



Ontario Renal Network

2016-2019

# Ontario Renal Network Palliative Care Report

Recommendations towards an approach for  
chronic kidney disease



**Ontario**  
Cancer Care Ontario

Brian T.

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## Supporting Mom's wishes

"My mother went on dialysis at age 85 and continued for five years; she went to the local dialysis unit for the last four. She had many different procedures over the years, but she was coping well—she was very independent. She had a personal support worker in twice a day for the last year of her life, but she continued to live on her own. She also had support from a not-for-profit seniors' organization whose mandate it was to help people stay at home as long as possible through volunteers, transportation and get-togethers.

She chose to withdraw (from dialysis) on her own. She didn't want to do it over the holidays or family vacations. She had a very specific date and planned six to eight months in advance.

She had it all figured out. It was amazing the way she went about telling her providers she wouldn't need their services anymore. I know she was tired. She was very active even on dialysis. Two of her priorities in life were her computer and reading. She lost her eyesight in her 89th year and her quality of life went down. She knew stopping (dialysis) was an option but was very concerned about what her sons would think of her. As sons we have to respect her choice—she's in a position we're not in. She had full support from everyone involved in her life.

She was able to access a spot in hospice with the help of her family doctor. He was very much involved with both my parents' care for the last 30 years.

She had a fantastic team in hospice; we couldn't have been more pleased. It was a wonderful experience in terms of people making that transition. It took all of the angst out of the whole process. We didn't do anything but get her there. They were fantastic and very supportive of her; we felt prepared. They were just great. We were able to stay with her the night she passed.

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.*

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## **About the Ontario Renal Network**

# Foreword

## A message from the Ontario Renal Network leadership team

Advanced chronic kidney disease (CKD) is a complex, life-limiting disorder for which there is no cure. Every year, thousands of Ontarians with CKD are treated with dialysis, as either a life-saving bridge to kidney transplantation or as long-term maintenance. For some individuals, however—particularly those who are elderly, are frail or have multiple comorbidities—the benefits of dialysis may be minimal, burdening patients with disability, significant adverse effects and diminished quality of life in exchange for poor survival rates. Anyone who has cared for people with end-stage CKD has at some point wondered whether there is a better option.

### A new approach

A palliative approach to care is a holistic, person-centred approach to caring for patients with a life-limiting illness and their families. It can occur alongside chosen treatment, with a focus on preventing and easing suffering and promoting quality of life. Treatment goals are based not solely on the patient's physical condition but also personal goals, preferences and prognosis.

Palliative care is a subject of intense interest in all areas of healthcare. As our population ages and rates of chronic illness reach epidemic proportions, end-of-life issues increasingly move front and centre in health systems planning. At the provincial level, significant changes are taking place in the field of palliative care to address gaps in the system and drive a standardized approach for the delivery of palliative care services in Ontario. The recently established Ontario Palliative Care Network has been tasked with implementing the provincial strategy for palliative care outlined in *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (see page 7). This network aligns with the Ministry of Health and Long-Term Care's strategy to prioritize patient choice in palliative and end-of-life care as highlighted in its *Patients First: A Roadmap to Strengthen Home and Community Care*, and will respond to the gaps outlined in the Ontario Auditor General's 2014 Annual Report.



**Rebecca Harvey** – Vice President,  
Ontario Renal Network



**Dr. Peter Blake** – Provincial Medical  
Director, Ontario Renal Network

## Centred on people with CKD

Although the need for palliative care services is not unique to the kidney care system, people with advanced CKD (especially those on dialysis) do have challenges that are distinct from those with cancer or other chronic illnesses. Healthcare providers, renal program administrators and people with CKD and their families highlighted the need for a tailored approach to palliative care during extensive consultations with the Ontario Renal Network for the development of the Ontario Renal Plan II. These insights were echoed by the recently published findings of the *Kidney Disease: Improving Global Outcomes* initiative on supportive care in CKD. This influential international document recommended leveraging existing supportive care models and services, and customizing them for people with CKD and their families.

Towards this end, the Ontario Renal Network convened a working group with representation from multiple disciplines and specialties, as well as from patients and their families. Their breadth of experience was vital, as CKD is a complex medical condition and no one discipline can address all aspects of care. Our consultations with patients and families showed that individual experiences are diverse. The working group's knowledgeable input, diligent efforts, discussions and consultations have now resulted in the development of this document. *The Ontario Renal Network Palliative Care Report: Recommendations towards an approach for chronic kidney disease* provides a provincial framework that will guide the integration of a palliative approach to care for CKD patients over the next three years, and offers key recommendations to implement the framework within Regional Renal Programs in Ontario.

## Caring, compassionate, consistent

Across Ontario, many healthcare providers already offer compassionate, personalized care to people with CKD who are suffering severe symptoms or are approaching the end of their lives. We hope that with sustained provincial palliative care leadership, this person-centred approach will become the standard everywhere and will be integrated into all care delivery throughout the often complex course of advanced CKD.

With this new approach, patients who may benefit from a palliative approach to care will be identified as early as is possible in their CKD course and will have the opportunity to have sensitive, honest and respectful discussions about options that will better meet their needs and preferences throughout the course of treatment, regardless of which treatment they choose. They will have the opportunity to receive information about these options and to share in decision-making. Healthcare providers will have the information, resources and expertise needed to initiate conversations



**Dr. Vanita Jassal** – Provincial Medical Lead, Palliative and Conservative Care, Ontario Renal Network



**Dr. Valerie Schulz** – Practising in Palliative Medicine, London Health Sciences Centre

about death and dying. Partnerships and communication among healthcare providers, particularly between nephrology and palliative care specialists, will ensure patients transition smoothly at every stage and across sites. Collaboration between Regional Renal Programs and the 14 regional palliative care programs will ensure consistent and coordinated implementation of these recommendations across the province.

We realize that this approach will require a fundamental change in the way we think about, provide and support care. But when we all begin to view palliative care as an integral part of—not an end to—kidney care, we will enable patients to exercise their care choices with clarity and support to ensure that their needs and preferences are met.

# About this report

## Work founded on a multidisciplinary team approach

In the spring of 2015, the Ontario Renal Network released the Ontario Renal Plan II (2015-2019). This plan serves as the provincial road map to guide how we will all work together over the next four years to continue to improve the lives of those living with CKD. It addresses patient care across all stages of the kidney care journey, from early detection through dialysis, palliative care and transplant.

