

# Serious Illness Care Program

*Reference Guide for Clinicians*

Fraser Health Advance Care Planning

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Adopted, November 2019.

# Introduction

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The Serious Illness Conversation Guide is designed to help you have compassionate and effective conversations with patients about values, goals and preferences. The questions in the conversation guide are not original or magical; rather they are the kind of questions that many experienced clinicians ask when exploring values and goals, tested for impact, and refined to optimize their wording and order. The Serious Illness Conversation Guide is one component of The Serious Illness Care Program, which also includes clinician training and system changes. Taken together, this intervention has been shown, in clinical trials, to result in more, better, and earlier serious illness conversations, positive impact on patients, and cost reductions in the last six months of life.

This version of the Guide represents a distillation of feedback from hundreds of clinicians and patients about how to use the Guide effectively. It synthesizes best practices in communication from many decades of teaching by many people. We are grateful to our teachers and colleagues, who have helped us learn these practices, to the clinicians who have helped us learn how to improve the Conversation Guide and this Reference Guide, and to the patients whose input and stories have shaped our thinking about how to better support meaningful conversations between patients with serious illness and their clinicians.

The Ariadne Labs Serious Illness Care Program Team, 2017

## **Acknowledgement**

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## **A note about terminology**

Throughout this document:

- The term “patient” refers to patient partners who are people who receive health care in all care settings.
- The term “family” refers to people who are close to patient partners, people who matter, not necessarily those who are related.
- Inclusive pronouns they/them are used instead of gender binary pronouns

The Regional Advance Care Planning Team, 2023

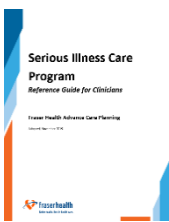
# Overview of Materials

## For Clinicians



### Conversation Guide

The backbone of this project, the Conversation Guide, will help you have successful conversations with your patients. It consists of steps to elicit important information from patients about their goals and values: setting up the conversation, assessing the patient's illness understanding and information preferences, sharing prognosis, exploring key topics, and closing and documenting the conversation.



### Reference Guide for Clinicians [this document]

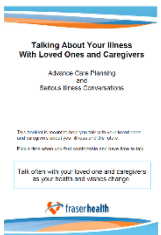
This Reference Guide is available to support you through all aspects of serious illness communication. It provides detailed information about how to introduce the serious illness conversation, what language to use, and tips for dealing with common patient scenarios.

## For patients and families



### Pre-Visit Letter

This letter is designed to prepare patients for a serious illness conversation with their clinician. It includes topics for patients to think about in advance, reinforces the importance of the conversation, encourages them to engage family members, and reassures patients that talking about the future will help them have more control over their care.



### Family Communication Guide

Designed for the patient's use with their family, this guide will help your patient talk with their family and friends about the same topics you bring up with them in your conversations. Like the clinician materials, it provides language for the patient to relay information to their family and to continue the conversation by exploring their concerns. We encourage you to remind your patients that this resource is available to them.

# How the conversation guide is organized



## SERIOUS ILLNESS CONVERSATION GUIDE A CONVERSATION TOOL FOR CLINICIANS

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
<b>1. Set up the conversation</b> <ul style="list-style-type: none"> <li>• Introduce purpose</li> <li>• Prepare of future decisions</li> <li>• Ask permission</li> </ul>	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want - <b>is this okay?</b> "
<b>2. Assess illness understanding and preferences</b>	"What is your <b>understanding</b> now of where you are with your illness?" "How much <b>information</b> about what is likely to be ahead with your illness would you like from me?"
<b>3. Share prognosis</b> <ul style="list-style-type: none"> <li>• Share prognosis</li> <li>• Frame as a "wish...worry" "hope...worry" statement</li> <li>• Allow silence, explore emotion</li> </ul>	"I want to share with you <b>my understanding</b> of where things are with your illness <i>Uncertain:</i> "It can be difficult to predict what will happen with your illness. I <b>hope</b> you will continue to live well for a long time but I'm <b>worried</b> that you could get sick quickly, and I think it is important to prepare for that possibility." <b>OR</b> <i>Time:</i> "I <b>wish</b> we were not in this situation, but I am <b>worried</b> that time may be as short as ____ (express as a range, e.g. days to weeks, weeks to months, months to a year)." <b>OR</b> <i>Function:</i> "I <b>hope</b> that this is not the case, but I'm <b>worried</b> that this may be as strong as you will feel, and things are likely to get more difficult."
<b>4. Explore key topics</b> <ul style="list-style-type: none"> <li>• Goals</li> <li>• Fears and worries</li> <li>• Sources of strength</li> <li>• Critical abilities</li> <li>• Tradeoffs</li> <li>• Family</li> </ul>	"What are your most important <b>goals</b> if your health situation worsens?" "What are your biggest <b>fears and worries</b> about the future with your health?" "What gives you <b>strength</b> as you think about the future with your illness?" "What <b>abilities</b> are so critical to your life that you can't imagine living without them?" "If you become sicker, <b>how much are you willing to go through</b> for the possibility of gaining more time?" "How much does your <b>family</b> know about your priorities and wishes?"
<b>5. Close the conversation</b> <ul style="list-style-type: none"> <li>• Summarize what you've heard</li> <li>• Make a recommendation</li> <li>• Check in with patient</li> <li>• Affirm commitment</li> </ul>	"I've heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I <b>recommend</b> that we ____. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
<b>6. Document your conversation on the ACP record</b>	
<b>7. Communicate with key clinicians</b>	

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### LEFT SIDE

#### Conversation Flow

This is a guide to help serious illness conversations flow and ensure you complete key steps of a successful conversation in an intentional sequence.

### RIGHT SIDE

#### Patient-Tested Language

These words have been tested with patients; they are aligned with the conversation flow for easy reference. Use these words to help ensure a meaningful and successful conversation. Omit questions you don't think are appropriate at this time.

