Yarning your Wishes

A palliative care book for Aboriginal & Torres Strait Islander people

South Eastern Sydney
Local Health District

NSW GOVERNMENT

Acknowledgment of Country

South Eastern Sydney Local Health District would like to acknowledge the Traditional Custodians on whose lands our facilities are located; the lands of the Dharawal, Gadigal, Wangal, Gweagal and Bidjigal peoples.

We would like to pay our respects to the Elders past, present and those of the future. We also acknowledge Aboriginal peoples' connection to country, culture and heritage.

South Eastern Boundaries' is based on the South Eastern Sydney Local Health District boundary map and replicates the locations of the facilities from Sydney's Central Business District in the north to the Royal National Park in the south

The Meeting Places (circles within circles) represent The Sutherland Hospital, St George Hospital, Prince of Wales and Royal Hospital for Women, Sydney and Sydney Eye Hospital, Calvary Health Care and War Memorial Hospital

The lines with dots represent the patient's journey from their homes, to and from the facilities where people access our healthcare services

The other symbols are the local Aboriginal Community Elders, Men, Women and Children who call the South Eastern Sydney area their country and home

The dark and light blue circles are the strong currents and waves which surround the beautiful coast line of the east coast

The assortment of coloured dot patterns are of the surrounding Aboriginal Nations which surround and connect all Aboriginal Nations and our people to each other in respect and harmony

Disclaimer

No person should rely on the contents of this toolkit without first obtaining advice from a qualified person.

SESLHD acknowledges that content in this toolkit has been extracted from materials created by Murray PHN and South Western Sydney PHN.

Throughout this document the term "Aboriginal" is used to represent "Aboriginal and Torres Strait Islander" in recognition that Aboriginal people are the original inhabitants of New South Wales.

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“Forever on Country”

Aboriginal Supportive & Community Care Artwork by Caitlin Trindall – MiriiArt

Grandfather Sun is the giver of life, warmth, and positive energy. The sun is in the centre of the artwork to reflect its significance, and to encapsulate the client’s connection with the sun throughout their life.

The dotted lines wrapping around the sun symbolise the different people, teams and services who support and care for the client. The sun rays coming out of the centre reflect the various pathways to care and comfort, and the journey a client takes as they return to country, both physically and spiritually.

In the background are many symbols of meeting places, which are representative of people and communities who have played a role in the client’s life; sharing joy, love and creating beautiful memories to be cherished forever.

A beautiful big whale tail is prominent to pay respect to the South Eastern Sydney Local Health District that the program covers, the beautiful lands of the Dharawal speaking people, specifically the saltwater people across our coastal regions. Adjacent to the whale tail are arched symbols which represent our Elders as our pillars of strength.

They serve to remind us of our ancestors who have guided us on our journey, and who we will be reunited with once again.

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What is meant by Country?

Country includes land, waterways, seas, skies as well as the energy and space in between. It also encompasses relationships. Relationships with plants, with animals, and with Ancestors (to name a few).

"First Nations relationships within Country are grounded in reciprocity. Reciprocity is about mutual respect and exchange.

So, while Country is place, it is also relationship."

Gemma Pol (Wiradjuri, Ngemba and Paakantji) - Common Ground (commonground.org.au/article/what-is-country)

Palliative Care Yarning

This booklet has been prepared to support Aboriginal people to journey into the health system through 'Sorry Business' (life-limiting illnesses). In consultation with Aboriginal Elders, we aim to connect health services with Aboriginal wisdom when assisting and caring for those with life-limiting conditions while honouring their connection with land, community, family and tradition.

We value the importance of advance care planning yarning, and this resource has been developed to provide culturally appropriate, respectful and mindful information to encourage Aboriginal people in opening conversations about their rights, wishes and how to plan when circumstances change through their lives.

We hope you, your family and community find this booklet useful, and we encourage you to share it with your mob.

Why yarning your wishes?

As we get older, we start to question how we will take care of business and wonder what the most important things for us are.

- We might want to be cared for by an important person in our lives
- We might want to wear traditional clothes or listen to music that we like
- We might want to be taken back to Country after we pass away
- We might want to know who will be responsible to take care of our business (money, belongings and healthcare)
- We might want to make sure that healthcare workers understand that we might need space for our family and mob to visit us

Planning ahead will help to honour what is important to you, what life means to you and what you want to happen even when you are not able to make decisions for yourself

How can I plan ahead?

You can start planning by yarning and making four documents.

