Australian Government
Organ and Tissue Authority

donatelife

Best Practice Guideline for Offering Organ and Tissue Donation in Australia

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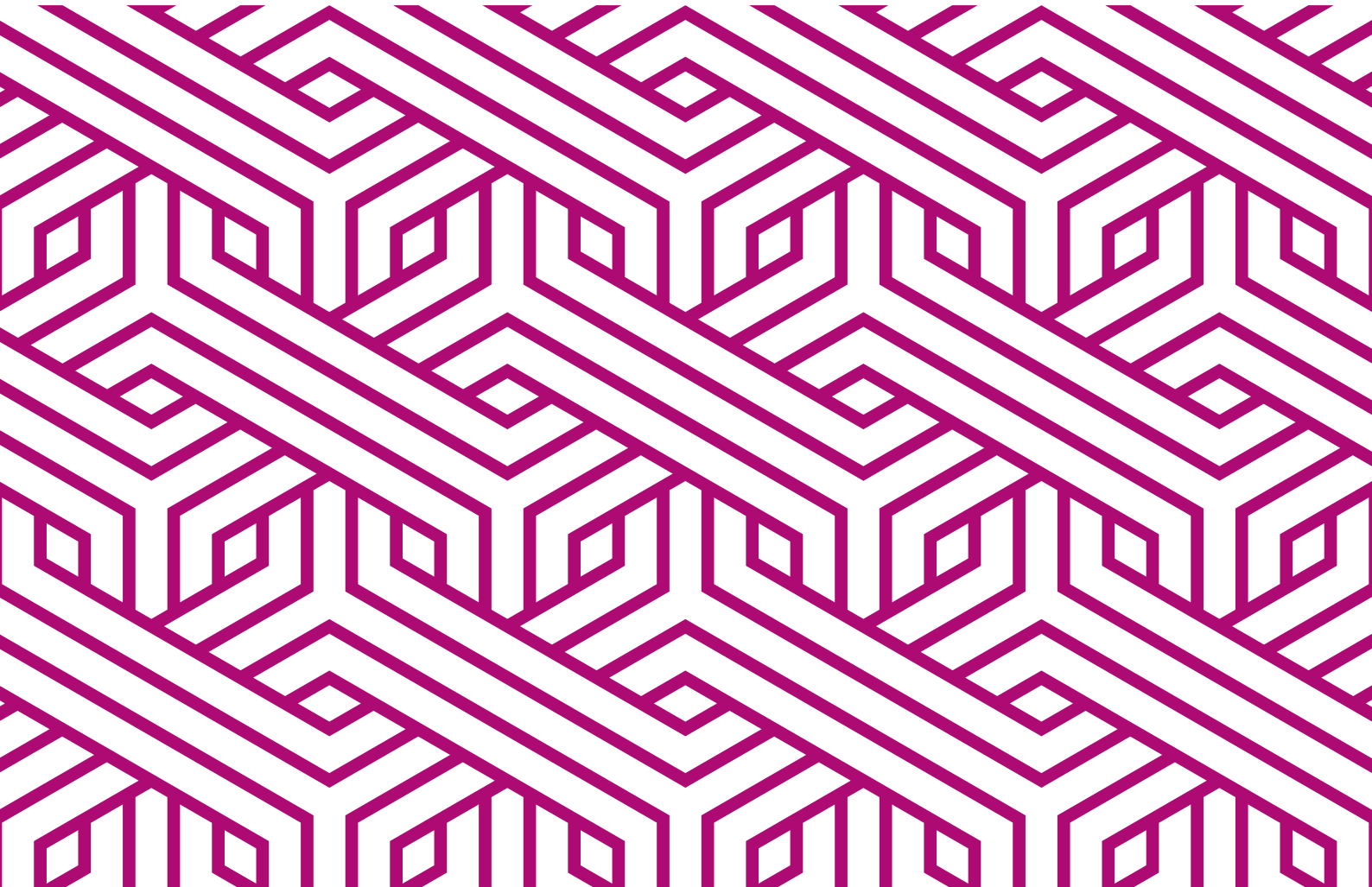

Foreword

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 is required to support families and their decision-making at this time, and it is critical that information is provided in a clear and sensitive manner that is appropriate to the needs of individuals.

