end-of-life ESSENTIALS
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My Toolkit

Checklist

Planning End-of-Life Care – Goals of Care

- [ ] Ask a patient if they would like to see a priest, minister, imam, rabbi or other. 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 into 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.

- [ ] Check that a patient nearing the end of life has 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?

- [ ] Check if your patient has discussed death and dying with their family. Discuss whether they have a current resuscitation plan in place.

- [ ] Practice asking open questions. For example: *I wish our treatments were more effective, but we cannot cure your illness. If you did become more unwell, what would be the most important things for you and your family?*

  Allow silences; give patients/their family members' time to think and respond, rather than react.

- [ ] Use the REMAP tool: http://vitaltalk.org/guides/transitionsgoals-of-care/ is a talking map that provides sign posts to support you through having a complex conversation with a patient.

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- [ ] Does your hospital assist with special parking permits for families who a revisiting patients who are dying?

- [ ] Tell a patient/family member about the My Values website (www.myvalues.org.au). This can help patients and their families formulate what is important to include in a care plan. It consists of statements to identify, think about and communicate preferences regarding medical treatment. Access the web page yourself and think about your own values regarding care if you became incapacitated.

- [ ] If you are looking after a patient in the last few days of life, use a Care Plan for the Last Days of Life. If you don't have one NALHN has developed one http:// training.caresearch.com.au/files/file/EOLC_plan_2016.pdf (developed by Government of South Australia, SA Health).

- [ ] Anticipating a conflict situation? Access the following guide to give you some step by step suggestions on how to best defuse the situation: http://vitaltalk.org/guides/conflicts/

- [ ] Family meeting: Fact Facts and Concepts #223, Palliative Care Network of Wisconsin: https://www.mypcnow.org/blank-u77fm provides an overview for running a family meeting to discuss end-of-life care goals.

- [ ] Take a few minutes to create a map of a patient's close ties and family. This can be the start of identifying a potential alternative decision-maker as well as identifying who needs to be included in discussions about the patient's care. Remember, 'family' is who the patient says it is. Notions of kinship may vary depending on the patient's cultural background. The closest person to a patient may be their spouse or same sex partner, biological, adopted family or in-laws, close friends, neighbours, or someone from their religious, ethnic or cultural community. The traditional 'next of kin' concept may not be appropriate for all patients. Ask them who is important to them.

- [ ] Can family stay overnight? If so, does the family/key person know that this is an option? This is likely to be more important as the patient nears the end of life.

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- [ ] Prepare families when the end of life is imminent. If families are not aware that their family member is expected to die soon, they may miss the chance to say goodbye. This can lead to feelings of regret and make the death harder to cope with. Are there any written materials that you can provide? Some family members may want to be there regularly throughout illness whereas others may wish to be less involved but may still want the chance to say goodbye. Make sure it is clear to the family that the patient is nearing the end.

- [ ] Before a family meeting, ask your patient if there are any aspects of their care, symptoms or condition that they would prefer to discuss in private (not in front of family). Agree a time to do this with the patient. Manage the meeting to focus on aspects of symptoms, care or treatment that the patient is comfortable being discussed in a group setting/with family.

Cultural Competence

Consider learning more about cultural competence, Centre for Cultural Competence Australia, training courses: https://www.ccca.com.au/

- [ ] Find out more about cultural practices or beliefs about illness and death in relation to an ethnic or religious group you have encountered in your professional practice recently. Remember that not all groups are the same. If in doubt, you can always ask the patient (or family member) about what is personally and culturally appropriate.

- [ ] Patient centred behaviour when treating a patient for a culturally and linguistically diverse background – i.e. If you need to use a translator to communicate with a patient, ensure you look at the patient and listen to the translator rather than looking at the interpreter. Maintain eye contact if culturally appropriate.

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☐ These resources from Vital Talk may be useful to share with colleagues

- Transitions / Goals of Care using the REMAP tool: http://vitaltalk.org/guides/transitionsgoals-of-care/
- Defusing Conflicts Moving the Conversation forward: http://vitaltalk.org/guides/conflicts/

☐ Make yourself aware of the ACSQHC End-of-Life Care Audit toolkit. Find the person in your organisation responsible for QA and bring it to their attention: https://www.safetyandquality.gov.au/our-work/comprehensive-care/end-life-care/end-life-care-audit-toolkit

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

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Thomas RL, Zubair MY, Hayes B, Ashby MA. Goals of care: a clinical framework for limitation of medical treatment. Medical Journal of Australia. 2014 Oct; 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

From Illawarra Shoalhaven Local Health District (via HealthInfoNet). In our care into your hands: 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

From SA Health: Pharmacological Management of symptoms for adults in the last days of life

PalliAGED: Palliative Care Aged Care Evidence: Goals of Care - Synthesis

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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

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

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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

Bloomer MJ, Ranse K, Butler A, Brooks L. A national Position Statement on adult end-of-life care in critical care. Aust Crit Care. 2021 Aug. Epub ahead of print. doi: https://doi.org/10.1016/j.aucc.2021.06.006

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v. 092021