Palliative Care Toolkit for Acute Care Nurses during COVID-19 Pandemic

As a result of the COVID-19 pandemic, a need for palliative and end-of-life support in the acute care setting is recognized as the possibility of increased mortality in the hospital due to COVID-19 rises. This toolkit is designed to assist Health Care Providers (Registered nurses, Licensed Practical Nurses, and Health Care Aides) in providing optimal palliative care and supporting end of life care for patients and their families/loved ones/caregivers.

Please call 403-944-8294 the Palliative Care Consult service with any questions or concerns you may have. We will answer your questions or direct you to the right resources.
OR
Find your acute care site central pager found on ROCA

SYMPTOM MANAGEMENT

- Symptom Management for Adult Patients with COVID - 19 - Link *NEW*
- Palliative Sedation Nursing Considerations – Appendix B / Link to come
- RASS Score and how to add in SCM – Appendix C
- Guideline for Treatment of Opioid Neurotoxicity – Link *NEW*

GOALS OF CARE

- Streamlined GCD Decision Making For COVID-19 - Link
- In-site AHS COVID-19 Advance Care Planning and Goals of Care Designations - Link
- Goals of Care Conversations with Vulnerable Patients during COVID-19 - Link

COMMUNICATION

- COVID-19 Ready Communication Skills: A Playbook of VitalTalk Tips - Link
- How to Help Your Patient Connect With Loved Ones – Appendix E

CARE BEFORE AND AFTER DEATH

- Considerations when talking with families before, during and after death – Link
- Preparing to talk with families before, during, and after death - Link
- Care After Death – Working with the Distressed Family - Link
- Care After Death - Full List of resources: Link
- Funeral home management/practices IN PROCESS - Link to come

CARE OF THE BODY

- Public Health Recommendations for Handling of Deceased Persons - Link *NEW*
- Safe Handling of Personal Property Post Death - Link *NEW*

AHS PEOLC, CZ Version 4 April 22 2020 Feedback: Amanda.lucas@ahs.ca

Staff Resources

Written Learning:

- Supporting your Mental Health Tips - Link
- Mental Health - what do you have control of? - Link
- Physical Health - https://www.downdogapp.com/healthcare - Link
- Practical and Emotional Preparedness - Link
- Self-Compassion - Link
- Self-care tip sheets - Link
- Going Home Checklist - Link
- **Text4Hope** is an evidence-based tool that helps people identify and adjust the negative thoughts, feelings and behaviors a pandemic might be expected to provoke. Text **COVID19HOPE** to **393939** to subscribe.

Additional Support:

- Mental Health Moment with Nicholas Mitchell provided regular new videos - Link
- EFAP – COVID-19 worker supports - Link
- Help in tough times - Link

Resources for Patients/Families/Caregivers

Caring for a loved one at End of Life:

- "A Care Giver's Guide: A Handbook about End of Life Care" - Link
- The Caregivers Resource – a brief version Link *NEW*
- What to Expect When a loved One is Dying - brochure for families - Link
- Practical Tips for Family When Considering Discharge Home from Hospital for End of Life Care – LINK to come

Grief and Bereavement Resources

- Alberta health Grief and Bereavement - Link
- Virtual hospice - Link
- For Caregivers and Patients with Advanced Disease - Link
- Sage Center/Hospice Calgary- Link
- MyGrief.ca - Link
- KidsGrief.ca - Link

Additional COVID Palliative Care Resources available on Sharepoint: Link
Access is available to all AHS staff
Open link and submit your name to request access

Appendix B

COVID-19 Palliative Sedation Nursing Considerations

Initiate the sedating medication(s)

- The therapeutic goal of palliative sedation is typically deep sedation or a score of -4 to -5 on the Richmond-Agitation Sedation Scale (RASS) (Refer to Appendix D of the Palliative Sedation Clinical Knowledge Topic for information related to monitoring for level of sedation and see RASS scale below).

Titrate medication (dose/rate) to achieve the desired level of sedation as specified in the MRP's order.

- The frequency of monitoring is determined by the practice setting and individual circumstances; level of sedation should be assessed at least as often as the specified bolus/titration interval.
- There is minimal risk of respiratory depression when using medications with a short half-life and initiating at a low dose, which is titrated based on patient assessment. Remember, patients receiving palliative sedation are actively dying and it is anticipated that their respirations will change as they near death; it is not a reason to decrease or stop the medication.