One of the goals identified in the Ontario Renal Plan II is to integrate patient care throughout the kidney care journey. This goal is supported by the strategic objective to establish an integrated process for early identification and management of people with CKD who may benefit from a palliative approach to care. *The Ontario Renal Network Palliative Care Report* lays the foundation for this work.

This report was developed by a multidisciplinary working group convened by the Ontario Renal Network. The working group was tasked with advancing the work of *Advancing High Quality, High Value Palliative Care in Ontario* by developing a provincial framework to guide the integration of a palliative approach to care for CKD patients over the next three years and to make key recommendations to implement the framework within Regional Renal Programs in Ontario.

The working group consisted of those who best know the realities of living with CKD: a patient representative, bereaved family members, and more than 20 partners from various clinical (nephrology, palliative, primary, community, psychiatry and hospice care), inter-professional (social work) and administrative (Regional Renal Program, Ontario Renal Network and Cancer Care Ontario) backgrounds. In addition to meeting as a broader group, the members worked collaboratively across six specialty groups, focusing on education, symptom management, transition to end-of-life, and linkages with community and primary care partners.

With this report we intend to show the need for a change in the way CKD patients receive palliative care in Ontario, create awareness for the provincial framework, and promote the recommendations to guide their adoption. Working together, we will ensure that people with CKD have access to an integrated model of palliative care.

## Terminology

Chronic kidney disease (CKD) is defined as the presence of kidney damage, or a decreased level of kidney function, for at least three months. CKD can be divided into five stages, depending on severity. Stages 1 and 2 are quite mild, while Stages 3, 4 and 5 are progressively more serious. Stage 5 CKD includes end-stage kidney disease (or end-stage renal disease, ESRD). People with Stage 5 CKD are typically on or about to start renal replacement therapy (i.e., dialysis or transplant).

In this document, “CKD” refers to advanced kidney disease—i.e., Stages 4 and 5.

# Palliative care in Ontario

## A growing need for all chronically ill patients

Death and dying are difficult subjects for almost all of us. Healthcare professionals may be particularly averse to talk about end-of-life issues because they are trained to focus on maintaining health, fighting illness and prolonging life. For many, death is seen as a failure, rather than an inevitability that we must all face one day.

Palliative care is a philosophy of care that aims to relieve suffering and improve the quality of both living and dying. It is also a topic of growing interest in healthcare. This isn't surprising, given that most Canadians die as a result of advanced chronic disease, such as heart disease, cancer or chronic kidney disease. People with these diseases may require extended care and support from family members and healthcare professionals over many years.

When patients receive hospital-based palliative care, they and their families benefit from reduced symptoms, increased satisfaction with overall care and greater emotional support, as compared with usual care.<sup>1,2</sup> From a health systems perspective, palliative care consultation programs have also been associated with significant reduction in intensive care unit stays and healthcare costs.<sup>3</sup>

Yet, despite the demonstrated advantages of palliative care, there remains a significant gap for appropriate services and support for people who need care for advanced chronic illness.

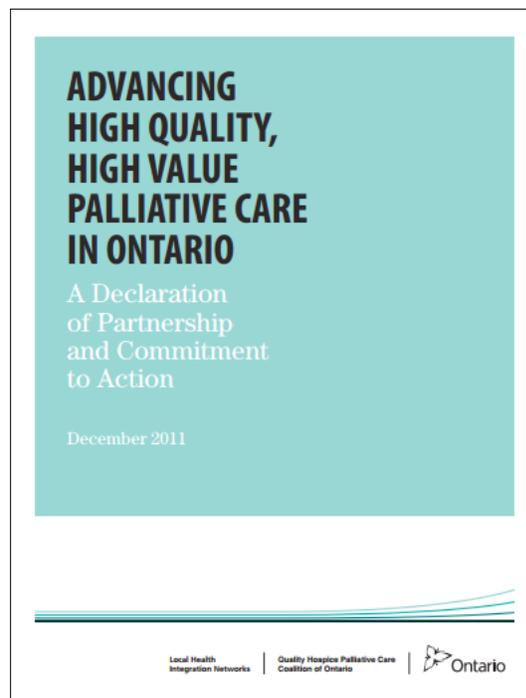
### Building on a common vision

In 2011, a partnership of more than 80 stakeholders from various healthcare organizations developed *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action*. This document presented a common vision for palliative care in Ontario, one in which everyone "with a progressive life-limiting illness, their families and their caregivers will receive the holistic, proactive, timely and continuous care and support they need, through the entire spectrum of care both preceding and following death, to help them live as they choose, and optimize their quality of life, comfort, dignity and security."<sup>4</sup>

## Two publications set the groundwork for a new approach to palliative care

### Declaration of Partnership (2011)

Sets forth a new vision and plan for palliative care in Ontario.



### Ontario Renal Plan II (2015-2019)

Prioritizes palliative and end of life care among renal patients.



May I

**“My husband started dialysis about three years before he died. He had diabetes and many health issues towards the end of his life. He decided to stop dialysis because it all became too much, the treatments and discomfort.”**

May I’s husband died three days after stopping dialysis. She says the support they received from other patients and family members they knew from the dialysis unit was extremely helpful. “They’re closer than family; they know what it’s like to go through all of this.”

## Palliative care: Beginning with a common definition

Palliative care, as defined by the *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* and endorsed by the Ontario Renal Network, is a holistic approach to active and supportive care for patients and their families facing a life-threatening illness.<sup>4</sup> The aim is to prevent and ease suffering, while promoting an excellent quality of life right up until the end of life.

### **Palliative care strives to help individuals and families to:**

- Address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- Prepare for and manage end-of-life choices and the dying process;
- Cope with loss and grief;
- Treat all active issues;
- Prevent new issues from occurring; and
- Promote opportunities for meaningful and valuable experiences, and personal and spiritual growth.

### **Palliative care:**

- Is appropriate for any individual and/or family living with, or at risk of developing, a life-threatening illness, at any time they are prepared to accept this type of care and support.
- May enhance other types of care—including restorative or rehabilitative care—or may become the total focus of care.
- Is most effectively delivered by an inter-professional team of healthcare providers skilled in all aspects of palliative care—including volunteer staff.
- Is most effective when the care is integrated at the clinical, organizational and overall system level.
- Is person and family centred, respecting people’s social, spiritual and cultural practices.
- Includes end-of-life care, but is not limited to the time immediately preceding death.

