Ontario Health
Ontario Renal Network

Multi-Care Kidney Clinic Goals of Care Discussion Guide

Resource for health care providers

Goals of Care discussions occur in the context of a serious illness when there are treatment or care decisions that need to be made. The discussions aim to ensure a person living with chronic kidney disease (CKD) (or, if the person is incapable, the Substitute Decision Maker [SDM]) understands the nature and trajectory of their illness, and to help health care providers understand the person's values and goals for their care. A person's goals and values may change over time, as new information or situations arise, so it is important that these discussions are ongoing and occur throughout the illness trajectory.

This resource is intended to guide health care providers as they engage people receiving care in Multi-Care Kidney Clinics (MCKCs) in Goals of Care discussions. Each discussion may not necessarily use all of the prompts in this discussion guide, and further discussions may occur over multiple clinic visits.

Goals of Care discussions are different from Advance Care Planning discussions. Advance Care Planning discussions are intended for people who do not need to make a care or treatment decision. Advance Care Planning focuses on identifying a person's SMD and exploring a patient's values to prepare a SDM to make care decisions in the future. It is not consent for future care.

For more information about the Person-Centred Decision-Making continuum, including Advance Care Planning, Goals of Care, and Treatment Decisions & Informed Consent discussions, please visit the Ontario Renal Network website: https://www.ontariorenalnetwork.ca/en/kidney-care-resources/clinical-tools/palliative-care

Goals of Care Discussions with People Receiving Care in MCKCs

MCKCs provide care to people with high risk of end-stage kidney disease (ESKD), including those with a wide range of health conditions and kidney function. People in MCKCs will need to make a number of crucial, stressful and often complex decisions about their care. As a result, people in MCKCs are often anxious or distressed. While not all individuals in MCKCs will require support to make decisions about ESKD treatment options (e.g. modality education), all people in MCKCs will benefit from meaningful Goals of Care discussions. Understanding what is important to our patients forms the basis for their ongoing care in MCKCs, and ensures their care is aligned with their identified preferences and goals.

Prepare for the Discussion

- Acknowledge your feelings about the Goals of Care discussion.
- Remind yourself of the fundamentals of good communication:

- Non-verbal communication skills such as sitting down and making eye contact.
- Encourage your patients to talk to you – they should be talking more than you.
  - Ask open-ended/clarifying questions.
  - Offer reflections – repeating the last word or phrase encourages your patient to tell you more.
  - Use silence to allow time for processing of information and emotions.
- Be prepared for emotions. Recognizing emotions and knowing how to respond empathetically is key to supporting patients as they move through a serious illness.

- Remember that you are there to help a patient make decisions – not convince them of your viewpoint.
- Know the available treatments, including the burden of the treatment, and its risks and benefits. Goals of Care discussions provide the basis for treatment decisions and informed consent.
- Find out if the patient would like to include their SDM, family or friends in the Goals of Care discussion. If the patient is incapable, the discussion must occur with the patient's SDM. The SDM is responsible for interpreting the patient's expressed wishes, values and beliefs to inform any health care decisions on behalf of the patient.
- Think about your patient. The reason for the Goals of Care discussion and the type of care or treatment decision will be different depending on the patient. Recognize that decisions are often "values-sensitive" and the person's goals and values will influence their decision. Age, degree of multi-morbidity, and kidney function may also influence their decision.
- Note that a Goals of Care discussion is not a code status discussion. Code status is just one decision among many that require a Goals of Care discussion. Some other examples of care or treatment decisions include:
  - A focus on symptom management and quality of life.
  - Prioritizing preservation of kidney function and/or maximizing life expectancy.
  - Conservative care versus type of renal replacement therapy in those who have received modality education.
- Introduce the purpose of the Goals of Care discussion to the patient. Visit the Ontario Renal Network website for resources about Goals of Care discussions to share with patients: https://www.ontariorenalnetwork.ca/en/kidney-care-resources/clinical-tools/palliative-care