Who do I yarn to?

Yarn to your family and those who you think will be making decisions about your health when you can't make decisions for yourself.

Yarn to your Aboriginal Health Worker. They can help you with understanding what is available in your region and can yarn up for your wishes.

What documents do I need to PLAN AHEAD?

WHAT DOCUMENT?	WHAT'S IT FOR?	WHO SHOULD I YARN WITH?
Advanced care Plan	What medical treatment & care do I want in the future?	My family and my GP
Will	Who will get my stuff after I pass away?	My family and a solicitor
Enduring Guardian: Medical & accommodation decisions	Who will make decisions about my health & where I live if I cannot make decisions?	My family and a solicitor
Power of Attorney	Who will make decisions about my money if I can't?	My family and a solicitor

What medical treatment and care do I want in the future?

ADVANCE CARE PLANNING

What is advance care planning?

Deciding what you do and don't want in your future medical treatments is called advance care planning. It involves yarning to your friends and family about things that matter to you like your choices and values.

Then making a document (called Advance Care Directive) to record your specific choices.

You can decide in advance:

- Where you would like to be cared for in your last days (for example, at home or hospital)
- Where you would like to be buried and if you would want to be taken back to Country
- Treatments you would like to receive or refuse (for example, surgeries, pumping on your chest and electric shocks if your heart stops beating, medication injected into your veins, putting breathing tubes in your throat when you can't breathe by yourself, etc). Advance Care Directives can be reviewed at anytime

Did you know?

Advanced Care Directives are legal documents that will only be used when you can no longer say what your wishes are.

I want more information – who should I talk to?

Talk to your Aboriginal Health Worker, solicitor or GP.

Ask your Aboriginal Medical Service for the Advanced Care Yarning – Giving our Mob a Voice kit.

Who will get my stuff after I pass away?

WILL

What is a will?

A will is a legal document that says who your stuff will go to when you pass away. It instructs who your money, property, land and belongings (photos, furniture, jewellery, artwork, etc) will go to.

Are wills expensive? Where can I make mine?

You can get help to write a will from a solicitor (lawyer), but they may charge a fee. NSW Trustee and Guardian also offer low-cost will services (contact details below). Some people choose to buy a will kit and write it themselves. This can be okay, but if it's not done properly, it can cause problems for your family later.

Where can I get more information?

Talk to your Aboriginal Health Worker or NSW Trustee & Guardian on 1300 364 103 or tag.nsw.gov.au (check these details)

Did you know?

Your will can also say where you want to be buried, including getting back to Country and funeral arrangements.

Who will make decisions for me if I can't?

POWER OF ATTORNEY

Giving someone Power of Attorney means that they can look after your bills and money if you can't. There are strict rules and guidelines for people who are given Power of Attorney to follow.

Putting this in place means that, if you are sick or can't manage your money by yourself, your Power of Attorney can use your money to:

- Pay bills – like telephone, internet, credit card
- Look after your home – pay rent or mortgage, pay for repairs
- Use your money to buy you the things you need – like food and clothes
- Ensure your money is available to pay for your care needs

Where can I make mine?

You can make your Power of Attorney document with your local solicitor or community legal centre.

Did you know?

You can decide how much power you can give to your attorney. For example, you might only give them the power to pay your bills.

ENDURING GUARDIANSHIP

An Enduring Guardian is someone who you ask to make decisions about your health and wellbeing needs if you can't make them. This includes:

- Where you live
- Discussion with doctors about treatment and medication
- Dental care
- Options for care including care in your home or a care facility

You can sign a document nominating someone to be your Enduring Guardian and you can change it at any time.

It should be someone you trust, who knows you well and understands your wishes. In Aboriginal societies, the next of kin is not always the preferred spokesperson for the patient.

Nominating someone of your choice to be your Enduring Guardian helps health care workers understand who you want them to talk to about your health and decisions.

Did you know?

Enduring guardians can't make decisions for you about your money, property, vote or make a will under your name.

