



# PROVINCIAL STANDARDS & GUIDELINES



## Integrative Palliative Nephrology Resource Guide

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Developed by the Palliative Care Committee



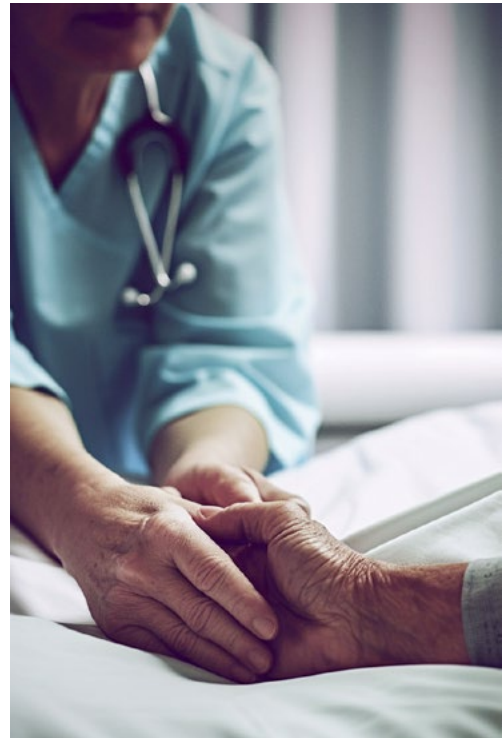
## INTRODUCTION

Integrating a palliative approach to care in conjunction with high quality nephrology care is essential for all people living with chronic kidney disease (CKD). It is a holistic approach where all team members have a role including family members, therefore all care providers in CKD need to understand how to support a palliative approach in all areas of kidney care. See appendix A: for the Bow Tie Model for Palliative Care in Kidney Care.

Integrating a Palliative Approach to Care (IPAC) in CKD is overall care that helps those living with CKD alleviate pain, symptoms and stress while receiving treatment with the primary goal to improve quality of life for both the patient and the family as they navigate their renal journey. A palliative approach with ongoing discussions is essential for comprehensive care of individuals to ensure CKD care addresses what is important to them to enhance their quality of life. Individuals who have these conversations with their clinicians about their values, goals, and wishes are more likely to receive the care they want, feel less distress and report better quality of life.

Building on the End of Life (EOL) framework, BC Renal engaged in an Integrative Palliative Nephrology project to enhance the capacity of renal health care professionals and embed a palliative approach for those with advanced CKD by changing culture, sharing knowledge, and developing resources to support clinicians. Resources were co-developed with patients who understood the complexities across the multi-faceted renal journey and included a multitude of perspectives encompassing cultural diversity, health literacy and diverse geographical settings. These resources are available at [www.bcrenal.ca](http://www.bcrenal.ca) along with additional links to resources from vetted reputable sources.

Some individuals progress in a fairly predictable patterns through these stages, others may shift more rapidly through some areas. Once in End Stage CKD, folks may transition between multiple modalities of renal replacement therapy including transplant, PD, HD to Home HD along with hospital stays for acute illness. As renal care professionals, we provide education, care and support to patients and families along this journey.



**Resources for Integrative Palliative Nephrology** (if dysfunctional link, search the topic at [www.bcrenal.ca](http://www.bcrenal.ca))

**ALL Kidney Care** – suggest all new team members start with ‘Strengthen Your Core’ modules, then work through other resources which apply in your clinical practice.

- This concept map identifies key points in the renal Journey which could trigger a palliative conversation [Starting the Conversation-Exploring Key Concepts Through the Renal Journey.pdf](#) (copy on page 4)
- This learning hub module curriculum provides an intro to key concepts for a palliative approach to CKD [Strengthen Your Core! Palliative Competencies - LearningHub \(phsa.ca\)](#) 8 Module Course
- Article: Understand the concept of Advance Care Planning (including the SIC Guide) <http://www.bcrenal.ca/resource-gallery/Documents/SIC-Conversation-Guide-Version3April2017.pdf>
- Serious Illness Conversation Guide (SICG) video links
  - [Serious Illness Conversation Guide Demo-Ariadne Labs](#) (12 min)
  - [Serious Illness Conversation Guide - Adapted Version - FHHA](#) (5 min)
  - [Adapting the Serious Illness Conversation Guide for pts from diverse communities](#) (52 min)
  - [Living the Best Life Possible: Doctor & Pt Conversations About Serious Illness & Mortality](#) (58 min)
- Staff and Physician Resource: [My Symptom Checklist Info Sheet.pdf \(bcrenal.ca\)](#) (ESAS)
- Symptom management resources: [Symptom Assessment and Management \(bcrenal.ca\)](#)
- Guideline for Kidney Care Clinics: [Conservative Care Pathway](#)

