

Cultural Heritage and End-of-life Caring: Personal Insights

Dr Priyanka Vandersman, BN BHons, PhD

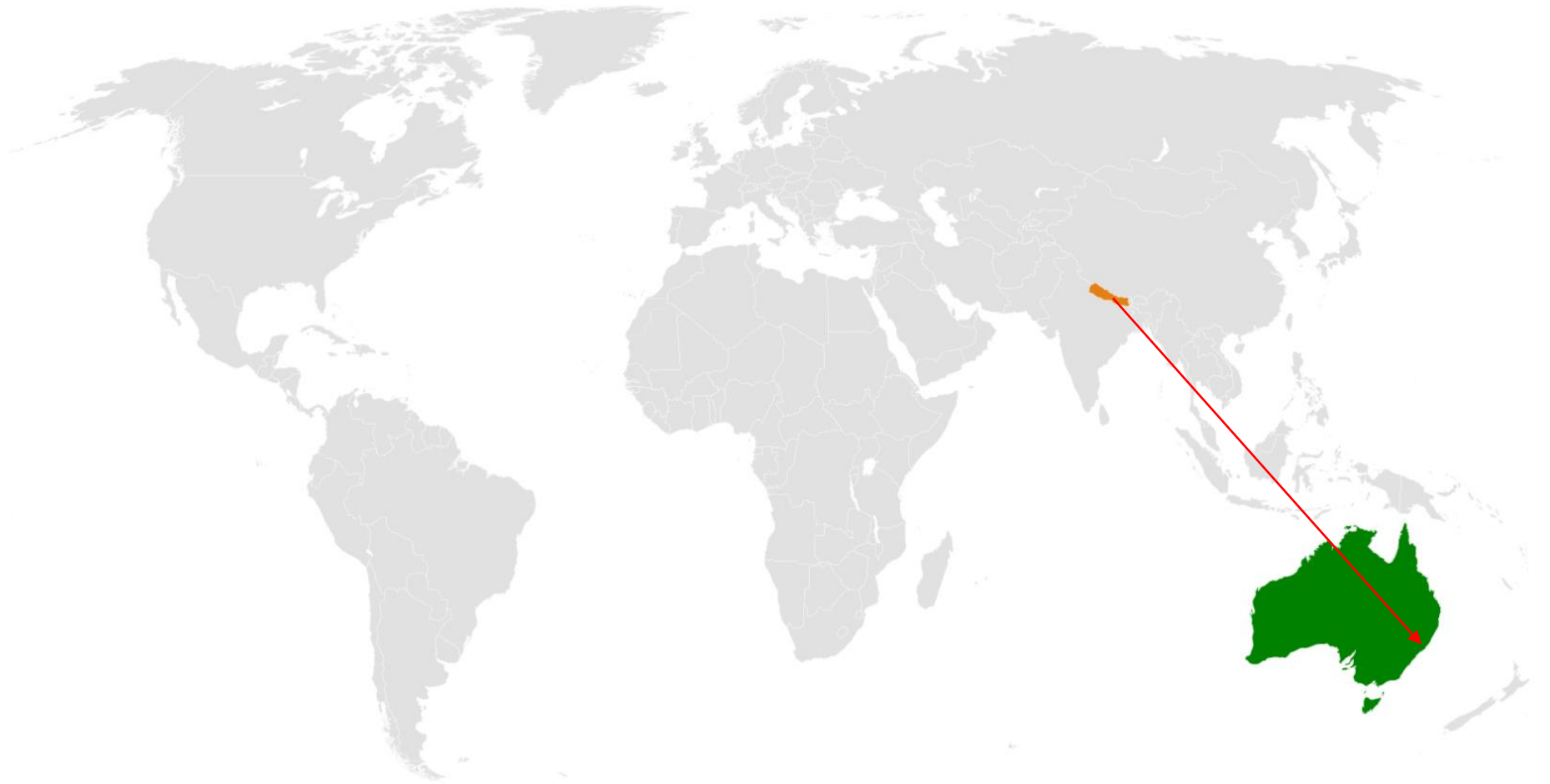


Research Centre for Palliative Care, Death, and Dying

CRICOS No. 0014A

Making a difference
to care at the end of life

The cross-cultural journey



My journey of caring

- PCW
 - Aged Care
 - Hospital
- Registered Nurse
 - General med/surg
 - Palliative care
- Research education and work [Hons, PhD]
 - Aged, chronic and palliative care
 - Teaching undergrad nursing students
 - Palliative care Research CNC– Concord Hospital
- Post Doctoral work
 - Aged care + Palliative + end of life care + technology



What is your calling??

Older people

Chronic
conditions

Palliative care

End of life care

Death and
dying



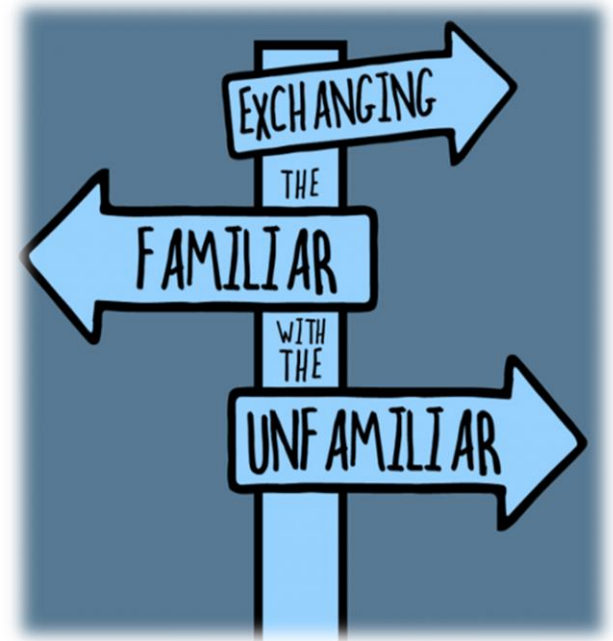


Caring and our Cultural lenses

- Influences and shapes:
 - attitudes and beliefs
 - actions
 - interactions & socializations

New and unfamiliar

- Home care- many older people lived by themselves.
- Residential care- living arrangement as a new concept
 - Family involvement in care/decision making
- Care in the last year of life
 - Health/care professional delivered/led
