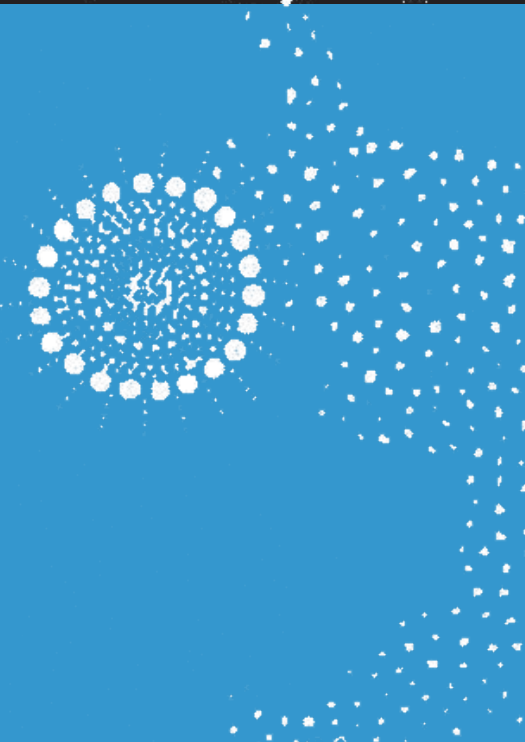


Yarning Our Wishes

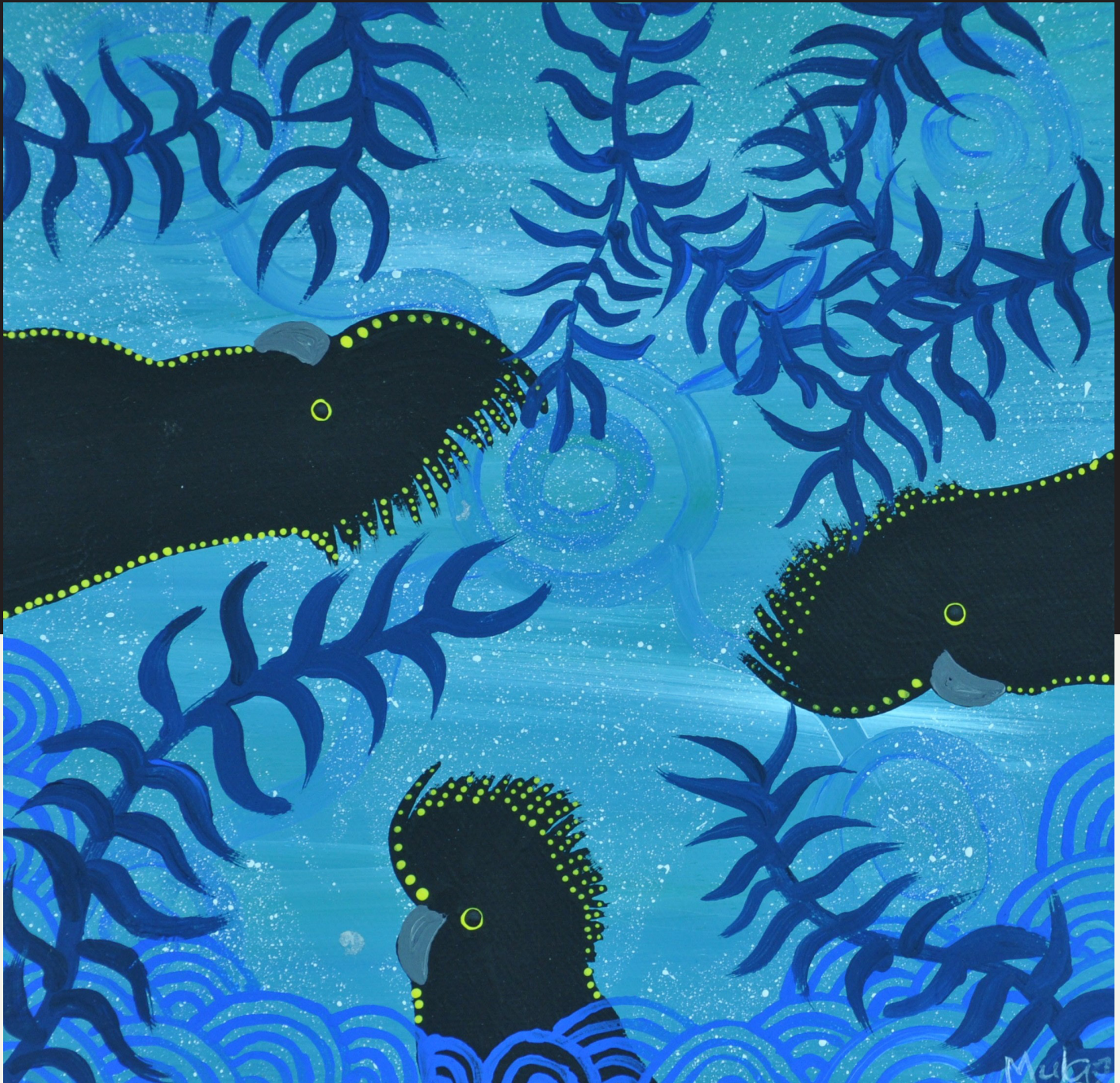


THE
GROUNDSWELL
PROJECT



NSW

Health



This is a guide to accompany the video 'Yarning Our Wishes':

<https://www.youtube.com/watch?v=02H3E3jbcBY>

It is aimed at health professionals and community organisations working in end-of-life care and with Aboriginal and Torres Strait Islander community members of Western Sydney. The guide highlights key points and learnings from the video, as well as other cultural considerations when working with this diverse and culturally rich group in end-of-life care.

This resource was produced in April 2021.

We are storytellers. We are listeners. We are very creative people. We are spiritual people.

The GroundSwell Project came together with partners, CuriousWorks, South Western Sydney Local Health District (SWSLHD) Palliative Care and Aboriginal communities in South Western Sydney, for conversations about what matters and what's missing when it comes to planning for and caring for someone when they are dying.

First Nations people have been caring for their dying community members for millennia. Family and kinship groups play an important role in this. How does advance care planning and palliative care fit into this? How can the health system adapt to be more culturally responsive for end-of-life care?

Aboriginal and Torres Strait Islander people have been storytellers for tens of thousands of years. They call it 'yarning', communicating about what is important, passing on knowledge, and telling stories. Yarning is integral to building strong relationships and trust. When it comes to end-of-life discussions, it's important to talk about yarning and to do it.

Yarning can take place at any stage or place of work, whether you work in health (such as in hospitals, general practices, palliative care, aged care and Primary Health Networks) or within the community across Western Sydney, through community services working with the aged, families, parents or children. And yarning can be used to talk about important end-of-life issues such as advance care planning, as Karen Beadson describes here:

