



Flinders
UNIVERSITY



Engaging with spirituality and spiritual care: Research, evidence and dissemination

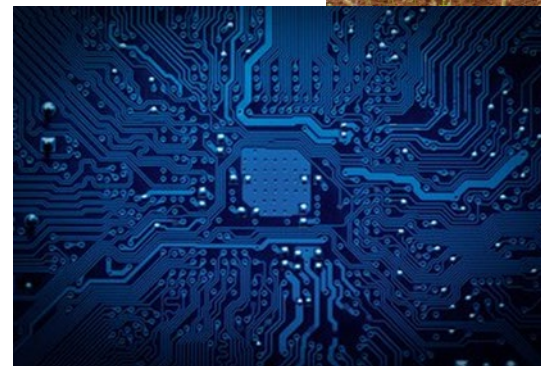
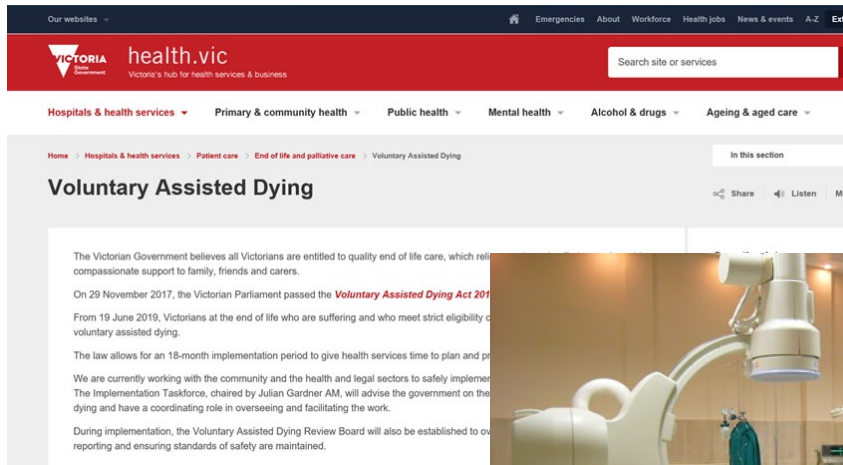
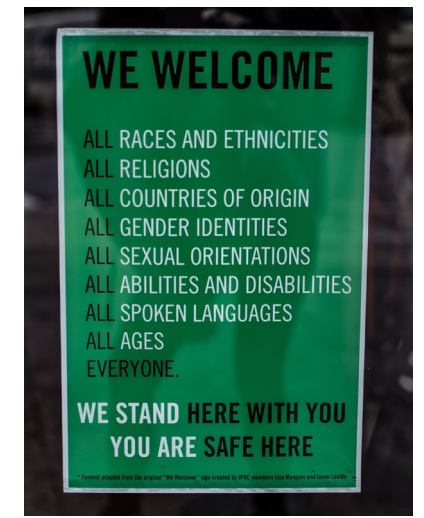
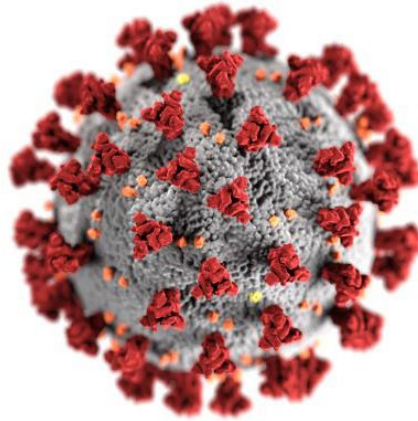


