

# Reference Book for Serious Illness Conversations

## Key ideas for successful serious illness conversations

### 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
- Managing your own and the patients' anxiety are key tasks in this conversation.
- Patients want the truth about what to expect
- Giving patients an opportunity to express fears and worries is therapeutic

### Practices

- Follow the guide while you are learning it
- Talk less than half the time
- Share your honest concerns about the future 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 conversation
- Provide reassurance only after the patient has shared his/her major concerns

# Introduction

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 Reference Book represents a distillation of feedback from hundreds of clinicians and patients about how to use the Serious Illness Conversation 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 Book, 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

# Serious Illness Conversation Guide:

## How the guide is organized

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 — is this okay?"</p>
<b>2. Assess understanding and preferences</b>	<p>"What is your understanding now of where you are with your illness?"</p> <p>"How much information about what is likely to be ahead with your illness would you like from me?"</p>
<b>3. Share concerns about the future</b> <ul style="list-style-type: none"> <li>• Frame as a "Wish...worry", "hope...worry" statement</li> <li>• Allow silence, explore emotion</li> </ul>	<p>"I want to share with you my understanding 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 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."</p> <p><i>OR</i></p> <p><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."</p> <p><i>OR</i></p> <p><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)."</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 goals if your health situation worsens?"</p> <p>"What are your biggest fears and worries about the future with your health?"</p> <p>"What gives you strength as you think about the future with your illness?"</p> <p>"What abilities are so critical to your life that you can't imagine living without them?"</p> <p>"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"</p> <p>"How much does your family 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 recommend 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>	

### 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.

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# Preparing Patients and Families for a Serious Illness Conversation

## At the visit before the Serious Illness Conversation visit:

- It is generally helpful to explain your plan to discuss serious illness care planning *before* the visit at which it will actually take place.
- To reduce patient anxiety, normalize the conversation by saying that this is an approach that is used for all patients with serious illness.
- 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 resources such as: PREPARE, Five Wishes, Speak Up, etc.

Some clinicians prefer to 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. A script or letter that you can adapt to your own style is available in Appendix A.

## Engaging patient and family together at the visit:

Having the patient and family member/friend present offers both opportunities and challenges. Here are some general principles to guide these situations.

- Be appreciative of the family member/friend's presence.
- Clarify the relationship between the patient and family member/friend. Is this person the health care agent or proxy?
- If this person is the health care agent, emphasize the important role that s/he 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 member/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 at the end of the conversation with the patient.
- When exploring information preferences, ask the patient whether s/he prefers to have the health care agent make decisions based solely on the patient's preferences, or whether they wish the wishes of the health care agent and/or other family members to determine the course of care.
- These are difficult conversations for family members/friends. Attend to the emotions of the family member/friend, using the same approaches that you would use with a patient – expect emotion, help the family member name their reaction, and respond with empathy and support.
- Consider engaging a social worker or other team members to provide extra support to you or to the family in difficult situations.
- Wrap up with an acknowledgment of the family member/friends importance and appreciation of their engagement in the discussion.
- Encourage patients and families to discuss these issues further.

## 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 and family
- 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 patient to remain in control and relieving the burden of decision-making in their loved ones	<i>It means you do not have to make any decisions if you would 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	<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>
If appropriate, state: no decisions needed today	This reduces anxiety.	<i>"We don't need to make any decisions today. I do want to begin these conversations so that we are both prepared for anything that could happen."</i>



## 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 his/her 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 appear to indicate 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 what to expect in the future 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.

## Discussing what to expect in the future/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, in a crisis. Starting to discuss about likely trajectory of a progressing illness early in the process 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 what to expect with patients is valuable for several reasons:

- It allows patients and family members 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.

## Three kinds discussions about the future

Discussions about what to expect in the future 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.

### Unpredictable

#### KEY IDEAS

For many conditions, it is impossible to predict how much time a patient is likely to have. This is particularly true of patients with chronic illness such as CHF, COPD, and those with cancer receiving new therapies.

#### TRY THIS STRATEGY

- **Use a hope/prepare framework:**

*“I am hoping that the new treatments 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.”*

### Function

#### 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 trajectory — 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.”*

## Time-based prognosis

### KEY IDEAS

Some 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. Although patients may not expect, clinicians often feel uncertain about telling time-based prognosis. If uncertain, use other strategies above.

Because this part of the conversation is difficult for us, we tend to talk too much and beat around the bush.

### TRY THESE STRATEGIES

- **When desired and knowable, 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.”*
- **Be simple and direct.**  
*“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.”*
- **Support hope:**  
*“I am hoping it will be on the long side of this range.”*
- **Be quiet.**
- **Explore patient’s reaction:**  
*“What is it like to hear this?”*

## 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 communicating your human concern for the patient.

“I wonder” is a gentle way to make a recommendation or suggestion.

