

**BEST
PRACTICE
GUIDE**



Serious Illness Conversations

**Improving Life with CF:
A Primary Palliative Care Partnership**

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Provider Best Practice Guide Series

Serious Illness Conversations

Improving Life with CF: A Primary Palliative Care Partnership

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Best Practice Guide: Serious Illness Conversations

This best practice guide:

- Defines **serious illness conversations** and explains the rationale for integrating these discussions into the care of patients with cystic fibrosis (CF) and their families.
- Describes a content framework for serious illness conversations.
- Describes a communication guide for serious illness conversations.

Serious Illness Conversations: Definitions and Rationale

• Definitions

- Serious illness conversations are **communications between health professionals and patients or families that focus on present or future health care and explore goals, values, preferences, concerns and fears.**¹⁻³ Serious illness conversations are best viewed as a process that unfolds iteratively throughout the course of an illness, with content that changes over time.
- Advance care planning (ACP) conversations **clarify and support an individual's understanding of goals, values, and preferences regarding future care.**⁴ ACP addresses the need for advance directives, but is best viewed as a broader process through which the patient explores and communicates goals, values, preferences, concerns and fears about future health care.

• Background

- Serious illness conversations could promote positive outcomes by supporting autonomy and coping, and increasing concordance between treatment decisions and preferences.^{2,3}
- Except for several surveys that suggest the need to improve the timeliness and conduct of ACP among those with CF,⁵⁻⁷ there have been no studies of serious illness conversations in this population. Nonetheless, the importance of ACP is suggested by the chronicity and burden of the illness, and the heterogeneity of issues during its course.

- To increase the number and quality of serious illness conversations (including ACP) in patients with CF and their families, a systematic approach is needed.^{2,8,9} This approach:
 - 1) identifies appropriate patients at appropriate times
 - 2) assists clinicians in pursuing specific objectives during each conversation
 - 3) uses a structured approach to communication
 - 4) helps in accurate documentation

Content framework for serious illness conversations

- **Rationale**

- Before engaging in a serious illness conversation with a patient or family member, the CF clinician should know: “**What are my objectives during this discussion?**” A content framework can help in planning these objectives.

- **General vs. specific objectives**

- The priority of a conversation may be to explore or clarify general information that helps the clinician better understand the person or family and provides a foundation for later conversations.
- The priority may be to explore or clarify specific information that helps the clinician plan treatment. This might apply to immediate or longer-term treatment choices.

GENERAL OBJECTIVES	SPECIFIC OBJECTIVES
<p>To discuss:</p> <ul style="list-style-type: none"> – Values and preferences <ul style="list-style-type: none"> • Decisional control preferences • Desire for information • View of ‘trade offs’ • View of treatments – Prognostic awareness – Life goals – Concerns and fears 	<p>To discuss:</p> <ul style="list-style-type: none"> – Treatment decisions <ul style="list-style-type: none"> • CFTR modulators • Lung transplantation • Hospitalizations, ICU stays • Respiratory support • Artificial nutrition – Hospice referral – Advance care planning

General objectives that can be prioritized during serious illness conversations

- **Values and preferences**

- Serious illness conversations that take place at times that are relatively stable clinically can be used to acquire information about an individual’s values or preferences that may be helpful at any point during care. It is helpful to consider these objectives from four perspectives: 1) **decisional control preferences**, 2) **desire for information**, 3) **views about trade-offs**, and 4) **views about treatment approaches**.

- **Decisional control preferences**

- The term “decisional control preferences” refers to the patient’s or surrogate’s preferences concerning the person or people who make health care decisions for the patient. From this perspective, patients or surrogates may be: 1) **relatively more active**: the patient or surrogate prefers to make decisions, 2) **relatively more passive**: the patient or surrogate prefers to defer decisions to a professional or family member, or 3) **preferring a shared approach**: the patient or surrogate prefers to make decisions together with a professional or family member.
- Decisional control preferences vary¹⁰ and may change over time, and there is no basis by which to predict an individual’s views without direct questioning (see box).

“When it comes to a decision about an important treatment for your illness, are you the kind of person who likes to make her/his own decisions, or do you rely on your family or your doctor to make the right decision for you?”

- Decisional control preferences should be evaluated periodically and documented.

- **Desire for information**

- There is variation in the extent to which patients or families desire information about illness.¹¹ There is no way to predict an individual’s preferences without direct questioning (see box).

“Are you the kind of person who wants to hear the details about your illness, or do you usually like more general information, with details only when the doctor feels that it is really important for you to know?”

- Desire for information should be evaluated periodically and documented.

