

# Presumed consent

## Odette Hutchinson considers the need for an opt-out scheme for organ donation

The successful development of organ transplantation is a remarkable medical accomplishment, an accomplishment regrettably characterised by a chronic shortage of available organs. Although scarcity of resources is certainly not a feature unique to organ transplantation in the UK, 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 this worsening shortage are poignant when it is estimated that 1,000 patients this year will die awaiting the gift of transplantation.

This persistent shortage of organs was addressed in January by the Organ Donation Task Force report, *Organs for Transplants*. The report examines current barriers to organ donation within the existing legal framework and sets out 14 separate but interrelated recommendations. If adopted, these will overhaul the transplant infrastructure in an attempt to deliver significantly improved rates of organ donation and transplantation. The authors of the report identified overwhelming public support for organ donation against a backdrop of less than 25% of the UK's population being registered on the NHS Organ Donor Register.

### Appropriate consent

Enacted in the aftermath of the Alder Hey and Bristol scandals, the Human Tissue Act 2004 stipulates that the use of organs from a cadaver for transplantation is lawful if done with 'appropriate consent'. 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. In the absence of a directive, consent may be given or withheld by a person, or persons who can be nominated under section 4 of the Act by a living adult to act in his or her interests after death.

Where the deceased 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, efforts are 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'. Difficulty arises, as the report notes, because when bereaved families are uncertain of their relative's wishes, 40% opt for the default position, and refuse to give appropriate consent to organ donation, according to figures from UK Transplant. As a matter of policy and even in circumstances where the deceased has made their wishes known in the form of registration, relatives' views are taken into account. Doctors are extremely unlikely to retrieve organs where relatives object, rendering relatives wishes the de facto authority in practice.

If we accept that concepts such as consent and the right to self-determination are of value within the practice of modern medicine, one might sensibly question whether that is inconsistent with permitting relatives de facto authority over what happens to a person's body after death. Clearly, there is a delicate balance that needs to be maintained between the wishes of the deceased, the interests and wishes of grieving relatives and the greater good. The present system struggles to maintain this balance.

### Does silence equal consent?

The system for organ donation in the UK is an 'opt-in' system, where individuals volunteer to become organ donors. Opt-in systems are commonly contrasted with 'opt-out' systems, which assume that every potential donor is willing to donate their organs (presumed consent); 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.

The British Medical Association supports a 'soft system' of presumed consent in which relatives' views would be taken into account. Instead of being asked to consent to donation, families would be informed that their relative had not opted out of donation. Unless relatives object, the donation would then proceed – once again and as under the present system,

doctors would be unlikely to proceed in the face of objections from the family.

The presumption behind presumed consent is that the general public is adequately well informed about organ donation that any failure to register an objection represents a willingness to donate, rather than apathy, lethargy or ignorance. It is important to acknowledge that silence or failing to register an objection is not synonymous with consent, because under a presumed consent system it is possible for organs to be removed without consent. Such a deviation from the prevailing ethos – that consent is a fundamental aspect of any legitimate form of medical intervention must be ethically defensible and transparent.

Perhaps as Emily Jackson notes in her book *Medical Law and Ethics*, transparency demands that we acknowledge that 'presumed consent' is simply tactful terminology for treating organs as a public good in the absence of a registered objection. Whilst the overriding policy objective – an increase in the number of available organs – is clearly desirable, the ends must justify the means; creating the illusion of consent is unacceptable in this context and runs the risk, in the absence of transparency, of undermining one of the bedrocks of medical treatment.

Meeting the increasing demand for organs requires us to recognise that the shortage can only be met through a multifaceted strategy. This may not only require legislative reform and the adoption of the recommendations laid out in the report, but may also ultimately require us to acknowledge that 'presumed consent', if adopted, may need to be enforced, and that to many will be unpalatable. ■

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