

PEPA/IPEPA Communication Guide:

Supporting access to palliative care for everyone



This guide will help you to have person and family-centred conversations with everyone you care for who is affected by life-limiting illness.

PALLIATIVE CARE EDUCATION & TRAINING COLLABORATIVE



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Who experiences barriers to accessing palliative care?

To effectively communicate, you need to understand the barriers that are experienced by many people in accessing palliative care, and the most helpful approaches to care to help overcome these barriers.

Recent reports have highlighted that there are various groups of people in our communities who experience barriers to the provision of palliative care.

These include:^{1,2}

Under-served populations:	People living with vulnerability:
Aboriginal and Torres Strait Islander peoples	Homelessness
People from culturally and linguistically diverse (CALD) backgrounds	Disability
Lesbian, gay, bisexual, transgender, intersex and queer people and other sexuality and gender-diverse (LGBTIQ+) peoples and communities	Mental health concerns
Ageing or frail people, particularly those living in residential aged care	Institutional care experiences in childhood
People living in rural and remote areas	Social isolation
Refugees	Economic disadvantage
Veterans	Survivors of trauma.
Prisoners.	



It is important to note that there is considerable diversity among people within and between these groups. There are also many people who experience more than one of these types of vulnerabilities.

What they have in common is that they all experience barriers to accessing palliative care.

A history of disadvantage, marginalisation and trauma contributes to an increased risk of chronic disease and life-limiting illness, and therefore an **increased need for palliative care**, especially later in life.

Unfortunately, the cultural and personal factors involved contribute to significant barriers to accessing healthcare, particularly palliative care.



Those who have the greatest need for palliative care, can be the least likely to receive it.

¹ Department of Health (2020), *Exploratory Analysis of Barriers to Palliative Care – Summary Policy Paper*.

² Australian Government, Department of Health (2019), *National Palliative Care Strategy 2018*.

What makes a difference?

A number of enablers of quality palliative care have been identified:

- Increasing community comfort with discussing death and dying
- Promoting community awareness and understanding of palliative care
- Facilitating timely initiation of palliative care
- Fostering a greater understanding of the needs of under-served populations
- Improving communication and information provision
- Enhancing provision of person and family-centred care
- Better supporting advance care planning.³

There are numerous projects, programs and resources that support these enablers. Resource links to these are included at the end of this guide.

This guide primarily provides information on ways to support:

1. **Helpful approaches to care**
2. **Culturally-responsive care**
3. **Communication**
4. **Understanding of the needs of diverse groups**

Improving access to palliative care for everyone, particularly those who experience barriers due to their background or life experience is a key focus for healthcare professionals and services.

³ Department of Health (2020), *Exploratory Analysis of Barriers to Palliative Care – Summary Policy Paper*.





The most important strategy for improving access to palliative care is to shift from providing *special* care to people from under-served populations to providing *inclusive* care to all people.³



Helpful approaches

Person and family-centred care

Person and family-centred care is respectful of, and responsive to, the preferences, needs and values of people and their families and communities.⁴

It is important to note that some people have a *chosen* family, and they may be closer to and more connected to them than their biological family. Healthcare providers need to consider a broad definition of family, being 'anyone a person considers to be their family', when having conversations in this context.

Person and family-centred care involves:

- Enhancing the capacity of health services to deliver palliative care that is flexible, individualised and delivered in the person and family's setting of choice

- Ensuring that the care facility or setting is appropriate for all populations, including physical access, accommodation options, artwork, signage etc
- Respecting the role of families and communities in decision-making and provision of care
- Ensuring that organisational policies, structures, systems and cultures are inclusive and support person and family-centred care
- Ensuring that staff are formally trained in being culturally-responsive to the needs of all communities.

⁴ Australian Commission on Safety and Quality in Health Care (2011) *Patient-centred care: Improving quality and safety through partnerships with patients and consumers*.



The *Patient Dignity Question* should be considered when interacting with anyone affected by life-limiting illness:

“What do I need to know about you as a person to give you the best care possible?”

This question can be used to identify care needs and plan management. The [Patient Dignity Inventory](#) (PDI) is an assessment tool that assists with detecting end-of-life dignity-related distress. It can assist the healthcare team to communicate more effectively, individualise supportive interventions and make referrals to other members of the team for specific needs.⁵

Trauma-aware, healing-informed approaches to care

In all of the groups that are included in the underserved or vulnerable populations, there is an increased likelihood of having experienced trauma. This may be the result of discrimination, marginalisation, or directly related to experiences of abuse.

Trauma-aware care is ‘a framework for service delivery that is based on knowledge and understanding of how trauma affects people’s lives, their service needs and service usage’.⁶

Healing-informed approaches can be used in interactions with all people but are of particular benefit to those affected by trauma.

⁵ Dignity in Care (2016) [The Patient Dignity Inventory](#).

⁶ Wall L, Higgins D, Hunter C. (2016). *Trauma-informed care in child/family welfare services*. Australian Institute of Family Studies.



