Making a Christian difference

CARE for Scotland's Response to the Consultation on the Proposed Organ and Tissue Donation (Scotland) Bill

Introduction

CARE for Scotland welcomes the opportunity to respond to the consultation by Anne McTaggart MSP on her proposed Organ and Tissue Donation (Scotland) Bill. CARE is a Christian charity which provides resources and helps to bring Christian insight and experience to matters of public policy. CARE works within the UK, in Brussels and at the United Nations to influence decision makers on matters relating to education, marriage, family life, sexual health and bioethics. CARE for Scotland is a department of CARE and has over 2,000 supporters drawn from across the denominational spectrum.

Responses to the Consultation Questions

1. **The overarching purpose of my proposal is to move from the current opt-in system to a soft opt-out system of organ donation. Do you support this move? Please indicate "yes/no/undecided" and explain the reasons for your response.**

No. CARE does not believe that the introduction of the proposed 'presumed consent' system would be in the best interests of our society as a whole. We believe that proposed system is ethically questionable. Moreover, we note the comment of the Scottish Council on Human Bioethics that Scotland already has a "*de facto* opt-out" system of presumed consent in that relatives are able to grant permission for organ donation when they have no knowledge of the wishes of the deceased person.[1] We note also that the system which is proposed is a 'hard opt out' system and not a 'soft opt out' system as is claimed in the consultation document. A 'soft opt out' system permits relatives to agree or refuse a request to remove the organs of a deceased person for transplantation purposes. The system proposed by the Member gives the relatives no say in cases where the wishes of the deceased person are unknown.

[1] Scottish Council on Human Bioethics, *Consultation: 'Organ and Tissue Donation (Scotland) Bill' nsultation response on behalf of the Scottish Council on Human Bioethics*, 25th September 2014, p. 2.

Christian Ethical Considerations

The first basis of our concern is that the proposal runs contrary to the Christian understanding of the human person as being created in the image of God. In Genesis 1:26, it is stated that human beings are made in God's image. God is crucially personal. This results, at least in part, from the fact that He is a relationship, Trinity. Human beings, uniquely made in God's image, also enjoy personhood and are as such differentiated from the rest of creation with the potential for relationship with God wherein our bodies become temples of the Holy Spirit. We are not part of a machine, neither are we part of an impersonal organic system. We are people and as such possess a measure of autonomy and freedom which cannot be disregarded without our being treated in a degrading way that is impersonal, dehumanising and suggests that we are not bearers of God's image.

This is where part of the problem arises with creating a system that treats human beings with any degree of automation and in so-doing bypasses their personhood. It is good that people choose to donate their organs – this should be encouraged. However, as soon as we introduce an impersonal legal arrangement which results in the taking of people's organs after death – without direct and honouring engagement with their personhood prior to death – we cannot guarantee that they are freely, directly and deliberately giving their consent and therefore their personhood is potentially disrespected. The problem is compounded by the fact that we are not dealing with the way humans use their free will to steward wider creation but with how they deal with their own bodies.

In this context, where the bodies of those who have not given express consent can automatically be claimed by the state (via the NHS), they effectively become impersonal commodities. Christian public policy is concerned with fighting for law that upholds human dignity, respecting the fact that we – including our bodies – are made in God's image and our bodies have the potential to be the temple of the Holy Spirit.

If we countenance any arrangement that denies this – e.g. presumed consent – we call into being a new framework, a new understanding of humanity that will alter the way in which our culture views people generally and not just in relation to organ availability. Even when justified in terms of serving a laudable goal, such a policy cannot but have damaging, long term cultural consequences. It would contribute to fostering the emergence of an impersonal, commodified view of humanity and of the human body which effectively treats humans and their bodies as a means to an end rather than an end in themselves.

Such a position denies the dignity that comes from being a bearer of God's image. Rather, it is based upon a utilitarian ethic in which the state makes a claim to ownership of the bodies of human beings and seeks to use them for the purpose it deems appropriate without the explicit consent of the individual concerned and/or his/her immediate relatives. It is a Pagan rather than a Christian understanding of human society in which the individual person is seen as belonging and subservient to the interests of the wider culture, social structures and organised vested interests. Such a system has the potential to be abused in order to meet the state's perceptions of the 'greater good' whilst the autonomy and discretion of the individual

may be violated. By establishing such a precedent, we are in danger of other, perhaps more disturbing, abuses being instituted at a later date. For example, should a system of euthanasia be introduced in Scotland, as was proposed in 2010, it is conceivable that those unable to give their consent and who have not opted out of the organ donation system may be euthanased and their organs harvested for transplantation purposes. Evidence from the Netherlands and Belgium shows a worrying number of cases in of people being euthanased without explicit request or consent having been obtained.[2] In Belgium, organ donation guidelines have been introduced to apply in cases of euthanasia.

