



# Integrated Palliative Nephrology in BC: Current State & What's Next

Dr. Gaylene Hargrove

on behalf of BC Renal Palliative Care Committee

November 27, 2020

# Territorial Acknowledgement

I acknowledge that the land on which I am presenting is the unceded and ancestral territories of the Lekwungen (Songhees and Esquimalt) and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

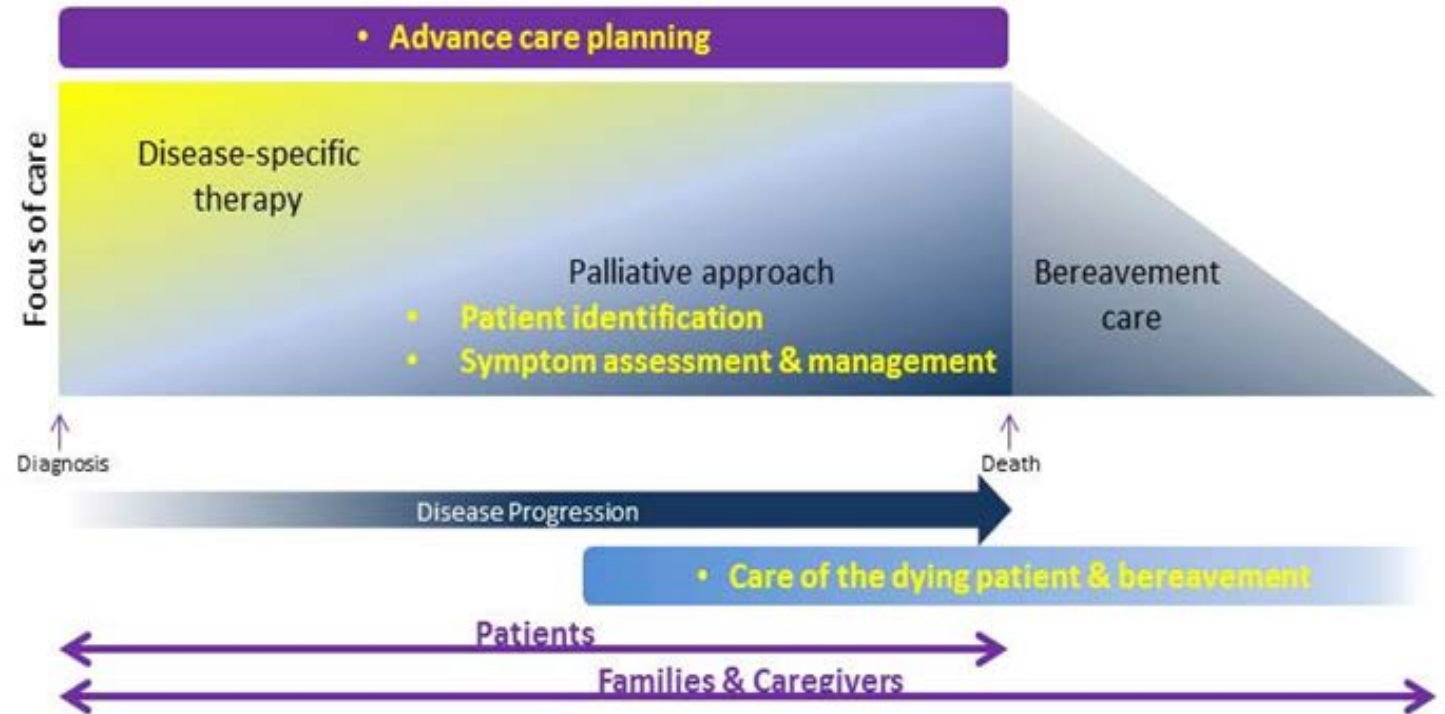
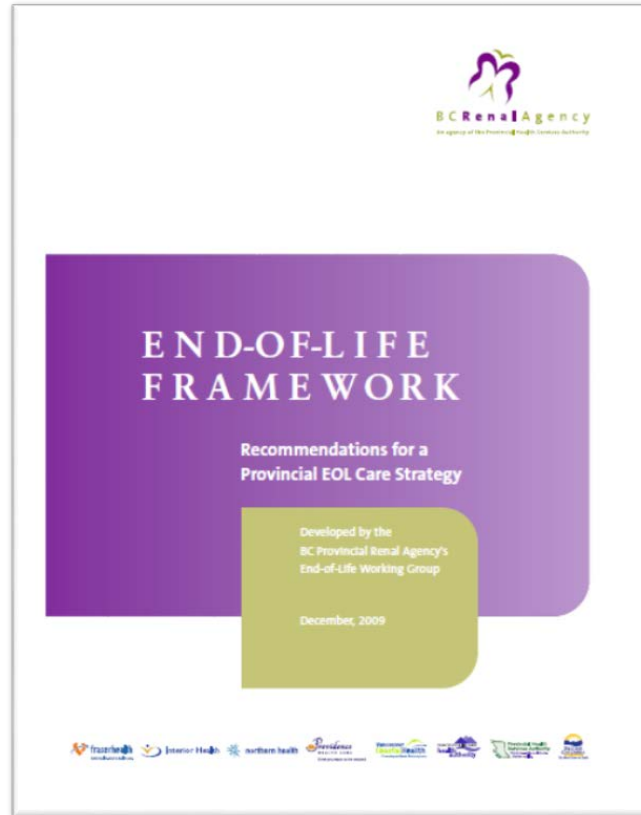