Acknowledgement of country

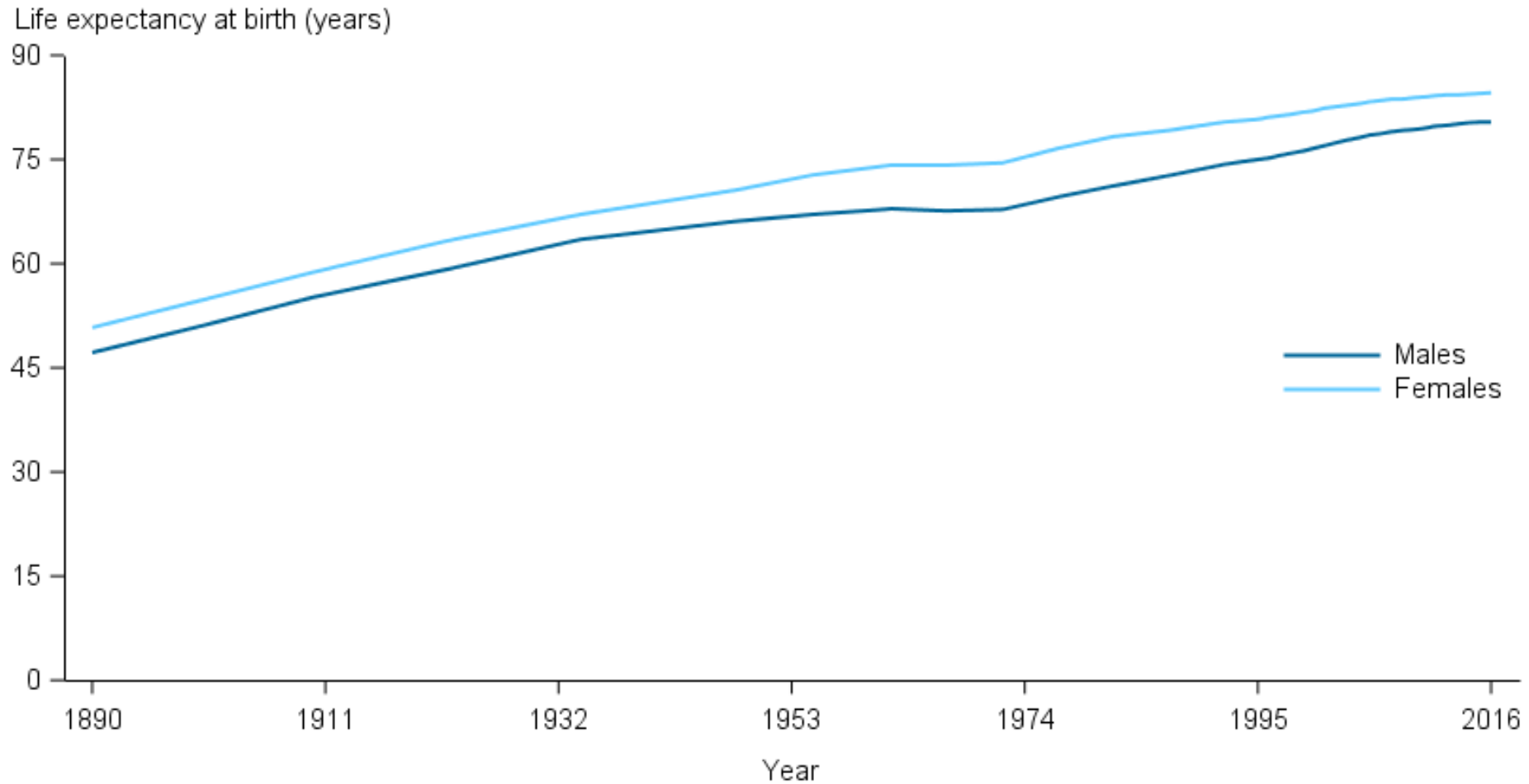
We recognise that Flinders operates on Indigenous peoples' traditional lands and waters and acknowledge their continued responsibility to care for country at the University's various teaching locations, including the lands and waters of the following peoples: Kurna, Arrernte, Boandik, Bungarla, Gunditjmarra, Jawoyn, Larrakia, Nauo, Ngarrindjeri, Peramangk, Wurundjeri, Yolgnu.

Ageing, caring, dying and grieving
Palliative care and spirituality
Research Centre for Palliative Care, Death
and Dying