Excellent care and communication ensures that families are supported during the donation experience. Evidence suggests that the care families receive and the quality of the communication with staff, including when discussing the option of donation, influences their satisfaction with the process as well as consent rates for donation.

This Guideline is designed to support health professionals involved in the family donation conversation process. The aim is to provide each potential donor family with access to a suitably trained clinician and donation specialist during the end-of-life care of their family member.

The training of donation specialists to support this Guideline facilitates informed decision-making by families with consideration of the benefits of donation for transplantation, the wishes of their loved one, and the impact of their decision. The aim is that families make a donation decision that acknowledges the patient's wishes, if previously known, their views and preferences, and that surviving family members will be comfortable with the decision. The Guideline is a key strategy of the Australian Organ and Tissue Authority (OTA) and DonateLife Network to promote better care for, and communication with families when organ donation is possible.

We would like to thank the families that we have the privilege to work with and who continue to be our most important teachers. We would also like to thank the Australian and New Zealand Intensive Care Society (ANZICS), College of Intensive Care Medicine of Australia and New Zealand (CICM) and the Australasian College of Emergency Medicine for their contributions and support for the Guideline. The Australian College of Critical Care Nurses has also contributed to the development of the Guideline through representation on the OTA Family Conversation Steering Group.

In addition, both ANZICS and CICM strongly recommend that intensivists involved in organ donation complete the core Family Donation Conversation (cFDC) workshop and repeat the cFDC workshop on a three to five year basis. This recommendation reflects the intrinsic role intensivists play in organ and tissue donation and also reflects that offering the opportunity of donation is a standard part of end-of-life care and support in Australia.

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The Guideline recognises that the circumstances surrounding each death will affect how organ and tissue donation occurs, but regards adherence to the elements of the Guideline to be appropriate and desirable in all instances. The Guideline encourages a team-based approach with the active participation of an FDC Trained Specialist and flexibility in how roles are undertaken.

[1] FDC Trained Specialist is a clinician who has completed the core Family Donation Conversation workshop. They may be donation specialist staff (donation specialist medical, donation specialist nursing or donation specialist coordinator) employed by the hospital or DonateLife Agency, or may be other senior hospital staff such as intensive care specialists who have undergone the appropriate training.

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 preferred approach to be taken for all potentially suitable organ donors. This includes early consultation with, or referral to, DonateLife, provision of specialist support to the family, team planning, a collaborative approach and team debriefing to review practice.

The objective of this Guideline is to articulate key principles and elements including goals of family communication, staff roles and responsibilities, timing and elements of the FDC, training requirements and review of practice.

The scope of the Guideline is donation by either the brain death or circulatory death pathways, which may involve organ and tissue donation but does not address tissue only donation. The Guideline does not provide clinical advice on identifying a potential organ donor, donor management, the organ and tissue donation process or assessing medical suitability. These elements should be managed 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.*

A glossary of key terms referred to 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.[1, 2]

Elements of the Guideline are supported by published literature and international guidelines:

- Early identification of potential donors and notification to a donation agency has been supported at both the level of the intensive care unit[3] and the bro ader health care system.[4,5]
- Knowledge of a patient's prior expressed decision regarding organ donation has been shown to be a significant factor in the likelihood in proceeding to donation, including in two Australian studies.[6,7,8]
- Formal training has been strongly supported in the literature with the level of experience and professional training of staff raising donation being a key factor in the effectiveness of donation discussions.[2,4,9,10,11]
  A statistically significant association between the presence of an FDC trained health professional at the family donation conversation and the rate of consent to donation has been reported in comparison to a request made by an untrained treating clinician.[9] Higher rates of consent (75%) were reported if the family donation conversation was led by an FDC trained professional who was in addition to the treating clinical team, as compared to when the conversation was led by an FDC trained professional who was also the treating clinician (55%).[6]
- Separation between notification of brain death or recommendation of treatment withdrawal and raising organ donation has been shown to have an impact on consent rates[2] and has been supported on an ethical basis to ensure there is no perceived conflict between patient care priorities and donation.[4] While this separation is usually a formal break between discussions, in some circumstances it may be a clear break in the one discussion after the clinician is satisfied that the family understand that death has occurred or is expected to occur.
- The quality of the donation conversation and information provided to families has been shown to impact on family decision making.[2,12]

1.3 FDC Trained Specialist

The term 'FDC Trained Specialist' is used throughout the Guideline to describe the donation specialist role that can provide additional expertise in supporting and informing families in end of life decision-making related to organ and tissue donation.

