

Transplantation – Opting in or presumed consent for organ and tissue donation?

May 2015



The Church of Scotland

Church and Society Council

Transplantation – Opting in or presumed consent for organ and tissue donation?

1.1 The Church of Scotland, along with many other Christian and faith groups, supports the practice of organ and tissue donation.¹ This is part of humanity's commitment to healing and, with the real potential for the death of one person to prolong or greatly improve the quality of the life of another, an action with strong symbolic Christian resonance.

1.2 In May 2014, the General Assembly requested this report on organ donation choices (and, by extension, we also consider the same principles to apply to tissue donation)] anticipating possible changes to the law in Scotland.

1.3 Currently in Scotland the system for using organ and tissue involves an active opt in by an individual: requiring them to sign up to the organ donor register. The relevant law is the Human Tissue (Scotland) Act 2006. Demand for organs far exceeds supply, and so there is a need to increase the number of potential donors.

1.4 The most recent year for which figures are available (2013/14) saw the highest ever number (106) of deceased organ donors in Scotland – an increase of nearly 60% from 2010/11. In addition, Scotland now has the UK's highest percentage of residents signed up to the NHS Organ Donor Register. Over 41% of the population had joined the register at the end of 2013/14, compared to the UK average of 31%, and 2013/14 saw the highest ever number (342) of transplant operations from deceased donors undertaken on Scottish recipients, an increase of almost 20% from 285 in 2011/12.² The numbers of children's organs available for transplant are generally small: in 2011/12 there were 6 organ donors under the age of 18 in Scotland (compared to 43 in UK as a whole), a single donor in Scotland in 2012/13, and none in 2013/14.

1.5 There is current active research on growing tissues and organs for transplantation in a laboratory setting, but such technology is unlikely to be available for routine clinical use for a number of years. In the meantime, retrieval of donated organs remains an important measure in saving and improving the quality of the lives of many.

1.6 There is current discussion around an opt-out model for organ and tissue donation, where it would be presumed that an individual had consented to allow their organs and tissues to be retrieved for transplantation unless they had expressed a contrary opinion, either in writing, or orally to family and friends. This policy has already been legislated for in Wales through the Transplantation (Wales) Act 2013), and the change will come into effect

¹ In the report of the Church and Society Council to the 2009 General Assembly, the Assembly agreed the following *Deliverance: 44. Encourage Church members to make blood donations regularly and to join the Organ Donor register and to make their wishes known to their family; and honour the families who have agreed to the donation of their loved ones' organs after death.*

In November 2013 the Church and Society Council signed the Church of Scotland up to the **fleshandblood** campaign: <http://fleshandblood.org/about/associates/churchofscotland/>

² Organ Donation and Transplantation in Scotland. How are we doing?

<http://www.organdonationscotland.org/pdf/files/assets/basic-html/page-1.html>

in December 2015. The Scottish Government plans to assess the impact of the change in Wales before considering a similar move in Scotland.

1.7 However, Labour MSP Anne McTaggart has launched a consultation for her proposal for a Members' Bill on Organ and Tissue Donation for Scotland, which would seek to introduce 'presumed consent' to Scotland. The Church and Society Council responded to this consultation, recommending that the Welsh experience be analysed first before making a decision for Scotland. There are at least two ethical issues which need to be considered:

- the nature of donation and gift
- not neglecting the opportunity to prolong and greatly improve the quality of a life if it is appropriate to do so.

We shall return to these questions later.

2 Organ Donation

In 2008, the Organ Donation Taskforce produced a report, *Organs for Transplants*³, setting out 14 recommendations which, it was suggested, would increase the number of organs available by 50% in 5 years. These recommendations have all been implemented and the increased number of organs for transplantation has exceeded the 50% target. There is now an 8% year-on-year increase in donors after brain death and a 16% increase in donors after circulatory deaths. The recommendations copy the 'Spanish model' of putting more staff (Specialist Nurses in Organ Donation or SNODs) into the intensive care units to identify potential donors and by skilled, sympathetic interaction with family members to obtain authorisation for organ retrieval.

