

# Topic 2 Toolkit: Workbook

Caring for Australian Indigenous peoples affected by life-limiting illness

## Overview

To provide quality, culturally-responsive care for people affected by life-limiting illness, health professionals need to be able to identify and respond effectively to individual needs. This Focus Topic Toolkit: *Caring for Australian Indigenous peoples affected by life-limiting illness* will help students to develop the skills needed to provide quality care, across various settings, to Aboriginal and/or Torres Strait Islander people with life-limiting illness, and their families and communities.

This toolkit is based on the core principles of palliative care and is designed to supplement the learning activities in the four [PCC4U Core Modules](#). The toolkit provides a range of learning activities and resources in relation to the topic. Educators can select any or all of the activities to best support the development of their students' palliative care capabilities.



# Learning outcomes

After completing the relevant sections of the focus topic toolkit, students will be able to:

1	Critically reflect on power, privilege and the institutional place of health services and professionals and how these impact on provision of palliative care for Australian Indigenous peoples.	[Section 1]
2	Describe traditional kinship systems, and spiritual connections to Country and culture that influence the views that many Australian Indigenous peoples have of health and wellbeing.	[Section 2]
3	Identify the key features of the United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP) that relate to provision of palliative care for Australian Indigenous peoples.	[Section 3]
4	Demonstrate an awareness of the historical and ongoing trauma that contributes to the current barriers that prevent Australian Indigenous peoples accessing palliative care services.	[Section 4]
5	Demonstrate enhanced capability in communicating with and delivering family-centred care to Australian Indigenous peoples affected by life-limiting illness.	[Section 5]
6	Recognise the cultural considerations associated with end-of-life care, grief and bereavement for Australian Indigenous peoples.	[Section 6]



# About the Toolkit

## Promoting a safe and respectful learning experience

PCC4U recognises that many healthcare students and professionals find it difficult to have conversations with people about cultural needs and preferences and are concerned about making mistakes. This can lead to avoidance of these conversations and avoidance of engaging in learning to develop skills.

**Engaging with Australian Indigenous peoples in a way that is respectful and acknowledges the health professional's willingness to learn is very important.**

## Terminology

Language and naming terms are interwoven in a history of domination and colonisation that continues to perpetuate misunderstanding and misrepresentation of Aboriginal and Torres Strait Islander peoples today. Accordingly, this resource provides some background to the terminology it uses throughout.

It is important to remember, that although the terms 'Indigenous', 'Aboriginal' and 'Torres Strait Islander' are commonly accepted, these are colonial labels that were imposed on peoples with diverse cultures and languages.

In the development of this toolkit, it was indicated that use of the term 'Aboriginal and Torres Strait Islander' when referring to Aboriginal and Torres Strait Islander people collectively, may lead to the incorrect assumption that there are just two cultural groups – Aboriginal people and Torres Strait Islander people.

Use of the word 'peoples' rather than 'people' can help address this but does not acknowledge that some people may identify as both Aboriginal and Torres Strait Islander.

This resource, in seeking to acknowledge the diversity of Aboriginal peoples and Torres Strait Islander peoples, who have distinct cultures, languages, kinship systems, Lore and customs, respectfully uses the following:

- **Australian Indigenous peoples** when referring to Aboriginal and Torres Strait Islander peoples collectively
- **Aboriginal and/or Torres Strait Islander person/family** when referring to individuals and family groups.

**Australian Indigenous peoples often identify with Country, Nation, Clan or Island groups. In healthcare practice, it is always important to ask how someone identifies and show respect and understanding by using preferred language and terms. These terms will vary from person to person and family to family, so it is essential to always ask.**

## Content Warning

The content in this toolkit challenges healthcare students to identify and reflect on entrenched beliefs and biases relating to racism and Australian Indigenous peoples. This process may be uncomfortable and overwhelming to some. It may also be triggering to students who identify as Aboriginal and/or Torres Strait Islander.

Suggested responses for educators to support a safe learning space:

- ① Brief students about the sensitive and potentially triggering nature of this content
- ① Allow students to determine the depth of engagement with these learning materials, as they feel ready
- ① Check in with students regularly to find out if additional support is required
- ① Advise students how to access additional support.