- Palliative care- difficult conversations, family distress, dying care, NBM.
- After death care



Coming face to face



- Beliefs
- Fears
- Awkwardness
- Skill needs

End of life
out of
home

Caring for a
resident who
has just died

Speaking
with
families

What are
the rituals
for death?

What
about my
spirituality?

No visitors
at the end
of life

NBM- Am I
starving this
person?

Am I a
bad
nurse?

Sharing integrated Wisdom



- Human
- Woman of colour
- Migrant
- Mother
- Nurse
- Researcher
- Educator

Acknowledging it



I'm not a robot



reCAPTCHA

[Privacy](#) - [Terms](#)

Human

Shaped by life experiences & culture



In the business of caring and giving, what matters is not the shape we hold- but that we care, and we give.

How to best give?



Knowing your shape might help you give [pour out] in the best way!

At ease with EOL caring?



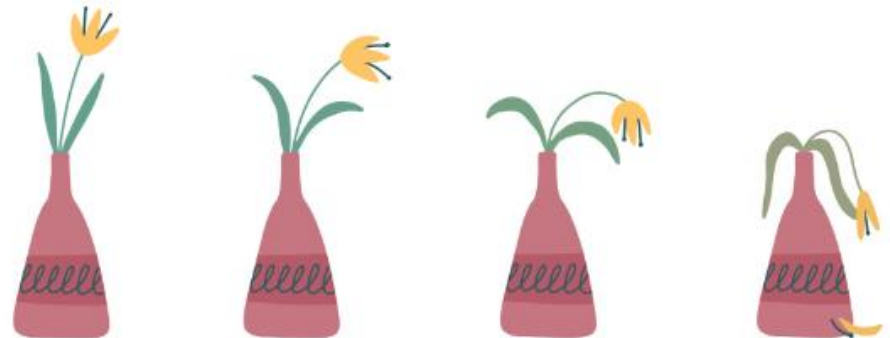
1. Death as part of life

Life has a 100% mortality rate

2. Death and dying does occurs across the community and all health + care setting

Caring for older people who are in the last year of life [and/or dying] is a core business of health care, aged care.

