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

IPEPA
Indigenous Program
of Experience in the
Palliative Approach

The design's core represents the individual, family and community. The eight symbols around this core represent the states and territories to reflect the national connection and wider community. It symbolises the safety of the environment, the reach and network that spread the word and education provided by IPEPA.

Together they can provide the right environment for Aboriginal and Torres Strait Islander peoples to understand palliative care and know that IPEPA is there to assist in the best way possible.

Your care. Our Mob.

About PEPA

In March 2019, PEPA engaged Aboriginal and Torres Strait Islander communities across Australia to understand, consult and codesign palliative care measures. Elders and community members in each jurisdiction, both urban and rural, contributed to this important conversation and IPEPA was born.

IPEPA is a grassroots approach to breaking down the barriers to palliative care for Aboriginal and Torres Strait Islander peoples across Australia. Informed by community, for community, IPEPA is embedding Indigenous knowledges across all PEPA resources and facilitating two way learning dedicated to:

1. Building the capacity of our Aboriginal and Torres Strait Islander workforce to deliver palliative care

2. Empowering Aboriginal and Torres Strait Islander communities with knowledge of palliative care, their rights and local services

3. Building the cultural responsive capabilities of the mainstream service providers to provide holistic and safe palliative care to Aboriginal and Torres Strait Islander peoples.

Acknowledgements

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The PEPA Team acknowledges the contribution of the following individuals and groups in the development of this resource:

- Aboriginal and Torres Strait Islander Advisory Group

- Aboriginal and Torres Strait Islander State and Territory PEPA staff

- The PEPA National Team

- State and Territory PEPA Managers

- Project Director Dist. Professor Patsy Yates, Queensland University of Technology

Aboriginal Flag designed in1971 by Harold Thomas, an Aboriginal artist.

Torres Strait Islander Flag attributed to the late Bernard Namok of Thursday Island.

The black represents the Aboriginal people, the red the earth and the spiritual relationship to the land, and the yellow the sun, the giver of life.

The flag was designed to be an eye-catching rallying symbol for Aboriginal people, a symbol of identity and unity.

The green stripes represent the land, the black stripes represent the people, the blue represents the sea, the white "Dhari" (headdress) is a symbol of Torres Strait Islanders and the white five pointed star symbolises the five major island groups.

The flag as a whole symbolises the unity of all Torres Strait Islanders.

Recognition

PEPA acknowledges and pays our deepest respect to the past, present and future Traditional Custodians and Elders of the many lands on which we work and live, and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

PEPA recognises the contributions and partnerships of Aboriginal and Torres Strait Islander and non-Indigenous Australians in the development, promotion and delivery of the program to ensure Aboriginal and Torres Strait Islander peoples have equal and genuine access to quality, holistic and culturally-responsive palliative care.
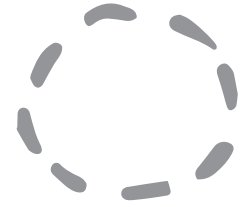
Using the guidelines

This document provides information for healthcare services about what should be known and understood, that will enable healthcare providers to deliver the best cultural care during the end-of-life journey for Aboriginal peoples and Torres Strait Islander peoples.

These guidelines outline practical considerations for providing person-centred palliative care for Aboriginal peoples, Torres Strait Islander peoples and their respective families, while being respectful of intercultural variations and individual choices.

End-of-life care requires sensitive interactions, these interactions will be different for every person. Establishing respectful interactions requires a communication style that enables honest, open sharing about the end-of-life care path. These interactions should seek to support quality of life, relieve troubling symptoms, ensure clear understanding and participation of all involved.

If a mistake, miscommunication or misunderstanding occurs, it is important for healthcare providers to take responsibility for their part of the miscommunication and how that has affected the relationship.

Addressing this miscommunication is important to ensure that the sick person and their family will feel safe in the service and reduce the chance that it will occur again. Recognising the misunderstanding reflects positive intent, honesty and integrity.

Recognition

Aboriginal peoples and Torres Strait Islander peoples are the original inhabitants and the Traditional Custodians of Australia, making up approximately 3% of the total Australian population.[1]

In 2016, 91% of the Indigenous population identified as Aboriginal peoples, 5% as Torres Strait Islander peoples and 4% as being from both Aboriginal and Torres Strait Islander origin.

Aboriginal peoples and Torres Strait Islander peoples belong to two distinct cultural groups. These cultural groups are not uniform in traditional or contemporary practices and vary between Aboriginal peoples and Torres Strait Islander peoples, although there are common threads between both.

Aboriginal Peoples:

- are associated with the land, mountains, deserts, rain forests and coastal areas
- refer to maternal or paternal families traditional land areas as Country
- self-identify by language group and traditional land area (also known as nation, clan)
- have knowledge tied to the environment, constellations, plants and animal life.

Torres Strait Islander Peoples:

- have a land and marine culture
- have five island clusters which identify language groups
- have beliefs connected to the constellations, seas and winds.

Footnote

1   Australian Bureau of Statistics. Cultural Diversity in Australia. 2016 Census Data Summary. 2017 April 2018]; Available from: http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Cultural%20Diversity%20Data%20Summary~30.

AIATSIS map of Indigenous Australia

Each coloured patch on the map represents an Aboriginal or Torres Strait Islander language grouping. The many groups shown on the map indicates the great diversity that is Aboriginal culture and Torres Strait Islander culture.

This map is just one representation of many other map sources that are available for Aboriginal Australia. Using published resources available between 1988–1994, this map attempts to represent all the language, social or nation groups of the Indigenous peoples of Australia.

