



Opt for Life:

Submission on the Human Transplantation Bill – In response to the Call for Evidence

Submitted by Shane Finnegan and Joe Brolly, Co-Chairs- Opt for Life

1. The current organ donation law is confusing and does not do what people expect it to do. It is described and marketed as an individual choice system when it is nothing of the sort. So, people are encouraged to join the organ donor register. They believe that when they have done so, nothing further is required and in the event of their untimely death, their organs will be retrieved. When we first raised the possibility of a new organ donor law with the First Minister and deputy First Minister both were taken aback when they realised that the system, in practice, is entirely dependent on family consent.

2. What we have always supported and promoted is a Family Consent Act, which is easily understood and easy to publicise. We discussed the issues with a group of thirteen Intensive Care consultants and they were unanimous that the crucial factor in gaining family consent is that the family have previously discussed the issue. At the decisive moment, if the family have not previously discussed the issue, then the family are more likely to refuse consent. In addition to this 68% of organ donors come from people who are not on the organ donor register hence the paramount importance of family discussion.

3. The Family Consent Act needs to be simple and easy to understand. The bill, in its current form is neither. The concept has been incorrectly altered – presumably by bureaucratic intervention- into a cut and paste version of the Welsh system. The phrase “deemed consent” needs to be deleted. It is meaningless, since the retrieval of organs must be entirely dependent on express family consent. Likewise, the phrase “family affirmation” needs to be deleted and replaced with “family consent”. We should add that we do not support deemed consent in any circumstances.

4. We have an excellent, well-resourced organ donation, transplantation infrastructure. The crucial thing therefore is that the organ donation act does not confuse the public. It must be positive, unthreatening and entirely based on family consent. This protects the rights of children, those with disabilities and reinforces the sacred principle that organ donation is a family gift.

5. There are sound competing arguments in relation to the merits of the opt out facility in the bill. Our view is that it will change the way we look at organ donation. The old (fallacious) question is “should I become an organ donor after death?” The new question will be “Is there any reason I should not be an organ donor after death?” we think, on the whole, that this will lead to a societal shift.

6. We are disappointed that the draft bill is so confusing. It needs to be reworked in plain English, sending out a simple, easily understood, non-threatening message. a) All organ retrieval requires



express family consent b) Those who do not wish to be considered for organ donation can opt out using the online register.

7. The bill is remediable but only with extensive amendment.

We would welcome the opportunity to present to the Committee.