



Approaches to Goals of Care Conversations

Resource for healthcare providers

Goals of Care conversations ensure a person living with chronic kidney disease (CKD) (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.

Adapted from Just Ask: A Conversation Guide for Goals of Care Discussions (Speak Up, 2017), this resource includes conversation starters to assist healthcare providers with engaging individuals in Goals of Care conversations. These discussions provide the basis for Treatment Decisions and Informed Consent. As the conversation should be natural and engaging, it does not necessarily need to follow the same order presented in this resource.

Note that additional conversation starters can be found on pages 3-4.

“The successes were in the initiation of conversations upfront, the plans in place and the services arranged to support Mom’s wishes.”

Brian T.'s mother, Doris, died in 2015 at the age of 90, after choosing to withdraw from dialysis.

1 Start the conversation

Goals of Care conversations should happen in a private and comfortable space, and therefore may need to be scheduled well in advance. Confirm the patient's preference when it comes to including family or friends in the conversation. If the patient is capable, explore if they have confirmed an 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.

Begin the conversation by establishing 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.”

Put the individual at ease with simple, open-ended questions about their family, living situation and adaptation to dialysis (if applicable). Allow the individual to express fear and frustration, and acknowledge their emotional distress. Ask specifically about the patient's symptoms including:

- Appetite
- Energy
- Itch
- Weight
- Pain
- Sleep

2 Confirm illness understanding

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

“How much do you know about your kidney disease 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?”

Depending on the risk of mortality (e.g., high-, medium- or low-risk), not all individuals will require the same conversation. 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.”

If the individual is not interested in having a Goals of Care conversation at this time, share with them that planning ahead can:

- Reassure patients that their wishes will be honoured if they become incapable; and
- Reduce stress for the patient’s family and friends if they are asked to make decisions on the patient’s behalf.

Explore the reasons behind the individual’s disinterest, and attempt to address any barriers and concerns. Plan a follow-up conversation to revisit the issue in the future:

“Can I ask the social worker to speak with you about this and I will come back in a few days to discuss it with you again?”

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.

3 Elicit values and define goals

Ask the patient about their past experiences, hopes, values and priorities. 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?”

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 pasttimes; and
- Work and educational aims.

Provide treatment options, with the aim of determining which options are likely to meet these Goals of Care:

“Based on what you said, it seems like [propose treatments that you recommend] would be in your best interest. How do you feel about that?”

Views on code status may naturally arise during Goals of Care conversations. If appropriate, proceed to discuss the patient’s views on resuscitation and aggressive treatment (e.g., cardiac compressions, intubation, prolonged ventilation, etc.).

Note that any treatment decisions made (including withholding or withdrawing treatment) during this conversation require the patient’s (or SDM’s) consent.

4 Allow for questions

Provide the individual with the opportunity to ask questions and resolve outstanding concerns:

“What are some of the questions you have about your Goals of Care?”

If the conversation is not going well at any time, try the following approach 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 Document the conversation

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. Document details including the name of the SDM, illness understanding, and other key issues raised during the conversation. Use these Goals of Care 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.”

6 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^{1,2}

Conversation flow	Suggested conversation starters
1. Start the conversation Introduce idea and benefits Ask permission	<ul style="list-style-type: none"> • As you begin dialysis [or settle into a routine], it is a good time to discuss your goals and preferences. It has been _____ since you started dialysis, which is a good time to discuss how things are going and review your goals and preferences—is this okay? • 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.
2. Confirm illness understanding Confirm the patient’s understanding of the serious nature of their illness	<ul style="list-style-type: none"> • How much do you know about your kidney disease and what it means for your health and quality of life? • What is your understanding of what lies ahead with your dialysis and overall health?
Assess individual’s interest in knowing more about prognosis	<ul style="list-style-type: none"> • What, if any, information about what lies ahead would you like me to share? • Sometimes people on dialysis are thinking about how long they might have. Is that something you are thinking about?
Normalize uncertainty of prognosis and difficult conversations by speaking in 3rd person by framing issues as general rather than as specific to the patient	<ul style="list-style-type: none"> • 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. • I understand that you want more accurate information about the future. The reality is that we can never be certain about the future. I wish I could be more certain but I will give you the information I have.

Goals of Care – Conversation suggestions^{1,2}

Conversation flow	Suggested conversation starters
<p>3. Elicit values and define goals Ask the patient about their past experiences, hopes, values and priorities</p>	<ul style="list-style-type: none"> • What are your hopes or personal goals as the illness progresses? • We want to make treatment decisions that honour what is important to you. What sort of quality of life would you find acceptable and what would you find unacceptable?
<p>After clarifying values and preference, determine overall Goals of Care</p>	<ul style="list-style-type: none"> • 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?
<p>Reduce general statements about Goals of Care to specific orders for medical treatment; propose what treatments may or may not work</p>	<ul style="list-style-type: none"> • 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...
<p>4. Allow for questions Provide the opportunity to resolve outstanding concerns</p>	<ul style="list-style-type: none"> • What are some of the questions you have about your Goals of Care?
<p>5. Document the conversation Summarize what you have heard Provide options Affirm your commitment to the patient</p>	<ul style="list-style-type: none"> • It sounds like _____ is very important to you. • Given your goals and priorities and what we know about your illness at this stage, I recommend _____. • We are in this together. • The team is here to support you and your family.
<p>6. Revisit the conversation Update the Goals of Care and Plan of Treatment accordingly</p>	<ul style="list-style-type: none"> • We talked about your goals and priorities earlier; I'm checking in now to see whether you've changed your mind about anything we discussed.
<p>If the conversation is not going well at any time</p>	<ul style="list-style-type: none"> • I talk with all my patients about this and I am asking you these questions because I care about your health. • 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 how aggressive to be or when to focus on comfort as the goal—this 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?

¹. Mandel EI, Bernacki, RE, Block SD. Serious illness conversations in ESRD. Clin J Am Soc Nephrol. 2017;12:854-63.

². 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.

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