It indicates only the general location of larger groupings of people which may include smaller groups such as clans, dialects or individual languages in a group. Boundaries are not intended to be exact.

David R Horton, creator, © Aboriginal Studies Press, AIATSIS and Auslig/Sinclair, Knight, Merz, 1996. No reproduction allowed without permission.

This map is not suitable for use in native title and other land claims.

Reflection

Recognise and respect that differences exist between people and cultures.

This document acknowledges and is respectful of the many people who did not grow up with their families and community, who grew up without the influence of their heritage or knowledge of traditional and contemporary cultural ways. Recognising the many factors that were involved (the dispersal, dislocation, isolation and lack of acceptance of Aboriginal people over many generations) is imperative. For these individuals, while family experiences and beliefs will vary, life experiences will direct beliefs and needs for care.

Many Aboriginal people have been relocated and no longer live on traditional country. This does not diminish cultural and spiritual connections to country.

Dispossessed of land and family, interruption of culture and intergenerational trauma have significantly impacted on the health and wellbeing of Aboriginal peoples and Torres Strait Islander peoples. The cultural capability of health services is an important additional factor impacting on health, influencing whether care will be accessed and the quality and effectiveness of the care received.[1]

There is a growing interest in Aboriginal peoples and Torres Strait Islander peoples and cultures. However, for many Australians there has been limited opportunity to interact with and learn about Aboriginal peoples and Torres Strait Islander peoples and the diverse cultures. This means that for many Australians, communication styles, family structures, diversity in lived experiences and the beliefs of Aboriginal peoples and Torres Strait Islander peoples can be unfamiliar.

Sometimes the usual ways we relate to people can cause them to feel unsafe, uncertain and offended. Our cultural bias influences our actions as our perceptions are shaped by our own cultural context and experiences. Using only one worldview, it is common to misinterpret an interaction or situation, which sadly leads to poor outcomes.[2]

Footnote
1   Australian Health Ministers' Advisory Council (2012). Aboriginal and Torres Strait Islander Health Performance Framework 2012, page 135-138.
2   NSW Department of Community Services (2009) Working with Aboriginal People, page 27.
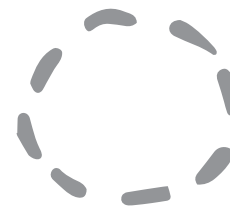
Everyone's business

The ambience of a service and the healthcare providers in the service play a critical role in creating a welcoming, safe, comfortable environment for Aboriginal and/or Torres Strait Islander sick people and their families.

Simple things to do:

- be open and welcoming with a smile
- introduce staff by name and work title, a notice board with staff photos can be a reminder
- use a positive tone of voice and listen to what the sick person and the family have to say
- be polite, honest, sincere and helpful
- employ Aboriginal or Torres Strait Islander people
- advise that palliative care is holistic care that supports quality of life, assessment and treatment for pain relief
- explain that to achieve quality of life, the care team listens to the sick person's concerns, beliefs, needs and choices and will seek to address concerns and needs by supporting choices
- try not to rush or bombard with questions
- display Aboriginal and Torres Strait Islander artwork, reconciliation statements, resources and or flags in the service.

Use plain language communications:

- avoid medical or nursing jargon unless necessary and explained
- clarify meanings of any unfamiliar terms
- explain the service processes and routines eg, meal times, doctor's visits, allied health professional visits, visiting times and rest times if applicable
- address queries or concerns when raised and keep informed on progress
- allow time to process information and for considering implications when responding to questions.

How to define
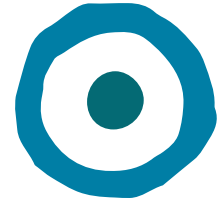
The only definition to be used:

In 1983 the High Court of Australia defined an Aboriginal or Torres Strait Islander person as:

- a person of Aboriginal or Torres Strait Islander descent
- who identifies as an Aboriginal or Torres Strait Islander
- and is accepted as such by the community in which they live.

Naming terms are interwoven in a history of domination, often with misunderstanding and misrepresenting Aboriginal knowledge and actions:

- generic terms like indigenous and aboriginal (both starting with lower case letters) means 'from the beginning' in relation to inhabitants, or 'natives' belonging to a land

- the term indigenous diminishes cultural identity, and the term should be avoided when addressing individuals or families

- in the 1980s, the term "Indigenous people", meaning culturally distinct groups affected by the processes of colonisation, was legislated nationally and internationally

- when writing names always start with a capital letter. Aboriginal identifies an Australian Aboriginal. Australian Indigenous people identifies Aboriginal peoples and Torres Strait Islander peoples

- avoid use of the acronyms A&TSI or ATSI in any written or verbal communications relating to an Aboriginal person(s) or a Torres Strait Islander person(s).

The following terms are derogatory, culturally disrespectful, discriminatory and racist. They must not be used when referring to Aboriginal peoples or Torres Strait Islander peoples:

- full-blood / mixed blood

- half-caste /quarter caste or any other fractional reference

- aborigines / blacks / blackfella

- whites

- yellafella

- those people.

Context

Power imbalances can occur in healthcare settings. The key to balance is to enable a safe, friendly environment, engage people to become partners and to participate in decisions about their healthcare plans.

Many Aboriginal peoples and Torres Strait Islander peoples have a strong relationship-based kinship system that provides the social structuring of family and the community (language group, nation or clan).

All interactions have a structured approach with specific purpose and meaning for those involved. Interactions are enabled through kinship connections that define the type of relationship and prescribe respectful interactions.

Inclusivity ensures everybody knows and understands their and others' roles, responsibilities, obligations and behaviours for the prescribed relationships.

