Australian Government
Organ and Tissue Authority

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Best Practice Guideline for Offering Organ and Tissue Donation in Australia

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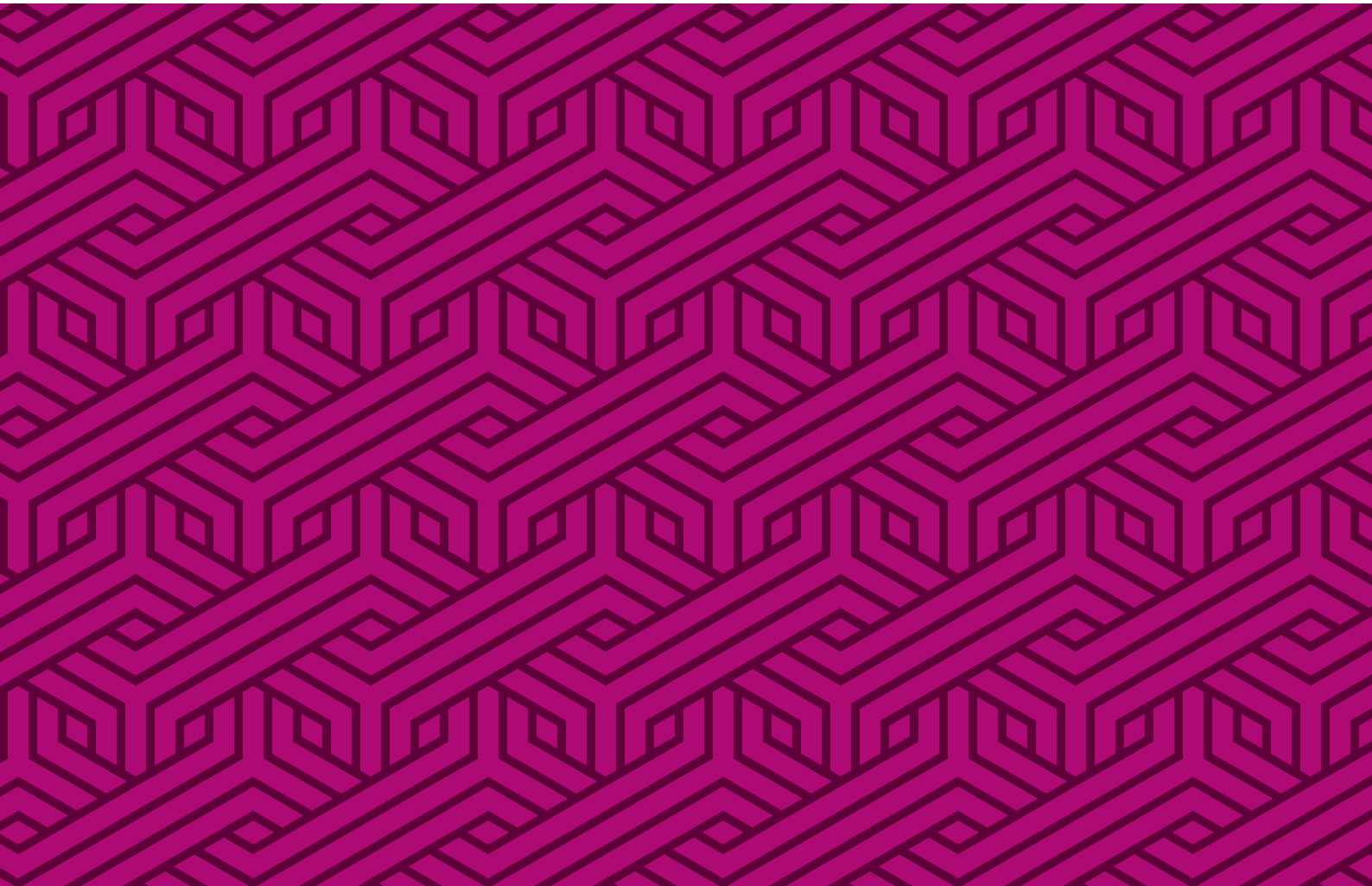

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Foreword

This is the second edition of the *Best Practice Guideline for Offering Organ and Tissue Donation in Australia* (the Guideline). Evolution of the Guideline is imperative to maintain currency and to continue to deliver a best practice approach in supporting families to make an informed decision about donation. A key component of this update is to incorporate the requirement for referral of all patients with planned end-of-life care in intensive care units and emergency departments to DonateLife so that the possibility of organ and tissue donation can be explored, and the routine involvement of a Donation Specialist Nurse in family donation conversations.

