

Applying a Diversity Lens to End-of-Life Care

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PALLIATIVE CARE EDUCATION & TRAINING COLLABORATIVE

PEPA Program of
Experience in the
Palliative Approach

PEPA Indigenous Program
of Experience in the
Palliative Approach

Funded by the Australian Government Department of Health



**TASMANIAN
HEALTH
SERVICE**



Program of Experience in the Palliative Approach (PEPA)

BUILDING
WORKFORCE
CAPACITY

PROVIDES LINKS
BETWEEN
SPECIALIST

PALLIATIVE CARE
PROVIDERS AND
OTHER

HEALTH
PROFESSIONALS

PROVIDES
PROFESSIONAL
DEVELOPMENT

OPPORTUNITIES
FOR CLINICIANS

Aim – To enhance the quality of palliative care service in all health sectors, increasing support for people who are dying, their families and carers. (PEPA, 2020)



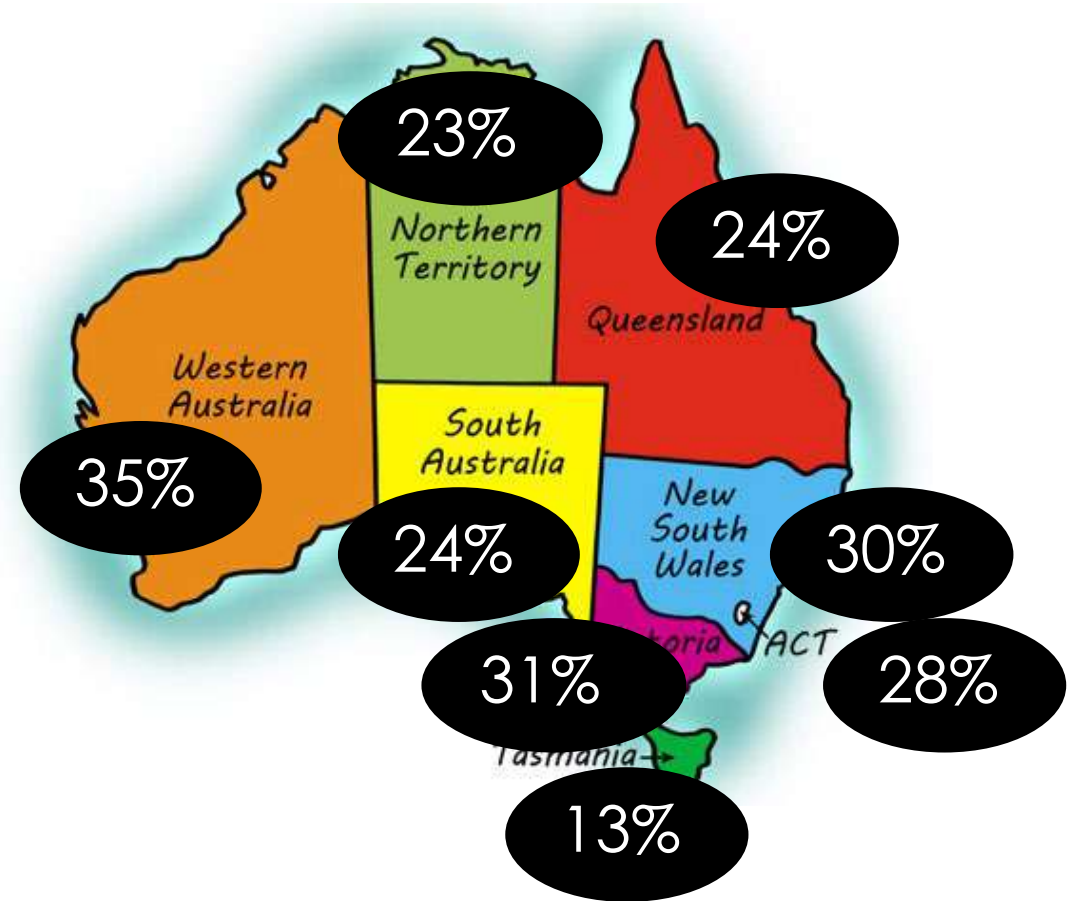
PALLIATIVE CARE EDUCATION & TRAINING COLLABORATIVE

PEPA Program of Experience in the Palliative Approach **PEPA** Indigenous Program of Experience in the Palliative Approach

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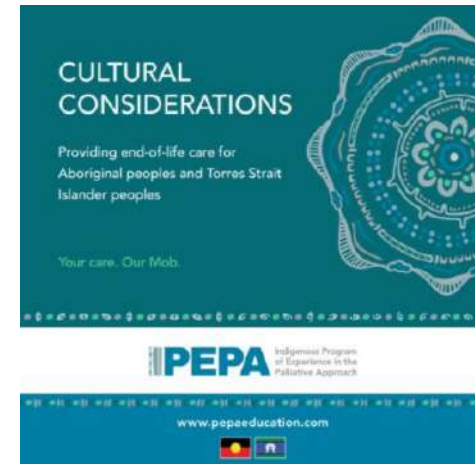
Challenges

- Increasing awareness of cultural and linguistic diversity in Australia
- Developing cultural competency
- Developing communication skills that respect the culturally diverse backgrounds of those living with life-limiting illness
- Embedding culturally-responsive practices in palliative care



Opportunities

- Capacity building
- Organisational
- Reflection
- Resources – Cultural Considerations, Communication guides and quick guides (to share a few)



Learnings

- Communication
- Collaboration



Delivering culturally responsive palliative care

“...quality palliative care ... is respectful of, and responsive to, the preferences, needs and values of individuals. ...It incorporates respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers and access to care”. (AHA, 2019)



Diversity in End-of-Life Care

Acknowledgement

Q: If you were diagnosed ...

- * Asked community partners
- * Within community capacity



- Multicultural, multifaith
- End of Life Care
- Palliative care
- The human right to health: WHO
- The right to a 'good death'
- Why diversity in EOL care?

* Pallotta-Chiarolli, M. & Rajkhowa, A. (2017).
'Systemic invisibilities, institutional culpabilities
and multicultural multifaith resistances.
Journal of Intercultural Studies, 38 (4), 429-42.
doi:10.1080/07256868.2017.1341013



- Not a blank slate to fill up
- Wisdom from lived experience is present
- Shared responsibility of whole community
- Does your service support these community connections?
- Isolated and seriously ill



What does this support look like?

- Co-designing psychosocial support for people with serious illness
- Training, supervision, support provided in language

Picture: United Spanish Latin American Welfare Centre volunteer staff/team provided emotional support, home visits, accompanied appointments



Picture: Ethiopian Orthodox Church palliative support volunteer program

- Overcoming taboos
- Identifying individuals in need
- Reconnected to community networks
- Practical needs, emotional support, companionship



PalliativeCare
VICTORIA
Living, dying & grieving well

Picture: Serbian Community Assoc of Australia palliative support volunteers

- Identified Serbian speaking older persons in residential-care
- Emotional support, outings

Extending ethnic aged care worker skills and knowledge

- Mercy Palliative Care
- Eastern Palliative Care/EMRPCC



ISLAMIC PERSPECTIVE ON END-OF-LIFE ISSUES

RESOURCES:

- Health Translations website
- Muslim Health Professionals Australia information brochure
- Queensland Health Care Providers' Handbook for the Muslim, Hindu and Sikh patients.
- PCV fact sheets and bilingual brochures in 20 languages.



Pal Care

initial, your doctor
with you

In Islam, death is considered a
natural cessation of the life of this
world and a transition to
the afterlife. Death, viewed from a
spiritual point of view, is an
opportunity to gain closer
contact with Allah (God).