# Overview

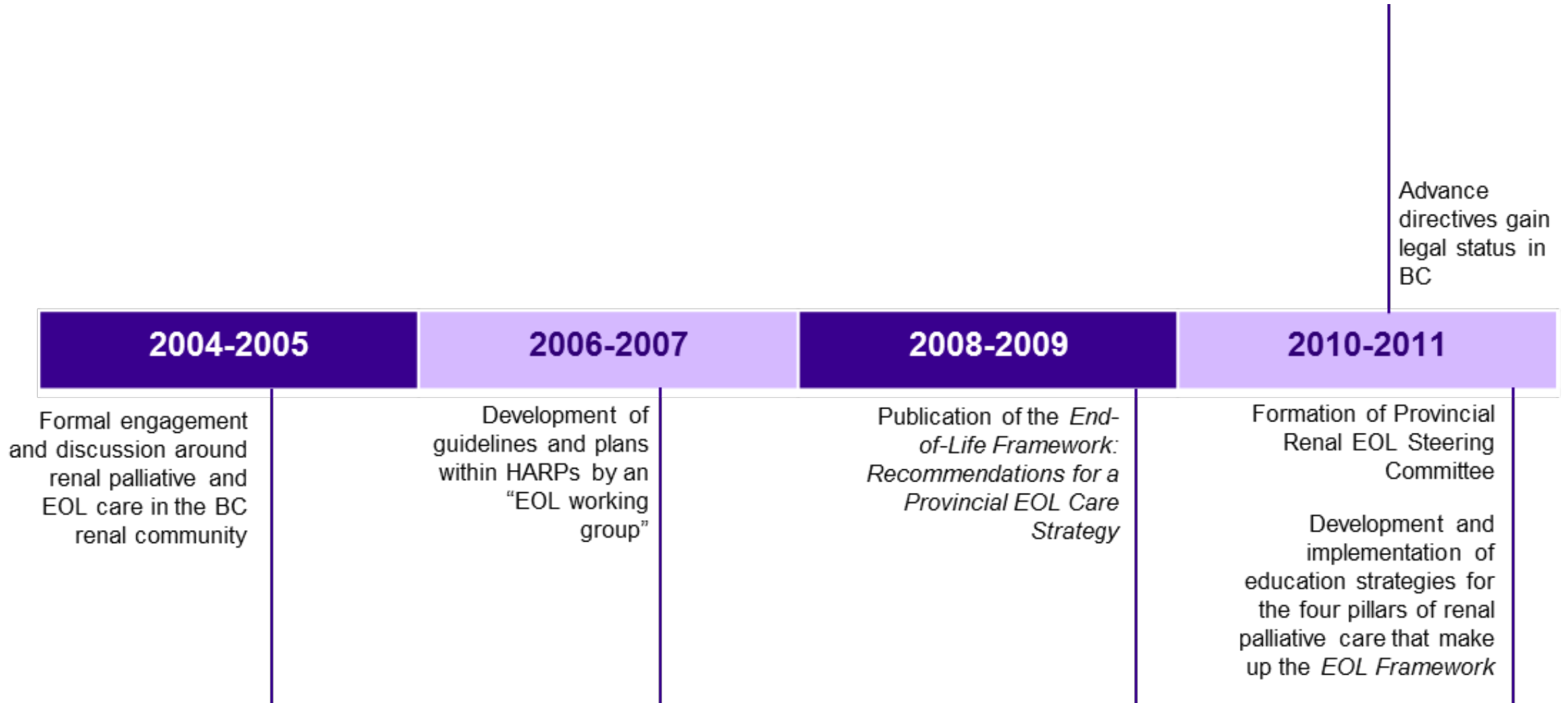
- Palliative approach to kidney care in BC: EOL Framework and beyond
- Advance Care Planning
- Symptom assessment & management
- Grief and Bereavement
- Lessons Learned
- Summary



# Framework for Palliative Approach to Kidney Care in BC



# Where we have been in kidney palliative care



# Where we have been in kidney palliative care (cont't)

	<p>Publication of <i>The Provincial End-of-Life Care Action Plan for British Columbia</i> by the Ministry of Health</p> <p>Establishment of the BC Centre for Palliative Care</p>	<p>Pub time Adv Pla a p Doc</p>
<p>2012-2013</p> <p>Publication of protocol and algorithms for symptom management</p>	<p>Launch of online training module for symptom assessment</p>	<p>Forma res worki to ad know gaps in palliative</p>

 Canadian Society of Nephrology / Société canadienne de néphrologie  
 CANADIAN JOURNAL OF KIDNEY HEALTH AND DISEASE  
*Journal canadien de la santé et de la maladie rénale*

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Original Research Article

## A Survey of Canadian Nephrologists Assessing Prognostication in End-Stage Renal Disease

**Brian Forzley<sup>1,2</sup>, Helen H. L. Chiu<sup>3</sup>, Ognjenka Djurdjev<sup>3</sup>, Rachel C. Carson<sup>1,4</sup>, Gaylene Hargrove<sup>1,4</sup>, Dan Martinusen<sup>4,5</sup>, and Mohamud Karim<sup>1,6</sup>**