The opportunity for organ donation is an infrequent event. It comes at an intensely emotional time for families and can be challenging for all involved. Specific knowledge and expertise is required to support families during this time and as they consider making a decision about donation. It is critical that information is provided in a clear and sensitive manner and that it is tailored to the needs of individual families. Excellent care and communication is a central part of supporting families during the end-of-life experience of a family member. Evidence suggests that the care families receive and the quality of the communication with staff, including when discussing donation, influences their satisfaction with the process as well as consent rates for donation.

This Guideline recognises the role of many health professionals involved in supporting families during this time. The Intensivist (or Senior Treating Doctor) manages the end-of-life care of a patient and guides their family through this process, with Critical Care Nurses playing an important role in patient care and family support. The guideline is designed to support all health professionals involved in the family donation conversation and to provide information about the role the Donation Specialist can have in these conversations.

The guidance provided in this document has the goal of ensuring families are supported in making an informed decision about donation. This informed decision making should take into consideration their loved one's wishes if known, their own views and preferences, along with accurate information about donation and what it can mean for themselves and for others. The Guideline is part of a key strategy of the Australian Organ and Tissue Authority (OTA) and DonateLife Network to provide better care and support for families who are considering the possibility of donation for their loved one and to provide every family of a potential donor access to a Donation Specialist during the end-of-life care of their family member.

We thank the families that we have had the privilege to work with and who continue to be our most important teachers. We also thank the Australian and New Zealand Intensive Care Society (ANZICS), College of Intensive Care Medicine of Australia and New Zealand (CICM), Australasian College of Emergency Medicine (ACEM) and the Australian College of Critical Care Nurses (ACCCN) for their contributions and support of the Guideline.

Both ANZICS and CICM strongly recommend that intensivists involved in organ donation complete the core Family Donation Conversation (cFDC) workshop, which includes content consistent with this Guideline. This participation recognises the leadership role of the intensivist in end-of-life care and their role in the collaborative approach in offering donation to families.

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Best Practice Guideline for Offering Organ and Tissue Donation in Australia

Element 1

Routine referral to DonateLife

Patients in the Intensive Care Unit (ICU) and Emergency Department (ED) for whom there is medical consensus for planned end-of-life care are referred to DonateLife (Agency or hospital Donation Specialist staff). Referral enables DonateLife to assess suitability for donation, check the patient's registration status on the Australian Organ Donor Register (AODR), and facilitates the involvement of a Donation Specialist Nurse* to support planning and family communications.

Element 2

Communicating end-of-life

The family are informed and understand that the patient has died, or that death is expected following the withdrawal of treatment.

Element 3

Planning the approach

A planning meeting occurs prior to the family donation conversation attended by the Senior Treating Doctor^, the Donation Specialist Nurse, relevant Critical Care Nurse/s and other appropriate staff. The discussion will include sharing information about the patient's AODR registration status and planning the roles each staff member will undertake during the family donation discussion.

Element 4

Discussing donation

Donation is discussed with the family in a collaborative approach involving the Senior Treating Doctor and the Donation Specialist Nurse. Information about donation, including the patient's registration status on the AODR, is shared to assist the family in reaching a fully informed decision about donation.

Element 5

Reviewing practice

A team review occurs after each family donation conversation process to provide an opportunity to reflect upon and improve practice.

* The term 'Donation Specialist Nurse' encompasses the roles of Donation Specialist Nurse, Donation Specialist Coordinator and Donation Specialist Nurse Coordinator.

^ The term 'Senior Treating Doctor' will be the treating Intensivist or Intensive Care Advanced Trainee in most cases or, if the patient is in the ED, the treating ED Physician or ED Advanced Trainee.

1 Introduction

1.1 Purpose and scope

The purpose of the *Best Practice Guideline for Offering Organ and Tissue Donation in Australia* (the Guideline) is to outline the best practice approach for referral of potential organ and tissue donors and discussing donation with their families. This approach is consistent with similar guidance in the United Kingdom, Canada and Spain.[1–3]

It outlines the elements of the approach and emphasises key principles. Aspects covered include those of routine referral to DonateLife, checking the AODR, planning for family communication, the importance of a collaborative approach, and the requirement for involvement of a Donation Specialist Nurse.

It is appreciated that the individual aspects of each patient's death and their family's circumstances will influence the timing and approach to discussing donation with the family. A flexible approach that is tailored to the specific circumstances is recommended with consistency in applying the principles and key elements in this Guideline where possible.

The Guideline applies to all patients at medical consensus of end-of-life to ensure that organ and tissue donation is considered at the right time. The Guideline does not address the communication approach for eye and tissue only donation, which can occur in a broader range of contexts including in persons dying outside of ICUs and EDs.