#### 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.”*

## *Indirect Discussion about the Future*

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 Guide about “tradeoffs” 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.

## **Addressing Emotions**

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

**Feeling connected reduces anxiety.** The key clinical challenge in talking with patients about serious illness is helping the patient tolerate 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 a family member 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.

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

*“Don’t tell my mother how sick she is. She couldn’t handle it.”*

### Key Ideas

Family members who say this are usually trying to protect a loved one.

Sometimes they have critical information about a loved one’s past vulnerabilities and coping that are important for the clinician to know.

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 demonstrates respect and concern for the family perspective.

Inform family member that clinicians have an obligation to share desired information with the patient.

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.

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.

### Try these strategies

- *Please tell me what your concerns are about my talking with your mother about her illness.*
- *How has your mom dealt with previous challenges like this with her health?*
- *What are your concerns about how sharing information with your mom could affect her?*
- *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.*
- *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.*
- *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*

## Avoidance

*"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 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.

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.
- The right people are not in the room (key family members or clinicians are absent).
- 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.
- Medical issues are contributing to anxiety.

### 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.**
- **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 or social work.**  
*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.*
- **Use "I wish" statements**  
*"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.**
- **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?"*  
*"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."*



## Unrealistic expectations

*"I'm a fighter and I am going to be fine."*

### KEY IDEAS

Being a "fighter" and being "fine" have many meanings.

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

Clinicians can help reshape the meaning of "beating" the illness.

Help patient focus on additional hopes beyond survival.

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

- **Explore what patient means:**  
*"Tell me more about ways you are a "fighter."*
- **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 a Plan B, in case things don't go as we hope."*
- **Align yourself with patient by acknowledging strengths and supporting goals, while also naming worries:**  
*"I know you are an incredible fighter and will continue to do whatever you can 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."*
- **Focus on what patient can do, regardless of disease progression:**  
*"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."*

## Direct confrontation

*“Are you telling me I’m dying?”*

### KEY IDEAS

Conversations about the future inevitably bring up fears about dying.

Patients who immediately jump to this question are telling us how frightened they are.

The key task of the clinician is managing anxiety, emphasizing what is still possible, while exploring the patient’s concerns and the medical realities.

### TRY THESE STRATEGIES

- **Ask the patient what makes them concerned:**  
*“It sounds like you are pretty worried about where you are, and worry you might be close to the end. Please tell me more.”*
- **Name and explore what is hard:**  
*“I know that this can be scary to talk about. What are your biggest fears?”*
- **Provide perspective:**  
*“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.”*
- **Be honest and as hopeful as you can realistically be:**  
*“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.”*

## Sadness and fear

*"This can't be happening. I have two kids at home."*

### KEY IDEAS

Responding to emotion is often a precondition for effectively addressing serious illness decisions.

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

Listening is therapeutic, 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.

### TRY THESE STRATEGIES

- **Allow silence for patient to express feeling.**
- **Name the feeling.**
- **Provide non-verbal support.**  
You may want to 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."*
- **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.**  
*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. We will include you as much as possible in this kind of decision.*
- **Avoid offering information that is not explicitly sought.**

## Anger

*"You don't know what you are doing."*

### 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."*
- **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 treatment. I will still work hard to do my best for you."*

## Dealing with Family Grief

*"I just know she is going to get better."*

### KEY IDEAS

When conversations begin late, and family members 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 about future to learning about the patient, the relationship between the patient and the family member, 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 members 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 member 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 members need time to process. Don't try to get to a decision immediately, but return to it soon, if necessary.**

# Addressing Religion and Spirituality

Honoring Individual Perspectives	
<p><b>KEY IDEAS</b></p> <p>Faith plays a big role in how people think about end-of-life decisions.</p> <p>Many patients won't talk about their faith unless the clinician opens the door.</p> <p>Demonstrating understanding and respect for faith increases trust in the clinician and in the care process.</p>	<p><b>TRY THESE STRATEGIES</b></p> <ul style="list-style-type: none"> <li>• <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?</i>  <i>Are there key beliefs that you would want to guide the care we provide?</i></li> <li>• <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></li> </ul>

“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> <ul style="list-style-type: none"> <li>• <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></li> <li>• <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></li> <li>• <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></li> </ul>