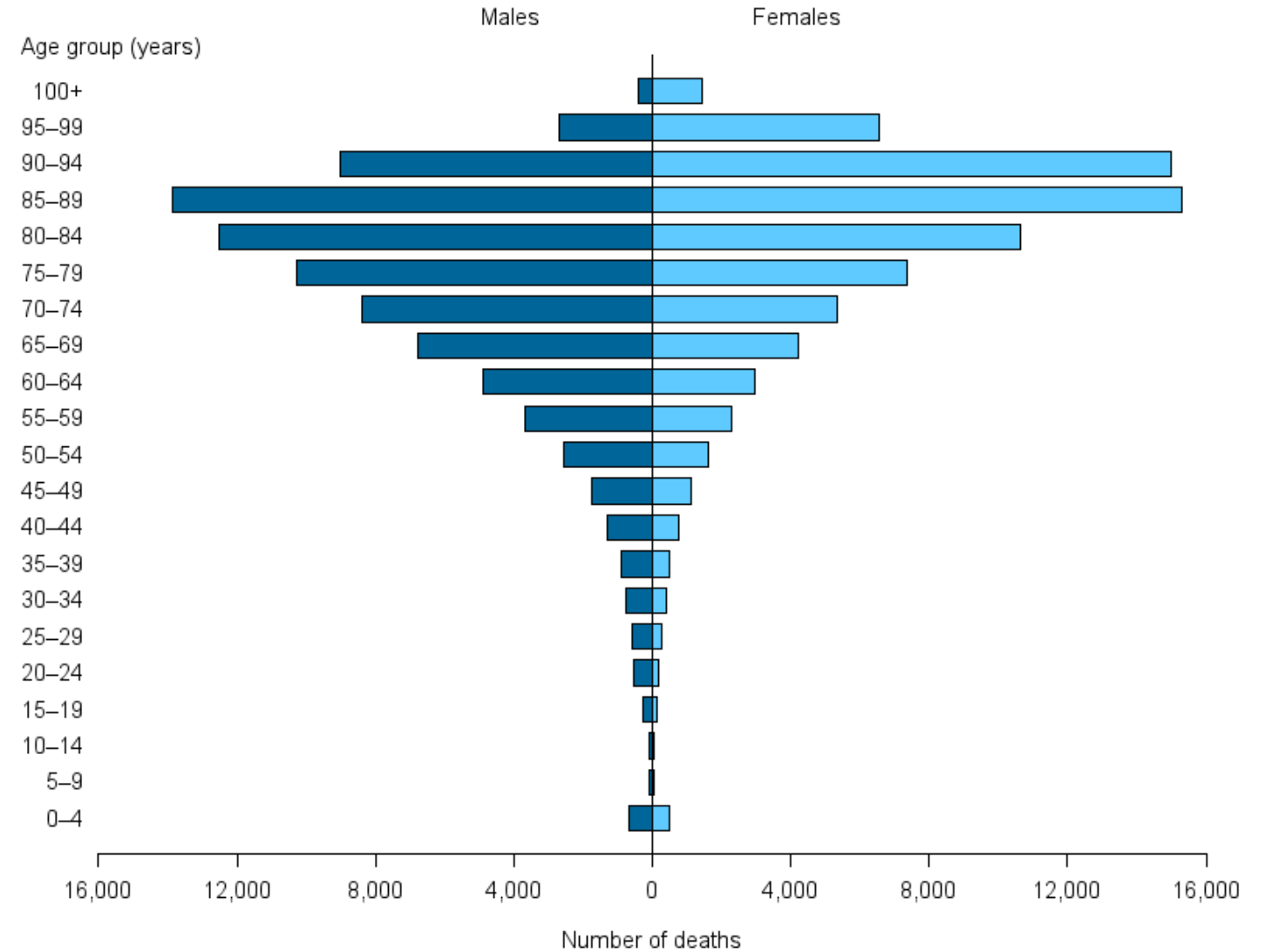
Our world has changed and is continuing to change



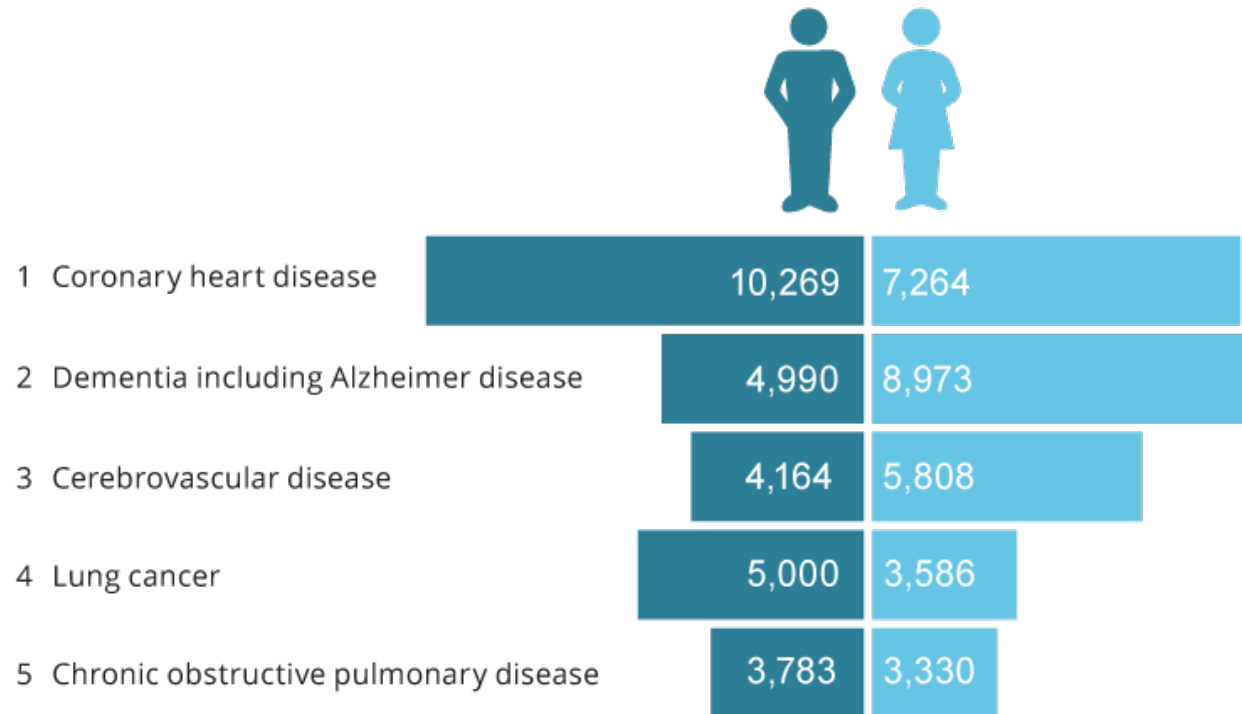
We're living longer



And we're dying older



So, what do we die of?



