Nursing Care of the ICU or HAU Patient at End of Life

Site Applicability

VCH Intensive Care Units (ICU), VGH High Acuity Unit (HAU), RH High Acuity Unit

Practice Level

Regulated Profession	Practice Area	Specialty Trained Basic Competencies
RN	Intensive Care Unit High Acuity Unit	**With advanced specialty education[1] and unit orientation where the following activities are core competencies and expectations of the role:** • Managing end of life care for the ICU/HAU patient • Removal of life support measures • Initiating and titrating opioid and benzodiazepine infusions

1 - Formal program of study in Critical Care or High Acuity Nursing (e.g. BCIT specialty education course or equivalent)\

Requirements

- **Administration of medications and withdrawal of life supportive measures (WLSM) require a prescriber order. See ICU Comfort Care Orders (Regional) PPO or See HAU Comfort Care Orders PPO** Cerner sites utilize the ICU/HAU Comfort Care Only PowerPlan Module.
- Donor referral will be made for any impending death as per VCH Policy Death – Universal Referral.

Algorithm(s)

See Figure 1. Initiating and titrating opioids and benzodiazepines flow diagram

Need to Know

- End of life (EOL) care is provided in collaboration with the patient, family and interprofessional team to deliver safe, compassionate, evidence-informed and culturally inclusive care.
- EOL care is individualized, person-centred and in accordance with the patient's values and preferences. It is delivered in a way that maintains dignity and respect.
- The focus of EOL care, including withdrawal of life supportive measures (WLSM), is to provide comfort, alleviate pain or distress. It is guided by the ICU Comfort Care Orders (Regional) PPO or HAU Comfort Care Orders PPO; Cerner sites utilize the ICU/HAU Comfort Care Only PowerPlan Module
- Family members are included in all aspects of EOL care according to their ability and preferences.

- See the Serious Illness Conversation Clinician Reference Guide for additional resources about communicating with patients and families.
- Consider seeking support from Ethics Services when values-related conflicts arise.
- This guideline applies to all ICU or HAU patients who transition to end of life in ICU or HAU, regardless if death is expected to occur in the ICU or HAU.
- For patients transitioning to organ donation after cardiac death (DCD), refer to additional requirements in the Donation After Cardiac Death Policy.
- For patients requesting or receiving Medical Assistance in Dying, (MAiD) refer to Medical Assistance in Dying (Responding to Requests) or Medical Assistance in Dying (MAiD): Nurses Supporting the Process and Aiding in the Provision of MAiD.
- EOL care involves continuously assessing and treating signs and symptoms of discomfort, pain, or distress and addressing the psychosocial and spiritual needs of the patient and family.
- EOL care begins before WLSM and continues after the patient has expired.
- WLSM is a planned and carefully thought-out procedure. It may include removal of artificial airways, invasive or non-invasive mechanical ventilation, supplemental oxygen, and/or vasopressors/inotropes, etc.
- Analgesic, sedative and other drugs are administered to prevent and relieve pain, agitation, anxiety, nausea, dyspnea, respiratory distress, and other signs or symptoms of discomfort.
- An analgesia-first approach is recommended: Opioids are used as first-line to treat pain and respiratory distress. Sedatives are used once pain and respiratory distress are effectively treated.
- Respiratory congestion is common and expected in the dying patient. It is often caused by pooling saliva or bronchial secretions. The sound may be upsetting for families and caregivers. The sound alone does not indicate respiratory distress and analgesia or sedation is not necessarily required.
- When titrated to achieve comfort, sedatives and analgesics do not usually hasten death, however, this remains a possibility. It is considered "acceptable that comfort medications may potentially hasten death as long as that is not the intended effect of giving those medications." (Bandrauk et al., 2018, p. 111)

Guideline

A. Prior to Initiating Comfort Care

- Contact BC Transplant (1-877-DONOR-BC) if not already done. If applicable, record Donor BC Reference Number on Organ/Eye/Tissue Donor Referral Worksheet. Death Universal Referral – Appendix G: BC Transplant GIVE Trigger. Cerner sites complete Donation Section of Expiration PowerForm.
- Ensure patient and/or family understands process of removal of life sustaining measures.
- Provide education and clarification for patient and/or family. Include treatment plan for pain and distress. Direct patient family to notify RN if signs and symptoms of distress are experienced or observed. Clarify fears or misconceptions about analgesia and sedation at EOL, focus on alleviating the patient's pain and/or distress.
- Connect patient and/or family with respiratory therapist (RT), physician, social worker (SW), Indigenous patient care clinician (IPCC), spiritual care practitioner (SHP) or other members of interprofessional team as needed.

- The bedside RN should participate in family meetings and goals of care discussions whenever possible.
- Ensure the ICU Comfort Care Orders (Regional) PPO or HAU Comfort Care Orders PPO is completed by provider and on the patient's chart. Cerner sites ensure ICU/HAU Comfort Care Only PowerPlan Module is completed.
- Prepare the environment by de-cluttering and/or removing unnecessary equipment
- Use a person centred-approach to engage in values-based discussions and what is meaningful for the patient at EOL.
    - **VGH ICU Wishing Well**: As appropriate, elicit EOL wishes and/or preferences and enact if possible Appendix D: ICU Wishing Well Guide for Staff; Appendix E: Wishing Well Pamphlet for Families
- Collaborate with the interprofessional team to devise a care plan for the following:
    - Symptom management, including pharmacological and non-pharmacological interventions
    - Sequence and pace of withdrawal of life sustaining measures
    - Patient and family support
- Consider a team huddle prior to **Phase One: Patient and Family Preparation**.

B. ICU/HAU Comfort Care Phase One: Preparation of Patient and Family

Assessment

- Assess patient for signs and symptoms of pain, agitation, anxiety, nausea, dyspnea, respiratory distress, or other discomfort.
    - Comprehensive pain assessment including behavioural pain scale (BPS) or numerical rating scale (NRS)
    - Assessment of anxiety, agitation/restlessness, and delirium including RASS and ICDSC
    - Respiratory distress, increased WOB, dyspnea, and accessory muscle use
    - Increased respiratory secretions and/or respiratory congestion associated with respiratory distress
    - Nausea and/or vomiting
- When possible, family members should be involved in assessing the patient for pain or distress.

