



A Communication Guide to Making Goals of Care Decisions

The following resources were used in the development of this guide:

You J, Dodek P, Lamontagne F, Downar J, Sinu T, Jiang X, Day A, Heyland DK for the ACCEPT Study Team and the Canadian Researchers at the End of Life Network (CARENET). What Really Matters in End of Life Discussions? Perspectives of Seriously Ill Hospitalized Patients and Their Families. CMAJ 2014 Nov 3 published online

Smith AK, White DB, Arnold RM. Uncertainty — The Other Side of Prognosis. NEJM 2013;368(26):2448-2450.

Parry R, Land V, Seymour J. How to communicate with patients about future illness progression and end of life: A systematic review. BMJ Supportive and Palliative Care 2014;4:331-341. Communication about serious illness care goals: A review and synthesis of best practices. JAMA Intern Med 2014; published on line October 20, 2014.

Roeland E, et al. When Open-Ended Questions Don't Work: the Role of Palliative Paternalism in Difficult Medical Decisions. J Pall Med 2014;17:415-421.

Lakin JR and Jacobsen J, Softening Our Approach to Discussing Prognosis. JAMA Int Med 2018.



For illnesses with higher levels of uncertainty, like COPD or CHF, consider something like:

"Some may live for years, some may only live for weeks but half will have died by 6 months. Of those who are alive, many would not be as healthy as you are now. It is hard to say for sure what will happen to you. We like to hope for the best and plan for the worst."

For illness where there is more certainty of prognosis but less time for the patient, like with many advanced Stage IV cancers, consider saying:

"I am sorry. Given your situation, you likely have only {weeks to months} or {months to a year or so} to live.

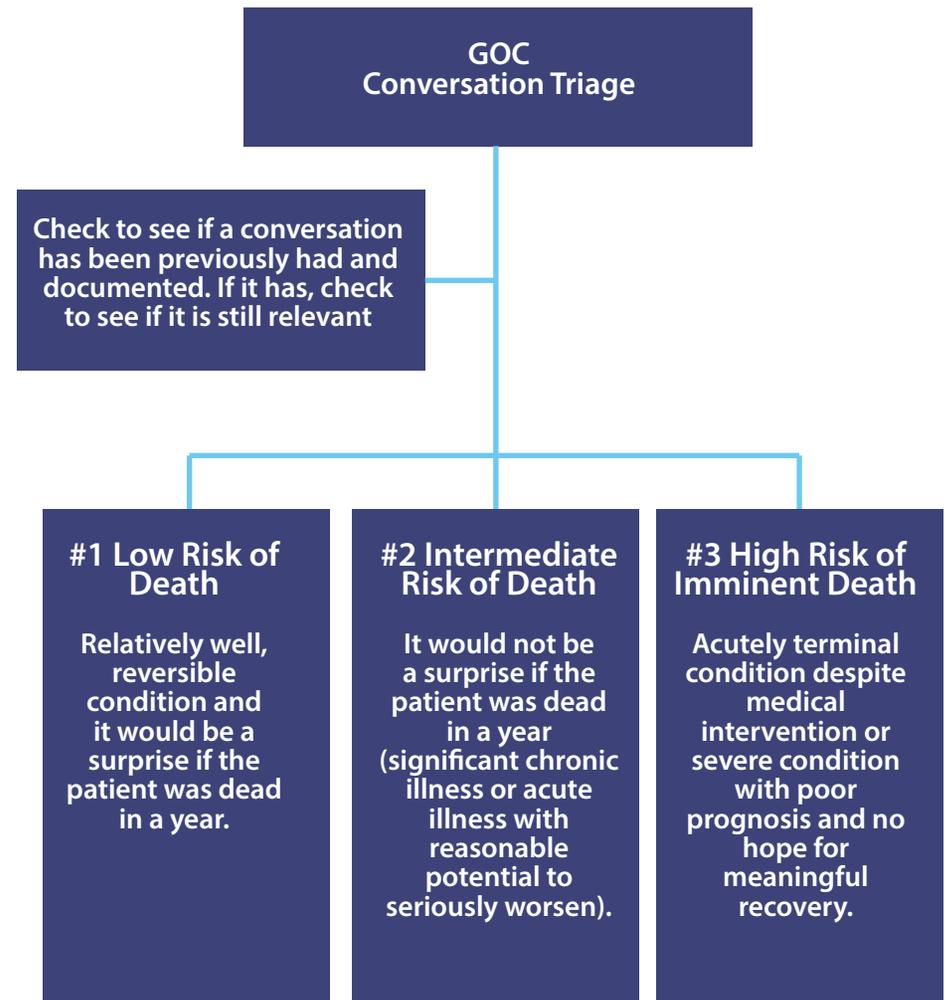
OR

"I expect a {low, moderate, or high} chance of success with the [proposed treatment]."