General Ethical Considerations

Firstly, a significant concern which has been raised is that there is a very real danger that a system of presumed consent could undermine donation as an entirely altruistic gift. The Archbishop of Wales has succinctly argued that "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."[3] If the proposed system of presumed consent is introduced, this notion of organ donation as a gift is at risk of being lost. The Organ Donation Task Force (ODTF) reports that representatives from the Donor Family Network also highlight the importance of the gift relationship. They were concerned that a presumed consent system, however weak, would promote conflict between families and clinical staff, conflict that would rapidly degrade the trust that was vital to decision making. Recipients and their families themselves are concerned that donation should always be a genuine gift: "The working group considering clinical implications heard powerful evidence from recipients of organs who stressed their need to know that organs had been freely given by donors and their families, and from donor families who often find great comfort in being an active part of the decision to donate."[4]

Secondly, the concept of presumed or deemed consent is a misnomer. In practice, it is not consent at all. A presumed consent system allows for the retrieval of organs from an individual upon their death if they have not stated whether they want to donate their organs. In many cases it is apparent that the individual concerned may well have consented but did not, for any number of reasons, register this while they were still alive. However, it is very likely under a presumed consent system that organs will be removed from individuals who would not have consented to their removal. For some, this prospect will be of real concern. The question needs to be asked as to whether we accept that the state can have a right over the bodies of human persons upon their death if they fail to make clear what their wishes are with regard to their organs.

In considering these concerns, it is salient to look to what has happened in Wales as the Welsh Government considered the introduction of presumed consent. There has been evidence that a number of donations have been lost as a direct result of what the Welsh

[2] An official report published in 2005 claimed that there were 550 cases of euthanasia without explicit request or consent in the Netherlands. Similarly, a studies have that between 32% and 45% of euthanasia deaths in Belgium were without explicit request or consent.
[3] http://www.bbc.co.uk/news/uk-wales-14998726
[4] UK Organ Donation Taskforce, *The Potential Impact of an Opt Out System for Organ Donation in the UK*, 2008, p4.

Government proposed. Dr Peter Matthews, a consultant in intensive care in Swansea, stated the following in oral evidence to the Health and Social Care Committee of the National Assembly of Wales when it was considering the Human Transplantation (Wales) Bill: "My own experience is that the British psyche has a particular view that what it should do is donate organs as an altruistic gift, and if it is felt that the state is going to take over the organs, then there is the potential that people who may have been willing to become a donor will not do so. We have seen two cases in Morriston where patients who were on the organ donation register, on hearing about this, said to their families that if the state was going to take their organs, they were no longer willing to give them. We lost two donations because of that. So, there is a potential backlash."[5]

It is also worth noting the fact that Wales was the only country in the United Kingdom to see a fall in the number of organ donations between 2011/2012 and 2012/2013. In 2011/2012, 67 deceased individuals donated their organs while in 2012/2013 this had fallen to 52.[6] This was a dramatic fall of 22.3% in one year. This was in contrast to England, Scotland and Northern Ireland, who all recorded a rise in the level of organ donation over this time period.[7] Undoubtedly, there could be a number of reasons as to why Wales experienced a fall in the number of deceased organ donors in 2012/2013 compared to the other three constituent nations of the United Kingdom. However, as Dr Matthews has indicated, a part of this could be the decision on the part of the Welsh Government to introduce presumed consent in contrast with the other nations of the UK.

It is not clear from the consultation if the principle of presumed consent will be applied to the sperm and eggs of deceased people in order to facilitate assisted reproduction for childless couples? If so, this raises a huge ethical problem with regard to the presumed consent proposal. It is likely to increase dramatically the number of people who will choose to opt out of the system.

