PROVINCIAL STANDARDS & GUIDELINES

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Recommendations to Support End-Stage Kidney Disease Patients in Their Last Days to Hours of Life

Created 2018

Approved by the BCPRA Palliative Care Committee

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IMPORTANT INFORMATION

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

For information about the use and referencing of BCPRA provincial guidelines/resources, refer to http://bit.ly/28SFr4n.

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1 Scope

The purpose of this document is to outline a standardized set of best practice end-of-life care recommendations to support care of adult end-stage kidney patients who are perceived to be in their last days to hours of life (terminal or actively dying kidney patients).

This document provides practical recommendations with a renal focus. Providers may also want to review other available guidelines and recommendations for taking care of dying patients that apply to all patients in their last days to hours of life.

These recommendations are intended to be used with health authority and facility health care policy. They will serve as a resource for any health care provider participating in the care of the dying ESKD patient. It is not implicit that the nephrologist will participate in the role of 'Most Responsible Physician' (which he/she may choose to); the nephrologist will usually participate in a collaborative capacity as a member of the multidisciplinary team.

Although not within the scope of this document, it is well recognized by the renal care community that palliative care implemented earlier in the ESKD patient journey (prior to discontinuing dialysis) improves the patient and family experience. Certain patients may present unique challenges that require a tailored, collaborative approach.

2 Guiding Principles: Palliative Approach to Care at the End of Life

Respect at the end of life involves understanding and honouring the wishes of patients and families. A holistic approach to comfort, including family and all team members, generally provides best outcomes. Understanding family wishes is of extreme importance, and ongoing conversations regarding what to expect at the end of life are crucial to the quality of care provided during end-of-life care.

Providing information and support – *It is critical that family and loved ones benefit from repeated contact with the health care team, including physicians. A prepared and supported family experiences less anxiety, a greater sense of value of this final time, good memories of the process and less fear of their own dying process.*

Provide families with oral and written information and support about what to expect at the end of life. Use unit-specific patient teaching materials on preparing for the death of a loved one:

- Review patient for symptoms that are not controlled.
- Assess family perception of patient's comfort.
- Assess family awareness of the situation and provide information in plain language.
- Review goals of care and irreversibility of unfolding events, particularly if the process seems to be taking longer than family expects.
- Ask family how they are doing and listen for signs of intense anxiety or distress (alert social work and/

or pastoral care if necessary).

- When providing patient teaching materials, you can say: "This information will help you to understand the natural process of coming to the end of life. I am happy to answer questions after you have read it."
- Duration of the dying process varies. Predictions can unsettle family. If asked how long dying will take, you may say: "We will take it day by day (hour by hour)." **See below for additional information**.

Patient trajectories at the end of life – While most patients remain fairly asymptomatic and lethargic, a small proportion of patients may develop neurological changes or a terminal delirium as they progress through their end of life, which may manifest as restlessness, confusion, seizures, myoclonus, or other non-specific level of consciousness (LOC) changes.

Time to death after stopping dialysis can vary and is hard to predict, particularly for patients with residual kidney function (e.g., many peritoneal dialysis patients). On average, an anuric patient on hemodialysis will die within 7 to 10 days after stopping dialysis.

Palliative sedation can be considered in cases of refractory and distressing symptoms such as terminal delirium, severe pain or dyspnea. This treatment may involve the escalation of pharmacologics such as infusions of midazolam, fentanyl, ketamine, and/or dexmedetomidine. The goal is to alleviate patient's symptoms and suffering, recognizing that doing so may hasten death although this is not the intention of the intervention.

A palliative care consultation and consideration for transfer to a tertiary Palliative Care Unit (PCU) is strongly recommended in these circumstances. Some medical wards may not have the capability (nursing expertise, equipment / infusers, etc.) to support these infusions, and oftentimes local palliative care expertise can help provide advice as to optimal location of care.

