

Resources

Dying, a normal part of life

Patient-Centred Communication and Shared Decision-Making

Recognising the End-of-Life

Planning End-of-Life Care – Goals of Care

Teams and Continuity for the Patient

Responding to Concerns

Emergency Department End-of-Life Care

Paediatric End-of-Life Care

Chronic Complex Illness End-of-Life Care

Imminent Death – How to Respond

Resources

Dying, a normal part of life

The Australian Commission on Safety and Quality in Health Care (ACSQHC) on End-of-Life Care, Part A – Processes of Care Sections:

- Patient-centred communication and shared decision-making
- Teamwork and coordination of care
- Components of care
- Use of triggers to recognise patients approaching the end of life
- Response to concerns

<https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-high-quality-end-of-life-care/>

The Australian Commission on Safety and Quality in Health Care (ACSQHC) on End-of-Life Care, Part B – Organisational Prerequisites:

- Leadership and governance
- Education and training
- Supervision and support for interdisciplinary team members
- Evaluation, audit and feedback
- Systems to support high-quality care

<https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-high-quality-end-of-life-care/>

Palliative Care Australia [Standards for Providing Quality Palliative Care for all Australians](#)

The Australian Commission on Safety and Quality in HealthCare [Fact Sheet on end-of-life care](#)

The Australian Commission on Safety and Quality in HealthCare: [National Safety and Quality Health Service Standards](#)

Resources

Dying, a normal part of life

End of Life Essentials [Glossary of terms](#)

End of Life Essentials: Able versus Novice: [Which one are You?](#)

Videos, Blogs and Podcasts

A TED Talk by Peter Saul: [Let's talk about Dying](#) (13 mins, 13 sec)

Palliative Care Victoria, Associate Professor Brian Le, [Communication at the end of life](#)

Further Reading

Waller A, Dodd N, Tattersall MHN, Nair B, Sanson-Fisher R. Improving hospital-based end of life care processes and outcomes: a systematic review of research output, quality and effectiveness. BMC Palliat Care. 2017 May 19;16(1):34. doi: [10.1186/s12904-017-0204-1](#)

Masso, M., Samsa, P. & Grootemaat, P. (2016). *Rapid review of the literature to inform the development of quality and safety indicators for end-of-life care in acute hospitals*. ACSQHC, Sydney. Available from: <https://www.safetyandquality.gov.au/our-work/end-of-life-care-in-acute-hospitals/tools-and-resources-for-health-services/>

Virdun, C., Lockett, T., Davidson, P.M. & Phillips J. (2015). Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. Palliative Medicine, 29(9),774-96. doi: [10.1177/0269216315583032](#)

Stansfeld, S. A., Shipley, M. J., Head, J., Fuhrer, R., & Kivimaki, M. (2013). Work characteristics and personal social support as determinants of subjective well-being. PLoS One, 8(11), e81115. doi: [10.1371/journal.pone.0081115](#)

Resources

Patient-Centred Communication and Shared Decision-Making

[Palliative Care Network of Wisconsin, Fast Facts #17, Patient-centred interviewing](#)

[Australian and New Zealand Intensive Care Society \(ANZICS\), 2014, Recommended language for communicating end-of-life care concepts](#)

[VITAL talk, Talking about dying: quick guide](#)

[Australian and New Zealand Intensive Care Society, 2014: ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill](#)

The Family Meeting, Fast Facts, Palliative Care Network of Wisconsin:

- [Part 1: Preparing for the meeting](#)
 - [Part 2: Starting the conversation](#)
 - [Part 3: Responding to emotion](#)
 - [Part 4: Causes of Conflict](#)
 - [Part 5: Helping surrogates make decisions](#)
 - [Part 6: Goal Setting and Future Planning](#)
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[SPIKES: A six step protocol for delivering bad news](#)

[End of Life Essentials: Exploring the patient's concerns about their end of life preferences / care](#)

[End of Life Essentials: Responding to emotional cues: The NURSES mnemonic](#)

[From the Good Life, Good Death, Good Grief website: Responding to difficult questions](#)

[End of Life Essentials Glossary of terms](#)

[End of Life Essentials Able versus Novice: Which one are You?](#)

Resources

Patient-Centred Communication and Shared Decision-Making

Videos, Blogs and Podcasts

CareSearch Blog: Mary Patetsos: [Providing person and family-centred palliative care for a culturally diverse Australia](#)

CareSearch Blog: KiM Devery: [Learning and vulnerability in end-of-life communication](#)

From The Palliative Care Bridge: A/Prof Richard Chye: [Medical decision-making and the ethics behind it](#)

Further Reading

Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev*. 2018 Jul 24;7:CD003751. doi: [10.1002/14651858.CD003751.pub4](#)

