

Philippa Taylor considers the complexities of presumed consent

ORGAN DONATION

Plans are well underway in Wales to introduce legislation for an 'opt-out system' (otherwise known as 'presumed consent') for organ donation. This would permit doctors to remove organs from any dead patient, unless they had specifically registered a formal objection to it.

Currently an 'opt-in' consent system operates across the UK. Individuals can authorise organ removal after death by joining the Organ Donor Register (ODR), or making their wishes known to their family. Families can also consent to donation of organs from a deceased relative, if that person has not made a known decision either way.

It is well known that there is a shortage of organs for transplant. The Welsh Government believes that a 'soft opt-out' scheme could increase rates of organ donation on death by 25%-30%. A soft opt-out scheme would authorise doctors to remove organs and tissue from any patient declared dead, unless the deceased had formally registered their objection. Families would 'be involved' in the decision-making process around donation.¹ A public consultation, seeking views on how best to implement the legislation, has taken place. The next step will be draft legislation for Welsh Assembly scrutiny.

At the same time, campaigns to introduce similar legislation in Scotland and England are gathering support. A new BMA report proposes options to increase the number of donors including a system of mandated choice, a regulated market, or paying the funeral expenses of those who sign up to the ODR and subsequently donate organs. The BMA advocates a soft opt-out system as their preferred option for the UK.²

So would an opt-out system increase organ donation rates? With prescient timing, new articles in *Transplantation* and the *BMJ* suggest otherwise. Research published in *Transplantation* found that donation rates in countries with opt-out laws do not differ dramatically from countries requiring explicit (opt-in) consent. Instead:

'...countries with the highest rates of deceased donation have national and local initiatives, independent of PC, designed to attenuate the organ shortage'.³

Another *Transplantation* paper notes that in the UK deceased organ donation has increased 25% in three years through implementation of measures that have transformed the infrastructure of donation,⁴ not through introducing an opt-out system.

Advocates of presumed consent often cite Spain as a legislation success story. Yet a *BMJ* article reports that:

'In fact, what Spain has shown is that the highest levels of organ donation can be obtained while respecting the autonomy of the individual and family, and **without** presumed consent.'⁵ (emphasis added).

Another *BMJ* article, reviewing countries with 'presumed consent' systems, concluded that various factors (such as the transplantation system, public attitudes and awareness) contribute to variation between countries and 'presumed consent alone is unlikely to explain the

variation in organ donation rates between different countries'.⁶

It could nevertheless be argued that it is worth proceeding with an opt-out system in case it might make a difference, and it would increase public awareness of the need for more organ donors on death.

This is where ethics come to the fore. Organ donation is a generous gift and an example of altruism. However consent to donation should always be voluntary (un-coerced), informed and autonomous. 'Presumed consent' is a misnomer, involving neither donation nor consent from the individual. Silence does not amount to consent. When organ donation becomes 'presumed', it is no longer a voluntary gift, nor a 'donation', but an obligation. It is about taking, not giving organs. Further concerns have been expressed about the body effectively belonging to 'the State' at death, and about controversies with the definition and diagnosis of death.⁷

Introducing a system that relies on presumed authority, based solely on people registering their decision to opt out, has to ensure that *everyone* is fully informed and understanding of the situation, knows their options and can easily and simply opt-out. Otherwise it cannot be ensured that every removal of human organs is appropriately authorised. The groups least likely to express their views, if they hold views on this, will include those who are disorganised, apathetic, disabled, less well educated or informed, lacking full capacity, of different languages and race, suffering from mental illness, dependent, those who have less ready access to information and those changing their minds. Silence in many of these cases should not amount to consent to donation under an opt-out system.

The primary factors influencing donor rates are the numbers of potential donors, provision of intensive care facilities, end of life care, use of transplant coordinators, trust in the donation system and trust in the medical profession (particularly those treating dying patients). This is surely where policy, and the money that follows it, should be directed, rather than towards ethically tricky, and unnecessary, presumed consent legislation.

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references

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