National Support Services	Healing Programs for Aboriginal and/or Torres Strait Islander people
<a href="#">Lifeline 13 11 14 (24hrs)</a>	<a href="#">Healing Foundation</a>
<a href="#">Beyond Blue 1300 22 4636</a>	<a href="#">Family Wellbeing Empowerment Program (Lowitja Institute)</a>
<a href="#">Link-Up Aboriginal Corporation 1800 624 332</a>	<a href="#">Marumali (to put back together)</a>
<a href="#">Kids Helpline 1800 55 1800</a>	<a href="#">Journey of Healing</a>
<a href="#">Mensline Australia 1300 789 978</a>	<a href="#">Seasons for Healing</a>
	<a href="#">Red Dust Healing</a>
	<a href="#">We Al-Li</a>

# Prerequisite knowledge: Cultural safety and culturally-responsive care

## Update Activities



**Key Point 1:** Feeling 'culturally-safe' is the experience of the care recipient, and not something defined by the caregiver.

**Update Activity:** To refresh your understanding of the expectations of registered health practitioners in Australia, review the following key documents:

- [National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020–2025](#)
- [Cultural Respect Framework \(2016–2026\) for Aboriginal and Torres Strait Islander health: a national approach to building a culturally respectful health system](#)



**Key Point 2:** Cultural awareness is not cultural safety.

**Update Activity:** To refresh your understanding, review a current textbook chapter on cultural safety in health, for example:

Cox, L., Taua, C., Drummond, A., and Kidd, J., (2021). *Enabling Cultural Safety*. In J. Crisp, C. Taylor, C. Douglas & G. Rebeiro (Eds.) *Fundamentals of nursing, 6e.* (pp. 49-83). Sydney: Elsevier.



### Key Point 3: A culturally-responsive approach to care is the 'how to' of cultural safety

**Update Activity:** Cultural Competence Continuum, developed as part of the Aboriginal Cultural Competency Framework provides a helpful reflection tool for organisational cultural competence.

Read through the descriptions for each of the points on the continuum and consider, how you would rate your most **recent practice setting**.

# Section 1: Power, privilege and the place of healthcare – impacts on palliative care

## Learning outcome

After completing this aspect of the focus topic, students will be able to critically reflect on power, privilege and the institutional place of health services and professionals and how these impact on provision of palliative care for Australian Indigenous peoples.



## Activity 1: Power and privilege



## Thinking Points

1. In her 2016 blog post, 'What I said when my white friend asked for my black opinion on white privilege', Lori Lakin-Hutcherson describes a number of experiences with racism across her lifetime that help to illustrate how white privilege can be understood:
  - If you've never had a defining moment in your life where you realise that skin colour alone makes other people hate you, you have white privilege
  - If you've never been 'the only one' of your racial group or colour in a class, at a party, in a workplace etc and it's been pointed out in a 'playful' fashion by the authority figure in the situation, you have white privilege
  - If you've never been on the receiving end of the assumption that when you've achieved something, it's only because it was taken away from a white person who 'deserved it' – that is white privilege
  - If no one has ever questioned your intellectual capabilities or attendance at an elite institution based solely on your skin colour – that's white privilege
  - If you have never experienced or considered how damaging it could be to grow up without myriad role models and images in school that reflect you in your required reading material or in the mainstream media – that is white privilege. [Excerpt].

Take a moment to think about these points and reflect on the influence of privilege in your day-to-day life.

2. Take one of the [Harvard Project's Implicit Association Tests](#) to help you understand more about your own implicit biases.





- What barriers can you identify (with reference to the content in this section) that influenced the end-of-life care experience for him and his family?

- In an ideal situation, how should the healthcare team have dealt with the situation described in this narrative?

- What changes could be made to this health service to ensure that they better accommodate families like George's in the future? For further information regarding this, refer to Activity 6

## Section 2: Australian Indigenous Cultures

### Learning outcome

After completing this aspect of the focus topic, students will be able to describe traditional kinship systems, and spiritual connections to Country and culture that influence the views that many Australian Indigenous peoples have of health and wellbeing.



### Activity 3: Australian Indigenous peoples



### Thinking Points

1. Reflect on your understanding of Australian history and current society, policy and practice.

What do you need to learn more about to help you develop an awareness of the needs and situations of Aboriginal and/or Torres Strait Islander people?

Go back through this section and explore the various learning resources. Make some notes about what you learn and discuss with a friend or colleague.