Complementing the kinship system are the beliefs, practices and lore (the culture), which is interwoven into reciprocal connections with the people, plants, animals, country and constellations (dreamtime / creation stories).

For many, sharing information to establish connection and relationship building provides the context to enable interactions. This reciprocal interaction is fundamental to participation with Aboriginal peoples and Torres Strait Islander peoples.

Context

Many Aboriginal peoples and Torres Strait Islander peoples hold strong spiritual and cultural beliefs about the cause of serious illness, which may conflict with the medical explanation. By demonstrating respect for diversity in the sick person's cultural and spiritual beliefs, a relationship of trust and rapport can be built.

The cultural belief that life is a continuum, Life-Death-Life, is common among Aboriginal peoples and Torres Strait Islander peoples. The underlying belief is that all living things (people, animals and plants) have a spirit; spirits are the continuum that connects the living to the past, present and future.

At the time of death, the spirit leaves the body to return to the Ancestors' country. After the finishing up/death, responsibility of family continues with ensuring the safe passage of the spirit to the ancestors and returning the body to country.

It may be culturally unacceptable for Aboriginal people and/or Torres Strait Islander people to finish up/die alone.

Be mindful:
Unspoken communication matters

The first interaction often sets the standard for ongoing communication:

* enable open two-way interaction to become the standard.

Be aware that Aboriginal culture has strong gender roles expressed through 'Men's Business' and 'Women's Business':

* women address women's matters
* men address men's matters
* however remember that some people may be comfortable with western ways of relating to men and women.

Aboriginal and Torres Strait Islander culture is structured and formal:

* addressing people by their proper title, for example as Mr or Mrs (name), Fr, Dr. is considered respectful and important when commencing a new relationship
* sometimes a person's documented name is not the name used, there are many reasons for this. If this occurs, ask the person, "I've noticed that your visitors call you by another name; is there another name you would prefer we use?"
* advise that the name preference will be recorded in the person's health record.

It is customary for Aboriginal people and Torres Strait Islander people when meeting with strangers to share both formal and personal information as a way of establishing a connection to each other. This forms the basis of the relationship:

* healthcare providers should introduce themselves by name, their position and something personal (eg, how long you have worked in healthcare, where you come from, or experiences working with other Aboriginal and/or Torres Strait Islander people).

Be mindful:
Unspoken communication matters
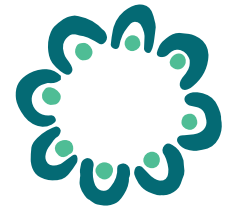
Aim to provide continuity and consistency in staff allocated to care for the sick person as this helps to build rapport:

- being introduced daily to new staff can disempower the sick person, lead to disengagement, difficulties with communication and may also have an impact on the pain levels of the sick person.

Aboriginal peoples and Torres Strait Islander peoples come from collective societies. There may be a family spokesperson or decision-makers that are not the sick person:

- often decision-making is the responsibility of the family and not the individual (sick person). Ask the sick person, "Can you tell me the right person to talk to about your health matters?"

- ask the sick person and family spokesperson if there are other decision-makers to involve in discussions about personal and health-related information

- the sick person may choose not to discuss death or dying with healthcare providers or some families may request that death and dying not be discussed with the sick person opting for the family spokesperson or decision-makers to be the ones to receive information, make decisions, act and speak on behalf of the sick person

- ensure that the family spokesperson or decision-makers are consulted on all matters relating to the healthcare of the sick person and are present for any sensitive conversations with the sick person

- alternatively, the sick person may choose to become an active participant in the end-of-life carepath

- clearly document all key people and their contact details in the sick person's chart.

Be mindful:
Unspoken communication matters
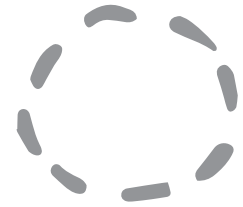
Some, but not all, Aboriginal people and Torres Strait Islander people avoid eye contact when communicating. Avoiding eye contact is a respectful act:

- with respected persons

- with someone of opposite gender

- if there is a difference in ages.

> Your actions should be guided by the Aboriginal person and/or Torres Strait Islander person, if they avoid eye contact, it would be respectful for you to practise the same.

Some Aboriginal people and Torres Strait Islander people are comfortable with silence during discussions:

- if this occurs, there is no need to talk through or rush silences

- take a minute to be contemplative about ongoing discussions

- allow time for silence – for some, it is customary to wait for a period of silence before speaking, if no silences occur people may never speak

- allow time for processing information and for considering implications when responding to questions.

> Interactions have a tendency to occur and flow when one person puts themselves beside the other person, rather than directly in front of the other person. This is similar to ensuring that you are not standing over anyone when you talk with them, but rather position yourself to be at a similar level.

Be mindful:
Kinship responsibilities

Aboriginal culture and Torres Strait Islander culture has a classificatory system of kinship that extends beyond family to the community. Kinship permeates every aspect of social organisation and structure, forming a framework for each person's identity, defining connectedness, roles, responsibilities, obligations and interactions with others. Kinship is the basis for all social interactions. Without this context, there is no need for any interaction.

The classificatory kinship system has many different types of relationships under one term:

* eg, Mother refers to maternal mother and her sisters; Brothers and Sisters refer to all your mothers, fathers, aunts and uncles children (providing large family groups).

The extension of kinship relationships to the community is complex and alters in different areas. Be aware that kinship connections are deeply rooted and multi layered, all relationships have roles and reciprocal responsibilities. There may be public perceptions that social greetings between Aboriginal people and or Torres Strait Islander people using terms brother, sister, Aunty and Uncle are just social greetings. Greater awareness of this acknowledgement being a recognition of acceptance, establishing connection or re-connecting a relationship.

