Proposals for Legislation on Organ and Tissue Donation: A Welsh Government White Paper

A Joint response on behalf of The Roman Catholic Church in Wales, The Church in Wales, and the Wales Orthodox Mission

Summary

1. This response primarily addresses the proposals in the White Paper at the level of principle. It is based on the conviction that organ donation is a profoundly Christian positive act. Our main concern is that the positive ethos of donation as a free gift is being endangered by an ill-judged or well-intentioned proposal to move from voluntary donation to presumed consent. However, if organs may be taken without consent, this is no longer "donation". This is not just a health matter but concerns serious human rights issues such as personal autonomy, as well as questions about the relationship of the state and the citizen. At the same time the belief that presumed consent would itself increase the number of organs available for transplantation is not supported by the available evidence, as is shown below (paragraphs 16-25).

Organ transplantation enjoys a high level of public support but it also involves the sensitive issue of respect for the human body after death, people's human right to privacy and respect for personal beliefs and religion. These are areas that need to be negotiated with care and, as far as possible, by consensus legislation. We therefore urge the Welsh Government to revisit the process and establish a cross party committee that could consider all the evidence submitted to the previous enquiries of the last three years: the Organ Donation Task Force, the Welsh Assembly Committee, the U.K. Parliament's Welsh Affairs Committee and also the substantial research conducted by the Universities of Ulster and Johns Hopkins.

Response

2. The Welsh Government has invited responses to the White Paper both "on particular aspects of the policy proposals" and "on the proposals more generally". This response will primarily address the proposals at the more general level, for it is important to resolve questions of principle before considering how to implement proposals in practice.

The value of organ donation

3. The basis of this response is a shared conviction that organ donation is essentially a profoundly Christian act that is positive both in its consequences for the recipient and as an expression of human solidarity across society. Nothing in this submission should be interpreted as a rejection of the practice of donation of organs after death where this is done with due sensitivity to medical, cultural and ethical considerations. On the contrary, the concerns that are raised here are precisely that ill-judged proposals might endanger the ethos of donation.

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4. Taking their starting point from Christ who healed the sick and who gave Himself for the good of others, Christians have welcomed the benefits that have come through organ transplantation. From the very first there have been strong authoritative voices that would encourage donation. There is, of course, diversity between and within Christian communities as there is diversity in wider society. There are differences of education, of personal and family experience, and different levels of trust in the establishment. There are also differences of view both about the practice of transplantation and about whether, and if so, how the law should change. This submission therefore cannot and does not presume to represent the views of every member of our respective communities. Nevertheless, precisely for this reason, the submission strongly urges that the law should not presume that individuals or their families would consent to donate their organs. While there is some evidence of a greater level of donation among Christians, and this is an activity that all Churches have encouraged, it cannot be presumed that all Christians have decided to donate their organs, and still less can this be presumed for the population as a whole.

5. This joint submission also expresses the concern that any change in the law should protect marginalised communities and individuals, especially those who are socially excluded or who have difficulty in making their views heard. As Christians we are particularly aware of the way that minorities, including religious minorities, can be endangered by the majority, as for example when the majority does not adequately respect the need for consent from someone who is a member of a minority community.

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2 For example, in 1956 when solid organ transplantation had yet to become common practice, Pope Pius XII argued that that would not be “a violation of the reverence due to the dead”. Rather, organ donation from the dead was justified because of “the merciful charity shown to some suffering brothers and sisters” (Allocation to Eye Specialists 14 May 1956).

3 Researchers have shown a statistically significant correlation between Catholicism and rate of donation (Parliamentary Office of Science and Technology “Organ Transplants” Postnote October 2004 Number 231, page 2, quoting Gimbel et al. 2003. Progress in Transplantation 13:15-23). [http://www.parliament.uk/documents/post/postn231.pdf](http://www.parliament.uk/documents/post/postn231.pdf). To date researchers have not investigated the relation between rate of donation and Christianity for other Churches, but there is no reason to think it any less.