# The realities of living with CKD

## Unique challenges for patients and care providers

Chronic kidney disease (CKD) and dialysis present challenges to patients and families that are unique from cancer and other chronic illnesses.

At least 15,000 people in Ontario have advanced CKD (2015). An additional 11,000 Ontarians have end-stage renal disease (ESRD, also known as Stage 5 CKD) requiring dialysis as a life-sustaining therapy.

While dialysis prolongs life for most CKD patients, the quality and quantity of life varies from patient to patient.<sup>5</sup> Many individuals with advanced disease experience distressing symptoms, including chronic pain, fatigue, cognitive impairment, depression and emotional stress.<sup>6</sup>

Increasingly, people with CKD on dialysis are often elderly and have complex medical histories. The fastest growth in the dialysis population has been among patients older than

75; the number of these patients on dialysis has doubled in the past 20 years.<sup>7</sup> Many of these elderly patients are dependent, frail and have multiple comorbidities.<sup>8</sup>

In addition, the life expectancy for people on dialysis is poor. The one-year survival rate for Canadians on dialysis is 85 per cent (2009 data), while the five-year survival rate is 43 per cent (2006). Life expectancy for elderly people is even worse: only 25 per cent of patients older than 75 years survive for five years.<sup>9</sup>

Given the burden of symptoms and poor prognosis, it is perhaps not surprising that, according to US data, an increasing number of CKD patients are dying after withdrawal of dialysis: 20 to 25 per cent in 2005, compared to less than 15 per cent in 1990.<sup>7</sup>

## Who are these patients?

A retrospective descriptive analysis was jointly conducted by the Institute for Clinical Evaluative Sciences (ICES) Kidney Dialysis and Transplantation Research Program (KDT) and the ORN. Health services and palliative care use were examined among 5,507 patients with End- Stage Renal Disease on chronic dialysis in the last 365 days of life. Data was used from a variety of linked databases. These datasets were linked using unique encoded identifiers and analyzed at ICES.

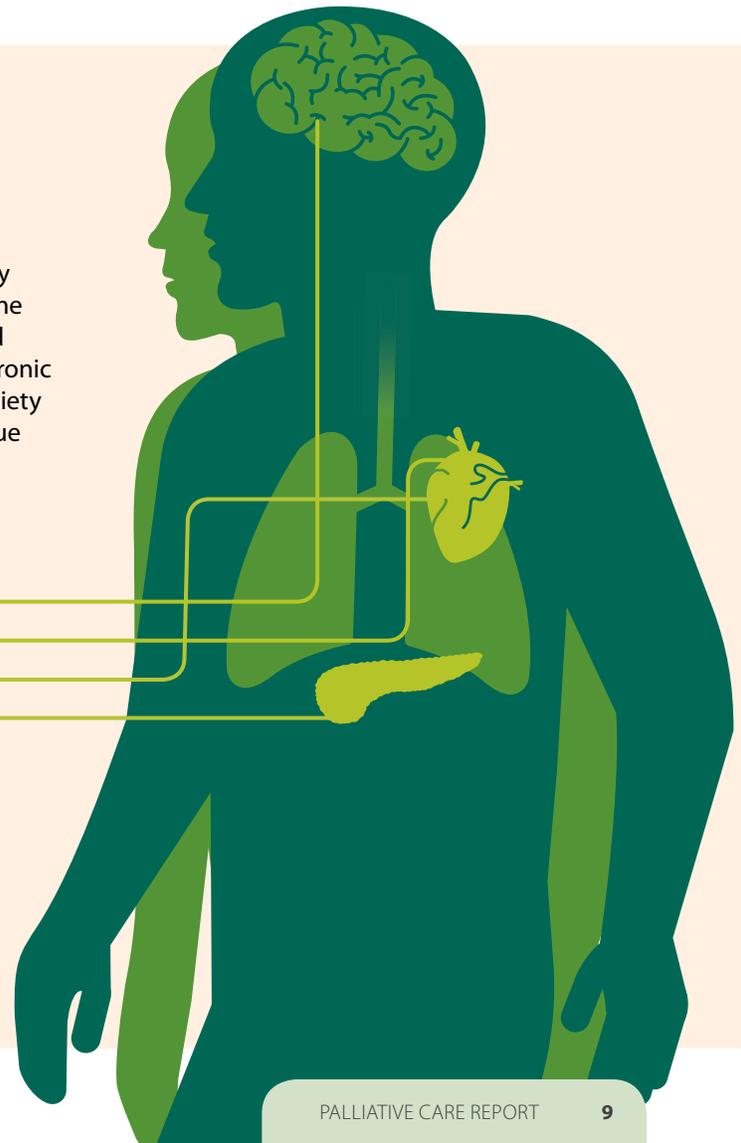
### Multiple Comorbidities

dementia  
hypertension  
cardiovascular diseases  
diabetes

**Advance Age:** 85% > 60 years old

**Short Life Expectancy:** 2.9 years

**58% Men**  
**42% Women**



## Dialysis and the palliative approach

There is an emerging dialogue around the role of a palliative approach to care for those on maintenance dialysis. For example, in a recent paper Vandecasteele and Kurella Tamura argue in favour of classifying patients into one of three treatment groups, each of which will have different expectations<sup>6</sup>:

1. Dialysis as a bridging treatment or long-term maintenance treatment, when the patient is expected to return to usual life activities;
2. Dialysis as a final destination, when dialysis treatment is used to alleviate symptoms but CKD and/or non-CKD disease continue to deteriorate; or
3. Active medical management without dialysis.

One interpretation of these recommendations is that those who have high levels of comorbidity with ongoing concomitant non-renal disease or an unclear prognosis fall under the second “final destination” group, and can be managed with the understanding that they are undergoing a palliative approach to dialysis care.<sup>10</sup>

Charlene B.

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**“My husband was on dialysis for about six months until his death. He was an inpatient and spent the last six months in ICU. The option to die at home was presented in December 2014. He stopped dialysis when they saw there wasn’t much left to do. He wanted to die at home, but the complications didn’t allow for it.”**

Charlene B. was frustrated with the challenges of getting information about her husband’s condition and treatment. “I felt like I was an inconvenience trying to get the right information. It was a continuous cycle of ‘what’s going on?’” she says. She hopes to see improved communication between patients’ family members and healthcare providers.