A complicated relationship with ageing

Older Australians are all of Australia and so are very diverse

Ageism affects workplace; healthcare; aged care; and families and local communities

Family structures are changing which impacts care possibilities

Care for those living in the community is heavily reliant on the contribution of informal carers

As people age they more likely to use aged care services.

Increasing intersect between ageing, caring, dying and grieving



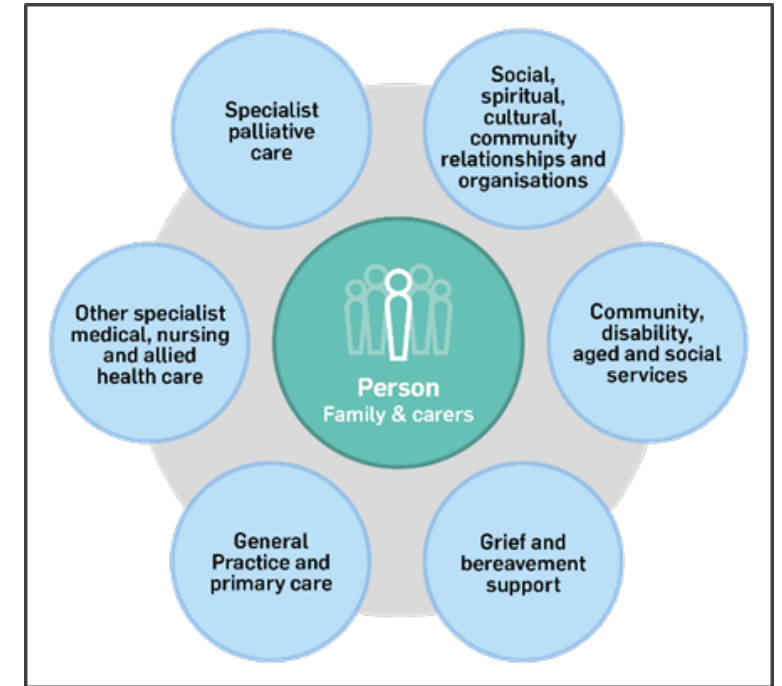
How does palliative care fit in?

The 2014 WHA 67.19 called for strengthening palliative care as a component of comprehensive care across the life course agreed.

http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

The 2018 National Palliative Care Strategy reminds us that the person and family sits at the heart of care and that

Palliative care is holistic care and will include attention to physical, emotional, psychological, social, and spiritual needs.



National Palliative Care Strategy 2018 Available
<http://www.health.gov.au/internet/main/publishing.nsf/Content/Palliative%20Care-1>

Spirituality and Dying

Growing recognition that spiritual care is a research and practice agenda for palliative care

Addressing existential distress and suffering beyond physical symptoms

In 2010 members of the European Association for Palliative Care (EAPC) founded a Spiritual Care Taskforce *to further evidence-based spiritual care by developing an agenda to inform research in this area, to improve staff competence and confidence and outcomes for patients and carers*

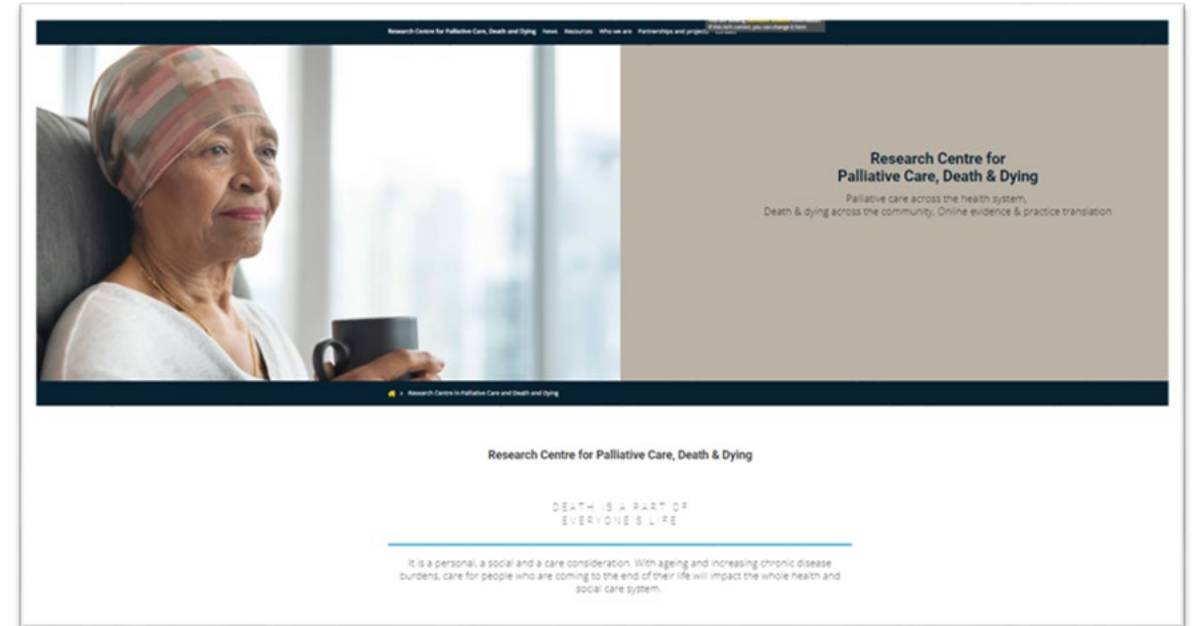
Systematic reviews identifying palliative care practices, competencies and processes to implement spiritual care