Intervention

- Implement individualized care plan according to patient and/or family needs.
- Discontinue investigations, interventions and therapies as directed by the ICU Comfort Care Orders (Regional) PPO or HAU Comfort Care Orders PPO. Cerner sites refer to ICU/HAU Comfort Care Only PowerPlan Module.
- Vital signs and monitoring that do not contribute to ensuring the patient's comfort should be discontinued at the earliest opportunity once vasopressors are stopped. Collaborate with and educate the patient and/or family as needed. (For DCD follow monitoring requirements in Donation After Cardiac Death Policy).

- If monitor is continued, enable EOL Profile on GE Monitor or adjust alarms as needed.
- To ensure patient comfort, continue to provide routine nursing care including:
  - Turns and repositioning q2h and prn
  - Personal hygiene (i.e. bathing, mouth care and eye care)
  - Dressing changes as needed
  - Care of tubes, lines and other invasive devices
- Interventions for other distressing signs or symptoms.

Non-pharmacologic management of pain/agitation/respiratory distress and respiratory secretions

Pain and agitation

- Consider positioning, hygiene and mouth care, warm blankets or cool cloths, music, massage.
- Facilitate family presence and/or comforting traditions.

Respiratory distress management and secretions

- Collaborate with RT and interprofessional team.
- Position with head of bed up, position to prevent/minimize airway obstruction, deep suction only if secretions appear to be causing respiratory distress.
- Respiratory congestion is common and expected in the dying patient. It is often caused by pooling saliva or bronchial secretions. The sound may be upsetting for families and caregivers, however, the sound alone does not indicate distress.

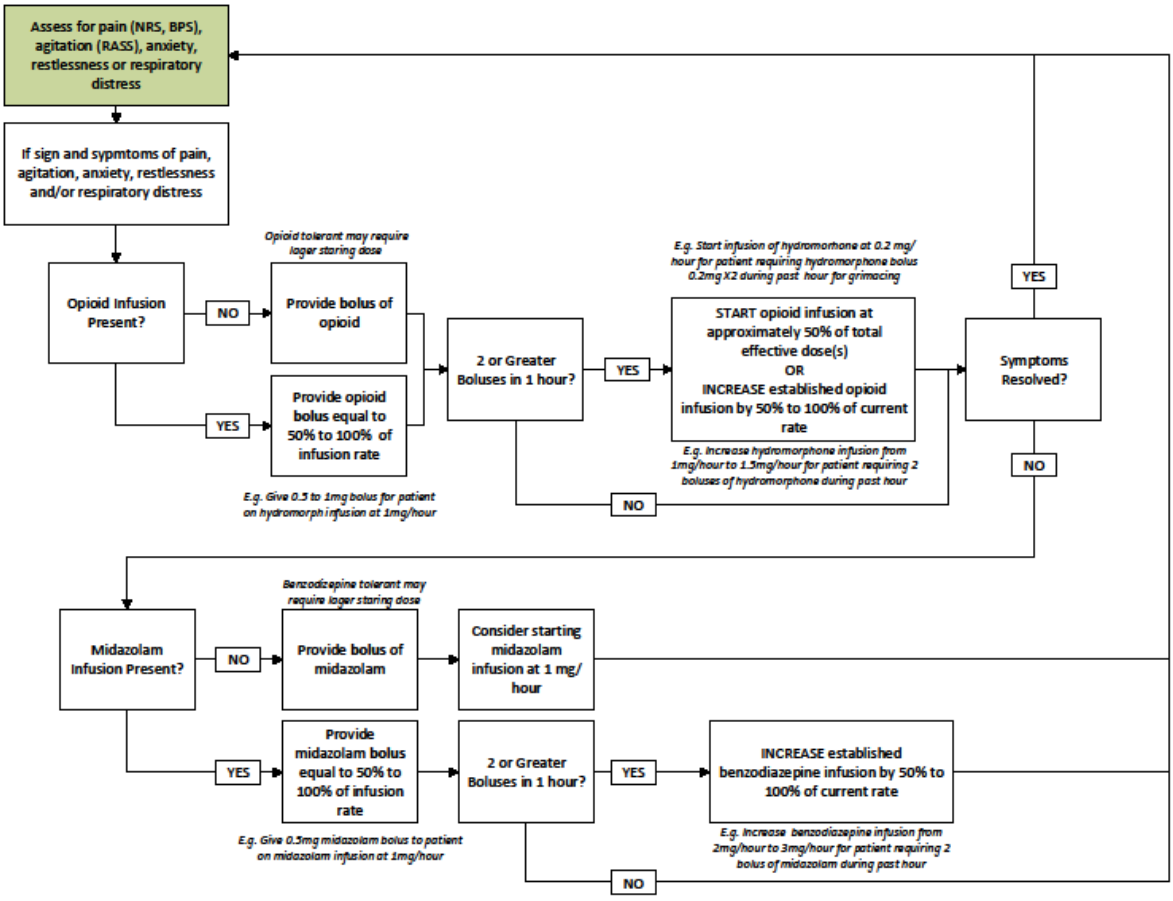
Pharmacologic management of pain/agitation/respiratory distress and respiratory secretions.

- Continue or initiate medications to prevent and manage pain, anxiety, restlessness, and/or respiratory distress as ordered using an analgesia-first approach.
- Consider need to pre-treat with analgesics or sedatives prior to activities that may cause pain or discomfort (e.g. extubation, turns, and dressing changes).
- End of life medications may include analgesics (usually morphine, hydromorphone), sedatives (usually midazolam, sometimes propofol in ICU), anti-emetics, and anticholinergics to reduce respiratory secretions (usually glycopyrrolate).
- If the patient has recently received paralytic drugs (neuromuscular blocking agents), confirm that the effect has worn off (e.g. peripheral nerve stimulator testing). If paralytic has not yet worn off, continue to ensure the patient has adequate sedation and analgesia.
- Do not discontinue invasive mechanical ventilation if patient remains chemically paralyzed, PEEP and FiO2 may be weaned.
- Analgesic and sedative medications are titrated to effect. See Table 1.

