General Considerations at End-of-Life

(last few days to weeks of life)

1 **Certain non-pharmacological interventions will become unrealistic (e.g. exercise).**

- Energy conservation will become more important.
- Ensure that appropriate supports (e.g. home care including nursing care) are in place to assist with activities of daily living, as needed.
- Continue ongoing discussions with patient and caregivers to address goals of care as condition and prognosis change

2 **Investigate for the cause of symptoms only if necessary to promote comfort or add to targeted symptom management.**

3 **Deprescribe and reduce pill burden.**

- Priority should be given to continuing quality of life and symptom focused medications (e.g. analgesics, bowel medications), especially in patients who want comfort as their main goal of care.
- Deprescribing needs to be individualized to the clinical situation. Specialists and pharmacists can help to determine the medications that can be stopped first.

4 **Medication toxicity and withdrawal continue to be important.**

With a focus on symptoms, comfort focused medications (e.g. opioids) need to be used carefully to ensure that benefits outweigh side effects. Careful history taking and physical examination should continue to rule out medication induced side-effects. See Delirium and Pain tips documents for more information (Links).

5 Consider the route of administration and medication availability at the site of care.

- Near the end of life, oral medications may no longer be an option.
- Intravenous routes are also not an option in home, hospices or nursing homes.
- The subcutaneous route is often the best choice in the last week to days of life.
- Ensure an adequate supply of injectable medications for those at home. 24/7 nursing support at home (even through home care) is not always possible. It is important to remember that family members might be the individuals drawing up syringes and administering medications. Simplify the number and frequency of medications, if possible. Consult palliative specialists or pharmacists for advice, if needed.

6 Provide patient and caregiver education around what to expect around the dying process

- Functional decline and increasing physical weakness are expected; they will most likely spend more time in bed and need help increasingly.
- Delirium is common at the end of life, and often in that context it will not be expected to be reversible. For most with advanced cirrhosis at end-of-life, they will increasingly become drowsy (often unrelated to medications). Occasionally, they may experience periods of restlessness where they may be noticeably confused and may not know what they want, consistent with a more agitated or mixed delirium. It may be difficult to know if they are in pain or whether it is more the confusion that is troublesome for them. They should know who to call if this develops and possibly what medications may be helpful. As they become weaker, upper respiratory tract secretions may accumulate and be heard as a 'rattle'. This is reflective of overall weakness and inability to clear secretions and not an inability to breathe. Patients are usually not distressed despite this 'rattle'. But, as it can be distressing for family to hear, certain medications may be considered to clear these secretions. The 'rattle' can persist despite these meds being dosed regularly.
- Glycopyrrolate 0.3-0.4 mg SC q1h prn (can move to q4hr ATC if needed). Glycopyrrolate does not cross blood brain barrier and has less sedation than scopolamine) OR
- Scopolamine 0.4 mg SC q1h PRN (can change to q4h ATC if the patient has needed more than 1-2 doses ; further increases to 0.8 mg SC q4h ATC and q2 h PRN if needed). Scopolamine preferable at end-of-life if more sedation will aid in comfort.
- Anorexia can be expected and patients will be expected to gradually stop eating and take in minimal fluids. Fluids given subcutaneously may be appropriate, but have to be carefully balanced with the risk of additional fluid accumulation (ascites, upper respiratory secretions). At the end of life, fluids do not prolong life or add to comfort unless they are used to prevent opioid neurotoxicity. The use of fluids subcutaneously should be assessed individually on a case-by-case basis and reassessed over time. At the end of life, artificial nutrition is not offered, as it is not beneficial only confers risk. If

artificial nutrition is already in place, it should be reassessed. Nutritional needs decline at end of life and patients do not generally suffer hunger at this stage.

- Due to overall weakness, patients may lose the ability to close their eyes and mouth completely. This may lead to dry eyes and dry mouth. Products are available to alleviate both (Isopto-tears or eye lubricant for eyes and Moi-Stir spray or oral balance gel for the mouth q1 hourly as needed). Regular mouth care will be more helpful in relieving dry mouth than any fluids (including subcutaneous administration of fluids).
- Even when patients appear unresponsive, we encourage people at the bedside to communicate and tell them what they want to say. Most likely they have a better sense of who is in the room and speaking than we know.

7 Reassess patient goals

- As the patient's condition declines and physical symptoms are increasing, goals may shift. Life prolonging interventions may no longer be in line with the patient's goals and they may want to focus more on comfort. This can be very individual and, if at all possible, best assessed by exploring the patient's goals while they are able to express their wishes clearly. If the patient is unable to speak for themselves, substitute decision makers can help to determine what they think the patient would want in this situation.
- Any significant change in disease trajectory or change in location would be a good time trigger a re-evaluation of the patient's goals, but certainly these can be addressed at any time as needed.

8 Continue to consider Palliative Consult Team involvement if there are ongoing issues around symptoms or location of care.

- Visit: https://www.albertahealthservices.ca/info/Page14778.aspx and look under "Finding Services in your area"

9 EMS Palliative and End of Life Care Assess, Treat, and Refer (EMS PEOLC ATR) initiative

- In urgent situations in the patient's home, front line paramedics and community clinicians work together to ensure that the management of the emergency (including symptom crisis) matches the patient's wishes and care plan. This may include providing support to patients in their homes (including nursing homes) rather than transporting to a hospital.
- Visit: https://www.albertahealthservices.ca/info/Page14557.aspx or https://www.albertahealthservices.ca/info/Page14899.aspx

10 Services required for caring for patients at home, location of care and location of death

- The most responsible healthcare provider (MRHP) has to ensure that the patient is registered with Home Care (HC), and has to work closely with HC to ensure that the patient and family are fully prepared, and receive adequate support to enable a death at home. The MRHP is usually the patient's family physician or a nurse practitioner acting as MRHP, and need to be involved for a successful death in the home.
- Visit: https://www.albertahealthservices.ca/info/Page15828.aspx for the Patient's Death in the Home Setting Provincial Guideline

11 What happens after death

- Pronouncement of a patient's expected death at home is not required; the patient's attending Physician (e.g., family physician) certifies the death by completing the Government of Alberta Vital Statistics Attending Physician's Medical Certificate of Death Form within 48 hours of the death unless the death is notifiable as per the Fatality Inquiries Act.
- The MD can refer to public health guidelines for reportable deaths depending upon location/province.
- Visit: https://www.albertahealthservices.ca/info/Page15628.aspx for Bereavement care resources

Additional Resources:

- **Patient Handout?** – if we want to include, develop similar to https://www.ckmcare.com/Resources/Details/143
- **Palliative Care Referral Services:** https://www.albertahealthservices.ca/info/Page14778.aspx
- **Grief Support Program:** https://www.albertahealthservices.ca/assets/programs/ps-1026229-grief-support-calgary-brochure.pdf
- **EMS Palliative Care and EOL Access:**
  - https://www.albertahealthservices.ca/info/Page14557.aspx
  - https://www.albertahealthservices.ca/info/Page14899.aspx
- **Death at Home:** https://www.albertahealthservices.ca/info/Page15828.aspx
- **Bereavement Care Resources:** https://www.albertahealthservices.ca/info/Page15628.aspx