

Dear Sir/Madam,

One of the arguments put forward for moving to an opt-out organ donation system is that most people are in favour of organ donation even though they do not get around to joining the ODR.

My own experience is that it is already too *easy* to become a registered organ donor without realising quite what you have let yourself in for. I learnt relatively recently that I had been registered as an organ donor for over 10 years as a result of information provided by my GP's surgery from when I registered with them. I recall ticking a number of boxes indicating that I would be willing to donate several of my organs for transplantation **after my death** (emphasis mine).

I had no idea then that this would be taken to indicate my consent to the removal of my organs in the event that I was diagnosed with brainstem death. I had taken 'death' to mean death in the commonly understood sense, implying a complete cessation of all bodily activity. Not knowing much about how organ donation really works, I did not realise how difficult (and in the case of most organs, impossible) it is to obtain transplantable organs from a real corpse. And I certainly had no idea that organs could be removed whilst the donor's heart is still beating and his/her body still warm, ventilated and (without muscle-paralysing drugs or anaesthesia) possibly reactive to trauma.

As none of these things were made clear to me, there is obviously something seriously wrong with the current system for indicating consent to organ donation after 'death'.

Unfortunately, nothing I see in the system being proposed for Wales makes me think that this problem of consent from ignorance / misinformation is to be addressed. Placing ministers under an obligation to promote transplantation will make it more difficult for them to be truthful and transparent about organ donation and provide potential donors with the kind of information they should be given when considering whether or not to opt out – information like the state their body would be in at the time of organ harvesting and the fact that immunosuppressant drugs would be needed to prevent their organ(s) being rejected by another person's body (unless donor and recipient are identical twins).

The Explanatory Memorandum of the Human Transplantation (Wales) Bill claims that a soft opt-out system is being proposed – even though it has been made clear that families will have no legal veto over their loved-ones' organs being harvested. Page 10 of the document describes soft opt-out systems as being 'where organs would become available for donation after death if the deceased had not opted out, but where families would retain full involvement in the process.' Given families' lack of a veto under the proposed system, it is difficult to see how they would 'retain full involvement in the process' and therefore how the system can truthfully be described as 'soft'. Being consulted on their relative's lifestyle / medical history – in order to help assess how suitable their organs are for transplant – hardly means retaining full involvement in the process.

Presuming consent to organ donation from silence and, quite probably, ignorance / misinformation and potentially in opposition to relatives' wishes appears to be a recipe for making a bad system worse.

Reference is often made to Spain in advocating an opt-out system – even though their change of system was made back in 1979 and did not in itself make much difference to donation rates (see <http://www.ont.es/publicaciones/Documents/Articulos/2010/BMJ%20Analysis%20on%20presumed%20consent.pdf>). However, the much more recent example of switching to an opt-out system provided by Brazil in 1997-98 should also be noted when considering whether the Bill could have any unintended consequences.

Two letters to the Western Mail from medical experts describing the state of a donor's body during transplantation are appended for your consideration.

Yours faithfully,
Jonathan Cundill

Letter 1: The truth about organ donation (Saturday, July 2 2011)

<http://www.walesonline.co.uk/news/letters-to-the-editor/western-mail-letters/2011/07/02/saturday-july-2-2011-91466-28980625/>

SIR – I read that Wales intends to adopt the “opt out” (presumed consent) system governing the procurement of organs for transplantation (“Presumed-consent organ donation still BMA policy”, June 29).

I therefore feel obliged to do what I can to alert the good people of the land of my birth to the full implications of that change – and, perhaps, of registration on the NHS Organ Donor Register under the present “opt in” system.

To take the latter point first, all those who have so registered must clearly understand that they are deemed to have agreed thereby to the removal of their organs while their bodies are still very much alive.

As a moment's thought should indicate, it is not possible to obtain healthy complex organs, which can be expected to function efficiently for years in another person's body, from someone who is truly dead in the commonly understood sense, ie an unresponsive cadaver whose heartbeat and breathing have long ceased.

Hearts for transplantation are taken from donors in whom they have been maintaining the blood circulation up to the time of their removal, oxygenation of their blood being maintained by continuing mechanical ventilation.

By virtue of that continuing life-support after the diagnosis and certification of death, donors' bodies remain reactive and may have to be paralysed with drugs to facilitate the organ procurement surgery. Some attending anaesthetists may give general anaesthesia also.

The diagnosis of death for that purpose will have been made on a very different basis from that used for the diagnosis of death in more than 99% of cases worldwide.

