

GOC Discussions – Structure, Flow and Suggested Language

PREPARE

- Make sure you have all the information you need to conduct an effective encounter:
 - Diagnosis and prognosis
 - o Uncertainties about the diagnosis or prognosis, including options for further investigation
 - o Options for treating or managing the condition, including the option to take no action
 - The nature of each option, what would be involved and the likely outcome
 - The potential benefits, risks of harm, uncertainties about and the likelihood for success for each option including the option to take no action
- You are there to guide the person through the decision-making process:
 - o Make sure the information you share about care and treatment options is objective
 - Be aware of how your preferences might influence the advice you give and the language you use
- Know who should be present for the conversation:
 - o Suggest including the SDM, to prepare them for future decision-making, if needed
 - o Suggest family/caregiver involvement in discussions, to foster shared understanding
 - Plan for a medical interpreter, when appropriate
 - Allocate enough time to give information and answer questions:
 - These discussions should be embedded in most clinical interactions as illness progresses and treatment options change
 - In some cases, it may be more appropriate to have a scheduled visit/meeting with dedicated time (e.g., at the end of clinic) to have a more fulsome discussion
- Consider a team approach to GOC:
 - o Ensure consistent messaging
 - Ensure roles are clarified
 - A physician or physician extender (e.g., Nurse Practitioner, General Practitioner in Oncology) can assess illness understanding and share prognosis
 - The remaining parts of the conversation can be facilitated by other team members
- Care should be respectful of gender, sexual orientation, socioeconomic status, housing, age, background (including self-identified cultural, linguistic, ethnic, and religious backgrounds), and disability.
- At the beginning of the visit collaboratively set an agenda. Example: "What information about your cancer (or your care and treatment) are you hoping to learn today?"
- If the objective of the discussion is illness understanding:
 - "I'm hoping we can talk about where things are with your cancer and what it means for your overall health. Would that be ok?"
- If the objective is informing and/or obtaining consent for care or treatment:
 - "I have the results of the [tests, imaging] you had yesterday. Are you ok if we talk about the results?" and "Would you like to talk about what this means?"

- "As discussed at our last visit, it's a good idea for us to plan together. We don't have to make decisions today, but I think it is a good time to start the conversation and to include your [substitute decision-maker, family, caregiver] in our discussions. Would that be okay?"
- "These discussions are an important part of the care we provide for all our patients"

EXPLORE ILLNESS UNDERSTANDING

- Ensure illness understanding so you know where the person is starting from. This is not only about a person's knowledge of their clinical situation, but about their feelings, and what it means in the context of their life.
- Start with neutral, open-ended, probing questions. Example: "Help me understand what you know about your cancer.... (PAUSE).
- Then, encourage the person to tell you more by listening to what they say and asking further clarifying questions. "You are right about the [treatment] tell me more about what you know about why we are using the [treatment]"
- Assess their interest in knowing more about the prognosis. *Example: "People with cancer often think about the future and what it might look like. Is this something you think about?"*
- Use silence to allow time for the processing of information and exploration of thoughts and feelings. Resist the temptation to finish a sentence or make their point for them.
- Offer reflection and validation by paraphrasing and restating both feelings and words. Examples "This has been a tough time for you and your family, and you have faced the challenges of this illness with great courage." or "I hear you saying that you aren't sure what to do now..."

INFORM – DIAGNOSIS AND PROGNOSIS

- Share information clearly and succinctly using plain, nontechnical language.
- Give information in 'small amounts' using one or two sentences at a time. Keep it simple.
- Use frequent pauses so the person has time to absorb what has been said (supportive silence).
- Wait for the person to respond before saying anything more. If they do not say anything, you can ask questions. Example: "What's going through your mind?"
- Respond compassionately. Example: "This is a lot for you to think about" or "You look like you feel overwhelmed."
- Avoid minimizing the bad news or changing the subject.
- Titrate the amount of information to the person's emotional state.
- Check for understanding using a "teach back" method (<u>http://teachback.org/</u>)
- Affirm your commitment. Example: "It's my job to help you get the best care possible."
- Discuss the meaning of the findings. Examples: "In my experience, people in your situation often [discuss illness trajectory]" or "We need to prepare for the real possibility that [specify the concern]"
- If appropriate, help find additional sources of support. Example: "Other people in your situation have found it helpful to talk to a social worker. I can refer you to a social worker who is an expert in supporting people coping with cancer."



