On their own terms
Putting advance care planning into practice

Starting the conversation in aged care

When Athena Ermides first came across an Advance Care Plan* nine years ago, she remembers thinking, “This is exactly what I need”.

As an experienced aged care worker, Athena felt that end-of-life matters were not being discussed in the aged care setting, despite most residents needing high-level care, and the management of multiple medical conditions. The uncertainty around a loved one’s preferences for care when ill or dying was causing considerable distress for residents, families and staff members.

As the General Manager at Berlasco Court Caring Centre, a 60-bed aged care home in Brisbane, Athena took it upon herself to establish a program for advance care planning, which has received an overwhelmingly positive response. “Initially, families were surprised, as no-one had ever spoken to them about an Advance Care Plan. But once they understood the purpose of this kind of document and the uncertainty it could resolve for family when having to make decisions on behalf of loved ones, they were more than happy to put one in place.”

The response of one resident’s daughter is particularly memorable, says Athena. “I recall her saying to me, ‘This is the only place I will bring my mother. You are the first person to raise this conversation with me. Thank you’.”

The transition into residential care, says Athena. “Before moving into Berlasco Court, all residents complete the Statement of Choices developed by the Queensland Government. This directly informs the decisions family members may be required to make on their behalf in the future. Having a clear plan in place makes for a much happier end of life – if there’s any such thing.”

While residents will develop a plan prior to admission, Athena stresses that advance care planning is an ongoing, incremental process.

“We facilitate conversations with patients and their families on a semi-regular basis to ensure that everyone is on the same page about preferences for future care.”

*Advance care planning documents can have different names depending on the state or territory. Find forms for your location at advancecareplanning.org.au
We facilitate conversations with patients and their families on a semi-regular basis to ensure that everyone is on the same page about preferences for future care. Staff will usually initiate this kind of discussion during the first appointment and then again upon admission, four weeks post-admission, at an annual case conference, and if the resident’s health deteriorates.

Athena says she can always tell if it is the first time a resident and their family are being asked to consider end-of-life issues. ‘We have a document called ‘Our Philosophy of Care’ where we talk about the importance of treating our residents with respect and dignity – particularly around the time of death. If an individual and/or their family have not considered end-of-life matters before, we tell them to take their time to become familiar with this document, then we can continue the conversation. It’s a ‘softly, softly’ approach.’

Conversations about end-of-life matters can and should be varied, particularly in a culturally and linguistically diverse environment, such as an aged care home, says Athena. ‘Being of a certain age, residents are usually quite accepting of their situation. However, family members can require a little more time and professional help to adjust to the idea of their loved one dying. In cases where there is resistance to this kind of discussion, collaboration with doctors from the Royal Brisbane Hospital through the Decision Assist program has been hugely helpful.’

End-of-life planning should be a whole-of-family discussion to avoid disagreements and distress when these plans need to be enacted in the future, says Athena. ‘It’s best to involve the whole family in these conversations from the very beginning. It’s really critical that everyone in the family is on board so there is no uncertainty or conflict at the time of death.’

Athena believes that aged care homes play an important role in supporting advance care planning. ‘Start having the conversation with residents right from the beginning and keep plugging away at it, bit by bit.’ She also recommends that aged care workers undertake formal education and training to gain confidence and feel comfortable having these conversations.

Awareness of advance care planning among healthcare professionals and the general community has grown significantly over the past five to ten years, says Athena. ‘Some residents are actually coming to us with an Advance Health Directive, and many others have had someone speak to them about it before. This has been a huge step forward, so I’m really optimistic about the future of programs that support these conversations.’

Advance care planning:

- is essential to person-centred care
- promotes care that is consistent with a person’s goals, values, beliefs and preferences
- prepares people and their substitute decision-makers for making healthcare decisions
- improves outcomes for people, their family and carers, health, aged and community care workers, and the health system
- is part of routine care, and the person’s healthcare journey
- is an ongoing process
- may be initiated or completed by the person themselves or by health, aged and community care workers.

For more information, visit decisionassist.org.au or call the Advance Care Planning Advisory Service on 1300 208 582 or email acpdecisionassist@austin.org.au

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