An FDC Trained Specialist has, at a minimum, completed the OTA's two-day core FDC workshop. FDC Trained Specialists may be DonateLife donation specialist staff (donation specialist medical, donation specialist nursing or donation specialist coordinator), or may be other senior hospital staff such as intensive care specialists who have undergone the core FDC workshop.

It is recommended that FDC Trained Specialists also complete the practical FDC workshop. DonateLife Agencies have the responsibility for working with hospitals to have available appropriately trained and skilled FDC Trained Specialists, which may include rostered on-call donation specialist staff (e.g. Agency donation specialist coordinators).

An FDC Trained Specialist should be involved early in the planning and should ideally actively participate in all family conversations about donation, in particular when donation is first raised with the family.

Optimally, the person undertaking the FDC Trained Specialist role in the Guideline is in addition to the treating clinical team. If treating clinical staff have also completed the core FDC workshop, involvement of a separate FDC Trained Specialist is still recommended.

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 made that is right for the patient and family, and one that the family will be comfortable with for years to come, regardless of whether the outcome is to agree to or decline donation.
- Supporting families during their time of loss and grief is an important part of the provision of care.
- Health professionals have a responsibility for offering and supporting fully informed decision making for patients and their families in all areas of health care including end of life care and organ and tissue donation.
- The opportunity for 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 team-based approach involving the treating clinical team, donation specialist staff and other support staff relevant for the family is critical in the planning, conduct and evaluation of all family donation conversations.

2.2 Key elements of the Guideline

There are eight key elements of the Guideline which are summarised on page 1 of this guidance document and the checklist at **Appendix B**. These elements are grouped in the following areas of practice:

- Providing specialist support
- Communicating prognosis
- Planning the approach
- Discussing donation
- Reviewing practice.

Providing specialist support	Communicating prognosis	Planning the approach	Discussing donation	Reviewing practice
• DonateLife notified • FDC Trained Specialist organised • If treating specialist is FDC trained, an additional FDC Trained Specialist should be requested to participate • Planning	• Family understands death or expected death following the withdrawal of treatment • Discussions about death and donation are separated	• AODR checked • Team planning meeting between treating clinical team and the FDC Trained Specialist • FDC roles agreed • Template available	• FDC Trained Specialist actively participates • If treating specialist is FDC trained, an additional FDC Trained Specialist should actively participate • AODR status shared with family • Donation decision	• Team review • Led by FDC Trained Specialist • Template available

2.3.1 Providing specialist support

Element 1

Identification of all potential organ donors and notification or consultation with the relevant DonateLife hospital team/ DonateLife Agency as early as possible. This enables early assessment of the potential for donation and facilitates the timely involvement of an FDC Trained Specialist to assist the clinical team in the planning and provision of patient care, family care and communication. End-of-life care and the family donation conversation are usually best managed in the ICU rather than the ED and should be provided by a suitably trained person.

Hospital staff should contact the DonateLife hospital team or DonateLife Agency at the earliest appropriate opportunity once a potential organ donor has been identified. Early involvement of donation specialist staff can assist with medical suitability assessment, donor management and advice regarding death determination, and ensure the timely involvement of an FDC Trained Specialist.

Involvement of an FDC Trained Specialist is important in ensuring that the Guideline and its key elements are followed and ensuring that all families have the opportunity to consider donation without judgements being made as to whether the family are likely to support donation or have capacity to consider donation in their time of grief. If there is no FDC Trained Specialist available within the hospital, early contact with the DonateLife Agency should enable an FDC Trained Specialist sufficient time to attend the hospital to participate with the treating clinical team in communication planning and family discussions.

Timing of physical attendance by the FDC Trained Specialist should be agreed between the treating clinical team and DonateLife for arrival before the team planning meeting. Earlier attendance may be mutually agreed so that the FDC Trained Specialist is available to provide advice to the clinical treating team to support the family conversations regarding brain death or treatment withdrawal noting that these conversations are the remit of the treating clinical specialist. It is recognised that family dynamics may determine timing.

