



**Ontario Health**  
Cancer Care Ontario



# Goals of Care Discussions: Clinician Resource

Ontario Health-Cancer Care Ontario Systemic Treatment  
Program & Goals of Care Working Group

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# Overview

A person's goals of care (GOC) are their overall priorities and expectations for health care; these are based on their personal values, wishes, beliefs, and perception of quality of life, and what they characterize as meaningful and important. Examples of GOC could be curing the disease, prolonging life, relieving suffering, optimizing quality of life, and maintaining control. A person can have several goals. A GOC discussion is focused on the current clinical context, and ensures the individual is better supported throughout their care journey. These value-based discussions focus on ensuring an accurate understanding of both the illness and care (or treatment) options, so the person (or their substitute decision maker) has the information they need to give or refuse consent to care (or treatment). These discussions often lead to the development of a Care or Treatment Plan. Barriers and enablers of GOC discussions are listed in [Appendix A](#).

## Evidence Summary

- Less than a third of people with advanced cancer have had a GOC discussion with their team<sup>1,2</sup>
- When discussions do take place, rates of documentation range from 6% to 20%<sup>3,4</sup>
- People facing serious illness prefer to actively participate in care planning<sup>5-8</sup>
- People with advanced cancer desire frank discussions with their clinicians about their prognosis and preferences for care, preferably early in the course of disease<sup>9-11</sup>
- People with cancer are more likely to receive care consistent with their preferences when they have had a GOC discussion with their physician, and are more likely to opt for symptom-directed care when there is a poor prognosis<sup>12,13</sup>
- There is a lack of GOC documentation templates used across cancer centres

## A Model for GOC Discussions

The approach described below is adapted from the GOC E-Learning Module<sup>14</sup>, the American Society of Clinical Oncology Consensus Guideline on Patient-Clinician Communication<sup>15</sup>, and Ariadne Labs Serious Illness Care Program<sup>16</sup>. In addition, throughout this document, you will find:

- Sample phrases to help build your skill in GOC discussions
- A Quick Note with five prompts to be placed on your desk or in your notes
- A documentation template which can be scanned into the electronic medical record (EMR) or used to build a standardized note template in the EMR system

We encourage you to review these resources and adapt or use them, as appropriate. We also encourage you to work with experienced and trained facilitators on skills practice, experiential role-playing scenarios, and direct observation of clinic encounters.

## 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
  - Uncertainties about the diagnosis or prognosis, including options for further investigation
  - 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:
  - 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:
  - Suggest including the SDM, to prepare them for future decision-making, if needed
  - 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:
  - 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 (<http://teachback.org/>)
- 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?”*
  - *“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.



## GOC Discussions – Suggested Language for Challenging Questions

**Illness Understanding/ Prognosis:** “I am healthy. Now you’re saying I need chemo and surgery. What will this do to my body?”

- **(Observation)** I can see how shocked you are considering how healthy you feel.
- **(Normalization)** Many people with cancer feel overwhelmed by these decisions.
- **(Validation)** It makes sense that you are feeling worried.
- **(Explore Emotions)** Help me understand what side effects from treatment worry you.
- **(Elicit Meaning)** What functions and abilities are essential for you to have a good quality of life?

**Illness Understanding/ Prognosis:** “I am a fighter, and I am going to be fine.”

- **(Validation)** This fighting spirit will help you in the times ahead.
- **(Hope)** I hope we can stop or slow down the growth of your cancer.
- **(Worry)** However, I worry about how quickly it is growing.
- **(Wonder)** I wonder if there are other things you could fight for if you can’t beat the cancer.

**Illness Understanding/ Prognosis:** “What will my quality of life be?”

- **(Hope)** I am hopeful we can help you get some of your strength back.
- **(Worry)** However, I am worried you may not get much stronger than you are now.
- **(Elicit Meaning)** Tell me about some things you might still enjoy doing even if you do not get stronger than you are now.

