

Serious Illness Care Program

Reference Guide for Clinicians

Key Ideas for successful discussions about serious illness care in outpatient, non-emergent, settings:

► 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 end-of-life issues
- 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)
- Giving patients an opportunity to express fears and worries is therapeutic



Practices

Do:

- Give a direct, honest prognosis when desired by patient
- Present prognostic information as a range
- Allow silence
- Acknowledge and explore emotions
- Focus on the patient's quality of life, fears, and concerns
- Make a recommendation ("Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend...")
- Document conversation

Do not:

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

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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.

Serious Illness Care Program: Overview of materials

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

Talking about your illness with loved ones and caregivers

This booklet can help you talk with your loved ones about your illness and the future. It is based on what you have already talked about with your clinician.

Talking about your illness with friends and family may not be easy, but it will help them understand what is important to you. It will also help them support you and your decisions.

Before you talk to your loved ones, think about when and where you want to talk. Choose a time and place when you feel relaxed. Be sure you have time to talk for a while. You can use the words in this guide, or use your own words — whatever is easier for you.

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.

Serious Illness Conversation Guide:

How the guide is organized

Serious Illness Conversation Guide



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



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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

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.”*

PROMPT	PURPOSE	SUGGESTED LANGUAGE
<ul style="list-style-type: none"> Introduce the idea and benefits 	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. 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"> Ask permission 	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>

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?”

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, medications), which may make future discussions less anxiety producing.

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...”
(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 end-of-life issues 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.**

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 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.”

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 a 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, overall¹:

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

The above statistics haven't changed in 40 years.

In-hospital CPR survival for cancer patients²:

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

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

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 metastatic cancer, its effectiveness is extremely low — between 2% and 6% — 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."

- **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, 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 its 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.

¹Peberdy MA et al. Resuscitation 2003

²Reisfield GM et al. Resuscitation 2006

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.

TRY THESE STRATEGIES

- **Provide prognostic information as a range, without providing too much specificity:**
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.”
- **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.”

Unpredictable prognosis

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. 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 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, in case things don’t go as we hope.

When it is time to make a plan

Making a recommendation

KEY IDEAS

Make recommendations only after you've had a chance to explore patient's values, goals, and priorities.

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 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."
- **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 patients 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."

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 THIS STRATEGY

- **Align with patient hopes, acknowledge concerns, then propose a way to move forward:**
"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."

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.
- 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

Some questions can be effectively handled by your staff, but *prognosis should not be delegated*.

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 EMR.**

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

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