- TIPS**
- You will have to adapt the nature (quantitative vs. qualitative; superficial vs detailed) of this discussion around prognosis to the person you are talking, based on their emotional response to the conversation and the answers to prior question and paying attention to the sophistication of their language/vocabulary.

Not all patients will require the same conversation. It depends on their risk of death. The figure below indicates that you are trying to categorize whether the patient is at low-risk of mortality (in which case a detailed GOC is not warranted), intermediate or uncertain risk (detailed conversation warranted) or imminently dying (conversation is focused on preferences or needs related to dying rather than medical treatment focused).

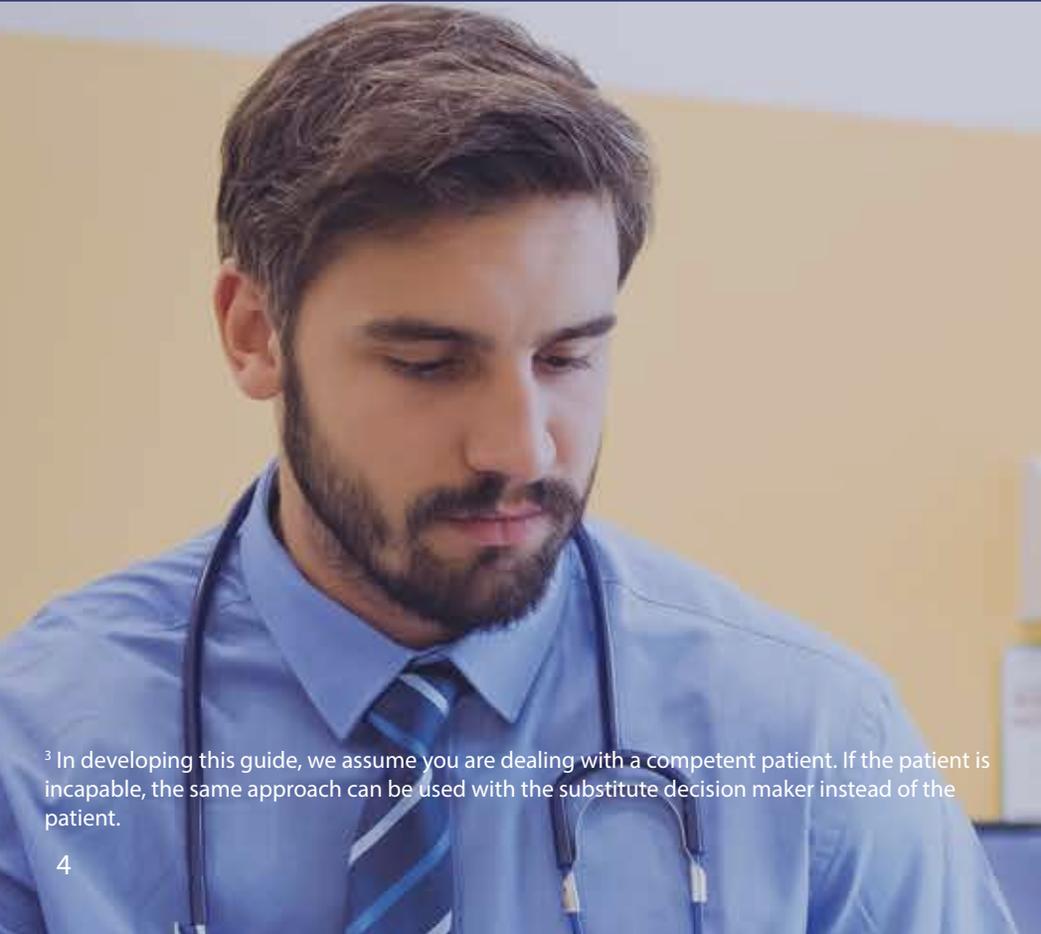


Initiating the conversation³:

For patients in Category #1, conduct a cursory scan of issues that might affect goals of care. For example, after assessing severity of current illness and pre-illness function and quality of life, you may say something like “There is no medical reason why we would not offer you the full extent and types of treatment at our disposal. However, given your own values, should we be aware of limits that you would provide on the types or extent of care that you would like to receive?”