# Creating a preferred environment for last days of life

## The relationship between palliative care and acute care visits

Many people expect that they will die in their home; in fact, home would be the first choice of setting to die amongst 75 per cent of Canadians who have a preference.<sup>11</sup>

And yet, according to a recent Ontario analysis\*,<sup>12</sup> few people with CKD die at home, and even fewer die having received community-based palliative care services.

Of 41,760 patients in Ontario receiving dialysis treatments between 2010 and 2012, 5,507 subsequently died. A retrospective descriptive analysis of health services and palliative care use by these 5,507 patients found that, within their last 30 days of life:

- **70% died in an acute care setting;**
- **Only 9% had at least one community palliative care visit;**
- **59% accessed medical services through an emergency department (ED); and**
- **38% had care escalated to an intensive care unit (ICU) setting.**

As other research has shown, an acute, non-elective transition to an ICU may be a traumatic and stressful experience that elicits uncertainty for chronically ill patients and their families.<sup>13</sup> The introduction of palliative care services may help avoid this trauma.

	Patients who received palliative care services in last 30 days of life	Patients who did not receive palliative care services in last 30 days of life
ED admissions in the last 14 and 30 days of life	38%; 57%	45%; 60%
ICU admissions in the last 14 and 30 days of life	12%; 15%	38%; 40%
Death in ICU	6%	36%
Death in acute care setting	33%	74%
Death at home <sup>†</sup>	18%	2%

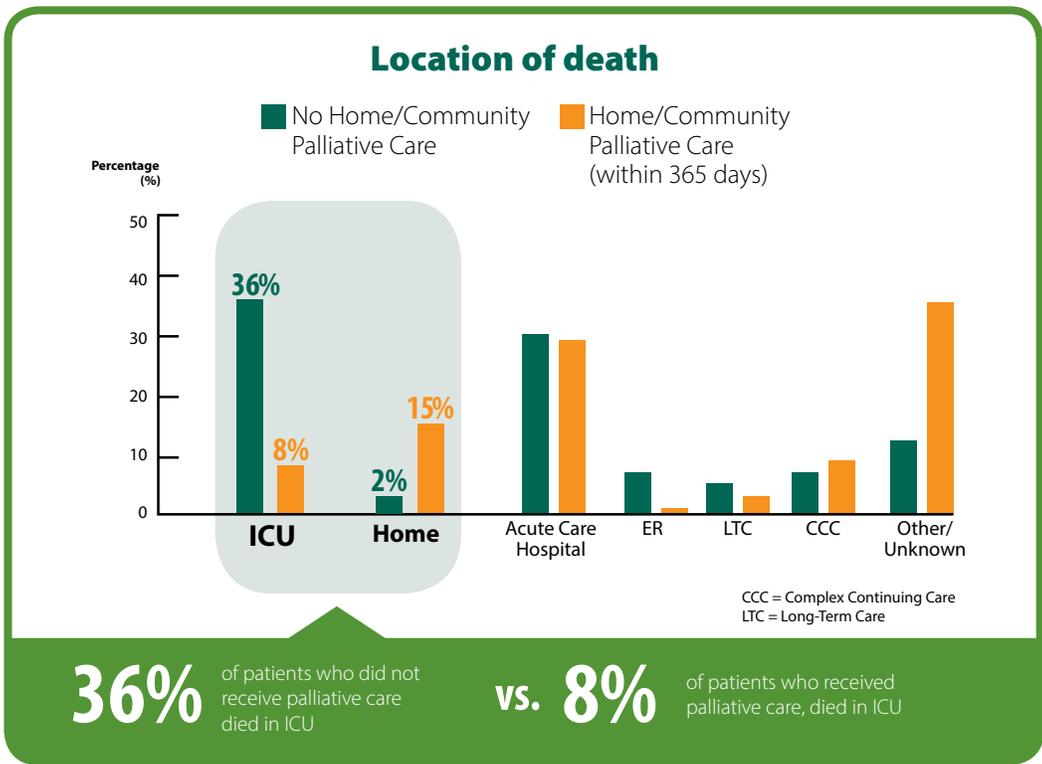
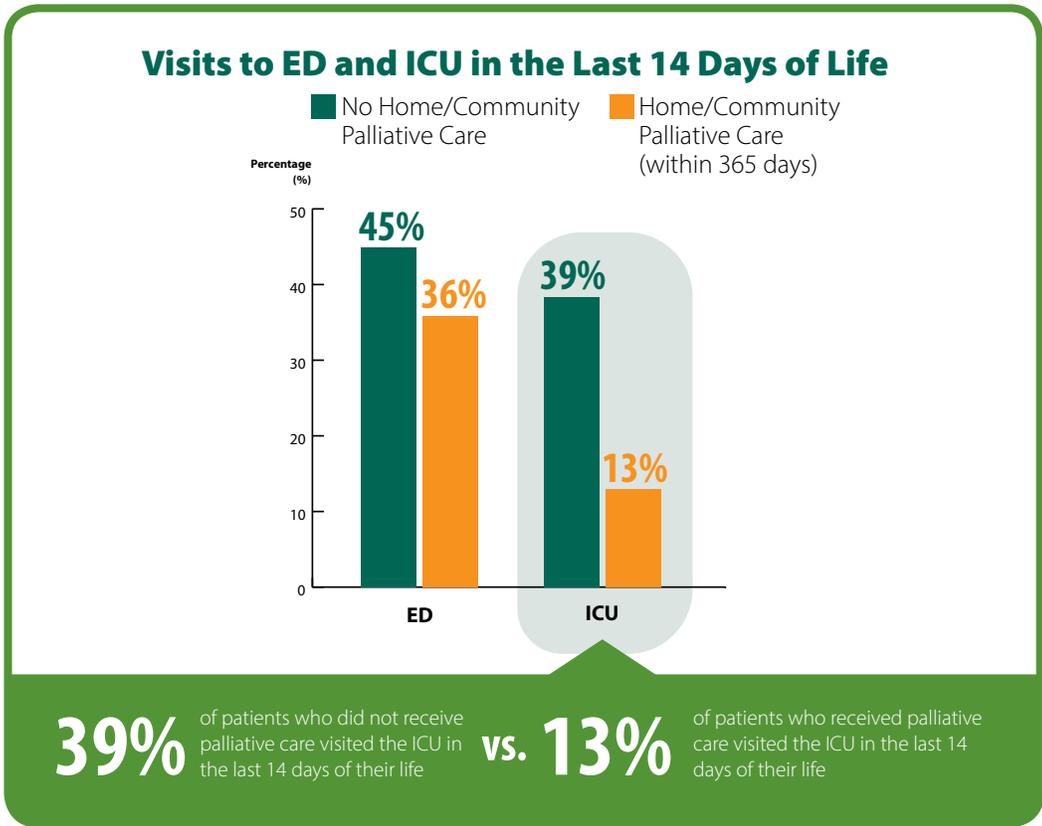
† These figures reflect known instances of death in the home; however, it is estimated that this number may be higher as many of the “Other/Unknown” deaths are estimated to have occurred in the home as well.