"Advance care planning can be done by anyone. It doesn't have to be by palliative care specialists or nurses or our palliative care workers who come in. It can start with the GP. It can start with the nurse on the ward. The person who has seen the person first and you can just start raising these conversations around, 'Have you thought about where you'd like to be cared for? In a hospital setting or at home? If it is at home, what do we need to put into place to make it the most comfortable for you?' ... we should be talking about cultural considerations."

Aboriginal and Torres Strait Islander communities have deep rituals, belief systems and values embedded around death and dying. This is another reason why conversations are imperative for clear guidance around end-of-life wishes.

"The best way to engage the Aboriginal and Torres Strait Islander community is just to talk to them and listen. Just sit down with them, give them the information, listen to their feedback and just keep having that yarning with them."

– Neville Williams-Boney

Did you know?

According to the latest census, Western Sydney has the highest population of Aboriginal people in Australia. Out of around 2 million people living in Greater Western Sydney, 250,000 identify as Aboriginal (Census 2016).

In 2016, there were more than 50,000 First Australians over the age of 60 and, by 2026, this number will grow to around 90,000. The need for understanding, communicating and sharing of end-of-life resources through yarning and listening is vital (Palliative Care Packages, natsicc.org.au).



Things to consider when yarning

Language

Medical terminology can be confronting and confusing for most people. Be mindful of your language talking about end-of-life issues, and make sure you communicate in a direct and accessible way.

“When I explain what palliative care is to my mob, which is very scary as it’s a ‘white’ word, but how I explain it to my mob is that it’s Latin for good quality care. It’s comfort care. So the word ‘palliative’: ‘Don’t get frightened by the word “palliative”; I tell them. It’s just a word connected to that comfort care. Palliative care is managing symptoms. Palliative care is managing your pain levels. Palliative care is around where you want to die. What your wishes are. What it’s going to look like for you. If it’s at home, it’s linking services to provide that cultural safety net and that support for you to pass at home. It’s about – if your wish is to die in a hospital, it’s still about connecting you to people such as our ALOs [Aboriginal liaison officers] who are very experienced in this area and very compassionate.”