– Views about trade-offs

- Values may be revealed by talking about trade-offs. Some individuals state that quality of life is more important than survival, some state that living longer is the priority, and some have a more nuanced view about how bad quality of life would have to become before it would overwhelm the desire for life-prolonging therapy.
- Views about trade-offs may be illuminated by direct questions (see box).

“People who have chronic illnesses differ in how they judge what is important. For example, some people say that quality of life is the most important thing, while others say that controlling the disease and living as long as possible is most important. Although this comparison doesn’t reflect how complicated these decisions really are, it is still helpful to know how you think about these kinds of trade-offs. What are your thoughts?”

- If views about trade-offs are explored, the information acquired should be documented.

– Views about treatments

- Decisions about a treatment may be facilitated if the patient had an opportunity in the past to speak generally about its use, and the benefits and burdens it may produce. The clinician can frame this discussion in terms of the possibility that the treatment may be recommended at some later time and use the conversation to correct misapprehensions and offer support.
- Views about treatments may be illuminated by direct questions (see box).

“Things are stable right now, and because they are, it is a good time to ask you a question about treatments that you don’t need to consider now but may have questions or concerns about. For example, many people with CF know that lung transplantation is a treatment for some situations. What do you know about the role of lung transplants for CF? Do you have questions or concerns about this?”

• Prognostic awareness

- Prognostic awareness may relate to the patient’s understanding of life expectancy or the expected course of the illness. Clinicians may find this communication challenging.
- Existing studies of prognostic awareness¹²⁻¹⁵ suggest that most patients have an incorrect understanding about prognosis, physicians believe that patients know more than they do, and vary in the extent they know and want to know information.

- The response to disclosure and awareness is complex and likely related to the type of information, the communication skills of the clinician, coping and adaptation of the individual, extent of family support, and other factors. Because there is no way to predict an individual's response to prognostic disclosure, it is best to assess by direct questioning (see box).

“What do you know about your illness, about how serious it is or about the treatment that is planned? Some people benefit from having more information about the prognosis or what to expect from treatment. Do you feel the need for more information?”

- If the patient desires information about life expectancy, consider whether it would be better to begin with a general description (time is limited, the illness is ‘terminal’). If more detail is desired, consider using a time horizon (e.g., weeks to months), with a best case-worst case description.
 - If the patient desires information about the expected course of the illness, explore whether the request is for information about symptoms, function, effects on the family, or other information.
- Life goals
 - A serious illness conversation may provide an opportunity for the patient to disclose and discuss information about life goals. This may be a positive experience, leading to a discussion about actions that could be taken that would promote closure and coping.
 - A discussion of life goals may focus on immediate goals, past milestones or events (life review), and/or legacy.
 - Direct questions about life goals are best. If regrets are expressed, they can be explored (see box).

“Although I know you pretty well, something we’ve not discussed before is how you think about your goals or accomplishments. Some people with CF have thoughts about things that they want to do or accomplish, and others think about things that have already taken place and what they mean now. Some people even think about how others will remember them in many years. Would you want to share any of this with me or our team?”

- Concerns and fears
 - The objective of a conversation may focus on concerns or fears. An open-ended question may initiate comments that can then be explored in relation to 1) concerns or fears about oneself and 2) concerns or fears about one's family (see box).

“I know that we spend a lot of time talking about treatments and how you are doing. I want to make sure that we deal with anything that specifically worries you or frightens you—about your CF or our treatments for it. What concerns you the most?”

Specific objectives that can be prioritized during serious illness conversations

- Treatment decisions
 - Conversations relatively early in the disease are the foundation for later discussions about specific treatments.
 - Insights about decisional control preferences, desire for information, and prognostic awareness, as well as earlier discussions about general perceptions of treatments, informs the framing and conduct of a conversation about a proposed treatment.
 - Prior conversations build trust and may have addressed specific concerns and fears that could potentially complicate discussions about a new therapy.
 - Patients with CF may require conversations about an array of therapies that vary in the potential for benefit, the burden associated with treatment, and the risk of serious adverse effects.
 - The principles underlying high quality serious illness conversations are relevant to discussions involving all types of treatments but are especially important in several contexts: 1) when the patient with CF has advanced illness, 2) when the treatment is associated with a high degree of potential harm or uncertain benefit, and 3) when the patient and family are relatively vulnerable because of high distress, comorbidities, or the existence of salient social determinants of illness.
- Hospice
 - Hospice is a health care system that can offer treatments and services consistent with specialist palliative care to eligible patients living at home or in a long-term care facility¹⁶. Serious illness conversations surrounding the decision to refer to hospice are challenging because of the connection between hospice and the end of life, misunderstanding about the nature of hospice care, and the uncertainty that many clinicians have about the regulations governing hospice eligibility and the services that are offered.
 - It is important that CF clinicians seeking information about hospice are knowledgeable about the Medicare/Medicaid hospice benefit and understand the extent to which the hospice benefits available from relevant commercial insurers mirror the federal benefit.
 - CF clinicians should develop a process with one or more hospice partners that can provide guidance about potential eligibility prior to referral (while respecting the privacy rights of patients and families), offer eligibility assessment and help with hospice conversations, and provide prompt enrollment for hospice services when eligible patients and families decide to elect the benefit. CF clinicians should provide education to hospice partners about the unique needs of this population in the advanced stages of illness.

