

# Serious Illness Care Program

## Reference Guide for Interprofessional Clinicians

**Key Ideas** for successful discussions about serious illness care across settings:

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### ► Principles

- *“Patients” includes patients, clients, residents, and their families as the unit of care across settings. “Clinicians” includes Physicians, Nurses and other Allied Health professionals*
- 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 *serious illness, declining function* and end-of-life issues
- Anxiety is normal for both patients and clinicians during these discussions
- Patients want the truth about prognosis, *disease trajectory and what to expect in the future*
- Titrate conversations based on patient’s responses (especially anxiety)
- Giving patients an opportunity to express fears and worries is therapeutic
- *These conversations may be formal and planned, or informal and unplanned*

### ► Practices

Do:

- *Explore patient’s understanding of their illness and what to expect in the future*
- *Discuss* prognosis directly and honestly when desired by patient
- Give a direct, honest prognosis when desired by patient
- Present prognostic information in a range
- *Discuss changes that could be expected as the disease progresses (i.e. functional, cognitive and social)*
- Allow silence
- *Listen actively*
- Acknowledge and explore emotions (NURSE mnemonic)

N – Naming  
U – Understanding  
R – Respect  
S – Supporting  
E – Exploring



This material has been modified by the Serious Illness Conversation Nurse Working Group (Canada). The original content can be found at <https://portal.ariadnelabs.org> and is licensed by Ariadne Labs under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License.

- Focus on the patient's quality of life, fears, and concerns
- *Acknowledge that these can be hard conversations and can be had over time*
- Make a recommendation ("Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend..." **OR** *"Based on what I have heard you tell me about what is important to you and what your concerns are, I recommend..."*)
- Document and *communicate* the conversation *so that it is available to the team (including patients)*

**Do not:**

- Talk more than half the time
- Give premature reassurance
- Provide factual information in response to strong emotions
- Focus on medical procedure

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**NOTE:** This document is NOT intended for use with patients. It is for your reference in honing end-of-life communication skills or when preparing for a conversation with an individual patient.

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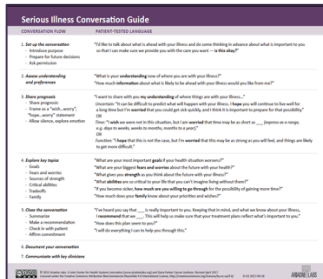
# Serious Illness Care Program: One conversation or many?

Some conversations are formal appointments or interviews with patients and families. Many allied health clinicians will have these conversations during moments of care – so they may emerge as informal and unplanned conversations. The *Serious Illness Conversation Guide* and this *Interprofessional Clinician Reference Guide* can help you have these conversations. Clinicians include physicians, nurses and other allied health professionals.

## Overview of materials

These tools are available to you, the clinician, to help you have successful conversations with your patients about serious illness care goals. Use these tools and the language within them at least 30 times so you become comfortable with the language and flow. Then, you can feel free to ad-lib.

### For clinicians

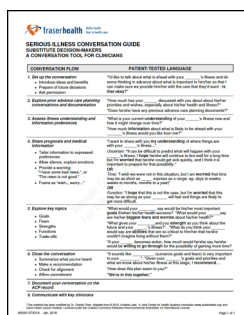


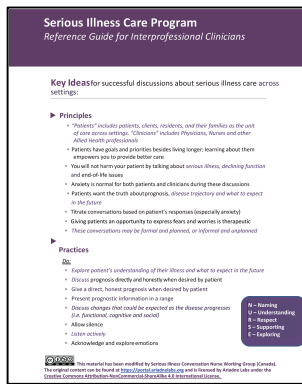
### Conversation Guide

The backbone of this project, the Conversation Guide (version 3), 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 (*i.e. what to expect as the disease progresses and/or functional decline is experienced*), exploring key topics, and closing and documenting the conversation.

### Conversation Guide Modified for use with Substitute Decision Maker or Family Member

This modified Conversation Guide (version 3) will help you have successful conversations with your patient's Substitute Decision Maker or family member. It consists of steps to elicit whether the patient has had previous advance care planning discussions or directives and whether the SDM or family member are aware of what the patient's healthcare preferences are. The guide follows the steps of setting up the conversation, assessing the SDM's or family member's understanding of the patient's illness and wishes, sharing prognosis and what to expect as the disease progresses, exploring key topics such as fears, worries and trade-offs, closing and documenting the conversation.





