



## Checklist

### End-of-Life Care for Diverse Communities

- ☐ Ask yourself, are you open to difference in people, patients, and colleagues? How do you model being inclusive of diverse communities in your professional practice?

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- ☐ Add end-of-life issues to your team meeting agenda. Share a couple of points that you have learnt from the End-of-Life Essentials Education Modules with your colleagues. Make a training request via your supervisor, or via your organisation's training manager, for specific workplace training on end-of-life care relevant to those with diverse needs at the end of life.

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- ☐ Remember to introduce yourself to each new patient and any family members. Be aware of the 'Hello, my name is...' campaign ([www.hellomynameis.org.uk](http://www.hellomynameis.org.uk)). Also consider using your pronouns (she/her, he/him, they/them) and ask what patients and families prefer. Do not make assumptions about gender or sexuality.

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- ☐ Ask your patient: *What is the most important thing I should know about you? Who is important to you?*

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- ☐ When a patient speaks a language other than English, make sure that an interpreter is engaged for important conversations and ensure you look at the patient while listening to the interpreter. Ensure your team knows that they need to make sure this is in place before they communicate with the patient. Do not ask family members to act as an interpreter. Also consider translated written information. Maintain eye contact if culturally appropriate.

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- ☐ Consider the broader multidisciplinary/interdisciplinary team. Would this patient benefit from assessment by a psychologist, psychiatrist or access to mental health services? Would they benefit from legal support to assist with EOL planning?

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- ☐ Ask a patient if they would like to see a priest, minister, imam, rabbi or other. Be mindful that religion is not the same as spirituality. Discuss how their spiritual beliefs might impact upon their care preferences or what happens to them once they die. Remember the patient may not adhere to all aspects of their reported faith – ask what is personally meaningful to them. Support the wishes of patients, families and carers who want to include religious or cultural practices in their care. This may include ceremonies, singing or particular foods. Don't be afraid to ask one of those present the significance of the ritual. Share any cultural knowledge you gain with colleagues or students.

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- ☐ Check if your patient has discussed the future or death and dying with their family (whoever their family are). Check that they have nominated someone to make decisions when they can no longer do this themselves. Have they discussed their wishes and preferences with that person? Are their wishes formalised in an Advance Care Directive or a medical power of attorney? And, if so, does the treating team have a copy?

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- ☐ Patient-centred behaviour when treating a patient includes compassion, empathy, and provision of information.

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- ☐ Is there any training in your organisation for Culturally Competent care or for LGBTIQ+ inclusive care? Are there policies and practices that align to these? Consider equity in access to care and that patients may have not felt safe accessing care in the past (or now) because of discrimination /stigma around homosexuality or mental illness.

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- ☐ Consider checking out some of the National Palliative Care programs which provide information and resources relevant to diversity:
  - CareSearch (Patient Diversity) <https://www.caresearch.com.au/tabid/6269/Default.aspx>
  - Advance Care Planning Australia (information in other languages) <https://www.advancecareplanning.org.au/languages>
  - End of Life Directions for Aged Care (ELDAC) (Diverse population groups) <https://www.eldac.com.au/tabid/5031/Default.aspx>
  - palliAGED (Diverse Australia) <https://www.palliaged.com.au/tabid/7105/Default.aspx>

**For resources go to the My Toolkit pages in End-of-Life Essentials website: <https://www.endoflifeessentials.com.au/>**

## Resources

### End-of-Life Care for Diverse Communities

#### General

Australian Government Department of Health: [Exploratory analysis of barriers to palliative care](#)

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ELDAC website:

- [Palliative Care in Diverse Populations](#)
  - [Financially or Socially Disadvantaged](#)
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CareSearch: [Systematic Review Collections](#) on many underserved populations including:

- [Aboriginal and Torres Strait Islander](#)
  - [Asylum seekers and refugees](#)
  - [Homelessness](#)
  - [Intellectual disability](#)
  - [Lesbian, Gay, Bisexual, Transgender, Intersex \(LGBTI\)](#)
  - [Mental illness](#)
  - [Multicultural](#)
  - [Prisoners](#)
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CareSearch: [For nurses - A population approach to palliative care](#), including:

- [Aboriginal and Torres Strait Islander Peoples](#)
  - [Homelessness](#)
  - [Intellectually Disabled](#)
  - [Lesbian, Gay, Bisexual, Transgender, Intersex \(LGBTI\)](#)
  - [Living Alone](#)
  - [Mental Illness](#)
  - [Multicultural](#)
  - [People with HIV/AIDS](#)
  - [Prisoners](#)
  - [Refugees and Asylum Seekers](#)
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# Resources

## End-of-Life Care for Diverse Communities

### LGBTIQ+

palliAGED website: [Lesbian, Gay, Bisexual, Transgender and Intersex \(LGBTI\) Individuals](#)

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ELDAC website: [Lesbian, Gay, Bisexual, Transgender and Intersex \(LGBTI\): Australia's ageing population](#)

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Australian Government Department of Health: [Exploratory Analysis of Barriers to Palliative Care – Issues Report on People who Identify as Lesbian, Gay, Bisexual, Transgender or Intersex](#)

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CareSearch: [LGBTI – Understanding palliative care needs of the LGBTI community](#)

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### Mental Illness

palliAGED website: [Mental Illness](#)

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CareSearch: [Mental Illness – Understanding the complexity of palliative care with mental illness](#)

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Health Translations website (Victorian Government): [Advance care planning for end of life for people with mental illness \(available in other languages\)](#)

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NSW Government: [Dignity, respect and choice: Advance care planning for end of life for people with mental illness – A comprehensive Guide](#)

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### Culturally and Linguistically Diverse Backgrounds

Australian Government Department of Health: [Exploratory Analysis of Barriers to Palliative Care – Issues Report on People from Culturally and Linguistically Diverse Backgrounds](#)

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palliAGED website: [Culturally and Linguistically Diverse \(CALD\) Communities](#)

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# Resources

## End-of-Life Care for Diverse Communities

ELDAC website: [Australia's ageing Culturally and Linguistically Diverse population](#)

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Palliative Care Victoria: [Information for health professionals – Culturally and Linguistically Diverse people](#)

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CareSearch: [Multicultural – Cultural and Linguistic diversity considerations in palliative care](#)

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Palliative Care Network of Wisconsin: [Fast Fact #154: The use of interpreters in palliative care](#)

\*Please do be aware that these resources are for the American audience with information relevant to their health care system, however the principles still apply.

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### Further Reading

#### General

Nelson KE, Wright R, Peeler A, Brockie T, Davidson PM. Sociodemographic Disparities in Access to Hospice and Palliative Care: An Integrative Review. *Am J Hosp Palliat Care*. 2021 Nov;38(11):1-13. doi: [10.1177/1049909120985419](#)

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#### LGBTIQ+

Carabez R, Scott M. 'Nurses don't deal with these issues': nurses' role in advance care planning for lesbian, gay, bisexual and transgender patients. *J Clin Nurs*. 2016 Dec;25(23-24):3707–3715. doi: [10.1111/jocn.13336](#)

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Cathcart-Rake E, O'Connor J, Ridgeway JL, Radecki Breitkopf C, Kaur JS, Mitchell J, Leventakos K, Jatoti A. Patients' Perspectives and Advice on How to Discuss Sexual Orientation, Gender Identity, and Sexual Health in Oncology Clinics. *Am J Hosp Palliat Care*. 2020 Dec;37(12):1053–1061. doi: [10.1177/1049909120910084](#) (FREE ACCESS)

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Haviland K, Burrows Walters C, Newman S. Barriers to palliative care in sexual and gender minority patients with cancer: A scoping review of the literature. *Health Soc Care Community*. 2021 Aug;29:305–318. doi: [10.1111/hsc.13126](#)

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# Resources

## End-of-Life Care for Diverse Communities

Kemery SA. Family perceptions of quality of end of life in LGBTQ+ individuals: a comparative study. *Palliat Care Soc Pract*. 2021 Mar;15:2632352421997153. doi: [10.1177/2632352421997153](https://doi.org/10.1177/2632352421997153)