Table 1. Initiating and titrating opioids and benzodiazepines

	Patient with NO opioid infusion	Patient with NO benzodiazepine infusion	Patient with established opioid or benzodiazepine infusion
Assess	Assess for signs and symptoms of pain (NRS, BPS), agitation (RASS), anxiety, restlessness, or respiratory distress. Consider need for pre-emptive analgesia.	Assess for signs and symptoms of pain (NRS, BPS), agitation (RASS), anxiety, restlessness, or respiratory distress. Consider need for pre-emptive doses. If S&S present use analgesia-first approach – follow first column.	Assess for signs and symptoms of pain (NRS, BPS), agitation (RASS), anxiety, restlessness, or respiratory distress.
Treat with boluses	If S&S **present** use analgesia-first approach, start with bolus doses and titrate to effect. Consider need for pre-emptive analgesia. If patient is opioid tolerant, a higher starting dose may be used (as per provider order). *Example*: morphine 2mg IV bolus or hydromorphone 0.4mg IV bolus	If signs and/or symptoms **persis**t start with bolus doses of benzodiazepine and titrate to effect. If patient is sedative-tolerant, a higher starting dose may be used (as per provider order). *Example*: midazolam 2mg IV bolus	If S&S **present** use analgesia-first approach, give **bolus dose of same drug at 50-100%** the infusion rate. *Example*: patient on established infusion of hydromorphone at 1mg/hr. Give 0.5-1 mg iv bolus for any signs and symptoms.
Advance to an Infusion	Start an infusion if **≥2 boluses within 1 hour** are required for symptoms. Starting dose of infusion should be **~50 percent of effective bolus dose(s)**. *Example*: hydromorphone 0.4mg IV bolus x2 doses were given in 1 hour for grimacing and suspected pain with good effect. Hydromorphone infusion initiated at 0.4mg/h.	Consider starting **midazolam infusion at 1mg/hr following the bolus dose(s)**	If ≥**2 bolus doses required in 1 hour**, consider increasing the infusion rate by **50 to 100 percent.** *Example*: Patient on established infusion of hydromorphone at 1mg/h received hydromorphone 0.5mg IV bolus x2 doses in 1 hour for grimacing and suspected pain. Infusion increased to 1.5 mg/hr.

Figure 1. Initiating and titrating opioids and benzodiazepines flow diagram



C. ICU/HAU Comfort Care Phase Two: Removal of Life Supportive Measures

- Consider team huddle prior to starting **Phase Two: Removal of Life Supportive Measures**
- Implement individualized care plan for WLSM according to patient and/or family needs.
- Provide education and clarification for patient and/or family. Include treatment plan for pain and distress treatment. Direct patient family to notify RN if signs and symptoms of distress are experienced/observed. Clarify fears or misconceptions about analgesia and sedation at EOL, focus on alleviating the patient's pain and/or distress.
- Connect patient and/or family with RT, MD, SW, IPCC, SHP or other members of interprofessional team as needed.
- The pace, timing and sequence of removing of life-supportive measures (vasopressors/inotropes, mechanical ventilation/oxygen therapy, artificial airway) is individualized to the patient's clinical situation and the patient and family's preferences.
- To ensure patient comfort, continue to provide routine nursing care as in **Phase One** above, including:

  - Turns and repositioning q2h and prn
  - Personal hygiene (i.e. bathing, mouth care and eye care)
  - Dressing changes as needed
  - Care of tubes, lines and other invasive devices
- Continue to assess patient for signs and symptoms of pain, agitation, anxiety, nausea, dyspnea, respiratory distress, or other discomfort as in **Phase One** above. When possible, family members should be involved in decisions about whether the patient is in pain or distress.
- Continue or initiate medications to prevent and manage pain, anxiety, restlessness, and/or respiratory distress as ordered using an analgesia-first approach. Follow recommendations in **Phase One** above. Table 1.

After death

- Notify MRP or delegate that patient has expired.
- Provide time for bereaved family members to be with patient.
- Provide emotional and psychosocial support as needed.
- Consider and carry out any patient-specific requirements and/or requests (e.g. religious/cultural rituals, special considerations for handling remains)
- Provide printed bereavement resources (e.g. VGH ICU/HAU Bereavement Packs available at desk or from SW) if not already done. Refer to SW if needed.
- Follow Death, Procedure After for care and handling of remains and transfer to morgue.
- Follow Donation after Cardiac Death (DCD)
- Contact BC Transplant (1-877-DONOR-BC) if not already done. See Death Universal Referral

Patient and Family

Communicating with and supporting patients and families through the dying process is challenging. These suggestions are adapted from Serious Illness Conversation Guide Clinician Reference Guide. See also RPACE resources

- Use a person-centred care approach that focuses on the patient's and family's values and preferences.
- Whenever possible RNs should participate in patient/family meetings to support decision-making, have a clear understanding of what is discussed and avoid inconsistent messaging. RNs may need to re-iterate or revisit what was discussed with the patient and/or family.
- **VGH ICU Wishing Well:** As appropriate, elicit EOL wishes and/or preferences and enact if possible. Appendix D: ICU Wishing Well Guide for Staff; Appendix E: Wishing Well Pamphlet for Families
- Supporting hope is important but avoid giving false hope.
- Shift focus to what is possible, re-evaluate and adjust goals with patient and family. (E.g. ensuring the patient is comfortable/peaceful with symptoms controlled.)
- Ask about what is meaningful for the patient and family, and any fears or worries. Explore options.

- Affirm ongoing commitment to caring for the patient "We will do everything we can to make sure that they are comfortable and well cared for."
- Connect patient and/or family with RT, MD, SW, IPCC, SHP or other members of interprofessional team as needed.
- Document conversations with patient and/or family.

Suggestions for dealing with intense emotions

- Tears and strong emotions are natural when discussing end of life issues
- Anxiety is normal for patients, families, and clinicians during these discussions
- Giving patients and families the opportunity to express intense emotions is important. It is therapeutic for clinicians to listen even if they can't "fix" the situation.
- Allow for silence. Be present but allow time to process. It is okay if you don't know what to say to the family.
- Express empathy "I am so sorry that this is so (difficult/sad/shocking) for you."
- Name the emotion and explore the emotion when possible.

Avoid the following

- Do not provide factual information in response to intense emotion
- Do not talk more than half the time
- Do not focus solely on medical or procedural information. Adjust the conversation according to the patient's and/or family's responses.
- Do not give false or premature reassurance
- Do not say, "We are stopping/withdrawing treatment," "There's nothing more we can do," "This isn't good quality of life."

