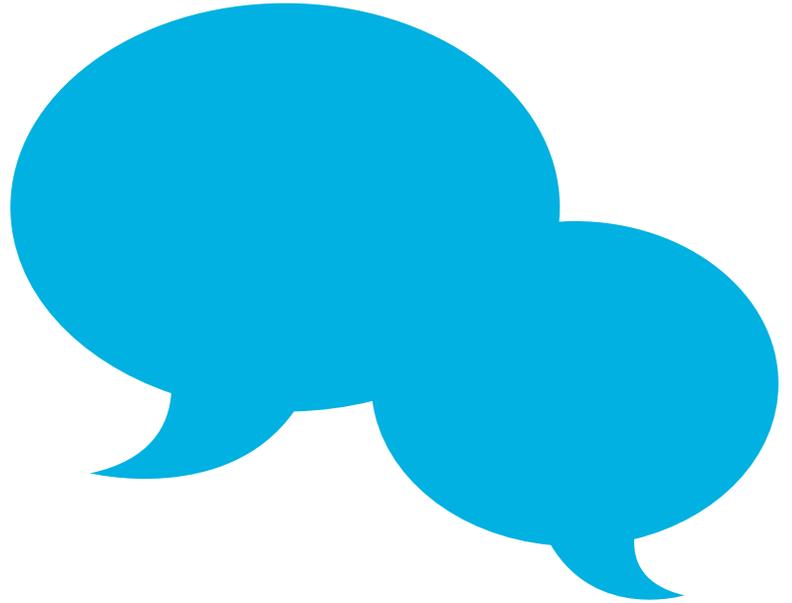




Approaches to conservative renal care conversations

Resource for healthcare providers



Healthcare providers can assist a patient (or, if the person is incapable, their Substitute Decision Maker(s)) to understand conservative renal care and make informed decisions about their care. This resource was designed to support healthcare providers in discussing complex conservative renal care topics with patients and their family/caregivers.

Conservative renal care is a treatment option for people with end-stage renal disease.

1 Defining conservative renal care

Patients and their family/caregivers are often unfamiliar with conservative renal care and it may be difficult for them to understand how it differs from other treatment options. It is important for healthcare providers to ensure patients understand what they can expect from this treatment option.

As part of defining conservative renal care, consider discussing the following:

- Conservative renal care is a holistic, person-centred approach to care. The patient's wishes, values and beliefs will guide development of a treatment plan.
- The focus is to preserve quality of life, address symptoms and maintain kidney function.
- Conservative renal care is not a "no treatment" option. Patients will receive active, high quality medical care to preserve kidney function for as long as they wish. With conservative renal care, the focus of care is on patient symptoms and optimizing patient goals.
 - > While efforts aim at preserving kidney function, the patient's kidney function will continue to decline until end of life.
- It does not include renal replacement therapy such as dialysis.
- Patients can change their mind at any point.

Differentiating conservative renal care from other treatments:

Often, conservative renal care can be confused with other forms of treatment and approaches to care. It may be helpful to clarify how it is different from the following:

Treatments and approaches to care	Comparison with conservative renal care
Dialysis Discontinuation A patient decides to withdraw from chronic dialysis.	When a patient chooses to discontinue dialysis the patient likely has little to no residual renal function – without dialysis ongoing care will focus on comfort to end of life. In conservative renal care, the patient has residual renal function and the focus of care is to preserve renal function.
Dialysis No Longer Possible A patient can no longer continue to receive dialysis care (e.g., failure to obtain access).	When dialysis is no longer possible the patient likely has little to no residual renal function – without dialysis ongoing care will focus on comfort to end of life. In conservative renal care, the patient has residual renal function and the focus of care is to preserve renal function.
Palliative Dialysis Chronic dialysis is given to a patient with short life expectancy who does not yet wish to discontinue dialysis but where symptom management is the primary goal.	While symptom management is also a goal with conservative renal care, management methods do not include dialysis.
Palliative Care An approach to care that focuses on relieving suffering and improving the quality of life for people with a life-limiting illness and their families.	Patients should be aware that all people living with chronic and life limiting illness, including but not limited to advanced kidney disease, receive palliative care regardless of their treatment choice (e.g., conservative renal care, dialysis and transplant).