Assess the patient regularly for:

- Level of sedation
- Relief of refractory symptoms
- Potential adverse effects

- Grimacing, restlessness, or agitation would indicate the need to administer a prn bolus dose of the sedating medication and/or increase the scheduled intermittent dose/ continuous infusion rate as per the MRP's order.

Document the administration of palliative sedation medications

- **assessment, administration of medication, use of prn bolus dose** and **titration** of dose/rate, along with associated rationale and response (RASS score)
- must follow practice standards within each care setting

Review of Medications/Care Plan

- Ensure all life prolonging interventions (e.g. hydration, antibiotics, etc.) and all medications, which are not contributing to the patient's comfort, have been discontinued.
    - The use of oxygen should be reviewed with consideration of the intent (comfort vs. life prolongation). It is recommended that patients requiring oxygen for comfort be transitioned to nasal prongs at the lowest possible flow rate.
- Ensure all medications necessary for comfort are ordered by a non-oral route.
- In most cases, continue **scheduled** analgesics and anti-emetics and discontinue all **prn** medications except the sedating medication. Once palliative sedation is initiated, all signs of discomfort are usually treated with a prn bolus dose of the sedating medication and/or increase in the scheduled intermittent dose/infusion rate.
- It is not necessary to check vital signs when patients are receiving palliative sedation.

Physical Care

- Care of patients undergoing palliative sedation must include a focus on dignity and personhood. The nurse must act as an advocate for the patient and family at this time.
- Optimize interventions such as personal hygiene and frequent mouth care.
- Position appropriately to maintain a patent airway. Reposition to optimize and maintain comfort. Frequent repositioning may not be necessary or beneficial for patients who are imminently dying.
- Assess for bladder fullness and constipation as this may increase agitation.
    - Interventions for bowels and bladder should be discussed with the MRP based on individual circumstance, comfort, and prognosis.
- Provide a private, peaceful environment.

Equipment and supplies

Continuous infusion:

- Infusion may occur by IV or SC route.
- Continuous Infusion Pump is required. Consider using longer tubing to provide physical distancing between nurse and patient.
- IV line WITH ports if MD requires access for direct administration of medication
- Medication mixed in a mini bag supplied by pharmacy
- Alcohol swabs
- 2-3 10cc syringes of normal saline to be used by MRP starting palliative sedation
- As needed, prepared and labelled syringes of benzos and/or opioids as ordered by MRP for direct IV administration (ie. Fentanyl and Midazolam)

Intermittent administration

- Subcutaneous injection sites (butterflies) for SC route
- Alcohol swabs/syringes/filtered needles/ sharps container – obtained from pharmacy
- Injectable medication

Home care/ISFL Considerations

- Preferred route will depend on setting of care and resources available (i.e. available medications from pharmacy, injectable or mini bag)
- Collaboration with home care for available nursing resources and support available
- Family may have to administer medication
- Unlikely to have IV access and/or pump
- Consider rural palliative in home funding program for private nursing support
- Assistance with EMS ATR in acute situation
- Consideration for PPE for home care COVID-19+ve patients

Education and Support for Patient and Family

- Ensure patients, families, and caregivers understand the key aspects of palliative sedation as explained below. It should be noted that, due to the emotional burden and stress on families at this time, key messaging often needs to be repeated. Nurses should be aware of their language and messaging to patients and families to avoid confusion or additional distress around the sedation.
    - **Purpose:** To relieve suffering and provide comfort in the final days of life by inducing and maintaining deep sleep when no other options are available to control distressing symptoms. The purpose is not to hasten death, but to ensure that a natural, expected death is peaceful.
    - **Procedure:** The patient is given sedating medication by intermittent injection or continuous infusion. Medications will be adjusted to obtain a deep level of sedation. The procedure is not the same as for Medical Assistance in Dying.
    - **Consequences:** The patient will not be able to communicate and will have limited ability to move independently, eat, and drink. The patient may become incontinent.
    - **Expected Cause of Death:** The patient will die as a result of the underlying disease, not as a result of the palliative sedation. Death may occur while receiving or soon after receiving sedating medications; however, the medications do not cause death.
- Provide opportunity for farewell and closure before initiation of palliative sedation as communication will not be possible once sedation is initiated.
- Provide ongoing emotional support to patients and families and offer additional education and support from other available services, such as spiritual care, social work, palliative consult team, and grief support, before, during, and after administration of palliative sedation.

