

What matters to you?

Values based Advance Care Planning
Keeping the conversation simple

People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars.

Atul Gawande 2010

Using stories as a conversation starter

Patients tell stories. Ask about their illness/frailty and how things have changed for them – over the past year, past six months, past month, past week... Using narrative history-taking, you may find that patients or their families will actually tell you what the end of the story is. Ask how they felt at pivotal points in the story, e.g., when told a diagnosis, admitted to hospital. Respond to and acknowledge emotions.

Using values based questions

- **What do you know of your condition/s?**
 - **What is the worst thing about your illness / condition?**
 - **What things matter most to you?** / What are your goals? / What are you most hoping for?
 - **What are your fears about what is to come?** / What do you worry about most?
 - **How do you like to make decisions?** / Who do you want involved? /
Are you someone who likes to know lots of details about your health?
 - **What would you like to do as time runs short?**
 - **How important is it to you to have more time?**
 - **What trade-offs are you willing to make?** Consider
 - a. managing pain and suffering;
 - b. longevity;
 - c. dignity; and
 - d. independence.
 - **How important are these considerations and which is the most important?**
- ✓ Use “*tell me more*” to encourage patients and families to expand on what they have just said, e.g., when the patient says that having to go to a nursing home would be the worst possible thing that could happen – follow up with, “Can you tell me a bit more about why it would be the worst possible thing?”
- ✓ These questions are a guide that can be adapted. Not all questions need to be asked.
- ✓ It is unreasonable to expect people to understand the full applications and implications of treatment under all potential scenarios. Clearly articulated values that avoid ambiguity, will help clinicians and substitute decision makers to stand in the person’s shoes.

Have the conversation and write it down – let’s help people get the care they would want.

These value based questions are based on work by US surgeon Dr Atul Gawande, Northern Health based palliative care physician, Dr Barbara Hayes, and Geelong based intensivist Associate Professor Charlie Corke.