# Key ideas for successful serious illness discussions:

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## Principles

- Patients have goals and priorities besides living longer; learning about them empowers you to provide better care
- You will not harm your patient by talking about their values and goals
- Anxiety is normal for both patients and clinicians during these discussions
- Patients want the truth about prognosis
- Titrate conversations based on patient's responses (especially anxiety)
- Give patients an opportunity to express fears and worries, this is therapeutic

## Practices

- Follow the conversation guide while you are learning it
- Talk less than half the time
- Give a direct, honest prognosis when desired by patient
- Allow silence
- Acknowledge and explore emotions
- Focus on the patient's quality of life, fears, and concerns
- Make a recommendation
- Document conversations
- Provide reassurance only after the patient has shared their major concerns

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# Preparing Patients and Families for a Serious Illness Conversation

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## Preparing for the Serious Illness Conversation:

- Explain your plan to discuss serious illness care planning before the visit at which it will actually take place.
- Normalize the conversation by saying that this is an approach that is used for all patients with serious illness. This helps to reduce patient anxiety.
- Emphasize that you prefer to do this when things are stable, before there is a crisis, so that there is more time to consider the issues.
- Informing the patient in advance allows the patient to prepare emotionally and cognitively. Since preparation usually reduces anxiety, giving patients some time to consider the issues tends to be helpful.
- Preparation also allows the patient to bring a family member or friend, if desired.
- Many clinicians find that scheduling a designated visit for a serious illness care discussion is useful in allocating appropriate time for the discussion, instead of tacking it onto an already-full clinical visit.
- The conversation should be framed as being about aligning the patient's values and preferences with the treatment plan ahead, **and not as an end-of-life conversation**, unless the patient is truly at the end of life.
- Many resources exist to help patients think about their values and preferences. Some patients might want to look at and complete resources before a serious illness conversations. These include: [My Voice](#), [My Voice in Action: A Supportive Workbook to My Voice](#), or [My Voice in Action: A Workbook for Advance Care Planning Easy Read Version](#).

Some clinicians [send a letter](#) to patients, outlining the purpose and process of a serious illness conversation. Others prefer to talk with the patient about it before scheduling it.

## Engaging patients and others that matter to them together at the visit:

- Having the patient and family/friend present offers both opportunities and challenges.
- Be appreciative of the family/friend's presence.
- Clarify the relationship between the patient and family/friend. Is this person the substitute decision maker?
- If this person is the substitute decision maker, emphasize the important role that they/they will play, and how valuable it is to have them present at this conversation so that they will be able to speak for the patient if it is ever necessary.
- Encourage the family/friend to listen carefully to what the patient says, and to identify, for further discussion, any issues that are unclear.
- Explain that you will be directing the conversation towards the patient, and that you will invite their input after the conversation with the patient.

- These are difficult conversations for family/friends. Attend to the emotions of the family/friend, using the same approaches that you would use with a patient – expect emotion, help the family name their reaction, and respond with empathy and support.
- Consider engaging a social worker or other clinician to provide extra support to you or to the family in difficult situations.
- Wrap up with an acknowledgment of the family/friends importance and appreciation of their engagement in the discussion.
- Encourage patients and others present to discuss these issues further

### Engaging the whole team:

Serious Illness Conversations can be conducted in several different ways, based on clinician and clinic workflow. Team communication, whether it takes place in person (ideal), or , is critical to consolidating perspectives and arriving at a care plan.

What you decide about how to carry out these conversations will depend on who is on your team, their skills and comfort, what clinical resources you have, your own practice style, and the patient's needs. Here are some options:

- The physician or NP conducts the entire conversation, documents and shares with the team.
- The physician or NP conducts the first part of the conversation, including sharing of prognosis
  - Another clinician is present and continues the conversation, and both document;or
  - The physician or NP informs another clinician about the patient's response, and the second clinician follows up at a later meeting; both document
- A nurse or SW prepares patient for the conversation and attends the meeting with the physician or NP and follows up after the conversation.

The patient should be informed about how the conversation will take place, and who will be involved. Especially for patients with high levels of anxiety or other challenging situations, it is helpful for a team member to prepare the patient for the conversation, and to encourage the patient to bring family/support people.



# Key Steps in The Serious Illness Conversation

## Initiating the conversation with a patient

**When:** The ideal time to introduce a discussion of values and goals is when the patient is relatively stable and not in a medical or emotional crisis. Crisis situations provoke high levels of anxiety for patients, which can make a conversation more stressful and difficult for the patient.

**How:** Use the ‘Set up the conversation’ prompts to help you remember the optimized sequence of ideas for introducing the conversation with a patient. In setting up the conversation, several key tasks need to be accomplished:

- Establish purpose of the visit clearly
- Normalize/contextualize the conversation
- Engage the patient by addressing benefits to patient, family and others support persons
- Manage the patient’s anxiety

The table below illustrates suggested language that flows from one idea to the next. Before starting the conversation, acknowledge that you will be using the guide: “I may refer to this Conversation Guide, just to make sure that I don’t miss anything important.”

Prompt	Purpose	Suggested Language
Introduce the idea and benefits	Describe the purpose of the conversation	<i>“I’d like to talk about what is ahead with your illness and do some planning and thinking in advance about what kind of care you might want in the future. This is part of the way we care for patients at this stage of illness.”</i>
	Normalize	Reassure patient, if needed, that there is no change in clinical status that prompted discussion  <i>“We like to discuss these issues when patients are stable, doing well and we are not in a crisis.”</i>
	State benefit and support	<i>“Talking about it now allows all of us time and space to talk and think these issues through, and to include your family in our discussion, now or later.</i>
	The “hook”: allowing the patients to remain in control and relieving the burden of decision-making in their loved ones	<i>It means you don’t have to make any decisions if you’d prefer not to, because we have time.</i>  <i>We want to help you stay in control of decisions about your care, and to ease things in case your family has to make difficult decisions on your behalf.”</i>

Ask permission

Give the patient control

*“Is this OK? If not okay, we certainly don’t have to do it today, but I will bring it up again for us to talk about later.”*

If appropriate, state: no decisions needed today.