Trauma-aware, healing-informed care involves consideration of these key principles:

Principle	Definition	What does this look like in practice?
Safety	Ensuring that the physical and psychological safety of the person and their family is addressed	Common areas, uniforms, artwork are welcoming and nonconfrontational
		Privacy is respected
		Staff use supportive language and respond with empathy
		Staff are trained in providing culturally-responsive care
		Close collaboration with experts who can provide specialised advice and care
Choice	The person and their family have choice and control	Educating and training staff regarding the prevalence and impacts of trauma and healing-informed approaches.
		People are provided a clear and appropriate message about their rights and responsibilities
		Flexible plans of care are offered
		Biases and stereotypes (eg, based on racial group, ethnicity, sexual orientation, age, geography) are recognised and addressed.



Principle	Definition	What does this look like in practice?
Collaboration	Making decisions with the person and their family and sharing power	People are provided a significant role in planning and evaluating services
		Power differences are acknowledged and addressed to support shared decision-making.
Trustworthiness	Establishing consistent boundaries and being clear about what is expected with regard to tasks	Respectful and professional boundaries are maintained
		Careful consideration of policies and practices to minimise the potential for retraumatisation
		Decisions are made with transparency and with the goal of building trust.
Empowerment	Focusing on the person and their family's strengths and empowering them to build on the skills they have to manage care and make decisions	Providing an atmosphere that allows people to feel validated and affirmed with each care interaction
		Supporting and communicating the belief in people's resilience and the ability to heal.



Culturally-responsive care

Communicating well is at the heart of palliative care, and a key part of helping a person and their family deal with the effects of serious or life-limiting illness. Effective communication across diverse groups, requires healthcare staff to provide care that is responsive to the person's culture and individual needs.

Cultural safety and culturally-responsive care

Cultural safety provides the framework to deliver culturally-responsive care.

Developing an understanding of culturally-responsive care requires acknowledgement of a these key points:

- 1 Feeling 'culturally safe' is the experience of the care recipient, and not something defined by the person providing care.
- 2 Cultural awareness is not cultural safety.
Being **aware** of various aspects of different cultural practices and protocols can help to guide communication. Cultural **safety** though, involves a life-long process of self-reflection and self-critique, encouraging a respectful attitude toward diverse points of view. It also means being prepared to guard against viewing one's own behaviours, beliefs and actions as the norm.
- 3 Cultural-responsiveness is the 'how to' of cultural safety.
It describes the ways that we need to engage with people to provide culturally-safe care. Cultural-responsiveness requires the ability to understand and interact with people across diverse cultural groups. Provision of culturally-responsive care can not only improve access to healthcare, but also the quality of care provided.



Understanding culture, identity, privilege, bias and discrimination

Developing culturally-responsive practice requires healthcare professionals to have an understanding of these key concepts:

Culture	Culture is an umbrella term which encompasses the social behaviour and norms found in human societies, as well as the knowledge, beliefs, arts, laws, customs, capabilities, and habits of people in these groups.
Cultural Identity	The definition of groups or individuals (by themselves or others) in terms of cultural or subcultural categories, including ethnicity, nationality, language, religion, and gender.
Power and Privilege	<p>Power refers to the capacity that a person has to exercise control over others, deciding what is best for them, deciding who will have access to resources, etc. In the context of the healthcare system, when referring to a person as having privilege, it is about the access they have to resources.</p> <p>Those with more power have unearned access to things that those without power, typically members of marginalised groups, do not have access to. The idea of unearned access is where inequity arises because access is based on an identity someone holds that has traditionally been associated with power in the society.</p>



Bias	<p>Bias is being in favour of, or against, a person or group, usually in an unfair way. Biases are learned associations, which develop over time, prompt feelings and attitudes about other people based on characteristics such as race, ethnicity, age, gender, sexual orientation, and socioeconomic status. Everyone has biases as part of the natural way our brains categorise things.</p> <p>Biases can be <i>implicit</i> (based on stereotypes people have learned that affect their behaviour and decisions in an unconscious manner), or <i>explicit</i> (attitudes and beliefs that people hold at a conscious level that are acted on with deliberate thought).</p>
Discrimination	<p>Discrimination is the outcome of either implicit or explicit bias. It results in people treating others unfairly because of their skin colour, racial background, ethnicity, age, gender, sexual orientation, and socioeconomic status.</p> <p>Discrimination can be shown in people's actions and attitudes, and it can also be reflected in systems and institutions.</p>

Becoming aware of our cultural identity, power, privilege and biases can lessen the impact that they have on our behaviour towards diverse groups of people.



Self-reflection guide

Engaging in critical self-reflection is an important way to support development in this area. Ask yourself:

- What do I think of when I consider 'culture'?
- How would I describe my cultural identity?
- What assumptions do other people make about my cultural background?
- In what ways am I privileged in this society?
- How can I become more aware of my biases, especially unconscious bias?
- When have I observed discrimination in my work or personal situation?



Be prepared for the conversation

Effective communication is a two-way process. It involves getting your message across as well as understanding what the other person has to say.

