



## Reflection on Best Practices – July

**2015**

**There has been much comment over the past two months regarding a review into the implementation of the Australian organ donation reform.**

Discussion about measurable outcomes and statistical analysis of performance has featured, and the views of the community regarding donors, donation decisions and donor family experiences have also been sought. It is hoped in the process of the review, the reviewers will clarify:

1. If Australia has integrated organ and tissue donation as an intrinsic part of quality end of life care; and
2. If a culture of donation has been established in our hospitals. A test of this achievement is the visibility of satisfied donor families within the community.

It is easy to slip into discussion about laws, regulatory frameworks and governance. In truth, best practice resides in the experience of the decision-making family and their satisfaction with the outcome. The capacity to make an organ donation decision is situated in the hope to help others, and belief that it is the 'right thing to do'. In principle, there is sufficient trust that most people in Australia will take the doctors' word on issues relating to the diagnosis of death, especially if what is said is consistent and aligns with their knowledge. However, most people have insufficient information to understand the organ and tissue donation process and this can prove a barrier to good practice. This problem may ripple into the community if

people believe that there has been insufficient care following a donation decision or feel bereft because they did not receive a 'thank you', or believe that their gift was not valued.

The US have a National Donor Family memorial, donation months are set aside to honour donors and their families and parades are held. A memorial medal and letter signed by the governor and sent to the donor's family is another example of ways the recognition of donation decisions. Donor family members are an intrinsic part of the donation team in some centres of excellence. For example, in Wisconsin, a donor mother was employed to lead the care of donor families. A range of programs for volunteer donor family members who are provided with appropriate training and support enable families faced with a donation decision to be offered the opportunity to talk to a donor family member while considering their options. In some areas the family are offered the support of a person from a similar cultural and religious background. Follow up care is often comprehensive and many families form a positive relationship with the donation organization that may continue for years. In the UK, family focused care means donor coordinators are encouraged to provide follow up care to donor families and if desired,

visit them at home.

There is little public acknowledgement of donors and their families in Australia. There are few donor memorials, and the ones that exist have often been organized or paid for by donor families. This public 'silence' makes it difficult to assure the community that making a decision to 'give' at death is the community norm. Organ donation is a gift that does not tangibly benefit the donor, or their family; but if appropriately acknowledged, it has the capacity to grow communities and humanity. Efforts to recognize individual families with symbols and gestures of support have been cherished by donor families (ATCA, 2008). An example is the reflection rose and rose pin which were replaced with the Donatelife logo.

Recognition of the gift of donation may take many forms. A powerful example of the community working in hand with health professionals is the use of donor quilts. In the ACT the use of lovingly crafted patchwork quilts created and donated for the care of donors have been used to help soften the seemingly harsh hospital Holly's Insight REFLECTION ON 'BEST' PRACTICES 6 environment. The quilts are provided to the family, as they leave the hospital as a means of offering solace to families. The benefits of this program have not only helped to humanize the tragedy for the family but have contributed to goodwill towards organ donation within the hospital community.

There are powerful stories of healing that have transpired from the use of the quilts including international recognition following the care of a young Malaysian donor whose father returned home with the 'quilt of love' that wrapped his son, to give to the young man's mother. The power of quilts inspired Transplant Australia to initiate the donor quilt project which was created with individual squares sewn by donor families to remember their loved one. The patchwork was stitched

together by volunteers to remember donors. Another community recognition of a donor and their gift was the Matthew Reynolds quiet room. This 'quiet' room was purposefully designed with the help of Matthew's family for the use of donor families as a 'safe place' in the intensive care unit at the Canberra Hospital. The costs associated with the construction were donated by community organisations.

At present a number of strategies are used to recognize donors including the West Australian honour board. Services of remembrance held across the country are extremely important opportunities for donor and recipients to come together and for recipients to acknowledge the donation. Many of these events receive little external recognition but could be used to highlight to the community that donation is valued. The opportunities for donor families and recipients to intermingle or be heard together have been carefully moderated, choreographed and limited in Australia. Conservative policies regarding recipient and donor family communication may contribute to a community perception that donation is something to hide. A push by donor families for the for the donation to be recognized on their loved ones death certificates has so far failed to gain traction. Care of the dying and their family cannot be left to chance.

Care must be underpinned by a transparent, compassionate and engaged national organization. It needs structures that are responsive to dynamic and complex situations and offers a relationship of mutual trust with the community who can offer much. Most people are forgiving if they know that care is given with integrity and compassion. The philosophy that must underpin any improvement process is - care, compassion and an ongoing public recognition that the gift of donation is cherished and not easily forgotten....