4 Pope John Paul II said that, “We should rejoice that medicine, in its service of life, has found in organ transplantation a new way of serving humanity”. Hence the Catechism of the Catholic Church states that “Organ donation after death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity.” For further references see UK Transplant leaflet of Christianity and organ donation [http://www.uktransplant.org.uk/ukt/how_to_become_a_donor-religious_perspectives/leaflets/christianity_and_organ_donation.jsp](http://www.uktransplant.org.uk/ukt/how_to_become_a_donor-religious_perspectives/leaflets/christianity_and_organ_donation.jsp)
The necessity of consent

6. Pastors, theologians and Church leaders agree that offering organs for donation can be a significant act of charity, and a reflection of God’s freely-given love and care for us, including the gift of life. A few examples should suffice:

7. “Above all, this form of treatment is inseparable from a human act of donation. In effect, transplantation presupposes a prior, explicit, free and conscious decision on the part of the donor or of someone who legitimately represents the donor, generally the closest relatives. It is a decision to offer, without reward, a part of one’s own body for the health and well-being of another person. In this sense, the medical action of transplantation makes possible the donor’s act of self-giving, that sincere gift of self which expresses our constitutive calling to love and communion.”

8. “Christian faith is a positive motivation for organ donation and a powerful incentive for many people to donate.” Organ donation is “an expression of the faith-based virtue of helping others; you might call it the ‘generous gift’ approach ... agreeing yourself to donating your own organs is easily understood as one person’s generosity towards others.”

9. From the point of view of Orthodox Christian ethics, organ or tissue donation can be understood as a generous and virtuous act. Organ transplantation “makes it possible to give effective aid to many patients who were earlier doomed to death or severe disability... The transplantation of organs from a living donor can be based only on the voluntary self-sacrifice for the sake of another’s life. In this case, the consent to exploitation becomes a manifestation of love and compassion”. The same principle applies to posthumous donation. “The posthumous giving of organs and tissues can be a manifestation of love spreading also to the other side of death.”

What is wrong with “presuming consent”?

10. The fundamental Christian objection to presumed consent is that this contradicts the rationale and ethos of donation. “Presumed consent” is not consent. Silence is not consent. If organs are taken for transplantation without consent there is no giving, there is only taking.

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5 John Paul II Address to 18th International Congress of the Transplantation Society (29 August 2000).


7 John Davies, Bishop of Swansea and Brecon

8 Russian Orthodox Church’s document The Basis of the Social Concept, XII.7 Problems of Bioethics.
11. It is sometimes said that Christianity has no official position on “opt-in” or “opt-out” systems of organ retrieval. However it is difficult to reconcile “opt-out” systems with the clear Christian commitment to voluntary donation. If the organs are taken without the prior consent of the deceased, or permission of a relative or friend speaking on behalf of the deceased, then the deceased is no longer a donor and taking the organs is no longer an act of donation. It is taking without asking. From a Christian perspective this fails to respect the enduring human meaning of the body. Instead of transplantation being an act of donation, an expression of solidarity between people, it becomes merely the medical use of a body.

12. Pope John Paul II clearly stated that without consent “organ transplantation and the grafting of tissue would no longer correspond to an act of donation but would amount to the dispossession or plundering of a body.” This understanding is also expressed in the Catechism of the Catholic Church which lays down that organ donation “is not morally acceptable if the donor or his proxy has not given explicit consent.”

13. From an Orthodox perspective, “donation... cannot be considered a duty. Therefore, the voluntary consent of a donor in his lifetime is the condition on which explantation can be legitimate and ethically acceptable”. Hence “the so-called presumptive consent of a potential donor to the removal of his organs and tissues, sealed in the legislation of some countries, is considered by the Church to be an inadmissible violation of human freedom”.

