

LEEDS DIOCESAN SYNOD MOTION: BLOOD AND ORGAN DONATION

A Background Paper from The Mission and Public Affairs Council

The Church of England and Organ Donation

1. Since the seminal first report of the UK Organ Donation Taskforce (2008), which set the national agenda for increasing and improving donor and transplant services, the Church of England has been active both in contributing to policy discussions and in assisting increased donor numbers. The Church of England asserts that *‘giving one’s self and one’s possessions voluntarily for the wellbeing of others and without compulsion is a Christian duty of which organ donation is a striking example. Christians have a mandate to heal, motivated by compassion, mercy, knowledge and ability. The Christian tradition both affirms the God-given value of human bodily life, and the principle of putting the needs of others before one’s own needs.’*¹

2. The Church of England has contributed to four major policy debates² in recent years and has taken part in six national initiatives³, including being a founder associate of the Flesh and Blood (FAB) Churches campaign.

Legislation, Regulation and Policy

3. Legislation relevant to blood and organ donation includes The Human Tissues Act 2004, The Mental Capacity Act 2005 and The Blood Safety and Quality Regulations 2005. The Human Tissue Authority regulates organ donation and transplantation, while NHS Blood and Transplant (NHSBT) is the Special Health Authority tasked with encouraging, monitoring and improving donor and transplant services.

4. Organ donation policy in England is described by NHSBT as ‘hard opt-in’, meaning that individuals who have notified their intention (verbally, in writing or through inclusion on the NHS Organ Donor Register) to donate their organs or tissues once they are deceased, cannot have their wishes countermanded by their legal representatives or next of kin (as in the case of a ‘soft opt-in’ policy). The NHS Organ Donor Register was modified in 2015 to allow anyone in the UK to register a decision to donate, to register a decision not to donate or to nominate others to make a decision for them after their death.

5. The Human Tissue Authority states that *‘If those close to the deceased person object to the donation, for whatever purpose, when the deceased person (or their nominated representative)*

¹ Church of England, Mission and Public Affairs Division: Response to the House of Lords EU Social Policy and Consumer Affairs sub-committee call for evidence: Inquiry into the EU Commission’s Communication on organ donation and transplantation: policy actions at EU level, October 2007

² ‘Give and Take? Human Bodies in Medicine and Research’ (Nuffield Council on Bioethics): July 2010

‘Donor Conception’ (Nuffield Council on Bioethics): May 2012

‘Organ donation - post 2013 Strategy (NHSBT)’: September 2012

‘Donation after Brainstem Death’ (UK Donations Ethics Committee)’ April 2014

³ Organ Donation Taskforce Consultation on views of Religious Groups: September 2009

Organ Donation Taskforce Further Consultation on views of Religious Bodies: September 2010

Flesh and Blood Churches Campaign 2012-

NHSBT Faith Summit: May 2013

NHSBT Faith Action Plan: December 2013

NHSBT Faith and Organ Donation Patient information leaflets: 2014

*has explicitly consented, the healthcare professional should seek to discuss the matter sensitively with them. They should be encouraged to accept the deceased person's wishes and it should be made clear that they do not have the legal right to veto or overrule those wishes (see the code of practice on donation of solid organs for transplantation)...Healthcare professionals should also consider the impact of going ahead with a procedure in light of strong opposition from the family, despite the legal basis for doing so.*⁴

6. In practice, clinicians will rarely, if ever, act against the wishes of next of kin as they are not bound by law to conduct organ retrieval even in cases where consent has been given. Where a deceased person's intentions are unclear or unknown, clinicians will seek consent from a legally nominated representative or if no such person has been appointed, next of kin.

7. In effect, while the law is clear that a 'hard opt-in' policy operates in England, in reality, this often equates to 'soft opt-in' practice, highlighting the role of family members and the need for excellent communication skills on the part of specially trained NHS staff: Specialist Nurse-Organ Donation (SNOD), whose role it is to discuss donation issues with family members.

Types of Donation and Current Statistics

8. In addition to blood donation, three types of organ donation are authorised in the UK: donation following brain-stem death (DBD), donation following circulatory death (DCD) and living donation (LD).

9. Current blood stocks vary according to blood type, but typically vary from 5 to 9 days supply.

10. Some 21 million people were registered on the organ Donor Register during 2014/15 (the latest year for full statistics), representing a significant increase from the 2007/08 base year figure of 15 million.

11. UK statistics for 2014/15⁵ indicate:

UK population 64m, total deaths 576,000, deaths in hospitals 287,000, potential donors 7450, eligible donors 5636, donation requests 3295, consented donors 1923, actual donors 1282.

12. The main areas in need of improvement lie along the transplantation pathway in ensuring that donation requests are made for all eligible donors and that the consent rate improves significantly from around 60% where it has plateaued for some time.

13. 2014/15 saw the first *decrease* in both donors and transplants for 11 years:

14. Compared with the previous year:

- There was a 3% fall in the number of deceased donors to 1,282
- The number of donors after brain death fell by 1% to 772, while the number of donors after circulatory death fell by 6% to 510
- The number of living donors fell by 5% to 1,092, accounting for approximately half of the total number of organ donors
- The number of patients whose lives were saved or improved by an organ transplant fell by 5% to 4,431
- A total of 3,575 patients had their sight restored through a cornea transplant, representing a fall of 3%

15. The total number of patients registered for a transplant had fallen slightly, so that:

⁴ HTA Code of Practice 1: Consent, Paragraphs 84,85: July 2014

⁵ NHSBT Overview of organ Donation and Transplantation: 2015

- there were 6,943 patients waiting for a transplant at the end of March 2015, with a further
- 3,375 temporarily suspended from transplant lists
- 429 patients died while on the active waiting list for their transplant
- A further 807 were removed from the transplant list. The removals were mostly as a result of deteriorating health and ineligibility for transplant and many of these patients died shortly afterwards.