**Mismatched Expectations/ Intense Emotions:** “What happens next? Am I going to die from this?”

- **(Wish)** I wish I could tell you that we could stop this cancer and you have many years left to live.
- **(Worry)** However, I worry you may only have weeks or months left to live.
- **(Observation)** I can see you did not expect to get so sick so quickly.
- **(Wonder)** Knowing you don’t have as much time as we hoped, can we talk about your goals for the next few weeks.

**Mismatched Expectations/ Intense Emotion:** “I don’t want to die! There must be another option”

- **(Validation)** This must be very scary for you.
- **(Explore Emotion)** Help me understand what you’re most afraid of.
- **(Reassurance/Support)** Even though we don’t have more options, you will always be cared for.
- **(Wonder)** I wonder if we can talk about what this means for you. What is most important to you given how things have changed?

**Mismatched Expectations/ Intense Emotion:** “I was promised a surgery. That’s why I did chemo!”

- **(Validation)** I’m sorry as this must feel like we let you down. This must be so hard for you.
- **(Wish)** I wish things were different. I wish your cancer had responded to the chemo.
- **(Hope)** Even though we can’t do surgery or more chemotherapy, we can do other things to help you feel better.

**Mismatched Expectations / Intense Emotion:** “This can’t be happening. I need to be at home for my kids.”

- **(Reassurance/Support)** We will do everything we can to help you live in a way that honours your wishes.
- **(Prepare)** I also want to be honest. It may be better for you to be in hospital because unexpected things can happen.
- **(Wonder)** Can we talk a bit more about this? I know this is a hard conversation, but it’s important we have a back-up plan in case we need it.

**Reluctance to Stop Treatment:** “If you just gave me the treatment, everything would be fine”

- **(Elicit Meaning)** Tell me what you hope treatment will do for you.
- **(Wish)** I wish I could tell you that more treatment would help you.
- **(Prepare)** We are in a different place now and treatment will not help you like it did before.
- **(Normalization)** For many people stopping treatment can feel like giving up. Many people feel better and live longer than expected after stopping treatment. This is because they don’t suffer the side effects and complications from treatment.
- **(Reassurance/Support)** There are other things we can do to help you feel better.

**Avoidance/Resistance:** “Are you giving up on me?”

- **(Reassurance/Support)** No matter what decisions we make, we are never giving up. We may choose to focus on different things that are important for your best quality of life.
- **(Elicit Meaning)** Can you tell me what in your life is most important to you?

**Avoidance/Resistance:** “Things seem to be going so well. Why do we have to talk about the future?”

- **(Validation)** I’m happy you are feeling so well.
- **(Hope)** I hope things stay this way for a while.
- **(Prepare)** I do worry that as your cancer grows, you may not feel as well as you do now.
- **(Reassurance/Support)** It’s a good idea for us to plan together so that we are prepared in case things don’t go as well as we hope.

**Avoidance/Resistance:** “I know I will beat my cancer. What’s the point in talking about Plan B?”

- **(Hope)** We talked about plan A today, and I hope it works as well as expected.
- **(Prepare)** However, not all cancers respond to these treatments.
- **(Reassurance/Support)** Even if Plan A does not work as we hope it will, we will look for other options that can help you. That is why I want us to talk about Plan B.

**Avoidance/Resistance:** “Why do we have to be negative? Can’t we focus on the positive?”

- **(Validation)** You’re right, it is important to focus on the good things in life.
- **(Prepare)** I want to be prepared to help you in the best possible way I can when you are not feeling well.
- **(Wonder)** I wonder if we can talk about what’s important to you, so we are prepared for when you are not feeling well.

**Avoidance/Resistance:** “I don’t really want to talk about it.”

- **(Observation)** I can see this is difficult for you.
- **(Explore Emotion)** Help me understand why you don’t want to talk about it.
- **(Validation)** It must be stressful to think about your illness/what lies ahead/test results.
- **(Reassurance/Support)** I’d like to talk about this with you so we can plan how best to help you.

**Avoidance/Resistance:** “It was awful to see my mom in pain from treatments. I don’t want that.”

- **(Validation)** Thank you for sharing that with me. It must have been very difficult for you.
- **(Explore Emotion)** Help me understand what your concerns are.
- **(Normalization)** When most people hear of a serious illness, they often think about what their loved ones went through, but this is your journey.
- **(Reassurance/Support)** I’d like to talk about this with you so we can plan how best to care for you.