Documentation

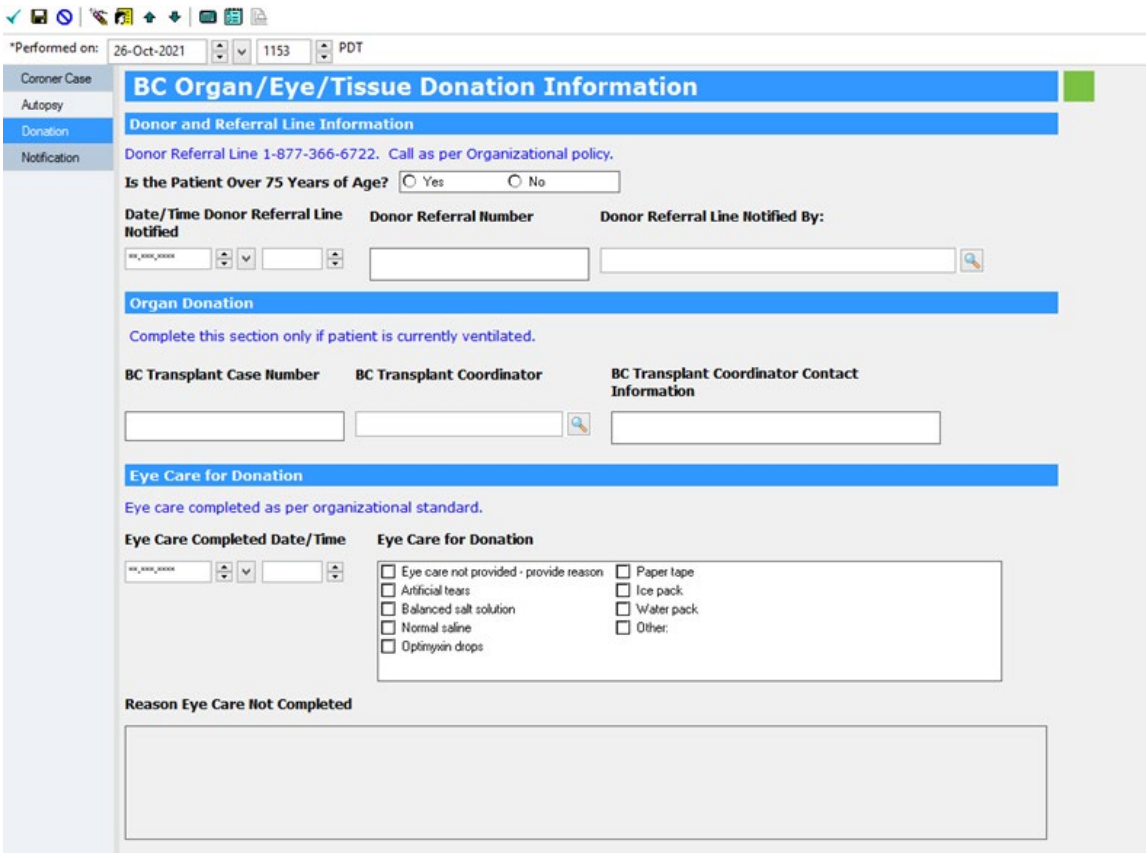
Non-Cerner Sites

- Document assessment, interventions, routine care, and patient responses ICU practice in the Nurses' Notes (NN), Critical Care Nursing Assessment Record (CCNAR) or Special Care Nursing Flowsheet (SCNAR), and the Critical Care Flowsheet (CCFS).
- Document Communication with patient, family, interprofessional team, including participation in family meetings in NN.
- Document medications on the Medication Administration Record (MAR), Pain Agitation and Delirium Record (PADR) or Pain Flowsheet, infusions on the CCFS and supplemental information in the NN as needed. Include indication and/or rationale (i.e. symptom assessment) for administering PRN boluses and adjusting infusions.
- Document sections One and Three on the Notice of Death form according to Death, Procedure After