This reduces anxiety

*“We don’t need to make decisions today. I do want to begin these conversations so that we are both prepared for anything that could happen.”*

## Exploring illness understanding

Conversations about the future need to start with an understanding of the patient’s perspective on their illness. Do they see it as serious? Do they perceive that it is progressing? What expectations do they have about the future? An understanding of patient’s perspective on their illness allows the clinician to assess the extent of alignment of patient expectations and medical realities. Patients whose understanding and expectations are well-aligned with medical realities are usually more prepared for a serious illness conversation. Patients whose understanding and expectations are significantly more optimistic than medical realities are likely to be at higher risk of future bad outcomes, and also will require particular gentleness, careful titration of discussion to avoid overwhelming the patient with anxiety, extra emotional support, and ongoing discussion.

## Discussing information preferences

Clinicians regularly hesitate to provide prognostic information out of concern that it may be harmful to the patient. Patients frequently describe frustration that they cannot get information that they want and need about prognosis from their clinicians. Asking the patient about what kind of information is desired allows the clinician to provide the type of information that the patient wants and needs, and also to avoid giving information that is not wanted or will be harmful. Knowing that one is providing information that is wanted by the patient helps the clinician feel more confident in opening this often-difficult part of the conversation.

It is important to recognize, though, that patients may not have thought about what information they want, or about what it would mean if they hear news they are not expecting and not wanting. It is often useful, when a patient says she wants “all the information”, to clarify what that means:

*You said you want to know everything about what is ahead with your illness. Does that include my best judgment about time? Or are you interested in knowing what life will be like for you going forward?*

## Discussing prognosis

Understanding and accepting that a serious illness is likely to end one’s life is a process, and ideally, should not have to happen all at once, nor in a crisis. Starting to discuss prognosis early in the trajectory of a progressing illness allows the clinician to titrate the kind and extent of conversation gently to avoid overwhelming the patient, and allows the patient to process, both internally and with family and friends, the realities of the illness.

Discussing prognosis with patients is valuable for several reasons:

- It allows patients and family to prepare for the future.
- It can empower them to focus on their most important goals now, rather than at some future time that may or may not occur.
- It allows patients to make more informed decisions about medical treatments. Studies show that patients with cancer who believed they were likely to live at least 6 months made decisions in favour of more interventions compared to patients who thought that there was at least a 10% chance of death within 6 months.
- Patients are generally overly-optimistic about prognosis (even when they receive accurate information). This may result in more deferral of personal goals and worse preparation for the end of life.

### Three kinds of prognostic discussions

Prognosis is not just about “will I live or will I die?” or “how much time do I have?”, but is also about “what will the quality of my life be like?” In addition, different illnesses allow different kinds of predictions about what is ahead.

Time-based prognosis	
<p><b>KEY IDEAS</b></p> <p>Many patients want our best estimate of how much time they may have given their stage of illness. Cancer may have a more predictable prognosis; less so for heart, lung, and kidney disease. Patients do not expect precision, but time estimates provide critical information that allow them to focus on what is important to them.</p> <p>Because this part of the conversation is difficult for us, we tend to talk too much and are not clear or honest about prognosis.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>When desired and knowable, provide prognostic information as a range, without providing too much specificity.</b> <i>“Days to weeks, weeks to months, months to years”</i></p> <p><b>Acknowledge prognostic uncertainty:</b> <i>“It could be shorter or longer.”</i></p> <p><b>Be simple and direct.</b> <i>“I wish I could give you a more optimistic answer, but I am worried that time could be as short as a few weeks to a couple of months.”</i></p> <p><b>Support hope:</b> <i>“I am hoping it will be on the long side of this range.”</i></p> <p><b>Be quiet</b></p> <p><b>Explore patient’s reaction:</b> <i>“What is it like to hear this?”</i></p>

Functional prognosis	
<p><b>KEY IDEAS</b></p> <p>For many conditions, it is impossible to predict how much time a patient is likely to have, but it is possible to predict their level of function, which may provide them with useful information for</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Provide information on what is likely and not likely to improve:</b> <i>“I think that your leg swelling may get better, but I think you will still need</i></p>

<p>planning and goalsetting. Providing functional prognosis — outlining what is and is not likely to improve in the future — helps patients understand what their lives will be like in the future, and allows them to make trade-offs that align with their values.</p>	<p><i>oxygen and I'm worried that this may be as strong as you feel."</i></p> <p><b>Support hope:</b> <i>"I think that you can continue to have good times with your family and take pleasure in small daily things."</i></p> <p><b>Affirm commitment to optimizing function:</b> <i>"We are going to continue physical therapy to give your body the best chance possible to regain some strength. And we're going to keep looking for other options that can help you feel as well as possible."</i></p>
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<b>Unpredictable prognosis</b>	
<p><b>KEY IDEAS</b></p> <p>For many conditions, it is impossible to predict how much time a patient is likely to have. This is particularly true of patients with CHF, COPD, and those with cancer receiving new therapies.</p>	<p><b>TRY THIS STRATEGY</b></p> <p><b>Use a hope/prepare framework:</b> <i>"I am hoping that the new therapies you are on for your heart disease will stabilize things for a long time, maybe even a few years, but we also need to prepare for the possibility that your disease could worsen very suddenly, and we might be faced with some difficult decisions. It would be good to talk more about what you would want if that were to happen."</i></p>