Role and contribution of tools such as FICA and HOPE, legacy work, dignity therapy

The Role of RePaDD

Specialist research centre at Flinders University looking at palliative care, death and dying

- Palliative care across the health system
- Death & dying across the community
- Online evidence & practice translation



The need for research around dying

Examining experiences, needs and responses of individuals and families

Understanding community attitudes and priorities

Identifying and addressing health professional and health system requirements for effective care provision

Investigating equity in access, use and outcomes

Enabling access to evidence and guidance for care providers

Developing new tools, resources, functionalities for care

Evaluating effectiveness of new models, approaches and tools

Assessing funding, policy, change management, care outcome measurement, care models

RePaDD Contributions

Provides access to evidence and resources through major projects (CareSearch, palliAGED)

Contributes to workforce capabilities through national programs (ELDAC, End of Life Essentials)

Understand consumer and community views and attitudes (eg Dying2Learn, Engagement Project)

Contributes to the underlying evidence base (eg Dying2Learn, Bereavement Study)



CareSearch Knowledge resources

PubMed Searches:
One click searches for evidence

Review Collection:
Systematic reviews
and structured
literature reviews

The image displays three overlapping screenshots of the CareSearch Knowledge resources interface, illustrating its capabilities for finding evidence and reviews.

Top Screenshot: PubMed Search Results

- Search Query:** (religion[mh] AND (advance care planning[mh] OR attitude to death[mh]) OR ...)
- Results:** 358 results.
- Highlighted Results:**
 - 1. **Review of yoga therapy during cancer treatment.** Datta R, SC, Addington EL, Soti S, Chou A, Cohen L. *Support Care Cancer*. 2017 Apr;25(4):1157-1172. doi: 10.1007/s00520-016-3559-9. Epub 2017 Jan 7. PMID: 28045855. Free PMC article. Review.
 - 2. **A systematic review of religious beliefs about major end-of-life issues in the five major world religions.** Chaturvedi R, Bhatnagar AR, Litzow MR, Syta G, James AD, Naphin SK. *Palliat Support Care*. 2017 Oct;15(5):609-622. doi: 10.1017/S1473901516001061. PMID: 28910283. Free PMC article. Review.
 - 3. **Patient's Perspectives on the Notion of a Good Death: A Systematic Review of the Literature.** O'Connor A, Madsen C, Rasmussen T. *J Pain Symptom Manage*. 2022 Jan;58(1):152-164. doi: 10.1016/j.jpainsymman.2019.07.033. Epub 2019 Aug 9. PMID: 31455463. Review.
 - 4. **"Song of Life (SOL)" study protocol: a multicenter, randomized trial on the emotional, spiritual, and psychological effects of music therapy in palliative care.** Worth M, Koehler F, Voller M, Bardenheuer HD, Otten B, Kessler J. *BMC Palliat Care*. 2019 Jan 30;18(1):4. doi: 10.1186/s12904-019-0097-6. PMID: 30700219. Free PMC article. Clinical Trial.
 - 5. **The influence of religious beliefs and practices on health care decision-making among HIV positive adolescents.** Lyon ME, D'Angelo LJ, Cheng H, Dallas RN, Garcia RA, Wang J. *Adolescent Palliative Care Consortium*. *AIDS Care*. 2020 Jul;32(7):949-959. doi: 10.1080/09540122.2019.1669322. Epub 2019 Sep 19. PMID: 3155560.
 - 6. **Spiritual assessment and spiritual care offerings as a standard of care in pediatric oncology: A recommendation informed by a systematic review of the literature.** Robert R, Bashir A, Jones BL, Robinson J, Larson K, Holden R, Smith B, Panko K, Koch K, Findley S, Walker MS.

