



**BC Renal Agency**

An Agency of the Provincial Health Services Authority

# END-OF-LIFE FRAMEWORK

## Recommendations for a Provincial EOL Care Strategy

Developed by the  
BC Provincial Renal Agency's  
End-of-Life Working Group

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## EXECUTIVE SUMMARY

Despite medical advances and improvements in technology, 515 British Columbians receiving long-term dialysis died in 2008. In the same year, 280 chronic kidney disease (CKD) patients approaching the need for dialysis opted to forgo treatment. These numbers underscore the need for a provincial framework that will provide high quality end-of-life care for chronic kidney patients.

*To ensure that nephrologists and clinical staff are knowledgeable and confident in EOL care, the BC Provincial Renal Agency (BCPRA) established an EOL Task Group to develop a provincial framework, guidelines and an educational strategy.*

The need for end-of-life (EOL) care strategies is also being triggered by advances in dialysis that make it increasingly difficult to identify the point at which a patient is recognized as “dying.” When this is combined with patients having incomplete information about their prognosis or a limited understanding of the progression of their illness, health care providers are left treating patients and families unprepared for difficult end-of-life decisions. As a result, palliative care is often delayed or not initiated for patients with end-stage renal disease (ESRD). This, in turn, leads to suboptimal quality of dying experience.

To ensure that nephrologists and clinical staff are knowledgeable and confident in EOL care, the BC Provincial Renal Agency (BCPRA) established an EOL Task Group to develop a provincial framework, guidelines and an educational strategy.

The key elements of EOL care for renal patients are Patient Identification, Advance Care Planning, Symptom Assessment and Management and Care of the Dying Patient/Bereavement.

## GUIDING PRINCIPLES

Understanding the possible illness trajectories and identifying ESRD patients at the highest risk of early death is important to providing high quality end-of-life care. There are a number of prognostication strategies that can help identify patients at the highest risk of mortality and/or greatest need for supportive care. The framework recommends the following strategies to aid in patient identification:

**Serum Albumin** – the lower the level, the higher the risk of death.

**Modified Charlson Comorbidity Index (CCI)** – a questionnaire that quantifies co-morbid illness.



**The “Surprise” Question** – The following questions should be asked of the clinical team “Would you be surprised if this patient were to die in the next 12 months?”

**Age** – the older the patient, the shorter the patient’s survival.

Other factors to consider are nutritional status, functional status and effect of sentinel events on prognosis.

## ADVANCE CARE PLANNING

Advance Care Planning (ACP) is a process by which people can think about their values regarding future healthcare choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their representatives and their healthcare team; and record their choices for healthcare in the event they can no longer speak for themselves. It includes attention to ethical, psychosocial, and spiritual issues, which relate to starting, withholding, and stopping treatment such as dialysis.

Clear, honest and straightforward discussions at a level understandable to the patient are critical to the success of ACP. Emphasizing prognosis and future care options, rather than technical processes, helps to enhance a patient’s self-reliance and ease their fears and uncertainties. It also gives patients the information they need to make decisions that are compatible with their values and beliefs concerning their limited future and eventual death.

There are excellent resources available on-line and in the BC regional health authorities to assist with ACP. BCPRA recommends aligning ACP education and resources with Fraser Health’s ACP Program, which is based on the *Gundersen Lutheran Medical Foundation’s Respecting Choices Advance Care Planning System*.<sup>®</sup>

## SYMPTOM ASSESSMENT AND MANAGEMENT

The symptom burden in EOL patients is known to be extensive, severe and with significant impact on quality of life yet research points out that patient’ often underreport their symptoms. Reasons for this include lack of awareness among staff of the presence and/or severity of symptoms, the perception of patients that staff is more interested in dialysis adequacy results, and patients being resigned to living with symptoms they believe are untreatable.

The literature indicates effective tools for assessing symptoms in ESRD patients are the Modified Edmonton Symptom Assessment System (ESAS) and the Modified Patient Outcome Scale (POS). The provincial framework recommends utilization of



these tools as well as mastering the principles of pain assessment and management. To manage “total pain” it is best to utilize an interdisciplinary team, along with a consultation to palliative care and/or a chronic pain clinic.

## CARE OF THE DYING PATIENT AND BEREAVEMENT

Care during EOL shifts from active management to the relief of symptoms, with an emphasis on comfort. This is a time when patients may need psychosocial and spiritual support. The renal care team can take steps to assist family/friends as well as team members’ deal with the emotional aftermath of a patient’s death. Strategies as identified in the framework include various ways to acknowledge the death as well as ensuring resource materials on grief and bereavement is available.

## EOL EDUCATIONAL STRATEGY AND SUSTAINMENT

Building upon the provincial framework document, a practical curriculum will be developed and disseminated to EOL renal champions within each HARP. The champions (individuals yet to be confirmed) are professional renal staff, with interdisciplinary representation, each possessing knowledge and/or a keen interest in EOL care. This group will receive intensive training through a two-day workshop sponsored by BCPRA, scheduled for late spring 2010. The workshop will be conducted by experts in renal EOL and palliative care and will address research, best practices, provincially accepted EOL guidelines, resources, and materials to support implementation. Following initial training, the “champions” will receive project support, through BCPRA, to aid the plan definition and implementation throughout the BC renal programs recognizing different areas will be at differing levels of readiness. As programs develop capacity provincial rounds focusing on the care challenges of ESRD patients will be coordinated. Embedding EOL skill into the day to day work of renal professionals is seen as feasible in smaller programs however larger programs will need to assess capacity, and alternative options regarding staff duties.







## 1. INTRODUCTION

*There are two groups of kidney patients who will benefit from interactions with health professionals skilled in EOL care provision. The first group of patients are those approaching the need for dialysis but who choose not to pursue treatment. In 2008, 280 BC patients made the choice to pursue conservative care. These individuals are often older, with multiple medical issues in addition to their kidney disease. The opportunity to provide coordinated supportive care for this group is high.<sup>1</sup>*

The second group includes dialyzing patients who experience a progressive decline in their functional status that is often punctuated by episodes of life-threatening exacerbations and complications.<sup>2,3</sup> Although we can not identify how many of the 515 BC patients receiving long-term dialysis who died in 2008 categorically fall into this group, the clinical opinion is that it would be a large percentage.

Advances in dialysis care have made it more difficult to determine when patients are in the terminal phase of their illness and need to be recognized as “dying.” This, combined with the fact that many patients have either incomplete information regarding their prognosis and/or minimal understanding of the progression of their illness, leaves the renal care team dealing with patients and families who are unprepared for difficult end-of-life decisions. What’s more, these decisions must often be made in the middle of a health crisis.

Palliative care is often delayed or not initiated for patients with end stage renal disease (ESRD) resulting in a suboptimal quality of dying experience.<sup>4,5</sup> Nephrology care practitioners need to feel confident in providing knowledgeable, compassionate EOL care to ensure CKD and ESRD patients and their families receive respectful, integrated, and high-quality end-of-life support.<sup>6,7,8</sup>

### **The End-of-Life Project**

The BC renal community’s focus on EOL care for chronic kidney patients began in 2004. Through a number of facilitated meetings spread over two and a half years, the necessary foundational work took place, culminating in identifying of three areas of focus for the renal community:



1. Recognition of the importance in synchronizing renal EOL care, Palliative care, care provided by the General Practitioners within larger health care forums such as Accreditation Canada standards, and the Ministry of Health Service (through their provincial framework for end of life care).
2. Promoting heightened awareness of patient needs for EOL care among renal care providers at the health authority and provincial levels. This includes analysis of best practice guidelines, skill enhancements for renal care providers, identification of process and outcome indicators.
3. Identification of existing areas of knowledge and practice within the renal EOL group, and potentially within the skill sets of other renal care providers that can provide support for continuing clinical growth.

From this larger EOL committee a smaller, more focused task group was struck in November 2008. To ensure progress in achieving the three identified focus areas, BCPRA contracted a research assistant and project manager to work with the EOL Task Group.

### **1.1 END-OF-LIFE TASK GROUP**

Since February 2009, the EOL Task Group has been working to review and modify existing guidelines, resources and develop an educational strategy for EOL care. The task group consists of three representatives from each HARP selected for their expertise and interest in EOL as well as their willingness to act as “champions” for EOL within their health authorities. As champions they will facilitate the implementation and integration of EOL care into the day-to-day work of their renal health care team. A work plan has been developed that articulates the purpose, objectives, activities and expected outcomes of the project.