Discussion Flow	Discussion Guide
To begin or introduce the discussion	• As you enter the MCKC, let's talk about your kidney disease and think about what is important to you now and in the future. This will help us work together to make sure your care aligns with what is important to you — is this okay? **OR**

	• If it is okay with you, I'm hoping we can talk about where things are with your kidney disease and where they might be going.
1. Explore illness understanding Confirm the person's understanding of the nature of their kidney disease	• It is helpful to start by learning what you already know about your kidney disease. Then we can start from the same place. • What have you been told about your kidney disease and overall health?
2. Inform Assess the person's interest in knowing more about their illness, trajectory and prognosis	*Ask for permission if there is information to share:* • I am wondering if it would be okay to give you some additional information about your kidney disease. • What other information about your kidney disease would you like me to share with you? *Note: this may include sharing information about kidney disease or about treatment options. This information may be new to the patient or SDM, and may clarify the seriousness of their disease. Be ready for emotional responses and practice good communication skills. For example, share information slowly and in parts, pause for reaction, and allow the person to absorb each piece of information.*
Normalize uncertainty of prognosis	*Some questions can lead to difficult conversations. These responses can help normalize uncertainty of prognosis and difficult conversations by speaking in third person, by framing issues as general rather than as specific to the patient* • We cannot fully predict what is ahead [specify the concern, for example, life expectancy or time to needing dialysis] and there is a good amount of uncertainty, but based on your health status and the best available information, I would say about…[provide a range of time]. • I wish I could tell you that you will get better, but I think we may need to prepare for the real possibility that your kidney disease may not improve.
3. Elicit values and define goals Ask the person about their past experiences, hopes, values, and priorities	• What is important to you based on what we talked about today? • What would be important to you if your health situation worsens? • What are your biggest worries about your kidney disease? • What gives you strength as you think about the future with your health? • What functions or activities are the most important to you? • What do you hope your treatment [specify the treatment, for example, the type of renal replacement therapy] will allow you to do?

	• What are you willing to go through to achieve what is important to you or to maintain those functions? • How much does your family know about your priorities and wishes? Have you discussed what is important to you, your goals, and your worries with your family?
After clarifying values, determine overall Goals of Care	• Given what you have told me and what I know about your illness, it sounds like _____ is important to you now. Have I understood correctly?
Examples of goals and values	• "I want to continue working at any cost." • "I have suffered a lot and want to avoid further pain." • "I am tired of the treatments and being poked and prodded." • "I do not want to spend any more time in hospital." • "It is very important for me to die in my own home." • "I do not want to go to a nursing home." • "I do not want to be a burden to my family and friends." • "I want to live longer to be there for my family." • "I want to go to my son's wedding next year."
4. Plan and Document Discuss clarifying values, determine overall Goals of Care	• Based on what you said, it seems like [propose treatments that you do recommend] would help you reach your goals. How do you feel about this? • Do you have any concerns with these treatments?
5. Revisit the conversation Update the Goals of Care and Plan of Treatment accordingly	• We talked about what is important to you earlier. 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 my patients about this, and I am asking you these questions because I care about your health. • We are in this together. The team is here to support you and your family. • I understand this is a difficult topic. When people get sicker, they often lose the ability to tell their health care providers about the kind of care they want. This leaves families and providers guessing about how aggressive to be with the treatment 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. Person-Centred Decision-Making: Documenting Goals of Care Discussions [internet]. Toronto: Speak Up Ontario; 2019 [cited 2021 January 20]. Available from: https://www.speakupontario.ca/wp-content/uploads/2020/04/GoC-template-Oct-2019-final-document-1.pdf
3. Ontario Palliative Care Network. Approaches to goals of care discussions: Resource for healthcare providers. Toronto: Ontario Palliative Care Network; undated [cited 2021 January 20]. Available from: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/ApproachesToGoalsOfCare.pdf