Do you support the Bill?

No. We support organ donation and transplantation and efforts to increase the number of donated organ available, but we believe that donation should always be on the basis of a deliberate, well-informed, voluntary decision. Consent in medical practice is always informed and voluntary.

‘Presumed consent’ in an opt-out system is based on the unfounded assumption that every single person who has not opted out was aware of the opt-out provision and has consciously taken a decision not to opt out. This is no consent at all and a ‘donation’ on this basis is not a donation willingly given but is akin to a tax extracted compulsorily. It means that the State claims to have ownership of our bodies after death unless we consciously reject this while alive.

We believe an opt-out system, in which no prior consent of the deceased has been given and where there is no definite evidence that the deceased had no objection to removal of organs or tissue, is ethically unacceptable.

If this Bill were to become law, it would be extremely difficult to ensure that everyone, especially those belonging to some minority or disadvantaged groups, was aware of the legislation and what it would mean in practical terms. Instead of a mere six months preparatory period it would require an ongoing campaign and even then it would be difficult to inform everyone. It is also likely that such legislation would adversely affect the trust of the public in the health professionals at the time of death.

The system in Scotland, since the Human Tissue (Scotland) Act 2006, is not entirely opt-in. This is because a nearest relative may (1) add to the list of body parts that can be removed and transplanted without knowing the donor’s wishes on these body parts and (2) give permission for removal of body parts even if they do not know if the person was in favour of this (section 7 of the Act). In any revision of the Act, we would prefer that these be altered, to remove any presumption of consent.

The role of the closest relative should be to inform if they were aware that the deceased had expressed agreement for their organs to be used for transplantation, not simply to state that they had never expressed an objection.

1. 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.

No. While we support organ donation and transplantation, we are not convinced that this Bill would achieve its aim. The Memorandum quotes a 2006 international study by Abadie and Gay in the USA which concludes that, even allowing for the important effects of other determinants, presumed consent had “a definite and sizeable effect on organ donation rates”.

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

Free Church of Scotland
However, we believe this has been overtaken by research published in Transplantation, the journal of the Transplantation Society, on 27 June 2012, which showed that there was no conclusive evidence that changing from an opt-in to an opt-out system had increased donor rates in countries where this had taken place. Other factors may well be more important. We believe attention should be focused on these factors and how their effect can be maximised. These include better education of the public, beginning in schools, and appointing specially trained staff in hospitals to liaise with relatives at appropriate times. The latter would help to reduce the number of relatives who refuse to allow removal of organs despite the deceased being on the transplant register.

At the very least, consideration of such legislation should be delayed until the effect of similar legislation in Wales becomes apparent after it becomes operative in 2016.

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

Yes, but we have some concerns. This system would only work well if the proxy was well informed of the actual wishes of the deceased with regard to removal of organs for transplantation. If the proxy was unsure of the wishes of the deceased, no removal of organs should be carried out. If they were removed, this would be tantamount to treating the appointment of a proxy as equivalent to consent for removal of organs for transplantation.

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

We have no comment to make on this.

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

Yes. Improve the opt-in system:

Opportunity should be taken to remove the elements of ‘presumed consent’ from the 2006 Act to make a robust opt-in system. Then every effort should be made to make this system work to its full potential through increasing public awareness and understanding of transplantation and stressing the philanthropic nature of donation.

**Improve the scope of the Act:**

Because it is unclear how many organs and tissues are covered in the Act, opportunity should also be taken to exclude from removal from the deceased for transplantation the following: (1) gonads, reproductive tissue and cells and (2) embryonic or foetal organs, tissues and cells.

Professor Donald MacDonald  
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On behalf of The Free Church of Scotland