

HEALTH AND SPORT COMMITTEE

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

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Introduction – The Bishops' Conference of Scotland

The Bishops' Conference of Scotland is a registered charity (No 16650). The Conference enables the Roman Catholic Bishops in Scotland to work together, undertaking nationwide initiatives through their Commissions and Agencies.

The members of the Bishops' Conference are the Bishops of the eight Scottish Dioceses. The Bishops' Conference of Scotland is a permanently constituted assembly, which has a number of commissions and agencies that assist it in carrying out its work.

The Catholic Parliamentary Office is an agency of the Bishops' Conference of Scotland and part of its remit is to engage with the work of Parliament and Government, including responding to consultations and calls for evidence on behalf of the Bishops' Conference.

The Bishops' Conference of Scotland welcomes the Health and Sport Committee's inquiry into the Human Tissue (Authorisation) (Scotland) Bill and is grateful of the opportunity to submit a contribution.

What do you think are the key strengths and weaknesses of the proposals to introduce 'deemed authorisation' for those who have not made their wishes on organ donation known?

The Catholic Church acknowledges the need for more organs to be donated to allow those who are suffering the opportunity to enjoy a better quality of life. Indeed the Church sees organ donation after death as a 'noble and meritorious act' to be encouraged as an 'expression of generous solidarity'. It is a gift and a sign of great love for one another. However, in order for this to be a true gift, it must be freely given and that is why the Church also teaches that 'it is not morally acceptable if the donor or his/her proxy has not given explicit consent'.

One of the main weaknesses of the Scottish Government's presumed consent approach is that it runs the serious risk of failing to increase the number of organs available for transplant.

Rather than presumed consent, we would like to see the introduction of new initiatives to encourage people to donate, similar to those introduced in Spain in 1989. Spain has significantly higher rates of organ donation than Scotland, and although an opt-out system had been in operation since 1979, it wasn't until Spain decided to proactively encourage organ donation in 1989 through a national public campaign and the creation of the Organización Nacional de Trasplantes (ONT) as part of the Spanish Ministry of Health that donor numbers increased. The ONT is a technical agency in charge of the coordination and

oversight of donation and transplantation activities in Spain, and it created a model of coordination in deceased donation that made the country evolve from 15 donors per million population to more than 30 per million. It did this by relying on designated professionals and coordinators based in every hospital who were responsible for organ donation. This coincided with a greater focus on education and a massive advertising campaign to highlight the importance of organ donation.

These changes worked and they thrust Spain to the forefront of organ donation across the world. As already stated, Spain had been operating a system of presumed consent (opt-out system) for a period of ten years prior to the changes detailed above without any significant effect on rates of donation. However, a significant increase in donations followed the practical, organisational changes made by the Spanish government (*L Hitchen, 'No evidence that presumed consent increases organ donation' BMJ 2008; 337*).

In the end it was the changes to the organisational structure of organ donation, rather than the formal introduction of a system of presumed consent, that brought about a greater increase in donations. Note also that Sweden switched to a system of presumed consent in 1996 but continues to have very poor rates of organ donation (15.8 per million), while the United States, which has an opt-in system, has an organ donation rate of 25.8 per million.

There is clearly scope to explore the Spanish model and proceed to implement changes to the organisational structure around organ donation, including investment in education and advertising and ensuring donor coordinators are present in all hospitals. The principal concern with presumed consent is that it denies individuals the right to make an informed choice about organ donation. It is vital that those whose organs are removed are given all the information necessary to allow them to make a positive, well-informed choice about what they would like the state to do with their organs on their death.

Presumed consent effectively means state ownership of citizens' organs until the citizen decides otherwise. It is a policy that seriously questions the need for the state to recognise the inherent dignity of each individual as, first and foremost, a human being and not just a statistic. It is also disappointing that the government has stated that it will not consider the mandated option as part of this consultation process.

In summary, Spain had been operating a system of presumed consent (or opt-out) for a period of ten years prior to the changes to the infrastructure detailed above without any significant effect on rates of donation. However, a significant increase in donations followed the practical, organisational changes made by the Spanish government. In the end it was the changes to the organisational structure of organ donation, rather than the formal introduction of a system of presumed consent, that brought about a greater increase in donations.