## Learning Resources

[AIATSIS map of Indigenous Australia](#)

Video: [Family and kinship](#) (1:08)

Videos: provided by the [National Centre for Cultural Competence](#):

[Moiety](#) (3:02)

[Totems](#) (3:51)

[Skin Names](#) (4:09)

[Lines of communication](#) (2:38)



## Activity 4: Connection to Country and Spirituality



### Video Resource

PCC4U/IPEPA Yarn: Cultures, beliefs and the end-of-life journey (5:34)



### Thinking Points

1. Consider the strengths of Aboriginal and/or Torres Strait Islander cultures and identify how these strengths would be of benefit for those affected by life-limiting illness?
2. Watch the video resource 'Cultures, beliefs and the end-of-life journey' and reflect on some of the beliefs that Australian Indigenous peoples might have with regard to health and wellbeing, and the end-of-life journey.



### Other Video Resources

- Importance of land (2:18)
- Who we are: Country/Place (6:30)
- Cultural knowledge (2:29)
- What are song lines? (1:52)



## Activity 5: Health and wellbeing



### Key Video Resource

Spirituality (Dadirri) (3:42)



### Thinking Points

1. Reflect on the concept of social and emotional wellbeing described in this section and review the 'wheel' diagram. How is this way of understanding wellbeing similar to or different from your perspective?
2. Watch the video resource 'Spirituality (Dadirri)' and engage in this brief meditation led by Elder, Dr Miriam-Rose Ungunmerr.



### Other Video Resources

- Wellbeing – what Aboriginal people know? CULTURE (8:35)
- Social and emotional wellbeing – Indigenous point of view (18:53)
- Resources from Australian Indigenous HealthInfoNet:
  - Country, culture and spirituality
  - Family, kinship and community

## Section 3: UNDRIP and the provision of palliative care

### Learning outcome

After completing this aspect of the focus topic, students will be able to identify the key features of the United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP) that relate to provision of palliative care for Australian Indigenous peoples.



### Activity 6: United Nations Declaration on the Rights of Indigenous Peoples



### Key Video Resource

[UN Declaration of the Rights of Indigenous Peoples](#) (10:27)



### Thinking Points

1. Watch the video resource 'UN Declaration on the rights of Indigenous Peoples' developed by the Australian Human Rights Commission. As you watch this video, write down what you learn about the meaning of this historic document to Australian Indigenous peoples.
2. Consider how the term 'self-determination' can be relevant at an individual level. How would you facilitate the right to self-determination for an Aboriginal and/or Torres Strait Islander person affected by a life-limiting illness?







- How were the rights to self-determination, dignity and palliative care supported in this story?

## Section 4: Historical and ongoing trauma and barriers to palliative care

### Learning outcome

After completing this aspect of the focus topic, students will be able to demonstrate an awareness of the historical and ongoing trauma that contributes to the current barriers that prevent Australian Indigenous peoples accessing palliative care services.

### Activity 9: Historical trauma

### Thinking Points

1. Reflect on the impacts of historical trauma outlined in this activity:

- Social exclusion
- Institutionalised racism and discrimination
- Undermining law, society, culture and belief systems
- Intergenerational trauma

Outline how your understanding of either Aboriginal and/or Torres Strait Islander health has changed as you have spent time focusing on historical events and their impact.

How will this newly recognised understanding impact the way that you practise and deliver care to Aboriginal and/or Torres Strait Islander people?

## Activity 10: Trauma, healing and resilience

### Key Video Resource

Intergenerational Trauma (4:02)

### Thinking Points

1. Reflect on the impacts of ongoing trauma outlined in this section and note the ways that your understanding of the health and wellbeing of Australian Indigenous peoples has changed as you have engaged with this content.
2. Watch the video resource 'Intergenerational Trauma' and consider the imagery and storytelling used in the video. How do these support your understanding of what health and wellbeing means for Australian Indigenous peoples, and the strengths of these cultures?

3. Go to the [Healing Foundation](#) website and spend some time reviewing their resources. Reflect on what you have learned about the trauma-aware, healing-informed approach to care.



## Related Links

- ① [Journey of Health and Wellbeing \(10:44\)](#)
- ① [Telling our Stories – Our Stolen Generations \(Jack Charles\) \(3:17\)](#)
- ① [Make healing happen: It's time to act – Healing Foundation](#)
- ① Tujague, N & Ryan, K. (2021). [Ticking the box of cultural safety is not enough: why trauma-informed practice is critical to Indigenous healing](#). *Rural and Remote Health the International Electronic Journal of Rural and Remote Health Research, Education, Practice and Policy*.