### **1.2 PURPOSE**

The purpose of the EOL project is to ensure quality EOL/palliative care for all renal patients in BC. This will be achieved by:

- Researching and compiling a comprehensive list of EOL resources and posting them on the BCPRA web site
- Developing a provincial framework and common definitions for EOL care in renal
- Identifying and adopting consistent guidelines and tools to assist in caring for renal patients who require EOL care
- Developing a sustainable educational strategy and implementation plans for each HARP
- Integrating the EOL guidelines and education strategy with the Ministry of Health’s palliative strategy and hospice palliative programs in each of the BC regional health authorities.



*The presentations established the context for the BCPRA'S EOL strategy and a common understanding of evidence-based best practices.*

### 1.3 PLANNING PROCESS

On June 3 2009 a panel of experts was selected from the BCPRA's EOL Task Group to determine the optimal approach to EOL guideline development and education. Dr. Sara Davison, a practicing nephrologist and associate professor at the University of Alberta Associate who has written extensively on the subject, was invited to present on the research and evidence-based best practice in EOL care for renal patients. Additional presentations on EOL/palliative strategies and frameworks were provided by Dr. Doris Barwich, Medical Director, Palliative/End-of-Life Care at Fraser Health Authority, Dr. Douglas McGregor, Medical Director, Palliative Care at Vancouver Coastal Health, and Dr. Ron Werb, nephrologist, Province Health Care. The presentations established the context for the BCPRA's EOL strategy and a common understanding of evidence-based best practices. Following the presentations the panel engaged in discussion and reached agreement regarding a conceptual framework, common definitions, guidelines and tools for each component of EOL care. They also agreed on the provincial approach to education and capacity building for each of the regional health authorities.

The outcomes of the day were as follows:

- EOL resources were reviewed for posting on the BCPRA web site
- The EOL Framework (developed by Providence Health Care) was adapted as the foundation for the BCPRA Provincial EOL Framework
- Definitions were established for Palliative Care, Supportive Care, EOL Care and Advance Care Planning
- The BC Provincial EOL framework and strategy were reviewed to ensure alignment and identify funding opportunities
- Research was presented and guidelines, tools and resources were identified for use by nephrologists and other health care providers to facilitate high quality eol care.

The EOL Panel agreed that:

- EOL guidelines/standards will be structured according to the following components of EOL care:
  - Patient Identification
  - Advance Care Planning
  - Symptom Assessment and Management
  - Care of the Dying Patient and Bereavement
- The approach to education will involve training a group of “champions” first using an intensive 1–2 day session in a central location sponsored by BCPRA. This will be followed by a province-wide rollout of education modules to local HARPs using delivery methods accessible to clinical staff (i.e. in-person, on-line, video tapes, telehealth, etc).



- ✓ Canadian and local experts will deliver the intensive session for champions. Local experts and trained champions will deliver general sessions and specific modules. Delivery will involve a combination of in-service and on-line, interactive methods. Experts and champions will be available to mentor local HARPs during implementation.
- ✓ Education programs, videos, booklets and other resources that currently exist in the HARPs will be made available to the BC renal community through the BCPRA web site.

## 1.4 DEFINITIONS

**Palliative Care** Is an approach to care that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.<sup>9</sup>

**The End of Life and End-of-Life Care** The period marked by disability or disease that is progressively worse until death; it is also considered to be the final stage of the journey of life. Care provided during this time is sometimes called hospice care, comfort care, supportive care, palliative care, or symptom management.<sup>10</sup> It involves providing reliable, skilful and supportive care for people with advanced, potentially fatal illnesses and for those close to them. It focuses on comfort, respect for decisions, support for the family, and treatments to help psychological and spiritual concerns.<sup>11</sup>

**Supportive Care** Supportive care helps the patient and family members to cope with the patient's condition and its treatment — from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness, or death and into bereavement. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.<sup>12</sup>

**The Palliative Approach** This concept is applied to the delivery of palliative care by health care providers to improve the quality of life of persons with a life-limiting illness, their family and informal caregivers. It may be used in all health care settings. It incorporates a concern for the holistic needs of individuals and their caregivers. The approach is reflected in the assessment process, the primary treatment of pain, and in the provision of physical, psychological, social and spiritual care. Application of the approach is not delayed until the end stages of an individual's illness but applied earlier to provide a focus on active comfort-focused care and a positive approach to reducing suffering and promoting understanding of loss and bereavement in the wider community.<sup>13</sup>

**Advance Care Planning** A process by which people can think about their values regarding future healthcare choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their representatives and their healthcare team; and record their choices for healthcare for possible future use in the event they can no longer speak for themselves.<sup>14</sup>



## 2. EOL RESOURCES

A comprehensive EOL resource list and a link to current health authority programs has been developed and posted on the BCPRA web site for easy access by renal professionals, patients and families.

Resources address the four components of EOL care, including Patient Identification, Advanced Care Planning, Symptom Assessment and Management, and Care of the Dying and Bereavement. Resources are organized into the following areas:

- Articles and Books
- EOL Education Program
- Health Authority EOL Program
- Reports, Presentations and Standards of Practice.



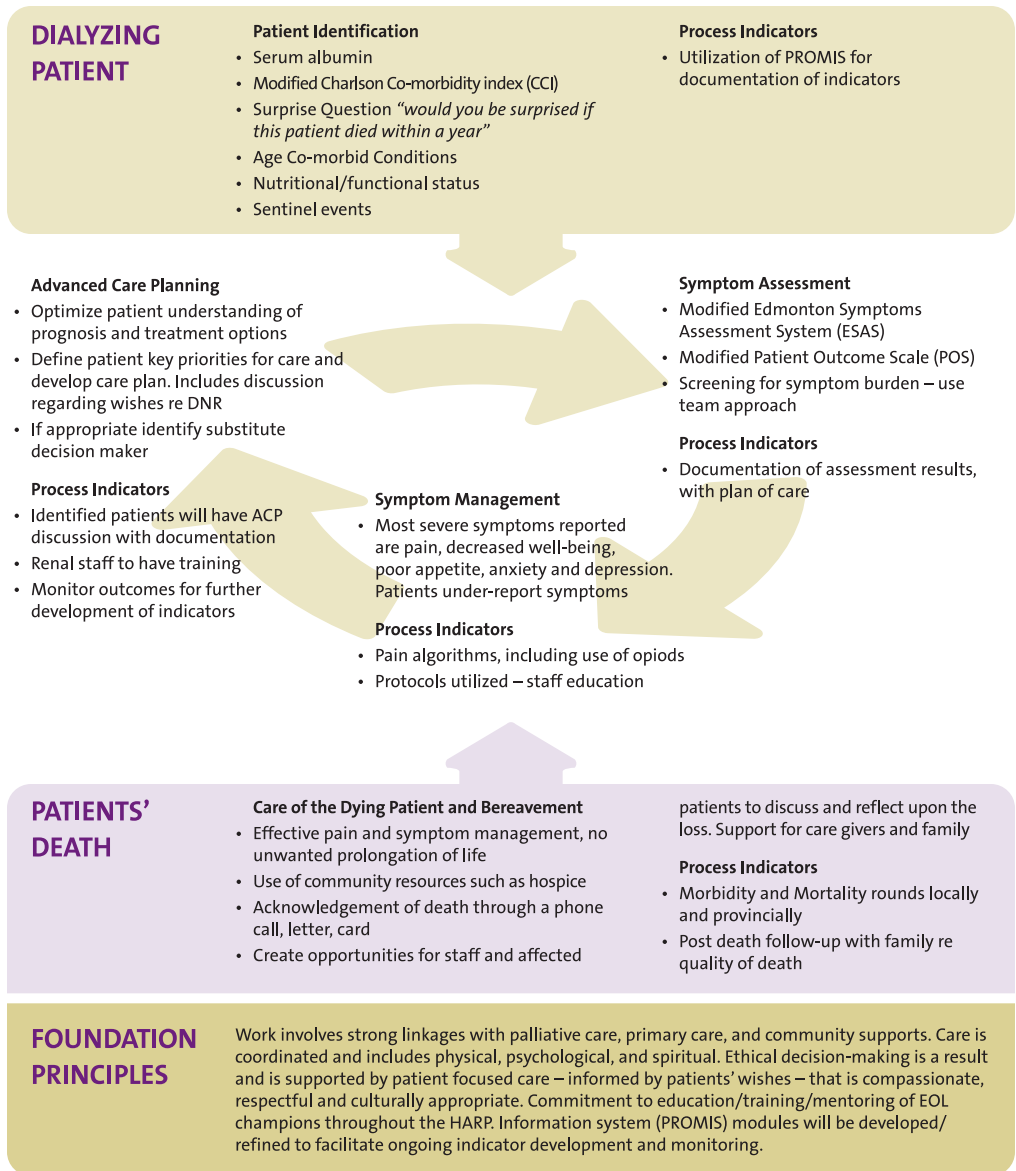


### 3. PROVINCIAL EOL FRAMEWORK

#### Provincial EOL Framework November 2009

Adapted from work done by Dr. R. Werb & S. Young, St. Paul's Renal Program

The EOL framework depicts the key elements of EOL care. BCRA guidelines and educational strategy will be structured in accordance with this framework.