3 The Spanish Model

3.1 In organ transplantation, the 'Spanish Model' for organ donation is often referred to and is held by many to be the current best practice. Assumed consent legislation was passed in Spain in 1979 but this made little impact on donor numbers. However in 1989 a national transplant organisation was set up putting a large emphasis on organ donation. Many more staff were employed, allowing a medically trained co-ordinator to be embedded in every intensive care unit throughout the country. This person has the responsibility of identifying every potential organ donor. Having been given the necessary training in discussing with the relatives of these possible donors and by spending time with the family members, the co-ordinators frequently gain consent from the relatives for the person to become an organ donor. In Spain this intensive approach to organ donation doubled the donation rate, and in other areas of Europe which then adopted similar systems the same result has been observed.

3.2 This approach of appointing a specially trained practitioner to every intensive care unit to identify all potential donors was adopted in the UK following the recommendations of the Organ Donation Taskforce's first report in 2008. Additionally, in the UK each Health Board (Hospital Trust in England, Wales and Northern Ireland) must have an Organ Donation Committee to oversee organ donation, and requires the Chief Executive to be accountable for the donor numbers within the Health Board's activities.

³ *Organs for Transplants: A Report of the Organ Donation Taskforce*. Dept of Health Publications 2008. <http://www.bts.org.uk/Documents/Publications/Organs%20for%20transplants%20-%20The%20Organ%20Donor%20Task%20Force%201st%20report.pdf>

3.3 The 2008 report from the Organ Donation Taskforce did not address the issue of presumed consent (opt-out), so a second report was requested from the group to consider this question⁴. In a very detailed report the taskforce noted that “before” and “after” studies in countries which have changed to an opt-out system the donation rate had risen by up to 25%, but that the legislative change was not the only factor because other initiatives were also introduced. These included increased funding for transplant programmes, better infrastructure and increased public awareness. The taskforce reported evidence that the recommendations proposed in its first report, if fully implemented, would achieve a greater increase in donor numbers than 25%.

3.4 There are also examples where a change to an opt-out policy has had detrimental effects on the number of organs retrieved for transplantation; for example, in Brazil, where the law had to be repealed because of mistrust in the government and accusations of body snatching, and in France where a specific case, although fully compliant with the law, caused a great deal of negative press and a fall in donor numbers. In its conclusion the taskforce could find no convincing evidence that the change to an opt-out system would deliver significant increases in the number of donated organs and stated that: “Only if donor numbers have not grown by 50% by 2013 should the question of opt-out be revisited.”⁵. As this target has been achieved, we would consider this a strong argument against revisiting the opt-out system.

4 Current practice

In the current “opt-in” process for organ donation everyone is encouraged to register as an organ donor and this list of possible donors is held centrally for the UK on the Organ Donor Register (ODR). At the time of a death the ODR is consulted and if the person is registered the SNOD will inform the family members that the person wished to donate his/ her organs. Barring any change of mind that the person may have had, or the organs being medically unsuitable, then that donation will proceed. This system is very effective: 90% of deaths which meet transplant criteria and where the person registered as a donor during life result in organ donation. When someone who has not registered on the ODR dies then the next of kin, according to a pre- determined ranking table, is asked to consider what the deceased may have wished and if deemed appropriate grant authorisation for the organs to be removed for transplantation.

5 Presumed consent / opt-out

In an opt-out scheme, people would need to register their wish not to be a potential donor in the event of death, and so the ‘norm’ in society would be for all people to be donors unless they had specifically said they did not want this. This system can be implemented as a ‘hard’ option where, at the time of death, unless the deceased is registered not to be a donor then the organs will be retrieved; or as a ‘soft’ option where, at the time of death of someone who has not registered his/her wish to opt out of organ donation, the family members will be consulted to ‘confirm’ that the deceased was happy to donate organs. This latter system affords the family the choice of agreeing to the organ donation or not.

⁴ The Potential Impact of an opt-out system for organ donation in the UK: An independent report from the Organ Donation Taskforce. Dept of Health Publications 2008 <http://dteg.org/ODT%20PC%20report.pdf>

⁵ Ibid p36

6 Wales

6.1 Following a campaign for an opt-out system for posthumous organ donation in Wales, legislation was passed by the Welsh Assembly in 2013. This will come into force at the beginning of December 2015 to change to a soft opt-out system in that part of the UK.

6.2 Although both the 'Spanish model' and changing to an opt-out system for authorisation for organ donation increase the numbers of available organs for transplantation, the effect is not additive. The most effective method to increase donations seems to be the 'Spanish model'. Thus, it is likely that, given the situation in Wales, with effective implementation of a model similar to the 'Spanish model' already in place, the additional increase in organ donations following a subsequent change to an opt-out process would not be large. There is therefore a good argument to await the results of the change in Wales to see if the size of any increase in organ numbers justifies the legislative and financial costs of changing to an opt-out system.