Canadian Journal of Kidney Health and Disease  
 Volume 4: 1-9  
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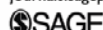


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Original Article

## External validation and clinical utility of a prediction model for 6-month mortality in patients undergoing hemodialysis for end-stage kidney disease

**Brian Forzley<sup>1,2</sup>, Lee Er<sup>3</sup>, Helen HL Chiu<sup>3</sup>, Ognjenka Djurdjev<sup>3</sup>, Dan Martinusen<sup>4</sup>, Rachel C Carson<sup>1,4</sup>, Gaylene Hargrove<sup>1,4</sup>, Adeera Levin<sup>1,3</sup> and Mohamud Karim<sup>1,5</sup>**

Palliative Medicine  
 2018, Vol. 32(2) 395-403  
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## Advancing Palliative Care in Patients With CKD: From Ideas to Practice

[Helen H.-L. Chiu, MSc, MHA](#) • [Donna M. Murphy-Burke, MHA](#) • [Sarah A. Thomas, BSN](#) • ...

[Mohamud Karim, MD](#) • [Gaylene M. Hargrove, MD](#) • on behalf of the BC Renal Palliative Care Committee •

[Show all authors](#)

Open Access • Published: November 08, 2020 • DOI: <https://doi.org/10.1053/j.ajkd.2020.09.012>

PlumX Metrics

Pre-proof: [https://www.ajkd.org/article/S0272-6386\(20\)31076-3/abstract](https://www.ajkd.org/article/S0272-6386(20)31076-3/abstract)

# Integrated Palliative Nephrology Project

- **Purpose:** To develop and implement a provincial strategy to effectively integrate a palliative approach for all patients with CKD and under the care of nephrologists in BC.
- Deliverables
  1. Education- Serious Illness Conversation (BCKD, KCC Lunch and Learn, Outreach Visits to HA), Train Champions in HA, ACP/mESAS PROMIS module training
  2. Dissemination/Culture Change/- Relationships with hospice programs, Division of Family Practice, BC Centre for Palliative Care, FNHA
  3. Document Development- Preparing to Stop Dialysis documents, Transitioning to Conservative Care, ACP tips of Renal Clinicians
  4. Evaluation Pre-Project, Environmental Scan; Mid- Chart reviews and Patient Interviews in each HA, Post-Chart views and patient interviews, SIC evaluations, Knowledge translation (ASN, International Congress of Palliative Care, BCKD 2019, Research Paper)



# Advance care planning (ACP)

- **Goal:** To enhance patient and family understanding of their health issues and identify their key priorities in care
- Provincial support:
  - Alignment with provincial and health authority efforts
  - ACP videos guide for MDs and staff to initiate the conversation with patients and their families
  - ACP module for process data capture in PROMIS
  - Serious Illness Conversation Guide training and resources
- While all should be equipped to have ACP conversations, social worker has been the key facilitator in ACP discussions in all health authority renal programs
- Timing of initiation varies

GP: BENZER, SUSAN DIANE  
Ph: TR: SP: SHAPIRO, REBECCA JEAN ...  
Name: BUCKLEY, TERESA  
RD: HOOLAEFF, CINDY  
SW: POLING, CONNIE

MOBILITY Selection | MOBILITY Selection History | **Advance Care Planning**

Advance Care Planning (ACP)

**Discussions**  
ACP discussion occurred  
Initial discussion date  
Latest follow-up discussion date

**Documents**  
Does any legal ACP document exist  
Does any other ACP document exist  
Does any ACP document exist in PROMIS: No  
Latest document date  
View / Upload ACP documents

