



Acknowledgement of Country

We acknowledge the traditional owners of this land and pay our respect to Elders past, present and emerging.

We also acknowledge the Stolen Generation and their families.

CULTURE COMMUNITY COUNTRY FAMILY CONNECTION

KINDNESS, COMPASSION

LIVING WELL AGEING WELL

SEEN, HEARD, RESPECTED, VALUED

RESPECT FOR ELDER

ENGAGEMENT, TRUST, HEALTH LITERACY

GETTING HEALTH CARE

HIGH QUALITY HEALTH CARE, EVIDENCE-BASED GUIDELINES

WHOLE PERSON, WHOLE OF LIFE

FAIRNESS, EQUITY, EVERYONE

DTA Webinar Series Webinar 6

Planning, Decision-making and End-of-life Care for People with Dementia

Diane Cadet-James and Dina LoGiudice



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Difficult content

- We want to acknowledge that the content of this webinar may be difficult.
- We encourage you to seek help if you need to (see resources at end)

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Aims of the Let's CHAT Dementia project

To increase:

- health service and community awareness of Cognitive Impairment / Dementia
- health service knowledge about and skills for preventing, detecting and managing CI/D
- detection rates of CI/D

To maximise:

- care of people with CI/D
- carer health and wellbeing





Let's CHAT Implementation best-practice dementia care

Let's CHAT Webinars:

1. GP webinar
2. Detection of Cognitive Impairment and Dementia
3. Health Care for People Living with Cognitive Impairment and Dementia
4. Health Promotion and Prevention
5. Health and Wellbeing of Carers of People with Cognitive Impairment and Dementia
6. **Planning, Decision-making and End-of-life Care**

Resources

- *Best Practice Guide to Cognitive Impairment and Dementia Care for Aboriginal and Torres Strait Islander People in Primary Care*
- *Summary Guide*



Key Messages from Webinar 5: Health and Wellbeing of Carers for People with Cognitive Impairment and Dementia

- Looking after the **health and wellbeing** of carers is an important part of dementia care.
- Supporting carers' health improves **QoL and health outcomes** for:
 - the carer.
 - person with cognitive impairment & dementia, their family and community
- It is important that health service staff can **effectively identify, educate** and support carers.
- Connecting carers with **culturally safe services**.





Webinar 6 Overview

Principles of care

The end of life in dementia

Planning

Decision-making

End-of-life care



Webinar 6 Learning Objectives

At the end of this
webinar, you
should be able
to:

Identify key aspects of planning that may be important to consider with the person with dementia and their families, including from an Aboriginal and Torres Strait Islander worldview.

Understand the health decline of the person with dementia.

Identify potential decision-making processes to be explored with the person with dementia and their families

Define end-of-life care

Recognise and locate health and other support services needed by the person with dementia at the end of life.

Activity

Not being a burden on my family

Being active and independent
for as long as I can

Being an organ and tissue donor

Following my cultural, religious or
spiritual practices

My pain and symptoms managed

The screenshot shows a web browser window with the URL dyingtotalk.org.au/card-game/dying-to-talk-indigenous-cards/. The page features a dark blue header with the 'dying to talk' logo and the text 'DISCUSSION STARTER ONLINE CARD GAME' next to a green paper airplane. Below the header, there are navigation buttons: 'RESTART', 'DOWNLOAD', 'PRINT', and 'EMAIL'. The main content area is divided into two sections. The left section, titled 'HOW TO PLAY', includes instructions: 'Click on the pile to draw a new card.', 'Drag and drop each card into a space on the right depending on whether it is very important, somewhat important, or not important to you.', and 'You may click and drag cards to move them after you have placed them.' Below the text is a small image of a colorful Aboriginal dot painting. The right section, titled 'VERY IMPORTANT', contains a grid of ten cards for selection. The first two cards are 'Being active and independent for as long as I can' and 'Dying on country'. The remaining eight cards are empty. Below each card is a text box asking 'Why is this card so important to you?'. The 'RESTART' button is highlighted with a red border.