## 4. EOL GUIDELINES: RECOMMENDATIONS TO THE FIELD

In the context of palliative care, Lunney et al.<sup>15</sup> describe four patterns or trajectories of health decline at the end of life. The diagram at the far left of *Figure 1* below illustrates the pattern for individuals who die of a sudden unanticipated event, such as a heart attack. The next diagram shows the pattern for people who enjoy relatively good health until experiencing a sharp decline over the final stage of life. This is a common trajectory for cancer patients. The diagram third from left shows the pattern for people who experience organ failure and a slow progressive worsening of health status, with ups and downs that are both physically and emotionally exhausting. Patients with deteriorating health despite dialysis often have high needs and live with a large symptom burden. In the trajectory of frailty, shown in the diagram on the far right, functional status declines gradually and constantly over time, resulting in progressively increasing dependence. Exactly where patients with ESRD fit within these four illness trajectories is somewhat unclear. Clinically, ESRD patients could follow trajectories 3 and 4, but this is only now being systematically studied. This uncertainty makes it difficult for healthcare providers to accurately know when a patient is in the terminal phase of their illness.<sup>16</sup>

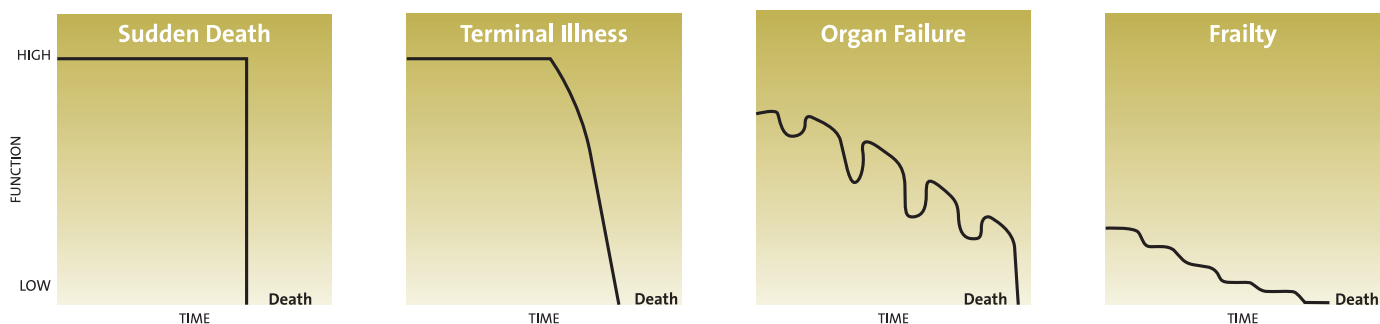


Figure 1. *Theoretical Trajectories of Dying* (Lunney, JR, Lynn, J, Foley, DJ, Lipson, S, & Guralnik, JM 2003).

Despite the prognostic uncertainties applying these trajectories, as they relate to a specific patient, can enable the healthcare team to anticipate, plan and deliver care that is appropriate for the health status of that patient.<sup>17</sup> It is understood that the medical complexities common to renal patients and the dialysis regime itself, are factors that will always influence the health status and care needs.



## 4.1 PATIENT IDENTIFICATION

One of the challenges in providing good EOL care for renal patients is not having a specific renal death trajectory. However there are a number of tools and strategies that can easily be introduced into the care of renal patients that will aid in the time identification of patients that are deteriorating despite dialysis.

### 4.1.1 Scope

This guideline recommends prognostication strategies that will assist the health care team to identify renal patients at highest risk of mortality and/or greatest need for supportive care.

### 4.1.2 Guideline

BCPRA recommends using the following prognostication strategies to identify patients at risk of early death:

1. Serum Albumin
2. Modified Charlson Comorbidity Index (CCI)
3. The “Surprise” Question
4. Age
5. Comorbid Conditions
6. Nutritional Status
7. Functional Status
8. Effect of sentinel events on prognosis.

Although it is important to consider all listed strategies, the first four are the most powerful prognostication tools. Research suggests use of several prognostication strategies to more accurately assess a patient’s EOL trajectory.<sup>18,19,20,21</sup>

**Serum Albumin** Serum albumin level, both at baseline and during the course of dialysis treatment, is a consistent and strong predictor of death. The lower the serum albumin level, the higher the risk of death (p.32).<sup>22</sup>

**Modified Charlson Comorbidity Index (CCI)** The modified CCI is a widely accepted, validated method, designed to quantify co-morbid illness. It is a composite score of age and multiple comorbid conditions used in longitudinal studies that provides a simple, readily applicable and valid method for estimating risk of death from comorbid disease. The modified version was developed for and trialed with the dialysis population<sup>23</sup> (*See Appendix A*).

**The “Surprise” Question** One of the most useful questions a care provider can ask of themselves when identifying patients who might benefit from supportive care is: ‘Would I be surprised if this patient were to die in the next 12 months?’ The intent of the surprise question is to counter the tendency of physicians to overestimate prognosis. Instead of

*Although it is important to consider all listed strategies, the first four are the most powerful prognostication tools.*



asking clinicians whether the patient will be dead in one year, it asks whether they think that the patient's death within one year is within the realm of possibility. The surprise question has been found effective in helping physicians identify patients who are terminally ill and for whom palliative care referral is appropriate.<sup>24</sup> Incorporating the surprise question into the systematic review of patients would help identify patients whose care plans need to include EOL planning, and potentially a referral to palliative care.

**Age** This is a powerful and consistent risk factor for death. The older the patient, the shorter the patient's survival is likely to be (p.31).<sup>25</sup>

**Comorbid Conditions** Comorbidity is a powerful predictor of mortality in patients with ESRD. The following comorbidities impact significantly on an individual's quality of life:

- Cardiovascular disease — This is the most common comorbidity for patients with esrd and is responsible for approximately half of all deaths on dialysis regardless of age, gender, ethnicity, nationality, or primary renal disease. The risk of a 40-year old on dialysis dying from a myocardial infarction is about 100 times greater than the risk for a person the same age with normal renal function (p.18).<sup>26</sup>
- Diabetes — Diabetes is a comorbid condition for 34% of dialysis patients in BC. Patient morbidity and mortality are much worse for renal patients with diabetes than for non-diabetic renal patients as many of the complications of diabetes will continue to progress after initiation of dialysis (p.16).<sup>27</sup>

**Nutritional Status** Malnutrition, which is caused by inadequate dietary intake or unmet increased nutritional requirements, is associated with increased infection, poor wound healing, muscle wasting, and increased mortality. It is also important to identify patients who have sudden weight loss (p.46).<sup>28,29</sup>

**Functional Status and Quality of Life** These terms generally refer to functioning or well-being in one or more domains (e.g., physical, psychological, social, occupational, sexual, etc.). Poor functional status is highly predictive of early death.<sup>30</sup> Poor health related quality of life (HRQL) has also been shown to be a predictor of poor outcomes in both American and European studies (p.72).<sup>31</sup>

**Sentinel Events** Sentinel events such as hospitalizations, acute illnesses or other unanticipated events can have a significant impact on quality of life and functional status.<sup>32</sup>

