Transplantation (Authorisation for the Removal of Organs etc.) (Scotland) Bill

CARE for Scotland

CARE for Scotland is pleased to submit evidence to the Health & Sport Committee. 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 and at the EU to influence decision makers on matters relating to family life and bioethics. We have over 2,000 supporters drawn from across the churches in Scotland.

Do you support the Bill?

No. CARE does not believe that the introduction of the proposed ‘presumed consent’ system would be in the best interests of Scottish society. We have two objections to this proposal: ethical and practical. These issues are interconnected as the practical failure of implementation of presumed consent is often linked to the fact that people respond negatively to the state claiming a right over people’s bodies. These concerns have not been adequately addressed by the Member in Charge of the Bill.

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 (Genesis 1:26). God is crucially personal and relational. Human beings, uniquely made in God’s image, also enjoy personhood and are differentiated from the rest of creation with the potential for relationship with God and with other people. 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, impersonal and dehumanising manner.

The problem arises with creating a system that treats human beings with any degree of automation and bypasses their personhood. It is good that people choose to donate their organs – this should be encouraged. However, if we introduce an 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 the organs are given freely and with consent and, therefore, the donor’s personhood is potentially disrespected.

If the bodies of those who have not given express consent are automatically 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, commoditised view of humanity.
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.

General Ethical Considerations

Firstly, there is a danger that a system of presumed consent could undermine organ donation as an entirely altruistic gift. The Organ Donation Task Force (ODTF) reports that representatives from the Donor Family Network 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:

Secondly, the concept of presumed or deemed consent is a misnomer. In practice, it is not consent at all. In some cases the individual concerned may have consented but did not, for any number of reasons, register this view while still alive. However, it is also 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 has 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. It would be inappropriate, in particular, for the sexual and reproductive organs of deceased persons to be transplanted into other people without the consent of the donor.

Thirdly, the proposed 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, it is not inconceivable should a system of euthanasia ever be introduced, that those unable to give their consent and who have not opted out of the organ donation system may be killed with their organs being harvested for transplantation purposes.

Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland? Please provide an explanation for your answer.

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2 Evidence from the overseas shows a worrying number of cases in of people being euthanased without explicit request or consent. An official Dutch report published in 2005 claimed that there were 550 cases of euthanasia without explicit request or consent in the Netherlands. Similarly, studies have shown that between 32% and 45% of euthanasia deaths in Belgium are without explicit request or consent. In Belgium, organ donation guidelines have been introduced to apply in cases of euthanasia.
We are not convinced by the international evidence that it will necessarily be the case that the introduction of this system will lead to an increase in organ donation. The debate has been confused because Spain is often claimed to have a system of presumed consent. However, that the country does not in practice utilise an opt-out system. While this may have been legislated for in Spain there is in practice no way to opt-out as there is no opt-out register. Spain in practice is using an opt-in model and it is the world leader in terms of deceased organ donation. The most successful country in the world, therefore, in terms of organ donation is using an informed consent, system. Other strongly performing countries in terms of organ donation, such as the USA, also use a system of informed consent (an opt-in system).

International experience shows that some countries with presumed consent systems have seen a decline in organ donation. In 2012, Chile moved from a system of informed consent to one of presumed consent. The donor per million figure fell from 8.6 in 2012 to 5.6 in 2013. Columbia is another country which operates a presumed consent system which has seen falling organ donation levels in recent years, falling from 12.3 per million in 2010 to 6.8 per million in 2013. Within Europe, Luxembourg, Slovakia and Sweden have all experienced a fall in the level of organ donation over recent years despite operating systems of presumed consent. In those states which have adopted an opt-out system and where levels of organ donation have increased there remains a question as to whether this was caused solely by the introduction of the presumed consent system or by other factors.

It is worth noting that a host of countries which operate opt-out systems have lower levels of organ donation than Scotland. In the year 2013/2014, Scotland had a donor per million figure of around 20. This was higher than Finland, Latvia, Sweden, Hungary, Poland, Slovakia, Luxembourg, Israel, Greece and Cyprus which all operate opt-out systems (see attached spreadsheet). It is worth noting also that Northern Ireland and the United States of America both have higher donor per million figures than Scotland and do not use an opt-out system like the one that has been proposed here. Northern Ireland has seen a dramatic rise in the level of organ donation in recent years, from a donor per million figure of only around 10 in 2009/10 to a figure now of 26.

What this suggests to us is that there are a number of factors which impact on the level of organ donation within a state. Yes, the consent of patients and families is a factor in the number of organ donations which take place and there is an issue with regard to the level of consent amongst donors. However, there are a wide variety of other factors involved. These can include training of medical professionals, availability of specialist nurses and doctors and the infrastructure in relation to organ donation.

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. In the period between the publication of the initial consultation in November 2011 and the passing of the Bill by the Welsh Assembly in July 2013, there was a fall in the number of organs donated. Evidence was presented to the National Assembly for Wales that a number of donations had been lost as a direct result of what the Welsh

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3 See [http://www.clinmed.rcpjournal.org/content/14/6/567.full.pdf+html](http://www.clinmed.rcpjournal.org/content/14/6/567.full.pdf+html) and [http://www.bmj.com/content/341/bmj.c4973.long](http://www.bmj.com/content/341/bmj.c4973.long)
Government proposed. Moreover, Wales was the only country in the United Kingdom to see a fall in the number of organ donations over the period. In 2011/12, 67 deceased individuals donated their organs while in 2012/13 this had fallen to 52. This dramatic fall of 22.3% in one year was in contrast to England, Scotland and Northern Ireland, which all recorded a rise in the level of organ donation over the period. It is unclear also whether the Welsh Act will have the desired effect of increasing the number of organs being donated over the longer-term as the legislation only comes into effect on 1st December 2015. It is premature, therefore, for the Scottish Parliament to press ahead with our Bill until a sufficient time has elapsed to allow for evidence to emerge as to the effect of the Welsh legislation.

Do you support the proposal of appointing a proxy? Please provide an explanation for your answer

Yes. We are of the view that a system which allows for the appointment of proxies facilitates the views of the donor to be considered prior to his/her death. Such a system would provide a greater degree of engagement with the personhood of the donor than the current practice of asking relatives of the deceased for permission to remove organs. In many cases the relatives may have no knowledge of the deceased person’s wishes. It may be that General Practitioners could record the views of patients when conducting Anticipatory Care Plans and/or point the patients who are willing to donate their organs towards the services of a proxy.

Do you have any comments on the role of “authorised investigating persons” as provided for in the Bill?

No

Is there anything in the Bill you would change? If yes, please provide more details.

We are concerned that the Bill does not explicitly set out a right of objection for families on the face of the statute. While we do not support the introduction of an opt-out system on practical and ethical grounds, if it was to go ahead we believe that it is imperative that an explicit right of objection for family members exists. While we acknowledge that the proposal of appointing a proxy is an improvement on the situation which pertains in Wales, we believe that the role of the family remains important in terms of the decision to donate.

CARE for Scotland, Public Policy, October 2015

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6 In England the increase was 14.5%, in Scotland it was 16% and in Northern Ireland 2.5%.