



# Journey to Dreaming Toolkit

## Acknowledgement

The Aboriginal Health and Medical Research Council of NSW would like to acknowledge the original custodians of this land and pay our respects to Elders past and present, for they hold the memories, the traditions, the culture and hopes of Aboriginal Australia.

## Journey to Dreaming Toolkit

### How to use this toolkit

This Toolkit refers to the sensitive, but very important topic of dying and death. Its purpose is to provide high quality information to help Aboriginal and Torres Strait Islander families and their healthcare workers provide family-centred palliative and end-of-life care for a loved one. It also contains some important information that might be useful for individuals needing end-of-life care.

Palliative care can be a difficult subject to think and talk about. Everyone is different, and so every conversation needs to be tailored to support a person's individual needs. This Toolkit helps promote open, honest ways to yarn that builds trust and can help the healthcare team enhance the quality of life of the person, and their family, by supporting personal choices that are respectful of family and culture (IPEPA, 2020).

### Overview

#### What is palliative care?

Palliative care is provided for a person who is living with a long-term (chronic) illness where there is no known cure. The main purpose of palliative care treatment is to ensure the highest possible quality of life. This means palliative care should have a holistic approach, supporting the spiritual, cultural, emotional, social, psychological and physical needs of the person and their family (VACCHO, 2019).

Palliative care is provided by a palliative care team. This includes a range of different members of a health care team such as Aboriginal Health Workers, Aboriginal Community Controlled Health Services, case managers, Aboriginal Home and Community Care Workers, and the family itself.



## Principles of palliative care

### Quality of life

The focus of palliative care is on quality of life. This means something different to everyone so to understand what this means for each person, you must yarn with them and find out how best to support them to live with purpose and comfort.

Palliative care aims to put the sick person and their family at the centre of their healthcare. This means they are listened to, informed, respected, involved in decision-making and their wishes are honoured throughout their healthcare journey.

### Palliative care is about:

- › **Living, not dying** – the intention is not to make life longer or shorter, but to respect the natural dying time.
- › **Quality of life** – supporting people to live as actively as possible in the time they have left.
- › **Holistic care** – looking after the whole person, not just focusing on their physical symptoms.
- › **Supporting families** – helping them cope during illness and loss, grief and healing.
- › **Inclusive care** – ensuring families are involved and respecting everyone's choices to provide individualised care.
- › **Comfort** – providing prevention and relief of pain and other distressing symptoms.
- › **Early identification and assessment** – supporting comfort-focused care and avoiding unnecessary treatments and hospitalisations.
- › **Respecting and supporting locations of care** – ensuring quality care is provided in the person's/family's choice of location; i.e. community, hospital or facilitating the choice to return to Country.

- › **Teamwork** – care is provided by a range of health professionals, trained volunteers, family, community and carers.
- › **Cultural safety and respect** – making sure the person, their family and their community are held in the highest regard, and providing care in a way that demonstrates respect for cultural practices and beliefs (World Health Organization, 2017; McGrath & Holewa, 2006).

### Care provided to a person and their family in line with the above principles ensures the following expectations are met:

- › They are at the centre of all planning and decision-making around palliative and end-of-life care.
- › Their individual, cultural and spiritual needs are honoured when care is planned and delivered.
- › They and their loved ones are treated in the way you would want to be treated in a similar situation.
- › Their preferences and values are recognised and respected.
- › The person and their family are treated with respect and dignity regardless of age, cultural background, religion or sexual orientation.

## Respect for cultural ways and language when talking about end-of-life care

Talking about end-of-life care with our loved ones can be difficult but it is important to begin this discussion so you can plan ahead. Here are a few guiding principles to keep in mind:

- › There is no right or wrong way to go about having this yarn, it's very personal to you, your family and friends, and to your cultural and religious beliefs.
- › Take time to think about what's most important to your loved ones and those around them. It is important not to rush this yarn.
- › Think about having a series of yarns over time. You don't need to resolve everything or make decisions all at once (HNELHD Aboriginal Health Unit, 2019).