#### 4.1.3 Process Indicators

PROMIS documentation of:

- Serum Albumin
- Modified Charlson Comorbidity Index (CCI)
- Asking the surprise question
- Patients having a higher risk for mortality, as indicated by the prognostication tools

**Renal staff have received training in patient identification.**



## 4.2 ADVANCE CARE PLANNING

Planning for EOL care has typically focused on completing the two types of advance directives (ADs) — *instructional* and *proxy*. Instructional directives specify patients' care preferences, while proxy directives appoint another person to act as a surrogate decision-maker (SDM). Although helpful, AD documents vary and tend to provide guidance for only a limited set of future medical possibilities. Research shows that fewer than half of all dialysis patients complete AD<sup>33</sup> and of those, most only outline limited treatment options and do not typically discuss or consider withdrawal of dialysis.<sup>34,35</sup>

Advance care planning (ACP) extends beyond ADs. It involves a process by which people can think about their values regarding future healthcare choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their representatives and their healthcare team; and record their choices for healthcare in the event that they can no longer speak for themselves.<sup>36</sup> ACP emphasizes not only decisions about whether to use a treatment but also practical arrangements, and includes attention to ethical, psychosocial, and spiritual issues related to starting, withholding, and stopping treatment such as dialysis.<sup>37,38,39</sup>

Advance care planning is an effective tool for facilitating communication among patients, their families and the health care team and is integral to providing high quality dialysis care.<sup>40,41,42</sup> As such, it is important to overcome the barriers to addressing ACP with ESRD patients. Potential patient and family barriers include a lack of understanding regarding prognosis, unrealistic patient and family expectations, and a reluctance to broach end-of-life discussions.<sup>43,44</sup> Barriers for professional staff include: limited time to engage in ACP, lack of consensus on when to start ACP conversations and who to include, lack of professional training and resources, personal discomfort with the subject, conflicting views between patients and providers<sup>45,46,47,48</sup> and concerns that initiating ACP discussions could destroy hope for patients.<sup>49</sup>

### 4.2.1 Scope

The following guideline offers a recommended approach for clinical teams when addressing advanced care planning with renal patients. It includes the goals of ACP, how to identify patients who could benefit most from ACP, how to initiate and structure ACP conversations, and how to integrate it into patient care.

### 4.2.2 Guideline

The primary goals of ACP are:

1. To enhance patient and family understanding of their esrd and eol issues, including prognosis and likely outcomes of renal replacement therapies and alternative plans of care.
2. To define the patient's key priorities in EOL care and develop a care plan that addresses these issues.

*Advance care planning is an effective tool for facilitating communication among patients, their families and the health care team and is integral to providing high quality dialysis care.*



Adapted from *Table 1*. Desired Outcomes for ACP in Patients with ESRD in Davison SN, & Torgunrud, C. (2007). The creation of an advance care planning process for patients with ESRD. *American Journal of Kidney Diseases*, 49(1), 27-36.

3. To enhance patient autonomy by shaping future clinical care to fit the patient's preferences and values.
4. To improve the health care decision process generally, including patient and family satisfaction.
5. To identify a substitute decision-maker for future medical decision-making (as appropriate).
6. To help the substitute decision-maker understand their role in future medical decision-making.
7. To promote a shared understanding of relevant values and preferences among the patient, substitute decision-maker and health care providers.

Through an improved ability to identify patients approaching the EOL phase (*see previous section on patient identification*) the renal care team will be better positioned to initiate conversations pertaining to EOL care. ACP discussions should be initiated early with ongoing communication, documentation and re-evaluation throughout the illness trajectory.<sup>50</sup>

Research indicates that ESRD patients feel their nephrologists are responsible for initiating and guiding ACP because physicians are seen as the primary source of medical information. However, not all patients want to talk extensively with their physicians and would rather address ACP issues with loved-ones.<sup>51</sup> While research supports a role for physicians and the health care team in initiating ACP conversations, providing information and, potentially helping patients work through end-of-life issues, the approach needs to be individualized to meet the unique needs of each person.

Clear, honest and straightforward discussions, at a level understandable to the patient, have been shown to be a critical element of successful ACP. Emphasizing prognosis and future care options, rather than technical processes, helps to enhance patients' self-reliance and ease their fears and uncertainties. Most importantly, it gives dialysis patients the information they need to make decisions about their limited future and ultimate death that are compatible with their values and beliefs. Cultural differences must also be considered, and the approach to ACP discussions should be tailored to the unique needs of the individual.<sup>52</sup>

The following steps are recommended to facilitate ACP in ESRD:

**Assess Understanding of Health Status, Prognosis and Treatment Options** It is important for patients and/or families to understand their overall medical condition and how illness and various treatment options will affect them within the context of their daily lives. A recent study affirms the necessity of providing truthful prognostic information to the patient and their families and that such information does not destroy hope.<sup>53</sup>

1. **Patient Participation** The key to effective ACP is the ability of the patient to fully participate. It is recommended that the health care team consider the following when engaging patients in ACP discussions:

Adapted from: Davison, SN, Seymour, J, Holley, J (2010 in press). Advance care planning in end stage renal disease. Supportive Care for the Renal Patient. Chapter 4: *Oxford Supportive Care*; Ed: Chambers, Germain, Brown; Oxford University Press, Oxford UK, and Harle, I, Johnston, J, MacKay, J, Mayer, C, Russell, S, Zwaal, C (2008 Jan 28). Advance care planning with cancer patients: guideline recommendations. Toronto (ON): *Cancer Care Ontario (CCO)*; 37. (Evidence-based series; no. 19-1).



- Ability to be involved in ACP (i.e. language limitations, cultural differences)
  - Interest in participating
  - Patient's perception of their level of control and power as it relates to health care decisions
  - Perception of potential benefits of participation in ACP
  - Resources (and support systems) to help participate in ACP
  - Person with whom the patient prefers to engage in ACP (helps to define roles for various health providers, family and/or friends).
2. **Patient Values, Beliefs and Preferences** Engage in conversations with patients and their substitute decision-makers about the patient's values, beliefs and treatment wishes to help promote shared understanding.<sup>54,55,56</sup>
  3. **Identify Goals of Treatment** The ideal time to establish a patient's wishes and goals for treatment is early in the trajectory of care, and can be done prior to the patient being on dialysis. Follow-up discussions are important after a change in treatment modality or any irreversible change in medical condition. Sentinel events, such as acute illness and/or hospitalization, provide opportunities to initiate ACP discussions.
  4. **Relationship between Patient and the Clinical Team** Create and use a shared language that patients and their families can understand. Use the patient's description and expression of their illness experience when facilitating ACP. Clinicians should also practice empathetic listening, affirm patients' self-worth and maintain trust, honesty, promise keeping, confidentiality and care.
  5. **Documentation** Document patient preferences, ads and related information, updating it as conversations occur. The patient chart should travel across health care settings to ensure that it is available to all those involved in the care of the patient.

The Fraser Health Authority (FHA) has invested significant resources in developing its Advance Care Planning tools and processes which are currently considered the “best practice” in BC. Fraser Health's program is based on the “Respecting Choices Advance Care Planning System”<sup>®</sup> offered by Gundersen Lutheran Medical Foundation in the US.<sup>57</sup> This group offers education programs as well as ACP resources, such as the Advance Care Planning E-book *My Voice*, the *Let's Talk* DVD, brochures, checklists and other resources. There is also a training workshop, “Starting the Conversation: Introducing ACP into Everyday Health Care,” designed for renal and/or chronic disease practice settings, to help staff introduce ACP to patients.

These resources are available for use by health authorities across BC and can be accessed from the Fraser Health website.



### 4.2.3 Process Indicators

- Renal patients (and their families) will have had an initial ACP conversation and (when willing) will have completed related documentation.
- Each renal program will have an ACP strategy and evaluation plan for program-wide integration based on their regional and HARP resources. As part of this plan there will be a process for communicating with patients and their families (i.e. introducing a green sleeve on the patient's chart), among team members, with other involved healthcare providers, and across renal programs about patients' ACP wishes.
- Renal staff will have received pertinent training in ACP.
- PROMIS documentation will be enhanced to enable electronic tracking of ACP and EOL wishes, including DNR (do not resuscitate) status.
- Outcome indicators will be established for ACP that could include measuring the impact on specific patient outcomes (for example: quality of life, psychological distress, coping mechanisms, quality of death, and family satisfaction with care).