The Guideline does not provide clinical advice on assessing medical suitability of potential donors, donor management, or the organ and tissue donation process. These aspects should be managed in consultation with DonateLife and in accordance with the relevant professional and ethical standards including the *Australian and New Zealand Intensive Care Society (ANZICS) Statement on Death and Organ Donation* and the *Transplantation Society of Australia and New Zealand (TSANZ) Clinical Guidelines for Organ Transplantation from Deceased Donors*.[4,5]

A glossary of key terms used in this document is provided at **Appendix A**.

1.2 Evidence base

The evidence base in this area relies on comparative and observational studies. Randomised controlled trials are very few. While there are areas of uncertainty, the published literature is suggestive that family satisfaction and consent rates are subject to influence by a variety of factors. These include the perceived quality of medical care, provision of adequate information, the process of offering donation and the training of the personnel leading this communication.[6,7]

Elements of this Guideline are formally monitored through the regular collection and analysis of DonateLife Audit data. The biennial National Donor Family Study[8] also provides valuable evidence for the ongoing review and enhancement of the care and support provided to families before, during and after donation.

The DonateLife Audit data shows a positive association with higher rates of donor identification and consent when the key elements of the Guideline are implemented. This includes routine referral to DonateLife of ICU and ED patients where end-of-life care is planned, checking of the patient's AODR status before donation is discussed, team planning before the family donation discussion, the involvement of Donation Specialist Nurses in family donation conversations, and team debriefing to review donation discussions.

In particular, the data from the DonateLife Audit highlights the importance of the role of the Donation Specialist Nurse in family donation conversations using a collaborative approach with the Senior Treating Doctor. Data consistently demonstrates that when donation discussions with families include a Donation Specialist Nurse, consent to donation is considerably higher compared to when no Donation Specialist was involved.

These findings are further supported by a study that examined the impact of DonateLife Donation Specialists (nursing or medical) on the consent rate in 'challenging' organ donation conversations. These are circumstances associated with a lower level of patient/family support for or awareness of donation, as characterised by the patient not being registered on the AODR and staff raising the topic of donation rather than family. The study reported the consent rate to be significantly higher

with involvement of DonateLife Donation Specialist staff (54%) as compared with other trained staff (33%) and untrained staff (28%).[9] Training was defined as having completed the two-day Family Donation Conversation core workshop. The level of experience and professional training of staff raising donation is regularly reported in the literature as being a key factor in the effectiveness of donation discussions.[1,2,6,10,11] The quality of the donation conversation and information provided to families has also been shown to impact on family decision making.[6,12]

1.3 Collaborative approach for offering organ and tissue donation

The Guideline recognises that offering organ and tissue donation should be considered a routine part of end-of-life care with the process best served by a collaborative approach involving the Donation Specialist Nurse and Senior Treating Doctor, supported by Critical Care Nurse/s and other members of the healthcare team.

The Senior Treating Doctor has responsibility for managing the end-of-life care of a patient and leading the end-of-life communication with their family. Critical Care Nurses support the process through reinforcing the medical information conveyed, often having developed rapport with the family while providing care to their relative. Consideration should be given to other staff who can assist in these conversations e.g. social workers, Aboriginal or Torres Strait Islander Liaison Officers and interpreters.

The Donation Specialist Nurse role is central to the family donation conversation. They provide detailed and accurate information about donation and have the skills to sensitively introduce the topic of donation and openly explore what donation may mean for a family, thereby assisting them in making a fully informed decision.

Specifically, Donation Specialist Nurses:

- have specialist knowledge related to donation and transplantation and can provide detailed and accurate information about the possibility and process of donation
- have access to real-time information about donation suitability for transplantation
- undergo specific, regular and focused training in communicating with families about donation and are regularly involved in donation conversations
- can provide support and guidance to hospital staff.

Donation Specialist Doctors may also assist in instances where a Donation Specialist Nurse is not available. Donation Specialist Doctors, through their donation role, have specialist knowledge about organ and tissue donation and may be able to assist in instances where a Donation Specialist Nurse is not available. In some regional and remote hospitals, local hospital guidelines will provide advice regarding other hospital-based staff who have been identified to assist in donation conversations. These staff should be called upon when a Donation Specialist Nurse or Donation Specialist Doctor is not available (following discussions with the DonateLife Agency). The DonateLife Agency will be able to provide telephone support to regional and remote hospital staff that can assist when undertaking donation discussions with families.