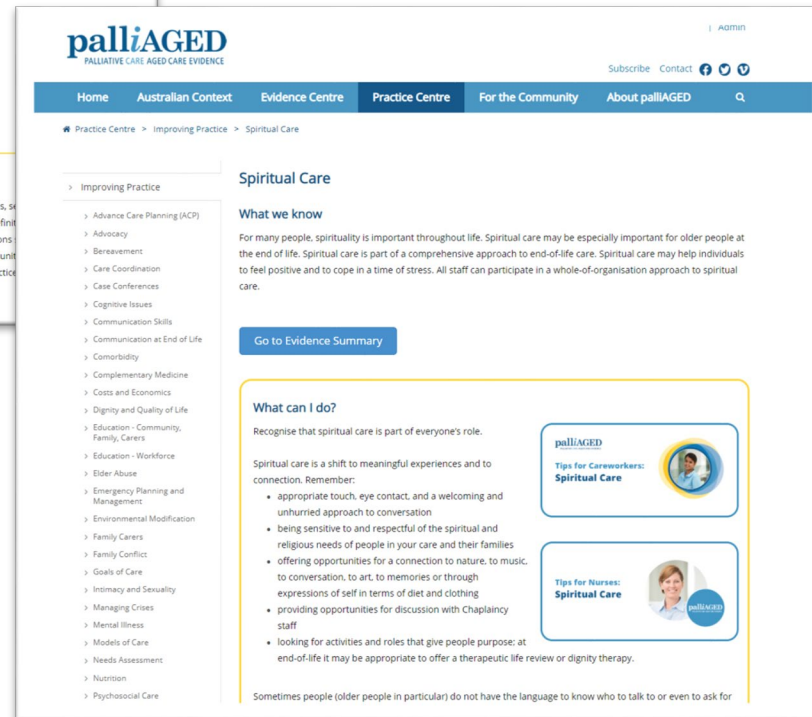
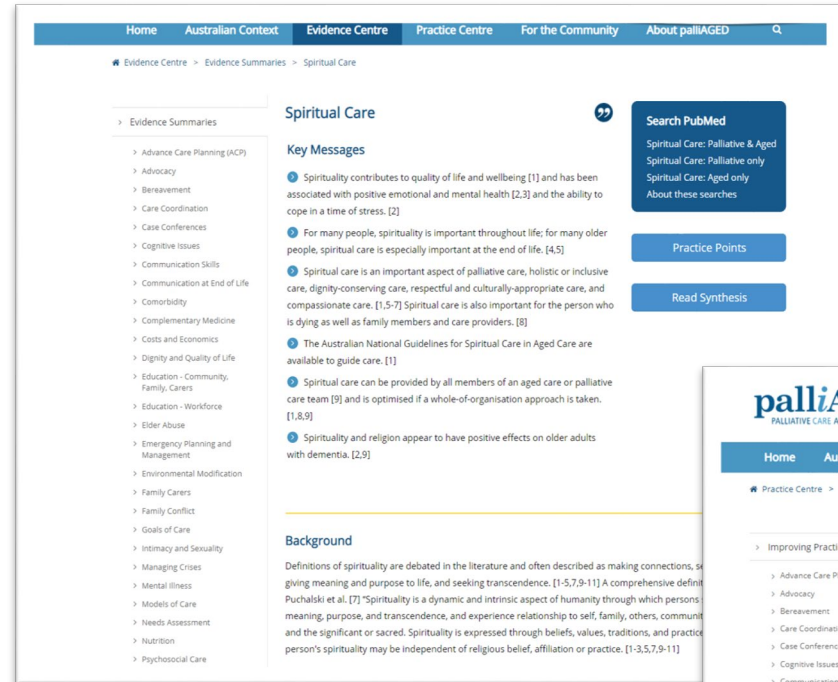
Middle Screenshot: Review Collection: Spirituality



- Search Query:** (religion[mh] AND (advance care planning[mh] OR attitude to death[mh]) OR ...)
- Results:** 79 reviews.
- Highlighted Results:**
 - 1. **Review of yoga therapy during cancer treatment.** Datta R, SC, Addington EL, Soti S, Chou A, Cohen L. *Support Care Cancer*. 2017 Apr;25(4):1157-1172. doi: 10.1007/s00520-016-3559-9. Epub 2017 Jan 7. PMID: 28045855. Free PMC article. Review.
 - 2. **A systematic review of religious beliefs about major end-of-life issues in the five major world religions.** Chaturvedi R, Bhatnagar AR, Litzow MR, Syta G, James AD, Naphin SK. *Palliat Support Care*. 2017 Oct;15(5):609-622. doi: 10.1017/S1473901516001061. PMID: 28910283. Free PMC article. Review.
 - 3. **Patient's Perspectives on the Notion of a Good Death: A Systematic Review of the Literature.** O'Connor A, Madsen C, Rasmussen T. *J Pain Symptom Manage*. 2022 Jan;58(1):152-164. doi: 10.1016/j.jpainsymman.2019.07.033. Epub 2019 Aug 9. PMID: 31455463. Review.
 - 4. **"Song of Life (SOL)" study protocol: a multicenter, randomized trial on the emotional, spiritual, and psychological effects of music therapy in palliative care.** Worth M, Koehler F, Voller M, Bardenheuer HD, Otten B, Kessler J. *BMC Palliat Care*. 2019 Jan 30;18(1):4. doi: 10.1186/s12904-019-0097-6. PMID: 30700219. Free PMC article. Clinical Trial.
 - 5. **The influence of religious beliefs and practices on health care decision-making among HIV positive adolescents.** Lyon ME, D'Angelo LJ, Cheng H, Dallas RN, Garcia RA, Wang J. *Adolescent Palliative Care Consortium*. *AIDS Care*. 2020 Jul;32(7):949-959. doi: 10.1080/09540122.2019.1669322. Epub 2019 Sep 19. PMID: 3155560.
 - 6. **Spiritual assessment and spiritual care offerings as a standard of care in pediatric oncology: A recommendation informed by a systematic review of the literature.** Robert R, Bashir A, Jones BL, Robinson J, Larson K, Holden R, Smith B, Panko K, Koch K, Findley S, Walker MS.