14. Within the context of the present debate, the Archbishop of Wales has given voice to this same shared Christian understanding of organ donation. “There is another theological argument. Organ donation surely ought to be a matter of gift. If one takes organs without consent, on the assumption that by not opting out, a person is tacitly assenting, then that is no longer a free gift to others. An organ donation ought to be precisely that, a gift, an act of love and generosity. Giving organs is the most generous act of self-giving imaginable but it has to be a choice that is freely embraced, not something that the State assumes. Put more crudely, it turns volunteers into conscripts. Presumed consent is not really consent at all, merely the assumption that there are no objections.”

15. The Christian tradition supports the idea that the state may require us to do (or refrain from doing) certain things with regard to our bodies, for our own good or that of others (for example, safety legislation; the smoking ban, even potentially applied to private cars where

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10 John Paul II Address to The Society for Organ Sharing (20 June 1991).

11 Catechism of the Catholic Church, 2296, emphasis added.

12 Russian Orthodox Church’s document The Basis of the Social Concept, XII.7.

13 Ibid.

14 http://www.churchinwales.org.uk/structure/bishops/sermonsb/b43.php
children are present; illegal drugs; in extreme cases, taking children into state care if parents are unable or unwilling to act in their best interests, or if they refuse essential medical treatment). Some Christians also argue that the state should be able to use organs from dead bodies without our explicit voluntary consent. However, those who argue in this way must acknowledge that taking organs without consent is not “donation”. The call to use organs without consent is no more or less than a call to abandon donation as the basis for organ transplantation.

Would presumed consent increase rates of transplantation?

16. It should not be taken for granted that changing the law to a system of opt-out / presumed consent would necessarily increase the availability of organs for transplantation. While some studies have shown a higher level of transplantation on average in countries with presumed consent laws,\textsuperscript{15} it is very difficult to show that this is due to such laws or that a change in the law in itself would necessarily have a positive effect.

17. Changing to a system of presumed consent was rejected by the House of Commons in 2004. The Department of Health, having reviewed the evidence from different countries, stated that “it considers changing legislation to be a high-risk strategy. Without clear public support, presumed consent may be counterproductive, leading to reduced donation rates.”\textsuperscript{16}

18. In 2008 the Organ Donation Taskforce was asked to consider the case for a change in the law to presumed consent. They commissioned research from the University of York which concluded that “The evidence identified and appraised is not robust enough to provide clear guidance for policy”.\textsuperscript{17} After the comprehensive review (still perhaps the best to date) the Report concluded that it was “not confident that the introduction of opt-out legislation would increase organ donor numbers, and there is evidence that donor numbers may go down.”\textsuperscript{18}

19. The country with the highest rate of organ donation is Spain, which has a law which allows organs to be taken with presumed consent. However, when Dr Rafael Mateo, President of the Spanish National Transplant Organisation, gave evidence to the Organ Donation Taskforce, he was explicit: presumed consent was not the reason for the success of the Spanish system. He reiterated this at a briefing on presumed consent reported in the \textit{British}

\textsuperscript{15} E.g. A. Abadie and S. Gay, “The Impact of presumed consent legislation on cadaveric organ donation: a cross-country study,” \textit{J. Health Econ} 25 (2006): 599-620 who suggested that presumed consent countries have roughly 25-30% higher donation rates than informed consent countries.

\textsuperscript{16} Parliamentary Office of Science and Technology, p. 3.

\textsuperscript{17} Organ Donation Taskforce (2008) \textit{The potential impact of an opt out system for organ donation in the UK: A report from the Organ Donation Taskforce}, Department of Health, London, paragraph 11.2, \url{http://www.ics.ac.uk/the_potential_impact_of_an_opt_out_system_to_organ_donation_in_the_uk}

\textsuperscript{18} Organ Donation Taskforce 11.5.
Medical Journal.¹⁹ When asked if a presumed consent law was the reason for the success of the Spanish system, he said:

"Is it because of the law? Not likely. We have always had the same law. The families are always approached. They always have the last decision, and there are great variations from region to region."²⁰