For potential donors in the Emergency Department (ED), referral to the Intensive Care Unit (ICU) and notification of hospital donation specialist staff or the DonateLife Agency should occur according to the GIVE Clinical Trigger or other hospital protocol.

End-of-life care and the family donation conversation are usually best managed in the ICU. 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. This would require the attendance of an FDC Trained Specialist in the ED.

ICU medical staff are integral to, and should be given the opportunity to lead the end of life communication and discussion with the family. Advice from DonateLife donation specialist staff (hospital or Agency) and involvement of an FDC Trained Specialist can guide and assist in this process.

Roles and responsibilities:

Treating clinical team	Identify potential organ donor
	Notify DonateLife donation specialist staff hospital or DonateLife Agency
DonateLife	Provide advice on donor suitability and management
	Ensure timely availability of an FDC Trained Specialist

Element 2

Specialist support is provided in a collaborative approach to plan and conduct family donation conversations. If the treating clinical specialist is an FDC Trained Specialist, it is preferable that an additional FDC Trained Specialist participate in the FDC process.

Early involvement of an FDC Trained Specialist can assist in planning family communication and facilitate incorporation of all of the principles and elements of the Guideline. At the discretion of the treating clinical specialist, this may include consideration of involving the FDC Trained Specialist in the communication with family regarding brain death or treatment withdrawal, and planning a response if the family raise donation at this time (see element 3).

The participation of an FDC Trained Specialist who is separate to the treating clinical team may be of assistance, even if the treating clinical specialist has undergone FDC training. This additional trained person is beneficial for the family and the treating clinical specialist as it is an additional dedicated source of information for the family about donation and enables the treating clinical specialist to continue their role in supporting the family in the end-of-life communication and care of the patient.

An FDC Trained Specialist may enable the treating clinical specialist to withdraw from the conversation at an appropriate time if they wish. This should occur after donation has been offered to the family, with explanation and when there is appropriate ongoing support being provided to the family by the FDC Trained Specialist. If the treating clinical specialist is FDC Trained and decides to have the donation conversation with the family without involvement of an additional FDC Trained Specialist, they should be able to commit to dedicating the time required for ongoing family conversations and support in the decision making process.

Roles and responsibilities:

Treating clinical team

Collaborate with FDC Trained Specialist in team planning, family conversations and team review

(elements 5, 6, 7 & 8)

It is recommended to involve a separate FDC Trained Specialist if the treating clinician is FDC trained

FDC Trained Specialist

Collaborate with treating clinical team in team planning, family conversations and team review

(elements 5, 6, 7 & 8)

2.3.2 Communicating prognosis

Element 3

The family needs to understand that the patient has died, or that death is expected following the withdrawal of treatment, before they are asked to consider organ and tissue donation. It is the responsibility of the treating clinical medical team to ensure that the family understand that death has occurred or is expected to occur

The treating clinical team retains leadership for family communications about the patient's prognosis, including suspected brain death, the conduct and outcome of brain death testing or the planned withdrawal of cardio-respiratory support and expected death. It is the treating clinical specialist's responsibility to ensure the family understands that death has or will 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 inevitable before they are asked to consider organ donation. The transition from a conversation about death to a conversation about organ and tissue donation should not be rushed. It is generally advisable to hold separate conversations with a short break between them. A break allows families to contact other family members and friends, attend to their personal needs or spend time at the bedside. A break also provides the treating clinical team with an opportunity to meet with an FDC Trained Specialist to discuss the case and plan next steps including the family donation conversation. The FDC Trained Specialist can provide advice on strategies to sensitively separate these topics or defer discussion about donation if the family raise donation early in the process.

Alternatively, and at the discretion of the treating clinical team, the FDC Trained Specialist can be invited to attend the family meeting regarding brain death or treatment withdrawal to support the clinical team and the family. This involvement additionally enables the FDC Trained Specialist to build 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.

While the Guideline recommends a formal separation of family meetings about death and donation, in some circumstances it may be appropriate to discuss donation within the one meeting if it is felt that this best suits the family's needs. This will vary depending on individual circumstances and will need to be managed by the treating clinical specialist. For example, the family may be aware of their relative's donation decision made during life and request that donation occur. In these cases it may be appropriate to proceed with the donation conversation followed by immediate referral to the DonateLife Agency.