Self-Care and Additional Supports

- Seek additional support for yourself and colleagues as required prior to and during the administration of palliative sedation.
- Review goals of treatment, as well as ethical concerns that may arise.
- Seek opportunities for debriefing after a patient has died. This may be particularly important when practicing in the community or in a setting that is not a dedicated palliative care area.
- Support may be available from a variety of services, such as spiritual care, social work, grief support, Employee and Family Assistance Programs, clinical ethics, and palliative care consult teams.
- In the Calgary Zone, the Palliative Care Consult Service is available to provide support to health care providers in all settings of care, including access to an on-call Palliative Physician Consultant after hours.

Appendix C

Richmond Agitation and Sedation Scale (RASS)		
+4	Combative	violent, immediate danger to staff
+3	Very Agitated	Pulls or removes tube(s) or catheter(s); aggressive
+2	Agitated	Frequent non-purposeful movement, fights ventilator
+1	Restless	Anxious, apprehensive but movements not aggressive or vigorous
0	Alert & calm	
-1	Drowsy	Not fully alert, but has sustained awakening to *voice* (eye opening & contact ≥ 10 sec)
-2	Light sedation	Briefly awakens to *voice* (eye opening & contact < 10 sec)
-3	Moderate sedation	Movement or eye-opening to *voice* (but no eye contact)
-4	Deep sedation	No response to voice, but movement or eye opening to *physical* stimulation
-5	Unarousable	No response to *voice or physical* stimulation

Setting up the RASS in SCM for Palliative Sedation

1. In SCM under the patients name select FLOWSHEET tab
2. Under Flowsheet Selection choose PATIENT ASSESSMENT TOOLS
3. Hover over the grey area on top of the assessment tools
4. Right click
5. Click ADD PARAMETER
6. Double click RICHMOND AGITATION SEDATION SCALE
7. Click the opened box of RICHMOND AGITATION SEDATION SCALE
8. Click on the ADD button
9. It will appear in the right hand window as an added parameter. Click OK
10. It will now show up in the ASSESSMENT TOOLS.

How to Help Your Patient Connect With Loved Ones During COVID 19 Pandemic: Tips and Ideas for Virtual and Non-Virtual Connection

Isolation, whether a patient has COVID-19 or not, can have a significant impact on a patient's emotion, spiritual and psychological health. Connecting with others eases loneliness, lifts spirits, and generates a sense of belonging.

Appendix E

Virtual Tips and Ideas

Video Chatting Apps:

Zoom: Video conference with up to 100 people for 40min. You can also share your screen (ie. play an online board/card game together)

Skype: A free app that allows for group video chat with up to 40 people Free Microsoft app, similar to Facetime. Allows for group video chats and can share your screen. Can call into a mobile phone or a landline, $5-10/month for unlimited calling in North America

WhatsApp: Free to use, can text, send pictures, voice and video call. Only requires wifi, no data charges, can install on any smart phone/tablet/etc. Can do group texts of any number, or video calls with up to 3 people. Cannot call a landline, or call a phone/device without the app installed

Google Duo: For android or iPhone. Video chat with up to 12 people at a time. Cannot call a landline, or call a phone/device without the app installed.

FaceTime: Built into apple devices. Allows iPhone users to connect face to face with up to 32 people. Only for apple devices. Cannot call a landline, or call a phone/device without the app installed.

Voice Recording Apps

VoiceMemo: already built into Apple devices, similar apps available for other devices. Allows someone to record a message that can be sent and played at another time. Ideal for situations where the person who wants to send the message is unable to call/connect at a particular time, or if you want the ability to replay the message. Good option if the patient would like to record something for their family (ie. reading a story for a grandchild)

Social Media

Social media platforms like Facebook, Twitter and Instagram all have direct messaging capabilities that allow for text conversation as well as the sharing of photos or videos. Send a direct message through Facebook Messenger, Twitter or Instagram to start a conversation. Facebook Messenger even has capabilities for video chat!