This interaction aligns within some kinship structures and may have specific roles and responsibilities.

Many Aboriginal people are bound by relationships and a sense of the right time to say and do things:

* it is generally not appropriate to confront or embarrass people in front of others including telling someone 'no'
* addressing concerns needs to be in a roundabout way with discretion for those involved
* some people may still be tied to these practices
* rushing through information can make people feel uncomfortable about participating and reluctant to engage, as they may perceive the healthcare provider is in a hurry.

Everyone has a role within the family and maybe the community, it includes the responsibility to care for all living things, for Country and a responsibility for someone else in the family. For those with knowledge about specific matters, they may also have responsibilities for that matter and possibly for the people that may need to access to it.

Be mindful:
Communication styles

Aboriginal culture is generally not confrontational. In traditional Aboriginal culture there is no obligation to answer questions:

- asking someone lots of questions may be considered a rude and ineffective way of finding information

- however, asking open-ended questions allows participation in the interaction.

Aboriginal people and Torres Strait Islander people frequently use indirect methods of communication. This reflects the value of respect for others:

- cultural avoidance behaviours in relationships are respectful

- previously mentioned avoidance of eye contact

- avoidance may be practiced within families eg, sister and brother; son-in-law and mother-in-law; daughter-in-law and father-in-law.

Ensure that the personal space of the sick person being cared for is respected:

- advise when clinical observations are going to be performed

- talk people through the experience.

Exchanging information will be part of the relationship with Aboriginal people and Torres Strait Islander people:

- like introductions, participants exchange formal and personal information

- often, you may need specific information, but the right person (spokesperson or key person) may not be there to give it to you

- it is necessary to allow for the right person to provide information

- expect that it may take quite a few exchanges before you are provided all the information you want

- be aware that any person may use their right to withhold information.

Do not make assumptions (based on other family structures) about who has the responsibility for decision-making within a family, or who is the appropriate person (or group of people) to give consent.

Be mindful:
Communication styles
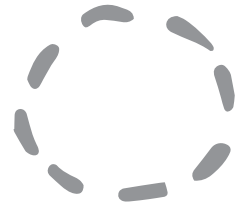
Some experts believe up to **90% of communication is non-verbal.** Non-verbal communication includes facial expressions, eye contact, posture, hand and feet movements, gestures, signs, body movement and placement, use of space and pace of information delivery.

Many Aboriginal people and Torres Strait Islander people may be very perceptive about body language:

- this observation of non-verbal signals forms part of any communication
- gestures or facial expressions may be used between family members instead of talking
- be reflective about your speech and body gestures
- encourage interaction by allowing time for people
- slow down if the sick person or family look disengaged or disinterested.

People's culture often defines their communication style. An open communicator will:

- be aware of body language (theirs and other person(s)
- speak in a clear tone, at a steady pace
- recognise known cultural matters
- engage the other party to give feedback and ask questions
- not interrupt when the other person is speaking.

Terminology

Providing plain language explanations in an open manner to the sick person and the family spokesperson will help to limit misunderstandings.

For both Aboriginal peoples and Torres Strait Islander peoples, English may not be the primary language:

- professional jargon and colloquialism should be avoided as it can easily be misunderstood

- consider whether an interpreter/translator is required (if available)

- consider the words and phrases that will be used and if these may have different meanings for different people

    - words may be taken literally, instead of a broader sense of the word
    - eg, 'as soon as possible' may mean different things to the initiator and the receiver

- allow time to process information and for considering implications when responding to questions

- do not try to copy or use 'pigeon language' to speak to people or interpret what people have said.

In healthcare situations, if jargon is used and not well explained, listeners may not understand. To avoid embarrassment, when confused about any interaction:

- many Aboriginal people will answer 'yes', they may sense it's the right time for this

- the sick person may say 'yes' to stop possible or further questioning or to end the discussion and remove themselves from this situation.

When using plain language it is important that people do not perceive this as patronising:

- talking down to anyone is disrespectful and disempowering

    - it reinforces the lived experience that people in positions of power are superior.

For those that speak languages other than English, often when speaking English there is a strong accent. It is important to practise a steady pace of speech as speaking quickly makes it difficult for listeners to define words.

If you are unsure about how the sick person and family members interact with each other and to understand any preferred methods for non-verbal communication, where possible ask the family spokesperson, the Aboriginal Liaison Officer or Aboriginal Health Worker.
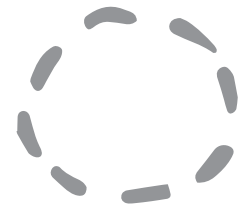
Dying and death

Direct statements about dying and death are not usually spoken in Aboriginal or Torres Strait Islander communities. Alternative terms used to refer to the terminally ill, dying and death include:

NOT GOING TO GET BETTER   SICK PERSON   BAD/SAD NEWS

FINISHING UP   PASSED ON / GONE   SORRY BUSINESS

Cultural and traditional beliefs are entrenched with spirituality that supports the cyclic belief of life-death-life. This ongoing journey is necessary for the next to occur. For many Aboriginal people and Torres Strait Islander people, their life experiences may have provided a mix of beliefs and practices. Many have been introduced to Christianity and for some, it plays a large part in their lives. For others while actively practicing forms of Christianity, when faced with the end-of-life journey, preparations are made with the spiritual journey in mind.

For many generations family and community have facilitated recognition of the concerns, beliefs, needs and choices of sick people by providing care at home in a person-centered familiar environment. In some instances families may require support and access to services during the end-of-life journey, while still wanting an active role in the care.

