

3 Questions to ask yourself that make difficult conversations about serious illness easier

Talking with your patients about their serious illness is not easy

We all have had that uncomfortable feeling of not knowing what to say or when to say it. Regardless of your role, ask yourself these three questions.

Where do I start?
What do I say?



Is a treatment or care decision needed?

No

Yes

Preparing

Deciding

1

Is a treatment or care decision needed?

The answer directs you to the purpose and outcomes of the conversation.

If yes, then you are supporting **deciding**. Make sure illness is understood and decisions align with a person's values and goals.

If no, then you are helping with **preparing**. Prepare a patient and substitute decision makers (SDM) for progressing illness and future decision-making.

70%

2

What do they know?

Up to **70%** of people do not understand that their serious illness cannot be cured and will progress over time. Exploring what the person understands about their illness helps you to know how much and what kind of information to offer.



3

What matters to the person?

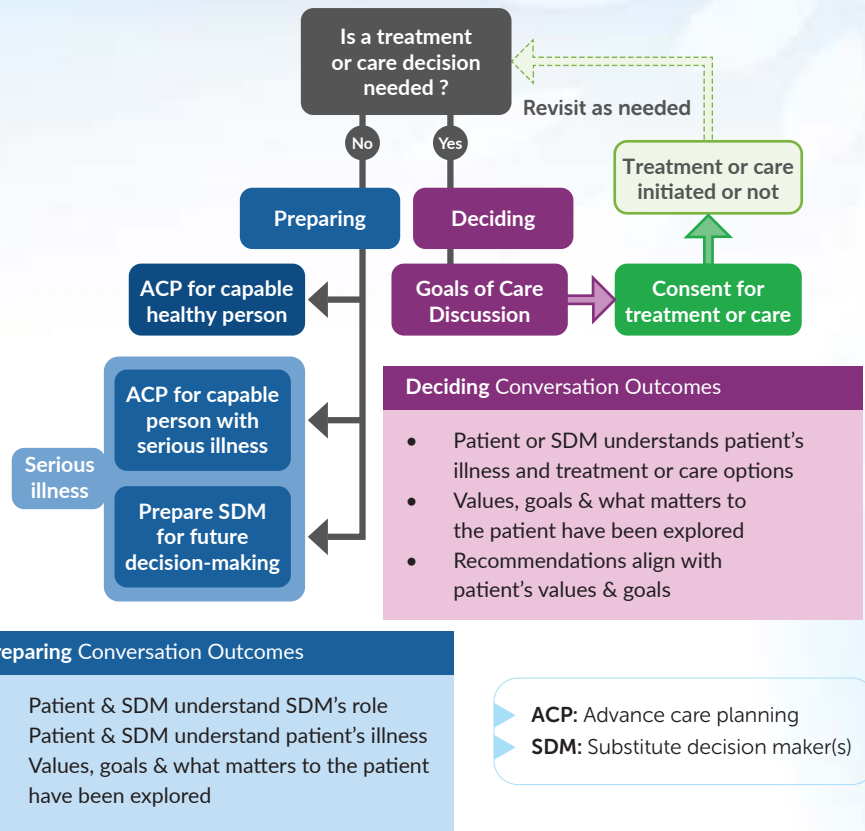
There is clear evidence that values and goals guide **as few as 10%** of clinician recommendations. Helping your patient express their values and goals will keep the person at the centre of the decision.

Benefits – When a seriously ill patient and their substitute decision makers (SDM) are prepared, outcomes are better, distress is less and clinicians have greater professional satisfaction.

1

Is a treatment or care decision needed?

This algorithm shows how advance care planning (ACP), even for a healthy person, fits in preparing for future health related changes and decision making, as well as the steps required for a treatment or care decision, including goals of care discussions. Below are lists of outcomes for both conversations.



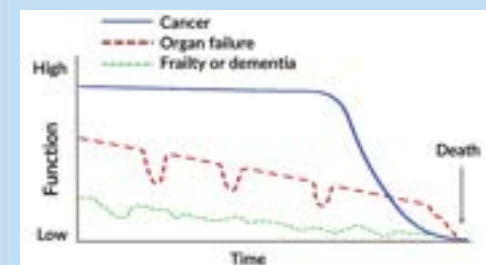
2

What do they know?

- **Why this is important?** – Most Canadians will die from serious illnesses yet most seriously ill people do not appreciate that their illness is progressive and not curable. This means that most of their decisions are inadequately informed. Many clinicians worry that by talking about the illness and its progression, the patient and their SDM will lose hope. Most patients and SDM who have conversations about serious illness however experience less anxiety when they understand their illness and how it will progress.
- **How to do this?** – This is not about teaching a person day-to-day self-management strategies for their illness. This is about the big picture of what to expect. Start by asking: "What do you know or have been told about your illness?" Listen carefully to a person's answer as this will give you a sense of how much and what kind of information to offer. When providing information, share small chunks at a pace that makes sense for the person. Use non-technical language and check that the person understands.
- **What are the tasks?** – When *preparing*, the tasks are to improve what the patient and substitute decision maker understand about the illness trajectory and what is expected to happen in the future. When *deciding*, the tasks are to assess for and address any information gaps to ensure the decision is informed.

Preparing

Improve what the patient & SDM understand about the illness trajectory and what is expected to happen in the future.



Deciding

Assess for and address any information gaps to ensure the decision is informed.

Graph of the three most common illness trajectories. Adapted from *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*, J. Lynn and D. Adamson (RAND Health report WP-137, 2003), rand.org/pubs/white_papers/WP137.html.

What matters to the person?

→ **Why this is important?** – *Thought Experiment: You were recently diagnosed with a neurodegenerative disorder. You are offered a new medication that halts disease progression for most people. Most however also experience a 30% loss of cognition. Would you take the medication?*

The only way you could make a decision for this scenario was to consider and apply what matters to you, or what you value. Ideally, all medical decisions are guided by our patients' own values & goals. Our tasks are to explore these then ensure our recommendations align.

→ **How to do this?** – Start by asking, "*Given what you know now, when you think about the future, what matters to you? What is most important for us to focus on?*"

Remember, the more a person's values and goals are directly used when decision-making, the more they will feel heard and understood.

What are the tasks?

Preparing

Ensure patients & SDMs have the information that would guide future decision-making. **Assist** future providers by documenting conversations.

Deciding

Elicit information you can use to determine which treatment or care option to recommend based on how it aligns with the patient's values & goals.

For more information

- Information for professionals providing care in Canada: canada.ca/palliative-care
- Palliative Care Innovation's related resources and training programs (English only): palliativecareinnovation.com
- *Preparing or Deciding: Simplifying serious illness communication* - Dr. Jeff Myers' video (English only): <https://youtu.be/lfKz3EZtUk>
- Information related to goals of care discussion (English only): goalsofcaremodule.com

Infographics and flowcharts

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