2 The Best Practice Guideline for Offering Organ and Tissue Donation in Australia

2.1 Guiding principles

The Guideline is underpinned by the following key guiding principles:

- The goal of discussions about donation is for a decision to be aligned with the patient's wishes (if known) and one that the family will be comfortable with for years to come.
- Supporting families during their time of loss and grief is an important part of the provision of care.
- Health professionals have a responsibility in supporting fully informed decision making for patients and their families in all areas of health care including end-of-life care and choices about organ and tissue donation.
- Donation is discussed with families of potential donors by staff who are skilled communicators, knowledgeable about donation and who have received specific training in this area.
- A collaborative approach involving the Senior Treating Doctor, Donation Specialist Nurse and other support staff, and that is tailored to the family circumstances, is critical in the planning, conduct and evaluation of all family donation conversations.

2.2 Key elements of the Guideline

A summary of the five key elements of the Guideline are on page 3 of this guidance document and the checklist at **Appendix B**. These elements are also summarised as:

1. Routine referral to DonateLife
2. Communicating end-of-life
3. Planning the approach
4. Discussing donation
5. Reviewing practice.

Routine referral to DonateLife	Communicating end-of-life	Planning the approach	Discussing donation	Reviewing practice
AODR check	Senior Treating Doctor informs family of death or expected death following withdrawal of treatment	Planning meeting between Senior Treating Doctor, Donation Specialist Nurse, Critical Care Nurse and other healthcare staff	Donation Specialist Nurse and Senior Treating Doctor collaboratively offer donation to the family	Team review
Suitability assessment	Family understands death or expected death following withdrawal of treatment	Family donation conversation plan agreed	AODR status shared with family	Led by Donation Specialist Nurse in collaboration with Senior Treating Doctor
Planning for Donation Specialist Nurse involvement in end-of-life communication and the family donation conversation	Discussions about death and donation are separated			

Element 1
Routine referral to DonateLife

Patients in the Intensive Care Unit (ICU) and Emergency Department (ED) for whom there is medical consensus for planned end-of-life care are referred to DonateLife (Agency or hospital Donation Specialist staff). Referral enables DonateLife to assess suitability for donation, check the patient's registration status on the Australian Organ Donor Register (AODR), and facilitates the involvement of a Donation Specialist Nurse to support planning and family communications.[6,10,13]

The treating clinical team should contact the DonateLife hospital staff or DonateLife Agency at the earliest opportunity once there is medical consensus that ongoing treatment is not in the patient's interests and the patient will be transitioning to end-of-life care. This ensures all donation opportunities are identified and assessed by DonateLife to determine suitability for organ donation with additional expert donation and transplantation medical advice sought if required. Advice regarding eye and tissue donation suitability can also be provided, in consultation with eye and tissue banks as appropriate.

The referral facilitates the timely involvement of a Donation Specialist Nurse to check the AODR and, if required, advise on the process of donation and plan for family communication. DonateLife can also provide advice, if needed, on death determination using either circulatory or neurological criteria and on donor physiological management.

The Donation Specialist Nurse will ensure that the AODR has been checked prior to the end-of-life conversation and this information will be shared with the treating clinical team. Having this information during the end-of-life conversation is helpful if the family unexpectedly raises organ donation.[14–16] The Donation Specialist Nurse can assist the treating medical team in planning family communication about end-of-life care and how to best respond if the family raises donation. It may also be helpful to include the Donation Specialist Nurse in the end-of- life conversation to assist and support the family if they do raise donation at this time.

A registered 'no' on the AODR does not preclude donation being raised with the family. Similar to if the patient had registered 'yes', the family donation conversation will seek to confirm whether the family were aware of their relative's donation intentions and whether they had changed their decision since registering on the AODR.

If a patient is deemed medically unsuitable for donation following referral to DonateLife, this outcome can be communicated to the family in order to avoid any future doubt or regret that donation was not explored at the time. This may be particularly important if the person had registered to donate on the AODR and/or previously expressed preferences about donation.

End-of-life care and the family donation conversation are usually best managed in the ICU. For potential donors in the ED, referral to the ICU should occur according to hospital protocols and practices. If this is not possible, it may be necessary to undertake all of the end-of-life care communication with the family within the ED including offering donation in a collaborative approach with a Donation Specialist Nurse.

Roles and responsibilities

Senior Treating Doctor	Refers patients in the ICU or ED with planned end-of-life care to Donation Specialist staff in the hospital or DonateLife Agency
	Plans for Donation Specialist Nurse involvement
DonateLife	Obtains status of patient's registration on the AODR prior to end-of-life conversations
	Provides advice on donor suitability and the donation process
	Plans for Donation Specialist Nurse involvement in family conversations and the donation process

Element 2
Communicating end-of-life

The family are informed and understand that the patient has died, or that death is expected following the withdrawal of treatment.

