



Make Your Decision Count

The 2017 Donatelife Week campaign has changed the relationship between the Australian community and Donatelife.

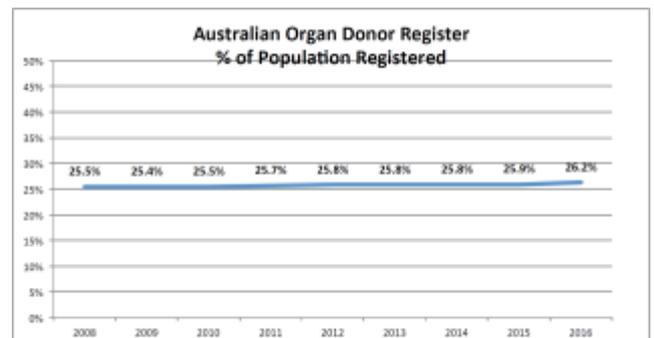
What is different? The mention of family has been removed from campaign messaging to focus entirely on Australian Organ Donor Register (AODR) registration.

Is this a problem? It depends on how you look at it. There are three trust implications for the community about the use of the register based on economic, practical and human factors.

First, let's look at the economics. More than \$13.4 million has been spent on Australian communication campaigns since 2010 (Woolcott, 2012). This impost on the tax payer flies in the face of evidence from Spain, Croatia, and Portugal that shows that a register and public campaigns are not required for high rates of organ donation—but instead, care and support for patients and their families at the end of life is essential. Evidence from Australia supports this view where donation rates have risen significantly since 2009 as a result of increased staff and organisational resources used to identify possible donors and request donation. A new training program to help staff discuss donation have contributed to consent decisions. Previously, few clinical resources were available to action organ and tissue donation, even if a family offered to donate.

Second, the practical assumption that donor registrations have contributed to the increased donation rate and should be

supported is incorrect. Importantly, since 2007 registered refusals to donate have increased almost tenfold, from 3,417 in 2007 to 30,566 as of May 31, 2017. Whereas, since 2007, the proportion of overall registrations on the AODR (based on population growth) have effectively 'flat-lined', as seen below. The consent rate (where deceased donation is requested by clinicians and agreed to) has been static over many years at around 60%. In this period, public support for donation has trended down from 98% in 2010 (Woolcott, 2010) to 80% in 2012 (Woolcott, 2012).



What does this mean? Why is it important?

These policy decisions impact people. For people waiting for a transplant, there is sometimes a belief that families of deceased patients selfishly and irrationally refuse to donate—even if their relative had previously agreed. Thus the urban myth that op-out increases donation and bypasses grieving

families to enhance rates of donation. 'Nudge tactics' are strategies used in Australia that underpin education for clinical staff about how to ask for donation. These tactics also underpin the AODR messaging. Organisations use 'nudge tactics' to meet targets that are dependent on individual decision-making. Governments use these strategies to address behaviours that are seen as illogical, determined by emotion – and not fitting policy agendas. These behavioural management tactics are used to 'nudge' or pressure people to make a decision that sits with the organisation's plans.

Some argue nudge strategies are paternalistic and undemocratic—particularly if information is poorly communicated or withheld, and outcomes are not what the decision-maker expected. The implications for the patient or family making deceased organ donation decisions are significant, and impact end of life experiences. The benefits for recipients and donors are substantial when things 'go well'. The harms if things 'go wrong' for the recipients and donors are substantial and include barriers to a 'good' or 'peaceful death', the risk of complicated grieving, heightened community distrust and refusals that may inhibit donation.

An ongoing failure of clinicians, academics, policy makers, politicians and governments to address the problem that deceased organ donation decision-makers must explicitly trust the information provided to them by clinicians caring for their relative because:

1. There is no universal definition of death or how it is determined;
2. There is limited evidence of quality review processes that ensure the diagnoses and treatment decisions made at death are in the interests of the dying/ deceased patient; and
3. Deceased organ and tissue processes vary and are unclear to many clinicians, and obscured from the public.

Registration is a useful tool if used appropriately. Individuals who complete the registration form are unlikely to understand the consequences of their decision and therefore not satisfy the legal requirements for medical consent. Families who face the organ donation decision at the time of a relative's death are generally dismayed to discover that the determination of death and donation practices are not what they or their family anticipated. Families indicate that having prior information about the processes would have helped them agree—but argue they need good clinical support to navigate the situation. This is particularly important if donation surgery takes days to arrange. End of life care cannot be separated from organ donation decisions, and this is where clinical practice needs to improve in Australia, and where overseas donation leaders excel.

There is plenty of evidence our community are generous and do not want to see people suffer. There is also evidence our community are desperate, because they have been told that the only way we can increase organ donation rates is to force the public to donate. The tragedy is the community are being manipulated to willingly take away the rights of families to have a say in what happens to their dying loved one.

It is a most brilliant manipulation by clinicians, governments, policy makers and politicians to shift responsibility for transparent, clinical care away from themselves, and to instead blame consumers: the community and grieving families when patients suffer and die from organ failure.

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