

## **My Symptom Checklist Questions and Answers for Staff/Physicians**

### **What is *My Symptom Checklist* (also referred to as the Edmonton Symptom Assessment System-revised: Renal or ESAS-r: Renal)?**

The ESAS is a clinically validated and reliable symptom measurement tool, extensively used for a number of chronic diseases including cancer, heart disease, and kidney disease. The original tool was developed by the Regional Palliative Care Program, Capital Health in Edmonton, Alberta. The current version of *My Symptom Checklist* in use within kidney programs in BC is adapted from ESAS-r: Renal with permission. ESAS-r: Renal was modified from the original ESAS for use with kidney patients. It is recommended for use across treatment modalities as indicated and in accordance with existing provincial and renal program guidelines and procedures.

### **How appropriate is *My Symptom Checklist* for kidney patients?**

*My Symptom Checklist* is well accepted for assessing the physical and psychological symptoms of patients with end-stage kidney disease.

### **How does it benefit patients?**

Helping patients experience satisfactory quality of life is a primary goal of kidney care. Research shows that kidney patients tend to under-report their symptoms and as a result are often under-treated. This could be due to an acceptance of pain and other symptoms as “normal” for kidney patients. Patients usually give different responses when asked. *My Symptom Checklist* allows us to dive deeper into how patients feel with their symptoms. Using symptom management strategies along with ongoing follow-up and monitoring of the patient should result in a decrease in symptom scores in the next administration of *My Symptom Checklist*. Systematic and ongoing use of the tool for symptom management has been shown to improve patient-reported quality of life.

### **Purpose of symptom assessment using *My Symptom Checklist*?**

The regular use of *My Symptom Checklist* allows systematically screening and monitoring for intensity of common symptoms over time. The assessment can provide alerts to health care professionals about symptoms that are causing patients’ undue discomfort, leading to further assessment and/or discussion prior to treatment. Regular assessments also enables tracking of the effectiveness of targeted symptom management strategies at the patient and program levels. The ultimate goal is to reduce symptom burden for kidney patients and thereby improve their quality of life.

### **Where to find a copy of *My Symptom Checklist*?**

A hardcopy of the form can be printed out in multiple languages from [www.bcrenal.ca](http://www.bcrenal.ca).

### **Who fills out *My Symptom Checklist*?**

*My Symptom Checklist* is a simple self-reporting tool, designed to be filled out by the patient on their own. If the patient cannot independently fill out the form, then it is completed with assistance from a family member, a friend or a kidney program staff member who is closely involved in the patient’s care.

**What symptoms are included on *My Symptom Checklist*?**

12 symptoms: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, pruritus (itchiness), sleeping problems and restless legs. There is also a rating scale for a patient to include and rate the severity of any other symptom that is not already listed.

**How are the symptoms rated?**

Patients are asked to reflect on what their symptoms have been like **over the past week** and rate their experience of 12 common symptoms on a scale of 0-10 by circling the most appropriate number to indicate how severe each symptom is: 0 means the patient is not experiencing that symptom at all; 10 means the patient’s experience of that symptom is severe. Patients can also add and rate a 13th symptom if they wish.

ESAS score	Severity
0	No symptom
1-3	Mild
4-6	Moderate
7-10	Severe

Summing the scores for all symptoms creates a measure of a patient’s overall symptom distress level.

**How does *My Symptom Checklist* help with symptom management?**

When administered on a regular basis, *My Symptom Checklist* allows tracking of changes in severity of symptoms that triggers action on the part of the kidney care team. The symptoms as well as the effectiveness of interventions may be evaluated and continue to inform symptom management. The symptoms can be assessed with regards to management individually, while summing the scores for all symptoms creates a measure of a patient’s overall symptom distress level.