**Protection:** “I can’t tell my family how I sick I am.”

- **(Explore Emotions)** Tell me what worries you most about telling your family.
- **(Validation)** I appreciate how important it is for you to be strong for them.
- **(Support)** I know this is difficult to talk about, because you care so deeply for your family. However, it may be a good time for us to talk with them.

**Protection:** “Don’t tell my mother how sick she is. She couldn’t handle it.”

- **(Explore Emotions)** Help me understand why you think your mother couldn’t handle this.
- **(Validation)** I respect your concerns.
- **(Inform)** At the same time, I have a professional responsibility to share information with her if she wants me to. I will ask her how much she wants to know and take her lead.
- **(Reframe)** It would be great if you could join us for this discussion. This will allow us to better understand what your mother wants to know.

**Family Involvement:** “My family will decide how to proceed”

- **(Explore)** What if your family wants your care to look different from what you might want? How can we include them in these conversations to make sure your care is based on what is important to you?

**Family Grief:** “I know she is going to get better.”

- **(Explore Emotions)** Help me understand what getting better means for your mom.
- **(Validation)** It must be difficult to imagine that she may not survive.
- **(Reframe)** It would help us to know more about your mom as we care for her.
- **(Elicit Meaning)** Can you tell me what about her life is most important to her?

**Honoring individual perspectives, religion, culture, and spirituality**

- **(Observation)** I can see your faith/beliefs is very important to you.
- **(Elicit Meaning)** What role does your faith/ beliefs have in how you make decisions about your care?
- **(Reassurance)** I will do everything I can to honour what is important to you as I care for you.

## GOC Discussions - Quick Note

### Goals of Care

1. What do you understand about your illness (cancer)? What does this mean for your future?
2. What are your fears and worries?
3. What is ‘most’ important to you?
4. What do you hope treatment will do for you?
5. What are you willing to cope with and not?

# GOC Discussions – Documentation Template

## GOALS OF CARE DOCUMENTATION SUMMARY

## DATE

## AFFIX PATIENT LABEL

### Reason for GOC discussion

- Treatment or care decisions to make
- Admission/Transfer to a New Facility
- Code status discussion
- Follow up from previous GOC discussion
- Information sharing
- Other \_\_\_\_\_

### Discussion Participants

- Patient    SDM    Family /Caregiver(s)
- Oncology Team    Allied Health

### What Information was Provided?

- Diagnosis \_\_\_\_\_
- Prognosis
  - Years
  - Many Months to Years
  - Months to a Year
  - Few months
  - Weeks to Months
  - Days to Couple of Weeks
- Treatment Approach
  - Aggressive treatment for possible cure
  - More effective lines of therapy to prolong life or help symptoms
  - Few options that will prolong life or help symptoms
  - Supportive Care only - no drug options to control cancer
  - Radiation for symptoms
- Treatment options (including Drugs/Regimens/Care) (please see dictated note for further details)

\_\_\_\_\_

- Expected benefits, risks, and side-effects of the treatment options

### Important Goals Identified:

- Not discussed
- None identified
- Able to eat and taste food
- Achieve a particular life goal
- Be at home
- Be aware
- Guided by religious/spiritual/cultural beliefs
- Independent
- Improve and maintain function/quality of life
- Prolong life
- Not be a burden
- Physically comfortable
- Provide support for the family
- Other \_\_\_\_\_

### Fears and Worries:

- Not discussed
- None identified
- Ability to care for others
- Burdening others
- Concerns about meaning of life
- Death or dying process
- Emotional/spiritual distress
- Finances
- Getting unwanted treatments
- Loss of control
- Loss of dignity
- Symptoms or side-effects
- Other \_\_\_\_\_

### Function/Abilities Important to Patient:

- Not discussed
- None identified
- ADL (dressing, hygiene, toileting, ambulating, eating)
- Without pain or discomfort
- Interact with others
- Talk
- Being conscious
- Other \_\_\_\_\_

**How much is the person willing to go through to achieve what is important to them? This may include exploring preferences for aggressive treatments and/or resuscitation, if appropriate (e.g., cardiac compressions, intubation, prolonged ventilation, etc.)**

\_\_\_\_\_

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### What Was the Outcome of the Discussion?