For patients in Category #3, the focus is on assessing illness understanding, communicating prognosis, and assessing patient/family supportive needs. A good opening line is “What have the previous doctors told you about what has been going on?”

Depending on the response to the above question, parts of the following pathway will be needed to move to plans for end-of-life care.



³ In developing this guide, we assume you are dealing with a competent patient. If the patient is incapable, the same approach can be used with the substitute decision maker instead of the patient.

Approach to Disclosing Prognosis

Normalize the uncertainty of prognosis; that we will never know with certainty what will happen to given individuals.

- *“I understand that you want more accurate information about the future. The reality is we can never be certain about the future. I wish I could be more certain but I will give you the best information I have.”*

Address patients’ and families’ emotions about uncertainty, acknowledging how difficult it may be for them not to know.

- *“It is tough not knowing what the future is going to bring.”*

Help patients and families manage the effect of uncertainty on their ability to live in the here and now.

- *“What can we do for you now, given we are uncertain about what the future will bring?”*

Use evidence-based tools/studies to estimate future quality and quantity of life.

- For example, if you are being asked to provide statements about ‘how long do I have to live’, consider going to ePrognosis (<http://eprognosis.ucsf.edu/>) or some other evidence-based source to determine best estimates given the patient’s disease or underlying condition. If asked about the chance of different outcomes associated with certain treatments, such as the probability of full recovery for in hospital cardiac arrest with CPR, use robust outcome data or validated clinical prediction rules. If there are no good data to support your prognostic declaration and you are relying on your clinical judgement, say so. In any case, consider providing estimates of outcomes in ways that continue to express ‘uncertainty.’ Some patients may prefer precision that comes from a quantitative representation of data such as:

“If there were 100 people with an illness just like yours, 50 of them or half would not be alive in 6 months.”

3. Reassess their informational needs – do they need more information about their medical illness, the proposed treatments and risk, benefits and outcomes of the proposed treatments. Consider using formal decision aids such as “Decision Aid for Deciding about Cardiopulmonary Resuscitation” (<https://planwellguide.com/resources/>).

4. Consult other allied health professional, such a social worker, ethics, spiritual care, or nursing, to provide the patient and family with ongoing support.

If the patient is emotionally distressed by the nature of the conversation, acknowledge that emotion and difficulty and say something like,

“I can see this conversation is tough for you. Can you tell me what is making it difficult?”

And then, after exploring this, gain permission to return to some of the tough parts of the discussion or negotiate to bring it up again.

- Use communication practices other than words that convey empathy and sensitivity, such as eye contact, sitting or bending down to be at the patient’s level, touch, pauses, and silence- that encourages the patient to talk and respond.

Pre-conversation considerations

- Before you begin this conversation with the patient, you may want to check with them to see if they want family or other people to be a part of these discussions.
- If applicable, consult with other members of the health care team involved in the patient’s care, to get a consensus of capacity of the patient to provide informed consent; the patient’s prognosis, planned treatments, and other related issues
- Clarify if the patient has appointed a substitute decision maker and encourage that person/those persons to attend especially if there are concerns about capacity.
- Review the hospital chart and talk to staff to see if there is an advance care plan or if wishes are previously documented or verbalized.



For patients in Category #2 and some patients in Category #3, consider the following pathway:

Explain the need to address their goals of care and assess prior conversations/documentation about their health care wishes.

"We try our best to keep patients in good health, but understand that there eventually comes a time when patients will start to get sicker despite our best efforts. Have you talked to anyone about your wishes for health care when you get really sick or are at the end of your life? And/or "Have you put anything in writing about your wishes?"