## 4.3 SYMPTOM ASSESSMENT AND MANAGEMENT

The symptom burden in dialysis patients<sup>58,59</sup> and patients being conservatively managed<sup>60,61,62</sup> is extensive, severe and significantly impacts quality of life. However, research findings indicate that renal patients often underreport their symptoms. The primary reasons for this include lack of awareness of staff of the presence and/or severity of symptoms in patients,<sup>63</sup> patient perception that staff members are more interested in their dialysis adequacy results,<sup>64</sup> and patients being resigned to living with symptoms they believe to be untreatable or unavoidable consequences of ESRD and its treatment.<sup>65</sup> Accurately assessing symptoms and implementing algorithms to manage symptoms can significantly improve a patient's quality of life and provide consistent treatment.<sup>66</sup>

### 4.3.1 Scope

A primary outcome of care for ESRD patients is their achievement of a satisfactory quality of life despite the presence of a chronic, life-altering illness. The health care team plays an important role in helping patients achieve this through accurate symptom assessment and management. Key to the success of these efforts is an in-depth knowledge of the symptoms patients are experiencing and how to treat those symptoms.<sup>67</sup> This guideline recommends symptom assessment tools and management strategies to assist the health care team to enhance renal patients' quality of life.

#### Symptoms Overview

The most common symptoms for dialysis patients include tiredness, decreased well-being, poor appetite and itching. The most severe symptoms are pain, tiredness, well-being, appetite, anxiety and depression.<sup>68,69,70,71,72</sup> Table 2 below indicates the percentage of patients who report various symptoms (n=531).

*A primary outcome of care for ESRD patients is their achievement of a satisfactory quality of life despite the presence of a chronic, life-altering illness.*

**Table 2: Burden of Symptoms in Dialysis Patients (Fainsinger & Davison, 2003)<sup>73</sup>**

	Intensity			
	0	1–3	4–5	6–10
Pain	37.5%	20.5%	16.0%	26.5%
Nausea	61.4%	24.0%	7.0%	7.6%
Depression	50.6%	22.6%	14.0%	12.8%
Anxiety	44.8%	26.4%	13.7%	15.1%
Drowsiness	32.1%	28.3%	21.0%	18.6%
Appetite	28.1%	28.4%	20.8%	22.7%
Wellbeing	18.4%	30.5%	27.3%	23.8%
Shortness of Breath	43.9%	25.0%	15.7%	15.4%
Pruritis	31.5%	27.4%	15.7%	25.4%
Activity	12.7%	23.5%	27.6%	36.2%

Additional symptoms commonly experienced in the last days of life for ESRD patients are similar to cancer patients and include increased nausea, respiratory tract secretions, terminal agitation, shortness of breath, fluid overload, convulsions and adverse drug effects.<sup>74</sup> Symptoms that are already present for ESRD patients, such as restless legs, pruritus and lethargy (p.228),<sup>75</sup> remain troublesome in the terminal phase.

#### 4.3.2 Guideline

##### Symptom Assessment

The literature recommends using the following symptom assessment tools to quantify the most commonly reported symptoms in patients with ESRD.

**Modified Edmonton Symptom Assessment System (ESAS)** ESAS is a measurement tool that has been extensively used in the palliative care setting. It has also been successfully used with the ESRD population in a modified version. The modified tool consists of 10 visual analogue scales with a superimposed 0–10 scale for pain, activity, nausea, pruritus, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. A rating of 0 represents ‘No’ and a rating of 10 represents ‘Severe.’ A total symptom distress score is calculated by summing the scores for all ten symptoms (ranges from 0 to 100).<sup>76</sup> (See Appendix 2)

**Modified Patient Outcome Scale (POS)** POS is a measurement tool that has been used primarily in the terminal cancer population and has potential for use with ESRD patients. The modified tool consists of a range of symptoms and asks patients to rate their experience of these symptoms using a 5 point Likert Scale, from ‘not at all – no effect’ to ‘overwhelming – can think of nothing else.’ (See Appendix 3)





### **Symptom Management**

The following guidelines are recommended for use in managing pain and other symptoms experienced by patients throughout their illness and at EOL.

### **Pain Management**

Pain is the most common symptom, occurring among 50% of dialysis patients.<sup>77</sup> Pain may be due to a persisting underlying systemic disease (such as ischemic limbs, peripheral neuropathies, osteoporosis or osteoarthritis) and/or numerous painful syndromes unique to CKD (such as calciphylaxis, renal bone disease and dialysis-related amyloidosis).<sup>78</sup> Pain impacts virtually every aspect of quality of life and is the number one concern for ESRD patients at the end of life; however, it is often under treated. For these reasons, it is very important for nephrologists and the clinical team to master the principles of pain assessment and management.<sup>79</sup>

One of the first principles of pain management is to believe the patient's report of pain and initiate discussions about their pain. It is important to differentiate between patients with recurrent or persistent pain who remain functional and those whose pain produces significant disability and suffering.<sup>80</sup>

It is not always possible to completely eliminate pain. A more realistic goal of pain management may be to optimize pain relief while focusing on disability issues to make patients more functional in their daily activities. The reduction of pain severity across the severity boundaries might be thought of as a clinically significant goal of therapy to help achieve this objective. The table on the following page outlines the facts on pain assessment and management.



## Fast Facts on Pain Assessment and Management (Davison SN, 2005)<sup>81</sup>

### The Essentials of Pain Management

1. Pain assessment and its response to treatment must be charted daily until pain is stabilized. The essentials of pain assessment are:
  - a. Believe the patient's report of pain
  - b. Assess pain in its site, character, intensity, extent, relieving and aggravating factors, and temporal relationships.
  - c. Use a simple assessment tool such as a numerical scale of 0 – 10.
  - d. Educate patients or their caregivers at home on pain assessment and charting.
2. Patients may have more than one kind of pain; each pain syndrome must be independently diagnosed and treated.
3. Aim to achieve control at a level acceptable to the patient. It may not be necessary or possible to make the patient completely pain-free.
4. Pain may be associated with and aggravated by other symptoms including psychological symptoms. The psychological state of the patient must be assessed and treated appropriately with equal concern.
5. Utilize an interdisciplinary team to manage "total pain." This may require a consultation to a palliative care team or a chronic pain clinic.
6. Have knowledge of opioids and adjuvants to opioids.
7. Recognize that misconceptions about pain and opioid therapy are still stumbling blocks to adequate pain control.
8. Refer for non-pharmacological interventions such as physical therapy (e.g. transcutaneous nerve stimulation, hot and cold therapy, exercise and neuromuscular massage) where appropriate.
9. Educate patients and their caregivers on the goals of therapy, management plan, and potential complications. This will help minimize non-compliance.

### Concurrent Psychosocial Issues

1. The pain threshold may be increased or decreased by associated psychosocial symptoms.
  - a. Good morale, mood, and nutrition increase the pain threshold, which means the patient feels less pain.
  - b. Anxiety, depression, and fears decrease the pain threshold, which means the patient feels more pain.



2. The concept of “total pain” refers to any unmet needs of the patient that may aggravate pain (e.g. financial, spiritual). Pain may not be controlled unless these associated symptoms or unmet needs are addressed.
3. Spiritual counseling in pain management may be useful in that spirituality helps the patient understand self better and may help the patient think beyond self and cope with pain better.
4. Psychological factors in response to acute pain are predictive of chronic incapacity.
5. Distress at and confusion about previous treatment has a powerful influence on patients.
6. Better management of psychological reactions at early stages of treatment has the potential for reducing distress and preventing unnecessary chronicity.

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#### **Guidelines for Using Opioids**

1. Use a specific opioid for a specific type of pain.
2. Use adjuvants judiciously to provide additive analgesia and minimize side effects.
3. The five essentials of opioid (analgesic) dosing:
  - a. **By mouth** whenever possible, drugs should be given orally.
  - b. **By the clock** schedule doses over 24 hours on a regular basis. Additional “breakthrough” medication should be available on an as needed (PRN) basis.
  - c. **By the ladder** use pain medicine “stepwise” according to the WHO analgesic ladder
  - d. **For the individual** there is no standard dose of strong opioids. The right dose is the dose that relieves pain without causing unacceptable side effects.
  - e. **Attention to detail** pain changes over time, thus there is a need for constant assessment and reassessment.
4. Know how to prevent and manage the side effects of opioids: nausea, sedation, constipation, cognitive impairment.