INFORM – CARE AND TREATMENT OPTIONS

- Focus on what can be done
- Clarify the goals of care and treatment so the person (or their SDM) understands the likely outcomes. Example: "The goal of this treatment is [cure (make your cancer go away), prolong your life, giving you more time, improve your quality of life]."
- Discuss frequency and nature of clinic visits, and/or hospital stays including length of time. Example: "This will require [#] visits to the clinic for [length of time for each visit]/ [#] days in the hospital / travelling to [location]".
- Discuss the potential benefits and burden. Example: "This treatment can help with [benefits] but you may feel [symptoms, side-effects]."
- Discuss the likelihood for success, risks, and uncertainty for each option. Example: "It is also important for you to know [likelihood for success, uncertainty, risks]."
- Discuss other options including taking no action. Examples: "You may also want to consider [other treatment/care options]" and "If you decide not to have treatment, [trajectory with no treatment]."
- Reinforce that they will not be abandoned, regardless of treatment choice. Example: "I want you to know that we will care for you and do everything we can to do what is best for you."

RESPOND TO EMOTION

- Acknowledge and name the emotions. Examples: "You seem sad today" and "Help me understand how you're feeling about what we discussed"
- Use partnership and supporting statements. Examples: "I know you have had a rough time and I want to do what I can to help you feel better."
- Use silence to provide reflective space
- Show compassion
- Attend to the emotional responses in the room

ELICIT GOALS AND VALUES

- Find out what they are worried about. Examples "What fears (worries) or concerns do you have about your cancer and overall health?"
- Find out what information they need for decision-making. Example: "What information do you need to make decisions about your care or treatment?"
- Learn about their goals, values, hopes, and priorities. Discuss their perception of quality of life and what they consider important moving forward. Examples:
 - "What do you hope treatment will do for you?" and "What is most important to you? What gives your life meaning? What does a good day look like?"
 - o "What symptoms, side-effects or situations would be hard for you to cope with?"
 - "Are you willing to cope with these symptoms, side effects or situations to achieve what is important to you?"
 - "What gives you strength when you think about the future?"



- Explore how a person's culture, religion or spiritual belief system may influence their decision making or care preferences. Example: *"How does your faith/beliefs affect your decisions about care (and treatment)?"*
- After clarifying values, determine overall goals of care: Example: "Given what you have told me and what I know about your illness, it sounds like [insert what you've heard, e.g., "living longer" or "being comfortable without symptoms" or "a mixture of..."] is important to you now. Have I understood correctly?"
- Anticipate that goals and preferences may change over time in response to disease- and treatment-related factors as well as physical and emotional changes. Example: *"In the past you expressed a desire to continue cancer treatment, but I can see this last treatment has been hard on you. I am wondering if your thoughts about treatment have changed?"*

MAKE A PLAN

- Work collaboratively with the person (or their substitute decision-maker) to determine a plan for care (or treatment) that will meet their identified goals and values. Goals and values can help to frame discussions about treatment recommendations, but they should not be used to restrict or limit treatment options.
- Summarize the conversation and discuss next steps. Examples:
 - "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 cancer, 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 we can do to help you feel better. Let's talk about them and decide which ones will help to meet your goals."
- Document discussion in the medical record. This documentation should be in an easily searchable location or separate document (e.g., after-visit summary), rather than being buried within a standard note.
- Close the conversation by affirming your commitment. Example: "We are here to support you and your family."
- Print out a copy of the Plan for the person, their SDM, and/or family/caregiver to help foster a shared understanding of next steps.
- Revisit this discussion regularly. Update the Plan accordingly.