- Cultural humility
- Ask, listen, learn from culturally diverse individuals, families.
- If you need resources, training or support contact:

Palliative Care Victoria

W: www.pallcarevic.asn.au

T: 03 9662-9644

E: info@pallcarevic.asn.au





Multicultural Perspectives on End of Life Care

Presenter:
Selen Akinci PICAC
NSW&ACT

Acknowledgement of Country





MULTICULTURAL COMMUNITIES
COUNCIL OF ILLAWARRA

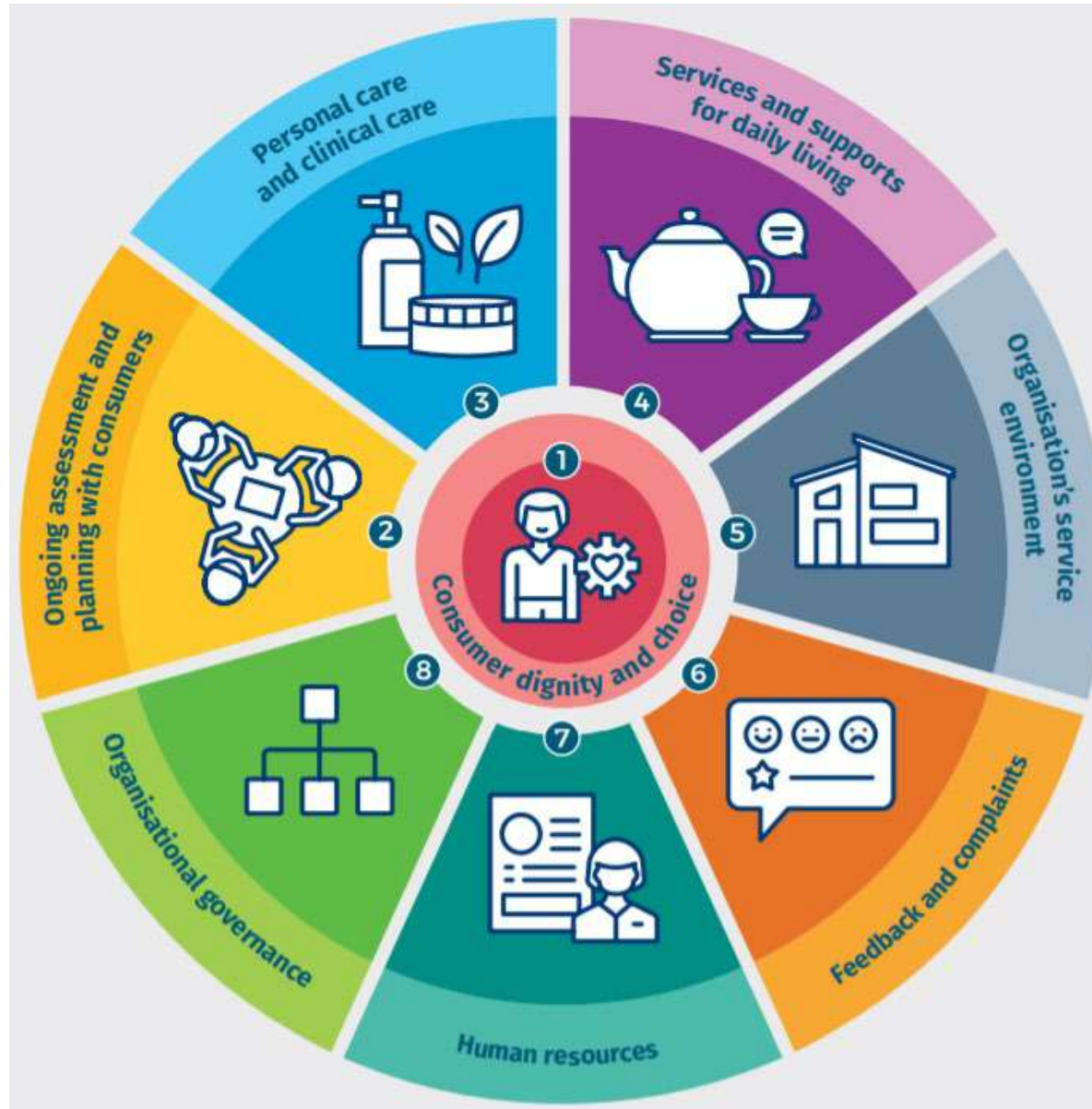
**Partners In Culturally Appropriate Care
(PICAC) NSW & ACT**

DIVERSITY | INCLUSION | RESPECT

Overview

- Multicultural perspectives on end of life care
- Resources

Aged Care Quality Standards



The Australian Context



**24.4m
POPULATION**

**120
COUNTRIES &
300
LANGUAGES**

**NSW 7.69m
ACT 395,790**

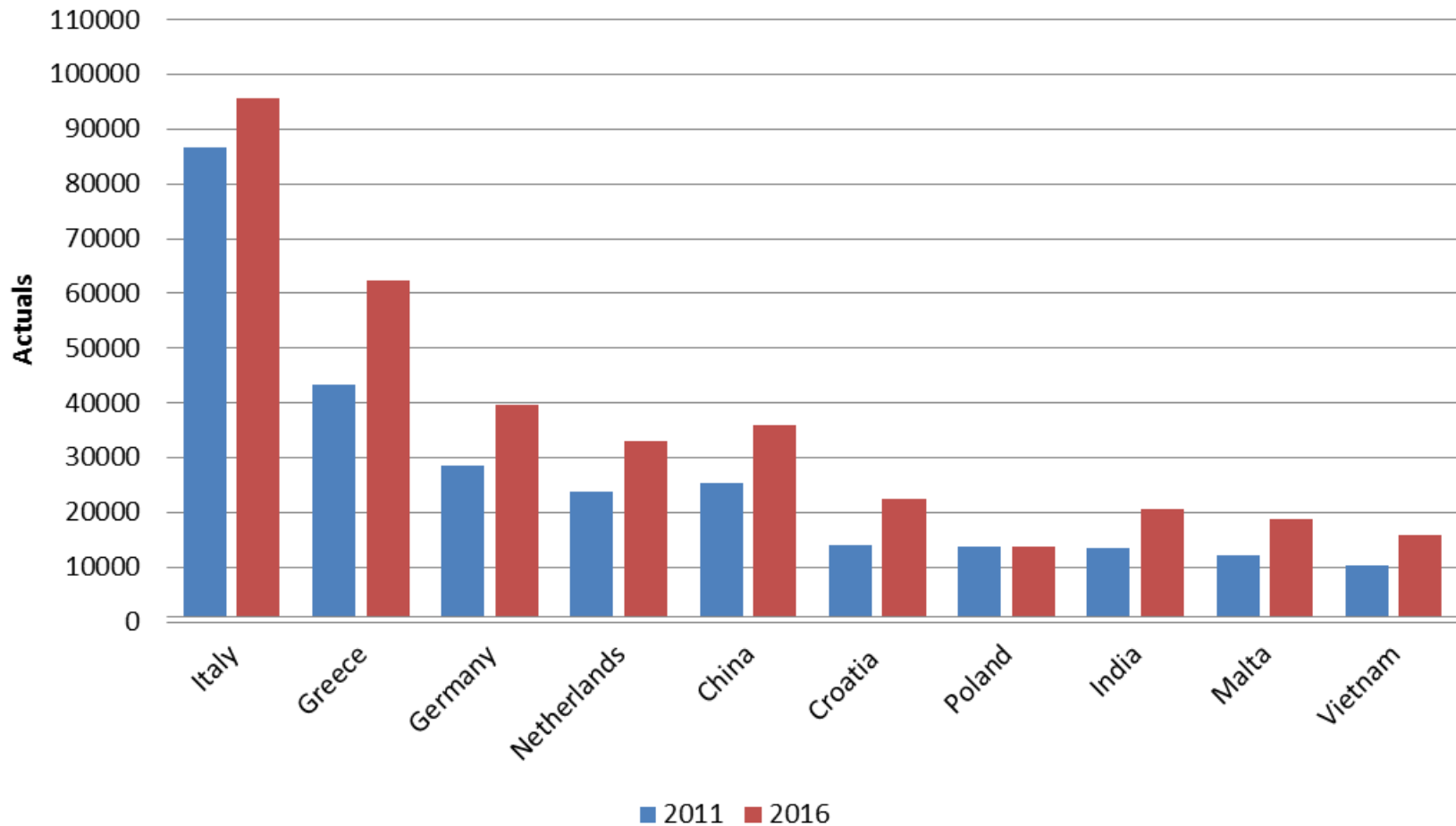
**ABORIGINAL &
TORRES STRAIT
ISLANDER
649,173**

**150
INDIGENOUS
LANGUAGES**

**33% BORN
OVERSEAS
(49% ONE
PARENT BORN
OVERSEAS)**

Countries of birth 70+ years

Australia



Top 10 CALD Population Groups excluding Australia

Source: ABS 2011 & 2016 Census data



Cultural Attitudes

- Cultural diversity
- Individualised care
- Religions

Skills and Knowledge

- Empathy
- Reflection
- Validation
- Negotiation





Decision-Making

- Who?
- When?
- How?
- Autonomy?
- Informed Consent?