Lippe M, Eyer JC, Rosa WE, McKinney Jr R, Patterson B, Matteo RA, Townsend H, Halli-Tierney H. Caring for an Unconscious Transgender Patient at the End of Life: Ethical Considerations and Implications. *J Hosp Palliat Nurs*. 2021 Aug; 23(4): 300–308. doi:[10.1097/NJH.0000000000000765](https://doi.org/10.1097/NJH.0000000000000765) (FREE ACCESS)

Lisy K, Peters MDJ, Schofield P, Jjefford M. Experiences and unmet needs of lesbian, gay, and bisexual people with cancer care: A systematic review and metasynthesis. *Psycho-oncology*. 2018 Jun;27(6):1480–1489. doi: [10.1002/pon.4674](https://doi.org/10.1002/pon.4674)

### Mental Illness

Baruth JM, Ho JB, Mohammad SI, Lapid MI. End-of-life care in schizophrenia: a systematic review. *Int Psychogeriatr*. 2021 Feb;33(2):129–147. doi:[10.1017/S1041610220000915](https://doi.org/10.1017/S1041610220000915)

den Boer K, de Veer AJE, Schoonmade LJ, Verhaegh KJ, van Meijel B, Francke AL. A systematic review of palliative care tools and interventions for people with severe mental illness. *BMC Psychiatry*. 2019 Apr;19:106 doi:[10.1186/s12888-019-2078-7](https://doi.org/10.1186/s12888-019-2078-7)

Jerwood J, Ward GE, Phimister D, Holliday N, Coad J. Barriers to palliative care for people with severe mental illness: Exploring the views of clinical staff. *Eur J Palliat Care*. 2018 Jan;25(1):20-25 (FREE ACCESS in [ResearchGate](https://www.researchgate.net/publication/328111111))

Jerwood J, Ward G, Phimister D, Holliday N, Coad J. Lean in, don't step back: The views and experiences of patients and carers with severe mental illness and incurable physical conditions on palliative and end of life care. *Prog Palliat Care*. 2021 Mar;29(5):255-263 doi:[10.1080/09699260.2021.1887589](https://doi.org/10.1080/09699260.2021.1887589)

O'Malley K, Blakley L, Ramos K, Torrence N, Sager Z. Mental healthcare and palliative care: barriers. *BMJ Support Palliat Care*. 2021 June;11(2):138–144. doi:[10.1136/bmjspcare-2019-001986](https://doi.org/10.1136/bmjspcare-2019-001986)

# Resources

## End-of-Life Care for Diverse Communities

Wilson R, Hepgul N, Higginson IJ, Gao W. End-of-life care and place of death in adults with serious mental illness: A systematic review and narrative synthesis. *Palliat Med*. 2020 Jan;34(1):49–68. doi: [10.1177/0269216319867847](https://doi.org/10.1177/0269216319867847)

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### Culturally and Linguistically Diverse

Jones T, Luth EA, Lin S-Y, Brody AA. Advance Care Planning, Palliative Care, and End-of-life Care Interventions for Racial and Ethnic Underrepresented Groups: A Systematic Review. *J Pain Symptom Manage* 2021 Sep;62(3):e248–e260. doi: [10.1016/j.jpainsymman.2021.04.025](https://doi.org/10.1016/j.jpainsymman.2021.04.025)

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McCleskey SG, Cain CL. Improving End-of-Life Care for Diverse Populations: Communication, Competency, and System Supports. *Am J Hosp Palliat Care*. 2019 June; 36(6):453–459. doi:[10.1177/1049909119827933](https://doi.org/10.1177/1049909119827933) (FREE ACCESS)

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Mayland CR, Powell RA, Clarke GC, Ebenso B, Allsop MJ. Bereavement care for ethnic minority communities: A systematic review of access to, models of, outcomes from, and satisfaction with, service provision. *PLoS One*. 2021 Jun 30;16(6):e0252188. doi: [10.1371/journal.pone.0252188](https://doi.org/10.1371/journal.pone.0252188)

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Rahemi Z, Williams CL. Does ethnicity matter-Cultural factors underlying older adults' end-of-life care preferences: A systematic review. *Geriatr Nurs*. 2020 Mar-Apr;41(2):89-97. doi: [10.1016/j.gerinurse.2019.07.001](https://doi.org/10.1016/j.gerinurse.2019.07.001)

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