

Press release

December 2011

Organ transplantation is ‘a gift’ for donor families as well as recipients

Organ transplantation, among the great achievements of modern medicine, is an overwhelmingly successful procedure, a ‘gift’ for donors and donor families as well as organ recipients.

That is the central finding of a new online section on organ donation that is being launched this week by the award-winning health website, Healthtalkonline, and funded by the Intensive Care National Audit & Research Centre (ICNARC).

The site (www.healthtalkonline.org/Organ_donation_and_transplant/organ_donation) presents video and audio interviews with 39 people with direct experience of organ donation. They include donor families who have consented to organ donation after the death of a relative, organ recipients who had transplant surgery to save or enhance their lives as well as living kidney donors.

With demand for organ donation consistently outstripping supply, it’s no surprise that all the recipients of donated organs express their appreciation of the scheme and say they are keen to persuade friends, family and members of the public to register as organ donors.

Less expected, perhaps, is the almost uniformly evangelical enthusiasm for organ transplantation among donor families. Many say they want to inform the public of the benefits of organ donation, specifically the comfort of knowing that someone else will have a better life as a result of a relative’s death.

‘We’re all glad that we’ve done it and if I’m having a bad day, it’s what gets me up in the mornings, knowing that there is something of Kirstie still out there,’ says Eunice, a 55-year-old accountant. Her daughter’s death, aged 26, after a car accident in 2006, she explains, ‘gave the gift of life to six other people and their families’.

Yet contributors to the site are critical of some aspects of their care during the already traumatic final hours of their relatives’ lives.

A key concern is the lack of warning to prepare relatives for the fact that the last sight of their loved one will be a still pink, warm body that appears to be breathing as they have to remain on a ventilator until the organs have been removed in the operating theatre.

Parents Craig and Sandra recall the ‘traumatic’ moment they had to leave their 11 year-old daughter Rachel who died of a brain haemorrhage in 2008. ‘I’d got my nurse’s head on and I knew she wasn’t

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there but it was still difficult to walk away,' says Sandra - while Craig admits: 'I still feel guilty for leaving her that day.' Liz, a 46-year-old mother of four, describes being 'haunted for the last ten years' at leaving her husband. 'As that man's wife, I still thought that I was sending him into an operating theatre and they were going to take his organs out and he was alive,' she said.

Some contributors say they disliked the extensive and detailed form filling prior to organ donation as well as having to listen to lengthy explanations of every step of the surgery involved – especially when they had already made up their minds to go ahead with organ donation.

Ann, 57, whose son Mike died aged 31, would have preferred, she said, to 'just be able to sign a form saying we have agreed to this, and we understand we could have been told all the details but we don't wish to know all the details. But, instead of that, we had to sit through her telling us very kindly, very nicely, as compassionate as she could possibly be, but she still had to tell us in detail how and when everything would be done. Which is a hard thing to listen to.'

Several donor families expressed their gratitude to surgical teams for 'fighting up to the end' to keep their relatives alive. They also made it clear that while they were enthusiastic about organ donation, most opposed presumed consent (opting-out), believing that organs must be donated freely by those who want to and that it should be a conscious decision. Another message was that donor families would prefer to be kept in touch with the recipients' welfare, though most did not get any news after the first year.

Dr Suman Prinjha, senior researcher at the Health Experiences Research Group, said: 'This new section is a huge affirmation by those with direct experience of organ donation. We hope that this research will contribute to the continuing improvement of this service - as well as raising awareness amongst the general public of what organ donation can mean to those who donate as well as receive organs.'

Professor Kathy Rowan, Director of ICNARC, said: 'Having funded two previous sections on Healthtalkonline, the feedback from these has highlighted to us the importance of making the views and experience of others accessible to all those involved in using, delivering and improving health services.'

Mr Chris Rudge, National Clinical Director for Transplantation 2008-2011, said: 'For too long we've thought about organ donation simply in terms of the patient who needs a transplant. These interviews demonstrate how important donation is to those left behind after the donor's death – the extraordinary comfort they can gain in seeing some good come from a tragic situation. Agreeing to organ donation was undoubtedly the right thing for them and their words should make us all think about this seemingly difficult and emotive subject in a new light.'

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Note for editors:

www.Healthtalkonline.org is an experiential website based on qualitative research led by experts at the University of Oxford and published by the DIPEX charity. It is funded by a wide range of statutory bodies and charitable trusts is recognised by the Department of Health and many other professional organisations.

The website which recently celebrated its tenth anniversary has more than a million hits a week and two million unique visitors every year. They log on to watch video and audio clips from interviews with over 2000 people about their experience of more than 70 health conditions.

Interviews with some participants can be arranged with prior notice.

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