\*This study was supported by ICES Western site and funded by the Ontario Renal Network, a division of CCO. ICES is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The research was conducted by members of the ICES Kidney, Dialysis and Transplantation team. The opinions, results and conclusions are those of the authors and are independent from the funding sources. No endorsement by ICES or the MOHLTC is intended or should be inferred.

Parts of this material are based on data and information compiled and provided by CIHI. However, the analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of CIHI.

Although exploratory, the data above presents a compelling case and early opportunity to ensure people living with CKD have access to palliative care services *at least* in the last 30 days of life.

It also suggests that patients who received palliative care services at some point in their *last year of life* were less likely to visit an ED and ICU, and be more likely to die at home when compared to those who did not receive palliative care services.



Anne O.

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## A personal choice

"I was diagnosed with polycystic kidney disease and have been on dialysis for four years. As the years have gone on and I've been in dialysis, I have become close friends to many people, many of whom have died. I see many people who do not speak English or have family members who visit them. I often wondered what would happen when it was my turn. Who would make decisions for me?"

I've done a lot of thinking about dying since I started dialysis. I have always been a very spiritual person. I called my bishop and talked to him about my right to choose not to be resuscitated if my heart should stop. I was adamant that I do not want to be resuscitated. I will never go into a nursing home; I'm very passionate about this. The bishop told me that he thought it was perfectly all right for me to stop dialysis when I thought it was time, and that it was my choice, which gave me a lot of relief. It was very, very important to me to have his blessing. After this, I talked to my social worker and she helped me plan my new advance care plan, did up all of the papers with me, and made it easier to talk to the doctor about my wishes. Then I called my boys to my home. I told them that I had something important to discuss with them, and I handed them each a copy of my plan.

I do not want them to feel guilty for any of my decisions. I went on to ask a friend of mine to become the executor of my will so that it will relieve any pressure from my boys. I want them to know exactly what to do and that it is okay, because—after all—I always make the decisions anyways.

I think that every patient needs to have these conversations. If we had better conversations about advance care planning and choices on treatment options, then maybe families would feel better and not force their loves to continue with treatment that they do not want to do."

*Anne O. is a single mother of five sons. This is an edited version of her story.*

# Identifying priorities

## Palliative service gaps across the province

Without a standardized approach to palliative care for CKD patients across Ontario, approaches to care are determined at the local level.

The Ontario Renal Network consulted with three Regional Renal Programs to learn about the care process for CKD patients as they progress from being identified as entering end-stage renal disease, through treatment modality choice and treatment, to declining health status and end of life. This review included care provided across settings (CKD clinic, primary care, community care and hospice) and, where possible, mapped the roles for healthcare professionals in order to outline a typical patient's trajectory in care.

While these Regional Renal Programs had robust processes in place for treatment and patient education about modality, the consultation revealed limited standard palliative care processes. Specifically:

Betty C.

**"We met with the dialysis doctor one year in advance of David going on to dialysis, which gave me some information into what was to come; but no one can really prepare you."**

Betty C.'s son had a well-planned start to dialysis after an accident that required her to make the care decisions for him. She was aware of the challenge in ensuring David's wishes were communicated to the necessary individuals. "I know that sometimes information about what you want for that person does not travel to the people it should."

### **A palliative approach is usually for conservative care and end-of-life care/patients.**

Two out of three of the consulted programs equated palliative care with conservative care or considered it only for end of life. Some components of a palliative approach (ongoing advance care planning discussions, symptom management) were shown as a distinct part of the conservative care trajectory, while treatment was emphasized in the dialysis trajectory.

### **There is a lack of standard education around palliative care for both healthcare professionals and patients within CKD clinics.**

While education around treatment modality choice was a standard part of most of the surveyed Regional Renal Program processes, there was minimal evidence of palliative care education being provided to patients.

### **Advance care planning is lacking or late.**

All three Regional Renal Programs had processes in place for advance care discussion and planning, but these discussions were often initiated late in the illness trajectory and incorrectly equated by providers and patients with Do Not Resuscitate orders or living wills rather than an ongoing proactive approach to care planning.

### **Providers perceive that patients with end-stage renal disease are not eligible for Community Care Access Centre palliative care or hospice services, resulting in patients not being referred.**

### **There is a lack of coordinated, collaborative, continuous care across care settings.**

Only one Regional Renal Program had standard processes in place to encourage partnerships in care across settings (i.e., social workers coordinated with Community Care Access Centres and notified the primary care providers of the patients' status).

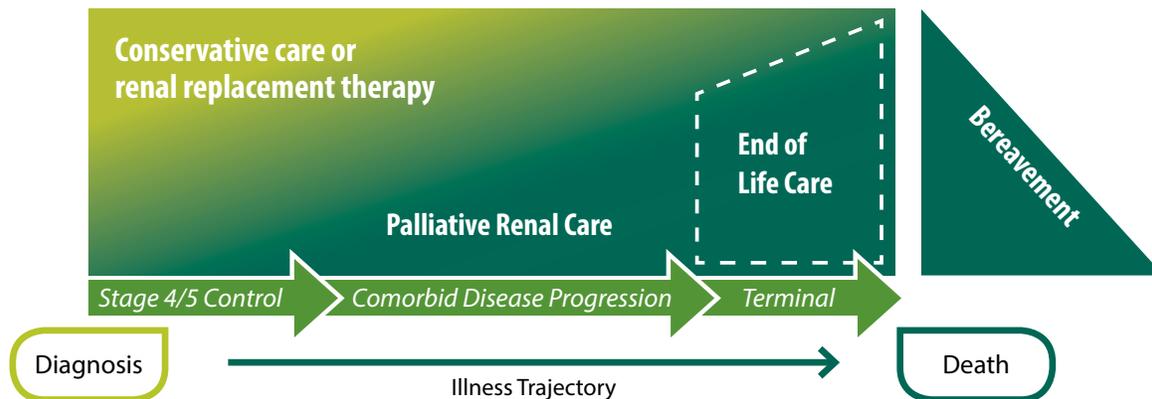
# A new vision for CKD patients

## Ontario Renal Network Palliative Report

The needs of patients with advanced CKD are unique. Many are elderly and are dealing with multiple progressive comorbidities, which together with CKD, decrease their life expectancy and increase their risk of dying in an acute care setting.