End of life care

- Family values
- Pain relief
- Communication of diagnosis
- Interpreter Use

End of life care

- Discussing terminal illness
- Stages
- End of life plans
- Advance care directives



Key Points End of Life Care

Quality of life

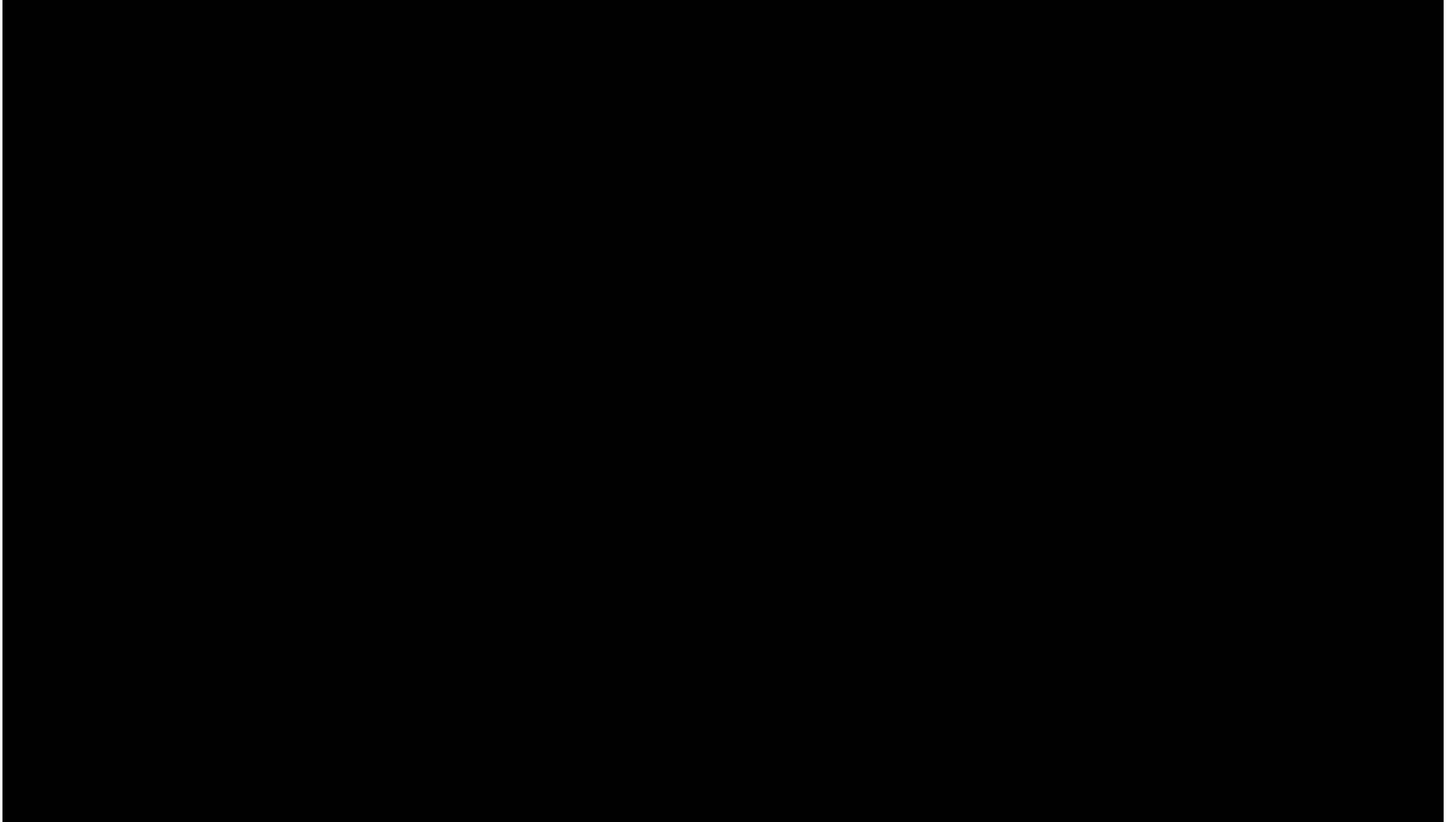
Person-centred care

Emotional and practical support

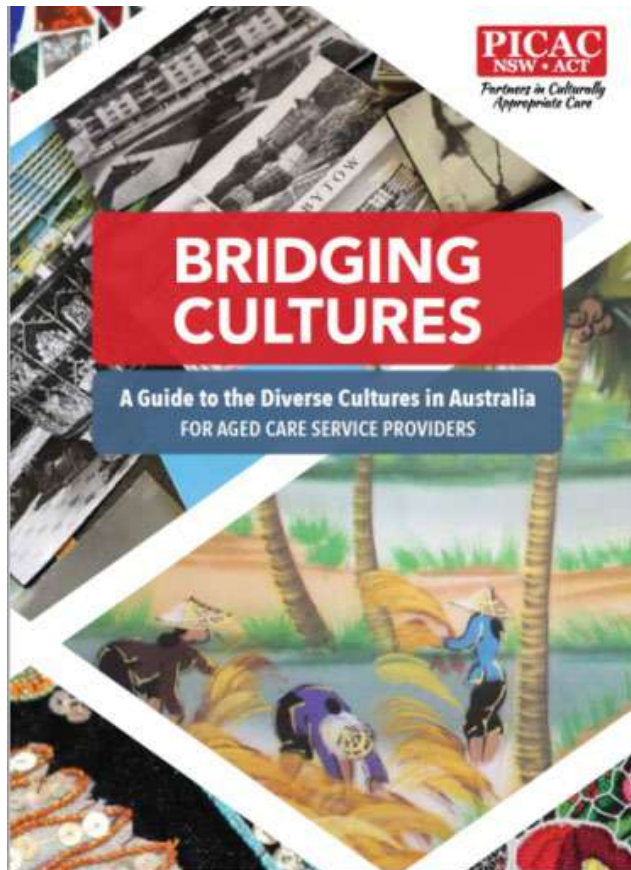
Everyone benefits

Multiple treatment

We can look at it Together



Useful Resources for Providers



CROSS-CULTURAL COMMUNICATION

- tips for your workplace

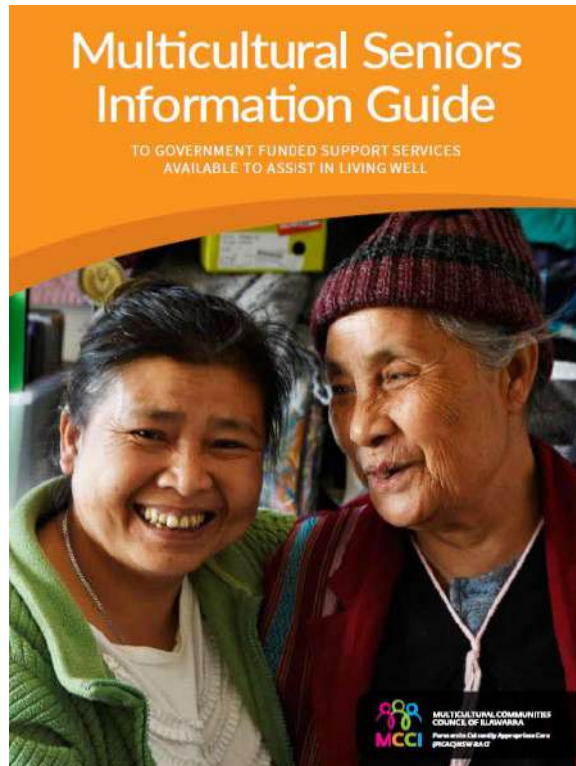
Having a diverse workforce is essential to the success of an organisation, let's start by improving how we communicate with each other

