



# PROVINCIAL STANDARDS & GUIDELINES



## **Systematic Symptom Assessment & Management** (using the Modified Edmonton Symptom Assessment System)

Created May 2017

Developed by the BCPRA Kidney Care Committee

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**IMPORTANT INFORMATION**

This BCPRA guideline/resource was developed to support equitable, best practice care for patients with chronic kidney disease living in BC. The guideline/resource promotes standardized practices and is intended to assist renal programs in providing care that is reflected in quality patient outcome measurements. Based on the best information available at the time of publication, this guideline/resource relies on evidence and avoids opinion-based statements where possible; refer to [www.bcrenalagency.ca](http://www.bcrenalagency.ca) for the most recent version.

For information about the use and referencing of BCPRA provincial guidelines/resources, refer to <http://bit.ly/28SF4n>.



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## 1.0 Scope of Guideline

The guideline discusses the assessment and management of symptoms in patients with chronic kidney disease (CKD) attending one of BC's Kidney Care Clinics (KCCs). KCC patients are currently not on dialysis, although all live with moderate to severe kidney disease.

The guideline makes recommendations about the assessment and management of symptoms in adult KCC patients.

## 2.0 Rationale

Symptom burden is high in patients with advanced chronic kidney disease (CKD). This burden has been shown to negatively impact quality of life (Davison, 2006).

A systematic review of the literature (KDIGO, 2015) concluded that the most common symptoms reported by patients with CKD were sleep disorders, pain, anorexia, nausea and pruritis. Studies differed as to the patient inclusion criteria, including whether the patients were on or not on dialysis.

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**Table 1: Symptoms in CKD: Literature Synthesis (source: KDIGO, 2015)**

Symptom	# Studies	# Patients	Mean Prevalence
Sleep disorders	40	7,391	60%
Pain	50	7,500	58% (mostly studies of HD pts; however, evidence suggests similar rates for late stage CKD patients on a conservative care pathway)
Anorexia	18	3,122	56% (range 9 - 82%)
Nausea	14	1,774	46% (range 9-90%)
Itching	24	19,226 (on dialysis)	41% (25% reported severe pruritis)
Constipation	17	2,001	40% (range 8-65%)
Vomiting	12	1,511	23% (range 11-68%)
Depression			22% in CKD, stages 1-4, 23% in dialysis patients (interview assessments)
Diarrhea	10	921	21% (range 8-33%)
Restless legs syndrome			10%-20%

The most frequently cited study specific to symptoms of conservatively managed CKD patients was conducted by Murtagh (2007). She concluded that conservatively managed CKD patients showed moderate symptom distress and health-related concerns, with marked increase in the last 2 months of life. Fatigue, itching, drowsiness, shortness of breath and swelling of arms and legs were the most commonly reported symptoms.

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**Table 2: Symptoms in Conservatively Managed CKD Patients: (Murtagh, 2007)**

Symptoms	Conservatively managed (n=66)		Last month of life (n=49)	
	Symptom prevalence	Prevalence by Severity (Quite a bit or very much)	Symptom prevalence	Prevalence by Severity (Quite a bit or very much)
Lack of energy	76%	36%	86%	69%
Itching	74%	32%	84%	43%
Drowsiness	65%	21%	82%	43%
Shortness of breath	61%	23%	80%	53%
Swelling arms, legs	58%	20%	71%	35%
Pain	53%	32%	73%	41%
Dry mouth	50%	20%	69%	20%
Anorexia	47%	11%	71%	37%
Sleep problem	41%	21%	43%	16%
Constipation	35%	8%	65%	10%
Nausea	26%	0%	59%	14%
Worrying	58%	15%	78%	22%
Feeling sad	53%	8%	65%	20%
Feeling nervous	42%	7%	55%	8%

Assessment and management of kidney-related symptoms is an important function of BC's Kidney Care Clinics (KCCs). (KCC Best Practices Paper, 2014).

This guideline provides direction to BC's KCCs in the implementation of a symptom assessment tool (the Edmonton Symptom Assessment System or ESAS), symptom management algorithms and workflow processes to support the systematic assessment and management of symptoms in BC's KCCs. The ultimate goal is to reduce the symptom burden in KCC patients and, thereby, improve their quality of life.

### 3.0 Recommendations

#### **Recommendation #1:**

**Utilize the modified Edmonton Symptom Assessment System (ESAS<sup>1</sup>) to assess the symptom burden of KCC patients who meet the following criteria:**

- eGFR < 15 mL/min/1.73<sup>2</sup>; &/or
- Reporting significant CKD-related symptoms.