6.3 It must be appreciated that what happens to a body after death and whether or not the deceased wished during life to donate organs are highly emotive issues. Also, discussions with a family at the time of the death of a loved one take place in very distressing circumstances. Under the present opt-in system, organ donation has always been seen as a gift. At the time of significant distress, people have made the altruistic decision to help other people by allowing their relative's organs to be used to prolong or greatly improve the quality the life of other people. This often allows the bereaved relatives to reflect later on the fact that, in the midst of their distress, other people have been helped.

23.6.4 In an opt-out system, however, all concept of a gift or of donation is lost, and it may simply become the accepted fact that following death organs are removed for transplantation. There must therefore be concern to maintain a balance, whereby the benefit to society of increased numbers of organs for transplantation justifies the potential loss of the concept of a freely given gift.

7 Potential harms

As has been stated, the primary purpose of a change in the system of gaining consent or authorisation for retrieval of organs after death would be to increase the numbers of organs available for transplantation. This would only be of overall benefit to society if the gain in terms of lives saved or prolonged outweighed any harm done by an 'opt-out system' of donation. The likelihood of a significant increase in transplantation has yet to be established, but it is also worth considering at this stage some of the potential harms from an opt-out system of organ donation.

8 Equality

The rights of the person who has not explicitly opted in as a donor must be carefully considered. Not all persons who fail to opt out will have wished to give consent for retrieval and transplantation of their organs in the event of death. We consider that there is a risk of inequality in accessing the means of opting out of organ retrieval. Some people will never want to address the concept of their death and therefore will not make a decision about

organ donation. People with social or emotional stresses or less family support may find it harder to have hypothetical discussions about dying and therefore to make their wishes about organ donation known to those who may be consulted in the event of their deaths. Some may not have the education, capacity or social circumstances needed to allow them to engage with health or legal organisations responsible for compiling the opt-out register. Those with learning difficulties, homeless people or mentally ill people are among the groups who may be, or who may perceive themselves to be, less able to opt out. Those with supportive families and better resources may be more readily able to make choices about organ donation and to opt out if that is their wish. There is therefore a danger that, in the long run, the pool of donors be drawn disproportionately from the 'voiceless'.

9 Loss of trust

There is also a risk of a loss of trust between families of critically ill patients and medical staff. What happens to the body after death may be important to the deceased, but perhaps more often, the handling of the body is not as relevant to the one who has died as to the bereaved family and friends. Many of us might wish consideration for the feelings of our loved ones to take precedence over our own wishes after our deaths, and therefore even if we had failed to opt out of organ donation, we may not strongly wish it to proceed if, in traumatic circumstances, the donation was likely to cause distress to a loved one. With an opt-out system, the default position may be to retrieve the organs of a recently deceased person, without requiring the authorisation of the person's family. There is a potential for harm to the bereaved, if they do not want organ donation to proceed, but feel that they cannot refuse in the absence of an opt-out order by the deceased. It is likely that this would be sensitively handled by medical teams and that the family's wishes would still be carefully considered but if the family feel removed from decision making by the absence of an opt-out directive, then we can foresee distress and loss of trust which could be harmful to the bereaved and to medical teams alike.

10 Reduced public support for transplantation

At present there is broad general public support for those people on transplant waiting lists and also for those who, sometimes tragically, become organ donors. However, there is the potential for an opt-out system to lead to cases where the bereaved family later resent the taking of organs and complain that their wishes were not considered or that they were pressurised into agreeing to organ retrieval. In the event of such cases being publicised, it may be that the general public becomes less supportive of the medical teams seen as the takers of the organs and perhaps even of the recipients of the organs. It is likely that a new policy such as this one would receive much publicity and be the subject of news interest. We are concerned that there could be sensationalised reporting of any cases of bereaved families who felt that organ retrieval proceeded against their wishes. There have been previous examples of prominent media attention leading to a reduction in the support for transplantation. For example, the Alder Hey Hospital scandal where children's organs were retained following post mortem examination for scientific research without the permission of parents. Even though the specific tissues in question were not being used for transplantation, there was enough of a link in the public mind for this to lead to a temporary dip in rates of organ transplantation.

