: the genetic makeup of an individual inherited from his or her parents.

Graft: living tissue that is transplanted.

ICU (intensive care unit): a specialist department of a hospital that provides intensive treatment for patients who are critically ill.
Induced pluripotent stem cell (iPSC) technologies: techniques to change ordinary cells of the body, such as skin cells, into ‘stem cells’ which have the potential to generate every other kind of cell.

Inotropes: drugs that change the strength of heartbeats and are used to manage various heart conditions

IVF (in vitro fertilization): bringing the (male) sperm and the (female) egg together in a glass dish (in vitro means ‘in glass’) to conceive a new embryo. An IVF child is popularly known as a ‘test-tube’ baby.

Lateran V: The Fifth Council of the Lateran was an Ecumenical Council of the church held at the Lateran in Rome between 1512 and 1517.

Lobe: a distinct, usually rounded, part or extension of an organ (such as the lung, liver or kidney).

Neurological: concerning the nerves in general or the brain in particular.

Oxygenated blood: blood that is carrying oxygen – which all the cells need to live – around the body.

Organ: a part of the body which performs a specific function.

Organism: an individual living thing: a plant or an animal.

Ossuary: a container for bones – a box or a building made to serve as the final resting place of human skeletal remains.

Paired organ: an organ the removal of which allows the donor to continue normal function.

Paired donation: a mechanism whereby a prospective live-donor and known recipient are paired with another live-donor and known recipient so that the first donor donates to the second recipient and vice versa.

Pituitary gland: the chief gland of the hormonal system, just below the brain.

Pontifical Academy or Council: an administrative or teaching body set up by the Vatican, but not, as such, an organ of the official teaching of the Church.

Pooled donation: a mechanism whereby a live-donor donates an organ to an anonymous pool in exchange for knowing that a particular patient will receiving a well-matched organ.

Post Mortem: ‘after death’.

Presumed consent: the taking of organs from the dead without express consent on the basis that the deceased previously had the opportunity to object to this happening and did not do so.

Recipient: in the context of organ transplantation, a recipient is someone who receives an organ.

Rejection: a negative reaction to foreign matter in the body.

Resuscitate: to revive someone who is unconscious or whose heart has stopped, especially with the help of complex medical equipment.
Simony: the attempt to buy or make a profit from sacred things, named after the story of Simon Magus who wished to buy the power to do miracles (Acts 8:18-24).

Social capital: the value of institutions, relationships, or social networks in relation to the quality and quantity of a society’s social interactions.

Solidarity: seeing others not in terms of their usefulness to us, but as neighbours and co-workers – sharers in a common life. The concept of solidarity is important in the social teaching of Pope John Paul II.

Soul: the principle of life of a living being; in human beings, the principle of their bodily and mental life.

Therapeutic purposes: the aims of curing disease, healing injury and easing discomfort.

Tissue type: characteristics that determine compatibility of organs with recipients.

Transgenesis: the process of adding or replacing a gene from one species into the embryo of another species.

Transplant: a living piece of tissue taken and transplanted somewhere else.

Tsantsas: a ‘shrunken’ human head used for trophy or for ritual purposes by certain tribes of the Amazon rain forest.

Vasopressor: a drug that supports the circulation by acting on the blood vessels.

Vendor: one who sells something, in contrast to a donor who gives something freely.

Ventilation: supplying someone with fresh air to enable him or her to breathe (see also elective ventilation).

Vital organ: an organ which is essential to the continuing life of the organism.

Xenotransplantation: transplanting tissue between animals of different species.
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Appendix I: On the Donation and Transplantation of Organs

Spanish Bishops’ Conference: Pastoral Secretariat of the Bishops’ Commission

The Donation of Organs Pastoral Exhortation

It is often said that contemporary technological progress is making us increasingly selfish and closed off from others. Yet, this progress also opens up new and unexpected ways to be charitable. We are referring to this wonder of science by which, through transplantation, we can apparently achieve a greater form of fraternal solidarity; we are able to share our body’s organs, and in this way, in death, find life.

This is a major issue that should seriously concern us as Christians: patients who until now could only be treated by haemodialysis, which prolonged their lives in an unstable condition, today have a more definitive solution through kidney transplants.

There are currently about 10,000 patients in Spain who are alive today because of dialysis, and the numbers are increasing. While this method allows them to live, and to some extent continue to work and lead a seemingly normal life, they face the slavery of being chained to a machine that purifies their blood for four hours, three times a week. They live, but on probation.

Apart from the price of treatment, which costs the State more than thirty billion pesetas a year, their existence remains seriously negatively affected with regard to their family, work and their own psychology. Many people watch years and years go by while waiting for what would be a definitive solution: a transplant that would allow them to return to a full and normal life. We are concerned about this situation, and equally about that of those who suffer from heart or liver conditions, diabetes, blindness, etc., whose solution may also come from transplantation.

However, the reality is that in Spain there are currently very few transplants, because there are very few donors. There are not many people who think that after their death they could still live on, somehow, and be useful to their brothers and sisters. At this time, when road traffic accidents cause dozens and dozens of deaths each week, it seems that we have failed to understand that even in this tragedy, a seed of life for others could be found.

It is surprising that one of the factors that hinders the generosity of many when it comes to the donation of organs is, it seems, certain religious reasons, or real or perceived religious prejudices. The respect that we owe to our bodies, which is rightly near-sacred, and on which we have preached so often from the perspective of the faith, has influenced some believers to resist organ donation.

Moreover, other factors, such as a lack of information and awareness, the traumatic and painful situation that families experience after the death of loved ones, human respect, fear of ‘what people might say’, and the funeral rites so rooted in our tradition, can hinder or prevent the donation of organs and lead to the idea that it is others who ought to help or that ‘everyone should solve their own problems’.

67 Unofficial translation by Stephen Barrie on behalf of the Anscombe Bioethics Centre with assistance from Amy Owens.
We, as pastors of the Church, have an obligation to dispel these misgivings.

It is true that some conditions are required to ensure the moral acceptability of transplants from the dead to the living: that the donor or his family acts with freedom and without coercion; that it is done for altruistic reasons and not for recompense; that there is a reasonable expectation of success for the recipient; and that it is proven that the donor is really dead.

When these conditions are met, not only does the faith have nothing against such a donation, but the Church recognises that it, in a beautiful way, imitates Jesus who gave his life for others. Perhaps no other action reaches such levels of the practice of fraternity. In this, we approach the free and effective love God feels toward us. It is a living example of solidarity. It is visible proof that the body of man may die, but the love that sustains it will never die.

What we say today has already been expounded by other bishops; this is not new in the thought of the Church: Pius XII expressed it when the first transplants or transfusions were made, and it has been repeated by subsequent popes. Most recently John Paul II said that he sees in the gesture of donation not only the aid given to an individual patient but ‘a gift to the Lord, who in his passion gave his whole self and shed his blood for the salvation of men’. It is, in truth, Christ himself to whom every donation is made, since He assured us that ‘Truly, I say to you, as you did it to one of the least of these my brethren, you did it to me’ (Matthew 25:40). And who is more like ‘the least of these’ than the sick?

We wish to express, in this pastoral exhortation, our encouragement: to patients and families who suffer and wait for our generosity; to associations of patients who earnestly carry out advocacy; to medical teams who with so much effort and commitment struggle to keep up and offer patients a better life; to the legislative bodies, administrators, and the media who have shown their sensitivity and concern for the problem. We also wish to show our appreciation to those who have decided to donate their organs after death.

Along with this encouragement and recognition, we ask that bureaucratic processes that can at times hinder the application of the law be expedited; that the effort to inform and raise awareness continue in order to find an effective solution to this issue. We hope that economic interests will never interfere with this delicate matter.

As we do not want our words just to remain as mere words: the signatories of this Exhortation declare our desire and intention to be donors, as far as possible, of any part of our body that might be useful, after our death, to any of our brothers and sisters. In this way we imitate Jesus who says ‘no one has greater love than to lay down his life for his friends’ (John 15:13) and who Himself gave His life for mankind.

