

The National Assembly for Wales Health and Social Care Committee

Consultation on the Human Transplantation (Wales) Bill

January 2013

Dear Sir/Madam,

Thank you for the opportunity to respond to the consultation on the Human Transplantation (Wales) Bill.

CMF has over 4,000 British doctors and 800 medical students as members. Through the International Christian Medical and Dental Association (ICMDA) we are linked with like-minded colleagues in over 90 other countries. 154 doctor members reside in Wales and there are 63 student members at the two Welsh medical schools.

The Christian Medical Fellowship has on a number of previous occasions expressed concern with the principles underpinning this Bill. We sent in a detailed response to the initial public consultation:

http://admin.cmf.org.uk/pdf/publicpolicy/Welsh_organ_donation.pdf

and the subsequent draft Bill:

http://admin.cmf.org.uk/pdf/publicpolicy/Organ_donation_Bill_response_0912.pdf. We have expressed significant opposition to both the concept of introducing presumed consent and the wording and operation of the draft Bill itself.

We note that similar concerns have been raised by other religious groups, notably Catholic and Muslim organisations.

Can consent truly be 'presumed'?

Presumed consent in effect equals no consent, unless there is an extensive public information programme, which would need to capture *the entire adult population* including those on the margins of society. Only this would ensure that those who do not opt out of donation have made an explicit choice, rather than doing so by default, by ignorance or by a lack of knowledge or understanding.

It will be almost impossible to guarantee that everyone is informed and understanding of 'deemed consent', knows their options and can easily opt out. Can consent be truly assumed from those who are disorganised, apathetic, disabled, less well educated or informed, isolated, lacking full capacity, of different languages and race, suffering from (temporary) mental illness, dependent, those who have less ready access to information and those who change their minds? As a minimum, the importance of allowing families a veto in such cases is obvious.

This makes the whole concept of 'presumed', or 'deemed', consent ethically problematic as well as complex, and very costly, to administer.

It is not even the most effective way to increase organ donor numbers. Research published in Transplantation has found that donation rates in countries with opt-out laws do **not** differ

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dramatically from countries requiring explicit (opt-in) consent. Moreover: ‘...countries with the highest rates of deceased donation have national and local initiatives, independent of PC, designed to attenuate the organ shortage.’ (See also: Coppen, R., Friele, R., Marquet, R. and Gevers, S. (2005). ‘Opting-out systems: no guarantee for higher donation rates.’ *Transplant International* 18: 1275-1279).

The Role of Families

Although the Welsh government has said all along that it will introduce ‘soft’ opt-out legislation, allowing the family of the deceased a role in the final decision, **the Bill as it stands does not in fact allow for this**. While provision is made in the draft memorandum (p20), there is no provision in the Bill itself for providing distressed relatives with a right to object to the removal of organs when no consent was given by the deceased.

Some people fear that if they became seriously ill, they would receive less thorough treatment if they were donors than if they were non-donors because doctors want their organs. This fear – which need not be well founded to have an effect – would increase if the family’s views were known to be overridden. People look to their families to protect them when they cannot protect themselves.

The Bristol and Alder Hey controversies were fuelled by the perception that families had no real power in decision-making with respect to what happened to their loved one’s body parts. They also showed how crucially important the body is to bereaved parents and friends, and illustrated the need to respect the human body, even in death, and not cause unnecessary distress to the mourners who have to live with the memory for the rest of their lives.

Conclusion

CMF is supportive of organ donation in principle. However we do not support presuming consent when it has not been given, nor do we support overriding the family and the important role they should play.

If this Bill becomes law, it is essential that the need to respect the views of the surviving family is within the legislation itself. The National Assembly for Wales should amend the Welsh Government’s Bill to make this commitment clear.

Yours faithfully,

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