2. **How essential is it to change the law (from an opt-in to a soft opt-out system) in order to achieve the intended benefits (increased transplant rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?**

It must be noted that there are a number of countries which operate with a system of presumed consent which have low levels of organ availability.[8] What is more, in presumed consent countries with high levels of organ availability, it seems likely that there are other factors that explain the high levels of donation. In the systematic literature review from the University of York which was commissioned by the ODTF when it considered this issue, it was noted that in countries which introduced presumed consent usually other significant changes were made at the same time. These included increased funding for transplant

[5] http://www.senedd.assemblywales.org/documents/s14202/30%20January%202013%20-%20Draft.pdf p10
[6] http://www.organdonation.nhs.uk/newsroom/news_releases/article.asp?releaseId=326
[7] In England the increase was 14.5%, In Scotland it was 16% and in Northern Ireland 2.5%.
[8] See the graph in the Welsh Government's international evidence review p57 found at http://wales.gov.uk/docs/caecd/research/121203optoutorgandonationen.pdf

programmes and better infrastructure for organ donation. Consequently, they suggested that it was often difficult to isolate which factor in practice led to increased levels of organ donation. In their review of the evidence they concluded that "the evidence identified and appraised is not robust enough to provide clear guidance for policy."[9]

Proponents of presumed consent systems often point to Spain as an example of why the UK should introduce such a system. Spain has one of the highest donation rates in the world and it has in legislation a form of opt out legislation. However, the founder of the Spanish Organ Donation Network, Dr Rafael Matesanz, has rejected such an analysis. Dr Matesanz suggested that the increased level of organ donation is "not likely" to have been caused by the law introducing presumed consent.[10] In practice, what he highlights as being crucial is the organisation in hospitals with regard to organ donation; having teams of transplant coordinators in every hospital is what really makes the difference.[11] As Fabre et al have noted, "the rate of organ donation and the refusal rate in Spain from 1979 (when their presumed consent legislation was introduced) to 1989 did not change remarkably by comparison with those of other European countries." In 1989, the donation rates in Spain and the UK were approximately the same and the refusal rates were similar (about 30-40 per cent). In 1989, however, Spain introduced a comprehensive, nationally organised organ donation system that included many innovations. It was this policy shift that led Spain's levels of organ donation to its current enviable levels.[12]

Since the publication of the ODTF report, a number of its recommendations have been implemented and this has seen a marked improvement in the level of donation as a consequence. That presumed consent is not the key is further underlined by the fact that in Sweden, where presumed consent legislation was introduced in 1996, organ availability remains lower than many countries that operate an express consent system.[13]

It worth considering practical concerns that the ODTF raised in their report on the subject. [14]

- The first is with regard to data security. It is clear that under a presumed consent system a decision not to donate organs could potentially be "socially stigmatizing."[15] This is in contrast to the current system, where opting in to donate your organs is seen as a virtuous act. Consequently, the protection of the register will be of importance. However, the authorities in the UK do not have a particularly good record on this front[16] and cases have been reported of sensitive personal data being lost.[17]

[9] Op cit. Organ Donation Taskforce p22
[10] Ibid.
[11] http://www.guardian.co.uk/world/2011/mar/31/spain-health-family-transplant
[12] It is also worth noting that it debateable as to whether Spain is actually an opt-out country at all. Professor John Fabre of Kings College London has argued strongly that it is not. See http://www.senedd.assemblywales.org/documents/s15736/HTInd80%20Professor%20John%20Fabre.pdf for more details.
[13] Donal McGlade, Gordon Rae, Carol McClenahan, et al. Regional and temporal variations in organ donation across the UK (secondary analyses of databases). BMJ Open 2011;1:e000055. doi:10. 1136/bmjopen-2011-000055 accessed at http://bmjopen.bmj.com/content/1/2/e000055.full
[14] Op cit Organ Donation Taskforce p19-21
[15] Ibid. p19
[16] See http://news.bbc.co.uk/1/hi/uk/7449927.stm

Significant resources would have to be invested to ensure that the register was protected.

- Secondly, there is a concern regarding the practicality of Scotland adopting a different system for organ donation to other constituent parts of the UK. Wales is going to face this issue. In the UK, Organ Donation operates on a nationwide basis. This means that organs from each constituent nation can be used in other areas of the UK. If Scotland and Wales have a different system from the rest of the UK, it could pose significant difficulties in this area.