## Reference Guide for Interprofessional Clinicians [this document]

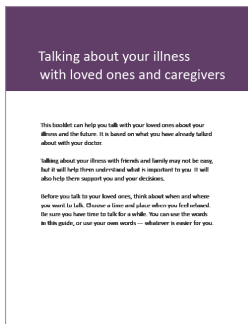
This reference *for interprofessional clinicians* is available to guide you through all aspects of serious illness communication. It provides detailed information about how to introduce the serious illness conversation, what language to use, and tips for dealing with common patient scenarios.

## 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. *This may be a useful tool in your setting.*



## Family Communication Guide

Designed for the patient's (*or Substitute Decision Maker'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.

# Serious Illness Conversation Guide:

## How the guide is organized

Serious Illness Conversation Guide	
CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
<b>1. Set up the conversation</b> <ul style="list-style-type: none"> <li>Introduce purpose</li> <li>Prepare for future decisions</li> <li>Ask permission</li> </ul>	<p>"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>"</p>
<b>2. Assess understanding and preferences</b>	<p>"What is your <b>understanding</b> now of where you are with your illness?"</p> <p>"How much <b>information</b> about what is likely to be ahead with your illness would you like from me?"</p>
<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>	<p>"I want to share with you <b>my understanding</b> of where things are with your illness..."</p> <p><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."</p> <p>OR</p> <p><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 ____ (<i>express as a range, e.g. days to weeks, weeks to months, months to a year</i>)."</p> <p>OR</p> <p><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."</p>
<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>	<p>"What are your most important <b>goals</b> if your health situation worsens?"</p> <p>"What are your biggest <b>fears and worries</b> about the future with your health?"</p> <p>"What gives you <b>strength</b> as you think about the future with your illness?"</p> <p>"What <b>abilities</b> are so critical to your life that you can't imagine living without them?"</p> <p>"If you become sicker, <b>how much are you willing to go through</b> for the possibility of gaining more time?"</p> <p>"How much does your <b>family</b> know about your priorities and wishes?"</p>
<b>5. Close the conversation</b> <ul style="list-style-type: none"> <li>Summarize</li> <li>Make a recommendation</li> <li>Check in with patient</li> <li>Affirm commitment</li> </ul>	<p>"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."</p> <p>"How does this plan seem to you?"</p> <p>"I will do everything I can to help you through this."</p>
<b>6. Document your conversation</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.**

# Initiating the conversation with a patient or Substitute Decision Maker

## 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.

## HOW

Use the ‘Set up the conversation’ prompts to help you remember the optimized sequence of ideas for introducing the conversation with a patient. 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.”*

Don’t forget there is a version of the guide you can use with family or a substitute decision maker.

PROMPT	PURPOSE	SUGGESTED LANGUAGE
<ul style="list-style-type: none"> <li>Introduce the idea and benefits</li> </ul>	Orient the patient	<p><i>“I’d like to talk about what is ahead with your illness and do some planning and thinking in advance.</i></p> <p><i>This is part of the way we care for patients at this stage of illness.</i></p> <p><i>We like to discuss these issues when patients are doing well and we are not in a crisis.”</i></p>
	State benefit and support	<p><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.</i></p> <p><i>It means you don’t have to make any decisions if you’d prefer not to, because we have time.</i></p> <p><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></p>
<ul style="list-style-type: none"> <li>Ask permission</li> </ul>	Give the patient control	<p><i>“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.”</i></p>

*“I’d like to talk about what is ahead with your illness and do some planning and thinking in advance about what is important to you so that I can make sure we provide you with the care you want. Is this OK?”*

*“This will help with decisions that will need to be made in the future with you or your family.”*

## Strategies for common scenarios

- 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 guidance for scenarios that can be challenging for clinicians.

### Patient says: “I don’t want to talk about it”

#### KEY IDEAS

Exploring why a patient does not feel able to talk about these issues can provide valuable information that helps you provide good clinical care.

Many patients are ambivalent about receiving information. They may want it but be 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.

There is a “differential diagnosis” of not wanting to talk about it that includes:

- 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.
- Patient needs more support (e.g., from a family member) to address these issues.
- This is a bad time because of other difficult events/stressors (e.g., symptoms, other life stressors).
- Patient has an anxiety disorder that makes it difficult to tolerate the anxiety of a discussion.