October 25, 1984

Javier OSÉS FLAMARIQUE, Bishop of Huesca and President of the Commission
Teodoro ÚBEDA WEIGHT, Bishop of Mallorca
Joseph GEA ESCOLANO, Bishop of Ibiza
Antonio deig CLOTET, Bishop of Menorca
La donación de órganos: Exhortación Comisión Episcopal de Pastoral

Suele decirse que el progreso técnico contemporáneo nos va haciendo a los hombres cada vez más egolastas y encerrados en nuestro propio corazón. Y, sin embargo, también ese progreso nos abre nuevos e insospechados caminos de caridad. Nos referimos a ese prodigio de la ciencia gracias al cual, a través de los trasplantes, parece lograrse una forma más alta de fraternidad, al poder compartir órganos de nuestro cuerpo y convertir así una muerte en algo de vida.

Es éste un problema que debe preocuparnos seriamente como cristianos: enfermos que hasta ahora sólo podían ser tratados en la hemodiálisis que prolonga la vida en condiciones precarias, hoy tienen una solución más definitiva gracias a los trasplantes de riñón.

En España hay en estos momentos unos 10.000 enfermos que siguen viviendo gracias a la diálisis. Y la cifra tiende a crecer. Y, aunque bendicen esta técnica curativa que les permite vivir y hasta, en alguna medida, seguir trabajando y hacer una vida normal en apariencia, conocen también la esclavitud de vivir, cuatro horas tres veces por semana, encadenados a la máquina que purifica la sangre. Viven, pero en libertad vigilada.

Y, aparte del costo de su tratamiento que supone para el país más de treinta mil millones de pesetas al año, sus existencias quedan, en lo familiar, en lo laboral, en su misma psicología, duramente condicionadas. Son muchos los que ven pasar y pasar los años en espera de lo que sería su solución definitiva: un trasplante que, éste sí, les permitiría regresar a su vida plena y normal. Nos preocupa esta situación e igualmente la de los enfermos cardíacos, hepáticos, diabéticos, con ceguera, etc. cuya solución puede estar en el trasplante.

Pero la realidad es que en España los trasplantes son por ahora muy escasos, porque son también muy raros los donantes. Son pocas las personas que piensan que después de su muerte aún pueden seguir viviendo, de algún modo, siendo útiles a sus hermanos. En este tiempo en el que el azote de la carretera produce cada semana docenas y docenas de muertos, no parece que hayamos comprendido que, aun de esa tragedia, podría extraerse una semilla de vida para otras personas.

Y lo asombroso es que uno de los motivos que frenan la generosidad de muchos en la donación de órganos es, al parecer, ciertas razones o prejuicios real o supuestamente religiosos. El respeto, justamente casi sagrado, que tantas veces hemos predicado desde la fe hacia nuestro propio cuerpo hace que algunos creyentes se resistan a la donación de órganos.

Por otra parte, la falta de información y mentalización previas, la situación traumática y dolorosa que los familiares experimentan ante la muerte de los seres queridos, los respetos humanos, el miedo al «qué dirán», los ritos funerarios tan anclados en nuestra tradición, dificultan o impiden la donación de órganos y pueden conducir a la idea de que son los otros los que deben ayudar o hacen pensar que «cada uno debe resolver sus problemas».

Nosotros, como pastores de la Iglesia, tenemos la obligación de disipar esos temores.

Es cierto que se exigen algunas condiciones que garanticen la moralidad de los trasplantes de muerto a vivo: que el donante, o su familiares, obren con toda libertad y sin coacción; que se haga por motivos altruistas y no por mercadería; que exista una razonable expectativa de éxito en el receptor; que se compruebe que el donante está realmente muerto.
Cumplidas estas condiciones, no sólo no tiene la fe nada contra tal donación, sino que la Iglesia ve en ella una preciosa forma de imitar a Jesús que dio la vida por los demás. Tal vez en ninguna otra acción se alcancen tales niveles de ejercicio de la fraternidad. En ella nos acercamos al amor gratuito y eficaz que Dios siente hacia nosotros. Es un ejemplo vivo de solidaridad. Es la prueba visible de que el cuerpo de los hombres puede morir, pero que el amor que lo sostiene no muere jamás.

Esto que decimos hoy, y que ya anteriormente otros obispos expusieron, no es ninguna novedad en el pensamiento de la Iglesia: lo expresó ya Pío XII en el momento en que los primeros trasplantes o transfusiones se hicieron. Lo han repetido los pontífices posteriores. Muy recientemente Juan Pablo II ha dicho que veía en ese gesto de la donación no sólo la ayuda a un paciente concreto sino «un regalo hecho al Señor paciente, que en su pasión se ha dado en su totalidad y ha derramado su sangre para la salvación de los hombres». Es, ciertamente, al mismo Cristo a quien toda donación se hace, ya que Él nos aseguró que «lo que hiciéramos a uno de estos mis pequeñuelos conmigo lo hacéis» (Mt 25,40). ¿Y quién más pequeñuelo que el enfermo?

Deseamos expresar, en esta exhortación pastoral, nuestro estímulo y aliento a los enfermos y familiares que sufren y esperan nuestra generosidad, a las asociaciones de enfermos que con empeño llevan a cabo una labor de sensibilización, a los equipos médicos que con tanto esfuerzo y entrega luchan por estar al día y ofrecer a los enfermos una vida mejor, a los órganos legislativos y administrativos y a los medios de comunicación social que han mostrado su sensibilidad y preocupación por el problema. Y queremos también mostrar nuestro reconocimiento a los que ya han decidido donar sus órganos en caso de muerte.

Junto a este estímulo y reconocimiento, pedimos que se agilicen los trámites burocráticos que, en ocasiones, pueden dificultar la aplicación de la ley; que se siga sensibilizando e informando en orden a una solución efectiva de esta problemática. Esperamos que nunca se interfieran en este delicado asunto los intereses económicos.

Y, como deseamos que nuestras palabras no se queden en simples palabras, cuantos firmamos estas líneas declaramos desde ellas nuestra voluntad de ser, en cuanto sea posible, donantes de cualquier parte de nuestro cuerpo que pudiera ser útil, tras nuestra muerte, a cualquiera de nuestros hermanos. Así creemos imitar a Jesús que dice «nadie tiene mayor amor que el que da la vida por sus amigos» (Jn 15,13) y que Él mismo dio su vida por los hombres.
Appendix II: *Pope John Paul II Address to the 18th International Congress of the Transplantation Society (29 August 2000)*

**Distinguished Ladies and Gentlemen**

1. I am happy to greet all of you at this International Congress, which has brought you together for a reflection on the complex and delicate theme of transplants. I thank Professor Raffaello Cortesini and Professor Oscar Salvatierra for their kind words, and I extend a special greeting to the Italian Authorities present.

To all of you I express my gratitude for your kind invitation to take part in this meeting and I very much appreciate the serious consideration you are giving to the moral teaching of the Church. With respect for science and being attentive above all to the law of God, the Church has no other aim but the integral good of the human person.

Transplants are a great step forward in science’s service of man, and not a few people today owe their lives to an organ transplant. Increasingly, the technique of transplants has proven to be a valid means of attaining the primary goal of all medicine – the service of human life. That is why in the Encyclical Letter *Evangelium Vitae* I suggested that one way of nurturing a genuine culture of life ‘is the donation of organs, performed in an ethically acceptable manner, with a view to offering a chance of health and even of life itself to the sick who sometimes have no other hope’ (No. 86).

2. As with all human advancement, this particular field of medical science, for all the hope of health and life it offers to many, also presents certain critical issues that need to be examined in the light of a discerning anthropological and ethical reflection.

In this area of medical science too the fundamental criterion must be the defence and promotion of the integral good of the human person, in keeping with that unique dignity which is ours by virtue of our humanity. Consequently, it is evident that every medical procedure performed on the human person is subject to limits: not just the limits of what it is technically possible, but also limits determined by respect for human nature itself, understood in its fullness: ‘what is technically possible is not for that reason alone morally admissible’ (Congregation for the Doctrine of the Faith, *Donum Vitae*, 4).