To effectively interact with people in diverse groups, it is important to consider that there can be variations across different groups with regard to:

- Communication styles
- Ways that emotions are expressed
- Nonverbal communication
- Use of humour
- Topics that are considered appropriate or not appropriate to talk about
- Silences in conversations
- The amount of information people can cope with in one conversation.

It is always advisable to ask rather than making assumptions about what is or isn't appropriate.

Before you have a conversation with someone, take a moment to consider the questions in this section and think about ways to talk to the person and their family about your questions.



This guide provides suggestions for what you can do or say in conversation with a person and their family. Refining these suggestions to suit your own communication style is important.



How do they like to be addressed?

Some people prefer formal titles (eg, Mr, Mrs, Dr), others prefer first names. It is helpful to ask what they would like to be called.

In some situations, using a term of respect when speaking with Elders is important (eg, Uncle or Aunty) but this should not be assumed.

What to say:

- *Hello Mr Singh, my name is Jenny. Would you prefer me to call you Mr Singh or is there another name you would like me to use?*
- *Hello Mr Jeffrey, it's nice to see you again. Last time you were here you asked me to call you Uncle John. Is that still OK with you?*

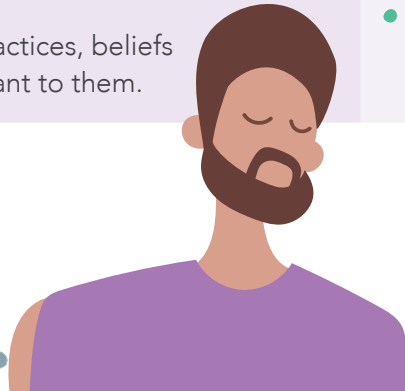
What kinds of spiritual practices are important to them?

There are a wide variety of spiritual practices between and among different groups. For example, it can be important for some people to fast at certain times, only eat certain types of food, and celebrate or perform rituals on specific days.

Respectfully asking questions about spiritual practices, beliefs and events will help you find out what is important to them.

What to say:

- *What kinds of spiritual practices are important to you and your family?*
- *When we are making plans for your care, please tell me if there are certain spiritual events, times or situations that need to be considered.*



Is showing respect for Elders important to them?

In some groups it is important to demonstrate respect for Elders through words and actions. It might be appropriate, with their consent to address the person as 'Aunty' or 'Uncle'.

Younger people might bow when speaking to an Elder to show respect. Standing above or over a person (especially an Elder) when speaking can be disrespectful. Sitting or crouching down (if the person is seated) can show respect when speaking to an Elder.

What to say:

- *I've noticed that you are called Aunty Joan by many of the other staff. Is that what you would prefer me to call you?*

Do we think of time in the same way?

Some cultural groups value time more than others. Healthcare systems are usually very dependent on schedules and time management.

Talking about this can help to avoid confusion and can prompt a conversation about the importance of appointment times.

What to say:

- *The healthcare world is very focused on times and schedules. Some people find this difficult. How do you feel about it? What can we do to support you to attend appointments?*



What do they believe about preventative health and the causes of serious illness?

Some people have strongly held beliefs about the causes of illness and ways to stay healthy. These beliefs may appear to conflict with the Western biomedical understanding. They might also be using traditional or alternative medicine to promote health or treat illness.

Demonstrating respect for diversity of beliefs and cultural practice can help to build trust and rapport.

What to say:

- *I'm interested to find out what you know about your illness and what you do to stay healthy. Can you tell me about that?*

Are there gender preferences that I should be sensitive to?

Relations between genders can differ between groups. For example, in some groups, it is not appropriate for men and women to make physical contact or discuss health matters. Respectfully asking about this will help the person and their family feel more comfortable with the care provided.

What to say:

- *Some people prefer to be cared for by a member of the same gender. What is important to you?*



How are their past experiences of the healthcare system influencing their choices now?

Experiences of healthcare and other institutions can differ greatly between groups. For some it can be a place of safety and comfort and for others it can be associated with negative experiences and trigger strong emotions.

Past trauma experienced in care situations might cause people to react negatively to sudden movements, loud noises, authority figures, uniforms, sirens, doors slamming etc.

It is important to observe the person and their family and watch how they react when you are talking about healthcare decisions and treatment options.

What to say:

- *I realise that some people might have had bad experiences in hospitals, institutions and other care settings. If you feel comfortable talking about it, I'd like to hear about your experiences and how you feel about being here today.*
- *Are there certain things that make you feel particularly uncomfortable that I need to be aware of? What helps you to feel safe?*

What behaviours or actions might seem impolite to them?

Behaviours or actions that are appropriate for some groups can be seen as rude by others (eg, in some groups, it is rude not to offer food to a guest, and rude to refuse it; it can be seen as rude to keep your shoes on in someone's home or be dressed in casual clothes when receiving guests).

It is important to be aware of sensitivities by observing the actions and reactions of the person and their family and asking respectful questions.

It is also important to find out what your organisational guidelines are around specific actions before you have the conversation.