Intravenous fluids are generally not helpful as body organs shut down. IV fluids may:

- Promote edema / third-spacing, which can be uncomfortable.
- Lead to pulmonary edema and increased dyspnea / respiratory distress.
- Require that IV catheter sit in situ (uncomfortable for patient).
- Increase risk for losing site and fluids being administered interstitially (uncomfortable for patient).

Education of family regarding the risks and benefits of intravenous fluids is essential to reduce miscommunication regarding dehydration and suffering. For some families removal of an IV line signifies abandonment, and reduction of the IV rate to TKVO may be the best plan to reduce family distress. Explain the meaning of IV fluids at the end of life to the family and provide them with unit-specific patient teaching materials regarding hydration at the end of life.

Oral intake – Discuss with families the meaning of nutrition / hydration versus hunger and thirst. When the patient is unable to eat / drink, support the family

to understand the dying process. Discuss the risks and benefits of eating and drinking.

Specifically, you can explain that nutritional needs at the end of life are minimal as the metabolic needs of the body decline. Nutrition and oral intake should therefore be patient-centred (i.e., avoidance of family-assisted feeding is recommended if the patient is not voluntarily seeking nutrition or is at risk of choking/aspiration) and align with patient symptoms.

At end of life, there is a shift of focus from quantity of food eaten to optimizing food enjoyment (e.g., relaxed dietary restrictions) and reducing food-related discomfort. Patients may choose to continue their own oral nutrition supplement for comfort. Parenteral (IV) nutrition does not prolong life or improve functional status and is not indicated. Mouth care techniques to help reduce symptoms of dry mouth and thirst include: oral cleaning, ice chips, lip moisturizers, and rinsing with cold water. Mouth care and including patients in the social aspects of mealtime can still be positive experiences for patients and their families.

Elimination: *Urine* – Foley catheter (with 10 mL lidocaine 2% jelly) may be of benefit if the patient becomes restless and is unable to empty the bladder. If there is little output, a disposable brief is sufficient. ***Bowels*** – Unless constipation is causing distress or discomfort, discontinue routine bowel care (see 3.5 End-of-Life Care Bowel Protocol for more details).

Vital signs, oxygen saturation and blood work – Vital signs, pulse oximetry and laboratory and diagnostic test results may become abnormal, and should not inform symptom-guided management. Routine nursing vital signs checks should be replaced by routine and frequent "symptom" signs checks to avoid sending an unintentional signal of abandonment to the family and patient at the end of life. The treatment of symptoms such as pain, confusion or respiratory distress is more beneficial than attempts at reversing the irreversible.

Suctioning is an uncomfortable procedure and comes at the risk of causing a gag reaction, which could result in vomiting and aspiration, and potentially a hastened death that is distressful. Suctioning stimulates secretions and mouth suction can disturb oral mucosa and create mouth ulcers. Unless a patient is able to express a desire for suctioning, it should be discontinued.

Opioids – A patient currently on regular opioids (opioid tolerant) should have additional PRN opioids available for additional pain or dyspnea management as well as active end-of-life pain / dyspnea crisis management. A patient not on regular opioids (opioid naïve) should have a PRN available to manage pain and/or dyspnea (see 3.0 End-of-Life Care Recommendations for more details).

Hydromorphone (Dilaudid) should be used preferentially (vs morphine) in a patient with end-stage renal disease, as it causes fewer adverse effects compared to using morphine (related to accumulation of metabolites). Consider not using morphine even if a patient is already on it.

Fentanyl can be considered, however, parenteral fentanyl is often too short-acting to provide lasting analgesia / anti-dyspnea effect, as fentanyl is mainly metabolized by liver enzymes and is less dependent on renal elimination. Topical fentanyl (i.e., fentanyl patch) can be helpful to achieve effective, sustained analgesia.

Oxygen – High-flow oxygen has not been shown to reduce symptomatic dyspnea and represents an intervention, which causes additional distress during end of life as the facemask equipment can be uncomfortable, loud, and claustrophobia-inducing. Use opioids for relief of dyspnea (see 3.0 End-of-Life Care Recommendations for more details).