Today's illnesses may be relatively new for some and the trajectories may not be known. It is important that the family is supported with relevant information about the trajectories for specific illnesses, the expected symptoms and milestones on the end-of-life pathway. Providing this information to key family members as it is needed helps with the family's understanding and can reduce the distress associated with grief and loss.
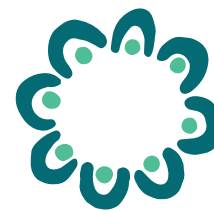
Taking care of business

Admissions

When a person is admitted to a palliative care service in either a hospital or community setting, **documenting all the key elements of personal demographic information, including Indigenous status is critical**. This is helpful for service providers, funding and statistical bodies and those accessing the service as it enables all stakeholders to benefit from the activity.

Acknowledge the person's identity

Diversity in Aboriginal and Torres Strait Islander culture includes appearance. The 'look test' or assumption based on how a person looks is not sufficient to complete accurate admission data about the cultural background of individuals. Ask if the person identifies as being an Aboriginal person and/ or Torres Strait Islander person. For example, ask

"Are you of Aboriginal or Torres Strait Islander descent?"

Some individuals may identify as having cultural affiliation with both cultures. Other individuals may not identify as having a cultural affiliation. This is a choice that needs to be respected. Individuals may have other beliefs that they would prefer documented.
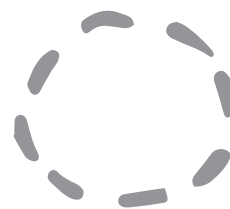
Taking care of business

Consent

If an Aboriginal or Torres Strait Islander Hospital Liaison Officer or Health Worker/ Practitioner is available to the service, ask the sick person and family if they would like contact with them and refer:

- it may help the sick person and family, if you refer to the Hospital Liaison Officer and or Health Worker by his or her name

- remember, these positions are often cultural brokers, providing dual support and advocacy for the sick person and their family by providing supportive information about the service, staff and the end-of-life care path while collaborating as a multi-disciplinary team member with the service and staff to share patient centred matters.

Understanding matters

To ensure the sick person, family spokesperson or decision-makers have a clear understanding of the prognosis, ask the sick person or family spokesperson:

"Can you tell me about your understanding of matters?"

Build on the known knowledge base, provide information as it is needed about end-of-life care and the likely path of milestones.

Follow up by asking open-ended questions and listen to responses to gauge the increase in knowledge.
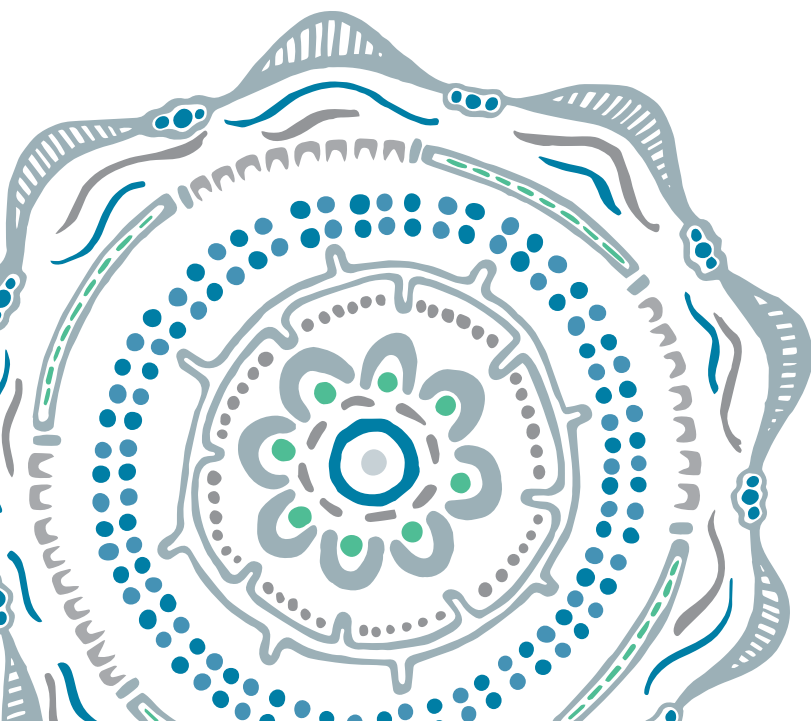
Taking care of business

Advance Care Planning

Raising discussion about an advance care plan early in the admission gives the sick person and family time to consider options:

- advising the sick person and family spokesperson about advance care planning will help to ensure that important matters are included in any care plans.

Topics to be discussed and identified in care plans include:

- concerns, beliefs, needs and choices.

A culturally-appropriate care plan is required, written in partnership with the sick person, family spokesperson or nominated others:

- advise that palliative care providers support quality care at the end of life, assisting sick people to live as well as possible while supporting family and carers during the end-of-life care path
- using a holistic model of care that aims to
  - relieve suffering and improve quality of life (defined by the sick person or family spokesperson)
  - assess and treat troubling symptoms, that will not hasten or postpone death
  - affirms life and regards death as a normal process
  - integrates psychosocial, cultural and spiritual care from a multi-disciplinary team

- recognises important (physical, social, emotional, cultural and spiritual) matters identified by the sick person and/or family spokesperson that will be incorporated into the care plan.

This may be new information to the sick person and family. It may take time to put the new information and questions into context, before responding:

- it may be one or two days later before a response is given.

Sharing Bad / Sad News

Initial conversations may stray from the topic before gradually coming to the point:

- it is important not to hurry but give the people involved time to prepare, to ask questions and for silence
- be honest but avoid direct or blunt statements especially when giving bad news about the sick person's condition
- it is common for people not to remember anything said after receiving bad news
- the sick person and their family may be reluctant to acknowledge bad / sad news, while at the same time prefer to know the truth of the situation.