What to say:

- *I noticed that you and your other visitors leave your shoes at the door. I need to keep my shoes on as part of my workplace safety guidelines. Is it alright if I bring some shoe covers to wear when I come next time?*
- *Thank you for your kind offer of food / drink / gifts. I feel very welcome here. Unfortunately, I am not allowed to accept this.*



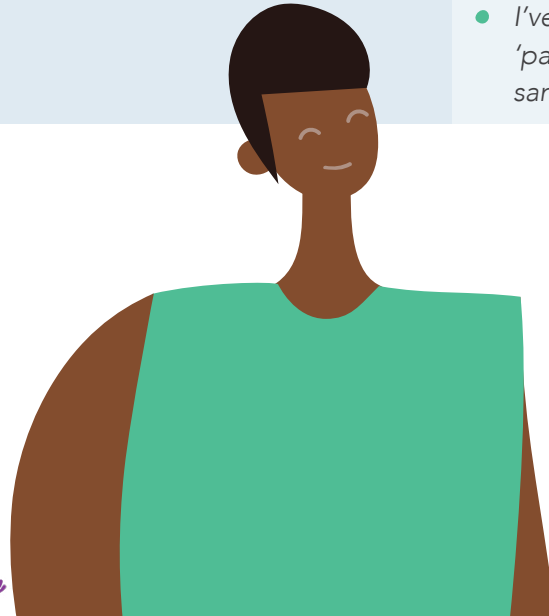
Can I talk openly about serious illness, dying and death? What words should I use?

For some people, these things are not spoken about directly. Using words like dying and death might be taboo or seen as bringing bad luck. Others can find them very confronting.

It is helpful in your first conversation to find out what the person and family prefer. You might notice that they use the words, 'bad news', 'passed away', 'finished up'. Taking your cues from the person and their family about the words to use is a good approach.

What to say:

- *We need to spend some time talking about what will happen as your illness progresses. Some people like to know lots of details and speak very directly about what will happen, others don't want to know too many details and use less direct words to talk about things. What would you prefer?*
- *I've noticed that you and your family use the phrase 'pass away'. If that's what you prefer, I will use the same words when speaking with you.*



What will I share about myself to make a personal connection and build trust?

While it is important to be professional in your approach, sharing something about yourself can help to make a connection with the person and their family.

It is important that whatever information you choose to share about yourself, it should be directed towards building a therapeutic or caring relationship.

Introductions that include your name and what you prefer to be called, as well as a bit of personal information (eg, where you're from, how long you've been in healthcare and something that you might have in common with the person) is a good place to start.

What to say:

- *Hello, I'm Dr Jones but you can call me Bill if you like. I haven't met you before, but I can see by your shirt that we are both proud Cowboys fans. How do you think they're going this season?*
- *It's good to see you again. I was up your way with my family a few weeks ago. What a beautiful part of the world!*

Is the language I'm using inclusive of people of all sexualities and gender identities?

Conversations about care should be inclusive of diverse genders, sexualities and bodies, and considerate of language preferences such as personal pronouns.

What to say:

- *What is your preference about use of gendered language (eg, she/her/woman, he/him/man, they/them/person)?*



Who would the person like to be present for the conversation?

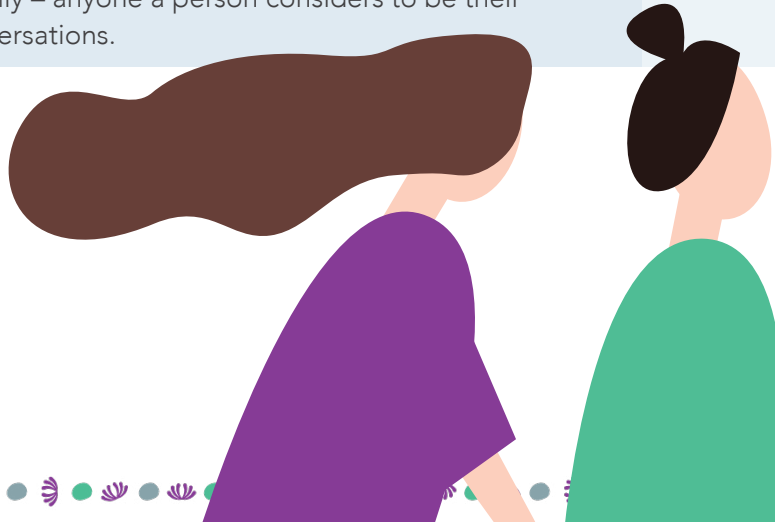
In some families, plans and decisions are made collectively or as a group. In conversations about a person's healthcare, there may be a family spokesperson or decision-maker who is not the individual, or their nearest family member.

In others, the person with the illness will be the one making the decisions and they may choose not to involve their family in discussions. Clarifying this in your first conversation is really important.

Some people have a chosen family, and they may be closer to and more connected to them than their biological family. It is important to consider a broad definition of family – anyone a person considers to be their family, when having conversations.