Caring for loved ones who are coming to the end of their life is done by many family caregivers.



At ease with Palliative care

Palliative care is an approach to care that emphasises quality of life when providing support for people with a life-limiting illness and their family and carers.

Palliative care may also be relevant to the older person approaching their natural end of life without a life-limiting illness but experiencing similar care issues.

At ease with Palliative care

‘What should I know about you as a person to help me take the best care of you that I can?’



Nil By Mouth [NBM]

Food as life- vitality

Feeding as expression of love and care

Food as a spiritual medium



Identify, Acknowledge



Nil By Mouth [NBM]



Knowledge building

- Diminished interest in eating and drinking at the EOL
- Swallowing compromised
- Some older people are beyond the stage of fighting weight loss at this stage.

EOL medications

- **Can End of life medications hasten death?**

EOL as a sacred time- Am I playing too close to the sacred?

I feel confused/anxious/uneasy/fearful about medications for end of life



Identify, Acknowledge, learn

EOL medications

• Can myths lead to human right violations ?

AJPH PAIN MANAGEMENT

Access to Pain Management as a Human Right

The concept of access to pain management as a human right has gained increasing currency in recent years. Commencing as individual advocacy, it was later embraced by the disciplines of pain medicine and palliative care and by mainstream human rights organizations.

Today, United Nations and regional human rights bodies have accepted the concept

Frank Brennan, MBBS, DCH, Dip Obs, FRACP, FACHPM, LLB, Diederik Lohman, MA, and Liz Guyther, MBChB, FCFP, MSc

See also Carr et al., p. 17; and also the *AJPH* Pain Management section, pp. 30–72.

"Pain-relief treatment . . . is a fundamental human right."
—M. A. Somerville¹⁰²¹⁹

"I put it to you that the relief of severe, unrelenting pain would come at the top of a list of basic human rights."
—M. J. Cousins²⁰⁵⁴⁹

management be an integral component of Universal Health Coverage (UHC), a critical objective of the World Health Organization (WHO).

undertreatment remains a major problem. There are many barriers to pain management: inadequate access to health facilities, lack of training of health professionals,¹⁰ lack of acknowledgment of pain,¹¹ and racial biases.¹² The opioid crisis in the United States

Myth Once on morphine the end is near.

Fact Morphine properly used does not cause death, the underlying illness does.

Myth Enduring pain will enhance one's character.

Fact Pain decreases quality of life and causes suffering.

Myth Tolerance to morphine will develop and higher doses will be needed.

Fact Tolerance develops slowly. Disease progression may cause increasing pain and increased need for analgesia.

Myth Morphine is a treatment for cancer.

Fact No, morphine is not a treatment for cancer, it is an analgesic medication used to relieve the symptoms of pain.

Myth Morphine is addictive.

Fact When given at the right dose to relieve pain, morphine is not addictive.

Myth Injections are better than oral.

Fact Oral preparations are as effective as injections; long-acting forms mean better pain control and less frequent administration.