Brooke J, Ojo O. Elements of a sustainable, competent, and empathetic workforce to support patients with dementia during an acute hospital stay: A comprehensive literature review. *Int J Health Plann Manage*. 2018 Jan;33(1):e10-e25. doi: [10.1002/hpm.2448](#)

Vanderhaeghen B, Van Beek K, De Pril M, Bossuyt I, Menten J, Rober P. What do hospitalists experience as barriers and helpful factors for having ACP conversations? A systematic qualitative evidence synthesis. *Perspect Public Health*. 2018 Jul 1;1757913918786524. doi: [10.1177/1757913918786524](#)

Brighton LJ, Koffman J, Hawkins A, McDonald C, O'Brien S, Robinson V, Khan SA, George R, Higginson IJ, Selman LE. A systematic review of end of life care communication skills training for generalist palliative care providers: research quality and reporting guidance. *J Pain Symptom Manage*. 2017 Sep;54(3):417-425. doi: [10.1016/j.jpainsymman.2017.04.008](#). Epub 2017 Aug 4

Gilligan T, Coyle N, Frankel RM, Berry DL, Bohlke K, Epstein RM, Finlay E, Jackson VA, Lathan CS, Loprinzi CL, Nguyen LH, Seigel C, Baile WF. Patient-clinician communication: American Society of Clinical Oncology Consensus Guideline. *J Clin Oncol*. 2017 Nov 1;35(31):3618-3632. doi: [10.1200/JCO.2017.75.2311](#). Epub 2017 Sep 11

Baik D, Cho H, Masterson Creber RM. Examining interventions designed to support shared decision making and subsequent patient outcomes in palliative care: A systematic review of the literature. *Am J Hosp Palliat Care*. 2018 Jan 1;1049909118783688. doi: [10.1177/1049909118783688](#). [Epub ahead of print]

Hobgood, C., Harward, D., Newton, K., Davis, W., (2005). The educational intervention "GRIEV_ING" improves the death notification skills of residents. *Acad Emerg Med*, 12, 4, 296-301. <http://dx.doi.org/10.1197/j.aem.2004.12.008>

My Toolkit

Resources

Recognising the End-of-Life

Australian and New Zealand Society of Palliative Medicine (ANZSPM) [Clinical Indicators for End-of-Life care and Palliative care](#)

Palliative Care Network of Wisconsin:

Fast Facts #235 [Prognostic Models in Critically Ill Adults](#)

(ICU) Fast Facts #253 [Palliative Care Consultation in the ICU](#)

From Palliative & End of Life care, A Blueprint for improvement:

- [Early recognition of approaching end of life](#)
 - [Quality care during the last days of life](#)
-

Professor Hal Swerissen Visiting Fellow, Grattan Institute, [Dying in Australia](#). Deeble Institute Workshop: End of Life Care 13 April 2016

End of Life Essentials: [Creating Conversations](#)

From the University of Edinburgh, the [SPICT tool](#)

From SA Health: [Pharmacological Management of symptoms for adults in the last days of life](#)

From Northern Adelaide Local Health Network: [An example care plan for the Last Days of Life](#)

From Queensland University of Technology: [End of Life Law Australia: Palliative Medication](#)

End of Life Essentials [Glossary of terms](#)

End of Life Essentials Able versus Novice: [Which one are You?](#)

Resources

Recognising the End-of-Life

Videos, Blogs and Podcasts

CareSearch Blog: Paul Tait: [Five quick tips for prescribing medicines in the last days of life](#)

CareSearch Blog: Maite Uribe: [Caring for dying patients in an acute hospital setting, three tips for getting it right](#)

The first episode of the RACP's CPD podcast Pomegranate, explores the [challenges doctors face in end-of-life decision making](#). Made by, and for, physicians, the peer-reviewed program features Fellows from across specialities and divisions speaking on issues that matter to them.

Further Reading

Chen CH, Kuo SC, Tang ST. Current status of accurate prognostic awareness in advanced/terminally ill cancer patients: Systematic review and meta-regression analysis. *Palliat Med*. 2017 May;31(5):406-418. doi: [Epub 2016 Aug 4](#)

Reid VL, McDonald R, Nwosu AC, Mason SR, Probert C, Ellershaw JE, Coyle S. [A systematically structured review of biomarkers of dying in cancer patients in the last months of life; An exploration of the biology of dying](#). *PLoS One*. 2017 Apr 6;12(4):e0175123. eCollection 2017.

Finlayson CS, Chen YT, Fu MR. [The Impact of Patients' Awareness of Disease Status on Treatment Preferences and Quality of Life among Patients with Metastatic Cancer: A Systematic Review from 1997-2014](#). *J Palliat Med*. 2015 Feb;18(2):176-86. Epub 2014 Sep 26.