## Activity 11: Barriers to and enablers of palliative care



### Key Video Resources

PCC4U/IPEPA Yarn: [Barriers to accessing palliative care](#) (3:36)

PCC4U/IPEPA Yarn: [Deep, genuine listening](#) (2:05)

Greg Chatfield's Story: [An Indigenous Palliative Care Journey](#) (13:57)



### Thinking Points

1. View the PCC4U/IPEPA Yarning video resources, 'Barriers to accessing palliative care' and 'Deep, genuine listening'. Identify practical ways through which you, as an individual health professional, can make a difference through the way you approach, communicate, accommodate, and build relationships and trust with Aboriginal and/or Torres Strait Islander people and their families.

2. View the video 'Greg Chatfield's story' and reflect on the following questions:

- What were the barriers experienced by Chatty and his family with regard to accessing palliative care?

- What influenced or enabled the family to access palliative care after their initial reluctance?

- What benefits do Chatty and his family talk about from their experience of palliative care?

- Consider the statement that Ros (palliative care nurse specialist) made,  
*“Chatty said, ‘Thank you for making me feel safe’. I think for Chatty it was that he trusted me with cultural care as well. I didn’t pretend to know what I should or shouldn’t do, but I listened to him, and he taught me what to do.”*

What was it about the approach of healthcare staff that supported Chatty’s feeling of safety in the palliative care service?



## Section 5: Communication and family-centred palliative care

### Learning outcome

After completing this aspect of the focus topic, students will be able to demonstrate enhanced capability in communicating with and delivering family-centred care to Australian Indigenous peoples affected by life-limiting illness.



### Activity 12: Palliative care is holistic and family-centred



### Thinking Points

1. Consider the 'living model' for Aboriginal and/or Torres Strait Islander palliative care described in this section and reflect on three elements that you, as an individual health professional, can improve to better support Australian Indigenous peoples affected by life-limiting illness. Make some notes on your reflections or discuss with a friend/colleague.
  
2. In the next conversation you have with an Aboriginal and/or Torres Strait Islander person or family you are providing care for, ask this question, "What specific values or cultural considerations would you like us to be mindful of while you are in our care?". Listen well to their response.



### Related Links

- 🎯 [Yarning about palliative care \(1:00\)](#)
- 🎯 [Aboriginal Palliative Care \(10:22\)](#)

## Activity 13: Communication

### Key Video Resource

Edited Version: Tom's Story (PART 1)

### Thinking Points

1. Review the video, 'Tom's Story (PART 1)' and consider the expert commentary:
  - Reflect on your thoughts about the interaction and the comments made

- How have you felt when you have cared for a person whose cultural background was different to your own?

- Using the clinical yarning framework, rewrite one of the conversations between Tom and Sarah or Nancy to reflect the principles of the framework.

- What changes can you make in your approach to Aboriginal and/or Torres Strait Islander patients and families to improve communication?

2. When you feel more confident in your communication skills, arrange to have some simulation or role play conversations with others who are also learning these skills. If possible, ask an Aboriginal and/or Torres Strait Islander health professional (or other healthcare worker who identifies as Aboriginal and/or Torres Strait Islander) to observe your conversations and provide their feedback.

3. Ask to spend time with an Aboriginal and/or Torres Strait Islander health professional as they work with their clients and observe their communication. Discuss what you learn with another student or colleague.



## Activity 14: Advance care planning conversations



### Key Video Resource

Finishing Up – Advance Care Plans on Groote Eylandt (16:12)



### Thinking Points

1. Review the video, 'Finishing up – Advance Care Plans on Groote Eylandt' and reflect on the approach of healthcare staff:

- What words do they use to talk about dying and death?

- How do they describe advance care planning?

- What are the important concepts that are explained?

- How do they show respect and cultural-responsiveness during this interaction? (Tip: you might find it helpful to go to Activity 12 to refresh your knowledge of key communication principles.)

- What kind of experience does this appear to be for the person and family involved?



## Related Links

- [Aboriginal and Torres Strait Islander Discussion Starter](#)
- [Advance Care Yarning: Decision making for end of life – for Aboriginal People in lutruwita/Tasmania](#)
- [Taking care of dying time \(4:11\)](#)
- [Discussing choices – Indigenous Advance Care Plans – A learning resource \(26:41\)](#)



## Activity 15: Symptom management



### Key Video Resource

Edited Version: Tom's Story (Part 2) (6:09)



### Thinking Points

1. Review the video, 'Tom's Story (Part 2)' and consider the expert commentary:
  - Reflect on how you would approach a conversation about using morphine for pain and symptom management in a situation like this where there was an obvious reluctance



- Write down the explanations you would use as well as other communication techniques that demonstrate respect and support the person to feel culturally-safe.