Palliative care services for these patients offer numerous benefits, including symptom management, increased quality of life, and advance care planning that leads to better end-of-life experiences, reduced acute care admissions and more appropriate use of healthcare resources.

Despite this, palliative care for people with CKD in Ontario lacks coordination and early planning, and is typically considered only at end of life, or for those who have chosen conservative treatment (kidney care without dialysis). This is in contrast to the model for palliative care presented by *Advancing High Quality, High Value Palliative Care in Ontario*, which presents it as available to patients and families from the time of diagnosis throughout the illness and bereavement experiences.<sup>4</sup> An adapted model for CKD care is shown below.



Adapted with permission from “Advancing High Quality, High Value Palliative Care in Ontario: Declaration of Partnership and Commitment to Action,” HPCO, 2011.

**The Ontario Renal Network Palliative Framework** will guide the approach for integrating palliative care into renal programs over the next three years. This framework was developed based on the findings of the current state review in the literature and Ontario data analysis, and through reviewing the approaches taken by other jurisdictions nationally and internationally.

The key factors identified as contributing to gaps in care and that are addressed by the Ontario Renal Network Palliative Framework are:

### Education

Lack of standardized education for patients and providers

### Integration

No standard identification, assessment and management of people with CKD who may benefit from palliative care  
Lack of availability of palliative care for every treatment modality

### Partnerships

Lack of coordination to ensure seamless care transitions for patients across care settings and Community Care Access Centres

### Capacity

Inadequate resources available in the community to provide a palliative approach to care for people with CKD

# GOAL

To improve quality and advance high-quality palliative care in Ontario for people living with chronic kidney disease by providing an integrated and continuous approach to care earlier and across care settings.

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## Objective 1

To develop **patient and provider education** around the initiation of an earlier approach to palliative care for people with CKD

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## Objective 2

To develop an **organized approach for the early identification, assessment and management** of people with CKD who may benefit from a palliative approach to care alongside their chosen treatment, with emphasis on supportive care and symptom management

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## Objective 3

To **build capacity, linkages and partnerships** to ensure coordinated and continuous management of patient needs across care settings

# At a glance

The following recommendations were developed to increase awareness and improve delivery of a palliative approach to care for people living with chronic kidney disease (CKD) in Ontario. These recommendations align with the provincial direction for palliative care and will be enabled through collaboration between Regional Renal Programs and the 14 regional palliative care programs.

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**1 Educate providers, patients and families** about the benefits of a palliative approach to care for people living with CKD to strengthen service capacity and build awareness.

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**2 Strengthen system accountability** by establishing local clinical champions within nephrology in the Ontario Renal Network Regional Renal Programs to support a palliative approach to care.

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**3 Support shared understanding** of palliative care needs for CKD patients through common terminology among providers across care settings to facilitate clear communication and terminology that is recognizable to patients and families.

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**4 Introduce conversations** about advance care planning and goals of care early. Create accountability to support and review these goals with patients regularly through their care journey.

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**5 Adopt a standard approach** to identify who may benefit from a palliative approach to care, to assess symptoms and to manage care.

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**6 Develop key performance indicators** to measure progress in the next three years.

# Recommendations

The following recommendations were developed to increase awareness and improve delivery of a palliative approach to care for people living with chronic kidney disease (CKD) in Ontario. These recommendations align with the provincial direction for palliative care and will be enabled through collaboration between Regional Renal Programs and the 14 regional palliative care programs.

## 1 Educate providers, patients and families about the benefits of a palliative approach to care for people living with CKD to strengthen service capacity and build awareness.

**1.1** Provide all healthcare providers with essential education through a multidisciplinary approach that aims to enhance the necessary skills and abilities to provide a palliative approach to care for people with CKD. Align education with the broader provincial framework.

Identify educational partners and inter-professional learning opportunities with nephrology, primary care, community, palliative and other key providers (e.g., Pallium Canada's LEAP course, nephrology training programs):

- Identify and train education facilitators (as defined by Pallium Canada's Certified LEAP Facilitator training program) to act as mentors and support ongoing knowledge transfer on a palliative approach to care.

Create or leverage existing local opportunities for inter-professional knowledge exchange, capacity building and care pathway development on an ongoing basis (e.g., nephrology rounds):

- Encourage CKD clinic collaboration with existing hospital and community-based specialist palliative care teams to share knowledge. Ensure a common understanding that a palliative approach to care should be available regardless of CKD treatment modality choice.

**1.2** Adopt/adapt provider education materials for a palliative approach to care and related communication strategies in alignment with provincial standards. Identify and develop CKD-specific materials when required.

Enable communication between patients, providers and families/caregivers, including:

- Crucial/difficult conversations with patients and families; and
- Multicultural considerations.

Introduce care resources and tools to support clinic staff, including:

- The process of advance care planning (how and when to engage), goals of care discussions, and provision of supportive documentation resources (e.g., the legal framework for healthcare consent, substitute decision-maker and power of attorney for personal care);
- Care pathways, symptom assessment and management guides, and statistics/outcomes associated with these tools;
- How to identify complicated grief;
- Bereavement support resources for families; and
- Customized regional resources (local champion, palliative care, pharmacy, nephrology, primary care, etc.).

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**1.3** Adopt/adapt patient and family education materials for advance care planning and end of life in alignment with broader provincial direction. Identify and develop missing CKD-specific materials when required, including visual, written and online educational resources to inform patients and families about a palliative approach to care and to empower them to make informed decisions.