You can find additional resources in the 'Other resources' section, or you can contact an Aboriginal Health Worker at your local Aboriginal Medical Service.

# Palliative care journey

## When does someone need palliative care?

A sickness that can't be cured is also known as a *life-limiting illness*. For our mob, the most common types of life-limiting illnesses are heart disease, diabetes, lung disease and cancer. Other life-limiting illnesses include chronic kidney disease, and dementia including Alzheimer's.

Palliative care is available to all people living with life-limiting illnesses no matter what type or where they are in their healthcare journey. Palliative care is not just for when someone is in the final days of their life, it can be provided after an early diagnosis, and at the same time as treatment - this will ensure quality of life and comfort remains central to the person's care.

Different palliative illnesses will have different pathways of decline (also known as illness trajectories). Some people get very sick and die quickly, others have a slow decline. People with chronic illness often have multiple episodes of being really sick, often in hospital, and can then recover in-between these times.

Palliative care during the final stages is about the provision of comfort. It can be hard to predict exactly when the end-of-life will be, which is why it's important to research the nature of the life-limiting illness and identify which pathway they are likely to follow. This information, together with a thorough assessment of what is important to the person and their family, can ensure quality, person and family-centred palliative care is provided.

When all treatment options have been exhausted, comfort care, such as pain management with a focus on maintaining quality of life, is used to manage a person's symptoms until their passing (Murray et al., 2005).

*Palliative care is helpful at any time once a person knows they have a life-limiting illness.*

## What does the palliative care journey look like?

The palliative care journey is different for everyone. Early assessment, identification and referral to necessary services can allow for appropriate management of pain and symptoms, care planning, and a greater level of control over the illness and its impacts for the person, family and carers.

How an illness progresses is different for everyone. Care needs throughout the palliative journey will therefore also change. It is important to have appropriate plans and support services available to assist in managing complex care needs.

## How can it help my mob?

*Palliative care services provide support by walking alongside the sick person and their mob on their journey with life-limiting illness towards the end-of-life.*

The main aim of palliative care is to help the sick person have the best quality of life possible, and to live with dignity and respect until they finish up. It also helps support families and the community in dealing with loss, grief and healing.

A team of specialists provide support wherever the sick person wants to be cared for – at home, on Country, or in the hospital or care home. They should be involved as much or as little as the person and family want them to be (IPEPA Southwest Aboriginal Community (WA), 2021)

## Location of Care

Not everyone with a life-limiting illness will need access to palliative care specialists or in-hospital care. For many people, care can be managed in community settings with the support of primary healthcare staff. Others will need access to specialist care from time to time for consultation and advice when symptoms (such as pain, psychological distress and reduced mobility) worsen (PEPA Project Team, 2020).

## The role of the Aboriginal Health Worker

Yarning with people about how they or their loved ones want to be cared for as they age or become sick is difficult.

Palliative care is a taboo subject for many communities. Dying and death is not widely discussed and some people think that talking about death can bring bad luck. The role of Aboriginal and Torres Strait Islander Health Professionals in helping people manage their fear, support effective communication and build trust is very important.

## Palliative care can help with:

<b>Physical pains and worries</b>	<ul style="list-style-type: none"><li>› Symptom management and assessment</li><li>› Comfort</li><li>› Medication support</li><li>› Specialist nurses and doctors</li><li>› Shared care with your GP.</li></ul>
<b>Movement and freedom</b>	<ul style="list-style-type: none"><li>› Occupational therapists can support the person to participate in activities to the best of their physical abilities</li><li>› Physiotherapists can help the person manage symptoms and pain through improved function and mobility</li><li>› Provision of equipment for home: including a hospital bed, wheelchair, walking frame, lifting hoist, shower chair and commode.</li></ul>
<b>Spiritual practice</b>	<ul style="list-style-type: none"><li>› Support of cultural beliefs and guidance</li><li>› Advocacy – supporting the person and family, their actions, and beliefs</li><li>› Yarning with family.</li></ul>
<b>Supports and services</b>	<ul style="list-style-type: none"><li>› Social workers</li><li>› Navigating systems – supporting the person and their family to access the right support from health services</li><li>› Respite support – caring for the family to ensure everyone's quality of life is supported.</li></ul>
<b>Planning the journey</b>	<ul style="list-style-type: none"><li>› Advance care planning</li><li>› Legal documents including wills, Enduring Power of Attorney (EPA) and Advance Care Directives (ACD).</li></ul>