### The "Wish/Worry/Wonder" framework

<b>I wish... I worry... I wonder...</b>	
<p><b>KEY IDEAS</b></p> <p>"I wish" allows for aligning with the patient's hopes.</p> <p>"I worry" allows for being truthful while communicating your human concern for the patient.</p> <p>"I wonder" is a gentle way to make a recommendation or suggestion.</p>	<p><b>TRY THIS STRATEGY</b></p> <p><b>Align with patient hopes, acknowledge concerns, then propose a way to move forward:</b> <i>"I wish we could slow down or stop the growth of your cancer and I promise that I will continue to look for options that could work for you. But I worry that you and your family won't be prepared if things don't go as we hope. I wonder if we can discuss a plan B today."</i></p>

### Indirect Discussion of Prognosis

While direct discussion of prognosis is desired by and useful for most patients, other patients choose not to know, or appear less ready to talk about, what is likely to be ahead. Feedback from patients and clinicians, as well as close observation of these encounters, shows us that even when the clinician does not directly address prognosis, patients take away important information about the status of their illness and what they can anticipate in the future. In particular, the questions in the Conversation Guide about "trade-offs" and "critical abilities" indicate to patients that they may have to face some difficult



decisions in which sacrifices will have to be made to achieve larger goals, and that loss (of abilities) is possible or expected. While indirect, these understandings may help patients begin to anticipate and prepare for the possibility of worsening disease and death. For some patients, this is enough prognostic communication for an early discussion. However, follow up conversations, with more specificity and directness, are usually necessary to help the patient's prognostic awareness align with the medical realities that are ahead.

# Addressing Emotions

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## The central task in Serious Illness Conversations is managing anxiety

**Feeling connected reduces anxiety.** The key clinical challenge when talking with patients about serious illness is helping the patient with the anxiety that arises in these conversations. Anxiety is a normal response to an amorphous or non-specific threat. Virtually all patients with serious illness live with this general anxiety, usually focused on survival. Relationships are a critical mitigating factor for anxiety. Thus, one critical task in talking with patients about an anxiety-provoking issue, such as serious illness, is building a strong relationship.

**Patients find conversations worthwhile, even if they raise anxiety in the moment.** Talking about serious illness inevitably raises in-the-moment anxiety for patients and families (and clinicians). This is not necessarily a bad thing – indeed, it is probably an essential feature of a conversation that focuses on serious illness care planning. However, our research shows that the overwhelming majority (nearly 90%) of patients who have these conversations find them to be worthwhile, and that these conversations, over the longer term, lower anxiety for the most anxious patients.

**Clinicians must titrate language and responses to keep anxiety within limits that are tolerable to the patient.** In conducting compassionate and effective conversations with patients, clinicians must “read” the patient’s cues about their anxiety level, respond to the patient’s emotion, and titrate their language and approach to keep anxiety within limits that are tolerable to the patient. When people are overwhelmed with anxiety, we inevitably invoke psychological processes, called defenses that help cope with this emotion. Sometimes psychological defenses are obvious: “I don’t want to talk about this;” or “I am going to be fine.” Other times, these defenses are more subtle or manifested indirectly or through body language – the patient may make a joke, become agitated, wring their hands, change the subject, or talk over the clinician. This conversation guide will help you handle some of the common responses that arise in conversations about serious illness in a gentle manner that supports the patient, and helps you move the conversation forward. Sometimes, as well, it is important to recognize that “moving the conversation forward” means abandoning it for now, focusing on strengthening your relationship with the patient, and returning at a later time to talk further.

## General principles for managing anxiety

- Conversations about serious illness bring up strong emotions for patients and clinicians.
- In talking about serious illness, anxiety is usually the most intense emotion for both clinician and patient.
- Anxiety is manifested in the clinical encounter through words, facial expression, body language, the use of psychological defenses, and affective expressions (tears, flushing, etc.)
- Anxiety is also reflected in the clinician’s affect. High patient anxiety makes the clinician more anxious, and is a clue to the patient’s state of mind.
- High clinician anxiety raises the patient’s anxiety. Pausing before starting this conversation to settle yourself, practicing the Guide, and developing your skills will lower your anxiety, and lead to less stressful and more effective conversation.
- Strong emotion tends to impair cognitive processing.

- Recognizing and acknowledging the patient’s emotions, and allowing the patient time to process them, allows the patient to move forward into cognitive processing of the information and making a plan.
- If the patient is in a crisis (medical or other life crisis), capacity for dealing with anxiety is diminished. If possible, delay a serious illness conversation until the crisis has passed. If not possible, recognize that you will have to proceed especially gently.
- Difficult conversations should be carefully “titrated” to keep the patient’s anxiety within a manageable range.
- Feeling connected is one of the strongest antidotes to anxiety, for most people. Expressions of empathy (e.g., “I can see how hard this is for you to talk about”, “I wish we were not in this situation”) and affirmation of connection (“We will work through these decisions together”) usually reduce anxiety.
- Offering the patient some element of control (e.g., “How much information do you want me to share with you about what is likely to be ahead?” or “Would you like to go ahead and talk about a plan today, or is this enough for now?”) allows the patient to self titrate anxiety-producing discussion.
- Having family/friends/others that matter present can lower or raise anxiety. Ask the patient whether it would be helpful or not.
- Talking “around” the issue rather than talking directly, raises anxiety. Be succinct, direct, honest and gentle.
- Use your team. Engage team members who have a close relationship with the patient to help support the patient during and after the conversation.

Conversations about serious illness are challenging because of the intense emotions that they usually bring up.

- Use this content to support your learning in anticipation of a patient conversation, or as follow-up after a challenging interaction.
- KEY IDEAS and STRATEGIES provide a mix of approaches and suggested language.
- The following panels offer general principles and guidance for scenarios that can be challenging for clinicians.

