

## ACCCN 2024 POSITION STATEMENT ON ORGAN AND TISSUE DONATION: THE ROLE OF CRITICAL CARE NURSES

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### INTRODUCTION

The ACCCN is the peak professional nursing association representing critical care nurses throughout Australia. ACCCN supports initiatives to promote and enhance the role of all critical care nurses within the health professional team. Organ and tissue donation processes vary across Australian states and territories. This position statement provides evidence-based guidance to support the provision of high-quality care for potential organ donors and their families, regardless of location.

### EXISTING KEY RESOURCES

The ACCCN recognise that a number of Australian peak bodies and professional organisations already provide policies and guidelines to inform, guide and support organ and tissue donation in Australia. These include:-

- OTA Best Practice Guideline for Offering Organ and Tissue Donation in Australia<sup>1</sup>
- OTA Best Practice Guideline for Donation After Circulatory Determination of Death (DCDD) in Australia<sup>2</sup>
- The Australian and New Zealand Intensive Care Society (ANZICS) Statement on Death and Organ Donation<sup>3</sup>
- ACCCN National Position Statement on Adult End-of-Life Care in Critical Care<sup>4</sup>
- Australian Commission on Safety and Quality in Health Care (ACSQHC) National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care<sup>5</sup>
- ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care<sup>6</sup>
- Australian Nursing and Midwifery Federation (ANMF) Position Statement on Organ and Tissue Donation for Transplantation<sup>7</sup>

Additional related guidelines pertaining specifically to organ transplantation in Australia include:

- Ethical Guidelines for Organ Transplantation from Deceased Donors<sup>8</sup>
- Clinical Guidelines for Organ Transplantation from Deceased Donors<sup>9</sup>

These documents provide detail on determination of death, organ and tissue donation after death,<sup>1,3</sup> organ donor and recipient eligibility, and organ-specific guidelines,<sup>9</sup> ethical guidelines,<sup>8</sup> and best practice in organ donation and patient and family-centred care.<sup>1,3</sup>

The Best Practice guideline from the OTA provides an approach for referral of potential organ and tissue donors, and for discussing organ donation with families.<sup>1</sup> This guideline includes that (i) the goal of donation conversations is to reach a decision that is concordant with the patient's wishes (if known) and one that the family will be comfortable with for years to come; (ii) supporting families during their time of loss and grief is an important part of care provision; (iii) clinicians have a responsibility in supporting informed decision making about end-of-life care and organ and tissue donation; (iv) clinicians who are skilled communicators, knowledgeable about donation and who have received specific training in this area should lead organ donation conversations; and (v) organ donation conversations should be collaborative, tailored to the family circumstances and involve the Senior Treating Doctor, DonateLife Donation Specialist Nurse and other support staff.<sup>1</sup>

**DonateLife Donation Specialist Nurses** are central to organ donation. They receive advanced education and training that equips them to sensitively introduce the topic and provide families with detailed, accurate information about the organ donation process.<sup>1</sup> DonateLife Donation Specialist Nurses may also explore what organ donation means for a family, and ensure family engagement tailored to family needs and circumstances, thereby supporting informed decision-making.<sup>1</sup>

## PURPOSE

This *ACCCN Position Statement on Organ and Tissue Donation* is designed to complement and build upon the existing resources by describing the role, obligations, expectations, and opportunities for critical care nurses in supporting organ and tissue donation, underpinned by Australian research evidence, and guidance from relevant Australian peak bodies.

## SUMMARY OF AUSTRALIAN RESEARCH EVIDENCE

Thirteen Australian studies, published between 2014 and 2022 provide empirical evidence about routine referral, the timing and approach to organ

donation conversations, family perspectives, caring for family, supporting clinicians and the importance of separating conversations and decision-making about death from organ donation.

In Australia, public attitudes towards death indicate that death is not just a biological process, but also a broader sociocultural concept, encompassing legal, cultural, spiritual and religious considerations.<sup>10</sup> A survey of the Australian public on attitudes towards organ donation indicated that the majority of people have a relatively pragmatic view focused on the potential benefit of organ donation, rather than the point of death itself.<sup>10</sup> As such, organ donation is a well-established clinical practice, largely supported by the Australian community.<sup>11</sup> Yet rates of organ donation remain limited by family consent.<sup>12</sup> Family decision-making is influenced by multiple factors including whether the patient was a registered donor, the context of the illness, knowledge of the patient's prior expressed wishes, cultural and religious factors.<sup>13</sup>