# Advance care planning

## Information for the individual needing end-of-life care

Having a say about your future medical treatment is called advance care yarning. This process involves thinking and talking about your values, beliefs, choices and what matters most to you. This gives your family, doctors, nurses and Aboriginal Health Workers the opportunity to respect your choices (HNELHD Aboriginal Health Unit, 2019).

You might assume your mob will know what your wishes are and what you may want at the end of your life, but everyone has different needs, wishes and expectations. This is why it is so important to yarn about what matters most to you now, while you are able to, to ensure your mob understands your wishes.

Big decisions don't need to be made in one go, but having early and regular yarns about your end-of-life care with your family, and healthcare team, can relieve the stress on you and your family, of having to make decisions without knowing your wishes. As a result of having these yarns, you may decide to appoint someone to make decisions on your behalf, this person is then known as your Person Responsible. It is important to let your healthcare team know who your Person Responsible is.

Once you have had these yarns, you may also choose to document your values, beliefs, health care choices, and what matters most to you, in what is called an Advance Care Directive (ACD).

**Ideally, advance care yarning should happen when the individual receiving palliative care is still well.**

<b>What does it say?</b>	<ul style="list-style-type: none"><li>› An Advance Care Directive says what healthcare treatments you would like to have, or refuse, should you become unable to make or communicate decisions yourself.</li></ul>
<b>Why is it important?</b>	<ul style="list-style-type: none"><li>› Because none of us can predict our future health needs. An Advance Care Directive makes it easier for your loved ones and healthcare staff to make decisions that reflect your choices and wishes.</li><li>› Technological advances mean there are treatments which can keep you alive when you are seriously ill or injured. This may prolong your life, but you may have different wishes about how you want to live, and the quality of life you want, in the last period of your life.</li></ul>
<b>When can it be made?</b>	<ul style="list-style-type: none"><li>› Your doctor will consider your Advance Care Directive to be valid only if:<ul style="list-style-type: none"><li>– You had capacity to make decisions when you wrote it, meaning that you fully understood the information available to you, and made an informed decision about the care you wish to receive.</li><li>– It has clear and specific details about treatments that you would accept or refuse.</li></ul></li></ul>
<b>When is it used?</b>	<ul style="list-style-type: none"><li>› An Advance Care Directive will ONLY be used when you do not have capacity/ability to decide for yourself or to communicate your wishes. An example is if you suffer a major stroke or heart attack and were unconscious and not expected to get better.</li><li>› Once finalised, your Advance Care Directive must be followed. Health professionals and family – even someone who is designated as a 'Person Responsible' – have no authority to override a valid Advance Care Directive.</li><li>› You can update or make changes to your Advance Care Directive at any time, as long as you have the capacity/ability to decide for yourself or to communicate your wishes.</li></ul>
<b>Where should I keep it?</b>	<ul style="list-style-type: none"><li>› You should keep your Advance Care Directive in a place that is easy for you or someone else to find. It's a good idea to keep a copy with you, or to keep a card in your wallet that lets people know that you have an Advance Care directive and where it can be found.</li><li>› You should also leave a copy with your Person Responsible, family and/or carer, doctor and/or healthcare facility and/or your My Health Record.</li></ul>

## Working together – open and respectful communication

### Information for the health care worker

Making the effort to deeply understand the values, beliefs, choices and what matters for the person and their family will create open and respectful communication which is important to ensure the right care is provided. Open and respectful communication is often taken for granted in our day to day lives, and it is not until there is a communication breakdown that we realise how vital it is to healthcare delivery, and supporting the person and their family throughout their palliative care journey.