## Protection

<b>“Don’t tell my mother how sick she is. She couldn’t handle it.”</b>	
<p><b>KEY IDEAS</b></p> <p>Family who say this are usually trying to protect a loved one.</p> <p>Sometimes they have critical information about a loved one’s past vulnerabilities and coping that are important for the clinician to know.</p> <p>Exploring concerns about why the patient should not be told, and what they think the patient knows about their medical situation allows critical information to come to the surface and</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><i>“Please tell me what your concerns are about my talking with your mother about her illness.”</i></p> <p><i>“How has your mom dealt with previous challenges like this with her health?”</i></p> <p><i>“What are your concerns about how sharing information with your mom could affect her?”</i></p>

<p>demonstrates respect and concern for the family perspective.</p> <p>Inform family that clinicians have an obligation to share desired information with the patient.</p> <p>Informing the family in advance that you will ask the patient how much information is desired, and will abide by the patient’s response may mitigate concern.</p> <p>Including the family in the exploration of whether the patient wants information builds trust that the clinician is respecting the patient’s wishes and including them in the process.</p>	<p><i>“I respect your concerns about your mom, and recognize that you know her better than I do. At the same time, I have a professional responsibility to share information with her if she wants me to.”</i></p> <p><i>“To make sure I give her no more information than she wants, I will ask her how much information she wants about what is likely to be ahead with her illness, and I will follow her lead.”</i></p> <p><i>“It would be great if you could join us for this conversation, if it is ok with your mom for you to be there. That way, we can all be on the same page.”</i></p>
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## Avoidance

<b>“I don’t want to talk about it”</b>	
<p><b>KEY IDEAS</b></p> <p>Exploring why a patient does not feel able to talk about these issues can provide valuable information that helps you provide good clinical care.</p> <p>Many patients are ambivalent about receiving information and discussing the future. They may want to talk about these issues, but are scared of what they will hear. Your steadiness and calm in approaching these issues will help the patient feel that talking about it is possible.</p> <p>There is a “differential diagnosis” of not wanting to talk about it that includes:</p> <ul style="list-style-type: none"> <li>• Patient has intense fears about the future and about dying that are overwhelming – if this is the case, finding a way to gradually introduce the subject may help the patient be better prepared for reality.</li> <li>• The right people are not in the room (key family or clinicians are absent).</li> <li>• This is a bad time because of other difficult events/stressors (e.g. symptoms, other life stressors).</li> </ul>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Explore patient’s reasons for not wanting to discuss this:</b></p> <p><i>“Help me understand the reasons you would prefer not to talk about this.”</i></p> <p><b>Elicit information about how patient thinks about planning for the future:</b></p> <p><i>“I’d like to understand what kind of thinking and planning you would find helpful as we think about what is ahead with your illness.”</i></p> <p><b>Ask about the positives and negatives of discussing these issues.</b></p> <p><b>If patient is ambivalent, acknowledge or name the ambivalence — also how difficult the situation is:</b></p> <p><i>“I hear you saying you know it is important to do some planning and also that you worry this process will be too overwhelming.”</i></p> <p><b>If patient expresses intense anxiety about dying, explore specifics or consider referral to palliative care, social work, spiritual care or Indigenous Health. Explore external supports.</b></p>



<ul style="list-style-type: none"> <li>• Patient has an anxiety disorder that makes it difficult to tolerate the anxiety of a discussion. Medical issues are contributing to anxiety.</li> </ul>	<p><i>“I hear that you are feeling very scared about what is ahead, including about dying. This is something we can talk about, if you would like to. Or I would like to have you see my palliative care colleague who really knows how to provide expert support in helping people cope with illness and decisions.”</i></p> <p><b>Use “I wish” statements</b> <i>“I wish that things were better so we didn’t need to talk about this.”</i></p> <p><b>Inform patient that you will bring this up at a subsequent visit; delaying the conversation until more support is available can help.</b></p> <p><b>If patient expresses more global anxiety, explore patient’s experience of anxiety in a non-threatening way and consider mental health referral:</b> <i>“Are you someone who lives on the anxious side of life? I think it might be helpful for you to have some extra support in dealing with your illness. I’d like you to meet with a mental health colleague who is an expert in supporting people in coping with illness.”</i></p>
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## Unrealistic Expectations

<b>“I’m a fighter and I’m going to be fine”</b>	
<p><b>KEY IDEAS</b></p> <p>Being a “fighter” and being “fine” have many meanings.</p> <p>Patients who are insistent that they will “beat” a progressing illness are usually terrified. Patients deny when their backs are against the wall.</p> <p>Clinicians can help reshape the meaning of “beating” the illness.</p> <p>Help patient focus on additional hopes beyond survival.</p> <p>Consider strategies to reduce anxiety (e.g. relationship building, encouragement of including</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Explore what patient means:</b> <i>“Tell me more about ways you are a “fighter.”</i></p> <p><b>Some patients want to be seen as fighters by beating their disease. Show respect for patient’s fighting spirit:</b> <i>“I think you have the capacity to continue to be a fighter no matter what happens with your disease. Let’s try to think together about a plan B, in case things don’t go as we hope.”</i></p> <p><b>Align yourself with patient by acknowledging strengths and supporting goals, while also naming worries:</b> <i>“I know you are an incredible fighter and will continue to do whatever you can</i></p>

<p>family, medications), which may make future discussions less anxiety producing.</p>	<p><i>to live and be well. I will continue to support you in dealing with your illness in the way that works for you. At the same time, I am worried that we may be getting to a tougher place. I can promise that we are going to leave no stone unturned in our effort to control your disease and help you live the way you want to live. And I think we need to do some planning in case things don't go as well as we hope."</i></p> <p><b>Focus on what patient can do, regardless of disease progression:</b> <i>"I can see what a strong force you are for your family. I think there is a lot you can do to help them deal with this difficult situation with your illness, by helping to prepare them."</i></p>
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## Direct Confrontation