Taking care of business

Family meetings

For many people, the unknown is the most frightening.

A coordinated 'Family Meeting' should be discussed and arranged early in the admission:

- open, honest shared knowledge allows awareness, some clarity for the family and reduces the risk for blame

- providing families with ongoing clarifying information as it is needed, supports family members to be less distressed as milestones occur

- address concerns as they are raised

- if specific symptoms are expected, advise the avenues to address any discomfort.

It's important to have a suitably sized room to ensure the family feels welcomed and valued:

- ask the family spokesperson how many people they think might attend the family meeting, together with health professionals it may be a large group.

Clarify and discuss the stage of illness, prognosis and illness trajectory:

- it is important for family to be aware of the big picture

- clarify the common signs and symptoms that are happening now and the expected progression

  - further discussion about recognising the milestones through the progression as they occur along the end-of-life care path can allow family to prepare.

Discuss aims for this admission:

- eg, control pain and nausea or for this to be the last facility admission opting for care at home

- explain supports available as an inpatient and as an outpatient in the community

- allow time for the family to discuss new information and respond

- the family may have questions and need to further clarify matters now or later.
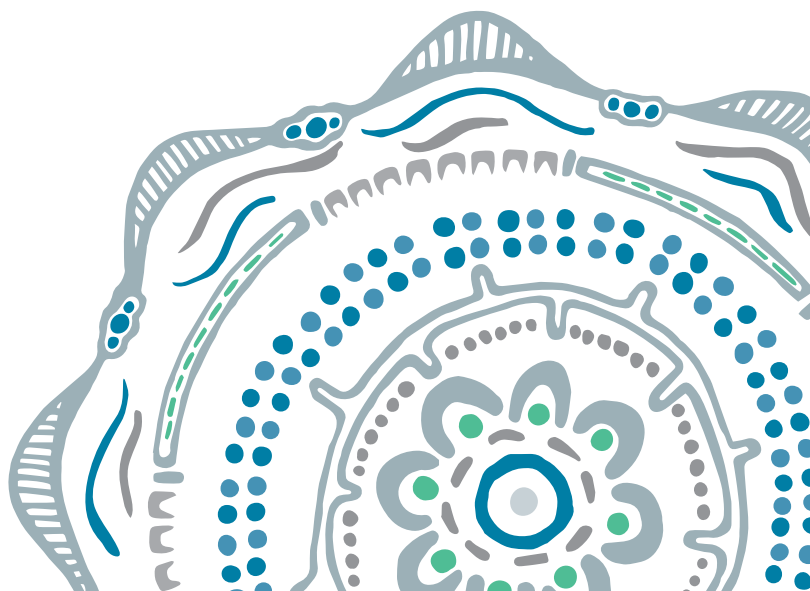
Taking care of business

Pain and other symptoms

Be aware of non-verbal signs of distress and pain:

- the expression of symptoms such as pain may be understated

- sick people are often reluctant to ask staff for assistance fearing they would be too much trouble for staff

- they may also be worried about becoming addicted to pain medications and/or

- they may be afraid that staff will ask probing and personal questions.

Ask specific but non-confronting open-ended questions and allow time for the sick person to answer. Some examples include:

Inclusivity

Time holds a different meaning for many Aboriginal people and Torres Strait Islander people, as life is not always structured around the clock, but rather around family or community needs:

- clarify times for medications using activities relevant to the family

  - eg, **1 tablet 3x a day could easily be breakfast, lunch and dinner**

- ensure a shared agreement and understanding of reasons and timing of appointments/visits and the duration of time this may take

- provide flexible appointment times, home visiting and family meetings as this shows respect for needs, builds trust and provides clarity for family.

- The information from these meetings needs to be shared with many.

"I can see you are in pain, does the pain keep you awake at night?"

"You seem worried, is it the pain that is worrying you?"

"Is there anything else you want to say about your pain?"

Taking care of business

In preparation for an impending death

For some, it may not be appropriate to finish up / die alone.

Find an opportunity to speak alone with the family spokesperson to identify if the sick person happened to finish up alone:

- who is the appropriate person to be informed of the passing.

Discuss and clarify all matters relating to the time immediately following the finishing up/death:

- any clinical processes that are required
- any family or cultural practices that will be occurring eg, using deceased name after death
- if there are time implications or constraints
- funeral directors
- any documentation and timeframes involved
- any ongoing interactions with the facility
- how any matters can be addressed for both the service and family.

It may be culturally inappropriate for a healthcare provider to contact the next of kin or inform them of the finishing up or passing on of a family member:

- in Torres Strait Islander culture, it is the responsibility of senior in-laws to inform the family members of the person's passing
- ask the spokesperson or key person about preferences for this communication.
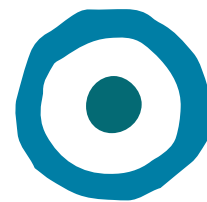
Finishing up

Cultural practices / rituals

Some cultural practices/rituals are highly visible but often not recognised as rituals.

Traditionally, people would be punished if they did not pay their respect to those preparing to finish up and their family members:

* in today's contemporary society, for many the importance of this practice is ongoing.

The gathering of family and community is a practice/ritual that marks the respect associated with a person's value to the community:

* many will come from long distances to help and support the sick person and their family

* many visitors may frequent the place where the sick person stays

* facilities may receive increased telephone enquiries about the sick person

* many visitors for one patient at a facility may be challenging for healthcare providers, allowing and accepting this practice/ritual enables the sick person's journey and provides the family a positive death experience in a service.