**Medical Orders**  
Does any medical order of scope of treatment exist  
Last order completed date

**Legislation**  
Which Legislation applies to the patient (Check all that apply)

## 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?”

## 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?”

## 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

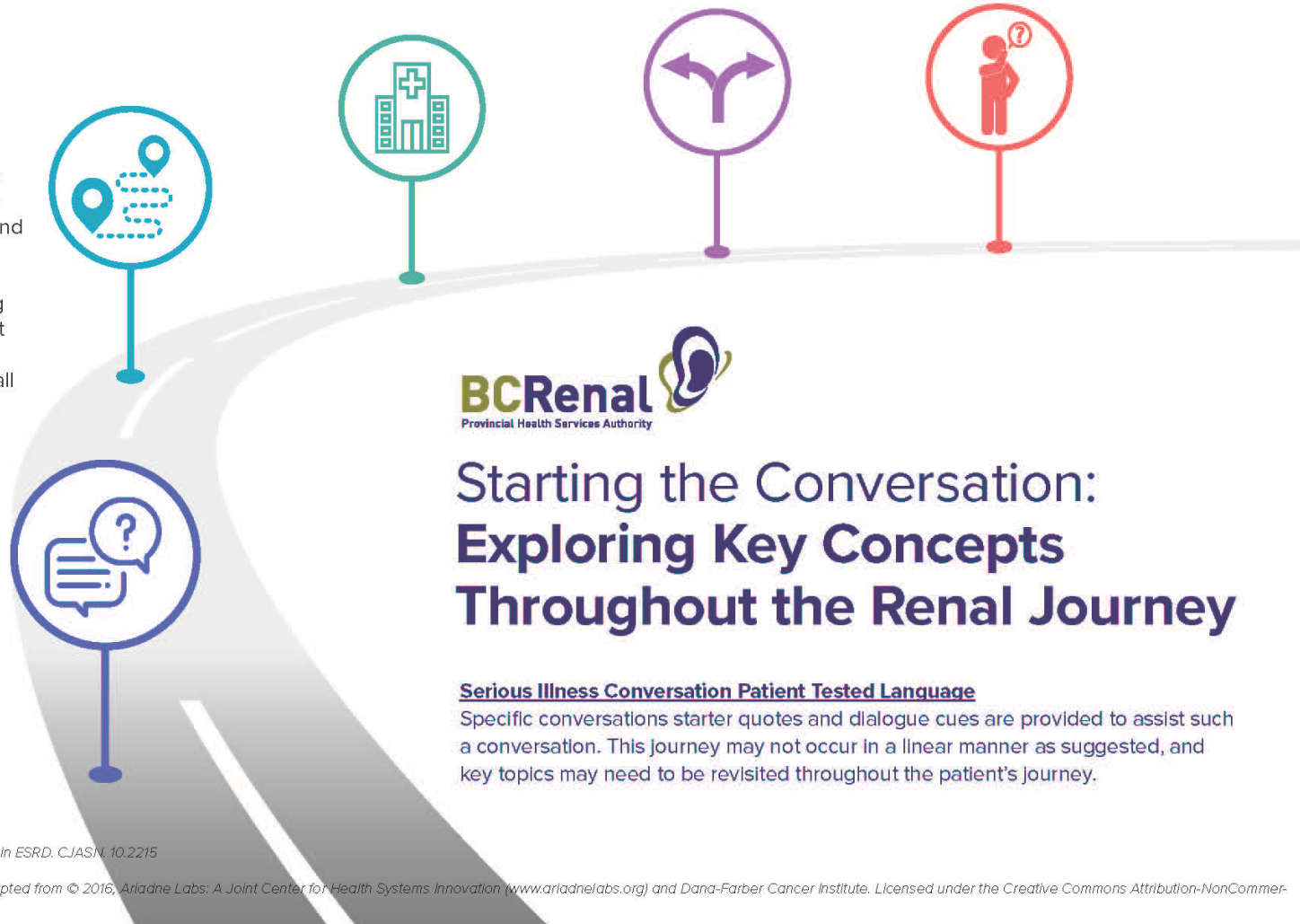
“You just had some setbacks with your dialysis access/had your dialysis access fixed, so if its OK with you I would like to discuss your goals and preferences.”

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

## 5. Dialysis Withdrawal Consideration

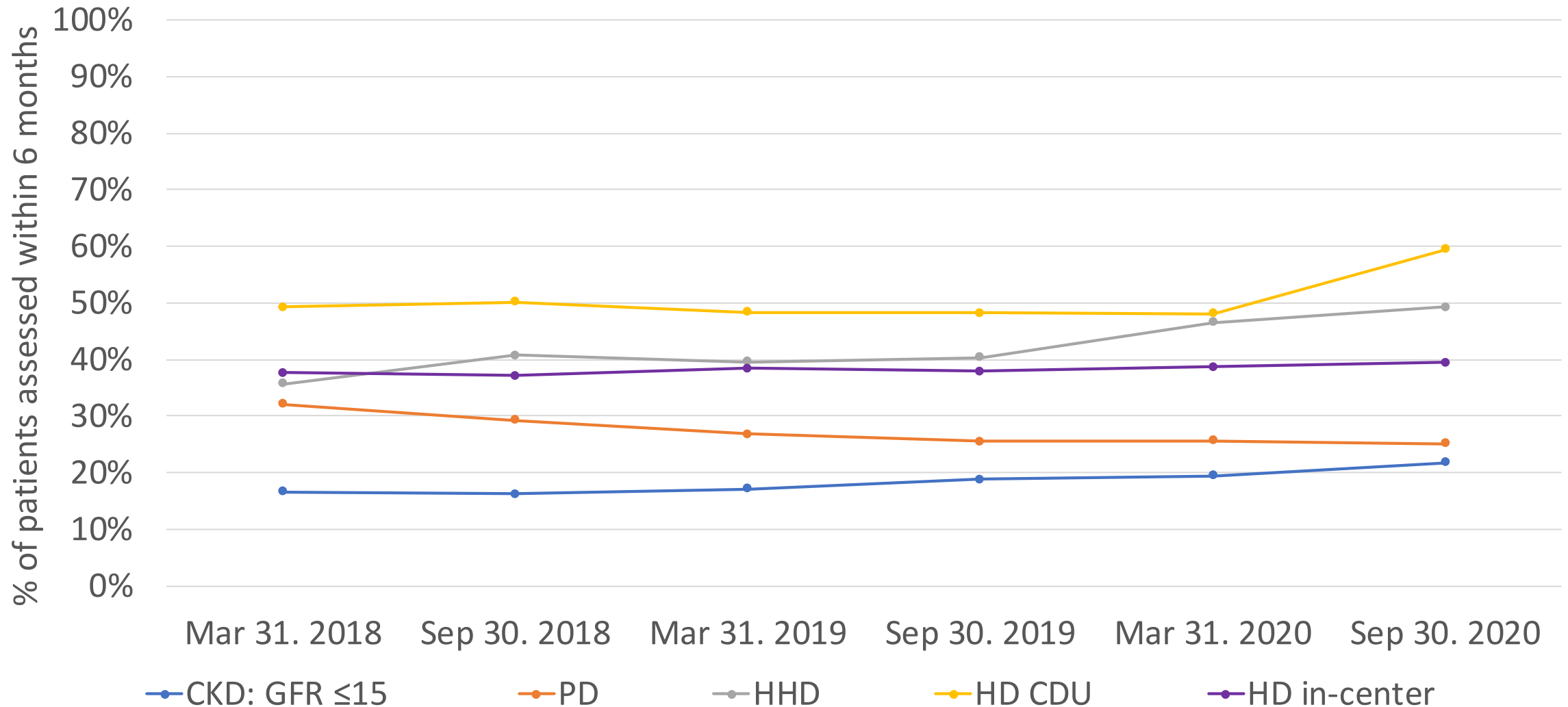
“I understand you have been thinking about whether you want to continue dialysis. Is it OK for us to discuss your goals and preferences so we can think about this together?”