The Senior Treating Doctor discusses the suspected neurological status consistent with death, the conduct and outcome of examinations to determine neurological death or the planned withdrawal of cardio-respiratory support and expected death. It is the Senior Treating Doctor's responsibility to ensure the family understands that death has or is expected to occur before organ and tissue donation is discussed.

It is important the family understands and accepts that the patient has died or that death is expected before they are asked to consider organ and tissue donation.[4,12] It is generally advisable, if possible, to separate the end-of-life conversation from the donation conversation. A break assists in ensuring that all family members have reached the same point of understanding regarding the end-of-life discussions and enables families to contact other family members and friends, attend to their personal needs, or spend time at the bedside with the patient. A break also provides the treating clinical team with the opportunity to meet with the Donation Specialist Nurse (if this has not already occurred) and to plan next steps including the family donation conversation. The Donation Specialist Nurse can provide advice on how to sensitively separate these topics or defer discussion about donation if the family raise donation early in the process.

The Senior Treating Doctor may choose to invite the Donation Specialist Nurse to attend the family meeting regarding neurological determination of death or treatment withdrawal in order to support the clinical team and the family. This involvement provides the Donation Specialist Nurse with the opportunity to develop rapport with the family, observe family dynamics and be present to offer information about donation if the family initiate and are ready to discuss donation at this meeting.

If the family raise donation early or during the end-of-life conversation, and a Donation Specialist Nurse is not present, it is recommended the Senior Treating Doctor acknowledge the family's request and advise that it would be preferable to defer the discussion. This enables the involvement of a Donation Specialist Nurse who will be able to provide accurate and more detailed information about donation. Once in attendance, and at a time that meets the family's needs, the Donation Specialist Nurse and Senior Treating Doctor can together continue the discussion about donation. If a Donation Specialist Nurse or Donation Specialist Doctor are not available to attend, then the local DonateLife Agency and hospital guidelines should be followed regarding who is the most suitable person to be involved in donation conversations.

Roles and responsibilities

Senior Treating Doctor	Considers inviting Donation Specialist Nurse into end-of-life meeting
	Discusses patient care and prognosis with family and ensures there is an understanding of death
	Separates conversations about death and donation to create time and space for family
Donation Specialist Nurse	Provides advice to treating clinical team in separating death and donation conversations
	Attends family meeting about death when invited

Element 3
Planning the approach

A planning meeting occurs prior to the family donation conversation attended by the Senior Treating Doctor, the Donation Specialist Nurse, relevant Critical Care Nurse/s and other appropriate staff. The discussion will include sharing information about the patient's AODR registration status and planning the roles each staff member will undertake during the family donation discussion.

A multidisciplinary team planning meeting should occur including all professionals who will be involved in the first family donation conversation and others who may have important information to share about the patient and/or family. This includes the Senior Treating Doctor, the Donation Specialist Nurse, Critical Care Nurse/s (e.g. bedside nurse, and/or nurse in charge) and other appropriate staff or personnel as required (e.g. interpreter, social worker, pastoral care, Aboriginal or Torres Strait Islander Liaison Officer, or religious leader).

Planning will include determining which professionals will be involved in the family donation conversation and agreeing the roles and responsibilities of all involved. The Donation Specialist Nurse and Senior Treating Doctor will agree the way the Donation Specialist Nurse will be introduced to the family (if not already introduced), how the opportunity will be created so they can develop rapport with the family, how the conversation will transition to raise donation, and how information about the patient's AODR registration status will be shared with the family.

The collaborative nature of the planning meeting should also include identifying which components of the conversation the Senior Treating Doctor or the Donation Specialist Nurse are best placed to undertake or respond to, based on the expertise, recency of training and experience regarding donation discussions held by each person. Both people should also view the collaborative discussion as a chance to support each other and as a possible training opportunity.

In this planning meeting the Donation Specialist Nurse, if unfamiliar with the patient and family, will seek to understand previous events and the family's experience since admission. This includes gathering relevant clinical and social patient and family information, and confirming that the family understands death has occurred or is expected to occur.

Planning also involves determining the best time for the family donation conversation and ensuring a suitable private and comfortable location for the meeting to be held. A family spokesperson should be informed that the discussion will involve the consideration of some important decisions and then consulted to identify which family members will be present.

The Donation Specialist Nurse will also discuss the plan for a team review after the family donation conversation and seek agreement on the way this review should occur (guidance on team review is in element 5).