Does your patient need support with leaving a legacy message or saying goodbye virtually? Here are some resources that may help:

RecordMeNow: A free app that can be downloaded onto a smart device or laptop for recordmenow.org. Provided guided questions and records answers to allow people to leave an emotional legacy message for their loved ones.

Saying Goodbye to Dying Family Member Over the Phone: Conversation Script – https://www.capc.org/toolkits/covid-19-response-resources/

How to Help Your Patient Connect With Loved Ones During COVID 19 Pandemic:
Tips and Ideas for Virtual and Non-Virtual Connection

No access to virtual devices? That doesn't mean connections can't be made between your patient and their loved ones. Here's some ideas you can provide to you patients or their families/loved ones.

Non-Virtual Ways to Reach Out

- Schedule phone calls often
- Bring in photos to put up in their room
- Have a CD player or iPod to play their favorite music
- Watch the same movie at the same time
- Read the same book
- Send handwritten cards or letters
- Crafts from kids/grandkids:
  - Get children/grandchildren to "Make a Hug":
    Take a light coloured bed sheet, lie it on the floor and lie down on top of it with your arms outstretched (like a snow angel). Trace out the arms with a thick marker, get up and you will be left with an outline of two arms that are not attached. Use the marker to attach the two arms making one really long arm with hands at each end, this is now a "hug" that can be wrapped around your loved one. You can decorate each "hug" with drawings, writing, poems, etc.
  - Handmade cards, pictures, cards etc.

"LOVE HUG"

- Modified Visit ideas (if possible/permitted)
  - If able, family can stand outside patient's window to connect though the glass or on a balcony if there is one
  - Sing a song through an open window
  - Talk on the phone while being able to see each other
  - Press hands against the same window pane

Alberta Health Services

A Caregiver's Resource for Caring for your Loved One at Home during COVID

From symptom management to emotional care

Appendix F

Pain

- The goal is to keep someone alert, with the pain under control as much as possible.
- If pain is constant, give the medication on schedule even if there is no pain at the time, this helps keep the pain away.
- If your loved one has pain between the scheduled doses, give a breakthrough dose (if prescribed).
- Keeping a record of your loved one's pain and the scheduled and breakthrough doses will help the doctor adjust the dose.
- If more than 3 doses of breakthrough medication were needed in 24 hours, tell the doctor or home care nurse as the dose may need to be adjusted.
- Monitor for side effects such as constipation, nausea, and any new confusion/agitation/drowsiness. Speak with the doctor or home care nurse if you notice them.

Confusion/Restlessness

- Tell the doctor or home care nurse if you notice the start of confusion and ask what can be done to reduce confusion.
- Remember that a person with a progressive illness may become confused due to the illness, infection, a side effect of medications, decreased fluids, or during the final days of life.
- Confusion may come and go and appear as increased sleepiness, agitation, being restless, hallucinations, strange thoughts, or as "pain all over".
- Maintain a calm, quiet presence and environment – keep loud conversations, radio, TV or other noise to a minimum.
- Use strategies that will help them stay orientated: a clock they can see, keep lights on during the day and off at night, gently remind them who you are and where they are, use a gentle touch to remind them of your presence.
- Explain any care or medications you are giving.
- Give medications for confusion as ordered by the doctor.

Shortness of Breath

- Keep a calm environment to help with the anxiety that comes with of shortness of breath.
- If the shortness of breath is made worse with movement, walking, talking, dressing, etc., make sure you allow them frequent rest periods so they can recover their breath.
- Provide medications such as inhalers as ordered to help manage symptoms. If they are having difficulty using the inhaler, contact the doctor or home care nurse.
- A fan is not recommended since it may inadvertently spread droplets containing COVID.
- Oxygen can be helpful in some cases depending on the cause. Ask the doctor or home care nurse about this.
- Help the person into a position that makes breathing easier – usually sitting up and leaning forward over the edge of the bed or other high table with weight through the arms or elbows. Some people prefer to sleep in a reclining chair or with their head raised.
- Let the person rest and breathe as fast as they feel they need to in order to get their breath back.
- Opioid medications such as morphine or hydromorphone can be helpful for shortness of breath. The principles of use are the same as for pain with scheduled and breakthrough dosing. The home care nurse and/or doctor will give guidance on dosing.