<h3>"Doc, are you telling me I'm dying?"</h3>	
<p><b>KEY IDEAS</b></p> <p>Conversations about the future inevitably bring up fears about dying.</p> <p>Patients who immediately jump to this question are telling us how frightened they are.</p> <p>The key task of the clinician is managing anxiety, emphasizing what is still possible, while exploring the patient's concerns and the medical realities.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Ask the patient what makes them concerned:</b> <i>"It sounds like you are pretty worried about where you are, and worry you might be close to the end. Please tell me more."</i></p> <p><b>Name and explore what is hard:</b> <i>"I know that this can be scary to talk about. What are your biggest fears?"</i></p> <p><b>Provide perspective:</b> <i>"I can tell that this is a hard conversation to be having. Right now, you are doing incredibly well. I am bringing this up now because of the uncertainty about what is ahead, and our need to be prepared in case something unexpected happens."</i></p> <p><b>Be honest and as hopeful as you can realistically be:</b> <i>"I do think you are in a very tough place, and your disease is worsening. I think time may be getting short. At the same time, you are still here, and still very much yourself, and I would like to focus on helping you feel as well as possible, spend time on what matters most to you, and being with your family."</i></p>

## Sadness and Fear

**“This can’t be happening. I have two kids at home.”**

### KEY IDEAS

Dealing with emotion is often a precondition for effectively addressing serious illness decisions.

Tears and other strong emotions are natural when discussing serious illness issues.

When patients express strong emotion, it is therapeutic for you to listen even if you can’t “fix” the situation.

Titration based on patient responses with gentle guidance allows forward movement without the patient being overwhelmed.

Sometimes, backing off is a good temporary strategy. Stay calm.

Patients are often frightened of alienating their clinician by crying – reassurance and staying present can mitigate this.

Most people feel better when they have a chance to express feelings.

### TRY THESE STRATEGIES

**Allow silence for patient to express feeling.**

**Name the feeling.**

**Provide non-verbal support.**

Offer tissues, or put a hand on a shoulder.

**Ask patient to describe what the tears are about:**

*“Help me understand what is making you so sad/upset/scared.”*

**Explore feelings:**

*“Tell me more.”*

**Express empathy:**

*“I am sorry that this is so sad/upsetting/scary for you. This must be so hard to hear”*

**Provide support and encouragement:**

*“I know this is a hard conversation to have, but I think it is important and that it will help make sure that we have a back-up plan in case we need one.”*

**Obtain permission to proceed:**

*“Can we see if we can talk a bit more about this?”*

**Demonstrate and express respect for patients’ emotional strengths:**

*“I can see you are a person who feels things strongly and I have a lot of respect for your strength in staying with this hard discussion”*

**If necessary, offer to take a break and proceed later:**

*“I can see that this is a really tough conversation for you. Let’s take a break for today and try to talk about it next time.”*

	<p><b>Provide targeted reassurance, if possible, after the patient has expressed his or her major concerns. Reassuring the patient before hearing what the patient is distressed about cuts off communication.</b> <i>“I wish I could promise you that you will be able to stay at home until the end. What I can say is I will do everything in my power to make that happen. I also want to be honest in telling you that unexpected things can happen that would make it better for you to be in the hospital or a hospice. We will include you as much as possible in this kind of decision”</i></p> <p><b>Avoid offering information that is not explicitly sought.</b></p>
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## Anger

<b>“You doctors don’t know what you are doing”</b>	
<p><b>KEY IDEAS</b></p> <p>Stay calm.</p> <p>Anger in this setting is usually about the message (e.g., “you are getting sicker”) rather than directed at you personally.</p> <p>Giving patients an opportunity to talk about their anger, and responding non-defensively, tends to be therapeutic.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>“I wish” responses are helpful:</b> <i>“I wish this cancer had responded to the treatment also.”</i></p> <p><b>Explore angry feelings, but use less intense language:</b> <i>“I can see this is really frustrating. Tell me more about the frustrations you’ve been experiencing.”</i></p> <p><b>Encourage patient to say what is on their mind:</b> <i>“As hard as it is, I want to learn as much as I can about what this is like for you, including about your frustrations.”</i></p> <p><b>Respond non-defensively:</b> <i>“I can understand how you can feel that I let you down, in not being able to find the right chemotherapy. I will still work hard to do my best for you.”</i></p>

## Dealing with family/friends/others that matter grief

### "I just know she is going to get better"

#### KEY IDEAS

When conversations begin late, and family/friends/others that matter have to come to terms quickly with the approach of death, they often struggle to accept this reality, or may completely deny it.

This reaction usually represents intense grief, which has not yet been confronted.

Shifting from a discussion of prognosis to learning about the patient, the relationship between the patient and the family/friends/others that matter, and what will be lost if the patient dies changes the tenor of the conversation, and allows grief to be expressed.

When grief is closer to the surface, and the family is not needing to protect themselves from their sadness, family are often more able to focus on what is best for their loved one.

Revisiting the conversation again soon can allow the family time to process the feelings that have emerged and to think in different ways about decisions.