Resources

Planning End-of-Life Care – Goals of Care

Thomas, R. L., Zubair, M. Y., Hayes, B., & Ashby, M. A. (2014). Goals of care: a clinical framework for limitation of medical treatment. *Medical Journal of Australia*, 201(8), 452-5.

Australian Centre for Health Research: Critical Conversations in Australian Centre for Health Research, Conversations: [Creating choice in end of life care](#)

Palliative Care Network of Wisconsin

Fast Facts #216: [Asking About Cultural Beliefs in Palliative Care](#)

Fast Fact #226 [Helping Surrogate Decision makers](#)

The Family Meeting, Fast Facts, Palliative Care Network of Wisconsin:

- Part 1: [Preparing for the meeting](#)
 - Part 2: [Starting the conversation](#)
 - Part 3: [Responding to emotion](#)
 - Part 4: [Causes of Conflict](#)
 - Part 5: [Helping surrogates make decisions](#)
 - Part 6: [Goal Setting and Future Planning](#)
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From ACI NSW: Aboriginal stories About Approaching the End of Life: <https://www.aci.health.nsw.gov.au/ie/projects/aboriginal-stories-about-approaching-the-end-of-life>

From Vital Talk:

- [Transitions / Goals of Care using the REMAP tool](#)
 - [Defusing Conflicts Moving the Conversation forward](#)
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From SA Health: [Pharmacological Management of symptoms for adults in the last days of life](#)

Resources

Planning End-of-Life Care – Goals of Care

From the Irish Hospice Foundation: [Supporting Families at End of Life](#)

From University of Edinburgh: [The SPICT tool](#)

End of Life Essentials [Glossary of terms](#)

End of Life Essentials Able versus Novice: [Which one are You?](#)

Videos, Blogs and Podcasts

CareSearch Blog: Charlotte Coulson: [Listen, pause, and breathe – guidance in delivering culturally acceptable palliative care](#)

CareSearch Blog: Linda Nolte: [How well prepared are health professionals to have tough conversations that matter?](#)

CareSearch Blog: Ben White and Lindy Willmott: [Support for health professionals to know more about end-of-life law](#)

From Radio National an interview with Leah Kaminsky: [Life Death and DNA](#)

Vital Talk: [Emotions as Data](#)

End of Life Essentials: Professor Imogen Mitchell: [Dying in Acute Hospitals an ICU perspective TI](#)

Further Reading

Vanderhaeghen B, Van Beek K, De Pril M, Bossuyt I, Menten J, Rober P. What do hospitalists experience as barriers and helpful factors for having ACP conversations? A systematic qualitative evidence synthesis. *Perspect Public Health*. 2018 Jul 1;1757913918786524. doi: 10.1177/1757913918786524. [Epub ahead of print]

Cohen-Mansfield J, Skornick-Bouchbinder M, Brill S. Trajectories of end of life: A systematic review. *J Gerontol B Psychol Sci Soc Sci*. 2018 Apr 16;73(4):564-572. doi: 10.1093/geronb/gbx093

Sharpe KK, Noble C, Hiremagular B, Grealish L. Implementing an integrated pathway to care for the dying: is your organisation ready? *Int J Palliat Nurs*. 2018 Feb 2;24(2):70-78. doi: 10.12968/ijpn.2018.24.2.70

Resources

Teams and Continuity for the Patient

Cancer Australia, 2016: [Running a multidisciplinary care meeting](#)

NHMRC: [Cultural Competency in Health](#) (PowerPoint Presentation)

Australian Indigenous Doctors' Association: [Resources on Cultural Safety, including a position statement, factsheet and toolkit](#)

AIHW Closing the gap: [Cultural competency in the delivery of health services for indigenous people](#)

American Psychological Association: [Culturally Diverse Communities and End-of-Life Care](#)

Centre for Cultural Diversity in Ageing [Palliative Care Resources](#)

Centre for Cultural, Ethnicity and Health [A framework for cultural competence](#) (for the health sector)

Agency for Healthcare Research and Quality, US, 2013 [Team STEPPS 2.0 pocket guide](#)

Hillman, K., Chen, J. (2008). Conflict resolution in end of life treatment decisions: *An Evidence Check* rapid review for the Centre for Epidemiology and Research, NSW Department of Health. Ultimo, NSW: The Sax Institute. Available at: <http://www.health.nsw.gov.au/research/Documents/14-conflict-resolution-end-of-life.pdf>

The following Fast Facts, Palliative Care Network of Wisconsin may be of interest:

- Fast Facts #183 [Conflict Resolution Part 1](#)
 - Fast Facts #184 [Conflict Resolution Part 2](#)
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End of Life Essentials [Glossary of terms](#)

End of Life Essentials Able versus Novice: [Which one are You?](#)

Resources

Teams and Continuity for the Patient

Videos, Blogs and Podcasts

TEDx talk by Amy Edmondson [Building a psychological safe workplace](#) (11 mins 26 seconds)

Agency for Healthcare Research and Quality, 2014 [Improve Teamwork and Communication](#)

Further Reading

Farmer, D. F., & Yancu, C. N. (2015). Hospice and palliative care for older lesbian, gay, bisexual and transgender adults: The effect of history, discrimination, health disparities and legal issues on addressing service needs. *Palliative Medicine and Hospital Care Open Journal*, 1(2), 36-43.