Ensuring a person-centred approach:

Healthcare providers should explore the needs and preferences of the patient and their family/caregivers, and provide them opportunities to ask questions. For patients who choose conservative renal care, it is important to revisit and confirm this treatment decision annually (at a minimum) and with any changes in health status. Healthcare providers should encourage patients to review the patient resource: **Conservative renal care: what can I expect?**



2 Discussing patient needs

A comprehensive and holistic assessment of patient and family/caregiver needs should occur on an ongoing basis to understand and respond to their current and future needs and preferences across all domains of care. To support your discussion and ensure comprehensive identification of needs, refer to the following domains of care¹ associated with illness and bereavement:



Domain	Description
1. Disease management	Primary diagnosis, secondary diagnoses, comorbidities, adverse events, allergies
2. Physical	Pain and other symptoms, cognition, function and safety, nutrition, wounds, habits
3. Psychological	Personality, strengths, behaviours, depression & anxiety, emotions, fears, dignity, independence, stress, coping responses, self-esteem
4. Social	Cultural values, relationships, isolation, safety, privacy, routines, legal, family caregiver protection
5. Spiritual	Existential or faith-based concerns, values, beliefs, practices, advisors
6. Practical	Activities of daily living (feeding, bathing, toileting, dressing), caring for dependents, instrumental activities of daily living (using the telephone, shopping, preparing food, housekeeping, laundry, using transportation, taking medications, handling finances)
7. End of life care/ death management	Life closure, gift giving, preparation for expected death, anticipation and management of physiological changes in last days and hours, rituals, pronouncement, perideath care, memorial services
8. Loss/grief	Loss, grief (acute, chronic, anticipatory), bereavement planning, mourning

③ Addressing sensitive topics

As a patient and/or their family/caregivers learn more about conservative renal care, they may wish to further understand the potential benefits and side effects of treatment and/or their prognosis. While these conversations may be difficult, it is important to support a patient's understanding of what they can expect in their care journey, as this will facilitate active patient participation in treatment decision-making and ensure informed consent. Patients may also need support in sharing their treatment decision with their family/caregivers.

Discussing the benefits and side effects of treatment:

- Have a Goals of Care discussion with your patients in order to facilitate your discussion about the considerations of each treatment option and how they align with the patient's wishes, values and beliefs. Commonly discussed topics include:
 - > Conservative renal care may mean fewer restrictions to how patients live their day-to-day life (e.g., non-restrictive diet, less frequent hospital visits).
 - > Care may be facilitated in the patient's preferred care setting.
 - > Patients can articulate a preference for non-invasive intervention as part of their care plan (e.g., together you can discuss reducing the use of needles as part of care).
 - > As the kidneys decline, symptoms may intensify, especially close to end of life.
- If a patient asks how conservative renal care compares with dialysis:
 - > Discuss intensity of treatment options in the context of the patient's wishes, values and goals of care.
 - > It may be helpful to explain that dialysis can be a more challenging treatment to tolerate for some patients as it includes getting an access point established (i.e. fistula) and receiving treatment multiple times per week for extended hours, either in-center or at home.
 - > If a patient would like to know about research in this area, describe how studies have shown that for older patients with advanced kidney disease who receive dialysis, the intensity of care is high and may be unwanted.^{2,3}

Discussing the patient's prognosis:

- Explain that prognosis will depend on various factors, such as health status, kidney function, diet, and/or other medical conditions.
 - > e.g., "We cannot fully predict what is ahead and there is a good amount of uncertainty. In general, it's expected to be in short years. This depends on health status and the best available information."
- If a patient asks if conservative renal care will mean a similar prognosis to dialysis:
 - > Explain that dialysis prolongs life for most patients with chronic kidney disease.
 - > If a patient would like to know about research in this area, describe that there is insufficient research to understand patient survival on conservative renal care. Studies show that for older patients (over 75 years) who have higher levels of comorbidity and poorer functional status, the survival advantage of dialysis may be limited and quality of life satisfaction decreases significantly after dialysis initiation.^{4,5,6}

Involving family and caregivers:

- When possible, the patient's family/caregivers should be included in clinic sessions and care planning. In some cases, conservative renal care can be a difficult decision for a patient's family or caregivers to accept.
- Patients may be affected by how their family/caregivers react to their treatment decision. Acknowledge the patient's feelings and provide support where possible. Take time to discuss and validate how the patient is coping.
 - > Have ongoing discussions with your patients about how their family/caregivers reaction affects them, revisit the patient's goals of care and help them to make their own treatment decisions.
 - > Connect patients or their family/caregivers to peer support groups and, if a patient is seeking spiritual support, suggest connecting with existing or community spiritual care.

4 Preparing for disease progression

Preparing for disease progression, including discussing crisis management and end of life, should happen early and throughout a patient's care journey. It is important to both recognize and respect a patient's willingness to participate in discussions about crisis management and end of life.

Crisis management:

As a patient's disease progresses, they may experience a severe event (either sudden or prolonged) within any domain of care. This can be distressing for patients and their family/caregivers.

- Providing examples of crises can help patients understand what to expect and normalize their experience:
 - > Symptom crisis (e.g., nausea/vomiting, itchiness, difficulty sleeping, trouble breathing, pain from other conditions).
 - > End-of-life crisis (e.g., acute confusion (delirium) and agitation).
 - > Practical care needs crisis (e.g., caregiver burnout, lack of personal support services).
 - > Social and psychological crisis (e.g., social isolation, anxiety).
- Patients and family/caregivers should be instructed on how to escalate a crisis, including providing relevant contact information and explaining what to do in the event of a crisis. Information on available after-hour supports should also be provided.
- Support the patient to communicate their preferences and goals of care and ensure they are incorporated in their care plan.
- Reassure family and caregivers that they will be supported throughout the patient's care journey and especially during times of crisis. Help them to understand their role and know whom they can contact for additional support.
- Encourage the patient and family/caregivers to keep their crisis management plan, DNR-C form, conservative renal care decision record, list of current medications, and other applicable information somewhere that can be easily accessed (e.g., on the fridge).