- R** **RECOGNISE** that we are human beings first and cultural beings second. There are many complexities which make us who we are even if we share the same gender, country of birth or the same religion. So don't judge people by their race, gender, sexuality, religion or religious beliefs or make jokes about these. This kind of behaviour could amount to discrimination and get you into trouble.
- E** **ENGAGE** your work colleagues in your conversation at every opportunity, they will really appreciate your effort. Regular conversations are the best way to improve your verbal communication skills in English or if you are learning another language. If you don't use it, you lose it.
- S** **SMILE** often, it takes no effort to produce and is good exercise for your face muscles too, helping you stay young and healthy. Also remember that non-verbal communication plays a significant role in how you communicate across all cultures. Did you know that almost 90% of all human communication is actually non-verbal?
- P** **PERSONAL** space should be respected. Being friendly is great, but being too friendly is not so good as it could make the other person feel uncomfortable. For example invading their personal space by standing too close when speaking with them or talking about matters which may be very personal. It could potentially be offensive to the other person.
- E** **ENCOURAGE** sharing of knowledge and culture amongst your work colleagues and across your organisation, you may be surprised by how much you have in common and how much you can learn from each other. Never waste an opportunity to learn something new or re-learn something old. If not, there is no guarantee that you will become older and wiser, just older.
- C** **CELEBRATE** diversity, it makes things so much more fun and interesting. Imagine if everyone in your workplace was just like you, how long could you really handle that? Be honest. Open your mind to the possibilities.
- T** **TALK** it out. Don't be afraid to seek clarification and ask questions if you're unsure or don't understand something. It is better to ask a few more questions than to say or do something you may regret later or start something that you may have to fix or do again.
- F** **FUN** is for everybody and it's great to share. Whether you're celebrating workplace achievements, employee birthdays and special occasions or cultural events such as Christmas, Chinese New Year, Ramadan or Deepavali, there is always a reason to celebrate and have fun. After all, in Australia we are known for finding any excuse to have a party.
- U** **UNDERSTANDING** is a great skill to have, and means you are able to see things from another person's point of view. It requires a lot of practice and you will need to do it often if you want to be really good at it.
- L** **LISTEN** twice as often, that is why you have two ears and one mouth. By listening to what others have to say, you reduce the likelihood of misunderstandings and your work colleagues may be encouraged to share their stories and ideas.

Interactive experience: Planning Ahead

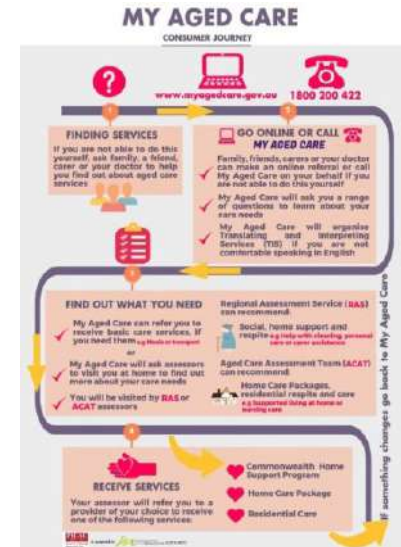


Useful Resources for Consumers



MY AGED CARE MAGNETS available in;

- English
- Vietnamese
- Turkish
- Hindi
- Chinese
- Nepalese
- Polish
- Arabic



CALD consumers' concerns about My Aged Care



DIVERSITY FRAMEWORK - ACTION PLANS FOR CONSUMERS

Resource

MCCI Website

<https://www.mcci.org.au/cultural-expertise/resources/>



Useful Links

- www.mcci.org.au
- www.culturaldiversity.com.au
- www.diversicare.com.au
- www.mac.org.au
- www.mrctas.org.au
- www.cotant.org.au
- www.fortisconsulting.com.au
- www.fecca.org.au
- www.mhcs.health.nsw.gov.au