What to say:

- *Who would you like to be involved in conversations about your healthcare?*
- *Who is the main decision-maker about your healthcare matters?*
- *Who do you consider to be family?*
- *Do you always want to have your family involved in conversations or would you sometimes prefer to speak with me alone?*



What aspects of nonverbal communication do I need to think more about with this person and their family?

A significant part of interpersonal communication is nonverbal. This includes personal space, facial expressions, eye contact, gestures, touch, tone of voice, silences etc. Many of these aspects vary between people of different cultures and life experiences. It is helpful to observe the person and their family to see what their nonverbal communication is like and be guided by the nonverbal cues you observe. For example:

Eye contact: Some people avoid eye contact when communicating with Elders as a way of showing respect. Many also do this when they feel afraid or uncomfortable. Interactions should be guided by the person and family. If they seem uncomfortable then this may be a cue for you to adjust your approach.

Personal space and body language: Conversations, particularly ones that involve sensitive issues, will flow more freely for many people when greater personal space is allowed and when your body language shows that you are listening (eg, open posture, leaning forward, eye contact as appropriate). Also, talking to someone while sitting alongside them, rather than directly opposite, and from the same level rather than standing over, can feel less confronting.

Silences: Some people are comfortable with periods of silence during conversations. If silences occur, there is no need to talk through them as they allow time for processing information and thinking about the implications when responding to questions. Some people wait for silence before they start to speak so if there are no silences in the conversation, they may not talk at all.

Gestures: In many cultures pointing fingers can be inappropriate, as can showing the soles of your feet, touching things with your feet or using your left hand to eat or pass objects. Being sensitive to the reactions of the person and their family will help you to identify these things.



What aspects of nonverbal communication do I need to think more about with this person and their family?

Touch: Many health professionals use touch as a way of showing care and support for the people they are looking after. However, this can be uncomfortable for people who have cultural protocols relating to touch, or those who have experienced trauma. Being aware of individual cues and responding appropriately is important. Apologising if you get this wrong will help to rebuild trust.

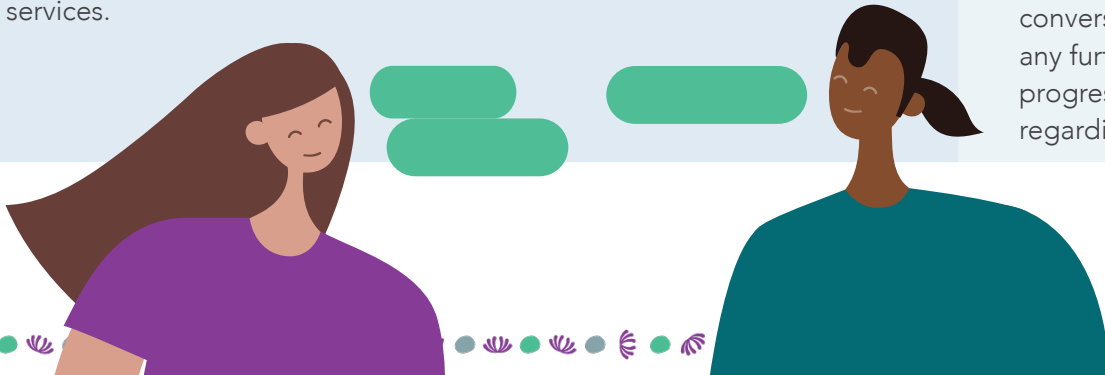
Emotional expression: Culture and life experience impact greatly on the ways that we express emotions. Some people display emotions very openly, while others are more subdued. In some groups or families, it is OK to shout or cry loudly in times of sadness, and in others it is expected that people will hold emotions in. Showing sensitivity to the diverse ways that people express emotion is an important part of establishing trust.

Do we need interpreter assistance for this conversation?

If English is not the person's strength in communication, it is helpful to find out if there is another person in the family group who can support communication. This should not replace using professional interpreter services.

What to do:

- If required, professional interpreter assistance should always be arranged for the first conversation with a person and family, and any further discussions focusing on illness progression/prognosis, and decision-making regarding care options.



Are my clothing and appearance demonstrating respect?

Some cultural groups have clear expectations about dress and the parts of a person's body that should be visible. For example, uncovered arms, shoulders, or legs might be seen as inappropriate. Some people can feel quite uncomfortable having a conversation with someone who is dressed in a way that they find inappropriate.

What to do:

- Dress in a way that is professional and demonstrates respect – no shorts, short skirts, singlets or thongs, and no clothing with strong language or images.
- If you think an aspect of your appearance might be causing someone to feel uncomfortable, take what steps you can to minimise this. For example, cover tattoos, remove or cover facial piercings, put something on over your clothes if you are dressed more casually.

In preparing for any conversation or interaction with people affected by life-limiting illness, it is important for you to ask yourself:

“What can I do to help this person feel safe, listened to and cared for?”



Background on diverse groups

It is important to remember that the best approach to improving access to palliative care is to move away from providing special care to people from under-served populations to providing *inclusive care to all people*.⁷

However, developing an appreciation for the needs and experiences of different groups is a key part of delivering culturally-safe and responsive palliative care.