*What does a good
passing mean to
you?*

Feeling at peace

Being comfortable

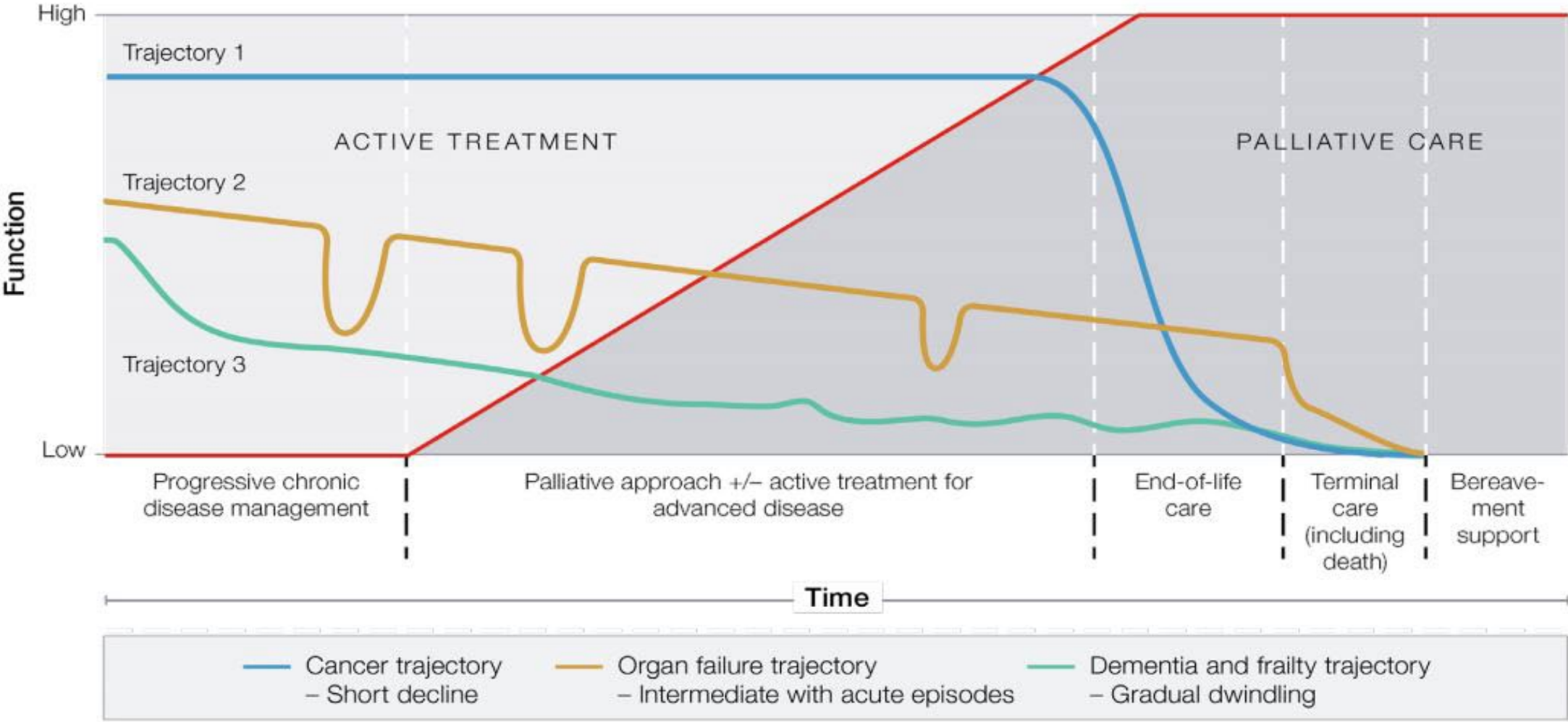
Not in pain

*Surrounded by
loved ones*

On Country



The course of dementia



Stages of cognitive impairment and dementia

	Mild cognitive impairment	Early dementia	Mid-stage dementia	Late-stage dementia
<i>General profile</i>	Not dementia. Able to function fairly normally but friends & family usually notice the person is having thinking problems. May revert to normal cognitive functioning	Thinking is noticeably affected.	Cognitive & behavioural problems from early stages become more pronounced. Physical function declines.	Progressively unable to speak or communicate.
<i>Cognitive symptoms include</i>	Increased forgetfulness, some difficulty concentrating, trouble finding words	Changes in memory, judgement, planning, mood & insight, episodes of confusion. Denial might be a factor.	Forgetting home address, names of close family, recent events	
<i>Possible functional impacts</i>	Getting lost, decreased work performance	Problems travelling alone to new locations, socialising (withdrawal from family & friends), managing finances, driving, completing more complex tasks easily or correctly	Needing assistance with ADLs, ranging to extensive assistance. BPSD. Onset of physical issues: incontinence, speech problems.	Assistance needed with most activities (e.g., using the toilet, eating). Loss of psychomotor skills, eg. ability to walk.
<i>Average duration</i>	2-7 years	2 years	4 years	1.5 – 2.5 years

The role of the health care team in end-of-life care

- Primary source of information about health status and prognosis
 - Supporting planning and preparation
 - Providers of health care
 - Guidance for accessing support services
-
- The health team needs to be equipped with knowledge and skills in applying a palliative care approach to dementia.