## 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 treatment directed at the underlying disease process.</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>Do not hedge (“Well, it might...”); evidence suggests that patients hear and remember positive but not negative messages.</p>	<p><b>TRY THESE STRATEGIES</b></p> <ul style="list-style-type: none"><li>• <b>Explore patient fears about stopping active treatment:</b> <i>“Can you tell me what your concerns are about stopping treatment X (e.g. dialysis, chemotherapy, milrinone, etc.)?”</i></li> <li>• <b>Be clear that more treatment may not mean more time:</b> <i>“Some studies suggest that stopping chemotherapy may not shorten time, and you may feel better.”</i><ul style="list-style-type: none"><li>○ <b>Check patient understanding, as this information may be counterintuitive to patients</b></li><li>○ <b>Reassure patient that you will continue to provide care:</b> <i>Even if we stop your dialysis, I will continue to see you regularly, monitor your symptoms, and make sure that you are as comfortable as possible.</i></li></ul></li> <li>• <b>If clinically indicated, make a direct recommendation against further disease-modifying treatment.</b> <i>“Your discomfort with the dialysis process, and the fact that you are feeling poorly all the time suggests that dialysis is really not providing you a benefit. Given this, it would be very reasonable to stop dialysis.”</i></li> <li>• <b>Don’t say you can reconsider disease-modifying treatment later if you can’t.</b> <i>“I wish I could tell you that I think you will be able to tolerate more chemo sometime in the future. But I am afraid that your cancer is what is making you so weak and sick, and that more treatment will only harm you.”</i></li></ul>

## Patient is not ready to make a decision but is declining rapidly

### KEY IDEAS

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

- **Acknowledge the patient's decline 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."*
- **If there is major discrepancy between the patient's understanding and expectations about their disease, and a rapidly worsening medical situation, naming this can help create space for an unwanted discussion.**  
*"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. "*



## 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.

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.”*
- **Assure continued support and care:**  
*“No matter what you choose, we will continue to provide you with intensive support and care.”*
- **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  
*“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 \_\_\_\_\_, its effectiveness is \_\_\_\_\_, even if we can bring you back, this is what you can expect.”*
- **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, 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 and ask them to affirm your decision.

## If timing is right to complete Medical Orders for Life Sustaining Treatment (POLST, MOLST, etc.) form

### KEY IDEAS

Completion of POLST should always follow a broader discussion of prognosis and values and goals

POLST translates the patients' values, goals, and treatment preferences into actionable medical orders that can help ensure the plans you make with patients are followed.

Patients who are good candidates for POLST are those who are seriously ill and/or frail, who you would not be surprised if they died in the next year AND who are clear about the level of treatment they want in an emergency or as their illness progresses.

### TRY THESE STRATEGIES

- *“Based on our conversation, I recommend we complete a POLST form together. POLST helps us translate the conversation we just had into medical orders, to ensure that, if something happens, you get the treatments you want and don’t get treatments you don’t want. Can we proceed?”*

- **NOTE: The following approach is based on the most common POLST Order formatting that divides treatment into Comfort Measures, Limited Treatment, and Full Treatment. Depending on how the conversation unfolded, you may have a clear idea of how to translate the patient’s goals into treatment preferences, but if it’s not clear, the following approach may help ensure you are speaking the same language:**

*“POLST allows us to write medical orders to say how much treatment you want if something were to change tomorrow: The first level we call comfort measures only – this means you want treatment for pain and comfort but you don’t want treatment to try to cure you or prolong your life. At this level, you are saying you don’t want to go back to the hospital unless they can’t keep you comfortable where you are. This level of treatment is what hospice provides.”*

- For MA MOLST, this corresponds to DNR, No ventilation, No hospital transfer. Write “Comfort Measures Only” on page 2.
- Encourage Hospice enrollment with this level of care if patient has  $\leq 6$  month prognosis.

It is common for patient preferences AND POLST orders to change over time. Most patients start with higher levels of treatment and move towards more comfort oriented treatment over time. A common mistake is completing POLST with orders that only cover how the patient wants to be cared for when they are dying. POLST orders should reflect how the patient wants to be treated if something happens tomorrow.

*“The Second level is limited treatment – it means you are ok going back to the hospital and for them to try to make you better, but you don’t want intensive care treatments like being on a breathing machine.”*

- For MA MOLST, this corresponds to No ventilation, Yes to non-invasive ventilation (may confirm), Yes to Hospital Transfer,
- Confirm with patient – so at this level, if your heart were to stop or you were to stop breathing, this means you WOULD NOT want them to try to revive you using CPR, you’d want to be allowed to die naturally, is that correct?
- If patient wants CPR but not Mechanical Ventilation, they likely misunderstand these treatments and further discussion is needed to discern what their real goals are.

*“The third level is called full treatment – at this level you are saying it’s ok to return to the hospital and that you are ok with going to the intensive care unit and being on a breathing machine if there’s a chance they can buy you more time.”*

- Confirm with patient: so at this level, if your heart were to stop or you were to stop breathing, this means you WOULD want them to try to revive you using CPR, is that correct?
- For MA MOLST this corresponds to Attempt Resuscitation, Yes to Ventilation, and yes to Hospital Transfer

- **You can ask about artificial fluid and hydration after discussing the other treatment orders, using what you learned in talking about their goals and treatment preferences to help them choose the option that is most congruent.**

- If patient wants a time-limited trial (in MA ‘A short time’) let them know this usually means in the 1-3 week range.