16. In spite of an increase in the overall referral rate of potential donors from 76% to 80% and the proportion of approaches involving a Specialist Nurse – Organ Donation from 76% to 78%, there was a fall in the overall consent/authorisation rate for organ donation from 59% to 58%

Issues for Consideration

17. In its submission to the NHSBT consultation on Organ Donation - post 2103 Strategy, the Mission and Public Affairs Council commented on a range of issues pertinent to increasing donor and transplant numbers.

18. The Consent System: The present ‘opt-in’ system is based on an understanding that individuals enjoy a ‘right to use’ their bodies while alive and have a right to decide, within limits, what ought to happen to them after they die. Current policy reflects a careful balance in the relationship between individuals, relatives and the state, with a presumption that the state does not have a right to dictate to either individuals or to their families how their bodies ought to be used.

19. While an ‘opt-out’ system does not give the state absolute rights over the use of an individual’s body, it does, however, represent a major, intrusive shift in the state’s relationship with its citizens. An overwhelming case that numbers of lives saved or enhanced would be significantly increased would have to be made before such a shift ought to be introduced.

20. The Transplant Pathway suggests that the most pressing problem in organ transplantation does not lie as much in getting more names on the Organ Donor Register as in making more effective use of the potential donors already registered. It is clear that much more could be done to narrow the gap between the numbers of eligible and actual donors, as well as maximising the number of transplants per donor. More consistent DBD testing, greater DCD referrals and increased SNOD intervention in approaching families for consent ought to have a marked effect in increasing the number of transplants taking place. Similarly, better use of donated organs, utilising techniques such as liver-splitting and further increases in the use of Living Donors should have a positive effect.

21. Greater public awareness and education with regard to the nature of the consent given by individuals signing the Organ Donation Register would also affect the number of transplants taking place. Greater opportunities to consider organ donation ought also to be provided.

22. Minority Ethnic Issues: There are issues specific to minority ethnic communities, although attempts to resolve these issues have not, as yet, been very successful. For example, 31% of individuals on the kidney active transplant list are from BAME backgrounds, while 6% of kidney donors are of BAME origin.⁶ On average, patients from the Black, Asian and minority ethnic communities wait a year longer for a kidney transplant than a white patient,

⁶ NHSBT Organ Donation, Transplantation and Waiting List Figures in the UK by Ethnicity: 2015

due to the lack of suitable organs. While ethnicity plays a role in matching tissue types in some cases, successful transplants can take place between people from differing ethnic groups.

23. In addressing issues specific to BAME individuals, it is essential that better ways of partnership working are developed with representatives of minority ethnic communities and those organisations in which members from minority ethnic communities form a significant part and in which they play a full role. In this context, faith communities have much to offer

24. End of Life Care and elective ventilation: The General Medical Council places a duty on doctors to act in a patient's best interests, while giving weight to patient or family requests for treatment, adhering to valid patient decisions for treatment to be withheld or withdrawn. It is essential that these principles are not breached, even in the pursuit of a good cause such as enabling organ donation.

25. Where patient consent is given for treatment to be prolonged beyond a point where it is medically beneficial to him or her, in order to facilitate organ donation, it could be argued that it is in that patient's overall best interests to comply with this request because of the beneficial psychological effects it will have. While there are limits to how far this argument can be reasonably sustained, it also forms part of the ethical basis for Living Donation.

26. Elective ventilation represents actively intrusive treatment that is not, medically, in the patient's best interests. By its nature, it is unlikely that medical staff will have opportunities to seek patient consent. Elective ventilation was practised in the UK between 1988 and 1994, but was halted by the Department of Health precisely because it breached the 'best interests' principle. In order for elective ventilation to become an acceptable practice, an effective Advanced Decision system would have to be devised.

27. Priority Care for those on the Organ Donor Register: While this proposal might result in an increase in numbers on the Organ Donor Register, it represents a clear breach of the principle that treatment is given solely on the basis of clinical need and not on the basis of perceived merit. If the merit principle were to be given formal approval for transplant protocols it would be difficult not to employ it in a wide range of other circumstances where lifestyle factors are relevant.

28. Living Donors: Living donation carries with it a degree of risk to the donor's health and, in some cases, a risk to life. At the same time it has the capacity to relieve suffering, giving hope and life, in a truly altruistic manner. Given an assurance of good physical and psychological profiling and accompanying counselling, living donation represents a valid means of giving to others but one which, in Christian ethics, would be regarded as an act of supererogation rather than a Christian duty.

Conclusion

29. Major advances have been made in organ donation and transplantation since the publication of the Organ Donation Taskforce in 2008, but further advances need to be made in order to meet continuing pressing demand so that individual's lives are both saved and enhanced. While increasing opportunities for people to sign the Organ Donor Register is important, the single most important contribution that the Church can make is to continue to provide information through such channels as the Flesh and Blood Campaign and to encourage its members to discuss their decisions with their next of kin and/or to appoint a nominated representative who can affirm their decision to clinicians in the event of their death. 'Have the discussion' is a simple message that has the potential to increase levels of consent and hence levels of donation and transplantation.

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