Roles and responsibilities:

Treating clinical team	Discuss patient care and prognosis with family
	Separate conversations about death and donation to create time and space for family
	Confirm family understanding of death, or expected death following the withdrawal of treatment, before donation is offered to the family
FDC Trained Specialist	Provide advice to treating team in separating death and donation conversation
	Attend family meeting about death at the treating team's discretion

2.3.3 Planning the approach

Element 4

The AODR is checked before the team planning meeting so that the patient's AODR registration status can inform team planning and be shared with the family as part of the donation discussion to inform the decision making process.

The FDC Trained Specialist will ensure that the AODR has been checked prior to the team planning meeting to ascertain whether the patient had made a donation decision during their lifetime. The team planning meeting (element 5) will discuss and agree the approach for the FDC including the communication of the patient's AODR registration status with the family in the donation conversation.

Checking the AODR and informing the family of the registration status of their relative is one way of providing families with valuable information to assist them in the decision making process about donation. This includes informing the family when there is an absence of a registration on the AODR and reassuring them that it is common for people not to register a decision and it does not necessarily mean that their relative does not support organ and tissue donation.

A registered 'no' on the AODR does not preclude the FDC (depending on the jurisdictional legal framework for consent). Similar to a registered 'yes', the FDC will seek to confirm whether the family were aware of their relative's donation intentions and whether they had changed their decision since registration on the AODR.

Roles and responsibilities:

FDC Trained Specialist	Obtain status of patient's registration on the AODR prior to the the team planning meeting (element 5) to agree approach for this information to be shared with the family in the donation conversation

Element 5

A timely team planning meeting occurs between the treating clinical team, an FDC Trained Specialist and other appropriate staff to plan the FDC and assign team roles for the family discussion.

The treating clinical specialist and team will ideally meet with an additional FDC Trained Specialist, preferably before the treating clinical specialist has communicated the final news of brain death or the planned withdrawal of treatment to the family and before the first conversation with the family to offer donation. The purpose of this meeting is to ensure the team have the same understanding of the situation and the plan for family communication. It is an opportunity to share relevant information about the potential donor and the family, to plan team roles and responsibilities and to agree on the approach for the family donation conversation.

The team planning meeting should be multidisciplinary 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 treating clinical specialist, bedside nurse(s), social worker and an FDC Trained Specialist. Consideration should also be given on a case-by-case basis for the need of additional members such as faith representatives and Aboriginal Liaison Officers who may have valuable information to share about the family's situation and ways to support them in the donation conversation.

In this meeting, an FDC Trained Specialist, if unfamiliar with the patient, will seek to understand previous events and the family's experience since admission, gather relevant patient and family clinical and social information and ensure that the family understands death has occurred or is expected to occur.

Planning will include determining which professionals will be involved in the FDC and consulting a family spokesperson to advise on which family members will be present in the next discussions, indicating that they will require some important decisions to be considered. Planning also considers the time and place of the meeting ensuring a comfortable and private place for the discussion, and the agreed approach to be taken including roles and responsibilities of all staff involved. The treating clinical specialist and FDC Trained Specialist will agree on a case by case basis the way the conversation will ideally transition to discuss donation, including how the patient's AODR registration status will be shared with the family, and specifically who will first raise the topic of donation and how the FDC Trained Specialist will be introduced to the family.

The FDC Trained Specialist will discuss intentions for a team review of the event after the FDC and the team will agree the way in which this review should occur (guidance on team review is in element 8).

The 'FDC team planning template' is provided at **Appendix C**. It is a useful tool for DonateLife donation specialist and other FDC Trained Specialists to complete in the planning process.

Roles and responsibilities:

Treating clinical team and support staff	Actively participate in the team planning meeting
	Share relevant patient and family information including clinical and social history
	Agree roles, responsibilites and approach for the FDC
FDC Trained Specialist	Actively participate in the team planning meeting using 'FDC team planning template' as a guide
	Obtain patient AODR status and share with team
	Agree roles, responsibilities and approach for FDC
	Confirm plan for team review after the FDC

2.3.4 Discussing donation

Element 6

An FDC Trained Specialist actively participates in the first conversation when donation is discussed with the family of a potential donor.

It is recommended that an FDC Trained Specialist should be present and actively involved in every conversation when donation is first discussed with the family of all potential organ donors. This enables them to share their donation expertise with the clinical team and provide information to the family in a sensitive, respectful manner when discussing the opportunity of donation.