- Advance care planning
 - ACP is a communication that clarifies and supports an individual’s understanding of goals, values, and preferences regarding future care⁴. Serious illness conversations should focus on ACP at some point early in the illness and periodically thereafter, particularly after significant medical changes.
 - One of the objectives of the ACP process is an advance directive, a statement made by a patient who has decisional capacity about future preferences for care. The advance directive becomes operative if capacity is lost.
 - Advance directives can designate one or more people to make decisions for the patient if capacity is lost, stipulate specific instructions for care in a specific context (typically advanced incurable illness), or do both.
 - The first type of advance directive, by which the patient designates one or more people to make health care decisions if decisional capacity is lost, is called a *durable power of attorney for health decisions*. The person who is designated is called the *health care agent* and the document that designates others is called a *health care proxy*.
 - The other types of advance directives—called *instructional directives*—give specific instructions about future care, referencing both treatments and context. There are several types:
 - Oral or written living will—instructions given verbally or written and signed before witnesses, which are documented.
 - Non-hospital do-not-resuscitate (DNR) order—a written physician order that after discussion with the patient, prevents emergency personnel from initiating CPR in the home.
 - Medical (or Physician) Orders for Life-Sustaining Therapy (MOLST or POLST; varies by state)—physician orders describing the care that should or should not be given, should the patient be unable to communicate.
 - If completion or revision of a health care proxy is the objective of the conversation, the clinician should:
 - Ensure that the health care proxy is completed as consistent with state law and names one or more health care agents.
 - Ensure that those designated as agents know that they have been selected for this role and accept it.
 - Attempt to provide for a conversation between the patient and his or her agents that can help the agents act at some later time by exercising either *substituted judgment* (acting as the patient would act if he or she could communicate) or an understanding of the patient’s *best interest*. The clinician should consider being present at this conversation to answer questions and pose scenarios, if possible.
 - Ensure that the health care proxy is given to the patient and retained by individual physicians and institutions that are the major care providers.
 - If completion or revision of an instructional directive is the objective of the conversation, the clinician should ensure that the documentation is consistent with state law and is made available to the patient and to individual physicians and institutions that are the major care providers.

Using a communication guide for serious illness discussions in patients with CF

- Communication guides
 - There is a robust literature describing communication guides and tools. Most incorporate a core set of principles¹⁷ that cover clinician preparation, an approach to introducing the purpose of the conversation, an assessment of illness understanding and prognostic awareness, delivering information, and responding to emotion.
 - A collaboration between the Cystic Fibrosis Foundation and the Academy of Communication in Healthcare has yielded a CF-specific communication guide—the *Partnership Enhancement Program (PEP)* (https://www.nacfconference.org/Home/PDFs/2019_NACFC/SPC_and_SC_Materials/SpC01_-_Partnership_Enhancement_Program/)
 - Other guides that are now widely applied include the *Serious Illness Conversation Guide* by Ariadne Labs (<https://www.ariadnelabs.org/areas-of-work/serious-illness-care>) and the resources developed by *VitalTalk* (<https://www.vitaltalk.org>).
- “When, What, and How (OPUS) approach”
 - CF clinicians may find one or more of these communication guides helpful. Another guide, called the “**When, What, and How (OPUS) approach**”, was developed with the content framework described above and is intended to 1) identify appropriate patients at appropriate times, 2) assist clinicians in pursuing specific objectives during each conversation, 3) use a structured approach to communication, and 4) help in accurate documentation.
 - **When** should the CF clinician engage in a serious illness discussion?
 - Consistent with the “*Models of palliative care delivery for individuals with cystic fibrosis: Cystic Fibrosis Foundation evidence-informed consensus guidelines*¹⁸” clinicians working with patients with CF and their families should engage in serious illness conversations:
 - Periodically during stable periods, and notably during annual evaluation
 - When clinical signs indicate progressive illness
 - When ‘trigger’ events occur, such as hospitalization or the need for a respiratory support device.
 - **What** should be discussed?
 - The content framework describes the objectives that might be pursued by clinicians as they prepare to have a serious illness conversation.
 - The objectives for each discussion may be singular (e.g., ACP) or multiple (values and preferences, including decisional control preferences, desire for information, and prognostic awareness).