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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**\*Disclaimer: This Goals of Care Documentation Summary is only intended to guide discussions on planning care and treatment and is not to be used as patient consent for any course of care or treatment**

### Provider Name & Designation

\_\_\_\_\_

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## Appendix A: Barriers and Enablers of GOC

Given the multifaceted nature of the barriers (**Table 1**) and enablers (**Table 2**) identified in the literature<sup>12</sup>, it is likely that strategies will be needed at multiple levels to achieve the positive outcomes of meaningful engagement in GOC.

**Table 1: Barriers to Goals of Care Discussions**

Health care provider/system factors
<ul style="list-style-type: none"> <li>• Clinician discomfort</li> <li>• Lack of confidence</li> <li>• Personal attitudes or beliefs</li> <li>• Difficult prognostication</li> <li>• Desire to avoid conflict, strong emotions, diminish hope</li> <li>• Lack of pre-existing relationship with patient/family</li> <li>• Suboptimal timing for discussion</li> <li>• Lack of time to have conversation with patients/families</li> <li>• Lack of training to have these discussions</li> <li>• Lack of communication skills</li> <li>• Lack of clarity around roles &amp; responsibilities of team</li> <li>• Availability or accessibility of GOC documentation</li> <li>• No organizational structure or processes in place</li> </ul>
Patient/family factors
<ul style="list-style-type: none"> <li>• Language barriers</li> <li>• Low health literacy</li> <li>• Religious/cultural approaches to GOC</li> <li>• Difficulty accepting prognosis</li> <li>• Difficulty understanding treatment options</li> <li>• Lack of family agreement in GOC</li> <li>• High emotional states</li> </ul>

**Table 2: Enablers to Goals of Care Discussions**

Organizational Support
<ul style="list-style-type: none"> <li>• Facilitating engagement and buy-in for GOC</li> <li>• Developing a culture of GOC (i.e., raising awareness about the importance of GOC discussions, reframing GOC as part of routine clinical practice and providing person-centred care)</li> <li>• Comprehensive policy to support GOC including implementation, monitoring, and evaluation</li> <li>• Communicating clear expectations for GOC</li> <li>• Directing resources towards facilitating GOC (e.g., funding, time, personnel, physical space)</li> </ul>

### Training and Education for Providers

- Undergraduate and postgraduate medical education initiatives to build foundational knowledge, and improve comfort with discussions
- Direct observation of clinical encounters
- Working with experienced and trained facilitators (e.g., Hospice Palliative Care Ontario's Health Care Consent Advance Care Planning Community of Practice regional champions)
- Role-playing scenarios and feedback to improve knowledge and skills related to communication
- Sharing resources and experiences within and among regions to facilitate and expedite knowledge translation
- Leveraging existing Ontario-based tools to support GOC

### Interprofessional Collaboration

- Integration of GOC into workflow
- Dialogue between team members to establish plan of care
- Consistent messaging to patient, SDM and family/caregiver
- Coordinating services to achieve patient GOC
- Team approach to GOC
- Ensure all members of the team have some responsibility for GOC
- Ensure role of each member are clarified
- Standardized form for GOC documentation placed in a consistent section of EMR
- Reminders to start/revisit discussions within the EMR
- Bring challenging discussions to case conferences to learn from colleagues

### Effective Communication

- Establish a rapport
- Provide patient information resources to enhance communication
- Suggest SDM, and family/caregiver involvement, where appropriate
- Plan for a medical interpreter or video/teleconference, where appropriate
- Ensure sufficient time for discussion
- Communicate clearly and succinctly in plain, nontechnical language
- Titrate information
- Check for understanding
- Have honest and realistic discussions
- Engage in active listening
- Respond compassionately
- Address questions or concerns
- Respect goals, values, hopes and fears
- Consider culture, religion, or spiritual belief system
- Provide referrals for additional sources of support, where appropriate