This element is supported by earlier elements of the Guideline to notify DonateLife of the potential donor at the earliest opportunity (element 1), the involvement of a separate FDC Trained Specialist if the treating clinical specialist is FDC trained (element 2), and the active participation of the FDC Trained Specialist in the team planning meeting (element 5) before the first family donation conversation.

Roles and responsibilities:

Treating clinical team	Collaborate with FDC Trained Specialist in family donation conversation, as agreed in the team planning meeting
FDC Trained Specialist	Participate in family donation conversation in collaboration with the treating clinical team, as agreed in the team planning meeting

Element 7

The opportunity for donation is offered to the family in a team-based approach, including the provision of accurate information about donation for transplantation.

The roles of the FDC Trained Specialist, who may be the treating clinical specialist, and clinical team members, as well as how the discussion will be conducted, will have been determined in the pre-planning meeting (element 5).

The FDC Trained Specialist will build rapport with the family and commence the discussion about donation. They will provide the family with factual information about the purpose of donation for transplantation and the possible benefits for recipients. The conversation will explore the patient's wishes if these are known and the family's role in the decision-making process. Questions will be accurately answered, uncertainties addressed and information about the process will be provided. A series of family conversations may be necessary.

Key topics that the FDC Trained Specialist may discuss with the family include:

- Donation helps other people through transplantation, with explanation of what organ and tissue donation and transplantation is
- Transplantation can be lifesaving and improve the quality of people's lives
- Donation is an infrequent event with there being few people who can donate organs and tissues to help others
- Organ and tissue donation is done with respect and dignity for all involved
- Many people are waiting for an organ or tissue transplant and the reasons why
- Many families say that donation has helped in their grief and provided them with comfort in their loss.

The FDC Trained Specialist will seek to understand the reasoning behind the family's decision making, including families who are not supportive of donation. Sensitive exploration can sometimes reveal misconceptions about donation. The family will be assured that whatever they decide, their decision will be supported. The discussion will be balanced, providing factual information about donation, and will in no way be manipulative or attempt to pressure families to donate.

The treating clinical specialist and other members of the team will continue to support the conversation and the family. When comfortable, the treating clinical team members may choose to withdraw from the meeting to attend to other responsibilities, whilst the FDC Trained Specialist continues to discuss donation and support the family.

Once the family have reached a decision, the next steps will be explained and the FDC Trained Specialist and treating clinical team will continue to support the family.

Roles and responsibilities:

Treating clinical team

- Participate in the FDC as agreed at team planning meeting (element 5)
- Commence meeting, make introductions and confirm family understanding of death (treating clinical specialist)
- Respect the family's donation decision and explain next steps
- Provide ongoing support to family

FDC Trained Specialist

- Participate in the FDC as agreed at team planning meeting (element 5)
- Provide the family with information about the opportunity to donate
- Support the family in their decision-making and answer any questions
- Respect the family's donation decision and explain next steps
- If the family consent, initiate donation process after FDC

2.3.5 Reviewing practice

Element 8

Team review occurs after each FDC process to provide an opportunity to reflect upon and improve practice.

A brief review of the FDC provides an opportunity for participants to reflect upon and evaluate how the process went. The FDC Trained Specialist is responsible for leading a team review meeting and at the team planning meeting should gain agreement from all staff participating in the FDC to attend this review (element 5).

The team review should take place soon after the FDC has concluded. 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. A 'FDC review template' is provided at **Appendix D** and may be a useful tool for DonateLife donation specialist staff and other FDC Trained Specialists to complete in the team review.

Roles and responsibilities:

Treating team, FDC Trained Specialist & support staff

- Provide feedback on FDC process in team review
- Complete FDC review template

3 Training and skills development

Specialist training for the FDC Trained Specialist in the Guideline is provided through the OTA's Professional Education Package (PEP) and specifically the core FDC workshop. The two day core FDC workshop provides detailed information about grief, family reactions to catastrophic news and skills for communicating with families to explain death and donation to support informed decision making.

Completion of the core FDC Workshop is the minimum requirement for any clinician to be considered an FDC Trained Specialist as described in the Guideline.