## **Dialysis (HD, HHD, PD)**

- [Transition from Dialysis Treatment to Palliative Care](#) for staff and physicians
- [Stopping Dialysis Treatment: What you need to know before deciding](#) for patients & families
- [Frequently Asked Questions about Stopping Dialysis Treatment: A guide for patients and families](#)

## Care of Dying & Bereavement

- [BC Renal EOL Framework-Care of the Dying and Bereavement \(p 30\)](#)
- [Recommendations to Support Renal Patients at End of Life.pdf \(bcrenal.ca\)](#)
- Bereavement resources: [http://www.bcrenal.ca/resource-gallery/Documents/PCC-Grief\\_and\\_Bereavement-A\\_collection\\_of\\_previous\\_presentations.pdf](http://www.bcrenal.ca/resource-gallery/Documents/PCC-Grief_and_Bereavement-A_collection_of_previous_presentations.pdf)
- Refer to resources available for families: [Palliative Care \(bcrenal.ca\)](#)

## Additional Resources and Vetted Links

- BC Centre for Palliative Care: [www.bc-cpc.ca/](http://www.bc-cpc.ca/)
  - For those new to palliative care: [Gain Palliative Skills \(GPS\) Learning Pathway](#)
  - BCCPC Newsletter subscription: [www.bc-cpc.ca CentrePoint](http://www.bc-cpc.ca/CentrePoint)
  - [www.bc-cpc.ca ECHO Project](http://www.bc-cpc.ca/ECHOProject)
- Pallium Canada: <https://www.pallium.ca/palliative-care-resources/>
  - [Providing Virtual Palliative Care](#)
  - [Trauma Informed Palliative Care](#)
  - [ACP and Goals of Care Discussions](#)
  - [Sign up for ECHO Project session emails](#)
- Canadian Virtual Hospice: [www.virtualhospice.ca](http://www.virtualhospice.ca)

### Strategies to maintain competence and confidence levels in Integrating a Palliative Approach to CKD Care

- Attend at least one ECHO session annually (60 minutes-- interactive and recorded)
- Register for a palliative newsletter (Centerpointe)
- Attend education sessions on IPAC from BC Centre for Palliative Care
- Be aware of the renal journey, listen and respond to patient cues for discussions
- Bring a palliative approach to care to team discussions

**Thank you for your commitment to providing high quality integrative palliative nephrology care!**

## 1. Chronic Kidney Disease/ Pre-Dialysis

“As we start to think about options and preparations, it’s a good time to discuss your goals and preferences. Is that OK?”

“How much do you know about your kidney disease and what it means for your health and Quality of Life?”



## 2. Dialysis Initiation

“As you begin dialysis and settle in to the routine, it’s a good time to discuss/review your goals and preferences. It’s been x months since you started dialysis, which is a good time to discuss how things are going and review your goals and preferences. Is that OK?”

“How has starting dialysis or being on dialysis affected your life? What is your understanding of what lies ahead with your dialysis and overall health?”



## 3. Post Hospitalization/ Dialysis Complications

“You have just been in the hospital. I’ve noticed that things have been getting more difficult for you. In light of that, this may be a good time to discuss what is most important to you if you are getting sicker. Is that OK?”

“How did this hospitalization change your understanding of the future of your health? How have things changed for you recently? What is your understanding of what lies ahead?”



## 4. Dialysis Access Issues

“You just had some setbacks with your dialysis access/had your dialysis access fixed, so if its OK with you I would like to discuss your goals and preferences.”

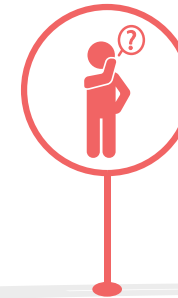
“What is your understanding of what lies ahead with your dialysis and overall health?”



## 5. Dialysis Withdrawal Consideration

“I understand you have been thinking about whether you want to continue dialysis. Is it OK for us to discuss your goals and preferences so we can think about this together?”

“What is your understanding of what it means to stop dialysis?”



