

## The family donation conversation: time to move to evidence-based practice

Helen Opdam

A federally funded national reform program to improve donation rates and processes in Australia began in 2009. Since then, there has been an 84% increase in deceased donation, with 378 organ donors in 2014 compared with the historical average of 205 per annum (2000–2008).<sup>1</sup> This increase has largely been achieved through improved donor identification and expansion of the donor pool, with uptake of donation after circulatory death accounting for 40% of the growth. Consent rates have remained somewhat static at 60% (2010, 54%; 2012, 61%; 2014, 59%), in spite of initiatives to raise community awareness and willingness to donate.

Calls to address Australia's consent rate have included adoption of "presumed consent" legislation, incentives and disallowing family override for registered donors.<sup>2</sup> There is little evidence that these approaches would lead to increased rates of donation in Australia and, as well as being costly to implement, have a risk of causing a decline in donation through loss of public trust.<sup>3–6</sup> A strategy with a good evidence base is to ensure an optimal approach in communicating with families of potential donors.<sup>7,8</sup> Identification of modifiable factors in family communication that influence the likelihood of consent has informed the development of best practice guidelines.<sup>9,10</sup> Perhaps the most important modifiable factor is to ensure that communication with the family is undertaken by skilled, trained and experienced staff who support donation.

A national initiative consistent with this approach has been the development of the professional education package for health professionals by the Organ and Tissue Authority (OTA), in collaboration with the Australian and New Zealand Intensive Care Society and the College of Intensive Care Medicine (CICM). The foundation modules of the professional education package are the core and practical family donation conversation (FDC) workshops that are targeted at intensivists, trainees, donation specialists and other staff who may have a key role in donation discussions with families.

In this edition of the Journal, Lewis and colleagues report on the implementation of a model of donation request in 15 hospitals in Australia involving staff who have attended the FDC training.<sup>11</sup> Their study evaluated whether components of the best practice model, as taught in the workshops, were used, including planning, the checking of donor registration status before a family approach, and

separating the communication conveying the fact of death or its imminence from the discussion about donation.

The study found that higher consent rates were associated with an FDC-trained person leading the discussions, particularly if this person was in addition to the donor's treating team.

It is not surprising that training results in improved outcomes, particularly when it comes to the optimal management of infrequent events. There remains, however, a need for more discussion in the intensive care community about who is best placed to lead these discussions, and how the implementation of any agreed model be achieved.

Intensive care specialists independently manage most donation discussions with families in Australia, with around one-third being undertaken by an FDC-trained clinician together with the treating clinician (the collaborative approach) or without the treating clinician (the designated-requester model). One-quarter of all CICM fellows have undertaken the core FDC workshop since its inception in 2012.

There are about 700 potential organ donors and request opportunities in Australia each year that occur across more than 70 hospitals, so any one intensivist is likely to have a limited exposure to managing these discussions, even in busy tertiary centre intensive care units.

One of the key elements of the Australian national reform program has been the employment of dedicated donation specialists in 78 hospitals across Australia, including all hospitals with significant donor potential. Medical donation specialists are mostly intensive care specialists who undertake the donation role part-time, and are responsible for ensuring that optimal donation processes within the hospital occur, including those for donor identification and request. Nurse donation specialists have the same purpose, with a subset in coordination roles undertaking the donation workup and providing 24-hour on-call availability. Donation specialist staff have in-depth donation knowledge, undergo communication training and have more frequent exposure to conversations with families about organ donation, and may therefore be better placed to undertake discussions with families about donation, either independent of or together with the treating clinician.

It is unlikely that one-off attendance at a workshop is sufficient to attain optimal requesting skills. The practical FDC training provided by the OTA and the simulation

training developed by the New South Wales Organ and Tissue Donation Service provide forums for practical role play-style training. This training has been shown in other countries to improve the quality of the communication as reported by families and requesters, as well as the consent rates.<sup>12</sup> We expect that this training would be repeated as a skills refresher on a regular basis. The OTA is now developing advanced FDC modules to build family support and requesting skills in specialist areas such as in the situation of a paediatric donor.

Countries with the highest consent rates, such as Spain (85%) and the United States (75%), largely attribute their success to having skilled, experienced dedicated requesters.<sup>3,8</sup> In Spain, these are intensivists who work part-time in medical donation coordinator roles. In the US, organ procurement organisation-employed nurses or requesters who are not health care trained attend the hospital to manage the family communication.

It is no longer reasonable to assume that untrained intensivists are best placed to independently manage FDCs. Intensivists should consider undertaking the core and practical FDC training and, together with their local hospital donation specialist colleagues and donation agencies, determine whether a select pool of requesters (medical and/or nursing) should be routinely called on to undertake this specialised communication with families of potential donors.

### Competing interests

None declared.

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