### *Separating death from organ donation*

For families, separating discussions about end-of-life care and death, from the topic of organ donation is important. This separation has been shown to increase organ donation consent rates.<sup>13</sup> Evidence from a national study involving family members suggested this was because family members had sufficient time to comprehend the prognosis, and accept the patient was going to die.<sup>14</sup> Several Australian studies also recommend routine referral of all dying patients admitted to critical care for assessment of suitability for organ donation by organ donation specialists.<sup>15-20</sup> Routine referral was thought to normalise the process for clinicians,<sup>16, 17</sup> act as a reminder for organ donation to be considered and minimise missed opportunities.<sup>17</sup> Routine referral may also alleviate clinician guilt<sup>16</sup> and take away the burden of ethical responsibility from any one clinician.<sup>17</sup>

### *Timing and approach to organ donation conversations*

Organ donation conversations are complex, and take place in environments which, for families,

are equally complex and unfamiliar.<sup>21</sup> When and where the topic of organ donation is first raised is an important consideration.<sup>13, 14</sup> Providing time and a private space for family members to gather, discuss donation, consider the patient's wishes and values, and make a decision that is right for them is essential.<sup>14</sup> Whilst there is some evidence to support that organ donation conversations should occur as soon as a decision is made to transition to end-of-life care,<sup>15</sup> other research suggests there is no clear consensus about when to initiate a first conversation about organ donation.<sup>12</sup> The amount, complexity and rapidity of information, and the short time with which to digest it, is a considerable impediment to organ donation decision-making.<sup>12</sup> When the topic of organ donation is raised, family members need clear communication, information,<sup>12</sup> and opportunities to ask questions.<sup>14</sup>

The approach to organ donation conversations must be founded on trust, open and honest communication,<sup>11</sup> respect, and autonomy.<sup>10</sup> Families want conversations to be handled with sensitivity and compassion, and for information to be presented in layman's terms, tailored to meet their individual needs.<sup>14, 21</sup> Organ donation conversations are also less complicated when the approach is made by clinicians with specialised communication training,<sup>21</sup> who are well-informed in organ donation processes, the individual patient situation, and present a unified front, thereby giving family members confidence in the donation process.<sup>16</sup> Evidence from several studies also demonstrated that organ donation consent rates were likely to be higher with more family conversations,<sup>13</sup> when a DonateLife Donation Specialist nurse was involved.<sup>14, 22</sup>

#### *Family perspectives*

Several factors influence a family's response when organ donation is raised. How the topic is raised, the context, the unfamiliar environment and individual beliefs about organ donation, may negatively impact a decision to donate.<sup>23</sup> Not knowing the person's wishes is known to make it harder for families to decide, and knowing that organ donation was concordant with a patient's previously expressed wishes can be a comfort.<sup>17</sup> A national study of family's perceptions of organ

and tissue donation also demonstrated that most donor families saw organ donation as a chance for something positive to come out of a personal tragedy, giving some meaning to their loss.<sup>14</sup>

#### *Caring for families*

Sensitive consideration of the family needs, including their most basic needs for food, water, information and being close to their relative, are fundamental to demonstrating support.<sup>20</sup> Maintaining high-quality care, and ensuring the patient is clean and looks comfortable, demonstrates caring and respect.<sup>20</sup> Family members want to know that clinicians continue to care and respect the patient,<sup>14</sup> in life and after death.<sup>20</sup>

There is some evidence that routine family follow up and bereavement support is integral to family care, irrespective of organ donation status.<sup>19</sup> Bereavement support can include practical information about the arrangements commonly required after death in hospital, and information about local bereavement services.<sup>19</sup> A structured approach to bereavement follow-up in collaboration with donation specialists has been shown to be beneficial.<sup>19</sup>

#### *Supporting critical care clinicians*

Critical care clinicians are integral to the organ donation process, reducing the burden of harm and increasing comfort.<sup>11</sup> Yet evidence suggests that clinicians, particularly those early in their career, can find it difficult transitioning from a role of primarily sustaining life to preparing for organ donation.<sup>17</sup> This cognitive dissonance can be overcome by supportive leadership and culture, a reliance on policy and protocols,<sup>17</sup> and an emphasis on end-of-life care quality as the evaluation metric, rather than organ donation consent rates.<sup>19</sup>

In terms of education, a pilot study of a national model for organ donation requests in Australia demonstrated that specialised communication training improved organ donation consent rates.<sup>21</sup> Other researchers advocate for targeted education for critical care clinicians in relation to donation after circulatory death (DCD),<sup>17</sup> to address perceptions that DCD is more complicated and counter clinician hesitance.<sup>16</sup> Irrespective of the outcome of organ donation

conversations, ongoing education and timely support for clinicians, before, during and after organ donation conversations is essential, particularly for those who encounter the event infrequently.<sup>15</sup>

### POSITION STATEMENT

The ACCCN's position is that every critical care nurse can make a contribution to organ and tissue donation.

