Serious Illness Care Program

Reference Guide for Clinicians

Key Ideas for successful discussions about end-of-life care:

Principles

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

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
- Fear silence
- Give premature reassurance
- Provide factual information in response to strong emotions
- Focus on medical procedures

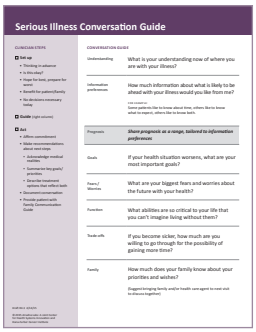
Contents

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 goals of care conversations with your patients who have serious illness. 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


Serious Illness Conversation Guide

CLINICIAN STEPS

- Set up
  - Thinking in advance
  - Is this okay?
  - Hope for best, prepare for worst
  - Benefit for patient/family
  - Set decisions-necessary limits
- Guide (right column)
- Act
  - Affirm commitment
  - Make recommendations, advise next steps
    - Acknowledge medical uncertainty
    - Summarize key goals/priorities
    - Describe treatment options that reflect both
  - Document conversation
  - Provide patient with Family Communication Guide

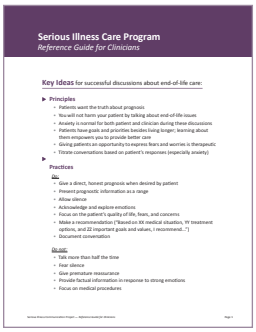
CONVERSATION GUIDE

Understanding	What is your understanding now of where you are with your illness?
Information preferences	How much information about what is likely to be ahead with your illness would you like from me?
Prognosis	*Share prognosis as a range, tailored to information preferences*
Goals	If your health situation worsens, what are your most important goals?
Fears / Worries	What are your biggest fears and worries about the future with your health?
Function	What abilities are so critical to your life that you can't imagine living without them?
Trade-offs	If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Family	How much does your family know about your priorities and wishes?

(Suggest bringing family and/or health care agent to next visit for illness discussion)

Conversation Guide

The backbone of this project, the Conversation Guide will help you have successful conversations with your patients. It consists of 7 questions that elicit important information from your patients about their goals and values.


Serious Illness Care Program
Reference Guide for Clinicians

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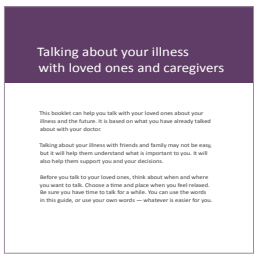
Reference Guide for Clinicians [this document]

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.

For patients and families


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 doctor.

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

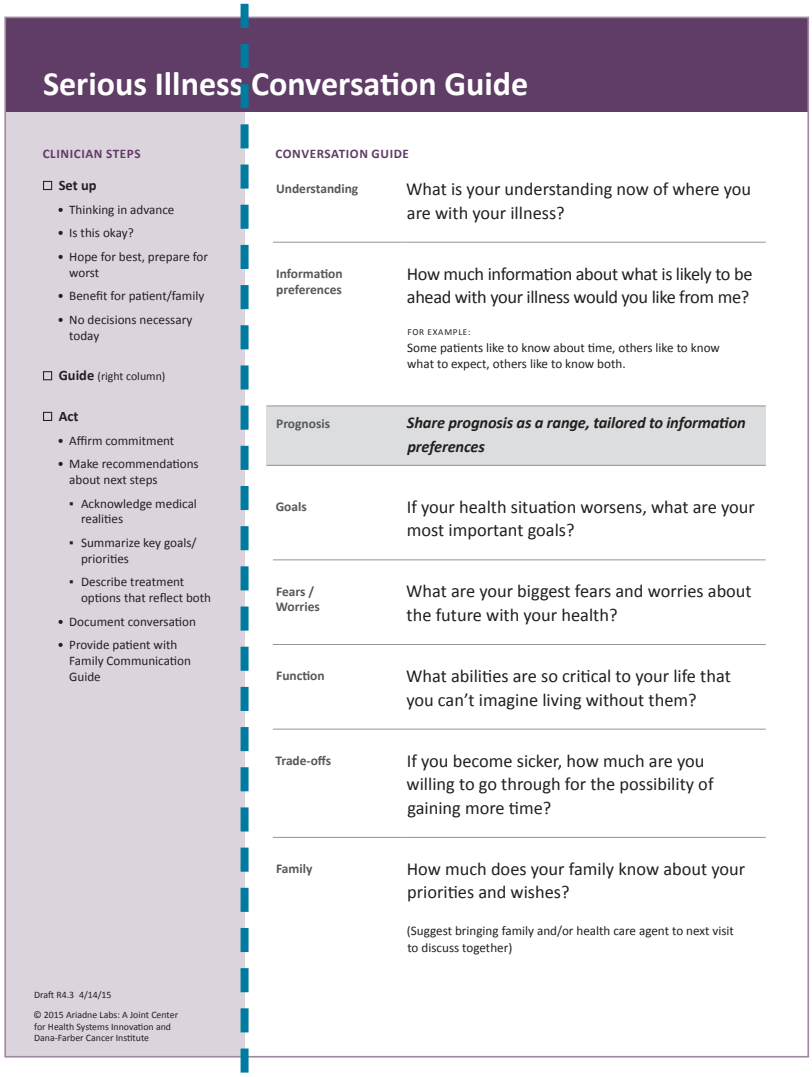
Designed for the patient's use with their family, this guide will help your patient talk with their family and friends about the same topics you bring up with them in your conversations. Like the clinician materials, it provides language for the patient to relay information to their family. We encourage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