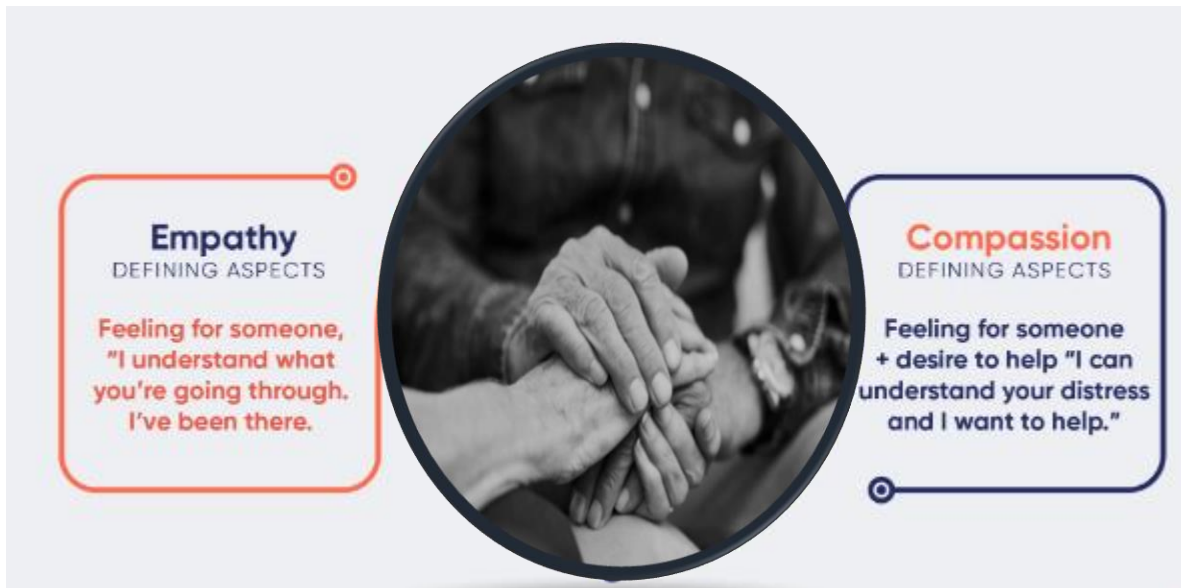
Myth Side effects (nausea, vomiting, constipation, sleepiness, etc.) are due to allergies.

Fact Allergies to morphine are rare, side effects can be managed and should be reported to the prescriber.

Caring for families at EOL

- EOL can be distressful for many families [and staff]
 - Grief and loss
 - suffering

To cater to family needs around EOL period can be emotionally taxing



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Empathy

DEFINING ASPECTS

Feeling for someone,
"I understand what
you're going through.
I've been there."

Compassion

DEFINING ASPECTS

Feeling for someone
+ desire to help "I can
understand your distress
and I want to help."

Identify, Acknowledge

Learn: Family communication

Family often look at us for support, or to understand the disease & symptom management, and end-of-life planning

*including what happens as a person is dying



I WANT TO
KNOW MORE

Human desire to be acknowledged, connected, & heard.

Learn: Family communication



Suffering is intolerable only if nobody cares

Dame Cicely Saunders

Caring in proximity of death

- Caring for the dying can be emotional.
 - **Mortality,**
 - **meaning**
 - **sadness**



**IT'S OKAY
TO REACH
OUT FOR
HELP.**

How do we move forward?

In the end, its about the older person



1. Pay close attention to what bothers you, and ask WHY?
 - Has my view of 'what an ideal [] should look like' has any thing to do with it?
 - Are my cultural lenses at play?
2. Is my resident/client/patient/ family bothered by it?
 - * Do I need to do anything about it ?
3. Can some skill building or education help?

What resources can support me?


The screenshot shows the CARESEARCH website interface. At the top left is the CARESEARCH logo with the tagline 'palliative care knowledge network'. To the right are options for 'Contrast' (with a black square selected), a search bar, and social media icons for 'Subscribe', Facebook, and 'Login'. A navigation menu below the header includes 'Home' (highlighted in blue), 'Community', 'Health Professionals', 'Evidence', 'About Us', and 'News'. The main content area features a large image of a young woman kissing an elderly woman on the cheek. To the right of the image is a white box containing the text: 'Palliative care evidence and tools for health professionals and information about death and dying for the whole community'. Below this text are three categories: 'Patients, carers, community' with a blue icon, 'Health professionals' with a green icon, and 'Evidence and translation' with a purple icon. A blue starburst callout is overlaid on the bottom right of the page, containing the text 'Healthcare setting'.


