end-of-life ESSENTIALS®
education for acute hospitals

My Toolkit

Checklist

Chronic Complex Illness End-of-Life Care

- [ ] Are there patients that are readmitted to hospital regularly, perhaps with exacerbations of ongoing conditions (such as chest infections in COPD? Think about these patients and ask the 'surprise' question about each of them: Would you be surprised if this patient dies within the next few months/weeks/days? You could also use SPICT (Supportive and Palliative Care Indicators Tool) to identify patients at risk of deteriorating and dying: https://www.spict.org.uk

- [ ] Put the ACSQHC infographic on high quality end-of-life care up in your tea room: https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/Infographic-essential-elements-for-safe-high-quality-end-of-life-care.pdf

- [ ] If your patient has not yet started a discussion about their end-of-life care or their future, then be proactive: start a dialogue. Even if that dialogue is that a discussion needs to happen soon. Provide some ideas for them to think about in formulating their preferences for care. You could start by asking them if they have appointed someone to make decisions in the event that they are no longer able to communicate. Use "other people" framing if that is easier: For example, *"Other people with conditions like yours sometimes plan ahead for unexpected events such as sudden admission to hospital and…"*

- [ ] Read this information from Advance Care Planning Australia: How to start a conversation. https://www.advancecareplanning.org.au/for-family-friends-carers/how-do-i-start-the-conversation

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Flinders University

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- [ ] Recognise if a patient uses an end-of-life trigger (see Recognising the End of Life). These are openings in the conversation where the patients makes a statement or asks a question of you that makes you think they are querying what is happening to them (it could be as direct as "Am I dying?" or a statement such as "I need more help to do things". If the patient wishes, start a conversation about their concerns and preferences. Use active listening and empathy but be honest and do not shy away from using the word 'dying', or provide false hope. Make sure their preferences are recorded and shared with other team members.

- [ ] Actively practice Self Care. Do you have any self-care practices? (See SELF CARE resources) https://www.caresearch.com.au/tabid/6344/Default.aspx https://www.caresearch.com.au/tabid/6413/Default.aspx

- [ ] 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/end-life-care/end-life-care-audit-toolkit

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

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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 / AIDS
- 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 #362 Parkinson's Disease, Palliation for Common Non-Motor Symptoms
- Fast Fact #360 The Surprise Question as a Prognostic Tool

End-of-Life Essentials: Glossary of terms

End-of-Life Essentials Able versus Novice: Which one are You?

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Resources

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Videos, Blogs and Podcasts

CareSearch Blog: Listen, Acknowledge, Respond project Team: Addressing the mental health needs of those living with dying

CareSearch Blog: Tim Luckett: 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: https://www.advancecareplanning.org.au/understand-advance-care-planning (Several videos from patients, nurses and doctors perspectives. Videos are between 1mins 17 seconds, and 4 mins 34 seconds in length).

Further Reading

Rawlings D, Winsall M, Yin H, Devery K, Morgan DD. Evaluation of an End-of-Life Essentials Online Education Module on Chronic Complex Illness End-of-Life Care. Healthcare. 2020 Aug;8(3):297. doi: 10.3390/healthcare8030297

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

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. 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;8(7):e020927. doi: 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;56(5):795-807. doi: 10.1016/j.jpainsymman.2018.07.008.

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Resources

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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. doi: 10.1093/intqhc/mzw060.

González-González AI, Schmucker C, Nothacker J, Nury E, Dinh TS, Brueckle M-S, Blom JW, ... Muth C. End-of-Life Care Preferences of Older Patients with Multimorbidity: A Mixed Methods Systematic Review. J Clin Med. 2020 Dec;10(1):91. doi:10.3390/jcm10010091.

DeCourcey DD, Silverman M, Oladunjoye A, Wolfe J. Advance care planning and parent-reported end-of-life outcomes in children, adolescents, and young adults with complex chronic conditions. Crit Care Med. 2019 Jan;47(1):101-108. doi: 10.1097/CCM.0000000000003472

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