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Adopt Canadian Hospice Palliative Care Association's (CHPCA) "Speak Up" resources to familiarize patients, families and substitute decision-makers with advance care planning, and educate them on the substitute decision-maker hierarchy and Power of Attorney for Personal Care assignment processes.

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Educate patients and families about shared roles in the decision-making process; e.g. through decision aids, "what to expect" and "what is important to you?"

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Ensure resources are available that reflect patients' cultural and spiritual needs; Regional Renal Programs to identify educational materials that meet the needs of their patient population.

Sharon N.

**"The decision to withdraw my mother from dialysis was made after the pain and sores on her feet continued to worsen after 10 months. During her time in the hospital, we were working with too many people and moving from place to place; different departments would know nothing about her."**

Sharon N.'s mother had been on dialysis for eight years before she died. Because no palliative care beds were available, she was admitted to a renal unit, where Sharon spent up to 12 hours a day at her side. Physically and emotionally exhausted, Sharon was not there when her mother died. "She didn't have someone there when she needed them. There needs to be more support," Sharon says.

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## 2 Strengthen system accountability by establishing local clinical champions within nephrology in the Ontario Renal Network Regional Renal Programs to support a palliative approach to care.

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**2.1.** Clearly identify roles and responsibilities for local clinical champions.

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**2.2.** Identify local champions within Regional Renal Programs and connect with regional palliative care programs in their LHINs (14 programs).

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Involve local champion in supporting change across care sectors to ensure processes meet the unique needs of CKD population.

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Engage local champions with regional palliative care programs, as facilitated by Regional Renal Program Directors.

**2.3.** Leverage or create additional opportunities for Regional Renal Programs to develop relationships with palliative care, primary care and community providers earlier for improved integration, collaboration and continuity across care settings. Some opportunities include:

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Promote collaboration between Regional Renal Programs and the regional palliative care programs.

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Identify a palliative care advisor as part of CKD clinic team who understands what resources are available.

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Conduct joint rounds with community and CKD clinics for shared patients.

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Strive to include the patient's primary care provider in joint rounds, or, at minimum, directly communicate with them after rounding:

- Nephrology should be available to primary care for communication, and providing support and resources to help manage patient's symptoms.

Margaret L.

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**“No one ever spoke to us about what to expect at the end of life.”**

Margaret L.'s 74-year-old husband had multiple comorbidities, including CKD for 22 years. At times, she struggled to understand the information her husband's physicians provided: “They talk in medical language rather than regular vocabulary.”

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### 3 Support shared understanding of palliative care needs for CKD patients through common terminology among providers across care settings to facilitate clear communication and terminology that is recognizable to patients and families.

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**3.1.** Adopt the following *Kidney Disease Improving Global Outcomes (KDIGO)* definition of Comprehensive Conservative Renal Care to ensure it is clear and seen as an active treatment plan/strategy:

**“Comprehensive conservative [renal] care (CCRC)** is planned holistic patient-centred care for patients with Stage 5 CKD that includes the following:

- Interventions to delay progression of kidney disease and minimize risk of adverse events or complications;
- Shared decision-making;
- Active symptom management;
- Detailed communication including advance care planning;
- Psychological support;
- Social and family support; and
- Cultural and spiritual domains of care.

Comprehensive conservative renal care is full renal care that does not include dialysis.”<sup>14</sup>

**3.2.** Identify additional terms that need definition and promote common terminology (e.g., palliative dialysis).

#### **Palliative dialysis**

An approach to dialysis care that prioritizes the relief of suffering over the attainment of treatment targets and includes holistic patient-centred care, active symptom management and emotional, social and family support.

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### 4 Introduce conversations about advance care planning and goals of care early. Create accountability to support and review these goals with patients regularly through their care journey.

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**4.1.** Support and encourage patient and family meetings.

Encourage private settings within clinics where patients and family members can discuss wishes and concerns.

Consider cultural and spiritual considerations in conversation and make any supportive resources available.

Identify point of contact within care team to support meetings and address ongoing questions and concerns.

Ensure that conversations are held with multidisciplinary members (e.g., pharmacy, social work) of the care team.

**4.2.** Support and facilitate peer support among patients and families/caregivers (e.g., sharing stories).

**4.3.** Establish frequency (yearly, at admission, change in health status, etc.) and accountability in programs to document and review advance care plans.

Determine the review and communication processes for sharing advance care planning information across care settings.

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## 5 Adopt a standard approach to identify who may benefit from a palliative approach to care, to assess symptoms and to manage care.

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### 5.1. Adopt identification criteria (e.g., the Surprise Question\*,<sup>15</sup> symptom or functional status) to identify who may benefit from further multidisciplinary assessment and more intensive education about a palliative approach to care.

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Encourage primary care providers to initiate advance care planning with people living with CKD or other advanced chronic disease, and those over the age of 65 years. Encourage collaboration between nephrology and primary care to support communication of advance care planning and continuity of care across settings.

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### 5.2. Adopt standard approach and tools to assess and manage symptoms.

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Build clinical provider confidence in managing symptoms through education and support resources.

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Create accountability for symptom assessment, treatment and followup.

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Engage and empower patients to report symptoms. Consider using waiting rooms as education and resource access centres.

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Identify:

- Evidence-based tool(s) for symptom assessment and management. Review how to best use the tool(s) to benefit CKD patients and the kidney care system;
  - One or more patient populations that are considered a high priority for symptom assessment and management, based on symptom burden and goals of care;
  - The frequency with which symptom assessment and management should take place in each patient population;
  - The delivery method that best matches the tool, its use, the patient population and setting, and other practical considerations, such as timelines for implementation and cost; and
  - The workflow, roles and responsibilities associated with all of the above.
- 

### 5.3. Define care pathways.

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Define roles across settings of care and referral/engagement triggers for other specialties and resources (e.g., Community Care Access Centres).

- Encourage partnerships between nephrology and primary care, community and/or palliative care providers who will provide shared care after identifying a patient who may benefit from a palliative approach to care.
  - Consider, when possible, the primary care provider who will provide ongoing symptom management for patients identified in partnership with local palliative care resources and who will act as an advocate for additional service referrals. Consider specialist palliative care consultations for more complex care and symptom needs.
  - Ensure ongoing conversations between providers and patients and family members to ensure timely referrals to specialists for care management.
  - Ensure clear communication between patients, families and providers across care settings during transition points in care about what to expect, and provide available supporting resources.
- 

Develop a comprehensive approach to discontinuing dialysis, consisting of a planned withdrawal process, with ongoing conversations between the care team and patients and families, and between providers across care settings.