Serious Illness Conversation Guide:
How the guide is organized

LEFT SIDE
Clinician Steps

A guide to help ensure you complete key parts of a successful conversation

- Essential clinician actions
- Follow this intentional sequence



Serious Illness Conversation Guide

CLINICIAN STEPS

☐ **Set up**
- Thinking in advance
- Is this okay?
- Hope for best, prepare for worst
- Benefit for patient/family
- No decisions necessary today

☐ **Guide** (right column)

☐ **Act**
- Affirm commitment
- Make recommendations about next steps
  - Acknowledge medical realities
  - Summarize key goals/ priorities
  - Describe treatment options that reflect both
- Document conversation
- Provide patient with Family Communication Guide

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CONVERSATION GUIDE

Understanding	What is your understanding now of where you are with your illness?
Information preferences	How much information about what is likely to be ahead with your illness would you like from me? FOR EXAMPLE: Some patients like to know about time, others like to know what to expect, others like to know both.
Prognosis	***Share prognosis as a range, tailored to information preferences***
Goals	If your health situation worsens, what are your most important goals?
Fears / Worries	What are your biggest fears and worries about the future with your health?
Function	What abilities are so critical to your life that you can't imagine living without them?
Trade-offs	If you become sicker, how much are you willing to go through for the possibility of gaining more time?
Family	How much does your family know about your priorities and wishes? (Suggest bringing family and/or health care agent to next visit to discuss together)

RIGHT SIDE
Conversation Guide

A language guide to help you discuss critical topics

- Proven language
- *Use these words* to help ensure a meaningful and successful conversation
- Omit questions you don't think are appropriate at this time

THE LEFT SIDE IS YOUR GUIDE

1. **SET UP.** Introduce the conversation in an intentional sequence to effectively prepare the patient for a successful discussion. (See page 5 of this guide.)

   NOTE: If the patient doesn't wish to discuss this, explore their reasons. (See page 6 of this guide.)

2. **GUIDE.** Use the words on the RIGHT SIDE to guide your conversation with the patient.

3. **ACT.** These steps can be in any sequence: Affirm your continued commitment to the patient and make appropriate recommendations (see page 12 of this guide), based on patient's preferences. Summarize for the patient their wishes, fears, and concerns. Confirm that you understand correctly. Document the conversation in the EMR, and offer the Family Communication Guide to the patient as appropriate.

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 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: "*This conversation can be difficult, and I hope you don't mind my using this guide to help me*."

PROMPT	PURPOSE	SUGGESTED LANGUAGE
• Thinking in advance	Orient the patient	*"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.* *We like to discuss these issues when patients are doing well and we are not in a crisis.* *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."*
• Is this okay?	Ask permission	*"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.")*
• Combined approach	Reassure patient about continued treatment	*"The first thing I want to reassure you about is that we are going to continue to treat your illness intensively and that we will work hard in our efforts to treat and control this disease and help you feel well."*
	Emphasize the need to plan	*"But we both know this is a serious illness. And we need to do some planning in case things don't go as well as we hope."*
• Benefit for patient/ family	State support for patient and family	*"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."*
• No decisions today	Emphasize that no decisions are necessary today	*"This is the beginning of a conversation, and we don't need to make any decisions today. We can keep talking about it as we see how things go."*

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 insight, approaches, and suggested language.
- The following panels offer guidance for seven scenarios that can be challenging for the clinician.

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 of discussion is to initiate discussion, not to make decisions.**
- **If patient expresses intense anxiety about dying, explore specifics or consider referral to palliative care.**
- **If patient expresses more global anxiety, consider mental health referral.**
- **If patient is ambivalent, acknowledge or name the ambivalence — acknowledge what a difficult situation the patient is in.**
- **Inform patient that you will bring this up at a subsequent visit.**
- **Use "I wish" statements (e.g. I wish that things were better so we didn't need to talk about this)**

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.**

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 next 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 end-of-life decisions.

Tears and other strong emotions are natural when discussing end-of-life 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?"
- **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?"
- **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."
  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[1]:

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

The above statistics haven't changed in 40 years.

In-hospital CPR survival for cancer patients[2]:

- 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.).

[1]Peberdy MA et al. Resuscitation 2003

[2]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 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 wide 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."**

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 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.**

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 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, 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 decision-making involvement 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."*