At time of death:

- Focus of care shifts to family and caregivers.
- Make the space and time to allow culturally and spiritually appropriate rituals / ceremonies. Consult spiritual care PRN.
- A physician visit is very beneficial for family. If the physician is not able to be there at the time of death, a bereavement phone call or note is much appreciated by family.
- Some questions to ask include: “How were his/her final moments?”, “How are you feeling?”, “Do you have any questions?”
- Taking time to review what has happened and to say goodbye is a healing practice.

3 End-of-Life Care Recommendations

3.1 Patient Identification and Goals of Care

- Death anticipated in days to hours (must be reviewed daily).
- Patient is bed-bound and taking minimal oral nutrition (Palliative Performance Scale (PPSv2) level – 10-40%).
- Patient prognosis and goals of care have been discussed with the patient and/or substitute decision maker and documented.
- Patient and/or substitute decision maker agree that a natural death is the goal of care.
- DNR accepted by patient and/or substitute decision maker: MOST status reviewed – commonly will be DNR M1.
- If appropriate, organ donation discussed with patient and/or substitute decision maker and appropriate forms completed (for more information contact BC Transplant at 604-877-2240; http://www.transplant.bc.ca/).

3.2 General Recommendations

Diagnostics	• Discontinue all laboratory and diagnostic imaging orders.
Nursing	• Discontinue suctioning. • Discontinue intake and output measuring, vital signs, weights, pulse oximetry and blood glucose monitoring; instead, do "symptom" signs monitoring. • Discontinue high flow oxygen. • Oxygen up to 4 L/min via nasal prongs PRN. • Urinary catheter PRN – avoid use if possible. • Discontinue enteral and parenteral nutrition if applicable. • Diet as tolerated – encourage reasonable fluid restriction to prevent fluid overload. • Private room if available. • Nurse may pronounce death as per facility policy. • Notify patient's primary care physician (GP or nurse practitioner). • Notify attending physician at time of death during regular hours. • Follow unit-specific procedure for adult patient death.
Dialysis access	• Discontinue flushing PD catheters. • Discontinue exit site care. • Tunneled CVC – if a patient requests CVC to be removed, it should be done by a qualified specialist, unless it is required for vascular access (e.g., for IV medications).
Intravenous fluids	• Discontinue IV fluids or reduce IV rate to TKVO.
Physicians	• Notify patient's primary care physician (GP or nurse practitioner). • Provide family support.
Social work	• Provide family support and offer unit-specific materials on preparing for the death of a loved one.
Spiritual care	• Participate in goals of care discussions. • Facilitate culturally sensitive conversations pertaining to cultural and ethical dilemmas. • Regular non-religious, supportive presence to patient / family in the EOL trajectory. • Rituals (i.e., prayers, sacrament of the sick, smudging) during last hours of life / post-death.
Medications	• See 3.3 Symptom Management Recommendations and 3.6 Tips for Stopping Oral Medications.
Cardiac Implantable Device	• i.e., ICD – Implantable Cardiac Defibrillator. • Encourage patients to consider deactivation of the ICD; discuss with patient's cardiologist and ICD / pacemaker clinic. • When patient ready, contact clinic directly to arrange deactivation of the device.

3.3 Symptom Management Recommendations

Physician orders are patient and unit-specific. For general recommendations, see below:

SYMPTOMS	POSSIBLE TREATMENT RECOMMENDATIONS
Mild pain and/or distressing fever	• Acetaminophen 650 mg PO/PR Q4H PRN (Maximum dose 4,000 mg per 24 hours; if elderly or liver dysfunction – 2,600 mg per 24 hours).
Pain and/or dyspnea	a) If NOT on opioids or elderly patient, use hydromorphone 0.25 mg subcutaneous Q1H PRN. b) If on opioids already, convert current regular Q4H PO opioid to subcutaneous route (one half of oral dose): • Hydromorphone 2 mg (1-3 mg) subcutaneous Q4H. • For breakthrough – hydromorphone 0.5-1 mg subcutaneous Q1H PRN (recommended 10% of total subcutaneous daily dose, or if total daily dose unknown, ½ the Q4H dose). • If death anticipated in 7-10 days (or longer), consider using low dose fentanyl patch (6.25 mcg/hr - 25 mcg/hr changed every 72 hrs).
Upper respiratory congestion and secretions	• Atropine 1% eye drops 2 drops on or under tongue Q2H PRN. • Glycopyrrolate 0.4 mg subcutaneous Q4H PRN (maximum 2.4 mg per 24 hours).
Nausea and/or vomiting	• Haloperidol 0.5 to 1 mg subcutaneous Q12H PRN (call physician if more than 2.5 mg is required in 24 hours).
Distressing restlessness / agitation	• Haloperidol (less sedating) 0.5 mg to 1 mg subcutaneous Q4H PRN (call physician if more than 2.5 mg from all sources is required in 24 hours). • Methotrimeprazine (more sedating) 6.25 mg to 12.5 mg subcutaneous Q4H PRN (call physician if requiring more than 25 mg in 12 hours).
Anxiety	• Lorazepam 0.5 mg to 1 mg sublingual or subcutaneous Q2H PRN (call physician if using more than 2 mg in 12 hours).
Crisis event	• See 3.4 Crisis Event for details.
Seizure	Initiate treatment as below and call physician: • If seizure lasts greater than 2 minutes: Midazolam: 5 mg subcutaneous stat. • If seizure lasts a further 5 minutes: Midazolam: 5 mg to 10 mg subcutaneous x 1 dose. If still not settled, call physician.
Myoclonic jerking	Initiate treatment as below and call physician: • Midazolam (faster onset / blood-brain barrier penetration, shorter effect duration) 1—2.5 mg subcutaneous Q2H PRN; or • Lorazepam (slower onset of action and longer action, but sublingual route available) 0.5-1mg SL/SC Q2-4H PRN.

3.4 Crisis: Severe Pain / Dyspnea, Terminal Hemorrhage, Seizure

Consider a 50% increase in the usual PRN doses of:

- Opioid:
  - Hydromorphone 4 mg subcutaneous stat, then 1-2 mg Q20MIN x3 PRN. May repeat Q20MIN x 3 PRN; if still not settled, call physician; OR
  - Continuous hydromorphone infusion: 0.25-5 mg/hr infusion (can be higher PRN).
- Sedative:
  - Methotrimeprazine: 12.5 mg to 25 mg subcutaneous x 1 dose; OR
  - Midazolam: 2.5 mg to 5 mg subcutaneous x 1 dose.

Consider a palliative care consultation and/or transfer to a tertiary Palliative Care Unit (PCU), given the escalation of patient needs.

Opioid crisis dosing guidelines for physicians:

- If on PO medications: Give half of regular Q4H PO dose via subcutaneous route.
- If on subcutaneous medications: Give the regular Q4H subcutaneous dose via the **subcutaneous** route.
- The **minimum** crisis order dose should not be less than what would be used for the opioid naïve patient.
- Opioid naïve patient: Give **hydromorphone** 1 mg to 2 mg subcutaneous. If elderly, consider giving 50% of this as a starting dose.

3.5 End-of-Life Care Bowel Protocol

- Complete bowel assessment.
- Determine level at which to start, based on bowel pattern, time since last bowel movement and bowel medication use prior to admission. Document level chosen in the appropriate unit-specific records system.
- Document all bowel medications and interventions administered and bowel movement information in the appropriate unit-specific records system. Include frequency, character, and amount of bowel movements.
- Subsequent rectal and/or abdominal examinations are to be documented in the appropriate unit-specific records system.

Indications:

- To prevent opioid-induced constipation.
- To manage constipation where dietary measures have failed, or previous laxative treatment unsatisfactory.

Contraindications:

- Do not follow protocol for ileostomy, short bowel syndrome, complete bowel obstruction, diarrhea, and impaction (impaction must be cleared prior to initiating protocol). If in doubt, contact physician.