The sense of acceptance, love and support is integral to the end-of-life journey for sick people.

The family may request that someone be allowed to stay with the sick person at all times:

* enabling this demonstrates cultural respect and allows for family's ongoing care responsibility

* this presence can include while the sick person is receiving clinical and personal cares

* if there is space to accommodate requests for more than one person to stay overnight, the family will be thankful

* provision of an end room is often helpful, especially if it links to an outdoor area where family and visitors may overflow

* families not supported to be with their loved one, find that their grieving is impeded as the sick person's needs, beliefs and choices were not valued, appreciated or followed

* disempowering and isolating the sick person hinders the end-of-life journey.
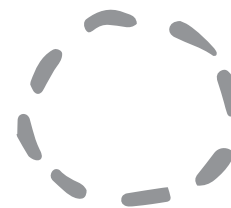
Finishing up

Cultural practices and rituals

Other rituals may be undertaken which may be less visible, only known to you because the family has made you aware with a specific request.

Frequently, in the week and days before passing on, the sick person may commence receiving spiritual visitors. They indicate that life's pathway is nearing its end and provide clarity about the journey ahead. A peacefulness is brought to the sick person.

- this may be known as 'deathbed visions'
- this belief is a spiritual and cultural practice and should not be confused with delirium.

In Torres Strait Islander culture, it is common for the sick person to mimic/simulate their totem:

- a totem may be an animal or a bird and often represents an individual or family group
- family recognise this action as being close to finishing up.

Rituals can occur at various times and locations:

- the timeframes may commence prior to the finishing up/passing on and extend to after the funeral service
  - eg, the place prior to passing away, where the sick person passes away, in the home of the sick one or their family, at the morgue or funeral home and the gravesite.

Aboriginal and Torres Strait Islander people have beliefs that support the notion that where people finish up is were the spirit stays. Enabling the spirit's journey to the ancestors is commonly a family responsibility but this can be hindered by a number of factors. A 'smoking ceremony' is a ritual that is performed by the Traditional Custodians. They assist spirits that may have been stuck where they finished up to leave and return to country and the ancestors.

Consider spiritual people coming into services to be greeted by those spirits stuck where they finished up. The smoking ceremony helps to release the spirit for the journey back to Country.

Finishing up

Death

The time of the sick person finishing up / dying will be experienced differently for every person.

A number of factors impact a person's reaction to finishing up / death:

- cultural norms
- beliefs of family and the community
- if people have experienced finishing up/ death before
- if experiences have been positive or negative
- were people prepared or was it a shock.

Everyone will react differently, some family members may:

- talk to the sick person throughout the journey
- call the spirit home by singing and or dancing
- wail or cry loudly
  - this is a normal reaction to loss and grief and should not be discouraged
  - if other people are concerned for the loud crying, recognise the loss that has occurred
- go quiet not wanting to talk
- get angry and blame someone for the loss
- want to stay near the deceased
- commence preparations for the body & the spirit's transition
- use comfort measures like prayers.

Sorry Business

As the sick person finishes up, the sense of loss and grief immediately confronts most.

Now, Sorry Business commences.

Until the whole family ceases all communication with the service, it would be respectful that:

- the deceased person's name is not mentioned nor are photos openly displayed in respect for the belief that to do so will call the spirit back preventing safe passage to the spirit world of ancestors

- for some families name calling is not a concern.

This is not a good time to introduce new people or services to the grieving family. Utilise current networks to respond to any concerns you may have for the family.
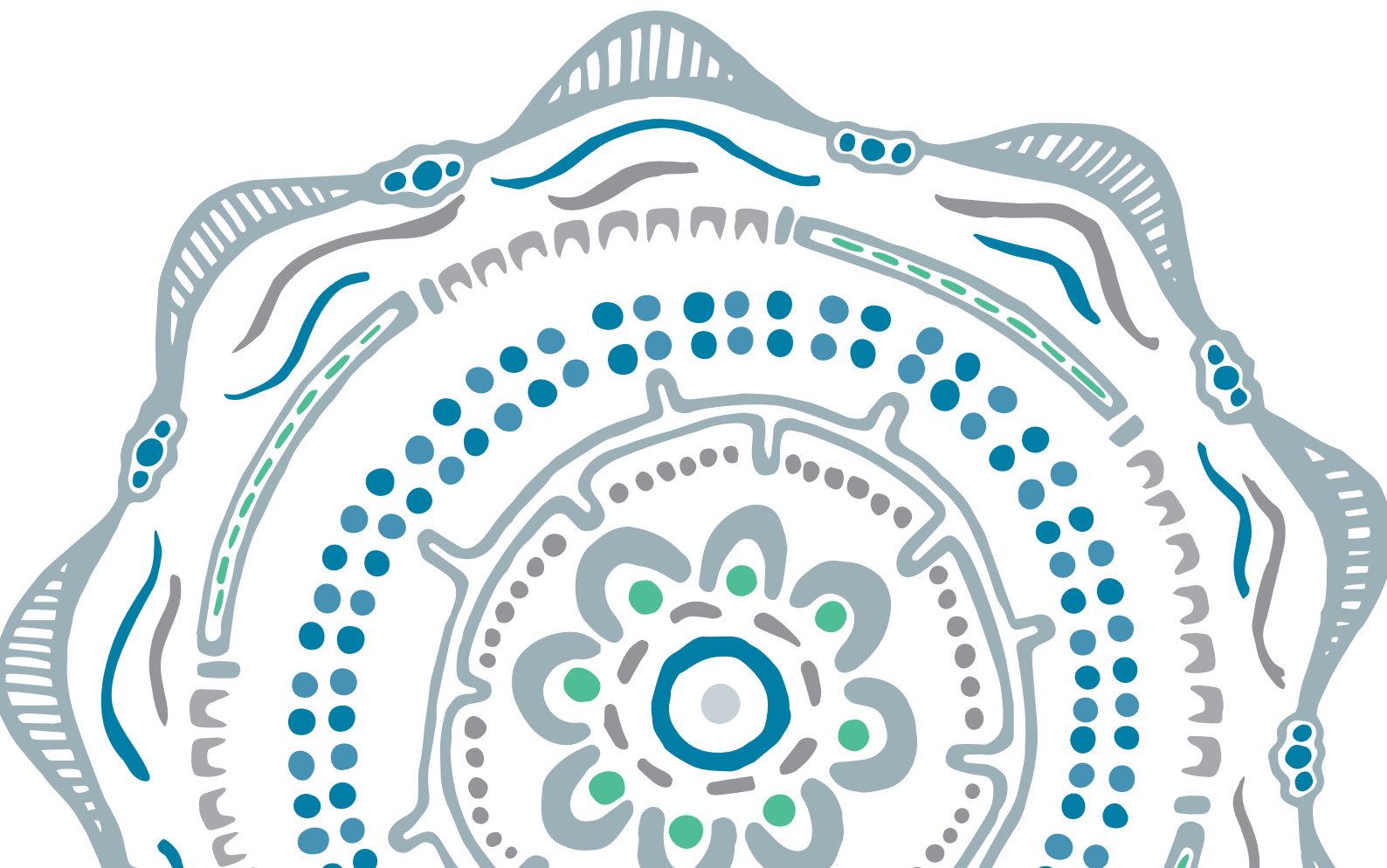
Working in two worlds