Roles and responsibilities

Treating clinical team and support staff	Actively participates in the planning meeting
	Shares relevant clinical and social patient and family information
	Agrees roles, responsibilites and approach for the family donation conversation
Donation Specialist Nurse	Actively participates in the planning meeting
	Shares patient AODR registration status information
	Agrees roles, responsibilities and approach for the family donation conversation
	Confirms plan for team review after the family donation conversation

Element 4
Discussing donation

Donation is discussed with the family in a collaborative approach involving the Senior Treating Doctor and the Donation Specialist Nurse. Information about donation, including the patient's registration status on the AODR, is shared to assist the family in reaching a fully informed decision about donation.

A collaborative approach requires involvement of a Donation Specialist Nurse in every conversation when donation is discussed with the family of a potential organ donor. With the expertise of both the Senior Treating Doctor and Donation Specialist Nurse, a collaborative approach ensures that families are provided with support and donation expertise to deliver accurate information to the family in a sensitive and respectful manner that is tailored to their individual circumstances.

It is important that the transition to the topic of donation occurs in a manner that facilitates the open sharing of information and further explores the patient's and family members' values, beliefs and preferences regarding donation.

The Donation Specialist Nurse is best placed to share factual information about organ and tissue donation, what it may mean in terms of enabling transplantation, their relative's AODR registration status, the donation process and to answer any questions that the family may have in relation to these aspects.

The collaborative team will sensitively support the family and assist them in making a fully informed decision about donation. They will explore a family's decision-making process to ensure that it is based on accurate information and that any decision is free of misconceptions. The family will be assured that, whatever they decide, their decision will be supported. The decision-making process can sometimes require a series of discussions over time.

The Senior Treating Doctor may choose to leave the meeting when comfortable to do so and the Donation Specialist Nurse will continue to support the family. This ongoing support may involve the Donation Specialist Nurse answering any questions the family may have about donation and providing further information about the donation process. Once the family have reached a decision, the next steps will be explained and the family will continue to be supported throughout the process, irrespective of their decision.

Roles and responsibilities

Treating clinical team	Senior Treating Doctor commences the meeting, introduces new staff and confirms family understanding of death
	Works in collaboration with the Donation Specialist Nurse in the family donation conversation, as agreed in the planning meeting
	Provides further information as required to the family
	Provides ongoing support to family
Donation Specialist Nurse	Offers donation to family in collaboration with the Senior Treating Doctor
	Provides the family with factual information about donation and transplantation, including patient AODR status, and answers any questions
	Supports the family in their decision-making
	If the family consents, undertakes next steps in the donation process

Element 5
Reviewing practice

A team review occurs after each family donation conversation process to provide an opportunity to reflect upon and improve practice.

A brief review of the family donation conversation provides an opportunity for participants to reflect upon and evaluate how the process went. The Donation Specialist Nurse is responsible for leading a review meeting and at the earlier planning meeting should gain agreement from all staff participating in the family donation conversation to attend this review (element 3).

The review should take place soon after the family donation conversation has concluded where possible. It is an opportunity for attendees to constructively provide feedback on what went well and what may have been done better or differently. The review should discuss whether the principles and elements of the Guideline were followed.

The most important outcome of the family donation conversation is that the family reach a decision that is right for them. An ongoing study[8] commissioned by the Organ and Tissue Authority examines family experiences of organ and tissue donation for transplantation. The insights gained from this study provide valuable evidence for the ongoing review and enhancement of the care and support provided to families before, during and after donation.

Roles and responsibilities

Treating clinical team and support staff	Provides feedback on the family donation conversation process
Donation Specialist Nurse	Reflects upon the family donation conversation process
	Complete the family donation conversation review template

3 Training and skills development

Donation Specialist Nurses are required to undertake extensive and regular communication skills training that are specifically focused on the complexities associated with donation conversations and how to provide information about donation to families experiencing acute grief.

All DonateLife staff are required to complete the core and practical Family Donation Conversation (FDC) workshop at employment, and to repeat the practical FDC workshop every two years, as outlined in role descriptions and the Clinical Practice Improvement Program (CPIP).

The practical FDC workshop provides the opportunity for small group skills practice and exploration of responses to family concerns with the support of skilled facilitators. In addition, focused skills training is provided on a regular basis to all Donation Specialist Nurses. This includes simulation, mentoring, coaching and focussed small group training on key elements of the family donation conversation relevant to Donation Specialist Nurses.