11 Virtue ethics and consequentialism

11.1 Two competing approaches to this question are virtue ethics (i.e. looking at the character and morality of an ethical framework which determines what action to take), and consequentialism, where a positive final outcome could override lesser ethical concerns about how those outcomes are reached.

11.2 A virtue ethics approach to the question of 'presumed consent' might say:

- Organ donation in the UK at present is a voluntary gift, freely given.
- The profound generosity of this decision suggests it is one of the greatest gifts one human being can give to another.
- Presuming consent is no consent at all, and the act of organ retrieval and transplantation can no longer be seen as being a consensual gift in the same way. 'Deeming' a deceased person to have given their consent is a legal fiction and is not real consent.
- The role of state intervention and control over such a personal aspect of life changes the relationship between the individual and society.
- Such a change could discriminate against groups who might not be aware of any change, through lack of knowledge or understanding.
- Current efforts to increase voluntary increase in donor registration appear to be working well, and there are still many other opportunities to improve the current system which is widely accepted and supported.

11.3 A consequentialist approach might respond:

- Any individual can still opt out, either in writing or simply by letting family, friends and medical staff know what their wishes are.
- A publicity and awareness raising campaign would help let everybody in society know – as well as catalysing a national debate about organ and tissue transplantation and end of life issues more broadly.
- It would be a moral wrong not to do everything ethical to prolong and greatly improve the quality of lives of those in need of transplant; if presumed consent increases the number of people receiving transplants then a change in society's view about organ and tissue donation / retrieval is acceptable.

12 A Christian approach

12.1 Roman Catholic, Anglican and Orthodox tradition would lean towards the virtue ethics approach; Thomas Aquinas' approach to both circumstances and intention has clearly informed the joint response by the three traditions to the Welsh legislation.⁶

12.2 However, it is true that Christians can hold a diversity of opinions on the question. The Presbyterian Church in Wales, in its response to a Welsh Government pre-legislative

⁶ Welsh Catholic Bishops:

<http://www.senedd.assemblywales.org/documents/s15617/HTOrg3%20Catholic%20Bishops%20in%20Wales.pdf>

Church in Wales Bishops:

<http://www.senedd.assemblywales.org/documents/s15615/HTOrg1%20Bench%20of%20Bishops%20of%20the%20Church%20in%20Wales.pdf>

consultation paper, outlined its support in principle for the change as it was ultimately designed to prolong or greatly improve the quality of people's lives.⁷

12.3 It is the view of the Church and Society Council that neither approach can be dismissed out of hand but both are valid understandings of this ethical question. At the current time, however, there is not yet evidence that such a change would necessarily significantly increase the number of organs available for transplantation. This is why the Council has supported the current strategy and the activities of the Scottish Government and NHS Blood and Transplant to increase the number of people registering for organ donation, for example through promotion of the *fleshandblood* campaign.

13 Conclusion

13.1 The Council anticipates that the results of the Welsh experience after the change in December 2015 will inform future debate about whether or not Scotland should change the current policy. From the Church's point of view there would need to be clear and substantial evidence that the change did have the effect of prolonging and improving the quality of more lives. In the meantime, the Council recommends that families and groups of friends are encouraged to discuss end of life issues in a calm and non-emotional setting at a time when death is not imminent. Such discussions can naturally include expression of views around organ donation and could be both helpful and comforting to relatives after a death.

13.2 As Christians, the Council supports the life-giving practice of organ transplantation and therefore the Council is keen to see promotion of donation of organs and a reduction in the suffering of those waiting for the chance of transplant surgery. However, the Council also recognises that many organ transplants involve the death of another, equally valued human being, often prematurely and in stressful circumstances in hospital. If an opt-out system of organ donation could significantly increase the numbers of organs available for transplant without harming those persons and families involved in the donation, then it might be justifiable and welcomed by the people of Scotland. The Council considers that further evidence of benefit without harm of such a system is needed before supporting the proposal for change in Scotland.

Deliverances agreed at the 2015 General Assembly:

Urge the Scottish Government to promote organ donation on the present system of consent and to monitor developments elsewhere.

Encourage congregations to consider promoting the *fleshandblood* campaign.

Urge members to join the Organ Donor Register, to advise their families and close friends of this decision, and to encourage them also to join.

For further information contact:

Church and Society

⁷ Pages 74-76: <http://wales.gov.uk/docs/dhss/consultation/120427odresp93-131en.pdf>

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