Bottom Screenshot: Spirituality PubMed Search

- Search Query:** (religion[mh] AND (advance care planning[mh] OR attitude to death[mh]) OR ...)
- Results:** 358 results.
- Highlighted Results:**
 - 1. **Review of yoga therapy during cancer treatment.** Datta R, SC, Addington EL, Soti S, Chou A, Cohen L. *Support Care Cancer*. 2017 Apr;25(4):1157-1172. doi: 10.1007/s00520-016-3559-9. Epub 2017 Jan 7. PMID: 28045855. Free PMC article. Review.
 - 2. **A systematic review of religious beliefs about major end-of-life issues in the five major world religions.** Chaturvedi R, Bhatnagar AR, Litzow MR, Syta G, James AD, Naphin SK. *Palliat Support Care*. 2017 Oct;15(5):609-622. doi: 10.1017/S1473901516001061. PMID: 28910283. Free PMC article. Review.
 - 3. **Patient's Perspectives on the Notion of a Good Death: A Systematic Review of the Literature.** O'Connor A, Madsen C, Rasmussen T. *J Pain Symptom Manage*. 2022 Jan;58(1):152-164. doi: 10.1016/j.jpainsymman.2019.07.033. Epub 2019 Aug 9. PMID: 31455463. Review.
 - 4. **"Song of Life (SOL)" study protocol: a multicenter, randomized trial on the emotional, spiritual, and psychological effects of music therapy in palliative care.** Worth M, Koehler F, Voller M, Bardenheuer HD, Otten B, Kessler J. *BMC Palliat Care*. 2019 Jan 30;18(1):4. doi: 10.1186/s12904-019-0097-6. PMID: 30700219. Free PMC article. Clinical Trial.
 - 5. **The influence of religious beliefs and practices on health care decision-making among HIV positive adolescents.** Lyon ME, D'Angelo LJ, Cheng H, Dallas RN, Garcia RA, Wang J. *Adolescent Palliative Care Consortium*. *AIDS Care*. 2020 Jul;32(7):949-959. doi: 10.1080/09540122.2019.1669322. Epub 2019 Sep 19. PMID: 3155560.
 - 6. **Spiritual assessment and spiritual care offerings as a standard of care in pediatric oncology: A recommendation informed by a systematic review of the literature.** Robert R, Bashir A, Jones BL, Robinson J, Larson K, Holden R, Smith B, Panko K, Koch K, Findley S, Walker MS.

palliAGED: Aged Care Resources





Tips for Careworkers: Spiritual Care

What it is: Spirituality can be a person's connection to other people, to nature, or to what gives them meaning and purpose. Spirituality depends on the person. It is not always about religion.

Why it matters: For many people, spirituality is important throughout life and at the end of life. Spiritual pain may lead to a physical response (e.g., increased pain) or an emotional response (e.g., anxiety, depression, or anger).

What I need to know: Spiritual support is an important aspect of palliative care. Showing respect and support for a person's spirituality can reduce the distress of being ill or dying. People may appreciate opportunity for discussion with chaplaincy staff, spiritual care practitioners, or faith representatives.

Do When you interact with the person use:

- appropriate touch
- eye contact if appropriate
- a welcoming unhurried approach to conversation and listening so that the person feels heard and valued.

Do Be sensitive and respectful of the spiritual, cultural and religious needs of people in your care and their families.

Do Offer opportunities for a connection with spiritual practices outside of those in the place of care.

Engagement Project

Working with three sector/groups across 2017-2020:

- Patients, Families and Carers
- Aged Care, and
- Allied Health.

Feedback on the content of CareSearch and palliAGED resources and their awareness and use of evidence based resources.