3. It must first be emphasized, as I observed on another occasion, that every organ transplant has its source in a decision of great ethical value: ‘the decision to offer without reward a part of one’s own body for the health and well-being of another person’ (*Address to the Participants in a Congress on Organ Transplants*, 20 June 1991, No. 3). Here precisely lies the nobility of the gesture, a gesture which is a genuine act of love. It is not just a matter of giving away something that belongs to us but of giving something of ourselves, for ‘by virtue of its substantial union with a spiritual soul, the human body cannot be considered as a mere complex of tissues, organs and functions … rather it is a constitutive part of the person who manifests and expresses himself through it’ (Congregation for the Doctrine of the Faith, *Donum Vitae*, 3).
Accordingly, any procedure which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally unacceptable, because to use the body as an 'object' is to violate the dignity of the human person.

This first point has an immediate consequence of great ethical import: the need for informed consent. The human 'authenticity' of such a decisive gesture requires that individuals be properly informed about the processes involved, in order to be in a position to consent or decline in a free and conscientious manner. The consent of relatives has its own ethical validity in the absence of a decision on the part of the donor. Naturally, an analogous consent should be given by the recipients of donated organs.

4. Acknowledgement of the unique dignity of the human person has a further underlying consequence: vital organs which occur singly in the body can be removed only after death, that is from the body of someone who is certainly dead. This requirement is self-evident, since to act otherwise would mean intentionally to cause the death of the donor in disposing of his organs. This gives rise to one of the most debated issues in contemporary bioethics, as well as to serious concerns in the minds of ordinary people. I refer to the problem of ascertaining the fact of death. When can a person be considered dead with complete certainty?

In this regard, it is helpful to recall that the death of the person is a single event, consisting in the total disintegration of that unitary and integrated whole that is the personal self. It results from the separation of the life-principle (or soul) from the corporal reality of the person. The death of the person, understood in this primary sense, is an event which no scientific technique or empirical method can identify directly.

Yet human experience shows that once death occurs certain biological signs inevitably follow, which medicine has learnt to recognize with increasing precision. In this sense, the 'criteria' for ascertaining death used by medicine today should not be understood as the technical-scientific determination of the exact moment of a person's death, but as a scientifically secure means of identifying the biological signs that a person has indeed died.

5. It is a well-known fact that for some time certain scientific approaches to ascertaining death have shifted the emphasis from the traditional cardio-respiratory signs to the so-called ‘neurological’ criterion. Specifically, this consists in establishing, according to clearly determined parameters commonly held by the international scientific community, the complete and irreversible cessation of all brain activity (in the cerebrum, cerebellum and brain stem). This is then considered the sign that the individual organism has lost its integrative capacity.

With regard to the parameters used today for ascertaining death – whether the ‘encephalic’ signs or the more traditional cardio-respiratory signs – the Church does not make technical decisions. She limits herself to the Gospel duty of comparing the data offered by medical science with the Christian understanding of the unity of the person, bringing out the similarities and the possible conflicts capable of endangering respect for human dignity.
Here it can be said that the criterion adopted in more recent times for ascertaining
the fact of death, namely the complete and irreversible cessation of all brain activity,
if rigorously applied, does not seem to conflict with the essential elements of a sound
anthropology. Therefore a health-worker professionally responsible for ascertaining
death can use these criteria in each individual case as the basis for arriving at that
dergee of assurance in ethical judgement which moral teaching describes as ‘moral
certainty’. This moral certainty is considered the necessary and sufficient basis for an
ethically correct course of action. Only where such certainty exists, and where informed
consent has already been given by the donor or the donor’s legitimate representatives,
is it morally right to initiate the technical procedures required for the removal of organs
for transplant.

6. Another question of great ethical significance is that of the allocation of donated organs
through waiting-lists and the assignment of priorities. Despite efforts to promote the
practice of organ-donation, the resources available in many countries are currently
insufficient to meet medical needs. Hence there is a need to compile waiting-lists for
transplants on the basis of clear and properly reasoned criteria.

From the moral standpoint, an obvious principle of justice requires that the criteria for
assigning donated organs should in no way be ‘discriminatory’ (i.e. based on age, sex,
race, religion, social standing, etc.) or ‘utilitarian’ (i.e. based on work capacity, social
usefulness, etc.). Instead, in determining who should have precedence in receiving an
organ, judgements should be made on the basis of immunological and clinical factors.
Any other criterion would prove wholly arbitrary and subjective, and would fail to
recognize the intrinsic value of each human person as such, a value that is independent
of any external circumstances.

7. A final issue concerns a possible alternative solution to the problem of finding human
organs for transplantation, something still very much in the experimental stage, namely
xenotransplants, that is, organ transplants from other animal species.

It is not my intention to explore in detail the problems connected with this form of
intervention. I would merely recall that already in 1956 Pope Pius XII raised the question
of their legitimacy. He did so when commenting on the scientific possibility, then being
presaged, of transplanting animal corneas to humans. His response is still enlightening
for us today: in principle, he stated, for a xenotransplant to be licit, the transplanted
organ must not impair the integrity of the psychological or genetic identity of the
person receiving it; and there must also be a proven biological possibility that the
transplant will be successful and will not expose the recipient to inordinate risk (cf.
Address to the Italian Association of Cornea Donors and to Clinical Oculists and Legal
Medical Practitioners, 14 May 1956).
8. In concluding, I express the hope that, thanks to the work of so many generous and highly-trained people, scientific and technological research in the field of transplants will continue to progress, and extend to *experimentation with new therapies which can replace organ transplants*, as some recent developments in prosthetics seem to promise. In any event, methods that fail to respect the dignity and value of the person must always be avoided. I am thinking in particular of attempts at human cloning with a view to obtaining organs for transplants: these techniques, insofar as they involve the manipulation and destruction of human embryos, are not morally acceptable, even when their proposed goal is good in itself. Science itself points to other forms of *therapeutic intervention* which would not involve cloning or the use of embryonic cells, but rather would make use of stem cells taken from adults. This is the direction that research must follow if it wishes to respect the dignity of each and every human being, even at the embryonic stage.

In addressing these varied issues, *the contribution of philosophers and theologians* is important. Their careful and competent reflection on the ethical problems associated with transplant therapy can help to clarify the criteria for assessing what kinds of transplants are morally acceptable and under what conditions, especially with regard to the protection of each individual's personal identity.

I am confident that social, political and educational leaders will renew their commitment to fostering a genuine culture of generosity and solidarity. There is a need to instil in people's hearts, especially in the hearts of the young, a genuine and deep appreciation of the need for brotherly love, a love that can find expression in the decision to become an organ donor.

May the Lord sustain each one of you in your work, and guide you in the service of authentic human progress. I accompany this wish with my Blessing.
Appendix III: Commission of the Bishops’ Conferences of the European Community (COMECE) Ethical Aspects of Organ Donation (11 October 2007)\(^68\)

The Bioethics Discussion Group of the Secretariat of the Commission of the Bishops’ Conferences of the European Community (COMECE) read with great interest the Communication from the European Commission to the European Parliament and the Council entitled ‘Organ donation and transplantation: Policy actions at European Union level’ dated 30 May 2007.\(^69\) In it the European Commission explains a number of measures that it plans to take to guarantee the quality and safety of transplanted human organs, to fight organ trafficking and to ‘increase organ availability’ (§1). Nobody would deny the importance of the first two objectives and the Bioethics Discussion Group fully acknowledges them. In addition, the Group highly commends the third objective of increasing organ availability, provided that it is pursued in a spirit of solidarity with persons who are suffering and with absolute respect for the persons concerned – both for those from whom it is planned to remove the organs and for their families. Provided that these conditions are met, the European Commission’s recommendation to set up an effective organisation in each country that will be able to pinpoint potential ‘donors’, organise organ procurement, allocate organs equitably on the basis of patient needs, implement transplants and facilitate cooperation among the various countries, cannot fail to be fully endorsed.