– Cheryl Porter-Pedras

Cultural considerations

Ask your client if there are any cultural considerations you need to be aware of when yarning. Do they wish to speak to someone who is male or female? Are there any cultural protocols you should be aware of? Is there a less formal way you can have a yarn and capture their end-of-life wishes? What is their family and individual totem? Could you ask your organisation for some cultural competency training? What are your client's beliefs around death and dying? How best could you support them?

Some questions to consider asking

- 'Where are you from? What (Aboriginal) country?' *Although a client may come to a South Western Sydney service, it is possible they are off country.*
- 'Who is your mob? Where are their families residing?' *This will lead to knowledge around family support at home or whether family is somewhere else.*
- 'Have you discussed with anyone your wishes around your health as your needs change? It is important to let your loved ones and doctor know your wishes.'
- 'What is important to you? Do you want to be cared for at home or at the hospital? If at home, what support is already there? How can we better support your carers and family members? Is there someone you'd like to make medical decisions for you if you're unable to?'
- 'Have you thought about your wishes of where you would like your body to be after death? Where would you like your body to go? Would you like to be buried, cremated or something else?'

"This is trying to find a way of putting our plan into action. Sharing it with our family and our kids because I think if we have a plan, put it together, you don't have that burden on our families to have to think, 'What should we be doing? Where should we be taking her? Should she go back to Country with her mother and father? Or can we keep her here where we are?' You're helping your kids with that burden because you've made that decision."

- Aunty Kay Bussell

Why it's important to have end-of-life discussions

"I think it's important to talk about. With my family, I have 55 grandkids and all of us think differently. There were a lot of opinions about what should have been done with Dad when he passed. If we had an Advance Care Directive, it would have just overridden anybody's concerns about stuff like that and would have saved us all this grief and trauma because there were fights amongst Dad's sisters and brothers about what should happen with him but had we had an Advance Care Directive from Dad, it would have just been what he wanted."

- Bevan Rankins

"Health providers have some expert knowledge. Aboriginal communities have some expert knowledge. We work together to share that knowledge so that we can care for someone at the end of their life."

- Cheryl Porter-Pedras

Acknowledgements

We would like to acknowledge the NSW Ministry of Health for funding this project. We would like to thank the Tharawal Aboriginal Medical Service and the Gandangara Local Aboriginal Council, as well as the service providers and community members who generously shared their voices in 'Yarning Our Wishes'.

We've been given permission from Leanne Watson, Artist and Managing Director of Darug Custodian Aboriginal Corporation, to illustrate this resource by herself and other artists with imagery of totems. One image used in this resource is of the black cockatoo which was communicated as an important family totem to one of the participants. Totems are a critical part of First Nations groups' cultural identity, with multifaceted and interrelated stories connected to song, dance and symbolism. They also may be something raised by community members as something of importance in relation to end-of-life care.

Resources

Here are some important resources about end-of-life care, particularly when working with diverse cultural groups:

'Yarning Our Wishes' on YouTube:

<https://www.youtube.com/watch?v=O2H3E3jbcBY>

A Journey Into Sorry Business, South Western Sydney PHN

<https://www.swsphn.com.au/aboriginal-palliative-care>

Easy-to-read resources from the Ministry of Health

<https://www.health.nsw.gov.au/palliativecare/Pages/easy-read-resources.aspx>

Supportive Care "Into the Dreaming": A Palliative Care Guide for Aboriginal and Torres Strait Islander people through "Sorry Business"

<http://www.hnehealth.nsw.gov.au/Aboriginal-Health/Documents/2019%20PALLIATIVE%20CARE%20BOOKLET.pdf>

Palliative care resources

[Aboriginal and Torres Strait Islander Peoples \(palliaged.com.au\)](http://palliaged.com.au)

Best practice

[Aboriginal and Torres Strait Islander Care \(caresearch.com.au\)](http://caresearch.com.au)

Australian Indigenous Health Info Net is a portal for information and resources across a wide range of Indigenous health matters.

<https://healthinfonet.ecu.edu.au/>

The palliative care and end-of-life care section is here:

<https://healthinfonet.ecu.edu.au/learn/health-system/palliative-care/>

It links to three subsections:

Culturally appropriate palliative care and end-of-life care

<https://healthinfonet.ecu.edu.au/learn/health-system/palliative-care/culturally-appropriate/>

Grief and bereavement

<https://healthinfonet.ecu.edu.au/learn/health-system/palliative-care/grief-and-bereavement/>

Planning ahead

<https://healthinfonet.ecu.edu.au/learn/health-system/palliative-care/planning-ahead/>