

PRESUMED CONSENT IN ORGAN DONATION: THE DEVIL IS IN THE DETAIL

SUMMARY

This article follows the recent publication of the Organs for Donation Task Force report, 'Organs for Transplants', and considers the debate surrounding a change in the law in favour of presumed consent in organ donation

INTRODUCTION

Modern medical law and ethics places a high premium on concepts such as individual patient autonomy, the right to self-determination and individual consent. The importance of consent in the context of organ donation should not be underestimated, because it is this core principle of value, which significantly constrains transplant activity in the UK. Although scarcity of resources is certainly not a feature unique to organ transplantation, it is axiomatic that the chronic shortage of organs limits our ability to deliver transplantation to people suffering from end-stage organ disease. The human costs of the endemic failure to obtain consent from the relatives of cadaveric potential donors are poignant when 1,000 patients this year alone will die awaiting the gift of transplantation¹

This persistent shortage of organs was addressed this month by the Organ Donation Task Force report, 'Organs for Transplants'. The report examines the current barriers to organ donation within the existing legal framework and sets out 14 recommendations. Which if adopted, will overhaul the transplant infrastructure in an attempt to deliver significantly improved rates of organ donation and transplantation².

In anticipation of the publication of the report the Prime Minister gave his backing to a change in the law, in favour of the principle of presumed consent in organ donation.

¹ UK Transplant: Press release 16/01/08

² www.doh.gov.uk

LEGAL AND ETHICAL ISSUES

In recent years and certainly prior to the publication of the report, there have been some significant initiatives, which have sought to improve the persistent shortage of organs. In particular, the implementation of the Human Tissue Act 2004, under this Act, transplantation in England, Wales and Northern Ireland is covered by a single piece of legislation. The Act clarified the legal position on the use of non-heart beating donors and facilitates the increasing use of live donors.

In essence, the Act states that the use of organs from a deceased for transplantation, is lawful if done with 'appropriate consent' (s1(1)(b&c)³. Appropriate consent to donation, in the case of an adult, means his or her consent, in practice carrying a donor card, or registration on the donor register constitutes appropriate consent and renders the removal of organs by doctors lawful. S3(6)⁴ does not stipulate that consent must be in writing. In the absence of a directive, consent maybe given or withheld by a person, or persons who can be nominated under s4 of the Act by a living adult to act in his or her interests after death.

Where the deceased person has not given consent and has failed to nominate someone to give proxy consent, or in circumstances where his or her nominee is unable to consent or it is impracticable to communicate with the nominee⁵. Efforts are to be made to find out whether the deceased has expressed their wishes about organ donation, in which case consent can be sought from someone in a 'qualifying relationship'.

Qualifying relationships are defined in section 27(4) of the Act and are ranked, so that the consent of a spouse or partner should be sought first and then that of a parent or child, followed by that of brother and sister and so forth.

Almost inevitably in the current climate, transplantation will come under the auspices of an overriding authority. It is crucial to recognise that the Human Tissue Act 2004 merely renders it lawful to retrieve organs where appropriate consent exists; it does not make it obligatory to do so. Relatives' views are taken into account, even if the deceased has made their wishes known. So whilst the deceased's family do not have a legal right of veto, in practice doctors are reluctant to retrieve organs where relatives object, rendering relatives wishes definitive.

It would not be unreasonable to suggest that permitting relatives definitive authority over what happens to a person's body after death, in practice (if not law), is highly inconsistent with the now dominant principle of patient autonomy and the right to self-determination, principally all though not

³ Human Tissue Act 2004

⁴ Human Tissue Act 2004

⁵ Under s 3(7) and 3(8) the Human Tissue Act 2004

exclusively, where the deceased has taken the trouble to make their wishes clear through registration.

Surveys have consistently demonstrated that the majority of the population support organ donation. A survey conducted in 2003 for UK Transplant showed that 90% of the public support organ donation. However, less than 25% of the UK's population is registered on the NHS Organ Donor Register. □ It is regrettable that when families do not know or are uncertain of their relative's wishes in excess of 40% opt for the default position, and decline to give appropriate consent.⁶

COMMENT

The recommendations made thus far by the task force are essential to improve the system of supporting organ donation. Yet, the gap between the number of organs available and the number of people needing a transplant shows no sign of abating⁷. Given very real human consequences of a failure to address this shortage, it is unsurprising that consideration is presently being given by the task force to rectifying the problem through reform of the law.

The present system for organ donation in the UK can be accurately described as a 'opt in' system, where individuals volunteer to become organ donors. Opt in systems are commonly contrasted with 'opt out' systems, often referred to as 'presumed consent', where it is assumed that every potential donor is willing to donate their organs, those who object to donation are able to 'opt out' by registering their unwillingness to donate. In its purest form, presumed consent permits automatic retrieval except in situations where the deceased has expressed an objection in his or her lifetime. This 'strict' form of presumed consent does not take into account the views of relatives.

A less strict version of presumed consent operates in Belgium where relatives are permitted to object to donation; the medical profession however, are under no legal obligation to seek the views of relatives. The onus falls upon relatives then to initiate the process of objection. Belgium experienced a 37% increase in the number of available kidneys the year following implementation of presumed consent. Certainly other jurisdictions that have implemented shades of presumed consent have witnessed similar improved rates of available organs.⁸

The BMA supports a soft system of presumed consent in which relatives' views are taken into account. Instead of being asked to consent to donation, they would be informed that their relative had not opted out of donation. Unless relatives object, the donation would then proceed.

⁶ UK Transplant. Potential donor audit, 36 month summary report 1 April 2003-31 March 2005

⁷ UK Transplant. Record year for transplants: Press release 27/04/07

⁸ Austria, Belgium, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Greece, Hungary, Israel, Italy, Latvia, Luxemburg, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Turkey.

There are obstacles that must be overcome if we are to move towards a legal framework in favour of presumed consent. The presumption behind presumed consent is that the general public is adequately well informed about organ transplantation that any failure to register an objection represents a willingness to donate, rather than apathy, lethargy or ignorance.

Changing the default position may subtly influence relatives' attitudes towards donation, and it may well lessen the decision-making burden at a traumatic time. A change in the law is not itself sufficient to achieve the significant increases required to address chronic organ shortages. Much more needs to be done in terms of education and training and far more needs to be done to support healthcare professionals that must broach the matter of organ donation with distraught relatives. The Organs for Donation report, certainly goes some way to achieving the improved delivery of organ donation and transplantation. As ever in the realm of healthcare policy and law, the overriding policy objective may be desirable, but the relative success of a shift to a system of presumed consent will depend on the fine detail and the Government's resolve to tangibly achieve its own objective.

Odette Hutchinson
Birmingham City University
odette.hutchinson@bcu.ac.uk