Hiruy, K., & Mwanri, L. (2014). End-of-life experiences and expectations of Africans in Australia: Cultural implications for palliative and hospice care. *Nursing Ethics*, 21(2), 187-197. doi: [10.1177/0969733012475252](#)

Koffman, J. (2014). Servicing multi-cultural needs at the end of life. *Journal of Renal Care*, 40(S1), 6-15. doi: [10.1111/jorc.12087](#)

Nancarrow, S. A., Booth, A., Ariss, S., Smith, T., Enderby, P., & Roots, A. (2013). Ten principles of good interdisciplinary team work. *Human Resources for Health*, 11(1), 19. doi: [10.1186/1478-4491-11-19](#)

Brown, J., Lewis, L., Ellis, K., Stewart, M., Freeman, T. R., & Kasperski, M. J. (2011). Conflict on interprofessional primary health care teams—can it be resolved? *Journal of Interprofessional Care*, 25(1), 4-10. doi: [10.3109/13561820.2010.497750](#)

Clark, K. & Phillips, J (2010). End of life care: the importance of culture and ethnicity, *Australian Family Physician*, 39 (4), 201-213.

Johnstone, M. J., & Kanitsaki, O. (2009). Ethics and advance care planning in a culturally diverse society. *Journal of Transcultural Nursing*, 20(4), 405-416. doi: [10.1177/1043659609340803](#)

Thomas, R., Wilson, D. M., Justice, C., Birch, S., & Sheps, S. (2008). A literature review of preferences for end-of-life care in developed countries by individuals with different cultural affiliations and ethnicity. *Journal of Hospice & Palliative Nursing*, 10(3), 142-161. <https://nursing.ceconnection.com/ovidfiles/00129191-200805000-00012.pdf>

Resources

Responding to Concerns

From Advance Care Planning Australia

- Health care Professionals information
- Information on advanced care planning in your state
- How to start a conversation

From QUT End of Life Law Australia:

- Capacity and Consent
- Adults and EOL decision making
- Organ Donation
- Euthanasia and Assisted Dying

Details of the Australian Health Practitioner Regulation Agency (AHPRA)
<https://www.ahpra.gov.au/>

Therapeutic Guidelines: Emergency Care presentations in palliative care

End of Life Essentials [Glossary of terms](#)

End of Life Essentials Able versus Novice: [Which one are You?](#)

Resources

Responding to Concerns

Videos, Blogs and Podcasts

Advance Care Planning Australia: <http://advancecareplanning.org.au/videos/> (Several videos from patients, nurses and doctors perspectives. Videos are between 1 minutes 17 seconds and 4 minutes 34 second in length).

Further Reading

Wilkinson H, Whittington R, Perry L, Eames C. Examining the relationship between burnout and empathy in healthcare professionals: A systematic review. *Burn Res.* 2017 Sep;6:18-29. doi: [10.1016/j.burn.2017.06.003](https://doi.org/10.1016/j.burn.2017.06.003)

Carter, R. Z., Detering, K. M., Silvester, W., & Sutton, E. (2016). Advance care planning in Australia: what does the law say? *Australian Health Review*, 40(4), 405-414. doi.org/10.1071/AH15120

Wilkinson H, Whittington R, Perry L, Eames C. Examining the relationship between burnout and empathy in healthcare professionals: A systematic review. *Burn Res.* 2017 Sep;6:18-29. doi: [10.1016/j.burn.2017.06.003](https://doi.org/10.1016/j.burn.2017.06.003)

West A. Associations among attachment style, burnout, and compassion fatigue in health and human service workers: A systematic review. *J Human Behav Soc Env.* 2015; 25(6):571-590. Epub 2015 Apr 14.

Resources

Emergency Department End-of-Life Care

From Advance Care Planning Australia:
Health care Professionals information
How to start a conversation

From ACI NSW Health: [End of Life Care in the Emergency Department](#)

Australasian College for Emergency Medicine: [Policy on End of Life and the Emergency Department](#)

The following Fast Facts, Palliative Care Network of Wisconsin may be of interest:

- Fast Facts #76 [Death Notification by Phone Part 1](#)
 - Fast Facts #77 [Death Notification by Phone Part 2](#)
 - Fast Facts #246 [Emergency Department management of Hospice Patients](#)
 - Fast Facts #298 [Palliative Care Consultation in the ED](#)
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Emergency Care Institute. [End-of-Life Care in the Emergency Department \[Internet\]](#). 2015

End of Life Essentials [Glossary of terms](#)

End of Life Essentials Able versus Novice: [Which one are You?](#)

Videos, Blogs and Podcasts

CareSearch Blog: Tracey Giles: [Family member experiences of the sudden, unexpected death of a loved one in an emergency department setting](#)

Advance Care Planning Australia: <http://advancecareplanning.org.au/videos/> (Several videos from patients, nurses and doctors perspectives. Videos are between 1mins 17 seconds and 4 mins 34 second in length).