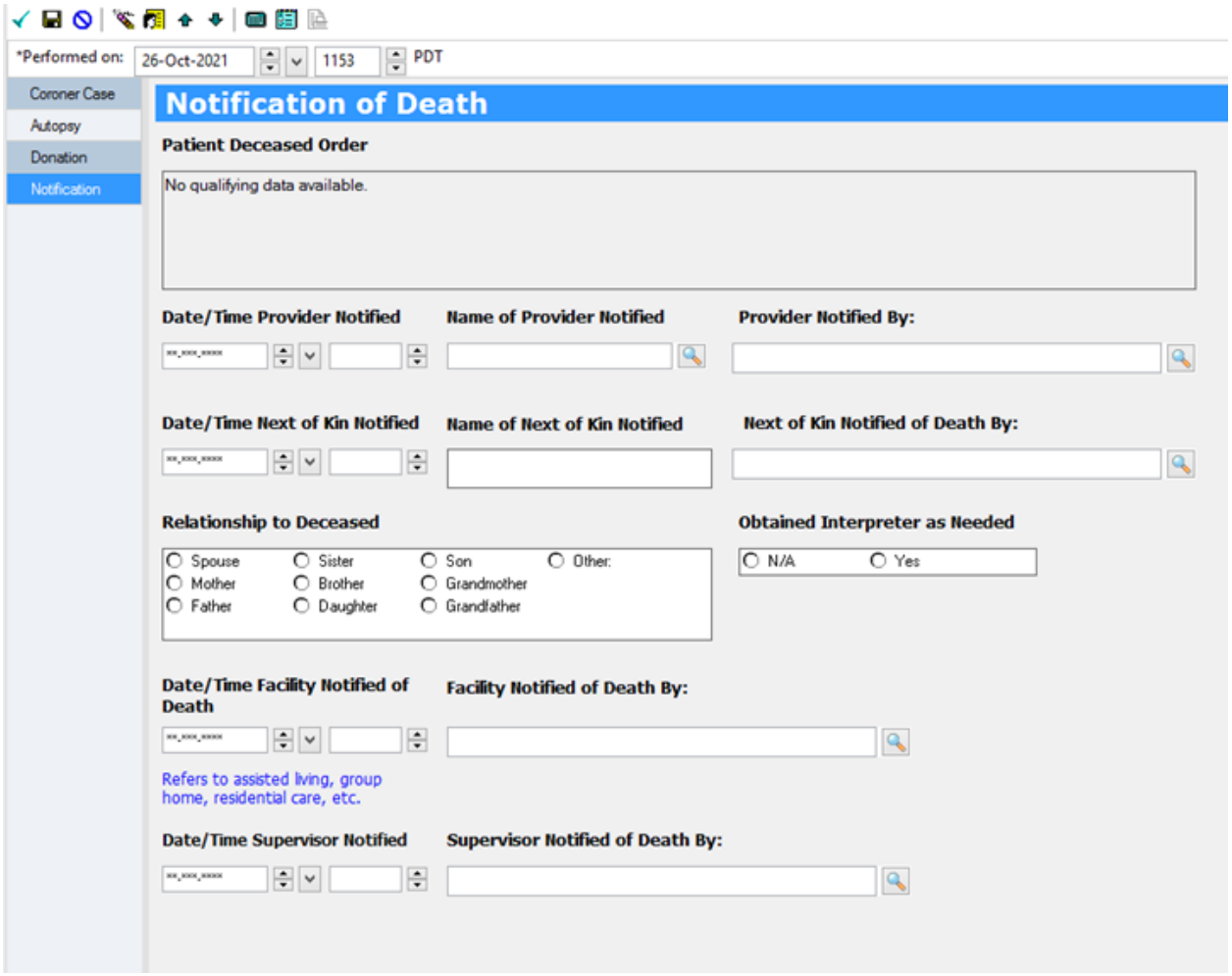
Cerner Sites

- Document assessment, interventions, routine care, and patient responses in Interactive View I&O sections.
- Document Communication with patient, family, interprofessional team, including participation in family meetings as a Nursing Narrative Note.
- In the electronic MAR, document medications administered. Document infusion titration in Interactive View I&O. Document response to all administered PRN medications on the eMAR.
- Once a patient has passed away, a Patient Deceased order is to be entered by the Provider. If patient death is expected and a Nurse to Pronounce Order is in place, the nurse may place the Patient Deceased order. The time of death ordered must be the actual time of death of the patient.
- Complete Expiration Record PowerForm and fill out the Valuables and Belongings PowerForm. Unit Coordinator to create a deceased encounter with new patient labels and an armband.

Expiration Record PowerForm – Organ Donation Section



Expiration Record PowerForm – Notification of Death Section



Staff Wellness Considerations

Balancing the physical and emotional needs of the patient and family at the end-of-life in the critical care setting is challenging. Bedside nurses and allied health staff spend a great deal of time with patients and their families in coordinating EOL care and these responsibilities can be felt as a privilege, a burden, or both. Frequent exposure to death and dying and the complex emotions involved can put clinicians at risk for emotional, physical, and psychological ramifications including compassion fatigue, burnout and vicarious trauma. It is therefore important to cultivate positive coping and resilience. Strategies must be individualized but may include:

- Acknowledge own and others' emotional state
- Personal coping strategies (stress reduction, rest, exercise, nutrition)
- Team-based strategies (formal or informal team pre-briefing and debriefing, supporting other team members, promoting a healthy workplace environment)
- Seeking additional support when needed. Resources are available from Employee Wellness.
- Ethics Services for support with moral distress among teams.

Related Documents

Related Policies and DSTs

- VCH Patient Experience Program
- Medical Assistance in Dying (MAiD) Resource Page
- Medical Assistance in Dying (MAiD) (Responding to Requests)
- Organ donation after MAiD
- COVID-19 Safe handling of bodies of deceased persons with suspected or confirmed COVID Interim guidance
- Reporting of in-hospital COVID-19 related deaths
- Apnea test for Neurologic Determination of Death
- Donation after Cardiac Death
- Death, Procedure after
- Universal referral
- Eye donation
- Release of Information and Belongings to Law Enforcement
- Safekeeping of Patient Valuables
- Procedure for Determining a Coroner Case (Appendix B in Death, Procedure after)

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Definitions

Analgesia-first approach

- The practice of using an analgesic (usually and opioid) before using a sedative for the purpose of treating pain and/or sedation. (Devlin et al., 2018)

Comfort care

- Goals of care are focused on promoting comfort and dignity and relieving suffering. Supportive care and symptom management are provided. Allows for natural death.

Dyspnea

- A subjective, uncomfortable feeling of shortness of breath that may or may not be associated with hypoxia/hypoxemia. (BC Centre for Palliative Care, 2017)

End of life (EOL) care

- Often used interchangeably with "comfort care", EOL care is any and all care that is provided to the patient at the end of life when death is foreseeable. Typically includes comfort care and may include removal of life-supportive measures.

Palliative care

- "is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (World health organization definition cited in BC Centre for Palliative Care: The First 5 Years 2013-2018)

Person-centred care

- "An approach that fosters respectful, compassionate, culturally appropriate, and competent care that is responsive to the needs, values, beliefs and preference" (Accreditation Canada Qmentum program)

Respiratory congestion

- The noise produced by the turbulent movements of secretions in the upper airways. May be a result of pooling saliva or bronchial secretions or both. The sound may be upsetting for families and caregivers. The sound alone does not indicate respiratory distress and analgesia or sedation is not necessarily required. (BC Centre for Palliative Care, 2017)

Respiratory distress

- Signs related to inadequate respiratory function. May include increased respiratory rate and/or work of breathing, accessory muscle use/abdominal breathing, hypoxia/hypoxemia. See also dyspnea. May be treated with opioids as first-line in comfort care. (BC Centre for Palliative Care, 2017)

Withdrawal of Life Supportive Measures (WLSM)

- The process of removing or discontinuing specific medical interventions with the understanding that the patient will most likely experience natural death from underlying illness or injury. (Bandrauk, Downar, & Paunovic, 2018). Also referred to as removal/withdrawal of life sustaining/life-supportive treatment (WDLST)

Appendices

- Appendix A: Bedside Checklist for End of Life Nursing Care
- Appendix B: 4 Questions to Guide End of Life Conversations
- Appendix C: Drug Titration 1 pager
- Appendix D: ICU Wishing Well Guide for Staff
- Appendix E: Wishing Well Pamphlet for Families
- Appendix F: Spiritual and emotional elements of death and dying
- Appendix G: BC Transplant GIVE trigger
- Appendix H: Enabling EOL Profile on GE Monitor

Appendix A: Bedside Checklist for End of Life Nursing Care

Before initiating Comfort Care

- ☐ Family meeting with decision to move to comfort care. Patient aware/involved in decision?
- ☐ ICU/HAU Comfort Care PPO completed by provider and on the chart
- ☐ All members of interprofessional team (including consulting services) aware of the change in goals of care
- ☐ Patient and/or family offered spiritual, religious or cultural support
- ☐ Appropriate services consulted (e.g. social worker, spiritual health provider, Indigenous patient care clinician, patient's own clergy/support)
- ☐ Pace, timing and sequence of removal of life-supportive therapies determined with interprofessional team according to patient, family preferences and clinical situation
- ☐ RT notified/included in plan for removal or modification of ventilation or oxygen therapy.
- ☐ Are there any specific religious/cultural practices or other special requests to be followed prior to, during, or at the time of death?
- ☐ Have the patient and/or family expressed any personalized end-of-life wishes or preferences? (E.g. Keepsakes, visitation, music? Has Wishing Well been offered?)
- ☐ Declutter patient's room. Provide chairs, tissues, dim lights as needed.
- ☐ Liberalize visitation as able, provide private space for family as able. Consider moving patient to a private room if possible.
- ☐ Has BC Transplant been contacted? Has Eye Bank been contacted? If no, call 1-877-DONOR-BC