The Bioethics Discussion Group stresses that organ donation must always be a donation made free of charge in a spirit of solidarity, that organ procurement must never be decided on financial grounds and that a human organ must never be considered or treated as a commodity. Moreover, the language used should avoid any commercial connotation; on the contrary, rather, it should reflect the spirit of solidarity.\(^70\)

I. ORGAN PROCUREMENT FROM DECEASED PERSONS

‘We should rejoice that medicine, in its service of life, has found in organ transplantation a new way of serving the human family.’\(^71\) Pope John Paul II reiterated this strong approval on a number of occasions, while emphasising that, even after death, ‘the human body is always a personal body, the body of a person’.\(^72\) This means that under no circumstances must a deceased person’s body be considered as an object to be disposed of at will or simply as a source of organs and tissues to be ruthlessly exploited.\(^73\)

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\(^{68}\) This Opinion of the Bioethics Discussion Group refers solely to organ procurement for transplantation purposes. It is not concerned with organ procurement for research purposes (which should be the subject of a special study). The subject of tissue harvesting is touched upon only in passing.


\(^{70}\) The European Commission Communication makes several mentions of the term ‘supply and demand’ for organs, borrowed from business terminology. It would be better to use systematically the terms ‘organ donation’ and ‘need for organs’.

\(^{71}\) Pope John Paul II, Address to the Participants of the First International Congress of the Society for Organ Sharing on 20 June 1991, § 1.

\(^{72}\) Ibid, § 4.

\(^{73}\) See the address of Pope Pius XII to the Delegates of the Italian Association of Cornea Donors and to Clinical Oculists and Legal Medical Practitioners on 13 May 1956, and the addresses of Pope John Paul II on 14 December 1989 to a working group of the Pontifical Academy of Sciences, on 20 June 1991 (op. cit.) and on 29 August 2000 to the 18th International Congress of the Transplantation Society.
On the Ethics of Organ Transplantation: A Catholic Perspective

Consent

It is common to use the term ‘donor’ to refer to a person from whom organs are procured. This reflects the currently widespread conviction that no organ should be removed without there being a prior act of donation or at least not without the prior consent of the deceased person, the consent of those responsible for representing that person or in charge of the custody of his or her body after death.

In Europe, the required form of consent varies according to the differing rationales of national legislation. In some countries, this consent must be given explicitly by the person from whom it is proposed to procure organs; failing that, the family is approached. Obviously it is important for consent to be given freely and knowingly. In other countries, consent is ‘presumed’ if the person did not oppose organ procurement during his or her lifetime. Should this ‘presumed consent’ principle be rigidly applied, it could permit the supposition that doctors are totally at liberty to procure organs as long as they are not aware of the deceased person’s prior refusal to be a donor.

Ambiguities of the ‘presumed consent’ system

The potential inflexibility of the presumed consent (or ‘opting out’) system is corrected or averted in a number of countries by a common practice among doctors of entering into dialogue with the family in cases where they are not aware of the deceased person’s prior wishes. Furthermore, this contact with the family is provided for by some national laws, if only to inquire what views the deceased person may have expressed to his or her relatives. This means that doctors frequently have to accept a family’s possible refusal. In this way they take account of the trauma that may be caused to relatives by interference with the integrity of a loved one’s body and they show respect for the bond between the deceased person and his or her family, treasured by immemorial tradition. Moreover, this is what led the French Bishops’ Conference to state firmly: ‘It would be inhumane to procure organs in cases where the family is opposed or has expressed strong aversion, acute distress, or has no prior knowledge.’

This applies especially where children, or more generally young people under the age of majority are involved. Clearly, the explicit consent of the parents is required in such cases.

Conversely, any ‘opting out’ organ-procurement system which is applied so rigidly that it allows the medical profession to remove organs from deceased persons who have not previously made known their refusal – by such means as computerised national registers – would be profoundly questionable. For the notion of ‘presumed consent’ to be meaningful, the public must have been duly informed, as soon as persons reach the age of majority! However, in countries where surveys have been conducted, they have revealed that the public is either unaware or does not understand the rationale of ‘silence gives consent’. It is therefore fundamentally deceitful to rely solely on alleged ‘presumed consent’.

Raising public awareness

However, respect for deceased persons from whom organs are procured and for their families is not incompatible with concern for those awaiting a transplant. In its Communication, the

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75 In Hungary, for example, the ‘opting-out’ system has been in force since 1998. However, in 2003, only 42% of the general public knew about the legal regulation. Cf. Szántó Zs et al: LAM 2004; 14(89):620-6 (article written in Hungarian, cited by Smudla A, Hegedűs K, Semmelweis University, Institute of Behavioural Studies, Budapest).
European Commission calls for increased public awareness. It rightly states: ‘Organ donation and transplantation are medical treatments that require the full participation of society for their development’ (§ 3.2.2.). Indeed, it will only be possible to increase organ procurement and to guarantee a high level of availability if doctors feel that they are supported by widespread agreement in society as well as by the agreement of the people directly concerned.

The Catholic Church is ready to participate in this effort to raise awareness of the needs of persons waiting for a transplant and to invite the public to agree to the post mortem removal of tissues and organs, from one’s own or a relative’s body, provided that this is carried out with absolute respect for human dignity and the rights of the persons concerned. Indeed, the Church has not waited to be approached by public authorities. As early as 1956, Pope Pius XII stated: ‘The public needs to be educated, and people should be informed, in an intelligent and respectful manner, that explicit or tacit consent to an infringement of the integrity of a dead body, for the benefit of ill persons, does not offend the reverence due to the deceased person, provided that there are valid reasons for such interferences with the body. All the same, this consent may inflict suffering and involve sacrifice for the relatives, but this sacrifice is blessed by compassion for our suffering brothers.’ 76 Pope John Paul II placed more emphasis on the consent of the ‘donors’ themselves when he stated in 1991: ‘But to offer in life a part of one’s body, an offering which will become effective only after death, is already in many cases an act of great love, the love which gives life to others.’ 77

To facilitate the support that we wish to have in European societies and from citizens, the public must be informed honestly about the facts of organ procurement, the precautions taken to respect the body of the deceased and the importance of transplants for ill people. It is also important to invite people to discuss these issues. The European Commission’s Communication states that ‘continued education should form an essential element of any communication strategy. People should be encouraged to speak about organ donation and to communicate their wishes to their relatives’ (§3.2.2.). Indeed, a European Eurobarometer survey revealed a strong correlation between the fact of having discussed organ donation within the family and the acceptance of organ removal by potential donors themselves and by their families. 78

A number of Bishops’ Conferences have already made appeals for reflection and for discussions within families, parishes, movements, schools, universities and youth chaplaincies. Such initiatives could be multiplied, inviting every individual, irrespective of age, to consider their own death and the service which they could render to sick people by organ donation. Depending on different national legislations, this could mean completing a ‘donor card’ or stating before witnesses that one does not object to having organs removed.

For the Catholic Church, only such personal consent, or at least the tacit and legitimate acceptance by the duly-informed relatives, – and for exceptionally important purposes – justifies the infringement of the integrity of the body after death. As much as it is legitimate to ‘invite’ people to agree to such infringements, it would therefore be questionable to make it a civil or moral duty.

76 Pope Pius XII, address of 13 May 1956, op. cit. (unofficial English translation).
77 Pope John Paul II, address of 20 June 1991, op. cit., §3.
Respect for the deceased person and for his or her family and offering the necessary support

In most cases, vital organs can only be procured for transplantation purposes when death has occurred under specific circumstances that are particularly shattering for the family. In such cases, the death has usually been nasty and unexpected. The grieving family must therefore be listened to and relatives must be allowed to raise any questions that are troubling them. The family, should they so request, must be given the necessary information about the reality of the death and the conditions under which organs would be procured. They must therefore be given time. It would be inhumane to pressurise the family, force their consent and obtain the organs with inappropriate haste. Some countries fully understand this and have set up special services to coordinate organ procurement and family counselling. It is desirable to provide relatives with psychological, spiritual and religious support from trained personnel where necessary.