#### TRY THESE STRATEGIES

**Explore the family members' perception of the patient's medical condition and future.** *"What do you think is likely to be ahead medically with your loved one?"*

**Look for an opportunity to share your observation about the family members' connection with the patient.** *"I can see how hard you are trying to do the right thing for your mom."*

**Asking the family to shift into sharing who the patient is and what the relationship means brings the patient into the room, and allows the grief to surface.** *"As we are trying to take care of her, it would help us to know more about her. Can you tell me about your mom, and about your relationship with her..." What is it like to imagine the possibility that she might not survive?"*

**Respond empathically to the family's narrative** *"I can see what a wonderful person your mom is, and how hard it must be to imagine that she might not survive."*

**Family need time to process. Don't try to get to a decision immediately, but return to it soon, if necessary.**

# Addressing Religion and Spirituality

Honouring individual perspectives	
<p><b>KEY IDEAS</b></p> <p>Faith plays a big role in how people think about end-of-life decisions. Many patients won't talk about their faith unless the clinician opens the door. Demonstrating understanding and respect for faith increases trust in the clinician and in the care process.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Open the door:</b> <i>"What kind of role does your faith play in your thinking about the care you want if you become sicker? Are there key beliefs that you would want to guide the care we provide?"</i></p> <p><b>Be explicit:</b> <i>"I can see your faith is a big part of how you think about things. I will do everything I can to honor that in the way I care for you."</i></p>

"We are hoping for a miracle"	
<p><b>KEY IDEAS</b></p> <p>The idea of a miracle can mean different things to different patients.</p> <p>Exploration of the meaning of the miracle and redirection can create the conditions for alignment and compromise.</p> <p>Emphasize what can be done to create conditions for "a miracle", while defining appropriate limits based on best medical practices</p> <p>Engagement of support from the patient's faith community or the health institution is often helpful.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Explore the meaning and type of miracle the patient is hoping for.</b> <i>"What kind of miracle are you hoping for that could help you with your illness?"</i></p> <p><b>Emphasize the different kinds of miracles that can occur</b> <i>"While we will keep hoping for a miracle that will restore your health, are there other things, short of that, that could happen and would be meaningful or miraculous, for you or your family – like people in your family getting over old disagreements, or using your example to get their own life together?"</i></p> <p><b>Affirm that you will provide the best medical care possible:</b> <i>"The best medical care for you right now is for us to treat your infection intensively and support you in getting through this acute infection. If the infection can't be stopped by usual treatments, we do not recommend using machines to keep you alive, because your cancer has progressed so much and we have no more therapies that can stop it. This allows time for a miracle to happen, if it is going to happen. Is this OK?"</i></p>

# Shared Decision-making

Patient is reluctant to stop disease-modifying treatment	
<p><b>KEY IDEAS</b></p> <p>Once it is clear there is no benefit from evidence-based interventions, it is important to discuss the option of stopping disease-modifying treatment.</p> <p>Patients may not want to stop treatments that are directed at their underlying disease because they fear loss of relationship with their team, worsening disease, or immediate death.</p> <p>Poor functional status is a key prognostic indicator of limited life expectancy and warrants a discussion of stopping disease-modifying treatment.</p> <p><b>Do not</b> hedge (“Well, it might...”); evidence suggests that patients hear and remember positive but not negative messages.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Explore patient fears about stopping active treatment:</b></p> <p><i>“Can you tell me what your concerns are about stopping treatment X (e.g. chemotherapy, milrinone, etc.)?”</i></p> <p><b>Be clear that more treatment may not mean more time:</b></p> <p><i>“Some studies suggest that stopping chemotherapy may not shorten time, and you may feel better.”</i></p> <p>Check patient understanding, as this information may be counterintuitive to patients</p> <p><b>If clinically indicated, make a clear, direct recommendation against further disease-modifying treatment.</b></p> <p><b>Reassure patient that you will continue to be their doctor:</b></p> <p><i>“I will continue to be your doctor if you choose to stop active treatment.”</i></p> <p><b>Don’t say you can reconsider disease-modifying treatment later if you can’t.</b></p>

Patient is not ready to make a decision but is declining rapidly	
<p><b>KEY IDEAS</b></p> <p>For patients who are declining rapidly, sharing information (including the clinician’s concern), and emphasizing that decisions are best made soon may help the patient move forward in considering these issues.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Acknowledge the patient’s decline this and focus on providing care aligned with patient wishes:</b> <i>“I am worried your disease is getting worse. If this is correct, I’d like to help you think through some of the decisions you may be faced with soon.”</i></p>

	<p><b>If there is major discrepancy between the patients’ understanding and expectations about their disease, and a rapidly worsening medical situation, naming this can help create space for an unwanted discussion.</b> <i>“I can see that you did not expect yourself to have become so sick so quickly. Unfortunately, that is where we are, and we have some urgent decisions to make today. I wish we did not have to be facing this now.”</i></p>
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<b>If timing is right for completion of MOST (Medical Orders for Scope of Treatment)</b>	
<p><b>KEY IDEAS</b></p> <p>Determining a MOST designation should always come after a broader discussion of prognosis and values and goals.</p> <p>MOST translates the patients’ values, goals, and treatment preferences AND medically indicated treatments into actionable medical orders that can help ensure the plans you make with patients are followed.</p> <p>A MOST is typically completed with patients who have advanced illness.</p> <p>It is common for patient preferences <u>and</u> MOST orders to change over time. Most patients start with higher levels of treatment and move towards more comfort oriented treatment over time. A MOST should reflect how the patient should be treated if something happens tomorrow.</p> <p>Determining CPR candidacy should always come after a broader discussion of prognosis and values and goals.</p> <p>Patients are often overly optimistic about the outcomes of CPR.</p> <p>Not offering an intervention like CPR can make patients feel abandoned. Using strong language, assure patient of all the things you will do (e.g.,</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Introduce treatments in context of values and prognosis:</b></p> <p><i>“We’ve talked about some of the key issues that are important as you get sicker, and I think it would be helpful to get a bit more specific about the types of treatments that do and don’t make sense in your situation.”</i></p> <p><b>Assure continued support and care:</b> <i>“No matter what, we will continue to provide you with intensive support and care.”</i></p> <p><b>Explore patient understanding about CPR:</b></p> <p><i>“One of the questions we should figure out is whether cardiopulmonary resuscitation makes sense for you. What have you heard about CPR?”</i></p> <p><b>Describe CPR:</b></p> <ul style="list-style-type: none"> <li>• Correct misunderstandings</li> <li>• Describe what it is, the risks and benefits, and possible outcomes</li> </ul>



intensive symptom control, emotional support for them and their families, etc.).

