

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

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)

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Open Ended Questions to Elicit End-of-life Goals

Are these questions part of your initial and on-going assessments?

- ☒ What do you know about your illness/disease? Is there anything else you would like to know?
- ☒ What concerns you most about your illness?
- ☒ How is treatment going for you?
- ☒ What has been the most difficult for you about this illness?
- ☒ What are your hopes about the future?
- ☒ What are your fears about the future?
- ☒ What matters the most for you?
- ☒ What gives you strength to cope with this situation?
- ☒ What do you think is most important to your family?
- ☒ What do you feel they need from you?
- ☒ What are your needs at this time?
- ☒ What are your concerns at this time/and for the future?
- ☒ What do you want to accomplish or do?
- ☒ What do you wish you could still do?
- ☒ What brings you joy/comfort?
- ☒ What is important for you to maintain control over?
- ☒ What do you feel you have control over...disease/pain/decisions?
- ☒ How do you feel about your treatments (medications, radiation, chemo)?
- ☒ If you have pain, what would be an acceptable pain level for you on a 0-10 scale?
- ☒ What activities such as music, art, reading, massage, touch provide peace or comfort to you?
- ☒ What is/are the most important relationship(s) in your life?
- ☒ How would you like to be remembered?
- ☒ Are there things left undone?
- ☒ Is there anyone you would like to see/talk to/visit with?
- ☒ What are you proud of? What are your greatest achievements?
- ☒ How and where do you want to live for the rest of your life?
- ☒ Where (environment) are you most comfortable?
- ☒ What are you hopeful about?
- ☒ What do you wish for?
- ☒ What spiritual or religious practices bring you comfort?
- ☒ Is spiritual peace important to you? What would help you achieve spiritual peace?
- ☒ What role would you like your physician to play in your journey (if any)?

Palliative Care Definitions:

Center for Medicare and Medicaid- CMS- (2012) <https://www.cms.gov/medicare/provider-enrollment-and-certification/surveycertificationgeninfo/downloads/survey-and-cert-letter-12-48.pdf>

“Palliative care” means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

National Consensus Project-2013-Third Edition (<http://www.nationalconsensusproject.org>)

“The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

CAPC-Center to Advance Palliative Care (<https://www.capc.org/about/palliative-care/>)

Palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of palliative care doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

World Health Organization (<http://www.who.int/cancer/palliative/definition/en/>)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;

- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

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www.mypcnow.org

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