THANK YOU

Contact Us



02 4229 7566



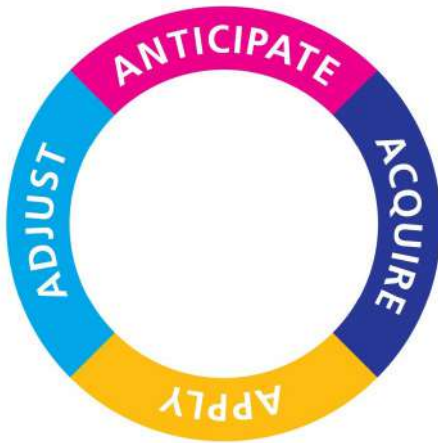
admin@mcci.org.au



mcci.org.au

DIVERSITY | INCLUSION | RESPECT

Supporting Multicultural Communities For Over 45 Years

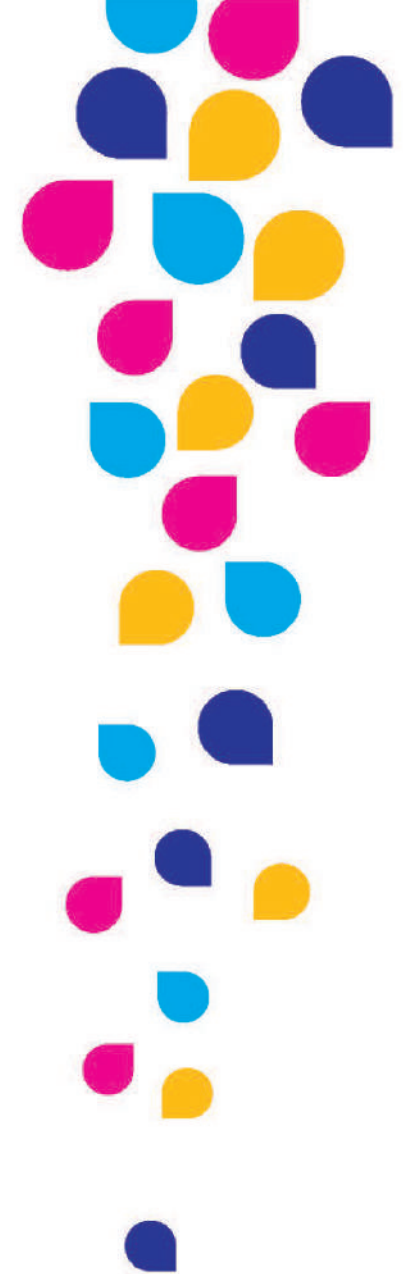


Recommended resources



Multicultural
Aged Care

Agnieszka Chudecka
Partners in Culturally Appropriate Care (PICAC) SA





Culture, Values and Attitudes



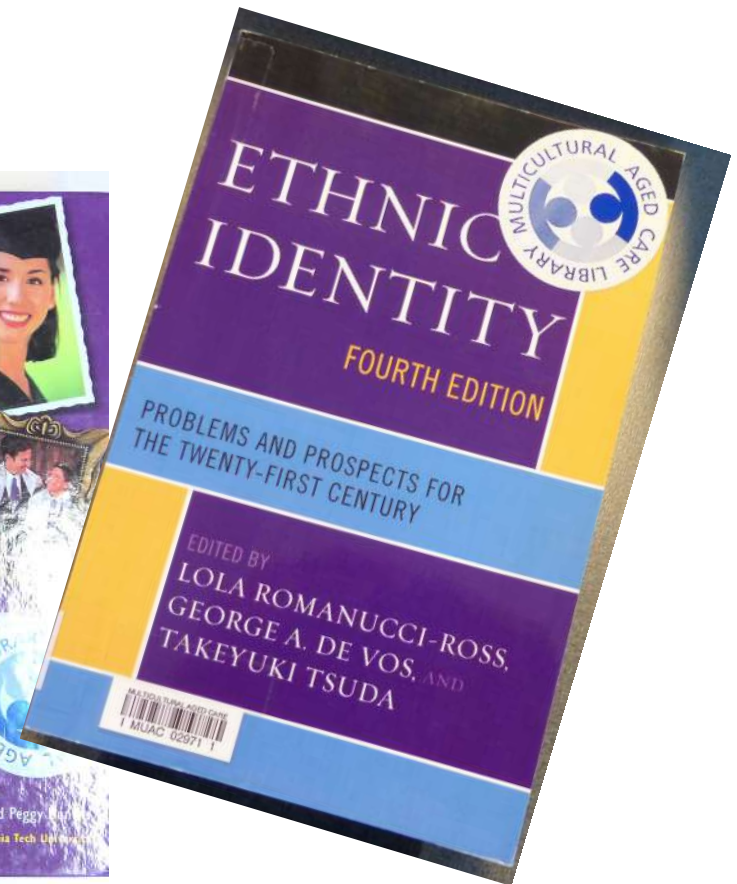
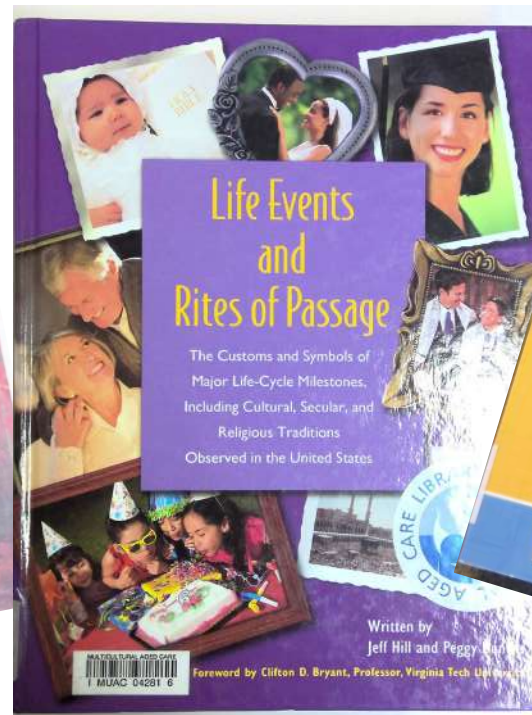
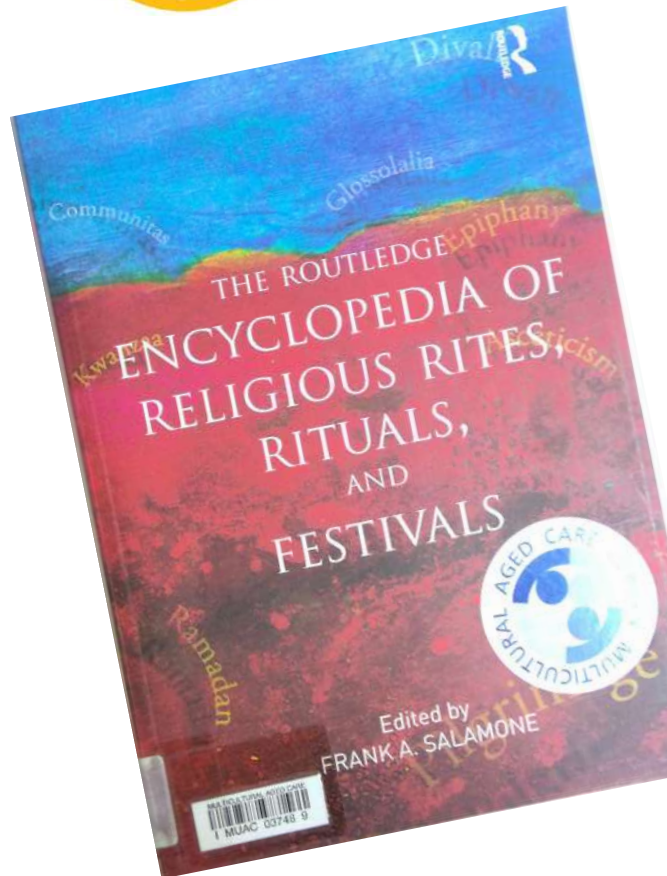
You are welcome to
browse our online catalogue
to review and select resources
that may inform
your service and care delivery

<https://library.mac.org.au/>





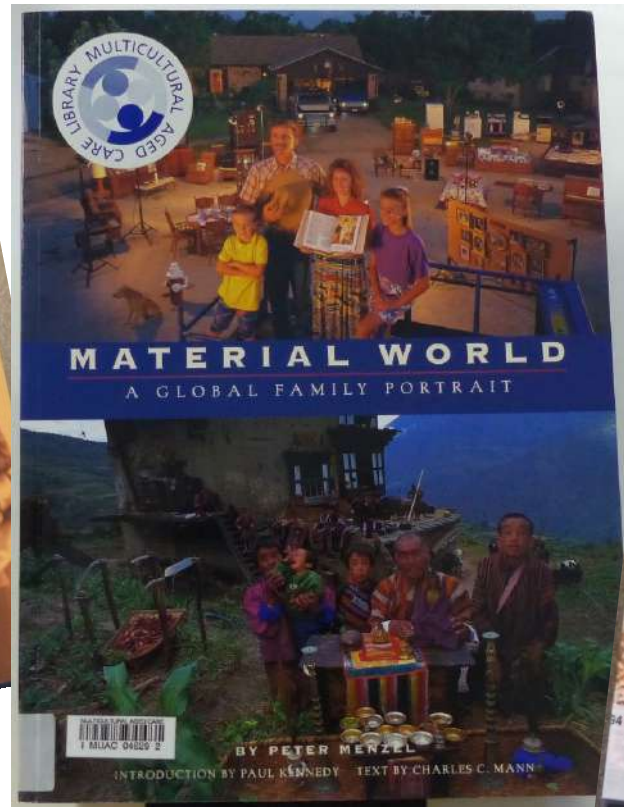
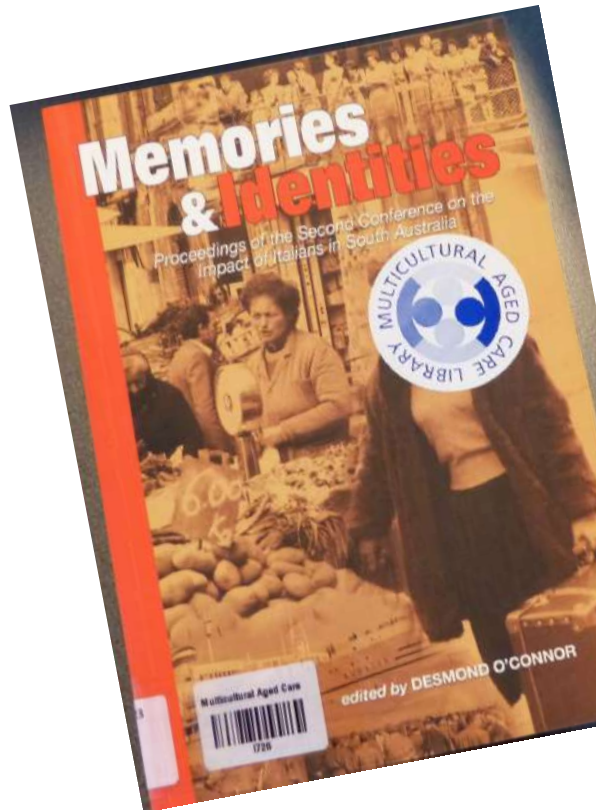
Rituals and rites



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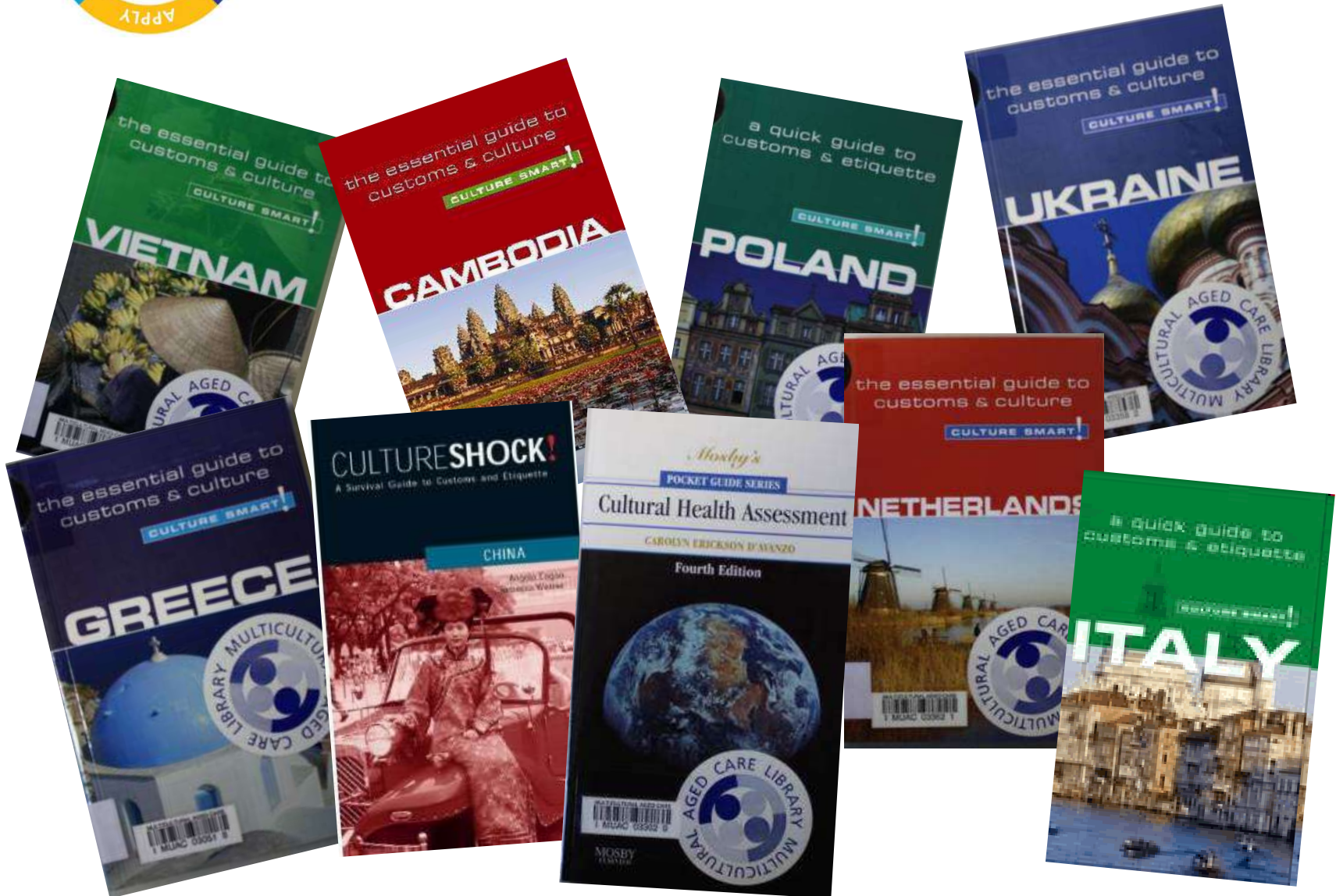
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Culture, Values and Attitudes