This guide provides brief information on the following groups along with links to key resources to learn more:

1. Aboriginal and Torres Strait Islander peoples
2. People from culturally and linguistically diverse backgrounds
3. LGBTIQ+ people
4. Refugees and asylum seekers
5. People living with disability.

Links to further information on these and other groups can be found in the 'Resource Links' section at the end of the guide.



⁷ Department of Health (2020), *Exploratory Analysis of Barriers to Palliative Care – Summary Policy Paper*.



Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples are the Traditional Custodians of the many lands that make up the country now called Australia.

This has always been a multicultural continent – there were many different language groups and cultural ways before the arrival of Europeans. Significant diversity of cultures, kinship systems and social structures, cultural protocols, Lore and ways of life exist among the different groups of Aboriginal and Torres Strait Islander peoples.

The legacy of dislocation and displacement resulting from colonisation, has many significant impacts on the experiences of Aboriginal and Torres Strait Islander peoples living in Australian society today.

- Around 3.3% of the Australian population identify as Aboriginal and/or Torres Strait Islander. Two out of three live in New South Wales or Queensland and only one in three live in a capital city.

- Aboriginal and Torres Strait Islander peoples are more likely to have serious chronic health conditions (including kidney disease and heart disease), more likely to be diagnosed with cancer at advanced stages, and less likely to access palliative care.

The cultural capability of health services is an important factor impacting on health, influencing whether care will be accessed, and the quality and effectiveness of the care received.

It is important for all healthcare providers to engage in ongoing professional development on cultural self-awareness and cultural safety, in order to provide culturally-responsive care for Aboriginal and Torres Strait Islander peoples.



National Cultural Safety Strategy

The [National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020–2025](#) provides the following information:⁸

Cultural safety is determined by Aboriginal and Torres Strait Islander individuals, families and communities.

Culturally safe practice is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism.

To ensure culturally safe and respectful practice, health practitioners must:

- *Acknowledge colonisation and systemic racism, social, cultural, behavioural and economic factors which impact individual and community health*

- *Acknowledge and address individual racism, their own biases, assumptions, stereotypes and prejudices and provide care that is holistic, free of bias and racism*
- *Recognise the importance of self-determined decision-making, partnership and collaboration in healthcare which is driven by the individual, family and community*
- *Foster a safe working environment through leadership to support the rights and dignity of Aboriginal and Torres Strait Islander people and colleagues.*

Resources:

[IPEPA – Cultural considerations: providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples](#)

[Healing Foundation – working with stolen generations](#)

[Gwandalan palliative care education modules](#)

[Caring@home project](#)

⁸ Australian Health Practitioner Regulation Agency (AHPRA), (2020), National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020–2025



People from culturally and linguistically diverse (CALD) backgrounds

Australian communities include many people who were born overseas, have a parent born overseas, or speak a variety of languages. The term 'CALD' is also used to describe people for whom English is not the main language and/or those who have cultural norms and values that differ from mainstream Australian society.

Australia has one of the most diverse populations in the world with 28% of people born overseas, 21% with a parent born overseas, and 21% speaking a language other than English at home. It is estimated that contemporary Australian society has 300+ languages, 270+ ancestries and 120+ religions.⁹

Migration patterns have varied over time with changes in the number of migrants and the country or region they have come from. In the early post-war years, many people came to Australia from Europe. From the mid-1970s the number of migrants from Asia increased and has continued to do so over the last four-decades, while migrants from the UK and Ireland have remained stable.¹⁰



- **Top 5 countries of birth for people living in Australia:**
England, China, India, New Zealand, Philippines
- **Top 5 languages spoken in Australian homes:**
English 73%, Mandarin 2.5%, Arabic 1.4%, Cantonese 1.2% and Vietnamese 1.2%
- **Aging population:**
37% of Australians aged over 65 were born overseas.



In general, older Australians from CALD backgrounds:

- Have poorer socioeconomic status
- Face significant language barriers in accessing services
- Need support to understand the role of palliative care
- Are more likely to prefer in-home care and have family members as carers.¹¹

Some people belong to multiple populations groups which may mean that they are more vulnerable. People from CALD backgrounds who are also LGBTIQ+, have dementia, chronic disease or disability, suffer financial disadvantage, are at risk of homelessness, are refugees, and those living in rural and remote areas, experience multiple barriers to accessing palliative care.

This means that health and aged care services need to understand and be responsive to individual needs and preferences.

Resources:

[PEPA/IPEPA Culturally-responsive palliative care for people from CALD backgrounds workshop](#)

[Culturally Inclusive Aged Care Practice Guides](#)

[Partners in Culturally Appropriate Care \(PICAC\)](#)

[Centre for Cultural Diversity in Ageing](#)

[Advance care planning in languages other than English](#)

[CALD Assist mobile app](#)

[Health translations – Palliative care](#)

[Palliative care for CALD communities](#)

[Translating and interpreting services](#)

⁹ Australian Bureau of Statistics (2016), Cultural Diversity in Australia.

¹⁰ Australian Bureau of Statistics (2019), Statistics: Migration Australia.