Obviously procurement procedures must respect the dignity of the human body, even after death. The body's visible appearance must be altered as little as possible and should be restored to its original state, as far as is possible. This also raises the issue of limiting the amount of tissues and organs procured from a single body. It is unacceptable to consider the human body as merely a source of tissues and organs to be exploited as required. Many countries facilitate organisational arrangements by procuring from a single body not only the vital organs but also tissues such as the skin and cornea. Families may well regard this as beyond the limits of what is bearable. The possibility of allowing donors or their families to limit the number of body parts to be removed should therefore be considered. In general, it would be wise to limit the number of organs taken from a single body. Except in cases where deceased people had announced their intention to donate most of their body parts while they were still alive, or in cases where the family gives its explicit agreement to such multiple procurement, it may be desirable to avoid removing tissues from bodies from which vital organs have already been taken.

Confirmation of death

Clearly it is essential for every country to take the necessary measures to ensure that organs are removed only when death has been duly confirmed in line with recognised criteria. Before organs are procured, it is normal for the declaration of death to be based, not on a cardio-respiratory criterion (the total and irreversible cessation of circulatory and respiratory functions) but on a neurological criterion (complete and irreversible cessation of all brain activity – referred to as ‘brain-stem death’ or ‘whole-brain death’). After wide-ranging debate, the Catholic Church pronounced its explicit opinion on this matter. On 14th December 1989, Pope John Paul II urged scientists, moralists, philosophers and theologians to continue their research. On 29th August 2000, he affirmed that doctors could use the neurological criterion defined above to confirm that death had indeed occurred. The German Bishops’ Conference had already reached this conclusion in August 1990.

79 Although Great Britain recognises a different criterion, it doubtless arrives at the same conclusion of brain-stem death, or total and irreversible cessation of all activity in the brain stem.
81 Cf. Pope John Paul II, address of 29 August 2000, op. cit.
82 Organ transplantations, Joint Declaration by the German Bishops’ Conference and the Council of the German Protestant Church, 31 August 1990.
There exists a range of indicators that prove that the neurological criterion has been met. Such signs may evolve in step with advances in knowledge and in research techniques. For instance, some countries have proposed replacing the recording of electrical impulses in the brain with an alternative examination. However, it is important for individual countries to determine and compel compliance with a coherent and adequate range of indicators that must be present before death can be confirmed, and for them to ensure strict compliance with such rules.

A deceased person’s family may find it very difficult to believe that their close relative is really dead. Oftentimes their death occurred unexpectedly and, because they are on life support, they look as though they are still alive (their chest continues to rise and fall, their heart beats and their body heat is maintained etc). The family is therefore entitled to express their distress and to raise questions, to be listened to attentively, and to receive patient and appropriate replies.

II. LIVING ORGAN DONATIONS

It is also possible to procure organs or tissues from the living. Procurement is acceptable only where the risks to the donor are low and reasonably proportionate to the expected benefits for the recipient. It is also important to be able to guarantee the quality of the information which has been provided on organ procurement, its risks and its constraints, as well as the free consent of the donor. This rules out organ procurement from minors or from legally incompetent adults. However, the very fact that a close relative is suffering from a serious illness, or the attitude of family members, can also exert strong pressures on the person whose tissue is judged to be the most compatible with the person awaiting a transplant. It may be desirable to have the intervention of a judge or of a specially appointed expert committee in order to guarantee, as far as is possible, this freedom of consent.

Owing to the increase in medical conditions suitable for organ transplants and to the small number of deceased people from whom organ procurement can be considered, there is in a number of countries a trend towards the expansion of organ procurement from living people who generously donate a kidney, or even part of a unique organ, such as the liver. This raises the issue of expanding the circle of people entitled to act as donors. Countries that accept only an ill person’s parents or grandparents, descendants, brothers and sisters as living donors have come to accept more distant relatives. It has even been suggested that unrelated living donors, known as ‘altruistic’ organ donors, be accepted. Such generous donations are only to be welcomed, provided that they are offered freely in an informed and disinterested manner. It is essential to ensure that such generosity does not mask a system of organ trafficking based on exploiting the destitute.

In 1990, the German Bishops’ Conference declared: ‘From a Christian standpoint, there is no fundamental objection to voluntary organ donation. Any hesitation stems solely from the possibility of abuse (such as trade in organs). According to Christian belief, life, and hence the body, is a gift from God which individuals may not dispose of as they please but which, after having carefully examined their consciences, they may use out of love for their fellow human beings.’ In 1991, Pope John Paul II considered it an act of great generosity

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83 This is not concerned with the procurement of bone marrow or blood because such tissues are renewable and relatively easy to procure.

84 Organ transplantations, Joint Declaration by the German Bishops’ Conference and Council of the German Protestant Church (EKD), op. cit. (unofficial English translation).
if people decide ‘freely and consciously (...) to give a part of themselves, a part of their own body, in order to save the life of another human being’. However, the Pope qualified this by saying: ‘A person can only donate that of which he can deprive himself without serious harm to his own life or personal identity, and for a just and proportionate reason.’

Such endorsements for living donations are accompanied by reservations. Living donations are valid only for ‘donations’, which are, by definition, free of charge, freely given and made in full knowledge of all the issues involved: thus, after full information of the benefits for the recipient and of the constraints and risks for the donor. However, such apparent generosity may conceal a very different picture: in particular a lucrative trade in human body parts and the exploitation of the poverty of people who cannot find other means of providing for their own, and their family’s needs. To prevent such trade in body parts, most national legislations recognise as potential donors only people in the organ recipient’s family circle (defined more or less narrowly from country to country).

Indeed, it is this concept of organ ‘donation’ that many countries have accepted and organised and the Church has approved. The notion of donation implies that it is free of charge. It would be contrary to human dignity to turn body parts into a commodity that can be bought and sold. However, this does not rule out donors from receiving compensation for actual expenses that they have incurred.

III. CONCLUSIONS

Seen from this standpoint, organ donation and transplantation represent both a genuine medical success story and an eloquent form of the kind of solidarity so necessary in our societies in order to keep alive their sense of human kinship. There are many people awaiting transplants. Nevertheless, this does not give them the right to someone else’s body. Even after death, the human body is not an object for ill people or society to use. However, society is fully entitled to organise organ procurement in a way that respects the spirit of ‘donation’ and raises public awareness of the needs of people with a failing body organ. It is legitimate for society to invite all individuals to demonstrate their generosity by consenting to an infringement of the bodily integrity of their relatives after death, or of their own body, either after death or perhaps during their lifetime.

The Catholic Church has on many occasions openly declared itself in favour of what can with honesty be termed organ ‘donation’. It could doubtless make an even greater contribution by playing a more active role in raising public awareness within its numerous communities and institutions in the various European countries. It might be useful to study this issue within the Commission of the Bishops’ Conferences itself.

*English translation from the original (French) version*

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85 Pope John Paul II, address of 20 June 1991, op. cit., §3.
87 The present Opinion deals essentially with questions related to the procurement of organs for transplantation. Many patients, for whom transplantation represents a real hope of staying alive or gaining a better quality of life, wait anxiously for an organ transplant. But, in most cases there remains the risk of rejection of the transplant; this requires immunosuppressive drug treatment which is itself not without secondary effects. Hence, transplantation has little to do with genuine recovery. It is therefore essential to pursue research into getting better control over the phenomenon of rejection.

Summary

1. This response primarily addresses the proposals in the White Paper at the level of principle. It is based on the conviction that organ donation is a profoundly Christian positive act. Our main concern is that the positive ethos of donation as a free gift is being endangered by an ill-judged if well-intentioned proposal to move from voluntary donation to presumed consent. However, if organs may be taken without consent, this is no longer ‘donation’. This is not just a health matter but concerns serious human rights issues such as personal autonomy, as well as questions about the relationship of the state and the citizen. At the same time the belief that presumed consent would itself increase the number of organs available for transplantation is not supported by the available evidence, as is shown below (paragraphs 16 – 25).