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



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

# Advance care planning (ACP) record rate



# Pivoting ACP Conversations in the Pandemic

- "Pandemic palliative care: beyond ventilators and saving lives" *Downar, J et.al. CMAJ 2020.doi:10.1503/cmaj.200465*
  - "...The COVID-19 pandemic will likely strain our health care system beyond capacity, and palliative care services will be needed across all care settings (incl. ICU)"
  - "...Failing to provide Canadians with effective palliative care would compound the tragedy the pandemic has already caused worldwide"

## **The tragedy to avoid:**

- Patients who choose not to have life-sustaining treatment (or are denied due to overwhelmed resource capacity) are not provided optimal symptom control; psychosocial supports are inadequate
- "They die at the wrong time, in the wrong place, and alone."**

# Palliative Care

BC Renal, working with kidney care professionals from across the province, aims to support the delivery of high-quality care for people with kidney disease in the last years, months or days of their lives, regardless of where they live in BC.

[www.bcrenal.ca](http://www.bcrenal.ca) → Health Professionals → Clinical Resources → Palliative Care

Guidelines & Tools      Resources



## Guidance for Implementation Advance Care Planning COVID-19

### Background

Proactive discussions about patient wishes, advance care planning, end of life care, and shared decision making around associated risks with treatment, is an essential part of routine renal care and more vital in a pandemic situation.

Clinicians should ensure patients receive the care they want, aligning the care that is delivered with the patient's values and goals. The importance of goal concordant care is not new or even substantially different in the context of this pandemic, but its importance is heightened.

Advance care planning before an acute severe illness related to COVID-19 and discussions about goals should be a high priority for three reasons.

1. Clinicians should strive to avoid intensive, life-sustaining treatments when unwanted by patients.
2. Avoiding non-beneficial or unwanted, high-intensity care becomes especially important in times of stress on healthcare capacity.
3. The provision of non-beneficial or unwanted, high-intensity care may put other patients, family members, and health care workers at higher risk of transmission of COVID-19.

### Suggested Implementation Plan

Steps	Suggested Steps	Description	Responsible
1 Identify Patients	<p>Who would most likely benefit from an ACP discussion in a pandemic?</p> <p>Patients deemed highest priority receive "Documenting Your Goals of Care" letter- see Appendix 1</p> <p>Suggestions for Identifying patients: Surprise Question - Would you be surprised if your patient died in 6-12 months?</p> <p>Frailty scale 4 and above:</p>	<p>Copies will be made and distributed in HD Unit to identified patients</p> <p>Copies available in English, Chinese and Punjabi</p>	Shared responsibility

Guidance for Implementation: Advance Care Planning Discussions: COVID-19

April 14, 2020



## Frequently Asked Questions about Stopping Dialysis Treatment

A guide for patients and families



### Documenting your Goals of Care

Effective Date: March 27, 2020

Dear Patient,

In light of the serious outbreak of the COVID-19 virus, we are asking you to reflect on your advance care planning: wishes, goals and fears. We understand you have been faced with many changes over the past days to weeks – thank you for your patience and understanding as we strive to provide the best possible care according to a thoughtful, organized plan developed by your multi-disciplinary team of renal care providers.

Those of you living with chronic kidney disease are potentially more vulnerable to severe complications of COVID-19 infection. This is why it's important for your care wishes to be documented clearly now, should your health status change during this time.

Over the next few weeks we will be approaching you to update your wishes in the Medical Order Scope of Treatment (MOST), which is a plan of care reflecting your treatment and care requests. Having conversations regarding what matters most to you through your illness journey is part of our high standard of care. Specifically, this refers to ensuring your wishes regarding the level and intensity of treatment are expressed, heard, respected and clearly documented.

These are uncertain times, but you can be certain, and reassured, that your renal care team will continue to support you through whatever challenges lie ahead.