20. In the light of this evidence it should not be surprising that the cross party committee of the Welsh Assembly which considered presumed consent in 2008 came to a similar conclusion. The majority of the Health, Wellbeing and Local Government Committee judged that "organ donation rates can be improved significantly without introducing presumed consent. More than that, we feel there is a danger that moves to legislate in Wales ahead of the rest of the UK could be a distraction from more productive improvements and could alienate public support for organ donation if not handled properly."²¹

21. The two most recent studies to look at presumed consent are from the University of Ulster and the Johns Hopkins University School of Medicine. In October 2011, a team from the University of Ulster compared donation rates for England, Wales, Scotland and Northern Ireland over two decades and also compared these rates with those of other European countries. They concluded that "Further exploration of underlying regional differences and temporal variations in organ donation, as well as organisational issues, practices and attitudes that may affect organ donation, needs to be undertaken before considering legislation to admit presumed consent."²²

22. The key paragraph from the Ulster study reviews the evidence from different countries. It is worth quoting in full:

"Hence, though Sweden applies presumed consent, its donation rate in 2009, at 13.8 deceased donors per million population (Scandiatransplant personal communication, 2011), was comparable with that of Germany (14.5 deceased donor per million population) and Denmark (14.0 deceased donors per million population); both of which require informed consent. The figures available for Ireland, where informed consent is needed, were 21.2 deceased donors per million population in 2009. The nation with the highest donor rate (34.4 deceased donors per million population in 2009), is Spain, which operates a ‘soft’ form of presumed consent where next of kin can object to organ donation. Yet, the impact of the

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²⁰ Organ Donation Taskforce 11.3. The fact that in practice Spanish physicians do not take organs without permission has led some studies to characterise Spain as having “presumed consent” legislation with “informed consent” as actual practice, see Parliamentary Office of Science and Technology, p. 2 quoting Council of Europe; National Transplant Organisation.


legislation has been questioned and the high rate of donor activity attributed to the ‘Spanish Model’ that demands an integrated approach with dedicated transplant coordinators, mainly intensive care physicians, involved in procurement. This highly coordinated network and the respect for autonomy given to the individual and their relatives is credited with improving donation rates of 14.3 deceased donors per million population in 1989 to rates of 33-35 deceased donors per million population in recent years.”

23. In November 2011 John Hopkin’s University published the results of in-depth interviews with transplant experts in 13 European nations with presumed consent legislation. They found that, despite the laws, the process of organ donation in those countries did not differ dramatically from the process in countries, such as the United States, that require explicit consent. “Opt-out is not the magic bullet; it will not be the magic answer we have been looking for,” said Dorry L. Segev, an associate professor of surgery at the Johns Hopkins University School of Medicine and leader of the study published online in the journal Transplantation. Implementing presumed consent legislation, Segev argued, would take a huge amount of time and energy with minimal payoff. Many countries with presumed consent have much lower rates of organ donation than the United States, he noted.

“With opt-out the perception becomes, We will take your organs unless you take the time to fill out a form. That’s a dangerous perception to have. We only want to use donated organs from people who intended to donate.”

24. It is notable that the latest figures for 2010-2011 show that Wales has already achieved a significant increase in its rate of donation. At 27.7 deceased donors per million this is now higher than the United States and is among the highest in Europe. There is every reason to think that further increases can be made through building on this success in public education, communication with relatives and more effective systems of transplant coordination. This real improvement has occurred without changing the law on consent. With high levels of public support, and recent initiatives giving significant improvements in rates of donation, this is no time to abandon the principle of voluntary donation.

25. Some people clearly believe that changing the law from opt-in to opt-out would itself improve the rate of transplantation, and this has been the basis of a very effective media campaign by some groups. However, this belief is simply not justified by the available evidence. It is a myth.

