

Q and A on presumed consent

What is the current situation with organ donation in Wales?

There are currently nearly 500 people waiting for a transplant in Wales. Someone dies every 11 days waiting to receive an organ. Although the work of the Donate Wales campaign and others has seen more people join the organ donor register rise by over 60,000 in the last two years the number remains low at just 28%¹.

Worryingly Wales is getting worse at converting people who die into organ donors. Dropping from 16.7 deceased donors per million to 13 between 2007-08 and 2008-09². This means that the chances of people waiting for a transplant, being given a new lease of life are reducing.

Why aren't there enough organ donors in the UK?

We know an overwhelming majority of people in Wales would like to donate their organs after death and help someone else to live. Unfortunately many of them do not get around to joining the organ donor register and discussing their wishes with their loved ones.

Recent polling commissioned by Kidney Wales of 1021 Welsh adults (Dec 2009) showed that whilst 71% of adults would be willing to donate an organ after death, we know only 28% have joined the Organ Donor Register.

What is presumed consent?

Presumed consent means that people are considered to want to donate their organs upon death unless they say otherwise. Normally this means that everyone is placed on a register to donate their organs when they die and they have the option of removing themselves from it.

How does that differ to the current situation?

Currently, people need to register to express they want to donate their organs. This will then be confirmed by their loved ones after death. If people don't join the register and discuss their wishes with loved ones it can mean they don't know what decision to take. That is why we would always encourage people to discuss their wishes with their loved ones.

What is the difference between hard and soft opt out?

¹ Figures obtained from NHSBT in Nov 09

² Working together to save lives. The Organ Donation Taskforce Implementation Programme's Annual Report 2008/09. p.25

A soft opt out means that loved ones have the option to decline to donate organs after death. A hard opt out means loved ones don't have that opportunity. Kidney Wales supports a soft opt out which means **only those that do want to donate do so.**

Will this solve the problem on its own?

A switch to presumed consent will mean there are more organs available for people waiting for a transplant. It will not on its own solve the problem of people dying waiting for a transplant that could mean they will live. We need to make sure that there is the infrastructure in place to support this.

Significant steps have already been made towards this, for example with the new transplant unit being built at the University Hospital of Wales and the recruitment of a network of donor co-ordinators across Wales.

How many additional organs do you think will help save lives?

Research by Johnson and Goldstein (2003) showed that moving to a opt out organ donation system could lead to an anticipated increase of 16.3% in the number of organs donated.

Doesn't opt out remove people's right to choose to donate organs?

Opt-out does not take away the right of the individual to decide whether they wish to donate or not. If a person does not want to donate their organs for transplant then they have the right to automatically take themselves off the register

Why do you support presumed consent?

In short, because it will save lives. Someone dies every 11 days in Wales whilst they are waiting for a transplant. We talk to patients who are waiting for a transplant who tell us day in day out they don't know how long they will be alive. They tell us that they feel like they are living life on death row. We know most people want to donate their organs and a move to presumed consent will allow that.

What is the situation in other countries?

Opt-out has been hugely successful in other countries. When Belgium introduced the opt-out system in 1986 its national rate of organ donation rose by 55% within five years. Belgians can take themselves off the Register at their local town hall, but only 2% have done so since the law was introduced. In Spain, where a similar system of opt-out exists, there are 35 donors per million population compared to just 12 in the UK. It is the only country that has witnessed a year-on-year increase in organ donation for the last ten years.

How will this work logistically

The lawyers will now need to work to iron out how this system will work in practice. Ideally we would like to see the UK move as a whole to a model of presumed consent. It is important that the NHS is ready for the changes, and additionally life saving organs, that a move to presumed consent will bring. That's why we support the Minister in allowing a decent period of time for people to prepare for this.

Who else supports a move to presumed consent?

Many people and organisations support the move to presumed consent. Critically, that includes groups such as the BMA (British Medical Association) which represents over 6000 health professionals like doctors in Wales.

Is it possible for Wales to 'go it alone' and be the only nation in the UK in operating an opt out system

When considering this the Welsh Assembly's Health and wellbeing committee concluded that when *'we looked at the current legal position and whether there was any fundamental reason why Wales should not seek the power to introduce presumed consent in Wales if there is the will to do so. We concluded the there was not.'*³

Kidney Wales agrees with this view. Whilst we would welcome a move to opt out in other UK nations the system would be no different to that if an Englishperson were to visit Spain. That is that unless it can be verified that organs wanted to be donated with the support of a loved one they will not be taken for donation. This system has operated well there for many years.

³ Health Wellbeing and Local Government Committee, Inquiry into Presumed Consent for Organ donation. July 2008.