Comfort Care Phase One: Patient and family preparation

- ☐ D/c investigations, interventions and therapies as directed by the ICU/HAU Comfort Care PPO
- ☐ Continue routine nursing care for comfort (hygiene, turns, dressing changes, line/tube care).
- ☐ Assess patient for pain, agitation, anxiety, nausea, dyspnea, respiratory distress, and other discomfort. When possible, involve family members in decisions about whether the patient is in pain or distress.
- ☐ D/c VS and monitoring that does not contribute to patient comfort at the earliest opportunity after vasopressors are stopped. Collaborate/educate with the patient and/or family. (If DCD, follow policy).
- ☐ If monitoring continued, enable EOL profile on monitor.
- ☐ Initiate or continue non-pharmacologic measures for pain, agitation, anxiety, nausea, dyspnea, respiratory distress, and other signs or symptoms of discomfort.
- ☐ Initiate or continue medications to prevent and manage pain, anxiety, restlessness, and/or respiratory distress as ordered. Use analgesia-first approach.
- ☐ Document assessment, interventions, routine care, and patient responses. Document medication administration including indication/rationale for PRNs and infusion adjustments.

Comfort Care Phase Two: Removal of Life Supportive Measures

- ☐ Does the patient and/or family understand the process of removal of life sustaining-measures?
- ☐ Continue routine nursing care for comfort (hygiene, turns, dressing changes, line/tube care).
- ☐ Remove or discontinue life supportive measures as per the ICU/HAU Comfort Care PPO. Coordinate with RT as needed. Document interventions and patient responses.
- ☐ Assess patient for pain, agitation, anxiety, nausea, dyspnea, respiratory distress, and other discomfort. When possible, involve family members in decisions about whether the patient is in pain or distress.
- ☐ Continue or initiate medications and non-pharmacologic measures for pain, agitation, anxiety, nausea, dyspnea, respiratory distress, and other signs or symptoms of discomfort. Use an analgesia –first approach.
- ☐ Document assessment, interventions, routine care, and patient responses. Document medication administration including indication/rationale for PRNs and infusion adjustments.

*Adapted from Crowe, S. (2017) End-of-life care in the ICU: Supporting nurses to provide high quality care. *Canadian Journal of Critical Care Nursing, 28*(1), p30-33.

Appendix B: 4 Questions to Guide End of Life Conversations

1. What is your understanding of where you/your loved one is with your/their illness?

2. What are their/your goals?

What are they/you hoping for?

What do they/you value?

3. What are your fears/worries?

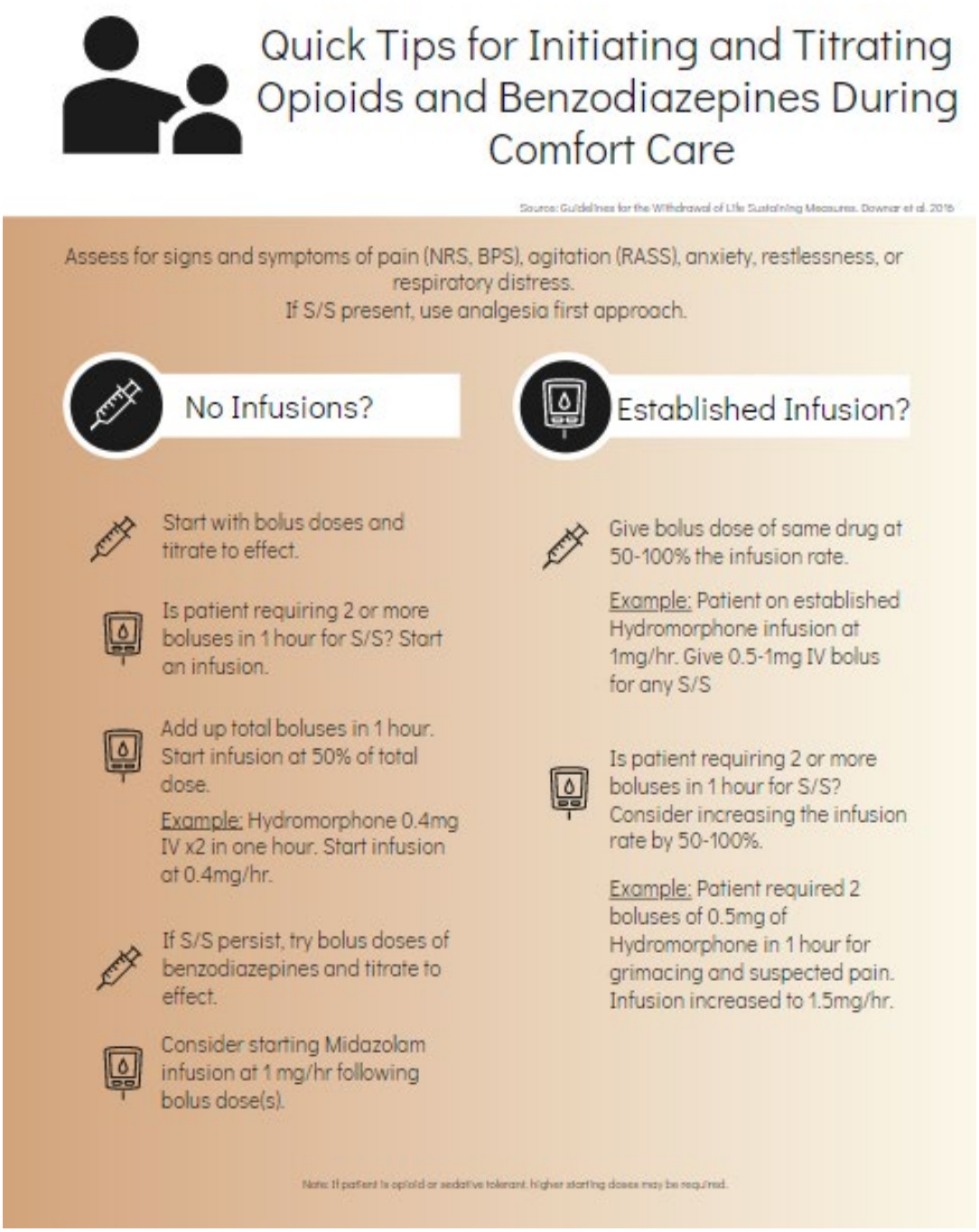
4. What do we need to know about them/you to give the best care possible?