23 Ibid, p. 6.


25 UK Transplant Organ Donation Activity 2011
Can we reasonably presume that people have consented?

26. It is frequently stated that “90 per cent of people in the UK say they support organ donation, but to date only 30 per cent have joined the NHS Organ Donor Register”, 26 in which case it might seem reasonable to presume that people would consent, if people are given ample opportunity to “opt out”. However, this 90% figure is from a survey by UK Transplant in 2003 which asked if people were “in favour of organ donation in principle”27. It was not a survey of how many people themselves wished to donate their organs. A more recent survey for Yougov in 2007 found that 62% of people were willing to donate. 28 This is a more realistic figure. There is evidence that people in Wales are more willing to donate,29 but research carried out by the University of Swansea in 200830 found that, if an opt out system were established in Wales only 60% would “definitely not opt out” with a further 16% saying they would be unlikely to opt out. This leaves 24% who would opt out, might opt out, or who did not know. Interestingly, in the same poll, 24% of people said they strongly disagreed with presumed consent and a further 15% said they tended to disagree with presumed consent. 31

27. These figures show that a significant percentage of people in Wales (between 24% and 39%) disagree with presumed consent and would not be willing for their organs to be taken without their prior consent or permission from those closest to them. As not everyone will get around to making their wishes known, it cannot reasonably be “presumed” that people have not made their wishes clear would have wanted their organs to be used for transplantation. There is a fair chance (perhaps one in four) that they would not have wanted this.

Improving refusal rates

28. In current practice (both in Wales and in most other countries), whether or not a person has signed the Organ Donation Register (or equivalent), specialist nurses and consultants also

26 For example, National Assembly for Wales Research Service Organ and Tissue Donation Paper number: 11/068, p. 3 http://assemblywales.org/11-068.pdf quoting NHS Blood and Transplant, Organ Donation online.


30 Opinion Research Service, from Swansea University conducted a telephone survey using structured questions to a representative sample of the Welsh population between 14th November and 8th December 2008.

ask the relatives whether they would permit organs to be taken. In the United Kingdom around 43% of families refuse permission. This is far higher than in other countries, such as Spain, where the refusal rate is around 9%. How can this issue be addressed?

29. The Organ Donation Task Force found that, whereas the overall family refusal rate is around 40%, if the person is on the Organ Donation Register then the refusal rate drops to 10%. This shows that families are generally supportive of the removal of the organs when they know that this is what the person wanted. The most effective way to increase rates of family permission for donation is therefore to encourage people to sign the Organ Donation Register and to encourage people to talk about the issue with relatives and those close to them. Any move that weakens the Organ Donation Register and leaves relatives unsure of what the deceased would have wanted is likely to increase refusal rates among relatives.

30. It should also be noticed that refusal rates in the United Kingdom are significantly higher now than they were in the 1990s. It is likely that there are many causes for this increase, including the Alder Hey scandal in 1999 where organs were kept without consent. A number of reports have emphasised the importance of maintaining public trust in the system and the importance of the principle of consent in maintaining this trust.

Consultation with relatives

31. The proposals in the White Paper call for a “soft opt-out” system in which the relatives will always be consulted. It is clearly important for the relatives and those close to the deceased to be consulted. However, the idea of “consultation” or of being “involved in the process” is ambiguous. The law needs to state unambiguously whether, in the absence of an explicit statement of the wishes of the deceased, the relatives will be able to refuse permission for the removal of organs.

32. A duty to consult, as currently proposed in the White Paper, is much weaker than a right to refuse permission. However, if relatives have no right to refuse permission in law, this represents a move of power away from the relatives of the deceased and towards the state.

32 Organ Donation Taskforce, 11.3.

33 Organ Donation Taskforce, 1.15.

34 According to the Parliamentary Office of Science and Technology (p. 3), in the 1990s the family refusal rate was 30% whereas by 2004 it had reached 42%.