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Develop comprehensive conservative care pathway for patients who choose or would benefit from comprehensive conservative care, with resources and workflow to support it.

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### 5.4. Ensure the availability of grief and bereavement support for families and caregivers.

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Identify communication strategies, program services and available resources to support families and caregivers.

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\*The Surprise Question: "Would you be surprised if this person died in the next year?"

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## 6 Develop key performance indicators to measure progress in next three years.

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### 6.1 Consider indicators across care settings and patient and family experience.

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Suggest measurements such as:

- Patient and family experience in care; consider leveraging CaregiverVoice<sup>16</sup> tool to measure patient and family experience at the end of life, in alignment with provincial initiatives;
- Proportion of patients who meet the criteria for evaluation for a palliative approach to care and who agree/choose this approach; meet criteria where dialysis would be considered; die having not undergone dialysis;
- Number of patients who have a substitute decision-maker or Power of Attorney for Personal Care assigned;
- Number of healthcare providers within each Regional Renal Program who participate in palliative education; and
- The use and usefulness of tools used to identify patients who may benefit from palliative care (e.g., Palliative Performance Scale <sup>17</sup>).

Shirley M.

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**“The hospital has a memorial service every year for the patients who passed away. It was really a lovely service, and a lot of people attended. If the family sent in a photo, they showed it with their name on the screen. My husband had a painting hobby, and at the service I donated one of his paintings to the hospital waiting room. It was really very nice.”**

Shirley M.'s husband suffered from multiple health conditions, including kidney failure (after 26 years with a transplanted kidney). “Everything was just more difficult on dialysis,” remembers Shirley. “When a nurse told him he had the choice to stop, he said, ‘I want this to stop and I want this to stop now.’”

# Appendix

## Glossary of terms and concepts related to palliative care

### Advance care planning

In Ontario, advance care planning is an iterative process that involves<sup>18</sup>:

- Identifying the substitute decision-maker who will make decisions on behalf of the patient should they become incapable; and
- Discussing a person's wishes, values and beliefs, and more generally their preferences for how they would like to be cared for in the event of incapacity to give or refuse consent.

Rather than being a single event, advance care planning is ongoing and dynamic, with the potential for personal preferences to change over time as health status changes. It may be initiated at any point in the healthcare process, and may involve individuals who are currently healthy.

### Comprehensive Conservative Renal Care

Holistic patient-centred care for patients with Stage 5 CKD that includes interventions to delay progression of kidney disease; includes active symptom management as well as emotional, social and family support; does not include dialysis.

### Goals of care

Goals of care are identified through open and honest communication between the patient and their healthcare team, and provide the foundation for shared decision-making about a patient's clinical care. Goals of care decisions pertain to the types and extent of clinical care to be provided, where care will be provided, and which healthcare providers will provide the care. Incorporating goals of care into the decision-making process provides an ethical and patient-centred framework to facilitate a well-thought-out and patient-directed approach to ongoing care.

### End-of-life care

End-of-life care refers to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future.<sup>19</sup> It constitutes active care aimed at helping patients and families to prepare for death, ensuring comfort, and making care decisions that are consistent with the patient's prognosis and goals of care.

### Frailty

A non-specific state of vulnerability caused by changes to a number of physiological systems, which may be related to a variety of physical, psychological, cognitive and social factors. Together, these changes lead to reduced function and strength, and affect the person's resilience and ability to cope with any stress, such as an infection, disease or personal loss.<sup>20</sup>

### Hospice care

In Canada, this term generally refers to residential end-of-life care for patients with non-complex needs, and to community-based, largely volunteer-run care that is provided in the home.

### Palliative approach to care

Integrates key aspects of hospice palliative care into the regular care a person receives, so that the appropriate care is available to individuals and families at appropriate times throughout the illness and in all care settings.<sup>21</sup>

### Palliative care

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems (e.g., physical, psychosocial and spiritual).<sup>22</sup>

### Power of attorney for personal care

Under the Substitute Decisions Act, 1992, "A person may give a written power of attorney for personal care, authorizing the person or persons named as attorneys to make, on the grantor's behalf, decisions concerning the grantor's personal care".<sup>23</sup>

### Substitute decision-maker

Under the Health Care Consent Act, 1996, a "substitute decision-maker" means "a person who is authorized under [the Health Care Consent Act, 1996] to give or refuse consent to a treatment on behalf of a person who is incapable with respect to the treatment."<sup>24</sup> The Health Care Consent Act, 1996 sets out a hierarchy of substitute decision-makers.<sup>25</sup>

For more terms, please see the Lexicon developed by The Way Forward: <http://www.hpcintegration.ca/resources/lexicon.aspx>.

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## About the Ontario Renal Network

The Ontario Renal Network—a division of CCO and the Ontario government’s chronic kidney disease (CKD) advisor—is committed to facilitating a provincewide effort to diminish the burden of chronic kidney disease on Ontarians and the healthcare system.

It provides leadership and strategic direction to effectively fund, organize and manage the delivery of kidney care services in Ontario in a consistent and coordinated manner. This includes preventing or delaying the need for dialysis, broadening appropriate patient-care options, improving the quality of all stages of kidney care, and building a world-class system for delivering care to Ontarians living with CKD.

The Ontario Renal Network consists of a vast array of partners including healthcare professionals, Regional Renal Program staff, partner health agencies and organizations, patients and families, and many others. By working collaboratively, the Ontario Renal Network can better leverage the competencies and assets of all, to better achieve our common goals of creating a safe, sustainable, efficient and effective kidney care system for Ontario.

In total, 26 Regional Renal Programs provide dialysis and other kidney care services to over 100 facilities (including hospital and community-based facilities). Community partners, such as long-term care homes and independent health facilities, also provide kidney care services.

People with CKD and their families are at the centre of the network. The Ontario Renal Network actively engages people with CKD and their families in the design, delivery and evaluation of Ontario’s kidney care system.

The Ontario Renal Network shares CCO’s mission of working together to improve the performance of Ontario’s kidney care system by driving quality, accountability, innovation and value.

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