Resources

Emergency Department End-of-Life Care

Further Reading

Cooper E, Hutchinson A, Sheikh Z, Taylor P, Townend W, Johnson MJ. Palliative care in the emergency department: A systematic literature qualitative review and thematic synthesis. *Palliat Med*. 2018 Jul 1;269216318783920. doi: [10.1177/0269216318783920](https://doi.org/10.1177/0269216318783920)

Cruz-Carreras, M.T., Chaftari, P., & Viets-Upchurch, J., (2018) Advance care planning: challenges at the emergency department of a cancer care center. *Support Cancer Care*, 26,2, 585-588. doi.org/[10.1007/s00520-017-3870-x](https://doi.org/10.1007/s00520-017-3870-x)

McCallum KJ, Jackson D, Walthall H, Aveyard H. Exploring the quality of the dying and death experience in the Emergency Department: An integrative literature review. *Int J Nurs Stud*. 2018 May 23;85:106-117. doi: [10.1016/j.ijnurstu.2018.05.011](https://doi.org/10.1016/j.ijnurstu.2018.05.011)

Cotogni, P., DE Luca, A., Evangelista, A., Fillipini, C., Gili, R., Scarmozzino, A., et al. (2017). A simplified screening tool to identify seriously ill patients in the Emergency Department for referral to a palliative care team. *Minerva Anesthesiol*, 83, 5, 474-484. doi: [10.23736/S0375-9393.16.11703-1](https://doi.org/10.23736/S0375-9393.16.11703-1)

Gloss K. [End of life care in emergency departments: a review of the literature](#). *Emerg Nurse*. 2017 May 12;25(2):29-38.

Seedhom, A.E., & Kamal, N.N. (2017) The Palliative Performance Scale Predicts Survival among Emergency Department Patients, Minia, Egypt. doi: [10.4103/IJPC.IJPC_50_17](https://doi.org/10.4103/IJPC.IJPC_50_17)

Carter, R. Z., Detering, K. M., Silvester, W., & Sutton, E. (2016). Advance care planning in Australia: what does the law say? *Australian Health Review*, 40(4), 405-414. doi.org/[10.1071/AH15120](https://doi.org/10.1071/AH15120)

da Silva Soares D, Nunes CM, Gomes B. [Effectiveness of Emergency Department Based Palliative Care for Adults with Advanced Disease: A Systematic Review](#). *J Palliat Med*. 2016 Jun;19(6):601-9. Epub 2016 Apr 26.

George N, Phillips E, Zaurova M, Song C, Lamba S, Grudzen C. [Palliative Care Screening and Assessment in the Emergency Department: A Systematic Review](#). *J Pain Symptom Manage*. 2016 Jan;51(1):108-19.e2. Epub 2015 Aug 31.

Cornillon, P., Loiseau, S., Aublet-Cuvelier, B., & Guastella. Reasons for transferral to emergency departments of terminally ill patients – a French descriptive and retrospective study. *BMC Palliat Care*, 15,1, 87. doi.org/[10.1186/s12904-016-0155-y](https://doi.org/10.1186/s12904-016-0155-y)

Resources

Paediatric End-of-Life Care

[Australian Paediatric Palliative Care website](#)

[Quocca Paediatric Palliative Care project](#)

[PCC4U has information on Paediatric Palliative care](#)

[WA Cancer and Palliative Care Network Paediatric and Adolescent Young Adult Palliative Care Model of Care](#)

[Australian Centre for Grief and Bereavement has paediatric information](#)

[CareSearch, Paediatrics](#)

[Palliative Care Australia: Paediatric palliative care position statement](#)

[From the Queensland Government: Palliative Care for Children with Cancer – A Guide for parents \(1MB pdf\) and ‘practical guide to palliative care in paediatrics’. \(2MB pdf\)](#)

[From QUT End of Life Law Australia: Children and EOL decision making](#)

[End of Life Essentials Glossary of terms](#)

[End of Life Essentials Able versus Novice: Which one are You?](#)

Resources

Paediatric End-of-Life Care

Videos, Blogs and Podcasts

CareSearch Blog: Elizabeth Shepherd: [A Rewarding Place to Work: My Personal Perspective on Paediatric Palliative Care](#)