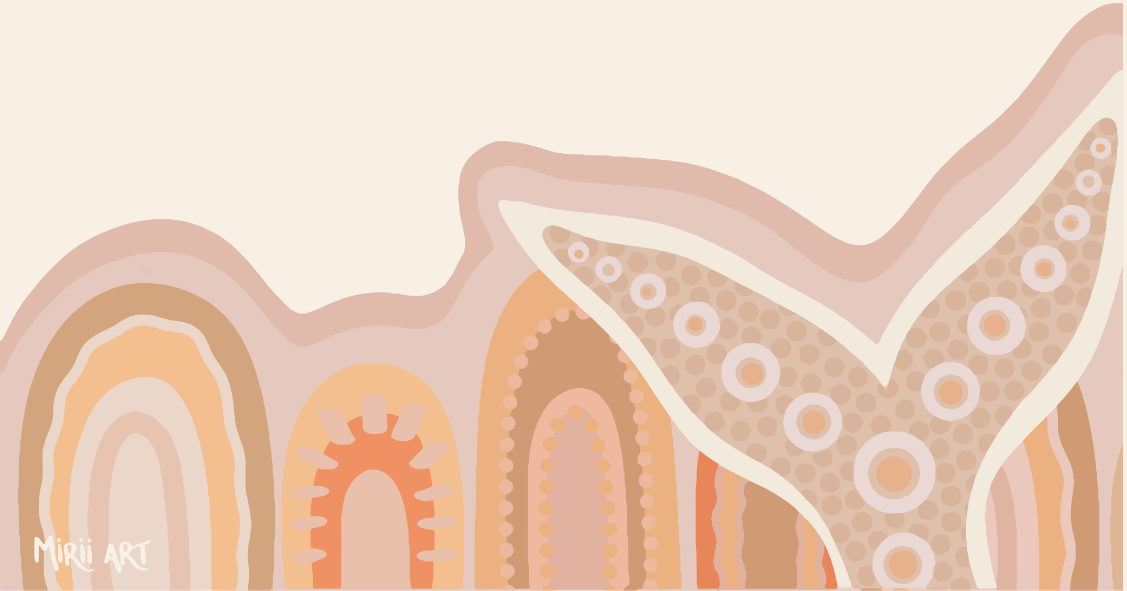
What is palliative care?

Palliative care strives to ensure quality of life for those who have an illness that can't be cured. It offers professional care, pain-free living and support for the individual, family and/or carer.

Where can I access palliative care?

- Palliative care can be offered in your home
- A palliative care unit
- Residential aged care
- In the hospital

Ask your Healthcare professional or GP to provide you with information on this process



How does palliative care support decision making?

Palliative care works through conversations that will help you and your family make decisions about your place of choice for care and your cultural needs.

Palliative care health staff (doctors, nurses, etc):

- Want to make your journey as comfortable as possible
- Are specially trained to work in this area
- Will support you where you want to be cared for
- Will provide support to family and/or carers when needed.

YOU CHOOSE who is involved in your care.

You could choose:

- Your GP and specialists
- Aboriginal health workers
- Palliative care services
- Home carers

What can palliative care help me with?

Palliative care services can provide specialist advice, support and effective care of symptoms to assist the family and persons living with an illness that can't be cured.

Depending on what you and your family want, the palliative care team will provide:

- Assistance for you and your family to come together to talk about Sorry Business
- Practical advice and support for the family and carers about making you more comfortable
- Management of pain and other symptoms, such as nausea, that you may be feeling
- Resources such as equipment you may need at home
- Links to other services such as home help and financial support
- Support and culturally appropriate care of what is most important for you
- Referral to bereavement services if needed to help and support family and community after a loved one passes away.

"We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, to love...and then we return home"

Aboriginal proverb

My Notes

This is a page where you can write down anything that you might want to think about later or talk to your family, Aboriginal health worker or the supportive & palliative care team.

How involved would you like to be in decisions about your care?

What brings you the greatest joy in life?

If you were very sick or at the end of your life, what would be some of the most important things to you?

If you needed increasing amounts of medical care or support from family, friends or carers at the end of your life, where would you want to be?

- ☐ At home
- ☐ In a hospital
- ☐ In an aged care facility (a nursing home)
- ☐ Living with a loved one Other

If you were at the end of your life is there anything that you would not want?

