

# HUMAN TRANSPLANTATION (WALES) BILL

**From Joyce Robins, Co-director Patient Concern**

## **Introduction**

Patient Concern is an independent voluntary organisation set up 13 years ago with the aim of promoting choice and empowering patients. Our core principle has always been active informed consent applicable in any medical context. Joyce Robins was one of the founders and has been Co-Director from the beginning.

## **Consultation Response**

The main change to be brought about by the planned Bill is the concept of ‘deemed’ consent. Deemed is a somewhat archaic word normally meaning ‘consider’ or ‘regard as’ and is absent from common vocabulary. It has presumably been chosen to avoid the term ‘presumed’, which has attracted much criticism. However it still means ‘pretend’ consent i.e. it is pretending that a patient has agreed to donation when they have done no such thing. In no other walk of life is the absence of refusal regarded as consent.

We consider the principles underlying this Bill to be unethical and unacceptable.

All the major studies of the organ donation system, including the Welsh Assembly’s own health committee (at which Patient Concern gave oral evidence), once they had considered all the evidence in depth concluded that the opt out system was the wrong way to go. They found no causal link between a change in the law and rising donation rates and decided that there were far more effective ways of increasing the donation rate. In fact, they considered that changing the law would only distract from the measures that need to be taken to improve the infrastructure so that real change is possible. The measures suggested by the ODTF are now on line to deliver a 50% increase by early this year, increasing to 60% by 1216-17, without spending millions on changing the law.

Opting out is a fundamental departure from the UK norm and our work with patients shows that, as a concept, it is poorly understood. The idea that any amount of publicity will ensure that everyone fully understands their options and the need to exercise them is fanciful. The experience of uploading summary care records under an opt-out system illustrates this point. When Patient Concern opposed this system we were assured that the blitz of information would be such that everyone would know and understand the changes. Later reports showed that in spite of all the publicity (including a letter to every household) most people had no idea that it had happened. The result is that millions of records have been uploaded without patients’ knowledge or consent.

This belief in a ‘silver bullet’ approach to solving the organ donor shortage has the potential for a number of unintended and unwelcome results. It is no longer honest to talk about ‘donation’ in the context of this Bill. A donation is a gift, willingly given,

and that cannot be assumed under these proposals. If families feel that they have no real say in what is happening to the body of a loved one, even though that person has not made a conscious choice, lasting damage could be done to the whole aura of the transplant programme.

It is important to remember UK history, which has involved major scandals involving organ removal without permission. This brought into being the Human Tissue Act 2004; its whole purpose being to ensure that consent is a positive action. Its Code of Practice spells this out. Presumably the Code will now be rewritten to take this right away from Welsh people. We consider this a backward step.

Memories may have dimmed but it would only take a couple of errors, where it could be shown that organs had been taken against the wishes of the deceased, to reawaken them and cause a media firestorm which could damage the whole transplantation process. Alder Hey set back organ donation in the UK by ten years and is one of the reasons that our transplant rate is so poor. We should remember that 2010 mistakes on the organ donor register, ignoring exclusions made by some donors, achieved global publicity. More publicity of this type could cause a serious backlash.

One of the fundamental beliefs behind the legislation is that this step will ensure that people talk more about the subject within their families and make their wishes known. We would suggest that this is a pious hope, unlikely to be realised. The death taboo is still strong – it is a subject that many people cannot and will not consider. Almost everyone cares what happens to their property in the future, yet only 30% of us make a will. This is a parallel with the proportion of apparently willing people who sign the donor register.

There can be no ‘full involvement’ of families once the right of refusal is taken from them. Refusal at the bedside among ethnic minorities is currently 75%. There is a real danger that an element of coercion is being introduced if they are then forced to justify their belief that this is not what their loved one wanted while someone – there is no explanation of who is to judge – ‘assesses’ the evidence. The system where a trained counsellor can take time to help the family reach the decision that is right for them is a distinctly preferable scenario to introducing legal obligation.

There may be many reasons for the disparity between the numbers of those who profess willingness to donate in a poll and those who sign the register – one being whether a ‘yes’ vote in the street reflects reasoned judgment taken after consideration. We note that mandated choice (far more likely to be informed choice) was the favoured route chosen by Welsh people in the early consultation but this was hastily abandoned as being too difficult. The simple solution of giving every patient an opportunity of opting in or out any time they access any form of health care – just as routinely as we record our next of kin seems a simple and obvious solution.

The implication that only a change in the law would suffice is simply spurious and smacks of political opportunism.

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