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Diagnosis and prognosis

- Recognising and respecting the preferences of the person with dementia
- Communicating with sensitivity:
 - Culturally appropriate and safe - seek local cultural knowledge and understanding
 - Recognising that patients and families may be feeling grief and uncertainty
- Clear and accurate information
- Timeliness – early discussion helps families and patients feel prepared for the future
- Ongoing education and support for the family about dementia that is relevant to family receptiveness and the stage of the disease.

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Clinical symptoms at end of life in a person with dementia

One study followed 323 people with severe dementia in residential care in USA for 18 months:

- 55% died
- 41% developed pneumonia, 51% had fevers, 86% developed an eating problem (including impaired swallowing that led to pneumonia)
- 46% felt short of breath, 40% complained of pain, 39% had pressure ulcers and 54% were agitated.

(Mitchell et.al 2009)

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Should we treat everything?

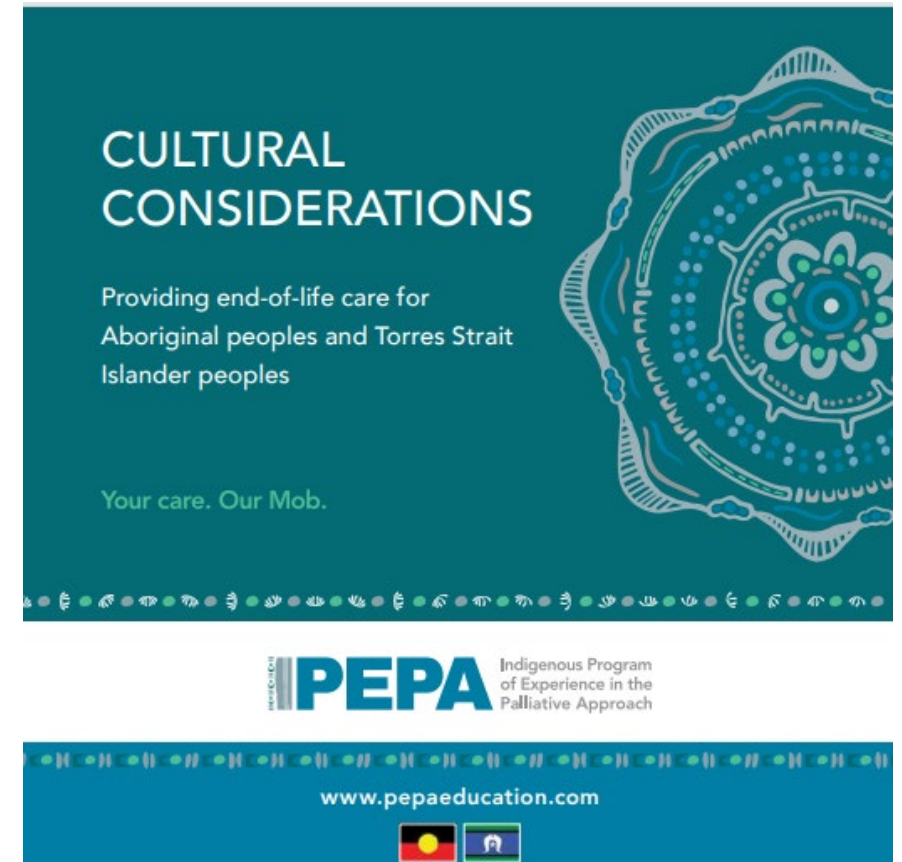
Principles of care: Optimise quality of life, maintain function, maximise comfort

Mitchell et al study also found that people with advance care plans, or with families who understood that their loved one was in the last stages of dementia, received less “futile treatments”

Futile treatment = treatment that is of no benefit, cannot achieve its purpose, or is not in the person’s best interests

Palliative Care

- Optimise quality of life, maintain function, maximise comfort
- Referral might be needed to specialist palliative care services
- How to make sure services are culturally safe?



CULTURAL CONSIDERATIONS

Providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples

Your care. Our Mob.