# Starting the Conversation: Exploring Key Concepts Throughout the Dialysis Journey

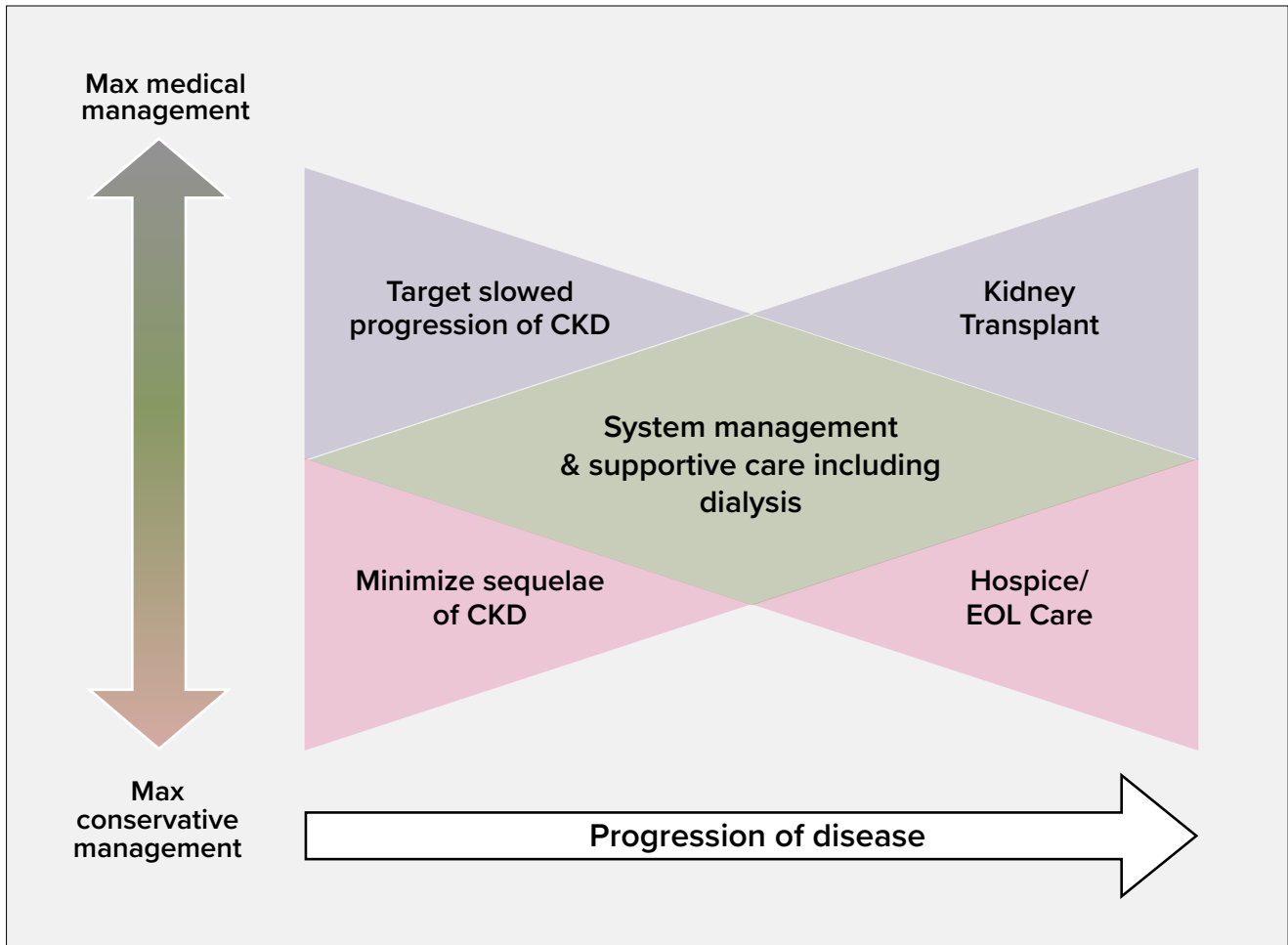
### Serious Illness Conversation Patient Tested Language

Specific conversations starter quotes and dialogue cues are provided to assist such a conversation. This journey may not occur in a linear manner as suggested, and key topics may need to be revisited throughout the patient’s journey.

*\*\*Ernest et al.,(2016) Serious Illness Conversations in ESRD. CJASN. 10.2215*

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## Appendix A: Bow Tie Model for Palliative Care in Kidney Care



- [The Bow Tie Model of 21st Century Palliative Care - Journal of Pain and Symptom Management](#) (General Palliative Care)

Article outlining the Bow-Tie Model of Palliative Care which describes Integrating a Palliative Approach to CKD Care and the dual approaches of disease specific/modifying care along with palliative strategies focusing on quality of life. This model promotes a care pathway where both approaches are integrated at the time of diagnosis with a gradual shift in focus over time from disease specific care to a palliative approach.

- [Adding Life to Their Years: The Current State of Pediatric Palliative Care in CKD - PMC \(nih.gov\)](#) (model applicable to all CKD)