CareSearch blog: Dr Anthony Herbert: [Improving Children's Palliative Care Close to Home in Australia](#)

The video '[Emily's story](#)' is designed to support the learning activities associated with the focus topic '[Caring for children with life-limiting conditions](#)' in PCC4U

Further Reading

Ekberg S, Bradford NK, Herbert A, Danby S, Yates P. Healthcare Users' Experiences of Communicating with Healthcare Professionals about children who have life-limiting conditions: A qualitative systematic review. *J Palliat Med*. 2018 May 15. doi: [10.1089/jpm.2017.0422](#). [Epub ahead of print]

Ghirotto L, Busani E, Salvati M, Di Marco V, Caldarelli V, Artioli G. Researching children's perspectives in pediatric palliative care: A systematic review and meta-summary of qualitative research. *Palliat Support Care*. 2018 May 29;1-12. doi: [10.1017/S1478951518000172](#). [Epub ahead of print]

Grimston M, Butler AE, Copnell B. Critical care nurses' experiences of caring for a dying child: A qualitative evidence synthesis. *J Adv Nurs*. 2018 May 5. doi: [10.1111/jan.13701](#). [Epub ahead of print]

Marsac ML, Kindler C, Weiss D, Ragsdale L. Let's talk about It: Supporting family communication during end-of-life care of pediatric patients. *J Palliat Med*. 2018 Jun;21(6):862-878. doi: [10.1089/jpm.2017.0307](#). Epub 2018 May 18.

Arruda-Colli MNF, Weaver MS, Wiener L. [Communication about dying, death, and bereavement: A systematic review of children's literature](#). *J Palliat Med*. 2017 May;20(5):548-559. Epub 2017 Mar 27.

Resources

Chronic Complex Illness End-of-Life Care

From Advance Care Planning Australia:
Health Care Professionals information
How to start a conversation

CareSearch: [Non-malignant /end stage disease](#)

The following Fast Facts from the Palliative Care Network of Wisconsin may be helpful:

- [Fast Facts #141 Prognosis in End-Stage COPD](#)
 - [Fast Fact #143 Prognostication in Heart Failure](#)
 - [Fast Fact #150 Prognostication in Dementia](#)
 - [Fast Fact #163 Decision making in Renal Failure](#)
 - [Fast Fact #189 Liver Failure Prognosis](#)
 - [Fast Fact #213 Prognosis in HIV / ADIS](#)
 - [Fast fact #201 Palliative Care for People With Huntington's Disease](#)
 - [Fast Fact #332 End of life Care for Patients With Schizophrenia](#)
 - [Fast Fact #361 Parkinson's Disease, Disease Trajectory](#)
 - [Fast Fact #360 The surprise Question as a Prognostic Tool](#)
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[End of Life Essentials Glossary of terms](#)

[End of Life Essentials Able versus Novice: Which one are You?](#)

Resources

Chronic Complex Illness End-of-Life Care

Videos, Blogs and Podcasts

CareSearch Blog: [Listen, Acknowledge, Respond project Team: Addressing the mental health needs of those living with dying](#)

CareSearch Blog: Tim Lockett: [What is needed to improve care planning for people living with dementia?](#)

Palliative Matters blog: [Palliative care is for people with chronic disease not just cancer](#)

Advance Care Planning Australia: <http://advancecareplanning.org.au/videos/> (Several videos from patients, nurses and doctors perspectives. Videos are between 1mins 17 seconds and 4 mins 34 second in length).

Further Reading

Eckert K, Motemaden L, Alves M. Effect of Hemodialysis Compared With Conservative Management on Quality of Life in Older Adults With End-Stage Renal Disease. *J Hosp Palliat Nurs*. 2018 Jun;20(3):279-85. doi: [10.1097/NJH.0000000000000444](https://doi.org/10.1097/NJH.0000000000000444)

Hamel AV, Gaugler JE, Porta CM, Hadidi NN. Complex Decision-Making in Heart Failure: A Systematic Review and Thematic Analysis. *J Cardiovasc Nurs*. 2018 May/Jun;33(3):225-231. doi: [10.1097/JCN.0000000000000453](https://doi.org/10.1097/JCN.0000000000000453)

Jabbarian LJ, Zwakman M, van der Heide A, Kars MC, Janssen DJA, van Delden JJ, Rietjens JAC, Korfage IJ. Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. *Thorax*. 2018 Mar;73(3):222-230. doi: [10.1136/thoraxjnl-2016-209806](https://doi.org/10.1136/thoraxjnl-2016-209806). Epub 2017 Nov 6.

