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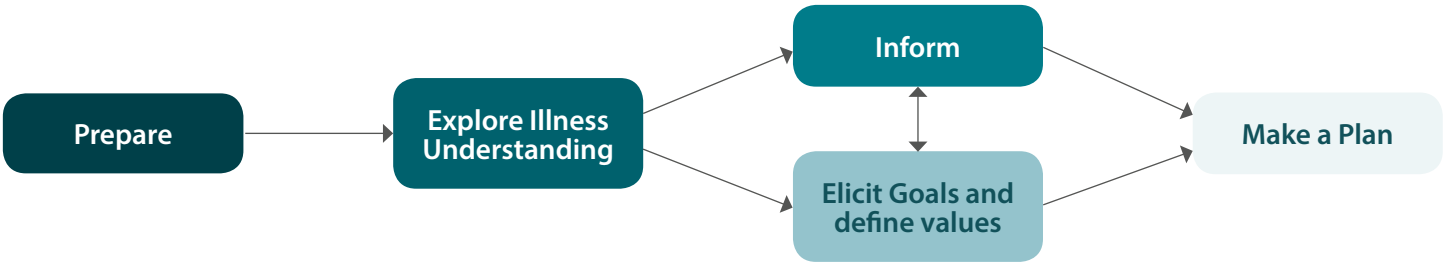
Network

Approaches to Goals of Care Discussions

Resource for healthcare providers



Goals of Care discussions ensure a person living with a life-limiting illness (or, if the person is incapable, the Substitute Decision Maker [SDM]) understands the serious nature of their illness, while helping healthcare providers to understand the patient's values and goals they have for their care. The discussion is focused on the current clinical context, and ensures the individual is better supported throughout their care journey. Importantly, Goals of Care discussions provide the basis for treatment decisions and informed consent.

The approach to a Goals of Care discussion is guided by the framework depicted in the image above. This framework and the content in this resource have been adapted from the Goals of Care E-Learning Module created by Leah Steinberg and Christine Soong (Sinai Health System, Toronto, ON). The discussion should be natural and engaging, so it may not always follow the same order presented in this resource.

Prepare for the Conversation

Before you initiate a Goals of Care discussion with your patient, you should prepare yourself:

- Become a medical expert for your patient
- Acknowledge your feelings
- Remind yourself of the fundamentals of good communication

Essential Communication Skills:

- Ask open-ended/clarifying questions
- Offer reflections and validation
- Use silence to allow time for processing of information and emotions
- Be prepared for emotions

Schedule the discussion in advance to make sure there is enough time, and try to find a private, comfortable space.

Find out if the patient would like to include their Substitute Decision Maker(s) (SDM), family or friends in the conversation. If the patient is capable, explore if they have confirmed their SDM. If the patient is not comfortable with their automatic SDM, discuss preparing a Power of Attorney for Personal Care.

If the patient is incapable, the conversation must occur with the patient's SDM, as the SDM holds responsibility for interpreting the patient's previously expressed wishes, values and beliefs.

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To begin the conversation

Establish rapport with the individual. Shake hands and introduce yourself and other healthcare providers who are present for the discussion. Convey empathy, and encourage response by using eye contact, touch and silence when appropriate, and sitting at the individual's level. Ask permission to begin the conversation:

"If it is okay with you, I am hoping we can talk about where things are with your illness and where they might be going."

1 Explore illness understanding

It is important to ensure the patient understands their illness before you begin to discuss their goals and values. This is not only about patient knowledge, but about the patient's feelings, and what the events mean in the context of their life.

Put the individual at ease with simple, open-ended questions about their family, living situation and response to treatment (if applicable). Allow the individual to express fear and frustration, and acknowledge their emotional distress.

Ask specifically about the patient's symptoms including:

- Pain
- Energy
- Appetite
- Nausea/Vomiting
- Anxiety & Depression
- Shortness of breath

If the patient is interested in knowing more about their current healthcare condition, confirm their understanding of the serious nature of the illness:

"How much do you know about your illness and what it means for your health and quality of life?"