Organ transplantation enjoys a high level of public support but it also involves the sensitive issue of respect for the human body after death, people’s human right to privacy and respect for personal beliefs and religion. These are areas that need to be negotiated with care and, as far as possible, by consensus legislation. We therefore urge the Welsh Government to revisit the process and establish a cross party committee that could consider all the evidence submitted to the previous enquiries of the last three years: the Organ Donation Task Force, the Welsh Assembly Committee, the U.K. Parliament’s Welsh Affairs Committee and also the substantial research conducted by the Universities of Ulster and Johns Hopkins.

Response

2. The Welsh Government has invited responses to the White Paper both ‘on particular aspects of the policy proposals’ and ‘on the proposals more generally’. This response will primarily address the proposals at the more general level, for it is important to resolve questions of principle before considering how to implement proposals in practice.

The value of organ donation

3. The basis of this response is a shared conviction that organ donation is essentially a profoundly Christian act that is positive both in its consequences for the recipient and as an expression of human solidarity across society. Nothing in this submission should be interpreted as a rejection of the practice of donation of organs after death where this is done with due sensitivity to medical, cultural and ethical considerations. On the contrary, the concerns that are raised here are precisely that ill-judged proposals might endanger the ethos of donation.

4. Taking their starting point from Christ who healed the sick and who gave Himself for the good of others, Christians have welcomed the benefits that have come through organ transplantation. From the very first there have been strong authoritative voices that would encourage donation.\textsuperscript{89} There is, of course, diversity between and within Christian communities as there is diversity in wider society. There are differences of education, of personal and family experience, and different levels of trust in the establishment. There are also differences of view both about the practice of transplantation and about whether, and if so, how the law should change. This submission therefore cannot and does not presume to represent the views of every member of our respective communities. Nevertheless, precisely for this reason, the submission strongly urges that the law \textit{should not presume that individuals or their families would consent to donate their organs}. While there is some evidence of a greater level of donation among Christians,\textsuperscript{90} and this is an activity that all Churches have encouraged,\textsuperscript{91} it cannot be presumed that all Christians have decided to donate their organs, and still less can this be presumed for the population as a whole.

5. This joint submission also expresses the concern that any change in the law should protect marginalised communities and individuals, especially those who are socially excluded or who have difficulty in making their views heard. As Christians we are particularly aware of the way that minorities, including religious minorities, can be endangered by the majority, as for example when the majority does not adequately respect the need for consent from someone who is a member of a minority community.

\textbf{The necessity of consent}

6. Pastors, theologians and Church leaders agree that offering organs for donation can be a significant act of charity, and a reflection of God's freely-given love and care for us, including the gift of life. A few examples should suffice:

7. ‘Above all, this form of treatment is inseparable from a \textit{human act of donation}. In effect, transplantation presupposes a prior, explicit, free and conscious decision on the part of the donor or of someone who legitimately represents the donor, generally the closest relatives. It is a decision to offer, without reward, a part of one's own body for the health and well-being of another person. In this sense, the medical action of transplantation makes possible the donor's act of self-giving, that sincere gift of self which expresses our constitutive calling to love and communion.’\textsuperscript{92}

\begin{itemize}
\item \textsuperscript{89} For example, in 1956 when solid organ transplantation had yet to become common practice, Pope Pius XII argued that that would not be ‘a violation of the reverence due to the dead’. Rather, organ donation from the dead was justified because of ‘the merciful charity shown to some suffering brothers and sisters’ (Allocution to Eye Specialists 14 May 1956).
\item \textsuperscript{90} Researchers have shown a statistically significant correlation between Catholicism and rate of donation (Parliamentary Office of Science and Technology ‘Organ Transplants’ Postnote October 2004 Number 231, page 2, quoting Gimbel et al. \textit{Progress in Transplantation} 13 (2003):15-23). http://www.parliament.uk/documents/post/postpn231.pdf, To date researchers have not investigated the relation between rate of donation and Christianity for other Churches, but there is no reason to think it any less.
\item \textsuperscript{91} Pope John Paul II said that, ‘We should rejoice that medicine, in its service of life, has found in organ transplantation a new way of serving humanity’. Hence the \textit{Catechism of the Catholic Church} states that ‘Organ donation after death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity.’ For further references see UK Transplant leaflet on \textit{Christianity and organ donation} http://www.uktransplant.org.uk/ukt/how_to_become_a_donor/religious_perspectives/leaflets/christianity_and_organ_donation.jsp
\item \textsuperscript{92} John Paul II \textit{Address to 18th International Congress of the Transplantation Society} (29 August 2000).
\end{itemize}
8. ‘Christian faith is a positive motivation for organ donation and a powerful incentive for many people to donate.’ Organ donation is ‘an expression of the faith-based virtue of helping others; you might call it the ‘generous gift’ approach... agreeing yourself to donating your own organs is easily understood as one person’s generosity towards others.’

9. From the point of view of Orthodox Christian ethics, organ or tissue donation can be understood as a generous and virtuous act. Organ transplantation ‘makes it possible to give effective aid to many patients who were earlier doomed to death or severe disability... The transplantation of organs from a living donor can be based only on the voluntary self-sacrifice for the sake of another’s life. In this case, the consent to explantation becomes a manifestation of love and compassion’. The same principle applies to posthumous donation. ‘The posthumous giving of organs and tissues can be a manifestation of love spreading also to the other side of death.’

What is wrong with ‘presuming consent’?

10. The fundamental Christian objection to presumed consent is that this contradicts the rationale and ethos of donation. ‘Presumed consent’ is not consent. Silence is not consent. If organs are taken for transplantation without consent there is no giving, there is only taking.

11. It is sometimes said that Christianity has no official position on ‘opt-in’ or ‘opt-out’ systems of organ retrieval. However it is difficult to reconcile ‘opt-out’ systems with the clear Christian commitment to voluntary donation. If the organs are taken without the prior consent of the deceased, or permission of a relative or friend speaking on behalf of the deceased, then the deceased is no longer a donor and taking the organs is no longer an act of donation. It is taking without asking. From a Christian perspective this fails to respect the enduring human meaning of the body. Instead of transplantation being an act of donation, an expression of solidarity between people, it becomes merely the medical use of a body.

12. Pope John Paul II clearly stated that without consent ‘organ transplantation and the grafting of tissue would no longer correspond to an act of donation but would amount to the dispossession or plundering of a body’. This understanding is also expressed in the Catechism of the Catholic Church which lays down that organ donation ‘is not morally acceptable if the donor or his proxy has not given explicit consent’.

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94 John Davies, Bishop of Swansea and Brecon.
95 Russian Orthodox Church’s document The Basis of the Social Concept, XII.7 Problems of Bioethics.
97 John Paul II Address to The Society for Organ Sharing (20 June 1991).
98 Catechism of the Catholic Church, 2296, emphasis added.
13. From an Orthodox perspective, ‘donation… cannot be considered a duty. Therefore, the voluntary consent of a donor in his lifetime is the condition on which explantation can be legitimate and ethically acceptable’.\(^9\) Hence ‘the so-called presumptive consent of a potential donor to the removal of his organs and tissues, sealed in the legislation of some countries, is considered by the Church to be an inadmissible violation of human freedom’.\(^10\)

14. Within the context of the present debate, the Archbishop of Wales has given voice to this same shared Christian understanding of organ donation. ‘There is another theological argument. Organ donation surely ought to be a matter of gift. If one takes organs without consent, on the assumption that by not opting out, a person is tacitly assenting, then that is no longer a free gift to others. An organ donation ought to be precisely that, a gift, an act of love and generosity. Giving organs is the most generous act of self-giving imaginable but it has to be a choice that is freely embraced, not something that the State assumes. Put more crudely, it turns volunteers into conscripts. Presumed consent is not really consent at all, merely the assumption that there are no objections.’\(^11\)

15. The Christian tradition supports the idea that the state may require us to do (or refrain from doing) certain things with regard to our bodies, for our own good or that of others (for example, safety legislation; the smoking ban, even potentially applied to private cars where children are present; illegal drugs; in extreme cases, taking children into state care if parents are unable or unwilling to act in their best interests, or if they refuse essential medical treatment). Some Christians also argue that the state should be able to use organs from dead bodies without our explicit voluntary consent. However, those who argue in this way must acknowledge that taking organs without consent is not ‘donation’. The call to use organs without consent is no more or less than a call to abandon donation as the basis for organ transplantation.