Noonan MC, Wingham J, Taylor RS. 'Who Cares?' The experiences of caregivers of adults living with heart failure, chronic obstructive pulmonary disease and coronary artery disease: a mixed methods systematic review. *BMJ Open*. 2018 Jul 11;8(7):e020927. doi: [10.1136/bmjopen-2017-020927](https://doi.org/10.1136/bmjopen-2017-020927)

O'Halloran P, Noble H, Norwood K, Maxwell P, Shields J, Fogarty D, Murtagh F, Morton R, Brazil K. Advance care planning with patients who have end-stage kidney disease: a systematic realist review. *J Pain Symptom Manage*. 2018 Jul 16. pii: S0885-3924(18)30347-6. doi: [10.1016/j.jpainsymman.2018.07.008](https://doi.org/10.1016/j.jpainsymman.2018.07.008). [Epub ahead of print]

Ng L, Khan F, Young CA, Galea M. [Symptomatic treatments for amyotrophic lateral sclerosis/motor neuron disease](#). *Cochrane Database Syst Rev*. 2017 Jan 10;1:CD011776.

Resources

Chronic Complex Illness End-of-Life Care

Cardona-Morrell M, Kim J, Turner RM, Anstey M, Mitchell IA, Hillman K. [Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem.](#) Int J Qual Health Care. 2016 Sep;28(4):456-69. Epub 2016 Jun 27.

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Resources

Imminent Death – How to Respond

From CareSearch – [Changes at the time of Death](#)

The following Fast Facts from the Palliative Care Network of Wisconsin may be helpful:

- Fast Facts #3 [Syndrome of Imminent Death](#)
 - Fast Facts #109 [Death Rattle and Oral Secretions](#)
 - Fast Facts #118 [Near Death Awareness](#)
 - Fast Facts #149 [Teaching the Family what to expect when the patient is dying](#)
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An article from Nursing Times (UK) [Personal care at the end of life and after death](#)

From the Royal Children's Hospital Melbourne: [Procedures at time of death in hospital](#)

From the Better Health Channel: [Death in Hospital](#)

End of Life Essentials [Glossary of terms](#)

End of Life Essentials Able versus Novice: [Which one are You?](#)

Resources

Imminent Death – How to Respond

Further Reading

Cohen-Mansfield J, Skornick-Bouchbinder M, Brill S. Trajectories of End of Life: A Systematic Review. *J Gerontol B Psychol Sci Soc Sci*. 2018 Apr 16;73(4):564-572. doi: [10.1093/geronb/gbx093](https://doi.org/10.1093/geronb/gbx093)

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Jansen K, Haugen DF, Pont L, Ruths S. Safety and effectiveness of palliative drug treatment in the last days of life - A systematic literature review. *J Pain Symptom Manage*. 2018 Feb;55(2):508-521.e3. doi: [10.1016/j.jpainsymman.2017.06.010](https://doi.org/10.1016/j.jpainsymman.2017.06.010). Epub 2017 Aug 10.

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Bloomer M, Morphet J, O'Connor M, Lee S, Griffiths D. [Nursing care of the family before and after a death in the ICU – an exploratory pilot study](#). *Australian Critical Care*. 26 (2013) 23-28

State-Specific Resources

State-Specific Resources – New South Wales

Palliative and End of Life Care: A blueprint for improvement, NSW Agency for Clinical Innovation: http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0007/240100/progress-report-palliative-and-end-of-life-care-a-blueprint-for-improvement.pdf

State-Specific Resources – Victoria

Victoria's end of life and palliative care framework, VicHealth: <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/palliative-care/end-of-life-and-palliative-care-framework>

State-Specific Resources – Tasmania

The Tasmanian Palliative Care Formulary https://www.dhhs.tas.gov.au/palliativecare/health_professionals/Tasmanian_Adult_Palliative_Care_Formulary

Palliative Care in Tasmania: Towards a Framework: https://www.dhhs.tas.gov.au/_data/assets/pdf_file/0015/235032/Palliative_Care_in_Tasmania-Towards_a_Framework.pdf

State-Specific Resources – Queensland

Palliative Care QLD Position Statements: <https://palliativecareqld.org.au/position-statements/>

Connecting end of life care in Townsville project: <https://palliativecareqld.org.au/celct/>

PalAssist: A guide to palliative care in QLD – booklet: <https://palassist.org.au/services/a-guide-to-palliative-care-in-queensland-booklet/>

Statewide strategy for end of life care 2015, Queensland Health: https://www.health.qld.gov.au/_data/assets/pdf_file/0022/441616/end-of-life-strategy-full.pdf

Resources

State-Specific Resources

State-Specific Resources – South Australia

SA Health End of Life Care Strategy (Last updated April 2018)

From SA Health: Resuscitation Planning – 7 Step pathway

State-Specific Resources – Western Australia

WA End-of-Life and Palliative care strategy (2018-2028)

State-Specific Resources – Australian Capital Territory

ACT Palliative Care Strategy (2017 - 2020) <https://www.pallcareact.org.au/wp-content/uploads/2017/11/Palliative-Care-ACT-Strategic-Plan-2017-2020-A4.pdf>