¹¹ Department of Health (2020), *Exploratory Analysis of Barriers to Palliative Care – Summary Policy Paper*.



LGBTIQ+ people and communities

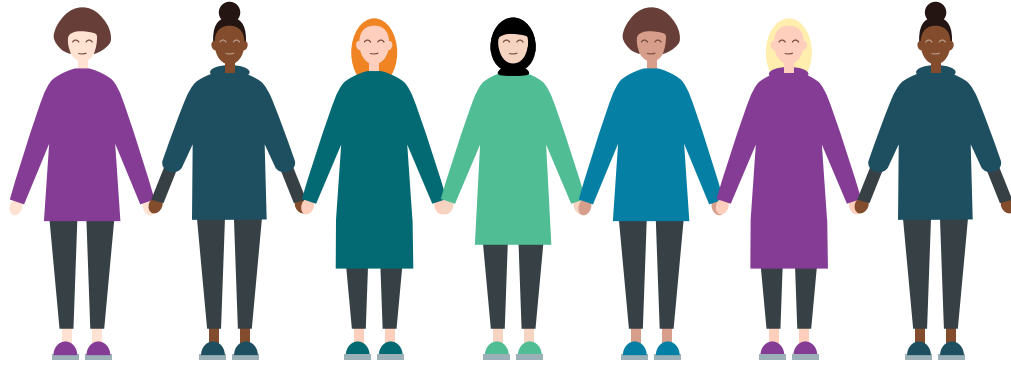
LGBTIQ+ is used to refer to a diverse group of people who identify as lesbian, gay, bisexual, transgender, intersex and queer and other sexuality and gender diverse (LGBTIQ+) people and communities. It is recognised that people's genders, bodies, relationships and sexualities affect their health and wellbeing.

While difficult to estimate, several studies suggest that around 10–11% of the total population of Australia have diverse sexual orientation, gender identity or intersex characteristics. While often seen as a single group, within LGBTIQ+ there are several distinct, but sometimes overlapping, demographics each with their own distinct histories, experiences and health needs.¹²

Barriers to palliative care:

All LGBTIQ+ people should feel confident that they can access inclusive palliative care that is safe and respectful. Current research indicates that there are many barriers that prevent this, including:

- Lack of awareness/understanding of palliative care
- Fear and experience of discrimination and bias, especially from faith-based services and in residential settings
- Heteronormative assumptions, including in publicity material, forms, and interpersonal communication



- Lack of recognition of LGBTIQ+ relationships and family of choice, including legal recognition
- Service providers' lack of knowledge, especially around trans and intersex healthcare
- Issues related to HIV/AIDS, including stigma, multiple morbidity, and neurodegenerative conditions.¹²

Providing inclusive palliative care:

The [National LGBTIQ+ Health Alliance](#) have been funded by the Australian Government, Department of Health under the 2020–2023 National Palliative Care Program to deliver a project which aims to improve the knowledge of care providers in the palliative care space.

PEPA/IPEPA will provide links to these resources as they are released.

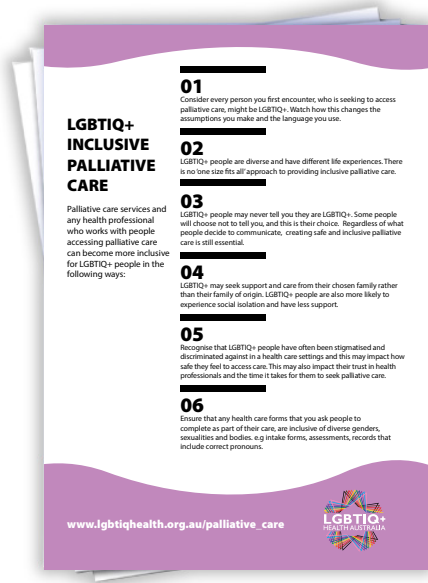
Resources:

LGBTIQ+ Health Australia (2021), [Palliative Care 11 tips poster](#).

Aged Services Learning and Research Centre (2011), [Respect my decisions: IT'S MY RIGHT! A guide to advance end-of-life care planning for gay, lesbian, bisexual, transgender & intersex people](#).

Dying Matters (UK) video resource: [End of Life care for LGBT people](#)

Acquaviva K. LGBTIQ-Inclusive Hospice and Palliative Care. A Practical Guide to Transforming Professional Practice. New York: Harrington Park Press; 2017. [Book]



¹² Department of Health (2020), 'Exploratory Analysis of Barriers to Palliative Care Issues Report on People Who Identify as Lesbian, Gay, Bisexual, Transgender or Intersex'.



Refugees and asylum seekers

Refugees and asylum seekers are people who are forced to leave their homes and seek protection as a result of conflict or persecution.

Under international law, refugees have a lawful right to enter a country for the purposes of seeking asylum, regardless of how they arrive or whether they hold valid travel or identity documents.



Asylum seekers and refugees will differ in their countries of origin, their reasons for leaving, their socioeconomic status and healthcare needs.