Respectfully yours,

Your Renal Care Provider Team



# Unique Challenges in COVID Times

- Virtual visits and physical distancing
  - Lack of privacy
  - Risk losing authenticity/sensitivity
  - For Indigenous patients – need to use a trauma-informed lens
  - Lack of sufficient time
  - Inability to engage all members of the health care team simultaneously
    - Zoom platform may help to overcome
- 'NO VISITOR' policy
  - Patients face end of life alone
    - May be 'negotiated' with staff/managers if confirmed COVID -ve

# Unique Challenges in COVID Times

- ACP Discussions and the 'Service Model' of care delivery
  - Physicians may be meeting a patient/family for the first time; primary nephrologist not available on the front line
  - Trusting relationship takes time to establish
  - Messaging/communication from other clinicians may be discordant → leads to confusion/mistrust
- Practical Tips
  - Take time to get to know what is important to this patient; connect with family members
  - Communicate clearly and frequently with the interdisciplinary team, as well as other physicians, incl. primary nephrologist
  - Remember to maintain the art and humanity in our practice

# Dialysis Resource Optimization Framework Guidelines for Emergency Triage

- Purpose:

- To assist dialysis health care providers in determining what type of care each patient will receive in the event of a pandemic, when the need for staffing or other resources may exceed available supply

- Scope:

- Adult population; focuses on hospitalized patients with acute kidney injury (AKI) in both critical care and non-critical care locations, with impact on chronic HD patients also taken into consideration
- A robust ethical framework is utilized to guide decision-making



# Sharing our learning with others

## **Balancing the Needs of Acute and Maintenance Dialysis Patients During the COVID-19 Pandemic**

Rachel Carson, M.D., Brian Forzley, M.D., Sarah Thomas B.SN., Nina Preto, LL.B. M.Sc. Ph.D., Gaylene Hargrove, M.D., Alice Virani, M.S. M.PH., Ph.D., John Antonsen, M.D., Michael Copland, M.D., Melanie Brown, M.D., Marie Michaud, M.D., Anurag Singh, M.D., Adeera Levin, M.D.

In press. *Clinical Journal of American Society of Nephrology.*

# Symptom Assessment & Management

- **Goal:** To relieve symptom burden that are generally under-reported in patients with kidney disease, thereby improving their quality of life
- Provincial support:
  - Symptom assessment module for process and outcome data capture in PROMIS
    - Trending of individual patient's symptoms to support care management
  - Algorithms for symptom management
  - Online training module and information sheet for MDs and staff
  - Symptom guides for patients

BCRenal

Kidney Services Health Info Research About Contact Health Professionals Learning Events Careers

Health Professionals / Clinical Resources / Symptom Assessment and Management

## Symptom Assessment and Management

My Symptom Checklist

- French
- Dutch
- Traditional Chinese
- Simplified Chinese
- Large Print English

My Symptom Checklist Information Sheet (Staff /Physician)

### Common Symptom Guides

- Constipation +
- Depression and Anxiety +
- Fatigue +
- Nausea/Poor Appetite +
- Muscle Cramps +
- Pain Management Resources +
- Pruritus +
- Restless Leg Syndrome +

Symptom Management videos from the CANA/CSN/CANN-NET 2018 Symposium

- How symptoms impact patient lives
- Causes and treatments (fatigue, restless legs)
- Quality of life strategies

Watch the videos >

PROVINCIAL STANDARDS & GUIDELINES

BCRenal

### DEPRESSION AND ANXIETY: THE ROLE OF KIDNEY CARE CLINICS

© 2016 BC Renal  
Developed by the Kidney Care Consortium

[www.bcrenal.ca](http://www.bcrenal.ca) → Health Professionals (or Health Info for patient resources) → Clinical Resources → Symptom Assessment and Management

# Why *My Symptom Checklist*?

- Standardized tool recommended in the EOL Framework
- Patient-reported outcome measure—aligns with Accreditation standards
- Available in multiple languages
- Data capture and individual patient trending of symptom burden over time are supported on PROMIS



**My Symptom Checklist\***

It is important that your care team understand and monitor your symptoms over time. This checklist helps us do this. For more information, please see letter on the other side of this form.

Date: \_\_\_\_\_ (DDMMYYYY)  
Time: \_\_\_\_\_ (HR:MM)

**PATIENT INFORMATION/LABEL**  
Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_  
PIN: \_\_\_\_\_

Please circle the number that best describes how you have been feeling over the PAST WEEK with each symptom.

Scale: 0 = no symptom      10 = the worst possible for the symptom

Symptom	0	1	2	3	4	5	6	7	8	9	10	Worst possible
No pain	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible pain
Not tired (tired= lack of energy)	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible tiredness
Not nauseated	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible nausea
Not depressed (depressed= feeling sad)	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible depression
Not anxious (anxious= feeling nervous)	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible anxiety
Not drowsy (drowsy= feeling sleepy)	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible drowsiness
Best appetite (feeling hungry)	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible appetite
Best feeling of well-being (feeling low or stressed)	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible feeling of well-being
No shortness of breath	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible shortness of breath
No itch	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible itch
No problem sleeping	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible problem sleeping
No restless legs	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	😊	Worst possible restless legs