Intensive care medical trainees are required by the College of Intensive Care Medicine to complete the core FDC workshop as part of their mandatory training requirements. It is also recommended that ICU and ED medical and nursing staff who have a role in end-of-life care and family donation conversations attend the DonateLife core FDC workshop. The workshop provides core information about the FDC process, including the expectations of treating clinical staff in the collaborative approach to family communication. The workshop provides information about grief, family reactions to catastrophic news and skills for communicating with families to explain death and donation so as to support informed decision making.

Details of the FDC workshops, including the workshop schedule, are available at www.donatelife.gov.au.

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Appendix A
Glossary

Australian and New Zealand Intensive Care Society (ANZICS)	The leading advocate on intensive care related matters in Australia and New Zealand, including research, ICU data collection, resources and professional education.
Australian College of Critical Care Nurses (ACCCN)	The peak professional association representing critical care nurses.
Australian Organ Donor Register (AODR)	The Australian national register for people to record whether they wish to be an organ and tissue donor for transplantation after death.
Australasian College of Emergency Medicine (ACEM)	The body responsible for training emergency physicians and advancement of professional standards in emergency medicine in Australia and New Zealand.
Clinical Practical Improvement Program (CPIP)	A program that comprises seven elements of clinical strategic focus with associated reportable key performance indicators (KPIs). These KPIs are key to achieving best-practice organ and tissue donation in hospitals with a focus on the intensive care and emergency department environments. The CPIP elements are implemented in all DonateLife Network hospitals and are fundamental to the work of hospital Donation Specialists and the DonateLife Agencies.
College of Emergency Nursing Australasia (CENA)	The peak professional association representing emergency nurses.
College of Intensive Care Medicine of Australia and New Zealand	The body responsible for intensive care medicine specialist training and education in Australia and New Zealand.
Critical Care Nurse	Nursing staff working in intensive care units who are involved in caring for critically ill patients and their families and may be involved in the donation process. Includes bedside nurses, nurse unit managers and senior nurse-in-charge.
DonateLife	The Australian Government brand for all initiatives undertaken as part of the national program to increase organ and tissue donation for transplantation.
DonateLife Agencies	Agencies that provide organ donation coordination services and through which the national DonateLife program is implemented in their respective state or territory. They employ staff to provide organ and tissue donation coordination services, professional education, donor family support, community awareness raising, and audit and data collection.
DonateLife Network Hospitals	Hospitals in Australia with DonateLife Donation Specialist staff that are embedded in the hospital or provide outreach services including undertaking the DonateLife Audit.
DonateLife Network	The national network of organ and tissue donation agencies, hospital-based staff and the OTA, focused on optimising organ and tissue donation practices and increasing rates of donation for transplantation.

Donation Specialist	Includes nurses in the roles of Donation Specialist Nurse, Donation Specialist Nurse Coordinator, Donation Specialist Coordinator and doctors in the role of Medical Donation Specialists. These staff are employed by hospitals or DonateLife Agencies and have specialist knowledge and experience in the process of organ donation from deceased donors for transplantation.
Donation Specialist Doctor	Incudes doctors in the roles of Donation Specialist Medical and Medical Donation Specialist.
Donation Specialist Nurse	Includes nurses in the roles of Donation Specialist Nurse, Donation Specialist Nurse Coordinator and Donation Specialist Coordinator.
Emergency Department Physician	An Emergency Medicine specialist, or other specialist with rostered responsibility for patients in the ED.
Family	In this document, 'family' means those closest to the person in knowledge, care and affection, including the immediate biological family; the family of acquisition (related by marriage or contract); and the family of choice and friends (not related biologically or by marriage or contract).[4,17]
Family Donation Conversation workshops	OTA/DonateLife workshop-based training that provides health professionals with knowledge and skills in relation to communication with families about death and donation and supporting families to make an informed donation decision.
Intensivist	An Intensive Care specialist, or other specialist with rostered responsibility for patients in the ICU.
Organ and Tissue Authority (OTA)	Australian Government statutory body established under the *Australian Organ and Tissue Donation and Transplantation Act 2008* to implement the national program.
Senior Treating Doctor	The treating Intensivist or Intensive Care Advanced Trainee in most cases or, if the patient is in the ED, the treating ED Physician or ED Advanced Trainee.
Transplantation Society of Australia and New Zealand (TSANZ)	The peak representative body for transplantation professionals in Australia and New Zealand.