CARESEARCH®
palliative care knowledge network


Contrast: Search... [Subscribe](#) [f](#) [x](#) [Login](#)

[Home](#) [Community](#) [Health Professionals](#) [Evidence](#) [About Us](#) [News](#)

Palliative care evidence and tools for health professionals and information about death and dying for the whole community

Patients, carers, community 

Health professionals 

Evidence and translation 

Healthcare setting

About CareSearch
Terms and Conditions
Accessibility
Contact us
Subscribe

CareSearch is funded by the Australian Government Department of Health and Aged Care.

What resources can support me?

> [Our Population](#)

> [Specific Needs](#)

- > [Aboriginal and Torres Strait Islander Peoples](#)
- > [Care Leavers](#)
- > [Culturally and Linguistically Diverse \(CALD\) communities](#)
- > [Financially or Socially Disadvantaged](#)
- > [Homeless People](#)
- > [Lesbian, Gay, Bisexual, Transgender and Intersex \(LGBTI\) Individuals](#)
- > [People with Dementia](#)
- > [Rural and Remote Populations](#)
- > [Spirituality and Faith](#)
- > [Veterans](#)

> [Aged Care](#)

> [Palliative Care](#)

> [A Consumer Focus](#)

Culturally and Linguistically Diverse (CALD) Communities

Culturally appropriate palliative care respects and supports individual cultural, linguistic and spiritual needs and preferences. Responding to individual needs is an important part of providing person-centred palliative care for our ethnically diverse population.

For people accessing Australian hospital palliative care services in the period July to December 2018, Palliative Care Outcomes Collaboration (PCOC) data shows that 83% were born in one of 15 countries. [1] Places of birth included: Australia (60.6%), England (7.1%), Italy (4.0%), Greece (2.2%), New Zealand (2.0%), Scotland (1.2%), Germany (1.1%), and China (1.1%).

Being able to communicate with patients and their families is also recognised as an essential component of quality palliative care. The most commonly preferred languages among these patients were English (88.4%) followed by Italian (1.9%), Greek (1.5%), Chinese (1.2%), Arabic (0.9%) and Macedonian/Croatian (0.8%). In all 15 specific languages were listed by 97% of all palliative care patients in this period.

The data from PCOC reflects our ageing population, with people aged 65 years or older accounting for 3 in 4 episodes of hospital based palliative care in this period. This explains why the list of preferred languages for

Key Resources

[Resources for Carers from CALD backgrounds \(Carer Gateway\)](#)

[Support for older Australians from CALD backgrounds \(My Aged Care\)](#)

[Multicultural \(CareSearch Review Collection\)](#)

[Centre for Cultural Diversity in Ageing](#)

[palliAGED Tips sheets](#)



Aged care setting

What resources can support me?

The screenshot shows the ELDAC website interface. At the top, there is a navigation bar with links for Home, Toolkits (highlighted), Service Development, Technology and Innovation, My Care Matters, Resources, Newsroom, and About ELDAC. Below this is a breadcrumb trail: Home > TOOLKITS > RESIDENTIAL AGED CARE > ORGANISATIONAL SUPPORT > DIVERSE POPULATIONS > SUPPORTING INCLUSIVE END OF LIFE CARE COMPANION GUIDES.

