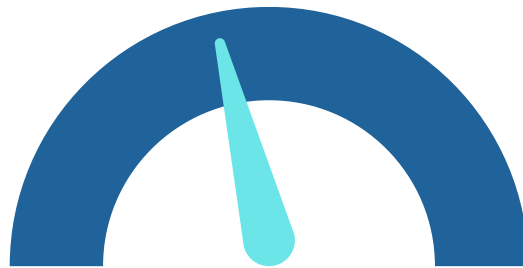


Advance care directives during end of life care

An advance care directive is a legally binding document that can include:

- who a patient wants to make medical decisions for them if they are unable (a substitute decision maker)
- what is important to a patient (eg. values, life goals and preferred outcomes)
- the medical care a patient would accept or refuse

Doctors' views of advance care directives during end of life care



Knowledge of the legal validity of ACDs

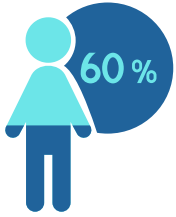
2.6 out of a possible score of 6 statements about the legal validity of:

- advance care directives
- the legal authority of enduring guardians and
- substitute decision makers
- treatment provision to patients without decision making capability

Junior Medical Officers (interns, residents, registrars, and trainees on clinical rotation) were asked to rank 1-4 the order in which individuals should be approached to be the person responsible if the patient did not have the capacity to consent to their own medical treatment.

- 75% correctly identified a guardian as the first person to approach if a patient did not have decision-making capacity
- 74% correctly identified a person's spouse or partner as the next person to approach
- 22% correctly identified an unpaid carer as the third person to approach
- 24% correctly identified a friend or relative as the fourth person to approach
- 17% identified all four in the correct order
- 14% did not identify any persons in the correct order

**Junior medical officers were shown two case studies and asked:
'as the treating physician, would you commence active treatment?'**



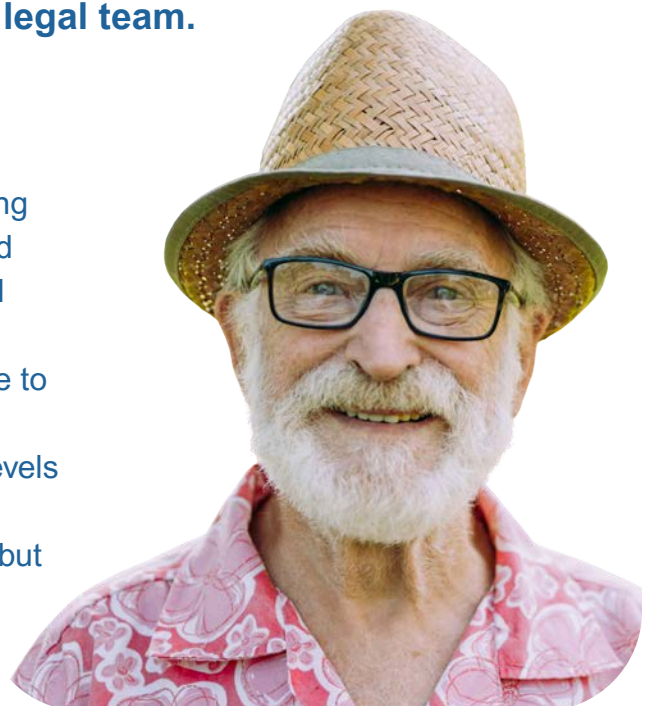
chose the legally correct option to not commence antibiotics for Maria, a frail 75-year-old woman with advanced dementia who presented to hospital in a delirious state with bacterial pneumonia. The most important consideration was that this option was consistent with the patients' wishes.

Maria made an advance care directive. Maria's directive stated that if she were to get a life-threatening infection, she did not want to receive antibiotics, but only be kept comfortable. Maria's designated substitute decision-maker provided her directive to her treating physician, but insisted that she be treated for the infection. If given antibiotics, Maria was expected to fully recover. If antibiotics were withheld, it was likely that Maria would die.



chose to commence active treatment for Michael, a 74-year-old man with moderate dementia and symptoms of acute stroke. While the advance care directive is relevant in the decision making process, other factors are more relevant including the stage of dementia and advances in treatment since the advance care directive was made. This decision may benefit from other supports such as from a hospital legal team.

Twenty years ago, while preparing for a physically challenging adventure, Michael completed an advance care directive stating that if he ever suffered a stroke, he wanted only to receive comfort measures. Michael presented to hospital with symptoms of a stroke. His arrival was within the timeframe to commence thrombolytic treatment, which would likely result in return to pre-stroke levels of function. His wife provided his treating physician with his advance care directive, but asked that active treatment be provided.



Nurses' views* on optimal end of life care

Indicators of optimal end of life care:

- physical symptoms managed well
- private rooms and unlimited visiting hours
- spend as much time with the patient as families wish
- end-of-life care documents stored well and easily accessed, and
- families know and follow patients' wishes

Through statistical modelling we identified four main groups of nurses:

- 50% took a 'whole system holistic' approach, endorsing most items across all domains of care
- 26% took a 'patient/provider-dominated' approach, with a focus on health care
- 18% took a 'family-dominated' approach, with a focus on involvement of families
- 6% took a 'system-dominated' approach, with a focus on documentation and visiting hours

*Nurses were working in Australia, Hong Kong and South Korea



INFORMATION SOURCES

Supported Decision-Making: A Good Idea in Principle but We Need to Consider Supporting Decisions about Voluntary Assisted Dying. Australia: ANU Press; 2022. <https://www.jstor.org/stable/j.ctv2bks5f6>

Bryant J, Waller A, Bowman A, Pickles R, Hullick C, Price E, et al. Junior Medical Officers' knowledge of advance care directives and substitute decision making for people without decision making capacity: a cross sectional survey. BMC medical ethics. 2022;23(1):1-74. <https://doi.org/10.1186/s12910-022-00813-9>

Waller A, Bryant J, Bowman A, White BP, Willmott L, Pickles R, et al. Junior medical doctors' decision making when using advance care directives to guide treatment for people with dementia: a cross-sectional vignette study. BMC medical ethics. 2022;23(1):1-73. <https://doi.org/10.1186/s12910-022-00811-x>

Waller A, Chan S, Chan CWH, Chow MCM, Kim M, Kang SJ, et al. Perceptions of optimal end-of-life care in hospitals: A cross-sectional study of nurses in three locations. Journal of advanced nursing. 2020;76(11):3014-25. DOI: [10.1111/jan.14510](https://doi.org/10.1111/jan.14510)



The National Dementia Helpline
Free call 1800 100 500
Email helpline@dementia.org.au

Useful links from the Dementia Australia website:

<https://www.dementia.org.au>

<https://www.dementia.org.au/living-dementia/later-stages-and-end-of-life>

<https://www.dementia.org.au/living-dementia/care-options/palliative-care>



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