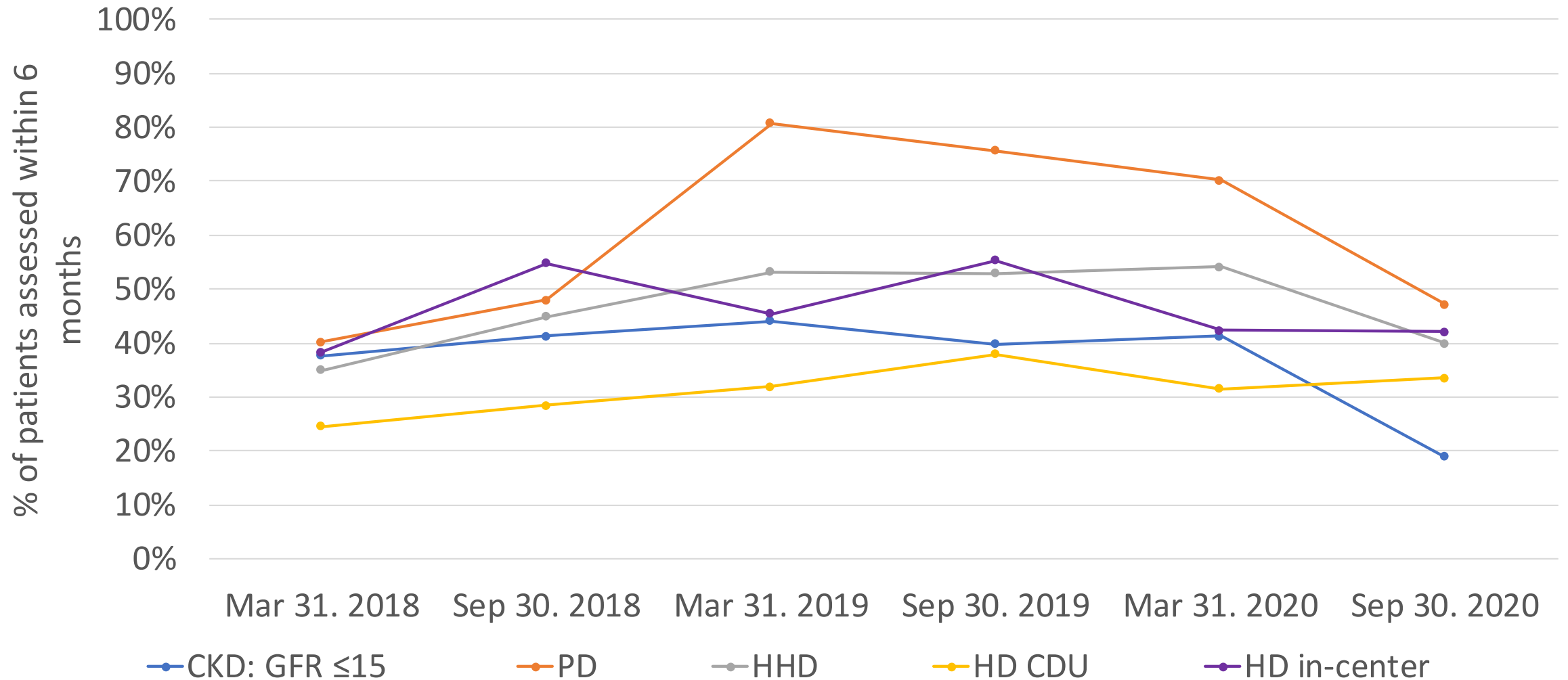
Any other symptom or concern? Please specify then rate below: \_\_\_\_\_

No symptom \_\_\_\_\_ Worst possible symptom \_\_\_\_\_

**This section to be completed by staff**  
Scale completed by: (check one)  
 Patient       Use progress notes to follow up on symptoms  
 Care Team Member Assisted       Care plan updated  
 Family Member       Results entered in PROMIS  
 Patient refused (note why if known)      Enter date: \_\_\_\_\_ Entered by: \_\_\_\_\_

BC Renal - BC Health Services Authority  
Supported from the End-of-Life Symptom Assessment System (EOL SAS) - Renal (EOL SAS) - Renal v1.0 (2018)  
Updated Oct 2018

# Uptake of Routine Symptom Assessment *Using My Symptom Checklist*



# Symptom Assessment & Management Improvement Project

To enhance awareness and support integration of routine symptom assessment and management using *My Symptom Checklist* to optimize quality of life for patients living with advanced CKD