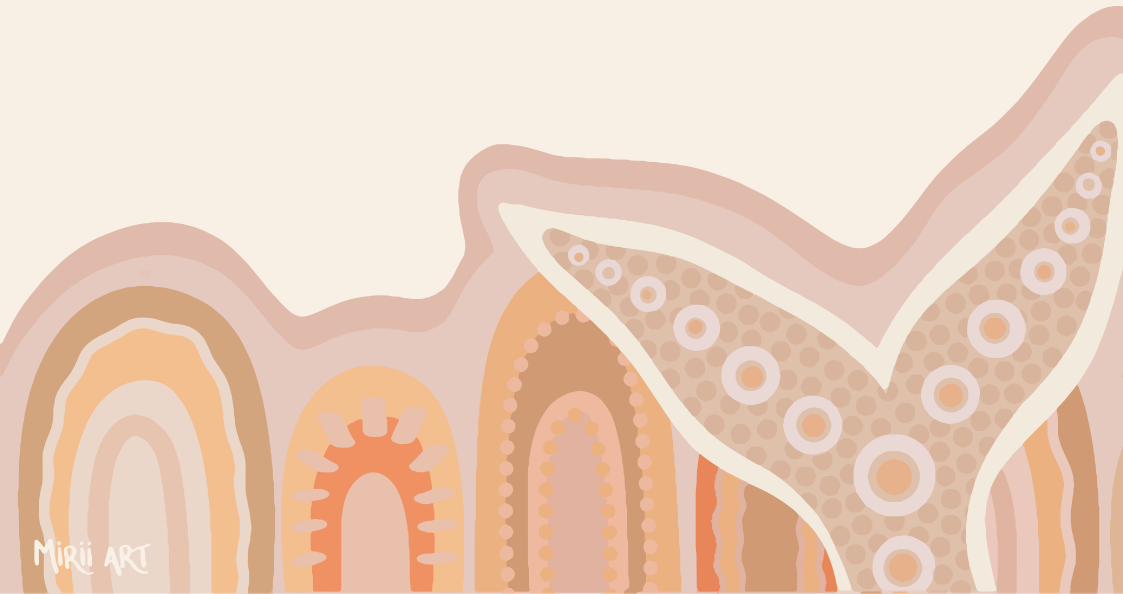
Do you have any fears or concerns about the end of your life or dying?

Is there anything else that is important to you about what you want at the end of your life that you would like to write down?

Help and Information

Help with legal documents:	
NSW Trustee & Guardian Can help with your planning ahead documents.	**Ph:** 1300 554 791 **Website:** www.tag.nsw.gov.au/wills/make-will/wills-aboriginal-people
Aboriginal Legal Service (NSW/ACT) Can help you find a local solicitor to make your Will.	**Ph:** (02) 8303 6600 **Website:** www.alsnswact.org.au
Funerals and financial assistance:	
Department of Human Services (Centrelink) Can help with disability, sickness and carer allowances.	**Ph:** 13 27 17 (Mon-Fri 8am-5pm) **Website:** www.humanservices.gov.au
NSW Aboriginal Lands Council Can help you to discuss your eligibility for Funeral Assistance Grants.	**Ph:** 1800 647 487 **Website:** alc.org.au/funeral-fund
Service NSW Provides a one-stop access to government services via online, phone or in-person at its service centres.	**Ph:** 13 77 88 **Website:** www.service.nsw.gov.au
Can Assist Financial and accommodation assistance for cancer patients.	**Ph:** 1300 226 277 **Website:** www.canassist.com.au
Medicare services for Indigenous Australians To see if you are eligible for Medicare help with cost of healthcare and medicine.	**Ph:** 1800 556 955 **Website:** www.humanservices.gov.au/individuals/subjects/ medicare-services-indigenous-australians

Extra support (health, bereavement, counselling)	
Lifeline A crisis line that provides phone support. Available 24/7.	**Ph:** 13 11 14 **Website:** www.lifeline.org.au
Cancer Council Provides cancer information support, financial support and hardship assistance.	**Ph:** 13 11 20 **Website:** www.cancercouncil.com.au/aboriginalcancer
Advance Care Planning Australia Provides advice, support, training and education around Advance Care Planning.	**Ph:** 1300 208 582 **Website:** www.advancecareplanning.org.au
Palliative Care Australia Palliative Care Australia is the national peak body for palliative care. They provide resources, events and advocate for palliative care.	**Ph:** (02) 6232 0700 **Website:** www.palliativecare.org.au
13Yarn A First Nations crisis support line. Available 24/7.	**Ph:** 13 92 76 **Website:** www.13yarn.org.au
Brother to Brother A crisis line that provides phone support for First Nations men. Available 24/7.	**Ph:** 1800 435 799 **Website:** www.dardimunwurro.com.au
Caring@home Provides tailored resources for families, health professionals and clinical services to support the provision of palliative care at home for First Nations people.	**Ph:** 1300 600 007 **Website:** www.caringathomeproject.com.au/Family-CarerResources/Aboriginal-and-Torres-Strait-Islanderfamilies-resources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