PEPA Indigenous Program of Experience in the Palliative Approach

www.pepaeducation.com

The poster features a teal background with a large, intricate white and blue circular pattern on the right side. At the bottom, there are small icons representing various cultural symbols and the Australian flag.

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5.1 Case Study: Aunty Molly

Aunty Molly is now 74 years of age. She was diagnosed with Alzheimer's Disease 6 years ago. At this stage, Molly needs help with most things. She can't walk anymore and is having trouble communicating.

When she was still able, Molly and Frank discussed her preferences for end-of-life care with Molly's GP and they were documented in an Advance Care Plan.



5.2 Case Study: Dementia progresses

Frank has been caring full time for his mother for two years now. Sometimes she doesn't even recognise Frank and her grandkids.

Molly's case manager mentioned to Frank that his mother's dementia was quite severe now.

One evening when Frank was on the phone, Aunty Molly slipped on the way to the toilet and broke her hip. She was taken to the local hospital.



Planning: ensuring your wishes are known

“Advance care planning is the process of planning for your future health care. It relates to health care you would or would not like to receive if you were to become seriously ill or injured and are unable to communicate your preferences or make decisions. This often relates to the care you receive at the end of your life.”

<https://www.advancecareplanning.org.au>

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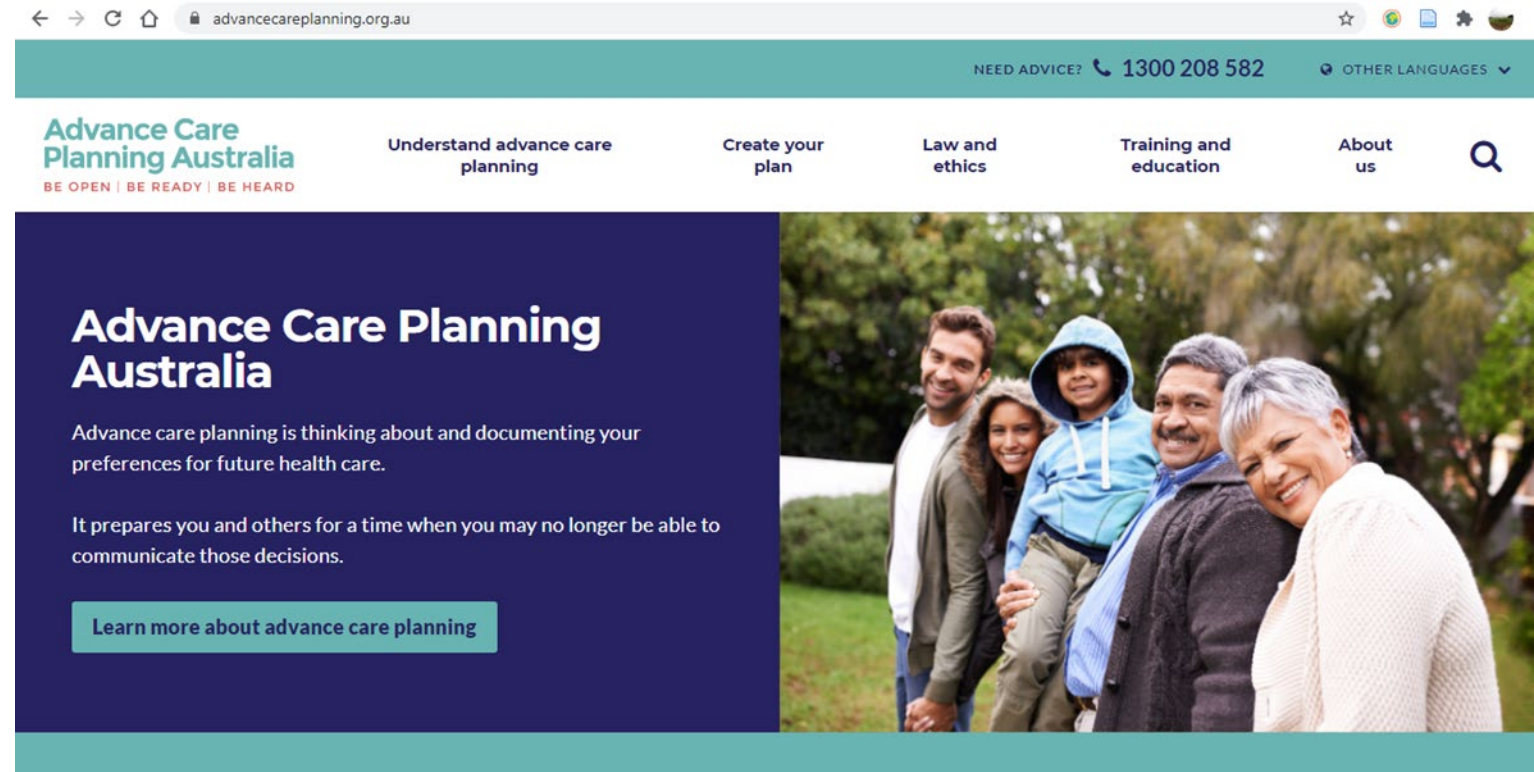
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Formal planning