## Successes

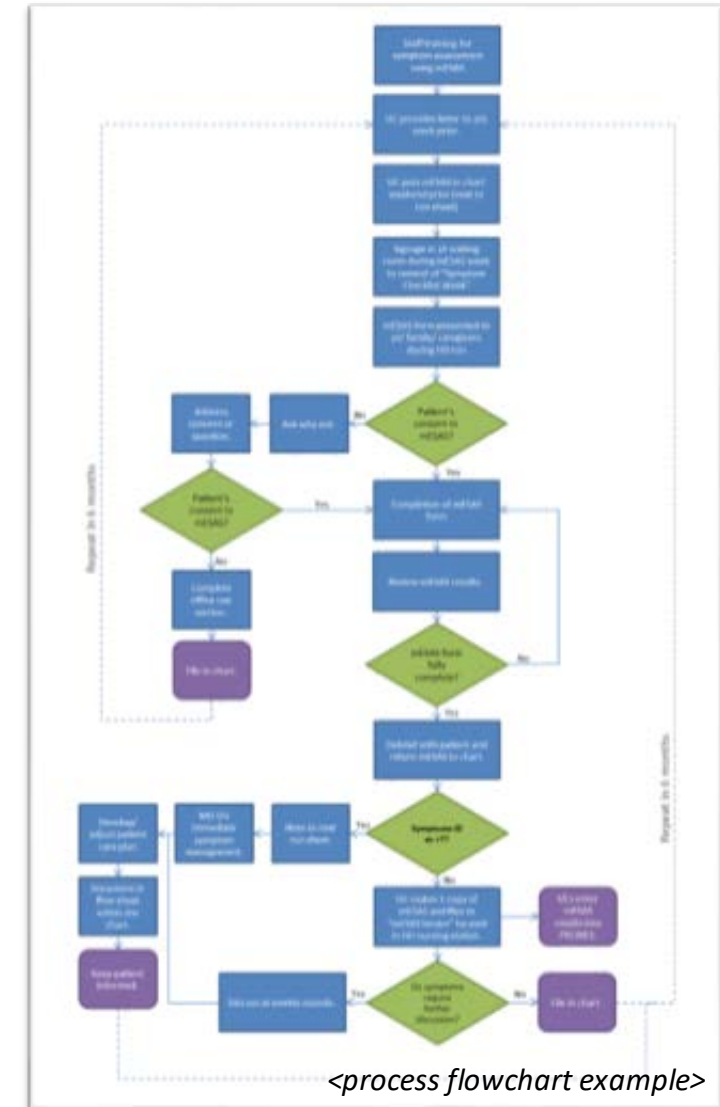
- Done in all kidney care settings!
- Identification & monitoring of symptoms
- Medication management
- Activating patients in their care
- Helping clinicians understand what matters to the patient → patient goal-setting

## Challenges

- Focus on the tool rather than the whole process
- Embedding in routine workflow
- Internal communication flow
- Time constraints with competing demands
- Symptom management beyond nephrology
- Integration in virtual visits

# Symptom Assessment & Management Improvement Project

- Focusing on the whole process
- Working group with health professionals and patient partners
- Questions to address:
  - How has the process changed patient care?
  - What has been challenging about the process?
  - What could we do to support each other in advancing person-centred care with the process?



# Symptom Assessment & Management Improvement Project

- Culture change takes time
- Focus on a common goal to improve care and quality of life
- Integration with existing workflow is key
- Successful implementation is contingent on engaging the multi-disciplinary teams at the frontline
- Including voices of patients and other key stakeholders from the planning to evaluation

*“The Committee’s accomplishments to date have set the foundation for alleviating some of the challenges faced by kidney patients. We, the Committee’s patients and health care professionals, are working together to deal with the important patient issues that haven’t received sufficient focus in the past.”*

- Routine indicator reporting enables progress over time
- Unique challenges and opportunities to embrace palliative care in the pandemic



# Grief & Bereavement: Be Kind

**CANADIAN Virtual Hospice**  
Information and support on advanced illness, palliative care and grief.

FOR HEALTHCARE PROVIDERS:  
MODULE 1

## Living with grief during COVID-19

Living with grief during COVID-19

**Resources for health care providers:**

<https://virtualhospice.us1.list-manage.com/track/click?u=c07fa235771066576396bbc7a&id=97b6240974&e=43d6b80d8e>

Staying well on the front lines of COVID-19  
**We will get through this together**

COVID-19 is having a profound effect on everyone working in healthcare. Now more than ever we need to support each other and find ways to recognize and address our own needs.

**You may be feeling...**

- Fear** for your own safety and that of your family, colleagues and friends.
- Frustration** with constant change and disruptions to work and life.
- Unease** about jobs, economy, the future.
- Overwhelmed** as if there's no end in sight.
- Grief** about the loss of "normal", loss of in-person connections, personal experiences of loss/death, and death of patients.
- Powerlessness** about feeling unable to "make it better".

**How this might impact you:**

- Difficulty sleeping
- Changes in eating habits
- Poor concentration and forgetfulness
- Irritability
- Avoiding connections with friends/family
- Changes in attitudes and thoughts

**What you can try:**

- Allow yourself to feel what you are feeling. Emotions are not right or wrong.
- Set realistic expectations. You cannot save and support everyone.
- Let go of what you can't control and focus on what you can.
- Set and maintain boundaries for yourself.
- Find room, if you can, for exercise, reading, stretching, music, etc.
- Seek support from colleagues, family, friends, professionals, and online.
- Take a break from your phone and the news.
- Remind yourself: This will not last forever.

During these uncertain times these are normal. If they are preventing you from your regular activities or affecting your health, contact your health provider or visit [ca.portal.gs](http://ca.portal.gs)

You can also visit [virtualhospice.ca/covid19](http://virtualhospice.ca/covid19)

# Summary

- Progress in palliative care in BC is foundational
- The pandemic offers unique opportunities for pivoting activities to focus on what matters to those whom we serve
- Our patients value relational, continuous, consistent and ethical care now more than ever
- Integrated palliative nephrology paves the way for person- and family-centred kidney care



# Thank You! Any Questions?

Website: [www.bcrenal.ca](http://www.bcrenal.ca)

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