#### ***Critical Care Units should***

- Follow best practice for organ donation as specified by relevant Australian peak bodies<sup>1-9</sup>
- Ensure hospital and ICU policies and procedures reflect best practice, and include:
  - Acknowledging the intersect between the potential for organ donation and broader end-of-life care practice, with bereavement support for families a core feature<sup>13, 19</sup>
  - That conversations about end-of-life care are best separated from organ donation conversations<sup>3, 13</sup>
  - Routine referral of all dying patients to organ donation specialists for assessment of suitability for organ donation<sup>15-20</sup>
  - The expectation of detailed documentation of discussions with families, including who was involved, in the patient's medical record<sup>24</sup>
- Optimise privacy for patients who are potential organ donors and their families<sup>14</sup> through the use of single patient rooms (where available)
- Provide a private meeting room (where available) for family meetings and organ donation conversations.<sup>20</sup>

#### ***Critical Care Unit Leaders (such as managers, liaison nurses and educators) should***

- Acknowledge that each critical care nurses' response to dying and/or organ donation is unique, underpinned by sociocultural and contextual factors,<sup>23</sup> religion and culture,<sup>4</sup>

irrespective of training, experience or seniority

- Ensure critical care nurses caring for a potential or actual organ donor have adequate clinical support from senior nursing staff, such as a nurse-in-charge or team leader<sup>1</sup>
- Respect a critical care nurses' right to refuse to participate in care or any procedure which they judge, on the basis of religious, moral or ethical beliefs, to be unacceptable<sup>7</sup>
- Facilitate critical care nurses' access to organ donation education and training<sup>13</sup>
- Liaise with organ donation specialists in the provision of bereavement support for all family members of patients who die<sup>19</sup>
- Encourage timely multidisciplinary in-house debriefing for all potential or actual organ donation cases, where requested or as a matter of routine<sup>3</sup>
- Encourage critical care nurses to seek individual support from staff leading organ donation practices, via psychological support services funded by their hospital or health service<sup>24</sup> or their own resources/network, and undertake self-care activities<sup>4, 25</sup>

#### ***Critical care nurses should***

- Be familiar with local organ donation policies and procedures, and the other organ donation and end-of-life guidelines and position statements already available<sup>1-9</sup>
- Seek professional development opportunities about organ donation<sup>1</sup>
- Exercise their right to refuse to participate in care or any procedure which they judge, on the basis of religious, moral or ethical beliefs, to be unacceptable<sup>7</sup>
- Seek to understand and comprehensively document patient and family member preferences for end-of-life care including care after death<sup>4</sup>
- Provide high-quality end-of-life care for the patient and family at all times, irrespective of organ donor status<sup>4, 5</sup>

- Seek to understand the family unit, role of family members, their values, beliefs, cultural and communication preferences, and clearly document in the patient's medical record<sup>4</sup>
- Attend and participate in family meetings so that family participation in conversations and decision-making is supported, according to family member preference<sup>4</sup> and contextual factors<sup>23</sup>
- Facilitate/advocate for a single room (where available) to enable family to spend time with a potential organ donor, and to optimise privacy for family members<sup>4, 14, 20</sup>
- In addition to the bereavement support provided by organ donation specialists,<sup>1</sup> provide written information about the immediate next steps after a death
- Participate in formal and informal debriefing as appropriate, and commit to prioritising self-care<sup>1, 4</sup>

## KEY DEFINITIONS

**Critical Care Nurse** – used to refer to all registered nurses working in critical care settings, with or without specialist critical care postgraduate education, and in any role, who may be directly or indirectly involved in the organ donation process.

**Deceased donor** – A person declared dead by established medical criteria, from whom organs and/or tissues are recovered for the purposes of transplanting to another person, the recipient. The two pathways to organ donation are donation after (i) brain and (ii) circulatory death.<sup>8</sup>

**DonateLife Donation Specialist Nurse** – also known as Donation Specialist Nurse Coordinator and Donation Specialist Coordinator.<sup>1</sup>

**Family** – can include those closest to the person in knowledge, care and affection, including the immediate biological family, family of acquisition (related by marriage or contract), family of choice (not related biologically or by marriage or contract) and friends.<sup>24</sup>