# 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)</li>   <li>• Changes in medical care plan.</li>   <li>• Completion of a POLST or MOLST form.</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> <ul style="list-style-type: none"> <li>• <b>Recommend next steps that are based on prognosis, medical options, and patient's values and preferences:</b>  <i>"Based on the ongoing worsening of your heart disease and your wishes to stay at home, I recommend that we enroll you in hospice, which can support you in being at home with your family, and also make sure that you are as comfortable as possible."</i> </li>   <li><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></li>   <li><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></li>   <li><i>"Since your family doesn't really understand yet 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></li>   <li><i>"Based on what you've said about how important it is for you to keep trying anything you can to prolong your life, even if it is hard on you, and your feeling that you don't want to be on kept alive on machines for a long time, I recommend that we write down a plan that you would want to be on a breathing machine for a few days, if we thought we could turn things around, but that you would definitely not want to be on it for a prolonged period of time. I also suggest we write down that you want your health care provider to make the decisions that she is most comfortable with, even if they are not exactly what you have told me."</i></li>   <li><i>"You have told me that your priority is to be able to stay at home with your family and that you don't want to go back to the hospital. In order to make sure that everyone follows your wishes, I recommend that we complete this form called Medical Orders for Life Sustaining Treatment."</i></li>   <li><i>"It sounds like we are on track with your care for now. Let's revisit the conversation again if you have more concern, or the situation changes."</i></li>   <li><i>"Does this plan capture what you want?"</i></li> </ul>

## 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
- 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.</p> <p>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> <ul style="list-style-type: none"> <li>• <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></li> <li>• <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></li> </ul>

Managing time	
<p><b>KEY IDEAS</b></p> <p>Some questions can be effectively handled by nurses, social workers, and case managers, but <i>prognosis discussions should not be delegated.</i></p> <p>The conversation can still be effective when spread over several visits.</p>	<p><b>TRY THESE STRATEGIES</b></p> <ul style="list-style-type: none"> <li>• <b>Share responsibility for specific questions with your Nurse, Nurse Practitioner or Social Worker, as appropriate.</b></li> <li>• <b>Make sure everyone documents the discussion in the EMR</b></li> </ul>

Documenting the conversation	
<p><b>KEY IDEAS</b></p> <p>Avoid using the computer while talking to the patient.</p>	<p><b>TRY THESE STRATEGIES</b></p> <ul style="list-style-type: none"> <li>• <b>Make notes on the guide if you need to remember specific things the patient says.</b></li> <li>• <b>If you must document while talking, make frequent eye contact with patient.</b></li> <li>• <b>When documenting, use the patient’s words to convey the patient’s perspective.</b></li> </ul>

# Appendix A

## Preparing the patient for the conversation: A script for a pre-visit conversation or letter

Some clinicians prefer to 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. Here is a script or letter that you can adapt to your own style:

**At your next appointment**, your doctor would like to talk with you about your illness, your goals and wishes, and planning for the future. This is an important part of the care we provide for all of our patients. Our team likes to start talking about this when patients are doing okay. Your illness is serious but stable, so now is a good time to talk about what is ahead, and to do some planning for the future. Patients who think through what is important to them and what their wishes are often feel less anxious, more at peace, and more in control of their situation.

### **Before your next appointment**

Please prepare for your visit by thinking about these things:

- What would you like to know about your illness and what is likely to be ahead?
- What kind of information would help you make decisions about your future?
- What is most important for you to have a good quality of life?
- What are the most important strengths that support you in dealing with your illness?
- What are you afraid of about your illness?
- What kinds of medical care do you not want?
- What do you think it would be like to share these thoughts with your family?
- If you haven't already identified a health care proxy, who would be able to fill that role?

### **Please bring to your visit:**

- If you have a health care proxy form that is not on file in our institution, please bring a copy.
- If you have a living will or advance directive, please bring a copy.

If you don't have these documents or have questions about them, talk to your doctor.

### **Talking about the future won't change your ongoing care**

Talking about the future won't change the plans we have made so far about your treatment, unless, of course, you want to. We will keep providing the best possible care to control your disease.

## You may find it helpful to bring other people to your next appointment

You can choose to bring the person who is your health care proxy or other family members to your next visit so they can be a part of the conversation. You can also bring your nurse practitioner, social worker, or chaplain if you like. Please let your doctor's office know if you would like to bring others to the appointment.

## We understand that your wishes may change over time

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions. **If you have questions before your visit, please contact: XXX**



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