#### TRY THESE STRATEGIES

- **Explore patient’s reasons for not wanting to discuss this:**  
*“Help me understand the reasons you would prefer not to talk about this.”*
- **Elicit information about how patient thinks about planning for the future:**  
*“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.”*
- **Ask about the positives and negatives of discussing these issues.**
- **Remind patient that goal is to initiate discussion, not to make decisions.**
- **If patient is ambivalent, acknowledge or name the ambivalence — also how difficult the situation is:**  
*“I hear you saying you know it is important to do some planning and also that you worry this process will be too overwhelming.”*
- **If patient expresses intense anxiety about dying, explore specifics or consider referral to palliative care.**
- **Use “I wish” statements (e.g. I wish that things were better so we didn’t need to talk about this).**
- **Inform patient that you will bring this up at a subsequent visit; delaying the conversation until more support is available can help.**
- **Acknowledging patient stress and a plan to return to these issues later can be helpful.**
- **If patient expresses more global anxiety, explore patient’s experience of anxiety in a non-threatening way and consider mental health referral:**  
*“Are you someone who lives on the anxious side of life?”*

Also consider referral to social work, counselling or spiritual care.

May delay until a family member can be present during the conversation.



## Patient says: “I’m going to beat this”

### KEY IDEAS

“Beating this” has many meanings. Explore them.

Clinicians have the power to reshape the meaning of “beating” the illness.

Patients who are insistent that they will “beat” a progressing illness are usually terrified. Patients deny when their backs are against the wall.

Help patient focus on additional hopes beyond survival.

If patient is in a particular crisis that may get better, it is often better to avoid addressing denial in that moment. Wait until the patient is in a less stressed frame of mind to address their denial.

Consider strategies to reduce anxiety (e.g. relationship building, encouragement of including family members, offer to discuss medication adjustments with patient’s physician or nurse practitioner), which may make future discussions less anxiety producing.

For patients who have misinformation or misunderstandings of their underlying illness, gently clarify information or ensure connection of the patient with their provider for clarifying conversations of their illness and its course.

### TRY THESE STRATEGIES

- **Align yourself with patient by using “I wish” statements:**  
*“I wish I could promise that we could beat this illness, but I can’t. What I can promise is 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.”*
- **Some patients want to be seen as fighters by beating their disease. Show respect for patient’s fighting spirit:**  
*“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 what other things you could fight for if you can’t beat the cancer/your disease” (e.g., by helping loved ones deal with hard realities, by participating in a clinical trial)*
- **Focus on patient strengths:**  
*“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 awful situation with your illness, by helping to prepare them.”*
- **Acknowledge patient’s desire to beat their disease, but persist in exploring issues common in worsening disease and moving the conversation forward:**  
*“We should hope for the best and prepare for the worst”*

## Patient is not ready to make a decision

### KEY IDEAS

Patients need time to absorb and integrate information and to prepare to make decisions.

Reassure the patient that decisions are not urgent and encourage them to talk with their families.

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.

### TRY THESE STRATEGIES

- **Reassure patient there is time to think things through:**  
*"I brought up these issues early so that you would have time to think about what's important to you. I'm not worried that anything will happen in the coming weeks." Let the patient know you will bring this up again.*
- **Encourage discussion with family:**  
*"These are difficult decisions and should involve your family. I recommend discussing it with them and then us talking about it again at your next visit."*
- **If the patient is declining rapidly, acknowledge this and focus on providing care aligned with patient wishes:**  
*"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."*

## Patient expresses intense emotion (Tears)

### 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."*
- **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."*
- **If emotion is very intense and persistent, explore whether a mental health referral would be helpful.**
- **Avoid giving false or premature reassurance to contain patient distress.**
- **Avoid offering information that is not explicitly sought.**

*"Do you want to take a break and talk about it next time?"*

Explore whether a referral to Social Work, Counselling, or Spiritual Care would be helpful.

## Patient expresses anger

### KEY IDEAS

Stay calm.

Anger in this setting is usually about the message (e.g., “you are getting sicker”) rather than directed at you personally.

Giving patients an opportunity to talk about their anger, and responding non-defensively, tends to be therapeutic.