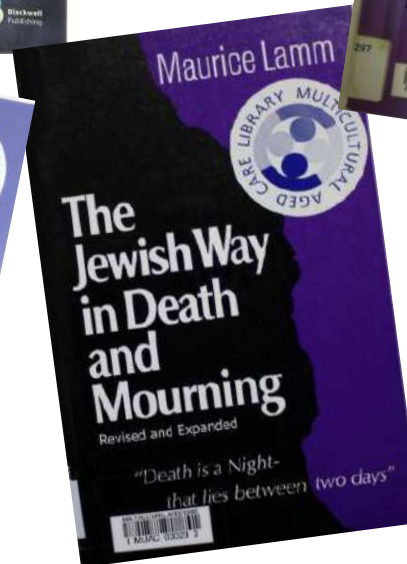
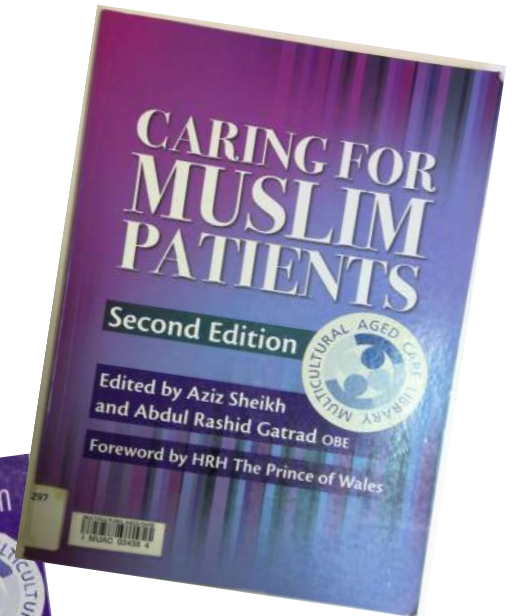
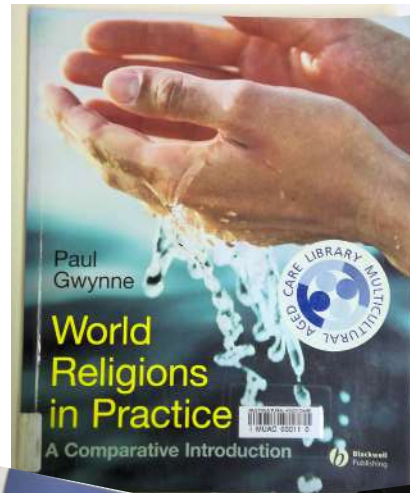
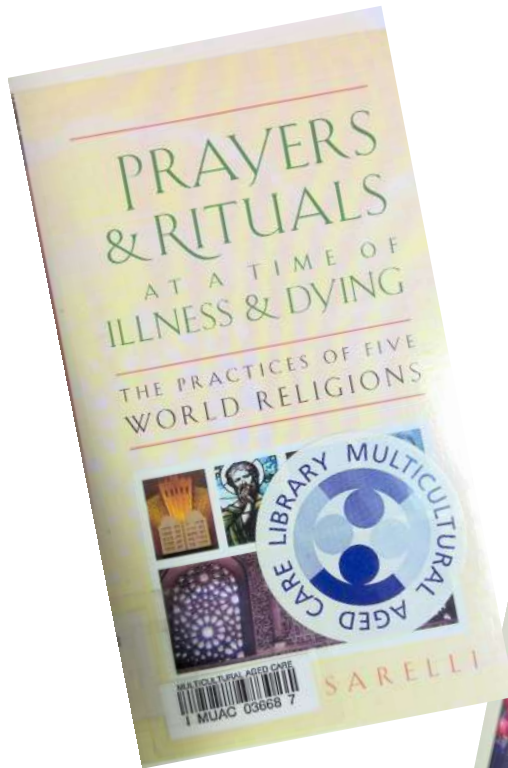
Rituals – religion and spirituality



<https://library.mac.org.au/>



Rituals – religion and spirituality



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Rituals – religion and spirituality



[https://www.mac.org.au/
wp-content/uploads/2019/06/
Bib-Palliative-Care-2019.02.pdf](https://www.mac.org.au/wp-content/uploads/2019/06/Bib-Palliative-Care-2019.02.pdf)

Thank you for attending
Let us keep in touch

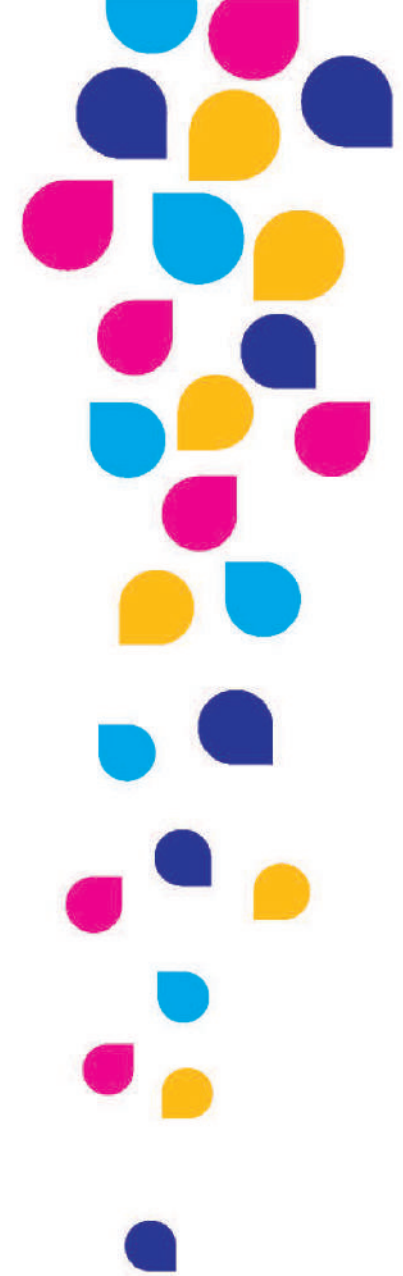
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For any further information
please contact:

Multicultural Aged Care Inc.