Adapted from Coastal 4 Questions to guide Goals of Care Conversations. RPACE https://one.vch.ca/dept-project/RPACE/Documents/Coastal-4-Questions.pdf

See Regional Palliative Approach to Care (RPACE) resources page

https://one.vch.ca/dept-project/RPACE/Pages/Resources.aspx

Appendix C: Drug Titration 1 pager



Appendix D: VGH ICU Wishing Well Guide for Staff

Appendix E: VGH ICU Wishing Well Pamphlet for Families

Appendix F: Spiritual and emotional elements of death and dying

Michael Pasche, Spiritual Care Practitioner, VGH

Clinicians can support patients in coping with the spiritual/existential elements of death. This can be particularly helpful when patients have declined an offer to speak with Spiritual Care. The Bio-Psychosocial Spiritual Model [1]of care is a way of providing holistic care to palliative patients. The patient is seen as having important needs in four. A clinician can support their patient by identifying and addressing each of these.

Step 1 – Intentionally include the Psychosocial and Spiritual dimensions of your patient/family member in your assessment.

- You may something like: ***"When considering significant life decisions, many people include a reflection on their emotional and social needs, as well as their spiritual needs. This will be different for everyone, but I'd like to make space in this conversation if any of these are important to you. I want you to know that I care about every aspect of your life, not just the physical, and that I will honor whatever is most important to you in this conversation."***
- Hopefully a conversation like this will help the patient to feel safe in discussing everything that matters to them, and provide an opportunity for either deeper discussion or referrals.

Step 2 – If the patient/family member indicates that their psychosocial and spiritual needs are important to them, respond in a way that is honest and accepting, and invites further exploration if desired.

- You may something like: ***"I get the sense that your psychosocial and/or spiritual needs are very important to you at this time. I'd like to be able to offer you as much support as I can in this area if it would be helpful in the context of our conversation."***

Step 3 –Proceed to the best of your personal and professional comfort level and scope of practice.

- You may say something like: ***"I will do my best to hear you and support you in these areas. While they may not be my primary area of expertise, I want to address them with you to the best of my ability."***

Step 4 – Recognize and address when you feel like you are at the limit of your comfort level or scope of practice.

[1] The Bioethics Institute of New York Medical College and The John J Conley Department of Ethics, Saint Vincent's Manhattan, New York, NY 10011, USA. daniel_sulmasy@nymc.edu

- You may say something like: ***"I can see that these are very important issues to you, and I want to support you in them to the best of my ability at this time. However, I may not be able to provide all the answers to the questions that I hear you asking."***

Step 5 - Offer a referral to Spiritual Care.

- You may say something like: ***"In order to best address the issues that you have raised, I would like to offer you a more specific resource. We have a Spiritual Care Practitioner whose role is to support patients spiritually and emotionally, either in their own beliefs and practices or more generally by talking and listening. He/She/They are non-religious and non-denominational, and professionally trained to support you in processing the issues that you have raised."***
- If they accept the offer of a referral, great. If not, proceed to Step 6.

Step 6 – If the patient/family member has indicated to you that they do not wish to have a referral to Spiritual Care, then you can only do your best to the limits of your personal and professional comfort level and scope of practice.

- There is nothing wrong with saying "I don't know the answer to that" if you genuinely don't. You have already told them that you are limited in your ability to respond to the psychosocial and spiritual/ existential issues that they have raised, so they will be aware that you are responding to the best of your ability. This is often the response of many trained spiritual care providers as well, and we often use it to begin a conversation rather than end it, by gently exploring with them for deeper thoughts or feelings.

- If you find yourself in the position of trying to engage the spiritual/ existential issues expressed by a patient/ family member, I would offer the following advice:
  - **Know yourself** – Are there any emotional triggers for yourself around religion/ spirituality, death, what happens after death, or existential questions about meaning and purpose of life in the context of critical illness and poor prognosis? Be aware of how and when a patient's questions or concerns mirror your own, or raise some strong emotion in you.

  - **Remember that they are the expert, not you** – Take a person-centered approach that seeks to understand them and draw out whatever is most meaningful to them. Get a sense of their personal life and history as well as family history to understand where their concerns and emotions are coming from. Often in the course of self-reflection people will identify their own answer.

  - **Try to identify their own internal and external resources** – I often use questions like "Where do you find peace or wisdom when you need it?" "What has given you strength or hope in the past when you have faced difficult decisions?"

- **Try to get a sense of "the feeling behind the words"** – It is important to discern what a patient/family member "really means" when they respond to your questions. A good place to start is if you notice a strong or immediate emotional response to a question eg. "I could never do that!"), or if they suddenly change their mind about something significant in their personal or medical decision making. Identify it openly and offer them the chance to reflect on it. You may something like ***"I notice that you responded quite strongly there; may I ask if that question resonated with you in some deeper way?"*** or ***"Your recent decision took me by surprise. I sincerely want to honor your choice in these matters; would it be okay if I asked you if there is any deeper meaning or feeling around this decision?"***

- **Be intentional about addressing the unspoken elements of your conversation** – This takes practice and increasing self-awareness, and in my experience involves listening to your intuition or your "gut feelings." It is perfectly acceptable to ask your families/patients ***"How are you feel about comfort care/ dying?"*** for example. This open-ended question makes room for every possible emotional response and may serve as the departure point for a deeper conversation around their personal values, hopes, dreams and fears. Again, you are always free to stay within your personal and professional comfort zone and scope of practice, and offer another referral to spiritual care if the conversation continues to get deeper than you are comfortable with.

- **Try to understand why they are making their choices** – If they seem strongly or even unreasonably committed to life prolonging measures, attempt to explore with them the psychosocial, emotional or spiritual reasons that may be affecting their decision making process. Be clear about understanding what they want: Are they afraid of dying, or are they wanting to live longer because of an attachment to something in their life? This is a valuable distinction to make with them and may help them to see their issues in a different context. If they seem to be afraid of dying, it is appropriate to ask why in a respectful way.