Aboriginal and Torres Strait Islander liaison officers / health workers / health practitioners

These positions deliver different services as directed by the facility or service. The role may be clinical, supportive, advocacy or referral-based.

These workers may provide a level of cultural brokerage and advocacy to assist services. As there is an understanding of Aboriginal peoples and Torres Strait Islander peoples and cultures as well as the health and medical system.

They:

- are a practical member of the multi-disciplinary team

- provide a practical and cultural support for the family and the service

- navigate the sick person and their family through the system of services, staff, practices and procedures

- assist the sick person and their family to receive and understand information and processes

- re-iterate information from previous clinical interactions which the sick person or family may not recall

- link to local services that can support the sick person and their family's social and emotional wellbeing

  – eg, Aboriginal Primary Health Services, Organisations, or Church groups

- share family based, culturally relevant information with the staff and service

- in a hospital setting, can also help the family/extended family to co-ordinate visits and also provide another avenue of support

- if you are unsure about cultural issues and beliefs or how to respect cultural boundary's during difficult conversations, ask the Aboriginal Liaison Officer / Health Worker.

Contact details

Aboriginal and Torres Strait Islander liaison officers / health workers / health practitioners

Please remember every Aboriginal & Torres Strait Islander person may have differing beliefs and practices. The diversity within states and territories is clear with different lore and cultural practices. Also keep in mind that some people may choose not to identify. They may not be linked with family and community supports or practice culture but may be more aligned to a particular religion. Open, clear communication, asking what the sick person & their family want is the key to any successful interaction. Never make assumptions!

Wishing you many successful interactions.

Name and contact details of local services:

_____

_____

_____

_____

_____

_____

_____

For further information about cultural protocols visit:

https://healthinfonet.ecu.edu.au/learn/cultural-ways/

For more copies of this document visit:

http://www.pepaeducation.com or email: PEPA@qut.edu.au

DISCLAIMER: This resource has been developed and reviewed by palliative care specialists, Aboriginal heath care providers, Torres Strait Islander healthcare providers and is based on best evidence at the time of writing. It is not the responsibility of, nor does it necessarily reflect the views of organisations to which individual team members may be affiliated or that of the funding body, the Australian Government Department of Health.

End-of-life journey

Uncle Mick created the artwork above after reflecting on what palliative care means to him as an Aboriginal elder and artist. This artwork is respectful of both Aboriginal cultures and Torres Strait Islander cultures using colours and symbols that reflect both cultures and celebrates the cyclical concept of Life-Death-Life:

- The footprints are the journeys taken to and from health services and end-of-life care services (at the top of the picture), where the healthcare staff gather to share important information and resources about the life-limiting illness and end-of-life care (shown by the helping hands coming in from the sides)
- The dotted circles at the bottom of the picture represent families and communities. Many have come in preparation for Sorry Business. Above this is the coolamon or canoe, both used for carrying items (food, babies or people) to nurture and support life
- The oval shapes in the centre represent moving through different stages in life's journey with the energy of the spirit as it leaves the journey in the last shape
- The spray of cascading white dots is symbolic of numerous things: the tears that come with Sorry Business, the Dhari and Spirit leaving the life journey and travelling back to the spirit world. As Sorry Business starts with the men and women, you can see the Spirit meeting with the past present and future (rippling effect).

Michael J Connolly…
Munda-Gutta Kulliwari

Michael J Connolly or Uncle Mick is an Aboriginal man from Charleville, south-west Queensland and a descendant of the Kullilla Tribe from the Thargomindah and Eulo region on his Father's side and from the Muruwari People from Goodooga and Brewarrina region of north-west New South Wales on his Mother's side who can trace their traditional trade and diplomatic links with Central Desert as well as South Australian and Northern New South Wales' Aboriginal Communities.

Recognising diversity in Aboriginal cultures and Torres Strait Islander cultures.
Respecting people, beliefs and choices.
Honouring the past, the present and the future.