PICAC SA

on tel. no: **+61 (08) 8241 9900**
or by e-mail: **macsa@mac.org.au**

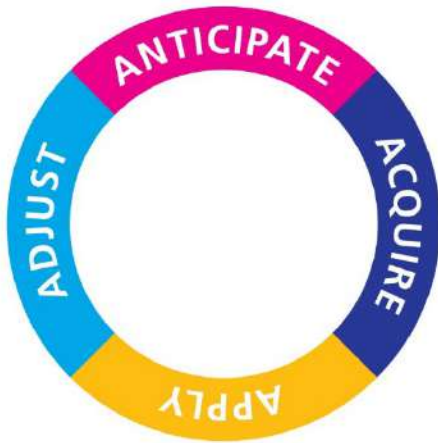
PICAC Alliance website:

<http://www.picacalliance.org/>



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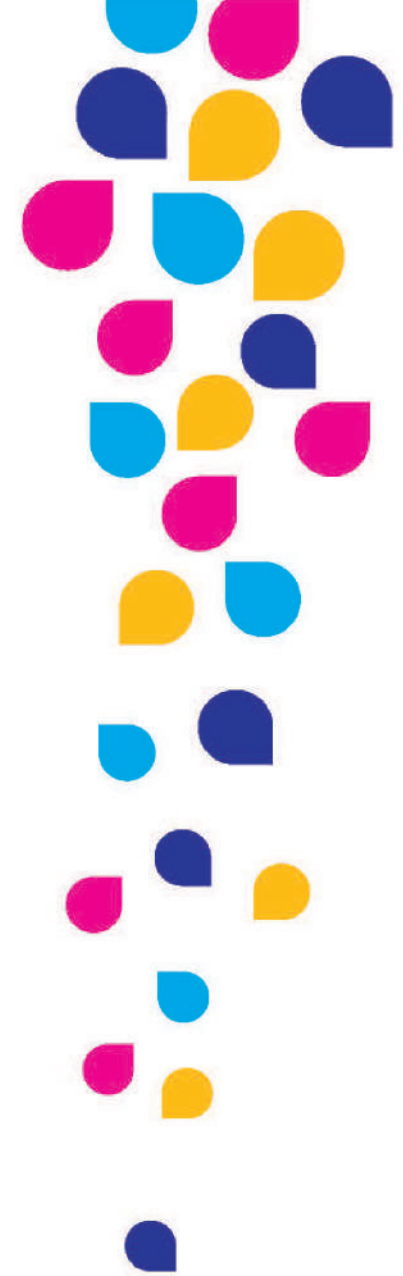


Diverse perspectives on End of Life Care



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Kaurna Acknowledgement

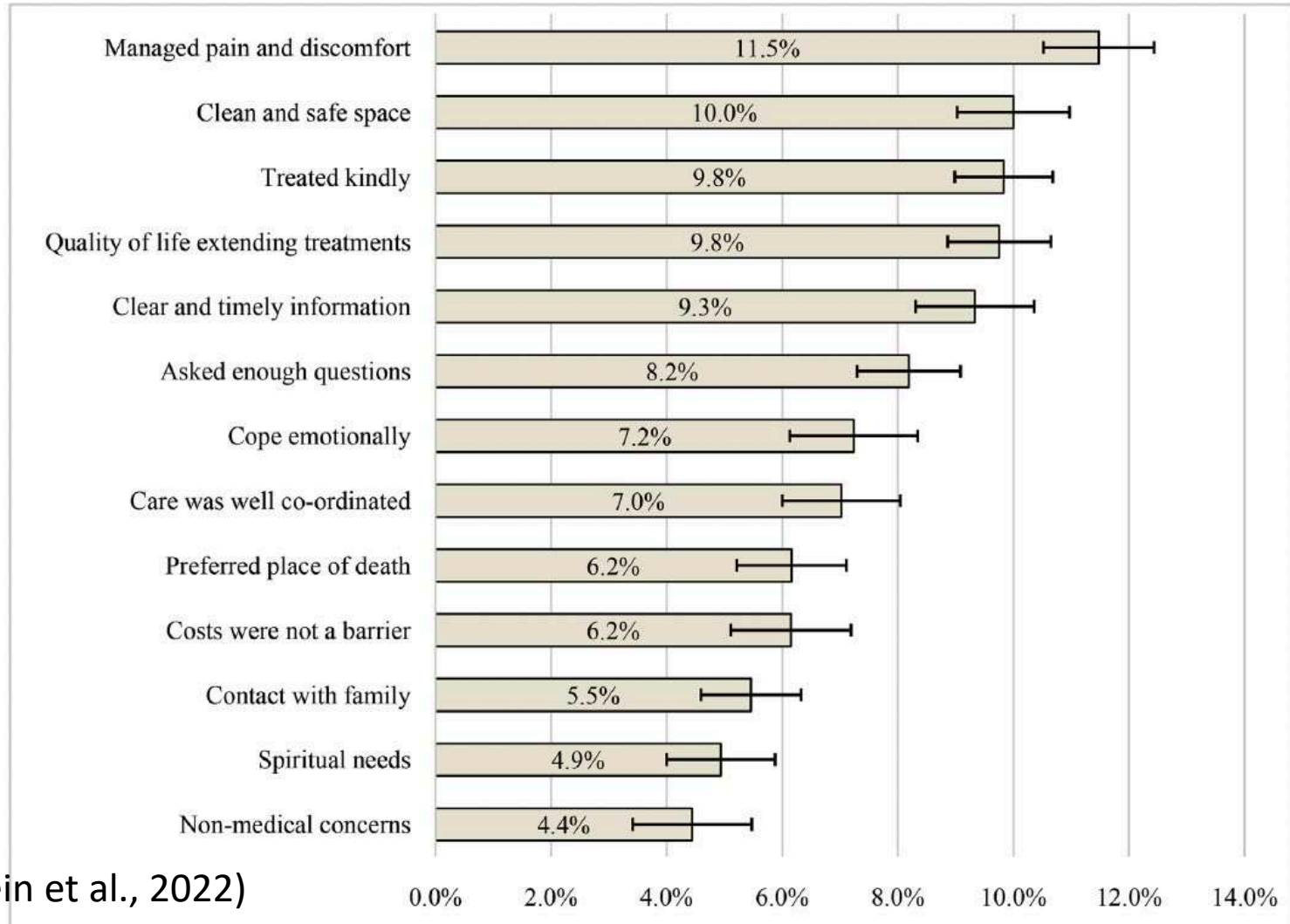
Adelaide and its surrounds are nestled within the lands traditionally owned and protected by the Kaurna people and their forebears for many thousands of years.

Throughout the Adelaide Plains, the Kaurna people have performed age-old ceremonies of celebration, initiation and renewal.

In convening this meeting, we take the opportunity to acknowledge and honour the Kaurna people's traditional ownership of this land, their living culture and the unique role they have played in the life of this region.



Consider Diverse perspectives



(Finkelstein et al., 2022)



Consider Diverse perspectives

Domain	Sub-Domain(s)
1. Stewardship and Governance	<ol style="list-style-type: none"> 1. Priority-setting and strategic planning of EoLC system 2. Laws, regulations, and standards 3. Public awareness and death education
2. Resource Generation (human, physical, and knowledge)	<ol style="list-style-type: none"> 1. Training (of competent and multidisciplinary care teams) 2. HCP staffing, benefits, compensation, and access to essential resources 3. HCP-centered support 4. Environment 5. Knowledge and evidence for policy and practice
3. Financing and Financial Protection	<ol style="list-style-type: none"> 1. Financial distress and fragility 2. EoLC financing and affordability of care
4. Service Provision	<ol style="list-style-type: none"> 1. Availability of facility-based, home-based, and community-based EoLC 2. Administration of symptom management 3. Care integration 4. Responsiveness
5. Access to Care	<ol style="list-style-type: none"> 1. Access to medicines 2. Access to physical care 3. Access to psychological care 4. Access to spiritual care 5. Access to social care 6. Access to bereavement care for grief management 7. Access to care navigation 8. Equity in access
6. Quality of Care	<ol style="list-style-type: none"> 1. Safety 2. Appropriateness (of care) 3. Coordination and continuity of care and support across phases/stages/transitions in EoLC 4. Health-related quality of life and alleviation of serious health-related suffering 5. Life continuity 6. Dignity 7. Empowerment 8. Hope 9. Caregiver-centered support (to manage caregiver burden)
7. Quality of Communication (within system and with patients/caregivers)	<ol style="list-style-type: none"> 1. Effective interpersonal interactions and relations 2. Effective communication

(Bhadelia et al., 2022)



Culture, Values and Attitudes

Factors identified as contributing negatively to EOL care include:

- 1) Lack of a recognition that EOL care is a human right
- 2) Absence of a national strategy for palliative care/not making palliative care a priority at the national level.
- 3) Limited or no integration of palliative care into the broader health system,
- 4) Lack of investment in EOL care leading to human resource shortages (i.e., lack of palliative care specialists), shortfalls in access to opioids, lack of dedicated facilities for patients at EOL, and no or limited access to home-based palliative and psychosocial care,
- 5) Lack of generalist or specialist palliative care training.
- 6) High cost of EOL care.
- 7) Lack of public knowledge and awareness of availability palliative care services
- 8) Poor or limited communication with patients and families on EOL care options
- 9) Lack of patient autonomy to make EoL decisions.
- 10) Lack of recognition of cultural factors associated with death and dying