### Communicating a diagnosis and prognosis

Delivering a diagnosis and prognosis can be difficult. Showing respect for the beliefs of the person and their family will assist with developing trust and rapport. It is also important to consider who the most appropriate person from the palliative care team is to have these conversations.

If you have been chosen to initiate this conversation with the person and their family, it is good to be aware of the following difficulties that may arise:

- › The person and their family may be reluctant to acknowledge bad news or may not understand what it immediately means for themselves or their kin.
- › The person and their family may need time to discuss the information to gain a complete understanding for all involved.

Clear and appropriate communication between the person, their family and the palliative care team will pave the way for the best care to be provided.

You can find additional communication resources listed under the section 'Other resources.'

## Self-care – recognising when caring for a family member in the home is too much

### Information for carers

Caring for someone requiring palliative care can be physically and emotionally draining. Some carers have said they feel like they are on a roller coaster with emotional highs and lows. Some say they get little time for themselves and feel overwhelmed and tired.

### Taking a break is important. Support is available.

Many different services provide respite care, which provides a break for the person and their families/carers when the demands of caring start taking a toll on everyone.

Finding these organisations and deciding on options can be complicated. Depending on where the person lives, availability, costs and arrangements may vary.

If you are in NSW and you are:

- |                                     |                                      |
|-------------------------------------|--------------------------------------|
| › Caring for a person over 65 years | <b>My Aged Care – 1800 200 422</b>   |
| › Caring for someone under 65 years | <b>Carer Gateway on 1800 422 737</b> |

Both services are open **Monday – Friday: 8am – 5pm.**

You can also contact your Aboriginal Health Service for social and emotional wellbeing support.

## Sorry business – place of death

It is important that each individual is able to choose their place of death and have the option of returning home, to their family or to Country.

Advance care yarning can help identify the persons cultural beliefs, values and protocols, including where they want to finish up. It is important to work with the person and the family to identify when it is most appropriate to have these yarns, and to identify what care plans are needed to be able to support this. Palliative care teams recognise this and can help make arrangements to suit. For example, they may be able to arrange for doctors or nurses to visit the individual at home and make sure they have access to the right medications to control symptoms such as nausea or pain.

If the individual is planning to return to Country, which is in a different region, the palliative care team can ask the local palliative care team to help (Queensland Health, 2015).

## Grief and bereavement support

### What happens when someone passes away?

Grief is a simple word that describes the natural but often complex reactions we experience after an important loss. All people experience grief differently, with it manifesting emotionally, mentally and/or physically, as well as potentially impacting on behaviour and even spiritual beliefs.

Families and communities that experience multiple people passing over a short period can be grieving for more than one person at a time. This is not uncommon and can cause grief to build.

Caring for someone with a life-limiting illness can impact on resilience and strength, which can reduce a person's ability to support themselves, their family, and the people they care for. Being self-aware of the effects of grief, stress, triggers and vulnerabilities is essential to avoid burnout or fatigue.

Support can be as simple as a casual yarn with family or friends or as formal as accessing support services from your Aboriginal Health Service or Local Health District Hospital (Australian Indigenous HealthInfoNet, 2021).

For more information on registering a death, writing a will or preparing a eulogy, please see the Appendix.