It is acknowledged that while attendance at the core FDC workshop is a prerequisite this does not necessarily mean that every participant will be fully equipped with the skills, or have the experience, to satisfactorily offer donation to families. Additional training and support is available through the PEP and by some DonateLife Agencies in the form of simulation and group activities. Complementary training is available through the one day practical FDC workshop of the PEP which provides opportunity for skills practice and exploration of responses to family concerns. The FDC e-learning program reinforces key principles of the FDC training and allows for ongoing learning. Details of the PEP, including the workshop schedule, are available at www.donatelife.gov.au.

DonateLife donation specialist staff are required to undertake more extensive and regular communication skills training, and are specifically required under the Clinical Practice Improvement Program (CPIP) to complete the core and practical FDC workshop at employment, and to repeat the practical FDC workshop every two years.

4 References

1 Siminoff LA, G. N. (2001). Factors influencing families' consent for donation of solid organs for transplantation. *Journal of the American Medical Association*, 286, 71–77.

2 Simpkin AL, R. L. (2009). Modifiable factors influencing relatives' decision to offer organ donation: systematic review. *British Medical Journal*, 339:b991.

3 Dickerson J, V. A. (2002). Organ donation rates in a neurosurgical intensive care unit. *Journal of Neurosurgery*, 97(4), 811-4.

4 Kotloff RM, B. S. (2015). Management of the Potential Organ Donor in the ICU: Society of Critical Care Medicine/ American College of Chest Physicians/Association of Organ Procurement Organizations Consensus Statement. *Critical care medicine*, 43(6), 1291-325.

5 National Institute for Health and Clinical Excellence. (2011). Organ donation for transplantation Improving donor identification and consent rates for deceased organ donation. Manchester.

6 Lewis VJ, W. V. (2015). Towards a national model for organ donation requests in Australia: evaluation of a pilot model. *Critical Care and Resuscitation*, 17(4), 233-238.

7 Marck CH, N. S. (2016). Potential donor families' experiences of organ and tissue donation-related communication, processes and outcomes. *Anaesthesia and Intensive Care*, 44(1), 99-106.

8 Marck CH, N. S. (2015). Factors relating to consent for organ donation: prospective data on potential organ donors. *Internal Medicine Journal.*, 45(1), 40-7.

9 National Transplant Organization. (2011). Good practice guidelines in the process of organ donation.

10 National Health Service (NHS) Blood and Transplant. (2015). Approaching the families of potential organ donors Best practice guidance.

11 Oh, T. (2015). Organ donation: how to increase the donor pool. *Anaesthesia and Intensive Car*e, 43(1), 12-13.

12 Neate, S. L. (2015). Understanding Australian families' organ donation decisions. *Anaesthesia and Intensive Care*, 43(1), 42-50.

Appendix A **Glossary**

Australian and New Zealand Intensive Care Society (ANZICS) The leading advocate on intensive care related matters in Australia and New Zealand.

Australian Organ Donor Register (AODR) – The Australian national register for people to record their decision about becoming an organ and tissue donor for transplantation after death.

Balanced approach – A balanced approach involves an open discussion with families, including the provision of factual information about why donation is important and the benefits of donation for transplantation. The approach avoids early closed questions that may result in uninformed reactive responses and supports the family making a fully informed decision irrespective of whether it is to consent to or decline donation.

Clinical Practical Improvement Program (CPIP) – Comprises 12 elements within the domains of clinical effectiveness, workforce, risk management and consumer participation and satisfaction that are implemented in all DonateLife Network hospitals to improve clinical practice in organ and tissue donation.

DonateLife – Australian Government program brand for the national reform program, including brand name and identity for the DonateLife Network and the national DonateLife Community Awareness and Education Program.

DonateLife Agencies – Organ and tissue donation agencies that are responsible for implementing the national reform program in their respective state or territory. They employ specialist staff in organ and tissue donation coordination, professional education, donor family support, communications, and data and audit roles.

DonateLife Network – National network of organ and tissue donation agencies, hospital-based staff and the OTA, focused on increasing organ and tissue donation.

Donation Specialist Coordinator – Registered nurse employed in a dedicated position funded within the national reform program with responsibility for working closely and collaboratively with DonateLife Network staff, as well as hospital staff to facilitate the process of organ donation and retrieval from deceased donors.