Appendix B
Checklist – Best Practice Guideline for Offering Organ and Tissue Donation in Australia

Elements of the Guideline		Element summary	Resources
Routine referral to DonateLife	1	Routinely refer all patients in the ICU and ED with planned end-of-life care to DonateLife (Agency or hospital Donation Specialist staff)	DonateLife AODR
		AODR check	
		Planning for Donation Specialist Nurse involvement in end-of-life conversation and FDC	
Communicating end-of-life	2	Family understands death or expected death following the withdrawal of treatment	ANZICS Statement DonateLife
		Discussions about death and donation are separated	FDC training
Planning the approach	3	Participate in a planning meeting to plan the FDC and share relevant information including the AODR status	DonateLife FDC training
		Agree roles, responsibilities and introductions for the FDC	
		Confirm intentions for team review after the FDC	
Discussing donation	4	Donation is offered to the family in a collaborative approach involving the Senior Treating Doctor and the Donation Specialist Nurse, supported by other healthcare personnel	DonateLife FDC training
		AODR status shared with family	
Reviewing practice	5	Team review led by Donation Specialist Nurse	Donation Specialist Nurse

Appendix C
FDC planning template

Each FDC process should involve a team planning meeting before the donation conversation. This template may be used to guide the team planning meeting and to record information before, during and after the meeting.

Patient details	
Name of patient	
DOB, age, sex	
Cause of death	
Details and status of the determination of neurological death or the planned withdrawal of treatment, and related family conversations *(include anticipated timing of family conversations about end-of-life if these have not already occurred)*	
Coroners case / details	
Transfer from another facility	
Clinical picture	
Course of admission	
Length of stay in unit	
Any complications / treatments / misadventure	
Current clinical considerations	
Any previous conditions / co-morbidities / high risk behaviours	
Family details	
Name and relationship of important family members, carers and friends	

Decision makers in the family / senior available next of kin	
How did the family react to the news of neurological death or the decision to withdraw treatment?	
What family members were present?	
How did they show their understanding that their relative had died or would die?	
Has donation been mentioned or volunteered by family or staff? If so, when was it raised, by whom and what was the outcome?	
Is there any indication of the family's current attitudes towards donation? If so, what is it?	
Are there specific issues that should be considered, such as: — Family dynamics? — Relationships with patient? — Grief risk factors? — Cultural, language or religious considerations for patient and for the family?	

Family Donation Conversation	
Planned time & location of FDC	Time: Location:
FDC attendees	Family: Staff:
Staff roles	
Introductions *(agree exact wording)*	
Who will offer donation and how? *(agree exact wording)*	
Outcome of AODR check and the approach for sharing this with the family	**Patient AODR decision** (please tick): ◯ Yes ◯ No ◯ Not registered
Plan for team review after FDC	Time: Location:

Appendix D
FDC review template

Each FDC process should be reviewed and discussed by the team as soon as practical after the FDC. This template may be used to guide the team review meeting and to record team discussions.

Date of team review	
Case identifiers:	

Referral to DonateLife and organisation of the Donation Specialist Nurse

What was done well?

What are the lessons from this case?

Communication with family about end-of-life

What was done well?

Were there alternative methods that could have been used to describe death or expected death to this family?

Were family conversations about death or withdrawal of treatment separated from the donation conversation? (please tick) ◯ Yes ◯ No

Was this appropriate and why?

Team planning

What was done well?

What are the lessons from this case?

Was the following information shared and discussed in the team planning meeting? (please tick)		
a Clinical picture of the potential donor	◯ Yes	◯ No
b Outcomes of previous family meetings	◯ Yes	◯ No
c Family dynamics and background	◯ Yes	◯ No
d Australian Organ Donor Register status of potential donor	◯ Yes	◯ No
e Decisions about roles for the Family Donation Conversation	◯ Yes	◯ No
f Agreement on how participants will be introduced	◯ Yes	◯ No
g Discussion of who will offer donation and how	◯ Yes	◯ No
h Planning about location for the Family Donation Conversation	◯ Yes	◯ No

If above information not discussed, why not?

What other information could have been discussed in the team planning meeting to enable the team to better support the family?

Did it feel like a team approach? (please tick)	◯ Yes	◯ No

Any suggestions on alternatives that could have been used?

Family Donation Conversation

What was done well?

What are the lessons from this case?

Was the donation conversation conducted as planned in the team planning meeting? (please tick) ◯ Yes ◯ No

Why? Why not?

Was any change to the planned approach appropriate?

Did it feel like a team approach? (please tick) ◯ Yes ◯ No

Any suggestions on alternatives that could have been used?

Were there any contributing factors or circumstances specific to this case (e.g. language barriers, religious or cultural issues, complex family dynamics)? (please tick) ◯ Yes ◯ No

Were there any additional ways that could the team have supported this particular family?

Do you believe the family received sufficient information to make an informed decision about donation? (please tick) ◯ Yes ◯ No

What additional information could have been provided to this family?

donatelife.gov.au