## Other resources – accessible online

<b>Palliative Care</b>	<ul style="list-style-type: none"><li>› Palliative Care Australia: Health professional resources</li><li>› Palliative Care Australia: member organisation (jurisdictional) contact details</li><li>› HealthInfoNet: Palliative care and end-of-life care</li><li>› VACCHO: Understanding the palliative care journey: a guide for individuals, carers, Communities and family</li></ul>
<b>Advance care planning</b>	<ul style="list-style-type: none"><li>› Dying to talk discussion starter cards</li><li>› Advance care planning Australia website</li><li>› Taking control of your health journey</li><li>› Taking care of dying time (video resource)</li><li>› NSW Health Advance Care Planning Information</li><li>› Creating an Advance Care Directive</li></ul>
<b>Communication</b>	<ul style="list-style-type: none"><li>› Sad News, Sorry Business</li><li>› Clinical Yarning eLearning Program</li><li>› Yarning about Palliative Care</li></ul>
<b>Symptom management and care needs</b>	<ul style="list-style-type: none"><li>› CareSearch: Patient care and conditions</li><li>› Therapeutic Guidelines: Palliative Care</li><li>› Palliative Care Australia: National Palliative Care Service Directory</li></ul>
<b>Grief, loss and healing</b>	<ul style="list-style-type: none"><li>› Good Grief – Seasons for Healing</li><li>› HealthInfoNet – Grief, loss and trauma</li><li>› Healing Foundation – Community Healing</li></ul>
<b>Self-care</b>	<ul style="list-style-type: none"><li>› Indigenous Wellbeing Centre</li><li>› Connect to Wellbeing – Aboriginal and Torres Strait Islander Stories (Video resource)</li><li>› HealthInfoNet –Taking Care of Yourself</li></ul>
<b>Information to help non-Indigenous healthcare staff</b>	<ul style="list-style-type: none"><li>› Cultural considerations: providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples</li><li>› CareSearch: Aboriginal and Torres Strait Islander Care</li><li>› Sad news sorry business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying</li></ul>

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## Appendix

### Registering a death and accessing a death certificate

When a family member or friend passes away, a medical team must observe the body to ascertain the cause of death. The medical team who certifies the death will then notify the Registry of Births, Deaths and Marriages within 48 hours of the death. The written notice from the medical team is then used to match information with the death registration statement from the funeral director.

It is common that a funeral director will register a death and apply for a death certificate on behalf of the family. This means you won't have to complete the application yourself, but the funeral director will ask you for some personal information about the person who has died. This includes details about their:

- › Birth, death and burial
- › Family members
- › Home address and occupation.

The funeral director will register the death within 7 days of burial or cremation. For more information on death certificates visit [www.nsw.gov.au/living-nsw/family-and-relationships/deaths/death-certificates](http://www.nsw.gov.au/living-nsw/family-and-relationships/deaths/death-certificates)

### Wills

A will is a legal document in which you nominate where you want your assets (money, belongings and property) to go after you die. You don't need a lot of money or belongings to make a will and it can take away some of the stress your family feels when they come together after your passing.

It is important to make changes to your will when things change in your life. Wills can be easy and don't have to be expensive, you can get a will kit from your local newsagency from around \$20-\$30.

A solicitor may charge you a fee for preparing the will. NSW Trustee & Guardian charge a fee for preparing a will unless you are eligible for a Centrelink Age Pension or Department of Veterans Affairs Pension, then it is free (HNELHD Aboriginal Health Unit, 2019).

### Writing a eulogy

A eulogy is a remembrance speech that pays tribute to someone who has gone on their journey to dreaming. A eulogy is delivered at a funeral or memorial service and highlights the unique qualities, importance and lasting impact of the person on their family and community. A eulogy reflects on what was special about the person and how they will be remembered now that they're gone. Points you may wish to include in a eulogy:

- › When and where the person was born
- › Nicknames and / or names known to others
- › Parents' names
- › Brothers and sisters and place in the family
- › Where they grew up
- › Early childhood including any funny or interesting experiences
- › Schools attended, awards gained
- › Academic or trade qualifications and achievements
- › Details of war or military service
- › Details of marriages, divorces, children, significant relationships
- › Details of grandchildren and great grandchildren
- › Details of any club memberships, positions held
- › Details of sporting achievements
- › Details of hobbies, interests, travel, crafts
- › Details of historical significance.

A successful eulogy does not have to be written by an expert to be meaningful. What matters is that the eulogy is heartfelt, respectful and true to the memory of the deceased.

When you give a eulogy, you help to honour a life, bring comfort to family and friends, and keep a legacy alive.