Management strategies for some prevalent symptoms in kidney patients have been developed into algorithms. These algorithms are posted on the BC Renal website: <http://www.bcrenal.ca/health-professionals/clinical-resources/symptom-assessment-and-management>

Patient materials for symptom management are also posted at <http://www.bcrenal.ca/health-info/managing-my-care/symptom-assessment-and-management>

**How often should the symptom assessments be done?**

To assess the effectiveness of symptom management efforts, there must be enough time between assessments. Optimal timing for assessments may vary among programs and individual patients’ visit schedules and conditions. Routine assessment every 6 months is recommended. However, assessment may be done more frequently as clinically appropriate depending on the type and severity of the symptoms being addressed. Please refer to provincial and renal program guidelines (e.g. BC Kidney Care Clinic Guideline: Systematic Symptom Assessment & Management) and procedures for specific recommendations.

**What are some tips for introducing *My Symptom Checklist* to a patient for the first time?**

Points to include when introducing a patient to the *My Symptom Checklist* for the first time:

- *My Symptom Checklist* will help kidney care staff to better understand any symptom that a person is experiencing and to help inform management of symptoms
- How to fill out the form
- Encourage reflection on how they have felt over the past 7 days
- What will be done with the results
- That they will be asked to fill out *My Symptom Checklist* on a regular basis
- That there may/ will be further requests to complete *My Symptom Checklist* as indicated

Responses to common questions about *My Symptom Checklist* are provided in the panel below.

**Responses to Common Patient Questions regarding *My Symptom Checklist***

**Why am I being asked to complete this form?**

This form helps you tell your health care team which symptoms you have—and how much those symptoms affect your daily life. It’s important we know which symptoms, if any, cause you distress. That way we can work with you to better manage your overall care.

**What happens with this information?**

We save your *My Symptom Checklist* results every time you complete an assessment. This helps us to better understand how things are going for you, and which symptoms are getting better or worse. If new treatment has been started because of what your scores have told us in the past, your latest score will help us understand if the new treatments are working and if we should adjust our approach.

**How do I rate my symptoms?**

For each symptom, a 0 means you do not have that symptom, and a 10 means it is the worst you can imagine. For example, if you’ve a good appetite and don’t have any trouble eating, for that symptom you would score 0. In assessing your symptoms, think back on how you’ve felt over the past week, not just at the present moment or just when you are on dialysis. If you’re unsure how to score a symptom, think about whether it has prevented you from doing things you usually do. If the answer is yes—then the score would likely be higher. If the answer is no—the score would be lower.

**Descriptions that may help some patients understand the words for symptoms:**

*Tired*: feeling lack of energy (but not necessarily sleepy)

*Nauseated*: feeling like throwing up; sick to stomach

*Depressed*: feeling sad or “blue”

*Anxiety*: feeling nervous or restless

*Drowsy*: feeling sleepy

*Appetite*: feeling hungry

*Wellbeing*: overall comfort, both physical and otherwise; truthfully answering the question “How are you?”

### **Where to document the results from *My Symptom Checklist*?**

Symptom scores from the patient's hard copy of *My Symptom Checklist* are entered into the patient's ESAS record within PROMIS. This creates a record of:

- The patient's reporting of their symptoms
- The effectiveness of efforts to manage the various symptoms over time

For symptom monitoring and management, PROMIS users can view symptom profile over time (trending graphs) of individual patients in the ESAS module.

Note: If the symptom screening using *My Symptom Checklist* was attempted but the patient declined to provide any scores, the PROMIS user may leave all the scores blank and select 'Patient Refused' on the 'Completed by' menu.

For more details, refer to

- PROMIS User Guide:  
<https://promis.phc.bc.ca/promis/manual/index.htm#!Documents/esassymptomassessments.htm>
- PROMIS training on Learning Hub: <https://learninghub.phsa.ca>
  - Course name: PROMIS 4 ESAS

The hard copy *My Symptom Checklist* is managed as per usual health authority practices.

### **Where can I get more information on *My Symptom Checklist*?**

Go to the Learning Hub: <https://learninghub.phsa.ca>

- Course name: ESAS Symptom Identification: BC Renal

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