35 “Trust, however, is key to the success of the organ donation system in the UK. If public trust is shaken, organ donor numbers are likely to fall rapidly and could take many years to recover”, Organ Donation Task Force 4.6; “Comments provided highlighted concern that an opt-out system had the potential to damage the relationship of trust between clinicians caring for people at the end of their life.” Welsh Assembly Government Consultation Paper, p. 10; “...and others believe due to the general public’s mistrust for the Government they will resist this type of system being imposed on them.” National Assembly for Wales Research Service, 4.1; “Without clear public support, presumed consent may be counterproductive, leading to reduced donation rates.” Parliamentary Office of Science and Technology, p. 3 emphasis added.
This is not just a matter of health but is about the right of the state to dispose of a body in a certain way even in the face of objections from closest relatives.

33. In practice it seems doubtful that specialist nurses in organ donation in Wales would want the power to overrule relatives so that organs were taken from those who had not given consent in the face of opposition from those who were closest to them. However, if this would not happen in practice, why does the Welsh Government need to create a power that would not be used? This power seems unnecessary while at the same time it threatens to undermine the very concept of free donation on which organ transplantation has hitherto relied.

The process of public consultation

34. In addition to grave concerns about the central proposal in the White Paper, there are also problems with the way in which this proposal has been brought forward.

35. Organ transplantation enjoys a high level of public support but it also involves the sensitive issue of respect for the human body after death. It involves people's human right to privacy and respect for personal beliefs and religion. This is an area that needs to be pursued with care and, as far as possible, by consensus legislation.

36. It is of extreme concern that while responses are being invited on the proposals in the White Paper, the central proposal, which is the shift from donation to presumed consent, is presented as a fait accompli. This approach threatens to polarise debate and to alienate those who have reasonable concerns about this proposal. Whatever the exact shape and scope of the eventual law, this is not the way to secure a broad consensus.

37. We therefore urge the Welsh Government to revisit not only the proposals but also the process. This issue is one that should be resolved as far as possible through open dialogue and consensus building and by a process that can secure the widest possible support. It should not be a party political issue. What is needed to rescue this process is for some independent, academic, or cross-party body to conduct a genuinely open consultation which would consider a range of possibilities without prior commitments to a particular legislative proposal. They might reasonably look at systems that include aspects of opt-in, opt-out and mandated choice. It would also helpfully consider the evidence submitted to the previous enquiries of the last three years: to the Organ Donation Task Force, to the Welsh Assembly Committee and to the U.K. Parliament's Welsh Affairs Committee and to consider the

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36 Some of these issues were raised in evidence submitted to the Welsh Affairs Committee when it considered Legislative Competence Consent for Organ Transplantation from a deceased adult. However, as the LCO was withdrawn, that Committee was not able to weigh this evidence or explore these human rights issues.

37 Organ Donation Task Force.

38 National Assembly for Wales (July 2008).

39 Welsh Affairs Committee Sixth Special Report into Proposed Legislative Competence Orders relating to Organ Donation and Cycle Paths (HC 896) http://www.parliament.uk/business/committees/committees-a-z/commons-select/welsh-affairs-committee/inquiries/parliament-2010/organ-donation-lco/, see in particular
research conducted by the Universities of Ulster\textsuperscript{40} and John Hopkins\textsuperscript{41}. For it is not at all clear that the present proposals have benefitted as much as they might from the evidence available.

38. If the proposals in the White Paper are not subject to independent scrutiny then there is a real danger that a change in the law would alienate a significant proportion of the public and undermine the positive image of organ donation and the reputation of Wales. For while a high rate of voluntary donation speaks of a culture of generosity, a system of presumed consent would “turn donation into action by default”.\textsuperscript{42}

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\textsuperscript{40} McGlade et al. “Regional and temporal variations in organ donation”

\textsuperscript{41} Boyarsky et al. “Potential Limitations of Presumed Consent Legislation”

\textsuperscript{42} As argued by UK Transplant: National Assembly for Wales, Health, Well-being and Local Government Committee, Committee Inquiry into Presumed Consent for Organ Donation - Evidence from UK Transplant.
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