- ➔ If yes, be sure, probe about the content of discussions and/or documents.
- ➔ If no, suggest that planning ahead can help patients be assured that their wishes will be honoured and reduce stress for their loved ones if they are asked to help make decisions on the patient's behalf at a time of serious illness. If time permits, encourage the patient to visit www.planwellguide.com to better prepare for these GOC conversations.

TIPS

- A good way to normalize a difficult topic is to speak in the third person framing the issues as universal or general, not specific to the patient.

Don't say: "If you get sicker, you are going to need to decide what you want." Say: "When people with serious illnesses get worse, they face decisions about their care. It is a lot less stressful on the patient and their family if conversations about their wishes happen before they get really sick."

- Depending on the clinical condition and whether you have the luxury of time, you may choose to seek permission to have the conversation now since it's a big conversation and the patient may not be in a good space for it. Furthermore, "asking for permission" is a good relationship building strategy and something that can help put clinician and patient on more equal footing.

Say, "Is it OK if we talk now about what we might do if you were to get really sick? Or sicker?"

If they say no, explore reasons behind their reticence to engage in this important conversation and try and resolve concerns or barriers. In the end, if the patient is not ready to have the conversation, make a concrete follow-up plan to revisit the issue in the future.

Say, "Can I ask the social worker (or family member) to speak to you about this and I will come back in a few days to discuss it with you again?"

Confirm Substitute Decision Maker

Nominating and preparing an individual to be a Substitute Decision Maker (SDM)⁴ and making sure they are on the same page with respect to the patient's wishes and the medical orders is the final step. If the patient has already engaged in advance care planning, this step may have already been completed. If not, ask:

➔ *"If you are unable to speak for yourself about medical decisions, who do you want to speak for you?"*

Explore if they have discussed their wishes with family, SDM, health care providers.

➔ *"Have you talked to {call the SDM by name or "your family"} about your wishes and these goals?"*

⁴This process of nominating a substitute decision maker must follow a process that is consistent with provincial health care law. For more information on this legal process, go to www.advancedcareplanning.ca and click on "Resources in your Province/Territory" under Quick Links.

TIPS

At any time, if the conversation is not going well (you feel stuck, the patient is confused, you are embroiled in conflict, or the patient is insisting on what you consider to be non-beneficial treatments), back up and try the following approach to getting the goals of care conversation back on track:.)

1. Explain your motives:

"I talk with all my patients about this and I am asking you these questions because I am concerned about your health."

OR

"When people get sicker, they often lose the ability to think clearly and to tell their doctors about the kind of care they want. This leaves families and doctors guessing about how aggressive to be or when to focus on comfort as the goal. This can be distressing for all, including that person. Can you help us understand what is important to know about you so that we can best care for you now and in the future?"

2. Clarify your understanding of their values. Make sure you are understanding what they are saying about their values and preferences. If they seem conflicted or uncertain about their values, consider values clarification tools found on www.planwellguide.com

(continued...)

TIP

- Some patients or families may not cope with the stress of medical decision-making during serious illness. If in the response to your open-ended questions you perceive maladaptive coping, consider being more directive and use declarative sentences to explain prognosis and appropriate treatments, such as: *“The cancer has spread despite our best treatments and I would like to involve health care providers (e.g. home care nurses, palliative care team members) that can help to provide the support you need and to talk through any decisions that need to be made.”*
- While most patients (and families) prefer a shared-decision making model, some will prefer to make the decision themselves (autonomous or active decision-makers). You can still make it easier on them by legitimizing the difficult decision by saying something like: *“I respect that you want to make the decisions yourself. My role is to ensure you are aware of the risks and benefits of various treatments. My hope is to continue to share this information with you. From my experience and clinical training, most people in your situation would benefit from {say what you think is the best treatment option}, but think about it and we can talk again.”*
- Be careful not to use *“what do you want us to do”* because that places decisional responsibility on the patients (or family). This may worsen their stress and anxiety if they want to play a passive or shared decision making role.

Allow for Questions and Resolve Outstanding Concerns

At some point, you should give the patient an opportunity to address unresolved concerns or questions and express fears. This may have come up earlier in the conversation but if not, ask:

- *“What are some questions you might have?”*
- *“What are some of the questions you have about your goals of care?”*
OR
- *“What are your worries or concerns?”*
OR
- *“Tell me about your fears about what lies ahead for you?”*

Illness Understanding

Assess the patient’s understanding of their illness. Check for an understanding of their diagnosis and prognosis.

