



CHURCH OF IRELAND

## Church and Society Commission

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The Health Committee Clerk,  
Room 419,  
Parliament Buildings,  
Ballymiscaw,  
Stormont,  
Belfast,  
BT4 3XX.

Dear members of the committee,

The Church and Society Commission (CASC) of the Church of Ireland has prepared the submission to the Committee for Health on the Introduction of a statutory Opt-Out system for organ donation in Northern Ireland.

CASC is an advisory group, serving the Standing Committee of the General Synod, and engages with legislatures and governments on a variety of issues, including legislation. The mission of CASC is to provide oversight and direction for the Church of Ireland's work, in respect to social theology in action. CASC's views only become representative of the Church of Ireland after being approved by its General Synod.

Yours Sincerely,

Rev Dr Rory Corbett  
Rt Rev Dr Kenneth Kearon (Chair)  
Church and Society Commission  
Church of Ireland

## **Submission from the Church of Ireland Church and Society Commission to the Committee for Health on the introduction of a statutory Opt-Out system for organ donation in Northern Ireland**

### **Background**

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. 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 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<sup>1</sup> 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 has sought 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 Archbishops of Armagh.

### **Experience of presumed consent**

Within the United Kingdom, Wales was the first nation to introduce a presumed consent policy for organ transplantation, passed into law in 2013 and implemented in December 2015. In a paper published in 2019<sup>2</sup>, the results were given comparing the results of the numbers of consents and numbers of actual donations in the first 18 months compared to the previous three years. In summary though there had been an increase in consent rate, it had been no greater than in the rest of the United Kingdom, and therefore the Wales increase could not be attributed to the Welsh legislation change. They did find that there had been an increase in

family over-ride of 5-7% during the three years before, and 15.1% for the first 15 months and 29.1% in 2016/17. In their conclusion, they stated: “Policymakers should not assume that soft opt-out systems by themselves simply need more time to have a meaningful effect. Ongoing interventions to further enhance implementation and the public’s understanding of organ donation are needed.”

A medical paper published in 2020<sup>3</sup>, on the Welsh experience after five years with presumed consent has shown that there had been a significant increase in the agreement rate of families when approached. However, the authors were unable to give an indication of the relative influences of the change in consent and of the result of two years of public education during the implementation phase and since then.

Spain is a country often used as an example of the effects of a presumed consent policy, and was reviewed by Fabre et al, 2010<sup>4</sup>. The policy was implemented in 1979, and in 1980 following a royal decree and subsequent legal interpretation then the way to establish the potential donor’s wishes was by asking the family, so in practice the system is Opt-In. Spain does not have an Opt-Out register, and therefore no money is spent on it nor on public awareness. Between 1979 and 1989, there was no change in the rate of organ donation or refusal. In 1989, the major change in the system was the placement of transplant coordinators at each procurement hospital. They were mostly intensive care physicians, but not part of the transplant team. They play an active part in co-ordinating the donation process. Training is organised nationally with regular courses for all those directly or indirectly involved.

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. Trust is so important as the patient does not appear conventionally dead, being warm and pink, and breathing, assisted. They need to be confident that there will be no under-treatment or withholding of treatment.

### **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. Policy-makers should note that an Opt-Out 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;

4. 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.

In relation to the change in ethos, the Commission welcomes the assurance from the Department of Health that following a change to presumed consent there would still exist the options of a written Opt-In, a written Opt-Out, and thirdly discussions between families and relevant medical professionals to let them know of a person's views. This approach would not, in fact, constitute a change from the present situation.

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.

#### **In the event of the passing of the proposed Act**

The Commission appreciated the opportunity to hear the proposed arrangements in particular those for the implementation of the new procedure for obtaining consent. The proposed programme of information and publicity of the public and the training of health professionals likely to be involved in the clinical care of that person, is entirely consistent with proposals we have made in the past to improve the success in obtaining consent, that is in public education and encouragement of family discussions, the use of cases that do become public as a singular opportunity to encourage people, and the further training of the medical staff and nurses in the recognition of potential donors, as well as experienced well trained empathetic transplant coordinators.

We would, however, ask that hospital chaplains are included in the training programme as they are so frequently present at this time in a person's life and providing pastoral care to the family. We note the emphasis made of funding and for time for all this to take place. We believe that if all this concentrated programme was instituted, then the increased consent rate would occur, leading to increased available organs, all without changing the form of consent. This is supported by the fact that there will be no changes in having registers for those opting in, those opting out and encouragement of family discussions. This would avoid any risk of changing the ethos of giving, the feeling that some shred of good has come out of their profound loss, and avoids a risk of an incomplete Opt-Out register.

In the event of presumed consent becoming law, this Commission will continue to recommend to the Church of Ireland, through General Synod, that the Church will continue to fully support and encourage people to be donors as exemplified in membership of the **fleshandblood** programme.

## References

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<sup>1</sup> Church in Society Committee (2008), Report to General Synod, Appendix B: Response to new organ donation proposals put forward by Prime Minister Gordon Brown

<sup>2</sup> Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study, Noyes J, McLaughlin L, Morgan K, et al  
Cite as BMJ Open. 2019;9(4):e025159

<sup>3</sup> The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system, Madden S, Collett D, Walton P, et al. Find at:  
<https://doi.org/10.1111/anae.15055>

<sup>4</sup> Presumed consent: a distraction in the quest for increasing rates of organ donation Fabre J, Murphy P, and Matesanz R. Cite this as: BMJ 2010;341:c4973