– **How** should the planned objectives of a conversation be accomplished?

- A structured approach reflects best practices and is summarized using the mnemonic, “**OPUS**”.

- “**O**” – **Opener**

- “**P**” – **Permission**

- “**U**” – **Understanding**

- “**S**” – **Support**

– “**O**” – **Opener**

- The “opener” refers to elements of the introduction—what the clinician does and says that can initiate meaningful communication about a sensitive matter. There are two elements:

1) Set the stage: Adequate time, privacy

2) Begin with a neutral opening statement that alerts the patient or family and states the type of objectives that the clinician perceives as important right now (see box).

“Now that you’re a teenager, you will be making more decisions about your own health care. I’d like to understand what you know about how your CF might change as you get older. That way I can try to answer questions you may have about what to expect in the future.”

– “**P**” – **Permission**

- Permission underscores the need to affirm the patient’s or family’s willingness to proceed. There are two elements (see box):

1) Should others be present to have this conversation, or parts of this conversation.

2) If the persons who need to be present are there, is it acceptable to proceed.

“Would you be open to a discussion about your illness? We might touch on some serious issues or focus on things that have been on your mind that you’ve not had the chance to describe before. I would like to know whether you are OK with a discussion like this, and if you are, whether we should proceed now or wait until other people whom you would want to be part of a discussion like this are here. Would you want others to be with you when we discuss your illness? If so, we’ll connect with them or reschedule.”

– “U” – Understanding

- Understanding refers to the information that will be received and provided. Several questions guide the exchange:
 - **“What does the patient or family know?”** This is a very useful first step. If focused on the patient’s general understanding of the illness, it is typically early in the course, or occurring as a patient is transitioning from pediatric to adult care (see box).

“What is your understanding about what it might be like to live with CF as you are getting older?”

Alternatively, the question may be specific and focused on the objectives of the conversation. For example, the question may be intended to elicit prognostic awareness (see box).

“What is your understanding about how serious your illness is right now? What are your expectations about the next weeks or months?”

Or the question may focus on a specific treatment (see box).

“You may know that some people with CF ultimately are offered a lung transplant. It is important to understand what you know about treatments for CF, including this surgery. What is your understanding about it?”

- **“Can more information be elicited?”** This second question is a reminder to assess and follow-up, eliciting more information, identifying gaps in knowledge or misconceptions, and providing a transition to the third element of “understanding” — what the clinician wants the patient or family to know.
- **“What information should be provided?”** Unless the conversation has veered into unexpected territory, the clinician should be able to proceed to information sharing consistent with the objectives planned for this conversation.

One favored approach to information sharing is the **“ask-tell-ask”** technique,^{8,19} which emphasizes the following: 1) give information directly, in short sentences and without medical jargon, 2) repeatedly stop and ask if the individual understands or has questions, and 3) periodically ask the individual to repeat a key point and correct any misunderstanding. Other ways to share information include “hope/worry statements” (“I hope that the situation stabilizes but I worry that you’ll worsen again”) and “hope for the best/prepare for unwanted outcomes” (“I share your hope that the situation stabilizes, but I also think that it is best to prepare for the possibility that you will worsen again.”).^{8,19}

- **“What more does the patient or family want to know?”** This last question is a reminder to sum up the information that has been shared and provide an opportunity for the patient or family to ask additional questions.

– “S” – Support

- Support refers to the approach to bring a serious illness conversation to a close. There are two elements:
 - **Expect emotion and respond.** Expressions of emotion by the patient or family can be difficult for the clinician. It is important to avoid backtracking on information just provided, providing false reassurance, or dismissing the emotion (e.g., “there’s no reason to feel this way”). The emotion expressed usually should be validated and normalized (e.g., “I know that this is hard,” “I wish that the news was better”). Therapeutic silence also may be appropriate—being present as the emotion is experienced without comment or judgment.
 - **Offer a plan.** A plan for next steps is reassuring and should be considered irrespective of the planned objectives of the conversation. The plan may be as straightforward as a timeline for a next assessment or a plan for a follow-up conversation. It may be more complicated if the objective involved planning for substantial changes in therapy.

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For more information, see Cystic Fibrosis Foundation Guidelines at
<https://www.cff.org/Care/Clinical-Care-Guidelines/>



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