Ritual

- 1: the established form for a ceremony
specifically: *the order of words prescribed for a religious ceremony*
- 2a : ritual observance
specifically: *a system of rites*
- b : a ceremonial act or action
- c : an act or series of acts
regularly repeated in a set precise manner



Merriam-Webster. (n.d.). Ritual. In *Merriam-Webster.com dictionary*.
Retrieved from <https://www.merriam-webster.com/dictionary/ritual>



Ritual

- a way of doing something in which the same actions are done in the same way every time:
- *Coffee and the newspaper are part of my morning ritual.*



Cambridge Dictionary. (n.d.). Ritual. Retrieved from <https://dictionary.cambridge.org/pl/dictionary/english/ritual>

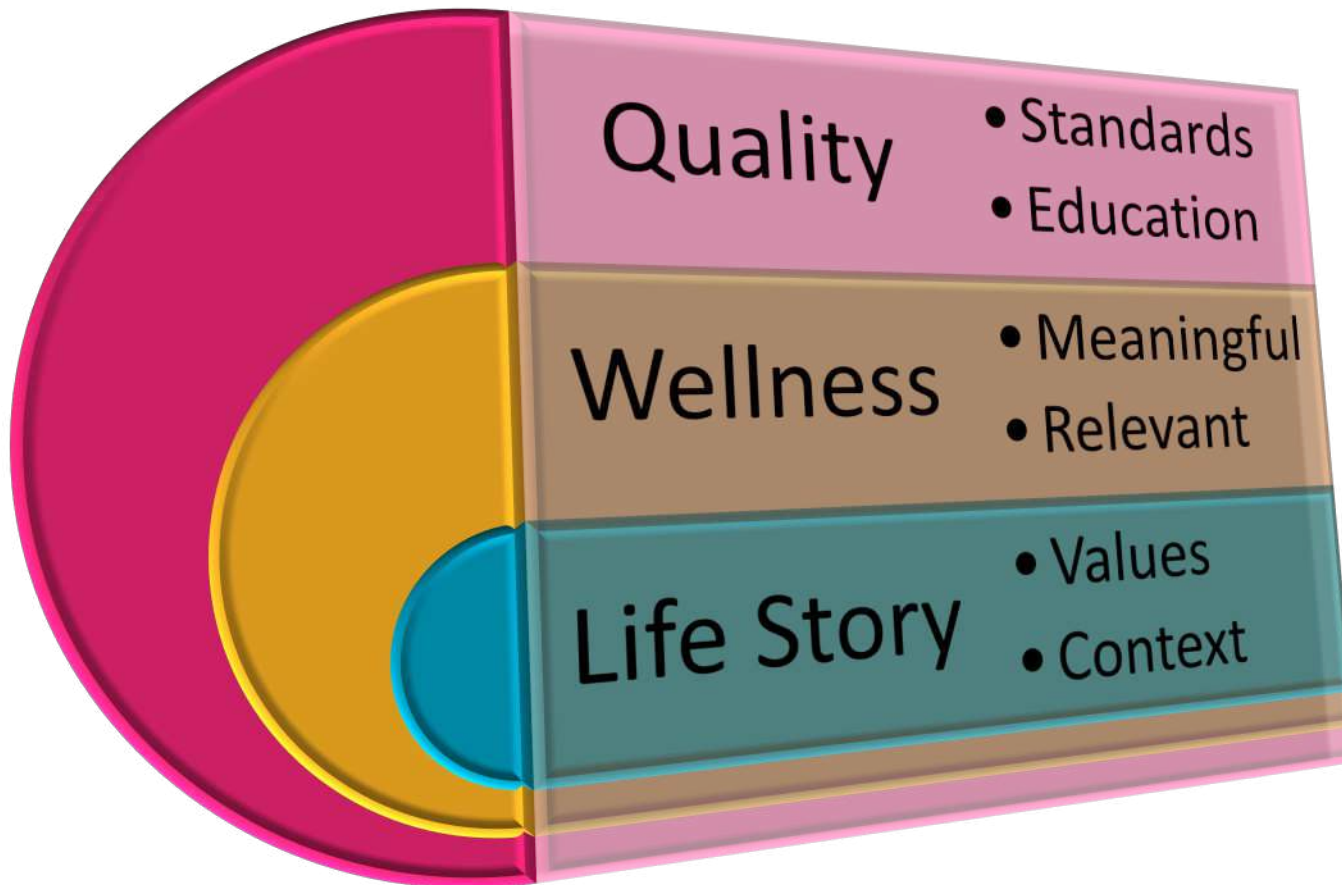


Explore Diverse perspectives





Towards Culturally Appropriate Care



Respond to Diverse perspectives

why / what / who / when / where

knowledge

resources

setting

type of activity

planning

policies and procedures

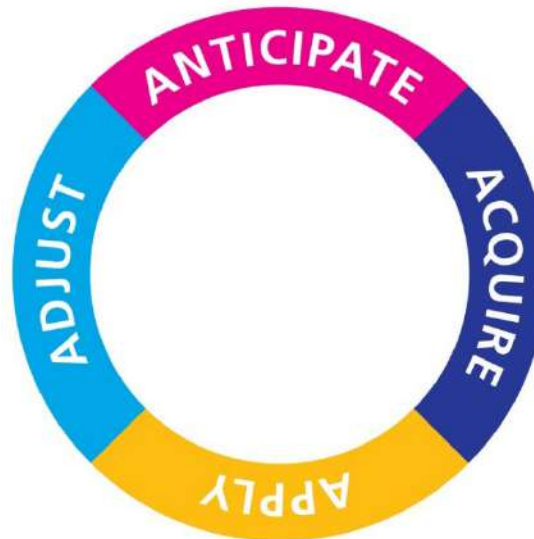
processes

feedback collection and analysis

continuous improvement

documentation

information sharing





References

Bhadelia, A., Oldfield, L. E., Cruz, J. L., Singh, R., & Finkelstein, E. A. (2022). Identifying core domains to assess the 'quality of death': A scoping review. *Journal of pain and symptom management*, 63(4), e365–e386.

doi:10.1016/j.jpainsymman.2021.11.015

Finkelstein, E. A., Bhadelia, A., Goh, C., Baid, D., Singh, R., Bhatnagar, S., & Connor, S. R. (2022). Cross country comparison of expert assessments of the quality of death and dying 2021. *Journal of pain and symptom management*, 63(4), e419-e429.

doi:10.1016/j.jpainsymman.2021.12.015

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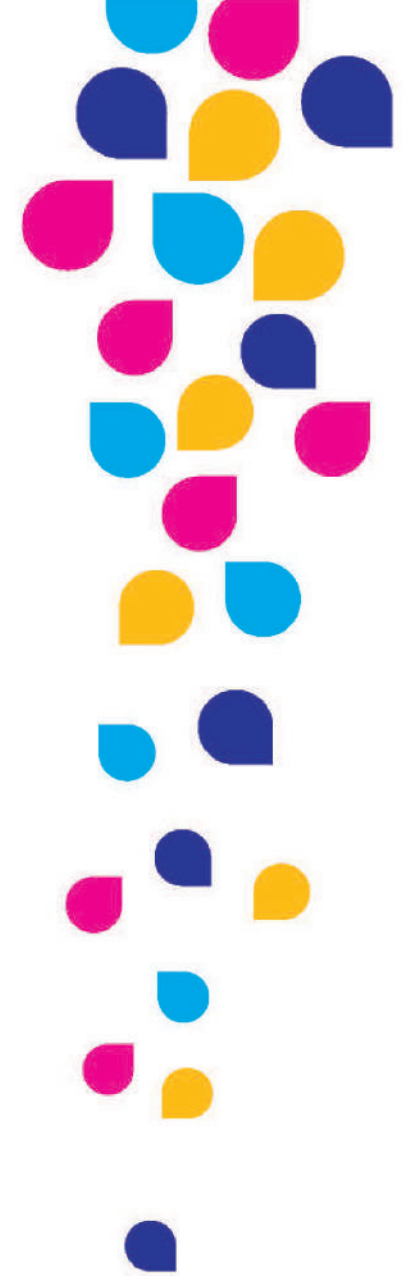
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