Priority topics and also best approaches



What we propose to do – Action Plan



Our priorities for the next 12 months:

- ☐ In response to your input we will focus on how CareSearch and palliAGED can best provide the most useful information and resources to support people, how and when needed
- ☐ Focus on 6 key topics
- ☐ Use articles and campaigns - linked to key messages, information and resources add to peoples 'toolbox'
- ☐ Use multiple channels for information dissemination
- ☐ 'Vehicle' to provide support & raise awareness



Key topics:

4. **Coping with change-** *changes and transitions, stages of need, care planning, recognising deterioration*
5. **Death, Dying, Loss and Bereavement** – *Ok to talk about death and dying, loss and bereavement in aged care*
6. **Holistic whole person centred care** – *physical, social, emotional, spiritual aspects of care –dignity of care*



D2L: Attitudes to death and dying

2015-2017 CareSearch work program included:

- Development of a MOOC on death, dying and palliative care in Australia to build community awareness of palliative care and death as a normal process
- Initially scheduled only for 2016 but interest was so high it was repeated in 2017 and in 2018 with additional activities and research scales

Research Approach

- Formal evaluation protocol
- Embedded research study looking at death competence
- Follow up participant survey on impacts
- Initially scheduled only for 2016
- Interest was so high it was repeated in 2017 and in 2018 with additional activities and research scales



Study Aims

- To determine what effect online learning and discussions within a MOOC on death and dying have on participants' feelings and attitudes towards death and dying as measured by the CDS
- To assess if health related quality of life as measured by AQoL and life meaning as measured by MLQ, is correlated with attitudes to death as measured by the CDS.
- To explore the consumers voice via content analysis of blogs/ conversations held online during the MOOC, and how this is associated with participants' socio-demographic characteristics and feelings towards life, death and dying (as measured with the AQoL, MLQ, and CDS).

CDS: Coping with Death Scale,
AQoL: Australian Quality of Life 4D Scale;
MLQ: Life Meaning Questionnaire

Basic Findings

People are willing to participate in online discussion around death and dying.

The MOOC was positively evaluated

MOOC is associated with improvement in death attitudes,. Death competence as measured pre-post with Coping with Death Scale shows a significant gain (even off a high base)

MiL and CDS: Greater presence of meaning in life, quality of life, age, death experience, and carer experience were each statistically significant unique predictors of death competence scores.

Presence of meaning in life was the strongest predictor of higher perceived competence in coping with death.

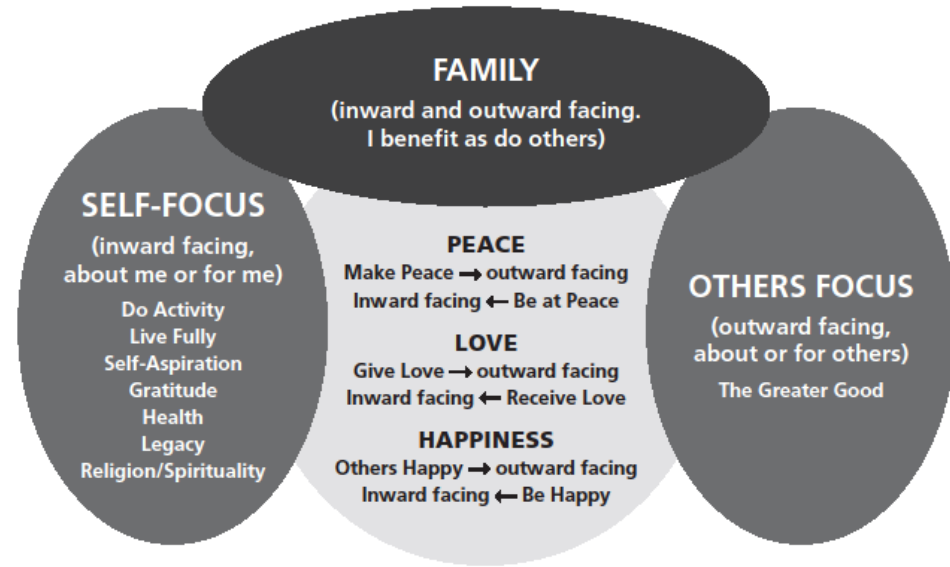
D2L: Before I die...

What do people consider is important when faced with their own mortality?

663 MOOC participants completed the following statement: “Before I Die, I want to . . .”.

Qualitative analysis and coding showed 12 themes.

Reminds us of importance of connection, resolution, meaning



The business of dying

Many deaths are expected. People have an awareness they will die.

Navigating dying can be complex negotiating systems, expectations and fears.

A social justice lens requires us to consider structural vulnerability and inequities in access to care at the end of life

More than physical care for the person is needed

Spirituality in its broadest context can support meaning and meaningfulness.



Thank you

Questions/Discussion

AMBITIOUS



INSPIRING



Flinders
UNIVERSITY

STAY
UPDATED



flinders.edu.au



[@flinders](https://twitter.com/flinders)



[@flindersuniversity](https://www.instagram.com/flindersuniversity)



[/flindersuniversity](https://www.facebook.com/flindersuniversity)



[flindersuniversity](https://www.youtube.com/flindersuniversity)