To emphasise this point, Wales introduced a soft opt-out system of organ donation in December 2015 and since then numbers of transplants have not increased.

The 2008 Independent Report by the Organ Donation Taskforce is worth referencing here. It states: "After examining the evidence, the Taskforce reached a clear consensus in recommending that an opt out system should not be introduced in the UK at the present time. The Taskforce concluded that such a system has the potential to undermine the concept of donation as a gift, to erode trust in NHS professionals and the government and negatively impact on organ donation numbers. It would distract attention away from essential improvements to systems and infrastructure and from the urgent need to improve

public awareness and understanding of organ donation. Furthermore, it would be challenging and costly to implement successfully. Most compelling of all, we found no convincing evidence that it would deliver significant increases in the number of donated organs.”

We would humbly submit that nothing has changed since this report in 2008.

With respect to the ability of a relative to authorise the removal of an organ: there must be appropriate safeguards in place and such an authorisation should be exceptional, for example, when an individual had no capacity to make the decision for a long period of time prior to their death or when it involves a child. Children should only be able to consent to organ removal for transplantation from age sixteen.

There is a risk of serious mistakes from the proposed system; for example, a relative authorising removal of organs of a deceased person who has not previously expressed their wishes regarding organ donation. How can there be any certainty about what the deceased wanted? It is a serious risk, one which would not exist in a purely opt-in system.

We have concerns around the proposal that presumed consent will apply to anyone who has been resident in Scotland for at least twelve months before their death. In order for this to work and in the interests of fairness the government must ensure that every person is aware of the system of presumed consent. This is difficult enough with individuals who normally reside in Scotland; it is extremely difficult to guarantee it for individuals who have only recently come to Scotland. There needs to be regular information/awareness raising campaigns to ensure people are aware of the organ donation system in operation in Scotland. We understand Wales operates such a campaign at least every 12 months.

The integrity of the human person is seriously impacted as a result of the state assuming control over each individual person's organs. As a result, citizens are at serious risk of falling foul of arbitrary and discriminatory choices made on their behalf. Not everyone will have the organisational or intellectual ability to challenge the State and/or the medical profession, and we have particular concerns that some groups will be poorly placed to do so, for example, the disabled, those in care of the State, the old/sick/infirm, and those who are from disadvantaged socio-economic backgrounds.

What do you think are the key strengths and weaknesses of the plans for authorisation of pre-death procedures?

It is critical that any pre-death procedures do not hasten death.

Do you have any other comments to make on the Bill?

As per our answer to question 1, the government should seriously consider introducing new initiatives to encourage people to donate, similar to those introduced in Spain in 1989. There must be scope to explore the Spanish model and implement the positive changes to the organisational structure around organ donation, including investment in education and advertising and ensuring donor coordinators are present in all hospitals. Here in Scotland we could take the best of the Spanish system and to use it to the advantage of those most

in need. Starting from the basis of the existing opt-in system, we can develop the way we manage organ donations, ensuring that there are suitably qualified personnel in every hospital committed to organ donation as well as undertaking a positive, eye-catching public awareness campaign through the media. If we do this, then there is no reason why we cannot experience the same significant increases enjoyed in Spain.

Obviously, high profile awareness campaigns and organ coordinators cost money, while simply switching to an opt-out system doesn't, but with lives at stake, we should be willing to invest in proven models which lead to the outcomes we'd all support. Presumed consent denies individuals the right to make an informed choice about organ donation. It is vital that those whose organs are removed are given all the information necessary to allow them to make a positive, well-informed choice about what they would like the state to do with their organs on their death. Presumed consent effectively means state ownership of citizens' organs until the citizen decides otherwise. We repeat, it is a policy that seriously questions the need for the state to recognise the inherent dignity of each individual as, first and foremost, a human being and not just as a statistic.

We are also concerned about the lack of a Code of Practice. This appears to be a significant oversight on the part of government. A Code of Practice would help all concerned to understand the legislation and allow them to apply it correctly.