- The United Nations High Commissioner for Refugees (UNHCR) estimates that at the end of 2020, there were 84.2 million forcibly displaced people worldwide. Around half of these people are internally displaced (within their own country) and the rest in other countries, as either refugees (those granted residency) or asylum seekers (those seeking protection whose claims are being assessed).¹³
- In the 10 years to 2018, Australia recognised or resettled 180,790 refugees. This represented 0.89% of the 20.3 million refugees recognised globally over that period.¹⁴

Barriers to palliative care

There are many challenges faced by refugees and asylum seekers. Some will have spent many years in refugee camps or have spent time in mandatory detention. They may have had little or no healthcare access. Many have come from low-income countries, with high prevalence of communicable diseases.

Asylum seekers and refugees have also lost their housing, income and position in society, employment, social support systems, cultural norms, religious customs and language. Many will have suffered psychological trauma through the death or separation of family. They may not know the whereabouts of family or friends, or even if they are alive.

Many will find it difficult to adjust to life in a new country after a prolonged period as a refugee. They may also face hostility when trying to re-settle into new communities. Loneliness and grief are often key issues.

Providing inclusive palliative care involves:

- Community education and awareness-raising, and identifying and supporting cultural champions
- Provision of culturally-appropriate and translated resources, access to appropriate professional interpreting services, and training for professional interpreters in palliative care concepts and terminology
- Improving the cultural competence within services, through education and training to increase understanding of the 'refugee experience', culturally-appropriate communication, and facilitating cultural elements and practices in service provision
- Taking time to build rapport with individuals, families and communities.¹⁵

Resources:

[Australian Refugee Health Practice Guide](#)

[CareSearch: Refugees and asylum seekers](#)

¹³ UNHCR (2020), Refugee Statistics

¹⁴ Refugee Council of Australia (2019), 2018 Global Trends

¹⁵ Department of Health (2020), 'Exploratory Analysis of Barriers to Palliative Care Issues Report on Refugees'.



People living with disability

Disability is an umbrella term that describes impairments of body function, structure, activity limitations or participation restrictions.

In Australia, around 18% of people have disability, another 22% of people have a long-term health condition but no disability. Close to 6% of the population have severe or profound disability, and require help with daily self-care, mobility or communication activities. Most people with disability (77%) report their main condition to be physical (eg, musculoskeletal

problems, hearing disorders, heart disease and stroke, nervous system disorders), with the remainder reporting mental or behavioural disability (eg, intellectual disability, mood affective disorders, dementia).¹⁶

People with disabilities often experience significantly poorer health than those without, and many are likely to require palliative care during their lives.¹⁷ However, challenges exist to ensuring access to quality palliative care that meets the needs of people with disabilities.



Providing inclusive palliative care involves:

- Community awareness-raising
- Education and training for palliative care, disability service staff and people with disability
- Support for carers and families
- Advocacy support
- Collaboration and inter-agency communication to boost capacity for community-based palliative care
- Development of organisational policies and processes to support delivery of palliative care.

Resources:

[Talking End of Life with people with intellectual disability](#)

[End of life and palliative care for people living with a disability](#)



¹⁶ AIHW (2020), *Report: Disability in Australia*

¹⁷ Department of Health (2020), *'Exploratory Analysis of Barriers to Palliative Care Issues Report on People with Disabilities'*.



Resource Links

Resources that support access to quality palliative care for under-served populations and those with experience of disadvantage:

Enablers	Resource links
Increase community comfort with discussing death and dying	Dying to talk (Palliative Care Australia) The Groundswell Project
Promote community awareness and understanding of palliative care	Compassionate Communities Dying2Learn Palliative Care Australia The Waiting Room Revolution
Facilitate timely initiation of palliative care	Supportive and Palliative Care Indicators Tool (SPICT) app Gold Standards Framework: Proactive Identification Guidance
Foster a greater understanding of under-served populations	CareSearch – Diverse populations CareSearch – Homelessness CareSearch – Prisoners CareSearch – Refugees and asylum seekers Culturally Inclusive Aged Care Practice Guides ELDAC – Diverse population groups Healing Foundation – Working with Stolen Generations



Enablers	Resource links
Foster a greater understanding of under-served populations <i>continued</i>	IPEPA – Cultural considerations: providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples LGBTIQ+ Health Australia – Palliative Care 11 Tips Poster palliAGED resources Partners in Culturally Appropriate Care (PICAC) Talking End of Life with people with intellectual disability
Improve communication and information provision	Advance care planning in languages other than English CALD Assist mobile app Centre for Cultural Diversity in Ageing Health translations – Palliative care Palliative care for CALD communities Translating and interpreting services Vital Talk – communication skills for serious illness
Enhance provision of person-centred care	Patient Dignity Inventory ACSQHC Patient-centred care
Better support advance care planning	Advance Care Planning Australia



Scan the QR code below for easy access to all the resource links listed in this guide.



https://padlet.com/pepa_workshops/communicationguide

This code or link will take you to the PEPA/IPEPA Padlet Resource for the Communication Guide.