Assess the patient's interest in knowing more about their prognosis:

"What, if any, information about what lies ahead would you like me to share with you?"

Be patient. People often know more than they say at first. It is more powerful for the individual to say the words, than for you to say it to them.

2 Inform

Provide information to the patient, based on their needs. This may include:

- Helping them understand their illness better
- Supporting them with processing their illness
- Supporting them to talk to their family

The information a person needs and can absorb will often depend on their illness understanding.

Be flexible in how you provide the information.

When Sharing Medical Information:

- Speak slowly, pause frequently
- Speak in plain English (no medical words)
- Check frequently for understanding
- Provide time for processing
- Ask them to repeat back what they heard

Give information in short pieces – one or two sentences at a time. Encourage the individual to ask questions, and resolve any outstanding concerns. Pause to see how the information is being heard and to allow for emotions.

If the individual experiences strong emotions, they will not be able to engage with you on a cognitive level.

Manage the emotions before you provide more information.

When Responding to Emotions:

Do:

- ✓ Allow them to happen
- ✓ Acknowledge them
- ✓ Respond openly and honestly
- ✓ Use silence
- ✓ Use "I wish" statements

Do Not:

- ✗ Move on until the emotions settle
- ✗ Offer premature or empty reassurances
- ✗ Backpedal

The individual's risk of mortality (e.g., high-, medium- or low- risk), will affect the nature of the discussion.

It may be helpful to speak in the third person and provide estimates of life expectancy using comments that are not specific to the patient. Normalize the uncertainty of prognosis rather than providing precise predictions of life expectancy.

"We cannot fully predict what is ahead and there is a good amount of uncertainty, but based on your health status and the best available information, I would say about…. It could be longer or shorter, though."

Note: Steps 2 and 3 often come into play together. You may switch back and forth between them within a single conversation.

3 Elicit values and define goals

Learn about the individual's past experiences, hopes, and priorities. Ask about their values and goals.

Examples of Goals of Care Include:

- I want to go to my son's wedding next year.
- I don't want to move to a long-term care home.
- I want to continue working, no matter what.

Consider reviewing goals related to:

- Family and friends, relationships and intimacy;
- Degree of dependence on others;
- Place of residence (e.g., retirement home, long-term care);
- Travelling, hobbies and pastimes; and
- Work and educational aims.

Find out what they are worried about and what resources they need.

Discuss their perception of quality of life and what they consider important moving forward:

"What are your hopes or personal goals as the illness progresses?"

Views on code status may naturally arise. If appropriate, proceed to discuss the patient's views on resuscitation and aggressive treatment (e.g., cardiac compressions, intubation, prolonged ventilation, etc.). Remember that all treatment decisions (including withholding or withdrawing treatment) will require the patient's (or their SDM's) consent.

4 Plan and Document

Work collaboratively with the patient to determine the care that will meet their identified goals and values and develop a plan. Goals and values can help to frame discussions about treatment recommendations, but they should not be used to restrict or limit treatment options.

- Ask if the patient is ready to discuss treatment options
- Relate treatments back to goals and values
- Get feedback to find out what options they prefer

"Based on what you said, it seems like [propose recommended option] would be in your best interest. How do you feel about that?"

Use caring, involved language, and make sure they understand what you are saying.

Document details including the name of the SDM, illness understanding, and other key issues raised during the conversation. Use the identified goals and values to inform the development of a Plan of Treatment. Record the patient's views on medications, tests, resuscitation, intensive care and preferred location of death. If a patient makes any treatment decisions relevant to their current condition (i.e., provides consent), these decisions can be incorporated into their Plan of Treatment. It is recommended that the individual receives a copy of the Plan of Treatment.

Affirm your commitment to the patient:

"We are in this together"

"The team is here to support you and your family"

Close the conversation and summarize what you have heard. It is important to emphasize and repeat what the individual has told you so they know they have been heard.

If the conversation is not going well at any time, try the following tactics to help get it back on track:

- Explain your motives;
- Clarify your understanding of the patient's values;
- Reassess the individual's information needs; and
- Consult other multidisciplinary healthcare providers.