In the UK that diagnosis is made for transplantation purposes on criteria considered inadequate in most parts of the world and recently rejected by the US President's Council on Bioethics. They require only simple bedside testing of some functions of the brain stem – the stalk which connects the spinal cord to the cerebellum (the “little brain”) and to the major part of the brain (the massive cerebral hemispheres).

It is alleged that these tests ensure there can never again be any form of consciousness, but there is no sound scientific evidence to support that claim. There is, however, evidence suggesting persisting function in brain stems pronounced “dead” by the UK criteria.

If there are some on the NHS Organ Donor Register who did not understand that the words “after my death” on the application forms (and Donor Cards) do not mean after death in the commonly understood sense – no heartbeat or breathing for long enough to ensure irrecoverability of any responsiveness or awareness – they may feel they “signed up” on a false premise.

They may even feel they were to some extent deceived by the wording and emotional appeals to register without being given a full and fair explanation of the nature of the offer sought. In such cases, their offers cannot be considered valid and they may wish to seek means of removal of their names or modification of their offer by imposing conditions such as a request for anaesthesia to cover the explantation surgery.

Turning to “presumed consent”, it will be assumed that people diagnosed “dead” by the UK Code of Practice criteria governing that diagnosis for transplant purposes have agreed – “consented” – to the removal of their organs while in that state unless they have registered prior objection.

The absurdity of that presumption – given the lack of certainty that everyone is fully apprised of the organ procurement procedure and has considered it while of sound mind – has been pointed out in submissions to the House of Commons Welsh Affairs Committee earlier this year (available online).

My plea is for the public to be fully informed about the procurement of organs for transplant – hitherto quietly concealed behind propaganda emphasising the plight of those hoping to acquire organs.

It is high time the truth was made generally known. The responsibility to make it known rests heavily and specially upon those who wish to impose an “opt out” system on the woefully uninformed, or misinformed, public.

They must also ensure that, when the public is so informed, there is a ready mechanism to hand for those who want to register their objection to being used as organ donors, as they are currently treated when only notionally dead.

DAVID W EVANS

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Letter 2: Death and donors (Saturday, August 29 2011)

<http://www.walesonline.co.uk/news/letters-to-the-editor/western-mail-letters/2011/08/29/western-mail-letters-monday-29-august-2011-91466-29319355/>

SIR – Dr Paul G Murphy (Letters, Aug 13) infers that Dr David W Evans’ anxieties on organ donation (Letters, July 2), that organ donors are not “dead” in the generally accepted sense, is only a personal view. Far from it!

If he searches the literature, as indeed he should, he will find many international authors in ethical and philosophical, as well as medical, journals, supporting his view. That is in spite of some editors choosing not to publish such information.

His statement that “The UK guidelines for the diagnosis of brain-stem death, prepared by the country’s most senior medical bodies [with a strong transplant interest – I would add], have been used for more than 30 years and have never been demonstrated to be incorrect” is only evidence of a self-fulfilling prophecy.

These tests, introduced to establish irrecoverability were used either to withdraw further treatment and allow the patient to die, or else to harvest organs for transplantation. In either case, death supervenes and complaints would be few.

A patient diagnosed as dead for transplant purposes will have all major organs continuing to function (or they would be of no use for transplantation). Characteristics of life remain – respiration (exchange of gases), heartbeat and circulation, metabolism and excretion, reproduction (with IVF, and the maintenance of existing pregnancy), and response to the environment.

This last includes responses to the trauma of operation, similar to those involved in any major operation, such that muscle-paralysing drugs and some form of anaesthesia are required when the surgery is performed.

Dr Murphy should be (and probably is) aware of this, but that information has never been part of the consent procedure on Donor Card or Register, and I have been unable to establish from UK Transplant any guarantee that a potential donor will in fact be given anaesthesia.

Some anaesthetist colleagues withhold anaesthesia on the grounds that it cannot be needed for a “dead” patient, in spite of visible reactions.

The majority (I am pleased to say) do give anaesthesia, “just in case” and to allay the anxieties of other staff in the operating theatre. Before giving their consent, patients might care to know of this.

More than four centuries ago, in *Romeo and Juliet*, Shakespeare used Friar Laurence to describe (apparent) death in a way that most people would recognise today:

No pulse

Shall keep his native progress, but surcease:

No warmth, no breath shall testify thou livest;

The roses in thy lips and cheeks shall fade

To pearly ashes; thy eyes' windows fall

Like death when he shuts up the day of life;

Each part depriv'd of supple government

Shall, stiff and stark and pale, appear like death.

(*Romeo & Juliet*. Act 4, Scene 1)

An organ donor will be warm, pink, supple, have pulse and circulation and be reactive. Surely those being asked to give consent, or if consent is to be presumed, should be allowed to know of the difference.

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