Encourage your patients to do some planning for the future:

- Power of attorney: medical and financial
- Wills and funerals
- Get finances in order
- Consider documenting care preferences and **Advance Care Directives**



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Planning

- Important to revisit these conversations over time as circumstances and understandings change.
- Can be difficult to have these conversations
- Some strategies...
- Great resource - Discussion Starter: Dying to Talk.



Aboriginal and Torres Strait Islander
Discussion Starter

WORKING OUT WHAT'S RIGHT FOR YOU

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Decision-making

- Provide opportunities for discussions as early as possible.
- Encourage the person with dementia to think about who to involve and to tell the health service their preferences.
- Provide support for appointed decision-makers
- Let's explore different types of decision-making: shared, supported and proxy.
- What are your experiences of decision-making in this community?
- How is privacy and confidentiality supported?

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End-of-life care: cultural focus

- Different Aboriginal and Torres Strait Islander Communities do things differently. Every person needs to be considered individually. There is no 'one size fits all' approach.
- Facilitate Connection to Country
- Focus on care that prioritises:
 - comfort
 - symptom management (e.g. pain, swallowing difficulties, pressure sores and agitation)
 - emotional and spiritual support
 - support for carers and family





5.3 Case Study: Aunty Molly

While Molly was in hospital, the health staff asked Frank whether she had Power of Attorney or if Molly had discussed her treatment wishes.

Molly had a hip operation but became unwell with delirium and pneumonia. The staff were worried that Molly wouldn't pull through.

Molly's health didn't improve and the palliative care team were involved. Frank wanted to care for Molly at home and the team were able to organize supports to make this possible.

Molly passed away two weeks later at home.

After a person has passed

- Be mindful that mourning practices and protocols vary
- Identify and be respectful of local cultural protocols
- The places of death and burial need to be carefully considered
- Check on family and carers and address their immediate needs



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Key Messages from Webinar 6: Planning, Decision-making and End-of-life Care for People with Dementia

- It is important to **provide services and support** that are **culturally safe and respectful** of local cultural protocols.
- **Early planning** is helpful for the patient, their family and the health care team.
- **Autonomy and personal preferences** should be respected at all stages of dementia, including through shared, supported and proxy decision-making.
- The **primary health care team** has a key role in supporting **planning, decision-making and end-of-life care**.



Thank you!



Questions?

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Planning Resources

- Advance Care Planning Australia
 - [Advance Care Planning for Aboriginal and Torres Strait Islander Peoples](#)
 - [Create your plan](#)
- Video resources
 - [Taking Care of Dying](#) – (Central Hume Primary Care Partnership)
 - [Finishing Up](#) – Advance Care Plans on Groote Eylandt
- Wills and POA:
 - [MoneySmart](#)
 - [State Trustees](#)

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Palliative Care Resources

- [Indigenous Program of Experience in the Palliative Approach \(IPEPA\)](#)
 - [Cultural considerations: Providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples](#)
- [Aboriginal end-of-life and palliative care framework](#), Dept. Health, WA Govt
- [Palliative Care Australia](#)
 - [Aboriginal and Torres Strait Islander Discussion Starter](#)

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Counselling Resources

- [Lifeline](#), call 13 11 44
- [Beyond Blue Support Service](#)
 - [Information for Aboriginal and Torres Strait Islander People](#)
- Yarning Safe'N'Strong
Call 1800 959 563
Email ysns@vahs.org.au
Facebook [@YarningSafenStrong](#)



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References

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., ... & Hamel, M. B. (2009). The clinical course of advanced dementia. *New England Journal of Medicine*, 361(16), 1529-1538.

[Best-practice guide to cognitive impairment and dementia care for Aboriginal and Torres Strait Islander people attending primary care \(Full Guide\)](#)

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Stay In Touch

<https://medicine.unimelb.edu.au/lets-chat-dementia>