Profession-Specific Resources

Profession-Specific Resources: Occupational Therapists

Care Search online resources: [Occupational Therapists](#)

Occupational Therapy Australia, 2015: [Occupational therapy in palliative care: position paper](#)

A video from the Palliative Care Bridge: [Managing Fatigue](#)

A video from the Palliative Care Bridge: [Manual handling: the role of the Occupational Therapist in palliative care](#)

CareSearch PubMed Search: [Occupational Therapists](#)

Profession-Specific Resources: Physicians

Riley, G. J. (2004). [Understanding the stresses and strains of being a doctor](#). *Medical Journal of Australia*, 181(7), 350-353.

Royal Australasian College of Physicians: [Collaboration and Teamwork](#)

Palliative Care Network of Wisconsin, 2016. Fast Facts #310 [The oncology-ICU-palliative care interface](#)

The Royal Australasian College of Physicians , May 2016 [Improving Care at the End of Life: Our Roles and Responsibilities \(1.04MB pdf\)](#)

The Royal Australasian College of Physicians, 2016. [End-of-Life care: Let's talk](#)

A video from the Palliative Care Bridge [Medical Decision Making and the ethics Behind it \(Associate Professor Richard Chye\)](#)

Australian and New Zealand Society of Palliative Medicine: [ANZSPM Quality End of Life Care Position Statement](#)

Profession-Specific Resources: Nurses

Blum, C.A. (2014). [Practicing self-care for nurses: A nursing program initiative](#), *Online Journal of Issues in Nursing*, 19(3), 3. doi: 10.3912/OJIN.Vol19No03Man03

Palliative Care Nurses Australia: [Competency Standards for Specialist Palliative Care Nursing Practice](#)

Resources

Profession-Specific Resources

Profession-Specific Resources: Nurses (*continued*)

CRANApplus [Position Statement on Palliative Care](#) (1.69MB pdf)

CareSearch website [Information for Nurses Section](#)

A video from the Palliative Care Bridge [Nursing assessment for palliative care](#)

CareSearch PubMed Search: [Nurses](#)

Profession-Specific Resources: Dietitians

CareSearch information for Allied Health: [Dietitians in palliative care](#)

A video from the Palliative Care Bridge: [Nutrition and Palliative Care](#) (Ms Melissa Scattergood)

A video from the Palliative Care Bridge: [Cachexia and Anaemia: what action is needed?](#)

CareSearch PubMed Search: [Dietitians](#)

Profession-Specific Resources: Physiotherapists

CareSearch Information for Allied Health: [Physiotherapists in palliative care](#)

Videos from the Palliative Care Bridge:

- [Management of the swollen limb](#)
- [Exercise in Palliative Care](#)
- [Managing Fatigue](#)

CareSearch PubMed topic Search: [Physiotherapists](#)

Profession-Specific Resources: Psychologists

CareSearch Information for Allied Health: [Psychologists in palliative care](#)

CareSearch PubMed topic Search: [Psychologists](#)

Profession-Specific Resources: Social Workers

CareSearch Information for [Social workers in palliative care](#)

CareSearch PubMed topic Search: [Social Workers](#)

Profession-Specific Resources: Speech Pathologists

CareSearch Information for Allied Health: [Speech Pathologists in palliative care](#)

Palliative Care Australia: [10 minutes with Laura Chahda](#) (Speech Pathologist)

A video from the Palliative Care Bridge [Speech pathology and palliative care](#) (Prudence Ellis)

CareSearch PubMed topic Search: [Speech Pathologists](#)

Resources for you to Adapt and Adopt

Here are some example phrases for you to adapt and adopt to your practice:

- Timing of discussion (86kb pdf)
 - Preparation for the discussion (80kb pdf)
 - Physical and social setting (117kb pdf)
 - How to discuss prognosis and end-of-life issues (145kb pdf)
 - General strategies to facilitate hope and coping during prognostic and end-of-life discussions (132kb pdf)
 - Commencing or changing disease-specific treatments (115kb pdf)
 - Cessation of disease-specific treatments (112kb pdf)
 - Introducing specialist palliative care services (120kb pdf)
 - Discussing life expectancy (126kb pdf)
 - Discussing future symptoms and symptom management (118kb pdf)
 - Advance care planning (127kb pdf)
 - Discussing the process of death and dying (130kb pdf)
 - Requests by family members to withhold prognostic or end-of-life information from the patient (115kb pdf)
 - Dealing with conflicts (eg, differing family opinions, conflicts between doctor and patient or doctor, patient and caregiver (110kb pdf)
 - Dealing with denial or expectations that are not consistent with clinical evidence (eg, requests for medically futile treatments) (115kb pdf)
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