

Church of Ireland Church and Society Commission

Response to Human Tissue Bill public consultation October 2017

The Church and Society Commission (CASC) of the Church of Ireland exists as an advisory group, serving the Standing Committee of the General Synod and engaging with government on particular issues, including issues of legislation such as this consultation. CASC has the permission of Standing Committee to issue statements under its own authority insofar as this is consonant with agreed Church of Ireland positions. Views expressed by CASC only become representative of the Church as a whole when given approval by the General Synod of the Church of Ireland.

Introduction

The Church and Society Commission of the Church of Ireland is fully supportive of the ethos that giving is an essential part of being a Christian, whether that be of financial aid, of time or of the person. Donation of organs of one's body to others is a supreme example of this both after death, and even more so as a living donor. It is part of this giving that it should be voluntary.

In its 2008 report to the General Synod, the Commission's predecessor – the Church in Society Committee – stated: "Organ donation is to be seen as an entirely consistent Christian act, both of caring for those less well off, and responding to Our Lord's example of, and instruction to, heal and show compassion."

In the light of the demand for donor organs and the reduction in deceased organs as a result of reduction in road traffic accidents, which is to be welcomed, and the significant mismatch between (a) the number of people who say that they would wish to be donors but who are not on the register, and (b) the number of people who are on the register and would be suitable as donors but whose wish is ultimately declined by family, it is understandable that discussion has been and is taking place to try and raise the rate of donation. This has, in particular, been directed towards the Opt-Out system. As part of a response to this need, the 2014 General Synod endorsed the **fleshandblood** campaign which aims to raise the profile of blood and organ donation within the Church and encourage such donation as a personal gift as well as equipping individuals and churches as advocates for donation. This campaign was launched in Armagh and Dublin, for Northern Ireland and the Republic of Ireland respectively, in March 2015 by the respective Archbishops of Armagh.

Presumed consent

A presumed consent (Opt-Out) system of organ donation has been considered and debated in the Oireachtas and Northern Ireland Assembly in recent years. The

Church and Society Commission, responding to an Assembly consultation on the issue in 2013, recommended that:

1. Expressed consent should continue to be the preferred option as the essence of altruistic giving, which lies at the heart of organ donation. This essence may be undermined by legislation for presumed consent;
2. Improved education measures and specialised training for medical professionals should be put in place and resourced appropriately before any proposed legislation;
3. There should be a real, healthy and respectful debate bound up in the common good.

Since we wrote this discussion document in 2013 there is increasing evidence that an Opt-Out system has not achieved the expected increase in organ donation, from brain dead, beating heart donors. In Wales during the first year after its introduction at the end of 2015, there was minimal change in number of total deceased donors: 61 for 2016/17 (64 for 2015/16; 60 for 2014/15,). From 2014/15, when publicity was at its height, the number of people opted-in, has increased by 140,000 but 176,000 have opted-out of the Organ Donor Register from 0 in 2014/15.

In Northern Ireland, following the introduction of an Opt-Out Bill presented by a private member to the Assembly in 2013, the number of donors on the Organ Donor Register has risen from 582,000 to 754,000. Again on the back of publicity at the time; this Bill was subsequently withdrawn in 2016.

Spain is a country often held up as the example of the success of an Opt-Out system. However, when closely looked at, there are major differences between their system and those that have been proposed in the Republic of Ireland. There is no way of registering opposition to organ donation. The Spanish legal system's interpretation is that the best way to establish the wishes of the deceased is by asking the family, and their wishes are final. Therefore the system in practice is one of Opt-In.

For 10 years after the change to an Opt-Out system there was no change in donation rates. At that stage, a major decision was made to put in transplant co-ordinators in each procurement hospital, and following this there was a major improvement in the rate of donation.

This has been supported by figures from the UK showing that in hospitals with trained transplant nurses the rate of successful donation was 10 times greater than in hospitals with none.

These results all point to the importance of the family and family involvement in decision-making. Death is a profound family matter, especially in a potential donation environment which is sudden and unexpected, being either the result of an accident or a catastrophic bleed in the brain. So trust is imperative. All the more so where there is a beating heart donor and the family must trust that their loved one really is dead, and that the patient has been fully and appropriately treated. There must be

confidence that an Opt-Out system would not lead to a change in end-of-life decisions.

1. Change in ethos

The policy would represent a fundamental change in the ethos of giving voluntarily (opting in) to one that is seen as giving by default, where the use of organs after death is presumed, and their use would be determined by the medical practitioners. Although this could be said to be meeting the apparent wishes of the public to be donors, whether or not they have registered, it does mean that organ donation in many cases will cease to be voluntary.

If this change were to take place then it would be important that the wishes of individuals could be recorded easily (particularly if they choose to opt out), and that the register is very accurately kept and is easily accessed by those who need to know, but also secure.

The Commission foresaw a situation where a person opts out but this decision is not shown when the register is accessed at the time but is only later noted. This could have very serious effects on confidence and rates of donation, to say nothing of a damaging impact on family members already dealing with issues of bereavement.

The Commission also felt that if there was to be a change then consideration should be given to two separate forms of consent: deemed consent whereby someone is on the register, because they have not opted out, and expressed consent where there is a written declaration of consent to donation after death. If the latter were given stronger value in law, it would then remove from families that decision at a time of great stress, and may encourage those who have not yet registered to do so. We feel that this suggestion should also be considered even in an Opt-In system.

2. Education beyond new legislation

We have already discussed the value of the presence of transplant nurses, with special training, in all hospitals, and not directly part of the transplant team. There is also a need for further training of medical staff to be more aware of potential donors in hospital areas outside intensive care units.

3. Ongoing debate

The Commission encourages Church members and elected representatives to recognise (a) the fact that if consent is changed to presumed, it would mark a fundamental change, and asks whether this would then still be an altruistic act, and (b) whether sufficient time has been given to explore the possibility of mandated consent whereby individuals are required by law to express their wishes. The Commission supported continuing publicity about signing on to the organ donation register and encouraged all citizens to discuss the issue and their own wishes with relatives.

Conclusion

The Church of Ireland is very supportive of measures to increase the availability of organs for transplantation, and wishes that this remains perceived as an act of giving. It remains our preferred option to maintain the status quo of an Opt-In consent with as stated above improved education both of the medical professions and the public, as well as a more secure place in law for those who choose to register their position. We feel that these changes should be implemented before considering any change in legislation, especially one that so significantly changes the concept of altruistic giving.

We do not feel that we can improve on a comment by Dr Margaret McCartney, a GP in Scotland writing in the *British Medical Journal*, this year, on this topic, who wrote: “But, above all, what is the effect of presuming donation? A forced, presumed, or expected gift is not a gift. A striking feature of families who have allowed donation has been the desire to help others and the feeling that some shred of good has come out of their profound loss. If the sum of free will to donate is decreased, how can this benefit be realised to the same extent?”

The Revd Dr Rory Corbett FRCP

On behalf of the Church of Ireland Church and Society Commission