On the left side, there is a vertical navigation menu with the following categories and sub-items:

- > Primary Care
- > Home Care
- > Residential Aged Care
 - > Clinical Care
 - > Education and Learning
 - > **Organisational Support**
 - > Support Systems
 - > Quality Improvement
 - > Standards and Funding
 - > Work Together
 - > **Diverse Populations**
 - > **Supporting Inclusive End of Life Care Companion Guides**
- > End of Life Law
- > Linkages
- > Dementia
- > Allied Health
- > Toolkit Educational Videos

The main content area is titled "Supporting Inclusive End of Life Care Companion Guides". The text reads: "The ELDAC Supporting Inclusive End of Life Care companion guides aim to assist aged care providers in the provision of culturally safe and inclusive end of life care by providing information, guidance and links to key resources. The companion guides support key resources developed by the Australian Government Department of Health: [Aged Care Diversity Framework](#), [Provider Action Plans](#) and the [Specialisation Verification Framework](#). The companion guides are not stand-alone resources and are to be used in conjunction with these essential documents. This [factsheet \(318kb pdf\)](#) provides a summary on the Supporting Inclusive End of Life Care Companion Guides. The companion guides were developed for these diverse population groups:

Below this text, there are two expandable sections:

- Aboriginal and/or Torres Strait Islander Peoples** (expanded)
- Culturally and Linguistically Diverse People** (collapsed)

The expanded section for "Culturally and Linguistically Diverse People" contains the following text:

In 2016, 1 in 3 older people were born overseas with the majority of these people born in a non-English speaking country. Many older Australians from culturally and linguistically diverse communities may face barriers in accessing services. Barriers may include: a lack of awareness and knowledge of the services that are available; system complexity; language barriers; and inadequate availability of culturally safe and inclusive care providers.

Many older people from culturally and linguistically diverse backgrounds experienced trauma during their migration. These past traumatic experiences, cultural differences, and limited access to health and other services throughout life play an important role at end of life in the provision of palliative care.

Supporting Inclusive End of Life Care: Older People from Culturally and Linguistically Diverse Communities

This resource is a companion document to the [Actions to Support Older Culturally and Linguistically Diverse People](#) and provides information, guidance and links to key resources to assist aged care providers in the provision of culturally safe and inclusive end of life care of older people with diverse backgrounds.

There is a photograph of an elderly woman with grey hair sitting in a wheelchair outdoors, smiling. A large blue starburst graphic is overlaid on the bottom right of the page, containing the text "Aged care setting".

What resources can support me?

pall AGED
PALLIATIVE AGE CARE EXPERTISE

Home Australian Context Evidence Centre Practice Centre **For the Community** About palliAGED

> Talking with Others
> Finding Support
> Making Plans
> Communication
> Cost of Care
> Discrimination
> Information in Your Language

> Illness and Family Caring

> At the End of Life

> Bereavement, Grief and Loss

> Finding Services and Support

> Developing Knowledge and Skills

Palliative care in your language

The focus of palliative care is quality of life. This may be very different to the types of care you are familiar with. If you want to know more about palliative care in your language, click on the following to find videos and/or podcasts from CareSearch.

More resources in your language

- Arabic - عربي
- Croatian - Hrvatski
- Cantonese - 廣東話
- English
- Greek - Ελληνικά
- Italian - Italiano
- Mandarin - 普通话
- Spanish - Español
- Ukrainian - Українська

Where can I go for palliative care support?

Click on the different care providers in the image below to learn where and how you can access palliative care support, what care is provided, and who pays. We also have an [accessible version](#) of this information.

