



## **The Power of the “ick” factor in Organ Donation – September 2013**

**Over the last few weeks a number of incidents in the public sphere have highlighted the problem of callous, inaccurate and insensitive representation of organ donation.**

The BBC faced strong complaint and approbation from the NHS for its depiction of organ donation in a recent television drama. In Australia last week a television program aired which presented a case of a death and subsequent organ donation. This program created outrage amongst nursing colleagues and those who are awaiting organ transplantation for its poor portrayal of organ donation and nurses. A strongly voiced view from my colleagues was that the outcomes could negatively colour the organ donation views of those who viewed the episode. This event coincided with a discussion about the release of a new book by a liver transplant surgeon aimed for public consumption, displayed in the new books section of a public library and picked up by a family member of an organ donor. This book was passed for review to Donor Families Australia. The donor family members were deeply distressed by insensitivity displayed in the portrayal of the organ donation surgical process and the apparent relegation of the donor to a vessel for organs.

A real anxiety about organ donation held by many in our community is sometimes referred to as the ‘ick’ factor and includes the idea of bodily mutilation, disrespect for the grieving family and confusion about the terminology and determination of death. The organ donation sector describes these fears as the ‘myths’ of organ donation. These fears and uncertainties are known

to intrude and sometimes strongly influence the decision making process of people contemplating their own or their relatives’ death and organ and tissue donation decision. Despite an increase in the number of organ donors in Australia since the introduction of funding to facilitate the clinical requirements of organ donation, 2013 figures indicate around 45% of families still decline the request for donation, a figure that remains effectively unchanged across the last decade. For this reason Australia still lags well behind most developed countries in organ donation rates with a rate half that of Spain who has the highest donation rate, and seeks family consent for every donation despite its Opt out scheme. It is possible that despite the altruistic character of Australians and a willingness to support the idea of organ donation; many of us carry a subconscious hesitation to agree to organ or tissue donation underpinned by distrust in the process.

I am saddened that despite the general acknowledgement in the public conversation in Australia that we should increase our organ donation rates with calls for opt-out legislative frameworks to over-ride the influence of families in the decision making process ; many thought leaders remain amazingly insensitive to the impact they have in influencing the organ donation decisions of the community. People who include not only those who may be required to make a

decision in the future about organ donation; but also grieving donor families who, having made a decision to donate, benefit from affirmation for what is often a harrowing experience.

The experience of empathy and compassion contribute to the trust and hope which is essential for families to make a decision to donate, and for our community to expect to donate as a normal part of end of life care. Families need to have the trust that their relative will be cared for and honoured and that their grief will be acknowledged. They need to have hope that their decision respects their loved ones wishes, and is validated with care for their loved one throughout the donation process. They require validation for their decision and acknowledgement of their gift.

We cannot blame families for declining to donate their loved ones organs when their first need to is protect and care for them and their bodies. The only place families can obtain information about organ donation processes in Australia is from the media and information in the public domain, and this is what they use to inform many of their decisions. This leaves the hospital staff with the difficult task of not only providing excellent care and communication in every facet of the patient journey, but it also requires skilled expertise to fully educate a grieving family about the organ donation process. For most people this is new and complex information, and is difficult to assimilate through the veil of emotion, shock and sleep deprivation.

There are no authoritative standardised public education resources available in Australia about what it is like to go through the experience of donating your relatives' organs, and what families should expect when faced with the decision. Until there is, it is beholden for us all to consider the impact of our words and their power. An interesting comment from a participant in a study I am conducting (who declined donation) was "- so much for the recipient but nothing for the donor". Please consider a more thoughtful approach to the

way we represent organ and tissue Connecting Donor Families If you would like to find out more about Donor Families Australia and how to become a member please visit our website: [www.donorfamiliesaustralia.com](http://www.donorfamiliesaustralia.com) Individually we do great things and affect those around us. Collective we do great things and affect a nation! Holly Northam is Assistant Professor in Critical Care Nursing at the University of Canberra. She is a Registered Nurse, Midwife and doctoral candidate exploring the experiences of families who have made organ donation decisions. Amongst her previous clinical roles Holly was an organ donor coordinator. Holly is a Director on the Board of Sharelife Australia. donation in public and professional communication. It has ramifications. For example, there were only four heart/ lung donors in Australia in 2012. The number of patients who die on the waiting list or are removed from the waiting list when dying are not published. Anecdotally the numbers are significant. I am sure it must be heart breaking to be waiting for a transplant and to be aware of the possible impact of this insensitivity. Importantly, please consider how your family would feel if asked to donate a loved ones' organs because in truth it can happen to any of us at any time.

*Holly Northam is Assistant Professor in Critical Care Nursing at the University of Canberra. She is a Registered Nurse, Midwife and doctoral candidate exploring the experiences of families who have made organ donation decisions. Amongst her previous clinical roles Holly was an organ donor coordinator. Holly is a Director on the Board of Sharelife Australia.*