End of life:

The patient and their family/caregiver should be supported to discuss and plan for what is important to them as the patient approaches the end of life.

While these conversations are difficult, the following may assist you to discuss end of life care with patients and families/caregivers:

- Provide examples to facilitate discussions about their preferences for care. The examples could be on discussion topics such as:
 - > "What care would you like to receive if ... were to happen?"
 - > "Would you have a preference for location to die? For example..."
- Explain how the delivery of end of life care may mean interaction with different providers but that the renal program will be available to support patients and family throughout the active dying process.
- Identify and define who they may communicate with or seek supports from:
 - > e.g., care coordinator, care team (e.g., multi-care kidney clinic team), palliative care (e.g., palliative care specialists), home and community care (e.g., hospice).

5 Communication tips

- Try to convey your message and questions in an approachable way. One example is to use the words wish/worry/wonder
 - > Wish: aligns with patient hopes, for example "I wish we were not in this situation, but your kidney function is continuing to decline..."
 - > Worry: subtle way to be truthful and sensitive, for example "I worry you and your family will not be prepared if things get worse".
 - > Wonder: subtle way to make a recommendation, for example "I wonder if we can discuss _____ today?"
- Consider open-ended questions when you are in need of a conversation opener or are having difficulty gaining information for patients and their family/caregiver:
 - > What is your understanding of your overall health and what lies ahead?
 - > Where do you draw strength from?

6 Additional resources

In addition to this resource, you may find the following helpful:

- Resources for Palliative Care – ontariorenalnetwork.ca/en/kidney-care-resources/clinical-tools/palliative-care, which includes:
 - > Resource for healthcare providers (e.g., Person-Centred Decision-Making, Approaches to Care)
 - > Resources for patients (e.g., Making Decisions About Care, Advanced Care Planning)
- Ontario Palliative Care Network’s Health Services Delivery Framework – ontariopalliativecarenetwork.ca/en/healthservicesdeliveryframework
- Health Quality Ontario Palliative Care resources – hqontario.ca/Evidence-to-Improve-Care/Quality-Standards/View-all-Quality-Standards/Palliative-Care
- Virtual Hospice – virtualhospice.ca/
- Pallium pocket book – pallium.ca/mobile-app-pocketbook/
- Serious Illness Conversation Guide – ariadnelabs.org/areas-of-work/serious-illness-care/
- Guide to Advance Care Planning – ontario.ca/page/information-seniors
- National Online Directory of Hospice Palliative Care Programs and Services in Canada – chpca.net/family-caregivers/directory-of-services.aspx
- Learning Essential Approaches to Palliative Care (LEAP) – pallium.ca

- > Tell me a bit about how kidney failure is affecting your life?
- > What is the hardest thing about this for you?
- When identifying steps or contact information for patients, develop a clear escalation process (e.g., consider a tree format).
 - > Identify who to contact, when to contact them, and which contexts.
 - > Identify when and how to escalate an issue.
- When possible, use case studies or walk through an example with the patient to illustrate concepts.
 - > For example, in conversations comparing dialysis and conservative renal care, when discussing expected symptoms, what to do in a crisis, etc.
- Offer cultural and linguistic supports where available.
 - > Visual cues can help patients to understand that these options are available and express their need for these services (e.g., wear a button that says “Je parle français” if you speak French).
 - > Seek hospital translation services if the patient and family/caregivers prefer to communicate in a language other than English.

1. Ferris FD, B. H. (2002). A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Ottawa: Canadian Hospice Palliative. Retrieved from: <https://www.chpca.ca/wp-content/uploads/2019/12/a-model-to-guide-hospice-palliative-care-2002-urlupdate-august2005.pdf>

2. Nesrallah G, Dixon S, MacKinnon M, et al. (2015) Palliative and end-of-life care service utilization patterns among Ontario residents dying on dialysis between 2010-2012. Poster session presented at: CSN Annual General Meeting; April 2015; Montreal, QC.

3. Ontario Palliative Care Network (2018). OPCN Regional Profiles 2.0. Internal document. Published July 10, 2018.

4. Kurella Tamura, M., et al., Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med*, 2009. 361(16): p. 1539-47.

5. Hussain, J.A., A. Mooney, and L. Russon, Comparison of survival analysis and palliative care involvement in patients aged over 70 years choosing conservative management or renal replacement therapy in advanced chronic kidney disease. *Palliat Med*, 2013. 27(9): p. 829-39

6. Murtagh, F.E., et al., Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant*, 2007. 22(7): p. 1955-62.