## REFERENCES

1. Organ and Tissue Authority. *Best Practice Guideline for Offering Organ and Tissue Donation in Australia*. April 2021. Barton ACT: OTA.
2. Organ and Tissue Authority. *Best Practice Guideline for Donation after Circulatory Determination of Death (DCDD) in Australia*. October 2021. Donate Life.
3. Australian and New Zealand Intensive Care Society. *The Statement on Death and Organ Donation*. 2021. Camberwell VIC: ANZICS.
4. Bloomer MJ, Ranse K, et al. A national Position Statement on adult end-of-life care in critical care. *Aust Crit Care* 2022; 35: 480-487. DOI: 10.1016/j.aucc.2021.06.006.
5. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care. Canberra: ACSQHC, 2015.
6. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential Elements for Safe and High Quality Paediatric End-of-Life Care. Canberra: ACSQHC, 2016.
7. Australian Nursing and Midwifery Federation. *ANMF Position Statement - Organ and Tissue Donation for Transplantation*. 2021. Melbourne: ANMF.
8. National Health and Medical Research Council. *Ethical Guidelines for Organ Transplantation from Deceased Donors*. 2016. Canberra: NHMRC.
9. The Transplantation Society of Australia and New Zealand. *Clinical Guidelines for Organ Transplantation from Deceased Donors*. 2022. TSANZ.
10. O'Leary MJ, Skowronski G, et al. Death determination, organ donation and the importance of the Dead Donor Rule following withdrawal of life-sustaining treatment: a survey of community opinions. *Int Med J* 2022; 52: 238-248. DOI: 10.1111/imj.15221.
11. Coleman NL and Bonner A. Exploring Australian intensive care physicians clinical judgement during Donation after Cardiac Death: An exploratory qualitative study. *Aust Crit Care* 2014; 27: 172-176. DOI: 10.1016/j.aucc.2014.04.007.



12. Neate S, Marck C, et al. Understanding Australian families' organ donation decisions. *Anaesth Intens Care* 2015; 43: 42-50.
13. Potter JE, Perry L, et al. Communication with families regarding organ and tissue donation after death in intensive care (COMFORT): A multicentre before-and-after study. *Crit Care Resusc* 2018; 20: 268-276.
14. Proof Research and Organ and Tissue Authority. *National Study of Family Experiences of Organ and Tissue Donation. Wave 4 Experiences in 2016 and 2017 - Research Report*. 2020. Canberra ACT: OTA.
15. Cignarella A, Redley B, et al. Organ donation within the intensive care unit: A retrospective audit. *Aust Crit Care* 2020; 33: 167-174. DOI: 10.1016/j.aucc.2018.12.006.
16. Milross L, O'Donnell T, et al. Perceptions held by healthcare professionals concerning organ donation after circulatory death in an Australian intensive care unit without a local thoracic transplant service: A descriptive exploratory study. *Aust Crit Care* 2022; 35: 430-437. DOI: 10.1016/j.aucc.2021.06.013.
17. Milross LA, O'Donnell TG, et al. Exploring staff perceptions of organ donation after circulatory death. *Aust Crit Care* 2020; 33: 175-180. DOI: 10.1016/j.aucc.2019.05.001.
18. Rakhra SS, Opdam HI, et al. Untapped potential in Australian hospitals for organ donation after circulatory death. *Med J Aust* 2017; 207: 294-301. DOI: 10.5694/mja16.01405.
19. Yeo NYK, Reddi B, et al. Collaboration between the intensive care unit and organ donation agency to achieve routine consideration of organ donation and comprehensive bereavement follow-up: an improvement project in a quaternary Australian hospital. *Aust Health Rev* 2021; 45: 124-131. DOI: 10.1071/AH20005.
20. Northam H, Cruickshank M, et al. "This is how it's got to happen". *Transplant J Australas* 2014; 23: 9-13.
21. Lewis VJ, White VM, et al. Towards a national model for organ donation requests in Australia: evaluation of a pilot model. *Crit Care Resusc* 2015; 17: 233-238.
22. Radford S, D'Costa R, et al. The impact of organ donation specialists on consent rate in challenging organ donation conversations. *Crit Care Resusc* 2020; 22: 297-302.
23. Moloney G, Sutherland M, et al. Don't forget the context when you are talking about organ donation: Social representations, shared mood and behaviour. *J Community Appl Soc Psychol* 2020; 30: 645-659. DOI: 10.1002/casp.2474.
24. National Health and Medical Research Council. *Ethical Guidelines for the Care of People in Post-Coma Unresponsiveness (Vegetative State) or a Minimally Responsive State*. 2008. Canberra ACT: NHMRC.
25. Bloomer MJ, Ranse K, et al. "Time and life is fragile": An integrative review of nurses' experiences after patient death in adult critical care. *Aust Crit Care* 2022. DOI: 10.1016/j.aucc.2022.09.008.