

Written submission to the Health and Social care Committee regarding proposals to introduce “deemed” (presumed) consent for organ donation.

Organ donation can be seen as a generous and free gift, and should remain as such. This is premised on respect for the human dignity of the donor and the recipient, and the high regard we place on human life. Another vital premise is that of free and informed consent, so that the donation of an organ is respected as a free gift. For the sake of these important premises, I am opposed to the introduction of presumed consent for organ donation.

Before we even consider the issue of consent for organ donation, we need to address the deeply concerning issue of what definitions are being used to determine whether someone is dead. Is ‘Brain-death’ actual death, to our certain knowledge? As David W Evans MD, FRCP has noted:

“The basis upon which a mortally sick patient is declared “deceased” – for the purpose of acquiring his or her organs for transplantation without legal difficulties – is very different from the basis upon which death is ordinarily diagnosed and certified and that highly relevant fact is not fully and generally understood.”

The proposals ignore the facts concerning this area of scientific dispute, yet this is a question with enormous ethical implications. Most organ donors are unaware that their hearts may be beating when their organs are taken, and that they may be pink, warm, able to heal wounds, fight infections, respond to stimuli, etc. They are also unaware of common practices of paralysing and (sometimes) anaesthetising supposedly brain dead donors before their organs are taken. Simply signing a donor card does not in any way indicate that the prospective consenting donor understands what will be involved - and those who are merely ‘presumed to consent’ by the State are likely to know even less.

It is extraordinary that the issue of determination of death, which must govern consideration of so many other issues in organ donation, is so often ignored, in spite of the US President’s Council findings and the growing scholarly literature on the question. That the public are not made aware of the controversy is deeply regrettable. Notions of informed consent, let alone presumed consent, are meaningless unless the facts of the matter are openly discussed and considered.

The evidence suggests that a system of presumed consent will not improve organ donation rates in Wales. As it stands, Wales already has one of the highest organ donation rates in Europe (27.7 per million). The UK’s Organ Donation Taskforce in 2008 concluded:

“...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.”

According to the Clinical Director of the *Organizacion Nacioanl de Trasplantes* in Madrid, Rafael Matesanz, the evidence for a positive impact of presumed consent is very thin.

“It [an opt out system] contributes little or nothing to the improvement of organ donation rates and, on the debit side, diverts precious resources to imaginary rather than effective solutions.”

Three further points should also be highlighted. First, the Welsh government must draw back from measures that could put added pressure and even soft forms of coercion upon the family of a deceased person, which could be the case if presumed consent is introduced.

Second, there is no respect for the right of conscientious objection for medical professionals and Welsh ministers, who will in different ways, be expected to comply with presumed consent as stated in the draft Bill. Conscientious objection is a vital right that must be protected.

The third point is that anyone living for 6 months or more in Wales will be opted-in. This is unfair and will pose a significant challenge when it comes to ensuring every single person is informed and allowed easy access to methods for opt-out, and also information on practices relating to definitions of death being used in medical practice.

For these reasons I hope that presumed consent for organ donation will not be introduced in Wales. Providing ethical standards are met regarding the determination of death, organ donation can be a praiseworthy practice. The evidence indicates that presumed consent is not ethical and practically ineffective.

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Emailed on 18th January 2013