**Would presumed consent increase rates of transplantation?**

16. It should not be taken for granted that changing the law to a system of opt-out/presumed consent would necessarily increase the availability of organs for transplantation. While some studies have shown a higher level of transplantation on average in countries with presumed consent laws,\(^12\) it is very difficult to show that this is due to such laws or that a change in the law in itself would necessarily have a positive effect.

17. Changing to a system of presumed consent was rejected by the House of Commons in 2004. The Department of Health, having reviewed the evidence from different countries, stated that ‘it considers changing legislation to be a high-risk strategy. Without clear public support, presumed consent may be counterproductive, leading to reduced donation rates.’\(^13\)

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9. Russian Orthodox Church’s document The Basis of the Social Concept, XII.7.

10. Ibid.


13. Parliamentary Office of Science and Technology, p. 3.
18. In 2008 the Organ Donation Taskforce was asked to consider the case for a change in the law to presumed consent. They commissioned research from the University of York which concluded that ‘The evidence identified and appraised is not robust enough to provide clear guidance for policy’. After the comprehensive review (still perhaps the best to date) the Report concluded that it was ‘not confident that the introduction of opt-out legislation would increase organ donor numbers, and there is evidence that donor numbers may go down.’

19. The country with the highest rate of organ donation is Spain, which has a law which allows organs to be taken with presumed consent. However, when Dr Rafael Matesanz, President of the Spanish National Transplant Organisation, gave evidence to the Organ Donation Taskforce, he was explicit: presumed consent was not the reason for the success of the Spanish system. He reiterated this at a briefing on presumed consent reported in the British Medical Journal. When asked if a presumed consent law was the reason for the success of the Spanish system, he said:

‘Is it because of the law? Not likely. We have always had the same law. The families are always approached. They always have the last decision, and there are great variations from region to region.’

20. In the light of this evidence it should not be surprising that the cross party committee of the Welsh Assembly which considered presumed consent in 2008 came to a similar conclusion. The majority of the Health, Wellbeing and Local Government Committee judged that ‘organ donation rates can be improved significantly without introducing presumed consent. More than that, we feel there is a danger that moves to legislate in Wales ahead of the rest of the UK could be a distraction from more productive improvements and could alienate public support for organ donation if not handled properly.’

21. The two most recent studies to look at presumed consent are from the University of Ulster and the Johns Hopkins University School of Medicine. In October 2011, a team from the University of Ulster compared donation rates for England, Wales, Scotland and Northern Ireland over two decades and also compared these rates with those of other European countries. They concluded that ‘Further exploration of underlying regional differences and temporal variations in organ donation, as well as organisational issues, practices and attitudes that may affect organ donation, needs to be undertaken before considering legislation to admit presumed consent.’

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105 Organ Donation Taskforce 11.5.


107 Organ Donation Taskforce 11.3. The fact that in practice Spanish physicians do not take organs without permission has led some studies to characterise Spain as having ‘presumed consent’ legislation with ‘informed consent’ as actual practice, see Parliamentary Office of Science and Technology, p. 2 quoting Council of Europe; National Transplant Organisation.


22. The key paragraph from the Ulster study reviews the evidence from different countries. It is worth quoting in full:

‘Hence, though Sweden applies presumed consent, its donation rate in 2009, at 13.8 deceased donors per million population (Scandiatransplant personal communication, 2011), was comparable with that of Germany (14.5 deceased donor per million population) and Denmark (14.0 deceased donors per million population); both of which require informed consent. The figures available for Ireland, where informed consent is needed, were 21.2 deceased donors per million population in 2009. The nation with the highest donor rate (34.4 deceased donors per million population in 2009), is Spain, which operates a ‘soft’ form of presumed consent where next of kin can object to organ donation. Yet, the impact of the legislation has been questioned and the high rate of donor activity attributed to the ‘Spanish Model’ that demands an integrated approach with dedicated transplant coordinators, mainly intensive care physicians, involved in procurement. This highly coordinated network and the respect for autonomy given to the individual and their relatives is credited with improving donation rates of 14.3 deceased donors per million population in 1989 to rates of 33-35 deceased donors per million population in recent years.’

23. In November 2011 John Hopkin’s University published the results of in-depth interviews with transplant experts in 13 European nations with presumed consent legislation. They found that, despite the laws, the process of organ donation in those countries did not differ dramatically from the process in countries, such as the United States, that require explicit consent. ‘Opt-out is not the magic bullet; it will not be the magic answer we have been looking for,’ said Dorry L. Segev, an associate professor of surgery at the Johns Hopkins University School of Medicine and leader of the study published online in the journal Transplantation. Implementing presumed consent legislation, Segev argued, would take a huge amount of time and energy with minimal payoff. Many countries with presumed consent have much lower rates of organ donation than the United States, he noted.

‘With opt-out the perception becomes: We will take your organs unless you take the time to fill out a form. That’s a dangerous perception to have. We only want to use donated organs from people who intended to donate.’

24. It is notable that the latest figures for 2010-11 show that Wales has already achieved a significant increase in its rate of donation. At 27.7 deceased donors per million this is now higher than the United States and is among the highest in Europe. There is every reason to think that further increases can be made through building on this success in public education, communication with relatives and more effective systems of transplant coordination. This real improvement has occurred without changing the law on consent. With high levels of public support, and recent initiatives giving significant improvements in rates of donation, this is no time to abandon the principle of voluntary donation.

25. Some people clearly believe that changing the law from opt-in to opt-out would itself improve the rate of transplantation, and this has been the basis of a very effective media campaign by some groups. However, this belief is simply not justified by the available evidence. It is a myth.

Can we reasonably presume that people have consented?

26. It is frequently stated that ‘90 per cent of people in the UK say they support organ donation, but to date only 30 per cent have joined the NHS Organ Donor Register’, in which case it might seem reasonable to presume that people would consent, if people are given ample opportunity to ‘opt-out’. However, this 90% figure is from a survey by UK Transplant in 2003 which asked if people were ‘in favour of organ donation in principle’. It was not a survey of how many people themselves wished to donate their organs. A more recent survey for Yougov in 2007 found that 62% of people were willing to donate. This is a more realistic figure. There is evidence that people in Wales are more willing to donate, but research carried out by the University of Swansea in 2008 found that, if an opt-out system were established in Wales only 60% would ‘definitely not opt-out’ with a further 16% saying they would be unlikely to opt-out. This leaves 24% who would opt-out, might opt-out, or who did not know. Interestingly, in the same poll, 24% of people said they strongly disagreed with presumed consent and a further 15% said they tended to disagree with presumed consent.

27. These figures show that a significant percentage of people in Wales (between 24% and 39%) disagree with presumed consent and would not be willing for their organs to be taken without their prior consent or permission from those closest to them. As not everyone will get around to making their wishes known, it cannot reasonably be ‘presumed’ that people have not made their wishes clear would have wanted their organs to be used for transplantation. There is a fair chance (perhaps one in four) that they would not have wanted this.

Improving refusal rates

28. In current practice (both in Wales and in most other countries), whether or not a person has signed the Organ Donation Register (or equivalent), specialist nurses and consultants also ask the relatives whether they would permit organs to be taken. In the United Kingdom around 43% of families refuse permission. This is far higher than in other countries, such as Spain, where the refusal rate is around 9% How can this issue be addressed?