- You may say something like ***"I hear you saying that you are afraid of dying. Is there anything specific about this fear that you would like to discuss?"***
- **Remember why you are having this conversation and return to the main point as often as necessary** – The goal of your conversation is ultimately to assist them in their medical decision making process and to feel comfortable with the decisions that they have or have not made. If your conversation starts to go too far into a counseling or reflective direction, it is appropriate to bring it back to the original point, and especially to now tie in the issues that they have raised. You may say something like ***"I hear you saying that you are afraid of dying because you are not sure what happens after that/ you feel that your children still need you. Do you think that these feelings might be a part of your decision making process with me today?"***

Terminology

Spirituality—Pertains to people's understanding of and beliefs about the meaning of life and their sense of connection to the world around them. It is multidimensional and can encompass both secular and religious perspectives [4]

Religion— organized or institutionalized belief systems that attempt to provide specific answers to humanity's general spiritual needs and questions. For many people, religion provides an important foundation from which to meet the numerous challenges that life presents. For others religion may be associated with negative experiences.

Faith—can mean a person's belief and trust in something (e.g., God) and may or may not pertain directly to religion (as in "What is your faith?").

Summary

The spiritual assessment is the first step towards addressing the spiritual as well as mental and physical well-being of patients. If done in a compassionate, culturally sensitive way, it can help provide a great deal of relief to our suffering patients.

Further Reading

Living at the End of Life: A Hospice Nurse Addresses the Most Common Questions: Karen Whitely Bell, RN (

What Dying People Want: Practical Wisdom for the End of Life. David Kuhl, M.D.

How We Die: Reflections on Life's Final Chapters. Sherwin B. Nuland

On Dying and Denying: A Psychiatric Study of Terminality. Avery D. Weisman, M.D.

Being Mortal: Medicine and What Matters in the End. Atul Gawande

Suffering and Spirituality: The Path to Illness Healing. Lorraine Wright, RN, PhD

Beliefs and Illness: A Model for Healing. Lorraine M. Wright, RN, PhD, Janice M. Bell, RN, PhD

Table 2. HOPE Questions for Spiritual Assessment

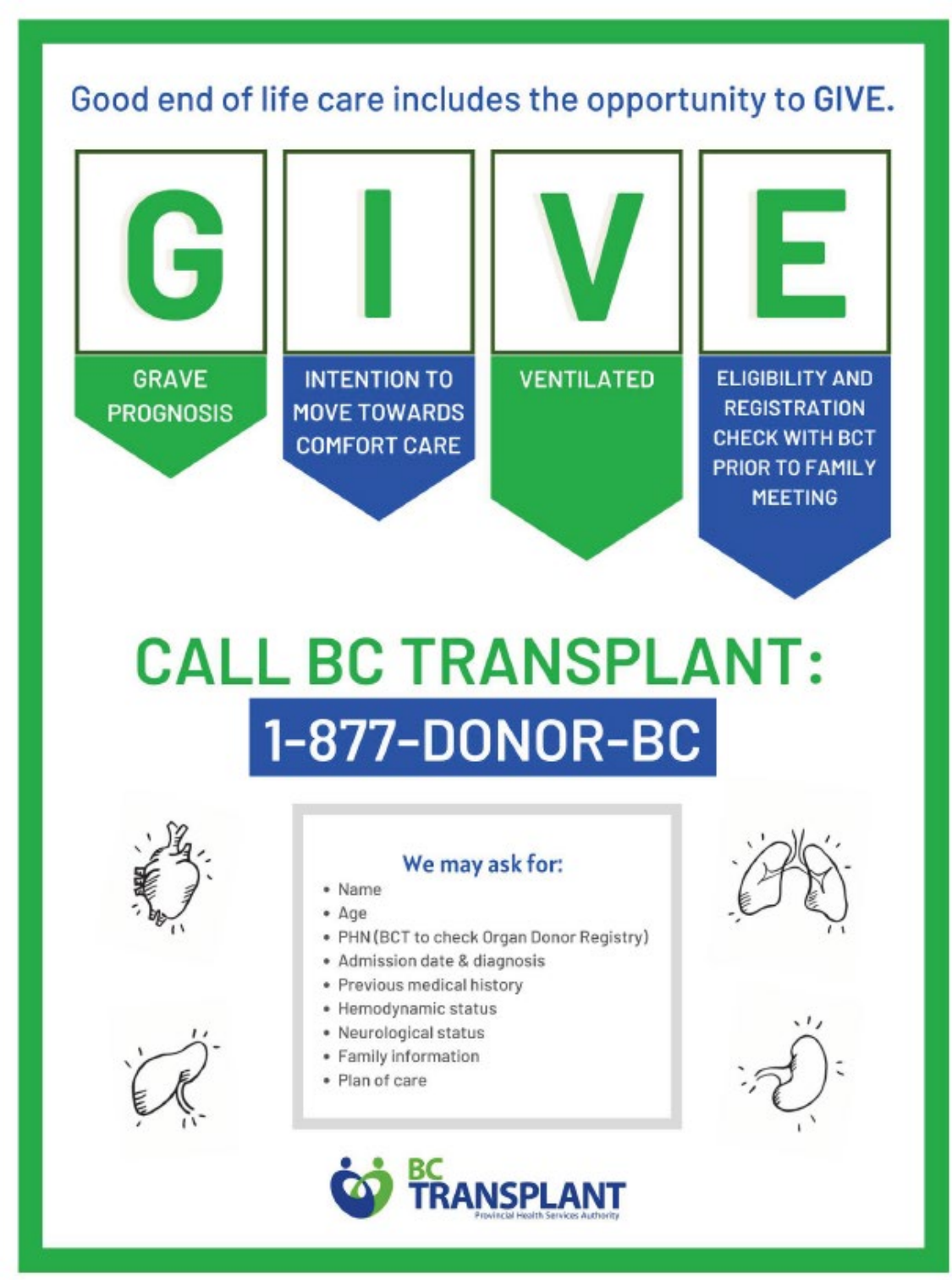
Category	*Sample questions*
H: sources of hope	What are your sources of hope, strength, comfort, and peace?
	What do you hold on to during difficult times?
O: organized religion	Are you part of a religious or spiritual community?
	Does it help you? How?
P: personal spirituality and practices	Do you have personal spiritual beliefs?
	What aspects of your spirituality or spiritual practices do you find most helpful?
E: effects on medical care and end-of-life issues	Does your current situation affect your ability to do the things that usually help you spiritually?
	As a doctor, is there anything that I can do to help you access the resources that usually help you?
	Are there any specific practices or restrictions I should know about in providing your medical care?
	If the patient is dying: How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

Adapted with permission from Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. Am Fam Physician. *2001;63(1):87.*

Table 3. The Open Invite Mnemonic