2. Find out about the kinds of roles that Aboriginal and/or Torres Strait Islander health professionals have in clinical practice settings in your state/territory.

3. Find out if there is an Aboriginal and/or Torres Strait Islander Community Controlled Health Service in your area. If there is, find out what their involvement is in caring for people affected by life-limiting illness.



### Related Links

-  [Improving patient understanding: a unique and valued profession – Aboriginal and Torres Strait Islander Health Workers \(3:33\)](#)
-  [Understanding morphine](#) – Cancer Council Qld



## Section 6: Cultural considerations at the end of life

### Learning outcome

After completing this aspect of the focus topic, students will be able to recognise the cultural considerations associated with end-of-life care, grief and bereavement for Australian Indigenous peoples.



### Activity 16: Cultural-responsiveness at end of life



### Key Video Resources

PCC4U/IPEPA Yarn: Cultures, beliefs and the end-of-life journey (5:34)

ECU Scenario: Passing On (4:54)



### Thinking Points

1. Review the video, 'Passing On' and reflect on the following points:
  - What is most important to the patient's daughter at this time?

- How does this differ from what is important to the nurse in the scenario?

- How could the nurse have improved her communication?

- In an ideal world, how should the healthcare team have dealt with this situation?

- What changes could be made to the health service to better care for both Aboriginal and/or Torres Strait Islander people who are at the end of life? Consider both physical changes as well as policy changes.

2. Look at the list of resources introduced in this section to help health professionals learn about cultural considerations for Australian Indigenous peoples receiving palliative care. Choose one resource to review and make some notes about what you learn and discuss your experience with a friend/colleague.

### Booklets and Guides:

- ① Cultural considerations – providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples (IPEPA)
- ① Sad News, Sorry Business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (Qld Health)

### eLearning Modules:

#### Gwandalan Palliative Care eLearning Modules:

- ① Introduction to Aboriginal and Torres Strait Islander Palliative Care and Cultural Practice
- ① Supporting Choices at End of Life
- ① Strengthening Partnerships.



## Activity 17: Cultural practices and rituals



### Video Resources


Final Footprints: Palliative Care Australia (11:38)



### Thinking Points

1. View the **Final Footprints** video and outline the key points that are made about what may be important to Australian Indigenous peoples and their loved ones as they approach end of life.
2. Find out about local Aboriginal and/or Torres Strait Islander communities in your area and what resources are available for healthcare professionals to guide culturally-responsive care during the end-of-life journey.
3. Reflect on your current or recent practice contexts. What support does the healthcare facility provide to support Aboriginal and/or Torres Strait Islander people and their families during the end-of-life journey?

## Section 7: Reflections on what you have learnt



It is essential for all healthcare professionals to develop the capacity for reflection and self-evaluation of their professional and personal experiences, and to consider how this can impact on themselves and others.

Consider the focus topic you have just completed and reflect on the following questions to assist with your ongoing development:

1. What key points have you learnt from the activities in this module that will help you in providing care for people with life-limiting illnesses and their families?

2. What specific strategies do you plan to incorporate as a graduate healthcare professional?

3. Do you see any difficulties using what you've learnt here as part of your practice as a healthcare professional? If so, what strategies might you use to address these difficulties

# Congratulations!

## You have now completed Focus Topic 2 of PCC4U.

You should now be able to:

Critically reflect on power, privilege and the institutional place of health services and professionals and how these impact on provision of palliative care for Australian Indigenous peoples.

**[Section 1]**

Describe traditional kinship systems, and spiritual connections to Country and culture that influence the views that many Australian Indigenous peoples have of health and wellbeing.

**[Section 2]**

Identify the key features of the United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP) that relate to provision of palliative care for Australian Indigenous peoples.

**[Section 3]**

Demonstrate an awareness of the historical and ongoing trauma that contributes to the current barriers that prevent Australian Indigenous peoples accessing palliative care services.

**[Section 4]**

Demonstrate enhanced capability in communicating with and delivering family-centred care to Australian Indigenous peoples affected by life-limiting illness.

**[Section 5]**

Recognise the cultural considerations associated with end-of-life care, grief and bereavement for Australian Indigenous peoples.

**[Section 6]**



You can download your Record of Participation from the PCC4U website.