Eight validated global symptom assessment tools of varying length and utility exist for CKD patients, including the ESAS (KDIGO, 2015). In BC, the ESAS has been selected as the recommended symptom assessment tool for use across modalities, including Kidney Care Clinics (KCCs). (EOL Framework, 2006).

ESAS is a 12-question self-report tool for screening symptom-related distress (11 symptom-related question and 1 open-ended question). Patients are asked to rate their symptoms over the past week between 0 (no symptoms) and 10 (severe symptoms). In BC, the patient-friendly title of the tool is “My Symptom Checklist” and the tool is available in multiple languages at <http://www.bcrenalagency.ca/health-professionals/clinical-resources/chronic-kidney-disease-ckd>. An information sheet for KCC staff/physicians is available on the same webpage. A self-paced learning module can be accessed at <https://ccrs.vch.ca> (Course Catalogue Registration System or CCRS; course name: ESAS Symptom Identification: BC Renal Agency).

Utilizing the ESAS to assist in the assessment of symptoms creates opportunities for conversations with patients about their symptoms and management options. It provides a clinical profile of symptom severity over time and a context within which symptoms can begin to be understood. The ESAS, however, is not a complete symptom assessment in itself - it is one part of a broader clinical assessment (Capital Health Regional Palliative Care Program, 2001).

#### **Recommendation #2:**

**Administer the ESAS to patients who meet the criteria in recommendation #1 every 6 months, or more frequently as indicated by the patient’s condition.**

The ESAS measures the patient’s opinion of the severity of the symptoms. Ideally, patients fill out their own ESAS. If the patient cannot independently do the ESAS, then it is completed with the assistance of a caregiver (a family member, friend or health care provider closely involved in the patient’s care). If the patient cannot participate in the symptom assessment, the ESAS is completed by the caregiver alone.

If the patient is not attending the clinic in-person, the ESAS can also be administered by a KCC team member by telephone or telehealth.

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<sup>1</sup> ESAS refers to the modified ESAS throughout this guideline.

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## **Recommendation #3:**

**Review the ESAS and, for symptom scores of 4 or above, complete a detailed assessment of the symptom(s) and develop a symptom(s) management plan.**

**Table 3:  
ESAS Symptom Scores & Severity**

Score	Severity of Symptoms
1 - 3	Mild
4 - 6	Moderate
7 - 10	Severe

Algorithms for the management of common symptoms are available at [www.bcrenalagency.ca](http://www.bcrenalagency.ca).

## **Recommendation #4:**

**Provide information to the patient's primary care provider (PCP) about their symptoms and severity:**

- For renal-related symptoms (e.g., pruritis), include a summary of the plan for managing the symptoms.
- For non renal-related symptom (e.g., pain), include relevant renal-related information to assist the PCP in managing the symptoms (e.g., medications to use and/or avoid in patients with chronic kidney disease).

Examples of ways to provide the relevant information to the PCP include:

- Adding the relevant information to a dictated letter;

- Sending a separate letter (+/- copy of clinic note) (see Appendix 1 for a sample) +/- the relevant ESAS and symptom management algorithm; and/or
- Telephoning the PCP

## **Recommendation #5:**

**Consider implementing the workflow outlined in Table 4 in KCCs to accommodate the systematic assessment and management of symptoms in KCC patients.**

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**Table 4: Recommended Workflow in KCCs for the Systematic Assessment & Management of Symptoms**

Step		Responsibility
<b>Patient who:</b> <ul style="list-style-type: none"> <li>• Has an eGFR&lt;15 mL/min/1.73<sup>2</sup> &amp;/or</li> <li>• Reports significant CKD-related symptoms</li> </ul>		
1	Discuss purpose of the My Symptom Checklist (ESAS) tool with patient/family.	RN or nephrologist/NP
2	Track when patients are due for ESAS.	Clerk
3	Give My Symptom Checklist (ESAS) to patient to complete while waiting for KCC appointment. <sup>2</sup>	Clerk
4	Fill out My Symptom Checklist (ESAS) in waiting room. Give to clerk.	Patient with help as needed from family /KCC team member
5	Place completed My Symptom Checklist (ESAS) on patient's file for KCC team to review during visit.	Clerk
6	Review My Symptom Checklist (ESAS) results with patient during visit.	Each member of KCC team
7	Develop symptom management plan(s) for moderate to severe symptom(s) (ESAS score 4 and higher). Place in chart. Utilize standardized algorithms, as appropriate.	Patient & KCC team
8	If moderate to severe symptoms, communicate findings and plans with PCP (see recommendation #4).	KCC team
9	Discuss plans for symptom management with patient.	KCC team
10	Enter My Symptom Checklist (ESAS) results into PROMIS.	Clerk
11	Place completed My Symptom Checklist (ESAS) into patient's file, if hard copies are usual practice within the KCC.	Clerk
<b>Every q 6 months thereafter (more frequently if indicated):</b>		
12	Give My Symptom Checklist (ESAS) to patient, patient completes & team reviews with patient as per steps 3 - 6.	Clerk and patient
13	Update symptom management plan(s). If new symptoms identified, follow the steps 7 and 8.	Patient & KCC team
14	Enter My Symptom Checklist (ESAS) results into PROMIS.	Clerk
15	Place completed My Symptom Checklist (ESAS) into patient's file.	Clerk