Home care services

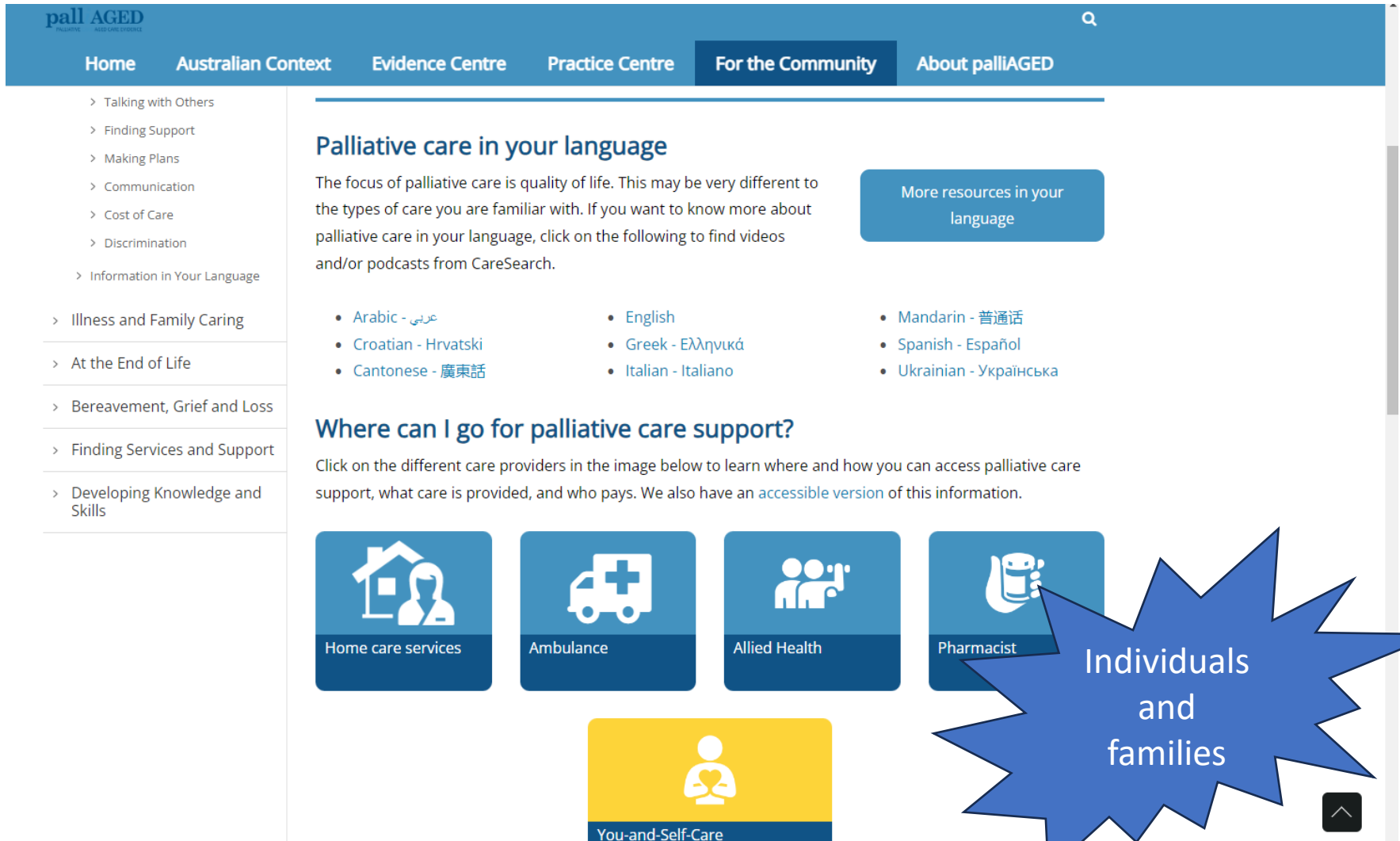
Ambulance

Allied Health

Pharmacist

You-and-Self-Care

Individuals and families



What resources can support me?

Home

Community 

Health Professionals

Evidence

About Us

News

Diversity



[Home](#) / [Community](#) / Diversity

Finding culturally appropriate resources in palliative care

Many people from diverse backgrounds find the health system difficult to navigate or the right support hard to find. These barriers can prevent them from accessing palliative care services when they or a loved one has a life-limiting illness. Information in the following sections can help to address these barriers.



For individuals

Find out where to go for help and who can support you with your



For health professionals

Learn about your diverse community and



Diverse populations

Learn about some of the groups with specific needs.



Healthcare rights

Understand everyone's right to health care within the palliative care system.

Individuals
and
families

Balancing act *'Human' & 'Compassionate'*





*Thank
you!*