- Provide [MOST brochure](#)

*“CPR is a procedure for patients who have died in which we try to restart the heart or breathing. In patients with \_\_\_\_\_, its effectiveness is \_\_\_\_\_, and even those who can be brought back initially have to be kept alive on breathing machines and almost never leave the hospital.”*

**Make a recommendation consistent with patient’s prognosis and preferences:**

*“Based on the spread of your cancer, the fact that we have no more treatments to stop the growth of the cancer, and the fact that CPR doesn’t work for patients with metastatic cancer, I recommend that we focus intensively on your comfort, on helping you have as much time as possible with your family, and on getting you home.”*

*“Based on the worsening of your (HF/COPD/CKD), the fact that there is no cure, and the fact that CPR doesn’t work for patients with this chronic illness, I recommend that we focus intensively on your comfort, on helping you have as much time as possible with your family, and on getting you home.”*

**Check for patient agreement:**

*“How does this plan sound to you?”*

**Emphasize the care that will be provided to the patient:**

*“I want to make sure you know that we will monitor you carefully, do everything in our power to help you feel like yourself and be comfortable, and arrange for the best possible support for you and your family through this process.”*

**Do not say “We will just give you comfort care.”**

**Do not offer CPR if its not clinically indicated:**

Inform patient that they are not a candidate for CPR because it will not be effective.

**You should ask about specific treatments that are relevant to their clinical course (illness context) and/or personal values.**

	<p>Using what you learned in talking about their goals and treatment preferences, discuss the options that are most congruent. Specific treatments/interventions/procedures: Blood products, non-invasive ventilation, enteral/parenteral nutrition, cardioversion, dialysis or other.</p> <p><b>Write the MOST Order</b> <i>“Based on our conversation, I am going to write what we discussed as a medical order. This will help us make sure – if you go to the hospital – that the doctors and nurses there know the treatments they should do.”</i></p> <p><b>Let the patient know the medically indicated designation you’ve chosen and relate it to the current medical context.</b></p> <p><b>Record Conversation and any specific interventions discussed</b> on the <a href="#">Fraser Health Advance Care Planning Record</a>.</p>
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# Making a plan

Making a recommendation	
<p><b>KEY IDEAS</b></p> <p>Make recommendations only after you've had a chance to explore patient's values, goals, and priorities.</p> <p>Recommendations can include:</p> <ul style="list-style-type: none"><li>• Additional discussion to clarify next steps</li><li>• A referral</li><li>• Engagement of other key people (e.g. family) Changes in medical care plan.</li><li>• Nothing more needs to be done now.</li><li>• Check in with the patient to make sure the patient understands and agrees.</li></ul> <p>How you make a recommendation influences the patient's choice and reaction.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Recommend next steps that are based on prognosis, medical options, and patient's values and preferences:</b></p> <p><i>"Based on the ongoing worsening of your heart disease and your wishes to stay at home, I recommend that we make a referral to our home health team, which can support you in being at home with your family, and also make sure that you are as comfortable as possible."</i></p> <p><i>"I can see that you are really uncertain about whether you want to try the BIPAP, because of worries that it will have a bad effect on your quality of life. I suggest that we set up another time to discuss this."</i></p> <p><i>"In order to help with your very natural worries about your children, I'd like you to see our social worker, who is an expert in working with parents in your situation."</i></p> <p><i>"Since your family is struggling to understand how ill you are, I recommend that you bring them in and that we talk with them together about where you are and what is likely to be ahead."</i></p> <p><i>"It sounds like we are on track with your care for now. Let's revisit the conversation again in a few weeks, or the situation changes."</i></p> <p><i>"Does this plan capture what you want?"</i></p>

# Managing the conversation: Practical challenges

- Time pressures can be a barrier to effective end-of-life conversations.
- Engage the whole team. Serious illness care planning is a team sport.
- Plan for enough time to have a meaningful conversation.
- Consider doing the conversation in segments if time is short or if the patient is easily overwhelmed.

Keeping patients on track	
<p><b>KEY IDEAS</b></p> <p>Patients wander when they are anxious or have other high priority issues to discuss. Patients usually recognize that you have an agenda and need to fulfill it within a limited time frame, if reminded.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Acknowledge that this is a tough conversation, and gently bring patient back to topic:</b>  <i>“I know this is hard to talk about, but I’d like to see if we can clarify a couple of things about what your worries are about the future.”</i></p> <p><b>Remind patient of time constraints:</b>  <i>“I wish we had more time to talk about your new dog, but I would like to get back to thinking about some future planning that I think we need to do.”</i></p> <p><b>Interrupt gently:</b>  <i>“Mrs. Smith, we need to get back to my question about your goals if time is getting short.”</i></p>

Managing time	
<p><b>KEY IDEAS</b></p> <p>Some questions can be effectively handled by your staff, but <i>prognosis should not be delegated</i>. The conversation can still be effective when spread over several visits.</p>	<p><b>TRY THESE STRATEGIES</b></p> <p><b>Delegate some questions to your Nurse Practitioner or Social Worker, as appropriate.</b></p> <p><b>Consider going through 2 questions per visit.</b></p> <p><b>Make sure everyone documents the discussion in the EMR.</b></p>

Documenting the conversation	
<p><b>KEY IDEAS</b></p>	<p><b>TRY THESE STRATEGIES</b></p>

Avoid using the computer while talking to the patient.

**Make notes on the guide if you need to remember specific things the patient says.**

**If you must document while talking, make frequent eye contact with patient.**

**When documenting, use the patient's words to convey the patient's perspective.**



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