Cough

- Like shortness of breath, cough can be managed with opioid medications such as hydromorphone or morphine.
- For a constant cough, scheduled and breakthrough dosing of an opioid is used. If the cough comes and goes, an 'as needed' medication may be all that is required. The home care nurse and/or doctor will give you guidance on the best medication and dose.
- Continue regular medications to help with breathing such as inhalers.

Secretions

- When a person is in their last hours or days of life, they may develop noisy secretion (mucus) in the back of their throat.
- Similar to snoring, the sound of the mucus is more distressing to those at the bedside than to the person themselves.
- It is caused by a small amount of mucus near the voice box in the throat. The person is usually deeply asleep and comfortable and not bothered by it.
- Occasionally medications can be given to help dry up mucus, but these medications can have side effects. Talk to the doctor.

Calgary Zone, Palliative and End of Life Care
April 13, 2020 V3 Feedback: lauren.hutchison@ahs.ca

A Caregiver's Resource for Caring for your Loved One at Home during COVID

From symptom management to emotional care

Final Hours and Days:

- When someone is in their last hours to days of life, they often sleep most of the time, have no interest in food or drink, have reduced or no urine output, have changes to their breathing pattern, and have changes to their skin temperature and colour.
- Continue to provide personal care and mouth care to keep their mouth moist. Continue to touch and speak to your loved one even if they no longer seem to be aware.
- For more information on the final hours and days, see "What to expect in the Final Days" – a paper copy can be obtained from your home care nurse, or visit: https://myhealth.alberta.ca/palliative-care/resources/final-days
- Your home care nurse can help provide information and support during this time.

Coping Skills:

- Set realistic goals for yourself for the amount of care you can provide.
- Try to set aside special time for other loved ones in your life; schedule it into your day.
- Break big problems down to a manageable size by working at them one step at a time.
- Take a break when you need it, and do not feel guilty.

Emotional Tips:

- Find ways to blow off steam. Try some vigorous exercise, pound a pillow, or sit alone in a car and scream - anything that works to relieve the tension.
- Have a good cry. It is a normal reaction and a good way of coping.
- Get resentment off your chest. If you need a sounding board, talk to a friend, family member, or professional.
- Step away from the situation if you feel your frustration rising, before you say something that you might regret in the heat of the moment.
- Practice deep breathing and relaxation techniques.
- Laugh without feeling guilty. It is a good way of releasing tension and reducing stress.
- Write your experiences in a journal as a way of releasing your emotions.
- Pat yourself on the back for all that you have done.

Communication:

- Your loved one may be experiencing many emotions such as fear, anxiety and anger. You can be a great support by being an active and interested listener.
- Be a sounding board for the person to talk about fears and concerns. Talk about your feelings and fears too.
- Accept what the person is saying, however different it may be from what you think.
- Talk about your concerns and encourage others in the family to do the same. Many people who want to talk about their fears are reluctant because they do not want to upset the family. On the other hand, respect the fact that the person may not wish to talk about some feelings and thoughts.
- Reminisce as a family to review your lives together. Remember the best and worst moments, family strengths, important times and events.
- Continue to enjoy things together that have meaning such as music, art, sports, movies or books on tape.
- Help the person to stay in contact with friends and outside activities by assisting with letter writing, emails, phone calls, and virtual visits when in-person visits are not possible.

Helpful Resources

- My Health Alberta: Symptom Management https://myhealth.alberta.ca/palliative-care/resources/symptom-management
- My Health Alberta: What to expect in the Final Days https://myhealth.alberta.ca/palliative-care/resources/final-days
- Canadian Virtual Hospice: provides information and support on palliative and end of life care, and on loss and grief for patients, families, and professionals. http://virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- A Caregiver's Guide – A Handbook About End-Of-Life Care https://www.stlazarus.ca/docs/publications/caregivers_guide_2015_en.pdf

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Adapted from "A Caregiver's Guide – A Handbook About End-Of-Life Care" by The Military and Hospitaller Order of St. Lazarus of Jerusalem in association with the Canadian Hospice Palliative Care Association