5 Revisit the Conversation

Revisit this discussion regularly, especially if the patient's health status changes. Update the Goals of Care and Plan of Treatment accordingly.

Goals of Care – Conversation suggestions[i,ii,iii]

Conversation flow	Suggested conversation starters
To begin the conversation Introduce idea and benefits Ask permission	• If it is okay with you, I'm hoping we can talk about where things are with your illness and where they might be going. • As you begin treatment [or settle into a routine], it is a good time to discuss your goals and preferences.
1. Explore Illness Understanding Confirm the individual's understanding of the serious nature of their illness	• I'd like to hear from you about your illness, and what it means for your health and quality of life? • What is your understanding of what lies ahead with your treatment and overall health? • It would be helpful to hear what has been going on from your perspective (or in your own words…) so I know what other information you might still need
2. Inform Assess individual's interest in knowing more about prognosis	• What information about what lies ahead would you like me to share? How do you like to get information? • Would you like statistics? Would you like to talk about the big picture? • Sometimes people with a life-limiting illness think about how long they might have. Is that something you are thinking about?
Normalize uncertainty of prognosis	• We cannot fully predict what is ahead and there is often some uncertainty. Based on your health status and the best available information, I would say about [provide estimated prognosis]… . It could be longer or shorter, though.
3. Elicit values and define goals Ask the patient about their past experiences, hopes, values and priorities	• What are your hopes or personal goals as the illness progresses? • Are there any milestones you have in mind that you would like to achieve? • We want to make sure the care you receive honours what is important to you. What sort of quality of life would you find acceptable and what would you find unacceptable? • When you think about the future, what do you worry about? • If time were limited, what would be most important for you? Where would you want to be cared for? • What would you want to make your final days be more peaceful for you and your family? • What has been the hardest part of this illness for you? What about your (wife, husband, partner, children)? • What do I need to know about you, or your personal, cultural or spiritual background that could help us provide you with the best possible care? • What are you hopeful for? Do you have any fears?
After clarifying values, determine overall Goals of Care	• Given what you have told me and what I know about your illness, it sounds like [insert what you've heard, e.g., "trying to prolong life" or "focusing on comfort" or "a mixture of…"] is important to you now. Have I understood your Goals of Care correctly?
4. Plan and Document Discuss treatments in relation to identified goals and values	• Based on what you said, it seems like [propose treatments that you do recommend] would be in your best interest. How do you feel about this? • Given what you have told me about yourself and what I know of your medical condition, I do not think that [treatments that you do not recommend] are right for you because of the following reasons… • We want to help you with your goals. There are different things that we can do to help you feel better. Let's talk about the options, and figure out which ones will help you meet your goals
5. Revisit the conversation Update the Goals of Care and Plan of Treatment accordingly	• We have talked about your goals and priorities before; I'm checking in now to see whether you've changed your mind about anything we discussed.
If the conversation is not going well at any time	• I talk with all of my patients about this. I am asking these questions because I care about your health, and I want to be open with you • I understand this is a difficult topic. When people get sicker, they often lose the ability to tell their healthcare providers about the kind of care they want. This leaves families and providers guessing about your goals, which can be distressing for everyone. Can you help us understand what is important to know about you so that we can give you the best care for you now and in the future?

i. Mandel EI, Bernacki, RE, Block SD. Serious illness conversations in ESRD. Clin J Am Soc Nephrol. 2017;12:854-63.

ii. Speak Up Ontario. Just ask: a conversation guide for goals of care discussions [internet]. Canadian Researchers at the End of Life Network. [undated; cited [2017 September]. Available from: http://www.advancecareplanning.ca/wp-content/uploads/2015/09/acp_just_ask_booklet-rev-july20_final-web2.pdf.

iii. Goals of Care E-Learning Module created by Leah Steinberg and Christine Soong (Sinai Health System, Toronto, ON).

For more information about the Ontario Palliative Care Network, please visit ***ontariopalliativecarenetwork.ca***

Need this information in an accessible format?
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