Level 1 – Prevention Once daily (bedtime)	Medications: 1. Sennosides: 12 mg to 36 mg PO at bedtime.
Level 2 – Prevention Twice daily (bid)	Medications: 1. Sennosides: 24 mg to 36 mg PO bid. 2. Polyethylene glycol (PEG – Restoralax): 17g daily PO, titrate to 17g PO bid if necessary. 3. Avoid lactulose where possible – lactulose can be very uncomfortable in some patients who have gut flora which metabolize the sugar and cause abdominal cramping/flatulence*. * Note: Lactulose is currently covered by BC Palliative Care Benefits, while PEG is not.
Level 3 – Constipation management No BM for 3 days or more. Do rectal examination and document on the appropriate unit-specific records system.	**<u>Continue previous medications PLUS: a), b), or c)</u>** Medications: a) **If soft stool in rectum**: Bisacodyl 10 mg suppository PR. If not effective within 1 hour, give Microlax enema or consider tap water/sodium bicarbonate/glucose enemas PR or PEG PO once daily. b) **If hard or impacted stool in rectum**: Oil Retention Enema PR. If not effective within 1 hour, give Microlax enema PR. Disimpact if indicated. c) **In no stool in rectum**: Perform abdominal examination and document. Assess abdomen for bowel sounds. If normal, give Microlax enema PR. If abnormal, call physician and/or palliative care team.
Level 4 – Constipation management No BM or insufficient result after Level 3 interventions.	Nursing assessment. May repeat above or consult with physician and/or palliative care team.
Outcome: After a BM, resume Level 1 or 2 (increasing dose(s) PRN) to maintain a BM at least Q3 days. It is not uncommon to require increasing doses of sennosides as the dose of opioid increases.	

3.6 Tips for Stopping Medications

If patient can no longer swallow, stop all oral medications. Some may need to be converted to another route. Note: The maximal subcutaneous volume that is usually tolerated is approx. 2cc, which may be a limitation to some subcutaneous formulations, unless a sufficiently concentrated preparation for the dose is available (e.g., furosemide, fentanyl).

- If unsure of which medications to stop after reviewing tool for stopping medications at end of life, consult your local palliative care consultant / program.
- Consider purpose of medications and impact if stopped, i.e.:
  - Do not stop fentanyl patch / pain medications / narcotics on dying patients.
  - Do not automatically stop steroids – can be converted to subcutaneous route.
  - Some diuretics may be beneficial to continue for symptom management of dyspnea.
- Depending on clinical context, decision to stop glucose monitoring and insulin administration can be considered.

4 Definitions and Abbreviations

- bid – bis in die (twice a day)
- BM – bowel movement
- CVC – central venous catheter
- DNAR – do not attempt resuscitation
- Dyspnea – subjective shortness of breath. Tachypnea or "fast breathing" (respiratory rate of more than 20/min) may be considered an indicator of dyspnea
- EOL – end of life
- ESKD – end-stage kidney disease
- GP – general practitioner
- HD – hemodialysis
- IV – intravenous
- MOST – medical order of the scope of treatment
- Opioid naïve – Patient has received less than 60 mg of oral morphine equivalents daily for less than 7 consecutive days.
- PD – peritoneal dialysis
- PO – per os (orally)
- PR – per rectum (by rectum)
- PRN – pro re nata (as needed)
- SL – sublingual (transmucosal absorption)
- SC – subcutaneous
- TKVO – to keep vein open

5 References

BC Health Authority guidelines used in the development of this guideline:

- Fraser Health – Regional Pre-Printed Orders for Actively Dying Protocol – May 2017
- Island Health – NRGH Comfort Care Orders for Patients Who are Actively Dying with End stage Renal Disease – Jan. 6, 2011
- Northern Health – Adult Palliative Care Orders – December 2017
- Providence Health Care – Terminal Care Orders (Last Hours to Days of Life) – Apr. 12, 2013

BC Provincial Renal Agency guidelines used in the development of this guideline:

- N/A

6 Sponsors

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Developed by:

- A working group of the BCPRA Palliative Care Committee

Reviewed by:

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Approved by:

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- BCPRA Medical Advisory Committee – May 3, 2018

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