### TRY THESE STRATEGIES

- **“I wish” responses are helpful:**  
*“I wish this cancer (disease) had responded to the treatment also.”*
- **Explore angry feelings, but use less intense language:**  
*“I can see this is really frustrating. Tell me more about the frustrations you’ve been experiencing.”*
- **Allow patient an opportunity to explore what it means to them to be talking about these end-of-life issues:**  
*“I am bringing up these issues because I want us both to be prepared for what is ahead. But what is it like for you to have me bring them up at this point?”*
- **Encourage patient to say what is on their mind:**  
*“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.”*
- **Respond non-defensively:**  
*“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 wish that things were different; I worry that that’s not what is happening here.”*

## Patient is reluctant to stop disease-modifying treatment

### KEY IDEAS

Once it is clear there is no benefit from evidence-based interventions, it is important to discuss the option of stopping disease-modifying treatment.

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.

Poor functional status is a key prognostic indicator of limited life expectancy and warrants discussion of stopping disease-modifying treatment.

Do not hedge (“Well, it might…”); evidence suggests that patients hear and remember positive but not negative messages.

### TRY THESE STRATEGIES

- **Explore patient fears about stopping active treatment:**  
*“Can you tell me what your concerns are about stopping treatment X (e.g. chemotherapy, milrinone, etc.)?”*
- **Be clear that more treatment may not mean more time:**  
*“Some studies suggest that stopping chemotherapy may not shorten time, and you may feel better.”* Check patient understanding, as this information may be counterintuitive to patients
- **If clinically indicated, make a clear, direct recommendation against further disease-modifying treatment.**
- **Reassure patient that you will continue to be their doctor:** *“I will continue to be your doctor if you choose to stop active treatment.”*
- **Don’t say you can reconsider disease-modifying treatment later if you can’t.**

## If timing is right for a code status conversation

### KEY IDEAS

Discussion of code status should always follow a broader discussion of prognosis and values and goals.

Patients are often overly optimistic about the outcomes of CPR.

In-hospital CPR survival, overall<sup>1</sup>

- Immediate survival: 30-45%
- Survival to discharge: 11-17%

The above statistics have not changed in 40 years.

In hospital CPR survival for cancer patients<sup>2</sup>:

- Overall survival to discharge: 6%
- Localized disease: 10%
- metastatic: 5%
- ICU: 2%

For patients with an underlying serious illness the survival rate is significantly reduced based on their illness.

Withholding an intervention like CPR can make patients feel abandoned. Using strong language, assure patient of all the things you will do (i.e. intensive symptom control, emotional support for them and their families, etc.).

<sup>1</sup>Peberdy MA et al. Resuscitation 2003

<sup>2</sup>Reisfield GM et al. Resuscitation 2006

### TRY THESE STRATEGIES

• **Introduce the concept of code status decision in context of values and prognosis:** *"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."*

• **Explore patient understanding about CPR:** *"One of the questions we should figure out is whether cardiopulmonary resuscitation makes sense for you. What have you heard about CPR?"*

• **Describe CPR:**

- Correct misunderstandings
- Describe what it is, the risks and benefits, and possible outcomes
- Share data about possible outcomes (if desired)

*"CPR is a procedure for patients who have died in which we use machines to try to restart the heart or breathing. In patients with a serious illness, its effectiveness is extremely low – 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 to have a further conversation with the patient's physician or Nurse Practitioner:**

*"Based on the spread of your cancer, the fact that we have no more treatments to stop the growth of 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."*

*"Knowing what is important to you and where you are in your illness and that CPR doesn't work for all patients I recommend that we take this conversation forward to your physician/Nurse Practitioner. This will help us make sure that your treatment plans reflect what is important to you."*

• **Check for patient agreement:** *"How does this plan sound to you?"*

• **Share the conversation with the patient's primary care provider**

• **Emphasize the care that will be provided to the patient:** *"I want to make sure you are comfortable and know that we will monitor you carefully, provide and arrange for the best possible support for you and your family."*

• **Do not say "We will just give you comfort care."**

**Do not offer CPR if it is not clinically indicated:** Inform patient that they are not a candidate for CPR because it will not be effective and ask them to affirm your decision.

# Discussing prognosis

## Time-based prognosis

### KEY IDEAS

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 they expect to give them time to prepare for what may come.

Patients who have had a time-based prognostic conversation with their physician/Nurse Practitioner may want further discussion.

### TRY THESE STRATEGIES

- **Discuss prognostic information as a range:**  
*Days to weeks, weeks to months, months to years*
- **Acknowledge prognostic uncertainty:**  
*It could be shorter or longer.*
- **Support hope:**  
*I am hoping it will be on the long side of this range.*

## Functional prognosis

### KEY IDEAS

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 planning and goal-setting.