- *“Tell me about your illness and how things have been going for you in the past few months?”*
OR
- *“What do you understand about your illness?”*

Assess the patient/family’s interest in knowing more about prognosis.

- *“Are you the kind of person who likes to know a lot of information, particularly about the impact of your illness on your quality of life or how long you have to live or how your disease will progress?”*
OR
- *“Some people like to know a lot of information about their illness, what their quality of life will be like in the future, and how long they have to live. Other people prefer not to be told a lot of information, and ask us to speak to their family members about these things. I’m OK with either approach, but I would like to know which one you prefer.”*

If they want information, check who they may want present for this conversation and proceed to additional questions found in “Approach to Disclosing Prognosis” on page 13. If no, go to next question.



Elicit Values and Preferences

Probe about values and preferences. If they have done ACP well, they may be clear on their values and able to articulate preferences. However, research shows that patients are often not able to see that their values conflict or compete with each other. Optimal values elicitation helps the patient see that expressing the importance of one value may come at the expense of another. For example, a patient may desire to prolong life as long as possible and also want a natural death (these concepts are often incompatible). If not, they may need some assistance and time with this task. Check if the patient needs more information about the various medical options at the end of life (e.g. What it means to be resuscitated or go to the ICU):

→ *“There are lots of different ways we can treat patients. Knowing more about you will help us make sure you are getting the treatments that are RIGHT for you. “Are you the kind of person that wants medical treatments to focus on the quality of your remaining days or to focus on prolonging your life as long as possible? (ie, what’s more important, quality or life or quantity of life.)”*

OR

→ *“Are you the kind of person that prefers a natural death or are you willing to accept the use of machines, such as breathing machines or kidney machines, to prolong your life as long as possible?”*

OR

→ *“We want to make treatment decisions that honor what’s important to you. What sort of quality of life would you find acceptable, and what would you find unacceptable?”*

When dealing with a substitute decision-maker, probe gently what they think the patient’s values and preferences are. You can use prior written or stated preferences as a starting point. Remind them that their responsibility is to help decide what is in the best interests of the patient (not what they, the substitute, want to happen). You can say something like, *“Given what we’ve discussed about their values and the medical information I’ve shared with you, what do you think the patient would have wanted? Or which medical treatment options do you think they would have preferred?”*

TIP

- Use hesitant, hypothetical language to broach this issue sensitively if the patient doesn’t seem to want to address it directly.

Say: “Suppose (say slowly)....your condition were to worsen, what concerns would you have?”

Shared Decision-Making Language

Following the clarification of their values and preferences, using a shared-decision making approach, determine the overall goals of care:



→ *Given what you’ve told me and what I know about your illness it sounds like [insert what you’ve heard here, e.g. “trying to prolong life” or “focusing on comfort” or “a mixture of...”] is important to you now. Have I understood your goals of care correctly?*

Once there is agreement on the overall goals of care, you need to reduce this general statement about goals to specific orders for medical treatments to be used or not used in the context of serious illness. You do this by proposing what treatments may work or should not be considered and seeking affirmation from the patient that this is acceptable.

→ *“Based on what you said, it seems like {propose treatments that you do or do not recommend} would be in your best interest. How do you feel about that?”*

OR

→ *“Based on what you’ve said, it seems like cardiac resuscitation or using breathing machines to prolong your life are not going to benefit you in your situation. We will still do all possible to keep you comfortable and treat reversible illness but in the event your heart and lungs stop, these life-sustaining treatments will not be used.”*

OR

→ *“Given what you have told me about yourself and what I know of your medical condition, I do not think that resuscitative measures are right for you.”*

Consult your local institution policies and procedures on how exactly to document this conversation and the resulting medical orders.

Note: Trying to prolong life does not equate to offering CPR. When CPR is very unlikely to meet the patient’s goals, discuss the other interventions that may be helpful, e.g., hospitalization, antibiotics, chemotherapy. If a patient wishes CPR, they should be offered to watch a CPR Video Decision-Aid, available on www.planwellguide.com prior to making the final decision.