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#### **Facts about Opioid Addiction**

1. The incidence of addiction in patients receiving opioid therapy for pain relief is no different from that of the general population at less than 1%.
2. Patients will become physically dependent when treated with opioids for a time and therefore will have effects of withdrawal if the opioid is stopped suddenly.
3. Physical dependency is easily managed by a slow taper of the opioid when pain has resolved.
4. Physical dependency is not synonymous with addiction.



5. Addiction is a psychological problem rather than a physical one and is characterized by patients engaging in manipulative behaviors to secure the drug.
6. Individuals who are addicted use opioids for reasons other than pain. Taking drugs for pain management is different from taking them for pleasure.

#### **Indications for Using Adjuvants with Opioids**

1. Adjuvants may be used with opioids to control side effects.
2. Adjuvants may be used for specific pains not responding well to opioids.
3. Adjuvants may be used as “opioid-sparing” agents to decrease the dose of opioid when side effects of opioids become troublesome.

#### **Pruritus**

Simply stated, pruritus is an unpleasant sensation that provokes the desire to scratch, sometimes in an uncontrollable manner. Pruritus is a common complaint among dialysis patients and is often quite distressing. Both the prevalence and pattern of pruritus varies. It can be persistent or recurring but commonly has an impact on the overall well-being of renal patients.<sup>81</sup> Despite documentation in ESRD literature for over 100 years, little research has been done in this area to help advance the ability to either alleviate or effectively manage pruritus.<sup>82</sup>

#### **Other Symptoms**

There are a number of other symptoms that can occur during the final stages of care.<sup>84</sup> These include:

- Restlessness and agitation
- Dyspnea
- Nausea and vomiting
- Respiratory tract secretions.

#### **4.3.3 Process Indicators**

- A process within each HARP has been developed and integrated into regular practice for routine screening and evaluation of defined symptoms
- All renal patients are screened for commonly associated renal symptoms, with those scoring high being referred to specific care pathways
- All renal staff has received pertinent training in understanding the etiology and pathophysiology of common renal symptoms, how to use assessment tools, protocols and algorithms, and what their role is within this process
- Review and enhancement of the PROMIS database for data entry regarding symptom assessment and management.



*Research shows that contact by the renal care team with a patient's family often ceases abruptly after the patient dies.*

#### 4.4 CARE OF THE DYING PATIENT AND BEREAVEMENT

Care during the end-of-life phase shifts from active management to relief of symptoms where comfort is emphasized. It is a time when individual patients may need psychosocial and spiritual support (p. 255).<sup>85</sup> What constitutes a “good death” will vary for each patient. This reality can create difficulty for a health care system that is not typically flexible or nimble. Additionally, health care professionals can find it ethically challenging when patients’ decisions differ from their own belief system, or when patients’ goals of care have not been met (*See Appendix 4: Principles of a Good Death*).<sup>86</sup>

Research shows that contact by the renal care team with a patient’s family often ceases abruptly after the patient dies. Staff and fellow patients are sometimes left unsure as to whether individuals have died or merely moved to another dialysis unit.<sup>87</sup> Renal programs do not usually have the resources or expertise to provide bereavement care. However, each health authority does have hospice and/or palliative care program(s) that they can access.

##### 4.4.1 Scope

The time to death after ceasing dialysis is approximately 8–9 days, with a few patients surviving upwards of one month (p. 254).<sup>88</sup> For patients who choose conservative care, the cause of death and the time line to death is more varied and less predictable (p. 255).<sup>88</sup>

This guideline is intended to assist in providing high quality care at the EOL.

##### 4.4.2 Guideline

Singer et al.<sup>89</sup> have identified the common elements of care that are important to address in the last days of life. They are:

- Effective pain and symptom management
- Avoiding unwanted and/or inappropriate prolongation of life
- Having a sense of control over the situation
- Having minimized the burden/stress for family member and loved ones
- Strengthening relationships with loved ones.

The mechanisms used to achieve the goal of high quality care in the last days of life may need to be developed at the program level but the common elements will include:

1. An agreed-upon care plan, ideally derived from the ACP, that identifies the individual patient’s direction for physical, emotional, and spiritual care.
2. The knowledge and ability to manage symptoms, with the support of palliative care specialists as needed.
3. An integrated, culturally-appropriate approach.



### Care after Death

Due to the nature of the business of dialysis units, there is often little time after a patient dies to do more than focus on the next patient. The renal team is comprised of individuals with a variety of belief systems, opinions, and approaches to managing death. Additionally, in this era of privacy the degree of disclosure of patient specific information must be established.

Some pragmatic suggestions for care after death include:<sup>90,91</sup>

*The renal team is comprised of individuals with a variety of belief systems, opinions, and approaches to managing death.*

1. Use a death/bereavement checklist that contains details of all the necessary steps the renal team must complete when a patient dies.
2. Ensure that the surviving family/friends are aware of community supports for managing grief and bereavement in a healthy way. This includes information on local hospices, support groups and bereavement counseling services (local and national organizations).
3. Consider ways to acknowledge the patient's death. This could include a notice in the waiting room, posting obituaries and/or placement of a ritual flower arrangement or card by the nursing station. Other options include a yearly memorial service, to which family and friends are invited.
4. Consider sending the family a condolence card or letter of sympathy. Some units send families an anniversary of death card in the first year.
5. Consider that it may be important for some of the renal staff to attend patients' funeral/memorial services.
6. Create opportunities for staff to discuss and reflect upon recently deceased patients in a respectful non-judgmental environment.
7. Ensure that staff is aware of bereavement and counseling services through employee assistance program.
8. Look for opportunities to expand knowledge and expertise of staff through continuing education on death/dying topics.

#### 4.4.3 Process Indicators

- Each renal program will develop a strategy to address the death of patients that reflects both their patient and staffing needs
- Morbidity and mortality rounds/conferences to allow further input from care team, emphasizing acp, control of pain and other symptoms, and review of overall character of the patient's last days and hours. Reviews of adverse outcomes in an educational and quality improvement context will increase staff sensitivity to patient care (p. 323)<sup>92</sup>
- Renal Palliative Care Initiative Quality of Death form and post death questionnaire
- Renal Palliative Care Initiative memorial service feedback survey
- QUAL-E – a brief measure of quality of life at the EOL.<sup>93</sup>



## 5. EOL EDUCATION

### 5.1 SCOPE

Minimal training pertaining to EOL care for renal patients is provided in the professional programs regardless of the profession.<sup>94,95,96,97</sup> The depth of knowledge needed, plus the reality that not all renal care providers want to develop this area of expertise, has directed the educational focus to be on developing champions from within the system. Champions will lead the educational spread through a train-the-trainer approach, mentoring co-peers, and modeling behaviors developing an interest among co-peers in their own skill development.

*Champions will lead the educational spread through a train-the-trainer approach, mentoring co-peers, and modeling behaviors developing an interest among co-peers in their own skill development.*

### 5.2 GUIDELINE

The EOL Expert Panel indicated that the following components should be followed when developing an education strategy:

- Train “champions” on the BCPRA EOL Task Group first as they will facilitate the training in their local HARPs, act as ongoing mentors, and have a key role in the ongoing dissemination of knowledge pertaining to EOL care
- Champions will be trained by recognized palliative and renal experts
- Provide core training in key concepts and elements first and share programs, tools and resources already used within BC health authorities (i.e. FHA, PHC and VIHA)
- Ensure that EOL educational programs and resources are provided on the BCPRA website and continuously updated
- Advocate for discipline-specific EOL training during the professional educational experience
- Use existing venues to provide ongoing EOL training/updates (e.g. BC Nephrology Days)
- Use pilot projects to demonstrate the benefit of EOL training and use of guidelines.

#### 5.2.1 Target Group

The target group for EOL education in BC is the multi-disciplinary team, including nephrologists, social workers nurses, nurse practitioners, pharmacists, and dieticians.

#### 5.2.2 Approach, Content and Format

Education will be based on current research evidence and focused on increasing knowledge in the key components of EOL care — Patient Identification, Advance Care Planning, Symptom Assessment & Management and Care of the Dying Patient/Bereavement.