113 For example, National Assembly for Wales Research Service Organ and Tissue Donation Paper number: 11/068, p. 3 http://assemblywales.org/11-068.pdf quoting NHS Blood and Transplant, Organ Donation online.
117 Opinion Research Service from Swansea University conducted a telephone survey using structured questions directed at a representative sample of the Welsh population between 14 November and 8 December 2008.
119 Organ Donation Taskforce, 11.3.
29. The Organ Donation Task Force found that, whereas the overall family refusal rate is around 40%, if the person is on the Organ Donation Register then the refusal rate drops to 10%. This shows that families are generally supportive of the removal of the organs when they know that this is what the person wanted. The most effective way to increase rates of family permission for donation is therefore to encourage people to sign the Organ Donation Register and to encourage people to talk about the issue with relatives and those close to them. Any move that weakens the Organ Donation Register and leaves relatives unsure of what the deceased would have wanted is likely to increase refusal rates among relatives.

30. It should also be noticed that refusal rates in the United Kingdom are significantly higher now than they were in the 1990s. It is likely that there are many causes for this increase, including the Alder Hey scandal in 1999 where organs were kept without consent. A number of reports have emphasised the importance of maintaining public trust in the system and the importance of the principle of consent in maintaining this trust.

Consultation with relatives

31. The proposals in the White Paper call for a ‘soft opt-out’ system in which the relatives will always be consulted. It is clearly important for the relatives and those close to the deceased to be consulted. However, the idea of ‘consultation’ or of being ‘involved in the process’ is ambiguous. The law needs to state unambiguously whether, in the absence of an explicit statement of the wishes of the deceased, the relatives will be able to refuse permission for the removal of organs.

32. A duty to consult, as currently proposed in the White Paper, is much weaker than a right to refuse permission. However, if relatives have no right to refuse permission in law, this represents a move of power away from the relatives of the deceased and towards the state. This is not just a matter of health but is about the right of the state to dispose of a body in a certain way even in the face of objections from closest relatives.

33. In practice it seems doubtful that specialist nurses in organ donation in Wales would want the power to overrule relatives so that organs were taken from those who had not given consent in the face of opposition from those who were closest to them. However, if this would not happen in practice, why does the Welsh Government need to create a power that would not be used? This power seems unnecessary while at the same time it threatens to undermine the very concept of free donation on which organ transplantation has hitherto relied.

120 Organ Donation Taskforce, 1.15.
121 According to the Parliamentary Office of Science and Technology (p.3), in the 1990s the family refusal rate was 30% whereas by 2004 it had reached 42%.
122 ‘Trust, however, is key to the success of the organ donation system in the UK. If public trust is shaken, organ donor numbers are likely to fall rapidly and could take many years to recover’ (Organ Donation Task Force 4.6); ‘Comments provided highlighted concern that an opt-out system had the potential to damage the relationship of trust between clinicians caring for people at the end of their life.’ (Welsh Assembly Government Consultation Paper, p. 10); ‘…and others believe due to the general public’s mistrust for the Government they will resist this type of system being imposed on them.’ (National Assembly for Wales Research Service, 4.1); ‘Without clear public support, presumed consent may be counterproductive, leading to reduced donation rates.’ (Parliamentary Office of Science and Technology, p.3).
The process of public consultation

34. In addition to grave concerns about the central proposal in the White Paper, there are also problems with the way in which this proposal has been brought forward.

35. Organ transplantation enjoys a high level of public support but it also involves the sensitive issue of respect for the human body after death. It involves people’s human right to privacy and respect for personal beliefs and religion.\(^\text{123}\) This is an area that needs to be pursued with care and, as far as possible, by consensus legislation.

36. It is of extreme concern that while responses are being invited on the proposals in the White Paper, the central proposal, which is the shift from donation to presumed consent, is presented as a *fait accompli*. This approach threatens to polarise debate and to alienate those who have reasonable concerns about this proposal. Whatever the exact shape and scope of the eventual law, this is not the way to secure a broad consensus.

37. We therefore urge the Welsh Government to revisit not only the proposals but also the process. This issue is one that should be resolved as far as possible through open dialogue and consensus building and by a process that can secure the widest possible support. It should not be a party political issue. What is needed to rescue this process is for some independent, academic, or cross-party body to conduct a genuinely open consultation which would consider a range of possibilities without prior commitments to a particular legislative proposal. They might reasonably look at systems that include aspects of opt-in, opt-out and mandated choice. It would also helpfully consider the evidence submitted to the previous enquiries of the last three years: to the Organ Donation Task Force,\(^\text{124}\) to the Welsh Assembly Committee\(^\text{125}\) and to the U.K. Parliament’s Welsh Affairs Committee\(^\text{126}\) and to consider the research conducted by the Universities of Ulster\(^\text{127}\) and John Hopkins.\(^\text{128}\) For it is not at all clear that the present proposals have benefitted as much as they might from the evidence available.

38. If the proposals in the White Paper are not subject to independent scrutiny then there is a real danger that a change in the law would alienate a significant proportion of the public and undermine the positive image of organ donation and the reputation of Wales. For while a high rate of voluntary donation speaks of a culture of generosity, a system of presumed consent would ‘turn donation into action by default’.\(^\text{129}\)

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\(^\text{123}\) Some of these issues were raised in evidence submitted to the Welsh Affairs Committee when it considered Legislative Competence Consent for Organ Transplantation from a deceased adult. However, as the LCO was withdrawn, that Committee was not able to weigh this evidence or explore these human rights issues.

\(^\text{124}\) Organ Donation TaskForce.

\(^\text{125}\) National Assembly for Wales (July 2008).

\(^\text{126}\) Welsh Affairs Committee Sixth Special Report into Proposed Legislative Competence Orders relating to Organ Donation and Cycle Paths (HC 896) http://www.parliament.uk/business COMMITTEES/committees-a-z/commons-select/welsh-affairs-committee/organ-donation-lco/consultations and Cycle Paths (HC 896) http://www.parliament.uk/business/committees/committees-a-z/commons-select/welsh-affairs-committee/enquiries/organ-donation-lco/consultations see in particular Written Evidence submitted by the Anson Centre for Bioethics Centre (which presents a Roman Catholic view) and written evidence submitted by The Wales Orthodox Mission.

\(^\text{127}\) McGlade et al. ‘Regional and temporal variations in organ donation’.

\(^\text{128}\) Boyarsky et al. ‘Potential Limitations of Presumed Consent Legislation’.

\(^\text{129}\) As argued by UK Transplant: National Assembly for Wales, Health, Well-being and Local Government Committee, Committee Inquiry into Presumed Consent for Organ Donation – Evidence from UK Transplant.
The Most Rev George Stack,
Archbishop of Cardiff (Roman Catholic)

The Most Revd Dr Barry Morgan,
Bishop of Llandaff, Archbishop of Wales (Church in Wales)

The Very Revd Archimandrite Father Deiniol,
Administrator, Wales Orthodox Mission (Eastern Orthodox)

The Rt Rev Thomas Burns,
Bishop of Menevia (Roman Catholic)

The Rt Rev Gregory Cameron,
Bishop of St Asaph (Church in Wales)

The Rt Revd John Davies,
Bishop of Swansea and Brecon (Church in Wales)

The Rt Revd Wyn Evans,
Bishop of St David’s (Church in Wales)

The Rt Rev Andrew John,
Bishop of Bangor (Church in Wales)

The Rt Rev Edwin Regan,
Bishop of Wrexham (Roman Catholic)

The Rt Rev Dominic Walker,
Bishop of Monmouth (Church in Wales)

The Rt Revd David Wilbourne,
Assistant Bishop of Llandaff (Church in Wales)
This report is the work of an international group of clinicians, philosophers, and theologians, convened by the Anscombe Bioethics Centre, Oxford. The aim of the report is to set out the ethical requirements which must be met if transplant medicine is to achieve its true end, and merit the support of Catholics and, more generally, of men and women of good will. It also addresses some new concerns which have arisen, within the Church and within society, about the ethical practice of transplantation, and in particular the criteria for diagnosing death and the issue of presumed consent.

‘I welcome this report as a source of reflection to help Catholics, and men and women of good will, to examine the ethical issues that surround organ transplantation so they come to an informed choice. I hope it will also be of use to healthcare professionals in reflecting on their practice, to practice ethically in the service of the human family.’

Archbishop Peter Smith