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.

### TRY THESE STRATEGIES

- **Provide information on what is likely and not likely to improve:**  
*"I think that your leg swelling may get better, but I think you will still need oxygen and I'm worried that this may be as strong as you feel."*

*"I wish things were different, but I think this might be as strong as you feel."*

- **Give honest statement about worsening trajectory**  
*"Patients with (name the disease) tend to experience worsening health, and more frequent hospital admissions/interactions with the healthcare system."*

- **Support hope:**  
*"I think that you can continue to have good times with your family and take pleasure in small daily things."*
- **Affirm commitment to optimizing function:**  
*"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."*

## Discussing prognosis continued

### Unpredictable prognosis (Uncertainty)

#### KEY IDEAS

For conditions like advanced heart and lung disease, which can remain stable, slowly deteriorate over time, or bring sudden and life-threatening crises, these scenarios should be communicated to patients. This allows them and their families to consider their values and preferences within this context, and to prepare.

#### TRY THESE STRATEGIES

- **Provide clear information about potential trajectories:**

*Heart disease is unpredictable **OR** It can be difficult to predict what will happen with your illness. People can live well for years, but sometimes things can happen quickly. I think we need to be prepared for a crisis, or sudden event, in which we may be confronted by some difficult decisions.*

- **Use hypotheticals:**

*If your heart failure **OR** illness were to suddenly worsen, you may not be able to return to where you are now or might need to be hospitalized or consider intensive treatments.*

- **Hope for the best, plan for the worst:**

*Even though this is difficult to think about, I am hopeful that you will have a lot of good time ahead and that doing some planning together can help you have a safety net **OR** a Plan B, in case things don't go as we hope.*



# Clinician changes focus to making a decision

For example, the clinician observes that the patient is “reluctant to stop disease-modifying treatment”, or “timing is right for a code status conversation”.

## Talking about making a decision

### KEY IDEAS

Either the patient, family or clinician has become involved in a conversation that is about making a decision (a treatment decision). Here we remind ourselves that we are trying to facilitate a listening conversation – re route the conversation along the lines of the conversation guide (i.e. move discussion to ask questions about worries, strengths, fears).

How you make a recommendation can influence the patient’s choice and reaction.

### TRY THESE STRATEGIES

#### Have you followed the guide?

#### Where did you get off track?

*Try to use the guide to find your place in the conversation.*

#### Be clear about their understanding of their disease and prognosis (i.e. more treatment may not mean more time):

*“Some studies suggest that stopping chemotherapy may not shorten time, and you may feel better.”*

*Check patient understanding, as this information may be counterintuitive to patients.*

#### Explore key topics (i.e. patient fears about stopping active treatment):

*“Can you tell me what your concerns are about stopping treatment X (e.i. chemotherapy, milrinone, etc.)?”*

#### Make a recommendation to have a further conversation with the patient’s physician or Nurse Practitioner:

*“Knowing what is important to you and where you are in your illness and CPR doesn’t work for all patients I recommend that we take this conversation forward to your physician/Nurse Practitioner. This will help us make sure that your treatment plans reflect what’s important to you.”*



# When it is time to make a plan

## Making a recommendation

### KEY IDEAS

Make recommendations only after you've had a chance to summarize a "patient's values, goals, and priorities *that reflects what they have told you.*"

How you make a recommendation can influence the patient's choice and reaction.

### TRY THESE STRATEGIES

**Recommend next steps that are based on prognosis, medical options and patient's values and priorities:**

*"Based on the rapid progression of your cancer/illness despite therapy, and your wishes to be at home I recommend that we enroll you in hospice, which supports people who want to be at home and with their families, and to provide intensive symptom treatment."*

*"I recommend that we refer you to home care that takes a palliative approach to your care, which supports people who want to be at home and with their families, and to provide active symptom management."*

**Be direct in making your recommendation:**

*Say "I recommend...." Rather than using a "menu" approach of options.*

## Talking about family involvement

### KEY IDEAS

Many patients prefer to have family wishes about care override their own.

Preferences about family involvement in decision-making vary a lot.

Family involvement in decision making helps them prepare for the patient's death. Preparation is associated with better bereavement outcomes.