<sup>2</sup> If ESAS is completed by telephone or telehealth, steps 3 - 6 will require modification.



## 4.0 References

BC Provincial Renal Agency, Best Practices: Kidney Care Clinics, 2014. [http://www.bcrenalagency.ca/resource-gallery/Documents/Best%20Practices-%20Kidney%20Care%20Clinic\\_0.pdf](http://www.bcrenalagency.ca/resource-gallery/Documents/Best%20Practices-%20Kidney%20Care%20Clinic_0.pdf). Accessed Nov 6, 2015.

BC Provincial Renal Agency, End of Life Framework: Recommendations for a Provincial End of Life Care Strategy. <http://www.bcrenalagency.ca/resource-gallery/Documents/EOL-Framework.pdf> Accessed Nov 6, 2015.

Capital Health Regional Palliative Care Program, Guidelines for using the Edmonton Symptom Assessment System (ESAS), 2001.

Davison SN, Levin A, Moss A, Jha V, et al. Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: developing a roadmap to improving quality care, *Kidney Int* 2015, 88:447-59. <http://www.ncbi.nlm.nih.gov/pubmed/25923985>.

Davison SN, Jhangri GS and Johnson JA. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: A simple assessment of symptom burden. *Kidney Int* 2006, 69:1621-1625. <http://www.ncbi.nlm.nih.gov/pubmed/16672923>

Davison SN, Jhangri GS and Johnson JA. Longitudinal validation of a modified Edmonton symptom assessment (ESAS) in haemodialysis patients. *Nephrol Dial Transplant* 2006, 21:3189-3195. <https://academic.oup.com/ndt/article/21/11/3189/1873844/Longitudinal-validation-of-a-modified-Edmonton>

Murtagh F. Symptoms in Advanced Renal Disease: A cross-sectional survey of symptom

prevalence in Stage 5 CKD managed without dialysis. *Journal of Palliative Medicine*, 2007, 10:6:1266 - 1276.

## 5.0 Sponsors

This provincial guideline was developed to support improvements in the quality of care delivered to patients with chronic kidney disease in BC. Based on the best information available at the time it was published, the guideline relies on evidence and avoids opinion-based statements where possible. When used in conjunction with pertinent clinical data, it is a tool health authorities and health professionals can use to develop local guidelines.

### Developed by:

This guideline was developed by a Working Group of KCC multidisciplinary care providers from across BC. The group included: a nephrologist, a palliative care physician specialist, registered nurses, pharmacists, social workers and a data coordinator.

### Reviewed by:

- BCPRA Kidney Care Clinic Committee
- BCPRA Palliative Care Committee
- BC PRA Medical Advisory Committee
- BCPRA Executive Committee

## 6.0 Effective Date

May 2017

This guideline is based on scientific evidence available at the time of the effective date; refer to [www.bcrenalagency.ca](http://www.bcrenalagency.ca) for most recent version.

## Appendix 1: Sample Fax/Letter to Primary Care Providers re Symptoms

### **Re: Patient Symptom Assessment**

Patients with kidney disease may develop a significant symptom burden as their kidney function declines. In order to identify and monitor these symptoms, the Kidney Care Clinic has implemented a simple evidence-based monitoring tool called the modified Edmonton Symptom Assessment System (ESAS).

Your patient's current ESAS is attached to this fax/letter. Scores for each symptom range from 0 (no symptom) to 10 (severe symptom). A symptom burden of 4 or more usually triggers a more detailed assessment by our team.

It is our goal to administer the ESAS at least every six months for patients who have an eGFR < 15 mL/min. We will fax/mail you a copy of this assessment tool, along with our clinic note that highlights those symptoms thought most likely to be related to their reduced kidney function and information on treatment strategies for the specific symptom.

We know that it is often difficult to manage the symptoms experienced by patients with advanced kidney disease; we are happy to offer you our support by phone, email or fax at anytime.

Respectfully,

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KCC Team to determine who to sign off (e.g., nephrologist, RN, etc).