3 **I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree? Please indicate "yes/no/undecided" and explain the reasons for your response.**

No. Families have the right to be consulted as appropriate in relation to ensuring the wishes of potential donors are respected. There is a real danger that the provision in the Bill which enables health professionals to disregard the views of relatives may be subject to Judicial Review under Articles 8, 9 and 10 of the ECHR. Relatives could claim that their rights have been ignored if they were not properly consulted prior to organs being removed.

4. **Do you think an individual should be able to appoint a proxy to the make the final decision regarding transplantation on their behalf? Please indicate "yes/no/undecided" and explain the reasons for your response.**

Yes. An individual should be free to designate a proxy decision-maker to ensure that their wishes and interests are safeguarded.

5. **My proposal is that only adults should be automatically opted-in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent as they currently do. This approach is I believe the best way to safeguard children and young people. Do you agree? Please indicate "yes/no/undecided" and explain the reasons for your response.**

It is right that children should be required to opt in. This should apply also to adults.

6. **Do you agree the age limit for an adult should be set at 16 years old? Please indicate "yes/no/undecided" and explain the reasons for your response. If you answered no, what would you consider a more appropriate age?**

[17] See http://www.bbc.co.uk/news/uk-northern-ireland-16610912 and http://www.bbc.co.uk/news/uk-northern-ireland-18497161 for examples of this.

The Scottish Government, with the support of other political parties, has legislated to introduce a 'named person' scheme for every person aged under 18. It seems somewhat incongruous that young people aged 16 and 17 would be treated as adults and could have their organs removed without having given consent whilst still being considered to need the services of a 'named person'. Clarification is needed from the Member as to whether the 'named person' will be asked if he/she is aware of the views of a deceased young person aged 17 or 18 with regard to the issue of organ transplantation in cases where relatives are unavailable. Furthermore, will the named person have authority to give approval for organs to be removed for transplantation purposes in cases where the views of a deceased child or young person aged under 16 are unknown and no relatives are available to be consulted?

7. **Do you agree the soft opt-out system should apply to people who have been resident in Scotland for a minimum period of 1 year prior to their death? Please indicate "yes/no/undecided" and explain the reasons for your response.**

No, since we do not agree in principle with the proposal. However, if such a system was introduced it should not apply to visitors to Scotland or those with foreign nationality who reside in Scotland. These people should still have to opt in to the organ donor register.

8. **If you answered no to the above how long, if any, should this period of residency last before they become subject to the soft opt-out system? Would this residency need to be for a continuous period?**

No comment.

9. **Do you think 6 months is a long enough period to run a campaign prior to change over?**

No comment.

10. **What is your assessment of the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?**

There are none for our organisation, but the NHS would incur expenditure advertising the new scheme. The NHS in Scotland is under considerable financial strain at the current time with the expectation of £450m of additional savings needing to found in the near future. The introduction of a presumed consent system would require an extensive awareness raising campaign to be launched and significant investment would be required to develop the requisite infrastructure to run the system. No estimate as to the cost this would impose in Scotland is detailed in the consultation. The consultation notes that in Wales it has been estimated that it will cost approximately £8 million over 10 years to set up and run the requisite infrastructure for the presumed consent system. As Wales has a population of just over 3m, it can be expected that the equivalent cost in Scotland might be up to £13m. In a time of financial stringency, questions need to be asked as to whether the introduction of such a system is the best use of resources.

11. Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

There is a danger of abuse, particularly if assisted suicide or euthanasia are legalised, which would run counter to all the principles of equality and justice.

12. Do you have any other comments on or suggestions relevant to the proposal?

The progress made by the NHS in recent years to improve the level of organ donation is admirable and to be commended. Continuing down the road of following the recommendations made by the ODTF would seem to be a better approach to take than introducing a system of presumed consent. Efforts in recent years have seen an increase of 31% in UK organ donation rates and there is no reason to believe this would not continue. Additionally, it would avoid the serious practical and ethical problems which arise from presumed consent. Moreover, there are other ethically uncontroversial means by which improvement can be made to the current system which would certainly increase awareness of organ donation and perhaps increase the number of organ donors. For example, all applicants for a driving licences and other official documentation (e.g. passports) could be mandated to respond to a question as to whether they are willing to donate their organs upon their death. Over a number of years such an approach could boost the number of organ donors in Scotland and avoid the ethical problems of presumed consent.

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