Donation Specialist Medical – Medical practitioner employed in a dedicated position funded within the national reform program with responsibility and accountability for the end-to-end process to optimise organ and tissue donation for transplantation in their hospital.

Donation Specialist Nursing – Registered nurse employed in a dedicated position funded within the national reform program with responsibility for raising awareness of, and providing educational services on organ and tissue donation for all medical, nursing and allied health staff that come into contact with the donation process. The position also works with hospital teams and DonateLife Network staff to identify and convert potential organ donors to actual donors.

Donor Family Study – Retrospective study that is conducted by the OTA every second year to seek feedback on the donation process from families who are asked to make a donation decision including families who choose to consent to donation and families who decline donation.

Family Donation Conversation (FDC) workshop - Workshop-based training that provides health professionals with the knowledge and skills to communicate with families about death and donation and to support families to make an informed donation decision.

FDC Trained Specialist – A clinician who has completed the core Family Donation Conversation workshop. They may be donation specialist staff (donation specialist medical, donation specialist nursing or donation specialist coordinator) employed by the hospital or DonateLife Agency, or may be other senior hospital staff such as intensivist care specialists who have undergone the appropriate training.

GIVE Clinical Trigger – The GIVE clinical trigger is a tool used in Australian hospitals to support clinical staff to identify potential organ donors; intubated and ventilated patients receiving end of life care.

Organ and Tissue Authority (OTA) – Statutory body established under the *Australian Organ and Tissue Donation and Transplantation Act 2008* to implement the national reform program.

Professional Education Package – Modularised program providing specialist training for conducting family conversations about death and the opportunity for organ and tissue donation.

State Medical Directors – Leaders of the organ and tissue donation sector in each jurisdiction who drive clinical practice, oversee organ and tissue donation processes and ensure consistency of practice within each jurisdiction.

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

	Elements of the Guideline		
	Element summary		**Resources**
Providing specialist support	**1**	Identify and refer all potential organ donors to DonateLife	GIVE trigger, DonateLife
		Request attendance by FDC Trained Specialist	
		Agree timing for arrival of FDC Trained Specialist with DonateLife to occur before the team planning meeting	
	2	Contribute to a collaborative approach involving a treating clinical specialist and preferably a separate FDC Trained Specialist if the treating specialist has completed the FDC training	Hospital list of FDC Trained Specialists
Communicating prognosis	**3**	Confirm family understanding of death or expected death following the withdrawal of treatment	ANZICS Statement, DonateLife, FDC training
		Separate the discussion with family about death and donation (ideally in separate meetings)	
Planning the approach	**4**	Ensure that the AODR is checked before the team planning meeting and shared with the family in the FDC	AODR
	5	Participate in a team planning meeting to plan the FDC and share relevant information including the AODR status	FDC team planning template
		Agree roles, responsibilities and introductions for the FDC	
		Confirm intentions for team review after the FDC	
Discussing donation	**6**	Ensure active participation of FDC Trained Specialist in the first conversation when donation is discussed with the family	DonateLife
	7	Offer the opportunity of donation to the family in a collaborative approach as agreed in the team planning meeting	FDC training
		Provide information to the family so they can make an informed and enduring decision about donation	
Team review	**8**	Participate in a team review session to discuss the FDC	FDC review template

Appendix C **FDC team 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 brain death testing or decision for withdrawal of treatment, and related family conversations	(include anticipated timing of family conversations about prognosis 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 brain 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 plan for sharing AODR status with family (please cirlce)	**AODR status: Yes No Not registered**
Plan for team review after FDC	Time:
	Location:

Appendix D **FDC team 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 and organisation of the FDC trained requester

What was done well?

What are the lessons from this case?

Communication with family about the prognosis

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? **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 pre-planning meeting? (please circle)

(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 circle) **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 circle) **Why? Why not? Was any change to the planned approach appropriate?**	**Yes**	**No**
Did it feel like a team approach? (please circle) **Any suggestions on alternatives that could have been used?**	**Yes**	**No**
Were there any contributing factors or circumstances specific to this case (please circle) (e.g. language barriers, religious or cultural issues, complex family dynamics)? **Were there any additional ways that the team could have supported this particular family?**	**Yes**	**No**
Do you believe the family received sufficient information to make an informed decision about donation? (please circle) **What additional information could have been provided to this family?**	**Yes**	**No**