### TRY THESE STRATEGIES

- **Explore:**

*"If your family has strong wishes about your care that are different from yours, how would you like us to decide on your care?"*

- **Encourage the patient to involve and prepare his/her family:**

*"I know these are really difficult issues to talk about, because you care so deeply for your family. But, involving them in decisions helps them prepare and cope."*

*"Do you want to set up a time where you, me and XX family can talk together about what is important to you?"*

# The “Wish/Worry/Wonder” framework

## I wish...I worry...I wonder....

### KEY IDEAS

I wish allows for aligning with the patient’s hopes.

I worry allows for being truthful while sensitive.

I wonder is a subtle way to make a recommendation.

### TRY THESE STRATEGIES

- **Align with patient hopes, acknowledge concerns, then propose a way to move forward:**  
*“I **wish** we could slow down or stop your cancer and I promise that I will continue to look for options that could work for you.”*

***“I wish we could slow down or stop your disease from worsening.”***

- *“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.”*

## Managing the conversation: *Practical challenges*

- Time pressures can be a barrier to effective end-of-life conversations.
- Plan for enough time to have a meaningful conversation *or plan to take up the conversation at another time, as needed.*
- *SIC are iterative, repetitive, and require a team based approach over time, where you may be involved at a point in time but that your conversations contribute to an overall shaping of a patient's illness journey.*
- *Plan to have the right people present or to have a plan to communicate conversations with other care team members (documenting to other members of the team, inviting resident/physician, family, etc).*
- Use these strategies to make the best use of your time with each patient.

### Keeping patients on track

#### KEY IDEAS

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.

#### TRY THESE STRATEGIES

- **Acknowledge that this is a tough conversation, and gently bring patient back to topic:**  
*"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."*
- **Remind patient of time constraints:**  
*"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."*
- **Interrupt gently:**  
*"Mrs. Smith, we need to get back to my question about your goals if time is getting short."*

### Managing your time

#### KEY IDEAS

The conversation can still be effective when spread over several visits.

#### TRY THESE STRATEGIES

- **Delegate some questions to your Nurse Practitioner or Social Worker, as appropriate.**
- **Consider going through 2 questions per visit.**
- **Make sure everyone documents the discussion in the patient's medical record.**

**Know where to document in your Health Authority.**

## Documenting the conversation

### KEY IDEAS

Avoid using the computer while talking to the patient.

### TRY THESE STRATEGIES

- **Make notes on the guide if you need to remember specific things the patient says.**
- **If you document while talking, make frequent eye contact with patient.**

*Tell the patient: "This is important to get right, so I'm going to make a few notes, as we talk. Is that OK with you?"*

## Unplanned/Informal conversations: using the guide in the process of care

### Patient says: "I am feeling terrible today, what if I never feel better than this?"

#### KEY IDEAS

- "In the moment", use the guide to have a listening conversation that helps the team understand the patient's perspective more clearly.
- Be prepared to move "in" and "out" of the SIC, especially if it occurs in the process of care, i.e. you may need to move "out" of the listening conversation to deal with problems that arise in the process of care and during the SIC.

#### TRY THESE STRATEGIES

**Deal with present and urgent issues** (i.e. give pain medication, finish dressing change) **and then moving back "in" and focus on the serious illness conversation:** "I think we were discussing your fears, could we get back to that now? I think this is a really important conversation for us to have today."

### Patient says: "What will happen the next time I am admitted to hospital? I just don't want to go to ICU again, it was awful."

#### KEY IDEAS

- Suggest setting up a time to have a SIC with either yourself or yourself, together with another member of the care team.

#### TRY THESE STRATEGIES

Remember you are trying to create a "listening conversation", so avoid solving problems and making decisions in this conversation.

Ask clarifying questions: "What was the worst part of the ICU/hospital stay for you?"

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### Useful tools for difficult conversations

- <http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>
- **Speak Up:** <http://www.advancecareplanning.ca>
- CPR Decision Aids: (<http://www.advancecareplanning.ca/resource/cpr-decision-aids/>)
- CPR Decision Aid: (<http://thecarenet.ca/docs/CPR%20Decision%20Aid%20revised%20to%20PDF%20brochure%20Nov%203%202009.pdf>)
- Ottawa Personal Decision Guide: (<https://decisionaid.ohri.ca/docs/das/OPDG.pdf>)
- The Conversation Project: (<http://theconversationproject.org>)



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