It is recommended that EOL guidelines be agreed to provincially to ensure best standard of care for all ESRD patients regardless of location. Implementation and sustained use of the guidelines throughout the HARPs would be a fundamental objective of the local champions (clinical professionals working in local HARPs who have an existing knowledge and/or a keen interest in EOL care).

The knowledge support and skill enhancement for champions across HARPs would be best provided by a two-day focused and intensive workshop, which the BCPRA will sponsor. The workshop would provide training on provincially accepted EOL guidelines, research and best practices in EOL care and how to provide in-service education to local HARP staff. Champions will be given presentation materials and a resource package to use when disseminating information and guidelines in their local HARPs.

After training, champions will work within their HARPs to facilitate integration of EOL guidelines into the ongoing work of renal staff. Annual education updates will be offered for champions to learn about new research findings and share their experiences regarding implementation.

### **5.2.3 Health Authority Renal Program EOL Training**

The EOL champions, with support from the EOL leadership group and the BCPRA, will discuss and design the EOL learning approach at the local program level. Training approaches could include on-site visits by a team of EOL experts and local champions, on-line programs, video tapes, satellite broadcasts, and resource packages. Innovation and collaboration will be emphasized.

Some health authorities are ahead in implementing specific components of EOL care in renal programs. FHA has implemented a comprehensive approach to ACP that includes a renal EOL pilot project to improve the internal processes between the renal program and hospice palliative care program. This pilot is nearing completion and has resulted in resources, such as pain and symptom support algorithms, ACP training, palliative care referral processes, and hospice transfer orders. Providence Health Care, through support from its hospital foundation, has sent nephrologists, nurses and other clinical staff to intensive palliative/EOL and pain management programs at Harvard University. They have also recently initiated an EOL project to enhance EOL care in the hemodialysis unit at the hospital. VIHA has organized professional education sessions for nephrologists and clinical teams on EOL care and has worked closely with the palliative care team and the Victoria Hospice Society to address EOL issues for their patients. In Interior Health, the Penticton renal program is currently piloting ACP in its hemodialysis unit. These programs are willing to share information and resources with the HARPs that do not have EOL education programs and resources. As such, the EOL training programs for local HARPs will build on these programs and tap into the expertise and resources that already exist in BC and across Canada.





#### **5.2.4 Resource Requirements**

BCPRA funding for:

- Experts to provide the two-day intensive training for EOL champions
- Travel/accommodation costs for experts to travel to local HARPs to provide training (as needed)
- Money for resource development or promotion of existing material e.g. booklets, videos, on-line programs.

Health authority funding to:

- Allow local staff to attend training.

#### **5.2.5 Process Indicators**

- Confirmation of “faculty” for the extensive training session
- Development of a curriculum for the extensive training session
- Development of resources and tools for extensive training session
- Implementation of extensive training session.





## 6. SUSTAINABILITY

The sustainability of knowledge and skill development among renal professionals in this specific area of patient care is very important – and will be very challenging. Improvements and changes are likely to be small and stepwise until there is a critical mass of practitioners who are able to offer high quality care during the final stages of life. However the renal community in BC is cohesive and there are a number of ways to raise the profile of kidney EOL care, including:

*Improvements and changes are likely to be small and stepwise until there is a critical mass of practitioners who are able to offer high quality care during the final stages of life.*

- Alignment with the Ministry of Health Services (MOHS) palliative care framework and strategy, with advocacy for renal patients whenever feasible
- Ongoing emphasis on patient involvement in care plans at early stages, which helps ensure their involvement as death becomes a stronger reality
- Use and refinement of guidelines
- Advocating to include a palliative component in fellowships and other aspects of professional training
- Ongoing research into this aspect of renal care
- Accreditation standards
- Refinements of quality indicators to help reflect practice changes and improvements
- Tracking of quality indicators and regular reporting through PROMIS.





## 7. RESOURCES

### PATIENT IDENTIFICATION

Brown, EA, Chambers, EJ, & Eggeling, C (2008). Palliative care in nephrology. *Nephrol. Dial. Transplant*, 23(3), 789-791. See table 1: Clinical features of end-of-life.

Modified Charlson Comorbidity Index from the Medical Algorithms website.

### ACP

Fraser Health Authority link to ACP resources:

### SYMPTOM ASSESSMENT AND MANAGEMENT

Dr. Kiaii, Nicole Gorman, Dr. Richard Crawford, Marianna Leung (Dec 2008):  
St. Paul's Hospital's Pruritus Protocol

Fraser Health Hospice Palliative Care Symptom Guidelines (not renal specific)

Fraser Health Renal Program:

- Clinical Pathway and Drug Choices for Chronic Pain in Patients on Dialysis-FHA Renal Program (Sept. 02, 2009)
- Renal Pain Tracking Tool (Feb. 08)
- Renal Pain Assessment Tool (final)
- Renal Pain Flow Sheet (Feb. 2009)

Mid-Atlantic Renal Coalition. (2007). *Clinical Algorithm and Preferred Medications to Treat Pain in Dialysis Patients*. Midlothian, VA, Mid-Atlantic Renal Coalition. Supported, in part, under CMS Contract #HHSM-500-2006-NW005C. Pain Management Assessment Algorithm

Modified Edmonton Symptom Assessment System

Murphy, EL, Murtagh, FE, Carey, I, & Sheerin, NS (2009). Understanding symptoms in patients with advanced chronic kidney disease managed without dialysis: Use of a short patient-completed assessment tool. *Nephron*, 111(1):c74-80. Patient Outcomes Scale Symptom Module



National LCP Renal Steering Group. (June 2008). *Liverpool care pathway for the dying patient: Guidelines for LCP drug prescribing in advanced chronic kidney disease*. Liverpool, UK: Marie Curie Palliative Care Institute.

Treatment Protocol for Pruritus from the Renal Palliative Care Initiative, Promoting Excellent in End-of-Life project website.

- Pruritus
- Nausea and Vomiting
- Restless Legs

World Health Organization's pain ladder

## CARE OF THE DYING AND BEREAVEMENT

Kidney End of Life Coalition. (nd).

- *Ways to Provide Support to Staff after Patient Deaths*.
- *The Renal Palliative Care Initiative, Memorial Service Manual* by L. M. Cohen (nd).

The Kidney Foundation of Canada. *Choosing to Stop Dialysis* (Brochure).

Victoria Hospice Society (2008). *Bereavement Risk Assessment Tool*.



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APPENDIX A

**Institute for Algorithmic Medicine**

**Comorbidity Index and Score of Charlson et al**

Purpose: To use the comorbidity score developed by Charlson et al to give an estimate of 10 year survival for a patient.

Age of the patient \_\_\_\_\_ years

Does the patient have?

AIDS?  Yes  No

Cerebrovascular disease?  Yes  No

Chronic pulmonary disease?  Yes  No

Congestive heart failure?  Yes  No

Connective tissue disease?  Yes  No

Dementia?  Yes  No

Hemiplegia?  Yes  No

Leukemia?  Yes  No

Malignant lymphoma?  Yes  No

Myocardial infarction?  Yes  No

Peripheral vascular disease?  Yes  No

Ulcer disease?  Yes  No

Click the appropriate column for each condition (give only 1 answer per row)

Diabetes mellitus  None  Without end organ damage  with end organ damage

Liver disease  None  Mild  Moderate  Severe

Renal disease  None  Mild  Moderate  Severe

Malignant solid tumor  None  Non-metastatic  Metastatic



## 191 PROGNOSTICATION IN PATIENTS RECEIVING DIALYSIS

### FAST FACTS AND CONCEPTS #191

**Author(s)** Matthew Hudson, Steven Weisbord MD, Robert Arnold MD

**Background** End stage renal disease (ESRD) is a highly prevalent and rapidly increasing condition. While dialysis prolongs life in patients with ESRD, life expectancy remains only a third to a sixth as long as similar patients not on dialysis. The overall one and five year mortality rates are 25% and 60%, respectively. Approximately 20% of ESRD patient deaths occur after a decision to stop dialysis, highlighting the importance of discussions of prognosis and goals of care with this chronically ill population. This Fast Fact reviews the current data regarding prognostication in patients receiving chronic hemo- and peritoneal dialysis. Note: renal transplantation reduces mortality and the following data do not consider patients with functioning kidney transplants.

**Prognostic Factors** Several patient-specific factors influence prognosis:

- **Age:** For 1-year increments beginning at age 18, there is a 3 to 4% increase in annual mortality compared to the general population. 1 and 2 year mortality rates go from 10 and 12% at 25–29 years of age, to 25% and 42% at 65–69 years, to 39% and 61% at 80–84 years of age.
- **Functional status:** the relative risk of dying within 3 years of starting dialysis is 1.44 for those with Karnofsky Performance Status scores of <70 (≥70 compared to those with a score see Fast Fact #13).
- **Albumin:** a low serum albumin level, both at baseline and during the course of dialysis treatment, is a consistent and strong predictor of death. For example, the 1 and 2 year survival of patients with an albumin of >3.5 g/dL is 86% and 76% respectively, compared to 50% and 17% if one's albumin is less than 3.5.

**Prognostic Tools** It has long been recognized that patient comorbidity is strongly correlated with prognosis in ESRD. An age-modified Charlson Comorbidity Index (CCI), which stratifies patients based on medical comorbidities and age, has been successfully used to predict mortality in dialysis-dependent patients (8):

**Modified Charlson Comorbidity Index** Total score is the sum of the comorbidity points

#### Comorbidity Points

**1 point each** for coronary artery disease, congestive heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disorder, peptic ulcer disease, mild liver disease, diabetes  
**1 point** for every decade over 40 (e.g. a 65 year old would receive 3 points).

**2 points each** for hemiplegia, moderate-to-severe renal disease (including being on dialysis), diabetes with end-organ damage, cancer (including leukemia or lymphoma)

**3 points** for moderate-to-severe liver disease

**6 points each** for metastatic solid tumor or AIDS



Modified CCI Score Total	Low Score ( $\leq 3$ )	Moderate (4-5)	High (6-7)	Very High ( $\geq 8$ )
Annual mortality rate	0.03	0.13	0.27	0.49

For example, a 66 year old male on dialysis with a history of CHF, COPD, and diabetes with retinopathy would have a CCI score of 9 and a nearly 50% chance of dying within a year. Using this, a provider could discuss with the patient his prognosis and use this to facilitate further discussion regarding planning for the future, including end-of-life decisions. The Index of Coexistent Disease (ICED), a general illness severity index, has also shown predictive power in ESRD. The scale's complexity and length however (it entails asking over 100 questions) limit its clinical usefulness.

**Summary** The age-modified CCI, in conjunction with other prognostic factors such as serum albumin and functional status, can be used to help facilitate discussions with dialysis-dependent patients and their families regarding goals of care and end-of-life planning.

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**ACGME Competencies** Medical Knowledge

**Keyword(s)** Prognosis





APPENDIX B

 <p><b>Edmonton Symptom Assessment System: Numerical Scale</b> Northern Alberta Renal Program</p>		
<p><b>Please circle the number that best describes:</b></p>		
No pain	0   1   2   3   4   5   6   7   8   9   10	Worst possible pain
Not tired	0   1   2   3   4   5   6   7   8   9   10	Worst possible tiredness
Not nauseated	0   1   2   3   4   5   6   7   8   9   10	Worst possible nausea
Not depressed	0   1   2   3   4   5   6   7   8   9   10	Worst possible depression
Not anxious	0   1   2   3   4   5   6   7   8   9   10	Worst possible anxiety
Not drowsy	0   1   2   3   4   5   6   7   8   9   10	Worst possible drowsiness
Best appetite	0   1   2   3   4   5   6   7   8   9   10	Worst possible appetite
Best feeling of wellbeing	0   1   2   3   4   5   6   7   8   9   10	Worst possible feeling of wellbeing
No itching	0   1   2   3   4   5   6   7   8   9   10	Worst possible itching
No shortness of breath	0   1   2   3   4   5   6   7   8   9   10	Worst possible shortness of breath
Other problem	0   1   2   3   4   5   6   7   8   9   10	
Patient's Name _____ Date _____ Time _____		Complete by (check one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Caregiver assisted
<b><i>BODY DIAGRAM ON REVERSE SIDE</i></b>		
April 12, 2002 C:\Data\Nephrology\Edmonton Symptom Assess Numerical Scale.doc		





## APPENDIX C

### Questionnaire POS-S1 — Patient

This form is available for use on page 44.

Questionnaire POS-S1 — Patient					
Below is a list of symptoms, which you may or may not have experienced. Please put a tick in the box to show how each of these symptoms has affected how you have been feeling over the last 3 days.					Date: ___/___/___
					Study No: _____
	Not at all No effect	Slightly But not bothered to be rid of it	Moderately Limits some activity or concentration	Severely Activities or concentration markedly affected	Overwhelmingly Unable to think of anything else
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breathe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mouth problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drowsiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless legs or difficulty keeping legs still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other symptoms? _____					
Which symptom has affected you the most? _____					
Which symptom, if any, has improved the most? _____					

### Questionnaire POS-S1 — Staff

This form is available for use on page 45.

Questionnaire POS-S1 — Staff					
Below is a list of symptoms, which the patient may or may not have experienced. Please record how these symptoms have affected the patient in the table below. Please put a tick in the box to show how you think they have been feeling over the last 3 days.					Date: ___/___/___
					Study No: _____
	Not at all No effect	Slightly But not bothered to be rid of it	Moderately Limits some activity or concentration	Severely Activities or concentration markedly affected	Overwhelmingly Unable to think of anything else
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breathe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mouth problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drowsiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless legs or difficulty keeping legs still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other symptoms? _____					
Which symptom has affected them the most? _____					
Which symptom, if any, has improved the most? _____					

# Questionnaire POS-S1 — Patient

Date: \_\_\_/\_\_\_/\_\_\_

Below is a list of symptoms, which you may or may not have experienced.

Study No: \_\_\_\_\_

Please put a tick in the box to show how each of these symptoms has affected how you have been feeling **over the last 3 days**.

	<b>Not at all</b> No effect	<b>Slightly</b> But not bothered to be rid of it	<b>Moderately</b> Limits some activity or concentration	<b>Severely</b> Activities or concentration markedly affected	<b>Overwhelmingly</b> Unable to think of anything else
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breathe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mouth problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drowsiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless legs or difficulty keeping legs still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Any other symptoms?

---

Which symptom has affected you the most?

---

Which symptom, if any, has improved the most?

---

## Questionnaire POS-S1 — Staff

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Below is a list of symptoms, which the patient may or may not have experienced. Please record how these symptoms have affected the patient in the table below. Please put a tick in the box to show how you think they have been feeling **over the last 3 days**.

Study No: \_\_\_\_\_

	<b>Not at all</b> No effect	<b>Slightly</b> But not bothered to be rid of it	<b>Moderately</b> Limits some activity or concentration	<b>Severely</b> Activities or concentration markedly affected	<b>Overwhelmingly</b> Unable to think of anything else
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shortness of breathe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weakness or lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vomiting (being sick)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mouth problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drowsiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Itching	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless legs or difficulty keeping legs still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in skin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Any other symptoms?

---

Which symptom has affected them the most?

---

Which symptom, if any, has improved the most?

---





## APPENDIX D

### Principles of a Good Death

1. To know when death is coming, and to understand what can be expected.
2. To be able to retain control of what happens.
3. To be afforded dignity and privacy.
4. To have control over pain relief and other symptom control.
5. To have choice and control over where death occurs (at home or elsewhere).
6. To have access to information and expertise of whatever kind is necessary.
7. To have access to any spiritual or emotional support required.
8. To have access to hospice care in any location, not only in hospital.
9. To have control over who is present and who shares the end.
10. To be able to issue advance directives, which ensure wishes are respected.
11. To have time to say goodbye, and control over other aspects of timing.
12. To be able to leave when it is time to go, and not to have life prolonged pointlessly.

Cited in Levy, J (2004). End of life. (Ch. 15, p. 257). In EJ Chambers, M Germain, and E Brown. Supportive care for the renal patient. Oxford: Oxford University Press. Original source from Debate of the Age, Health and Care Study Group. (1999). *The future of health and care of older people: The best is yet to come*. London: Age Concern.









## **BC Renal Agency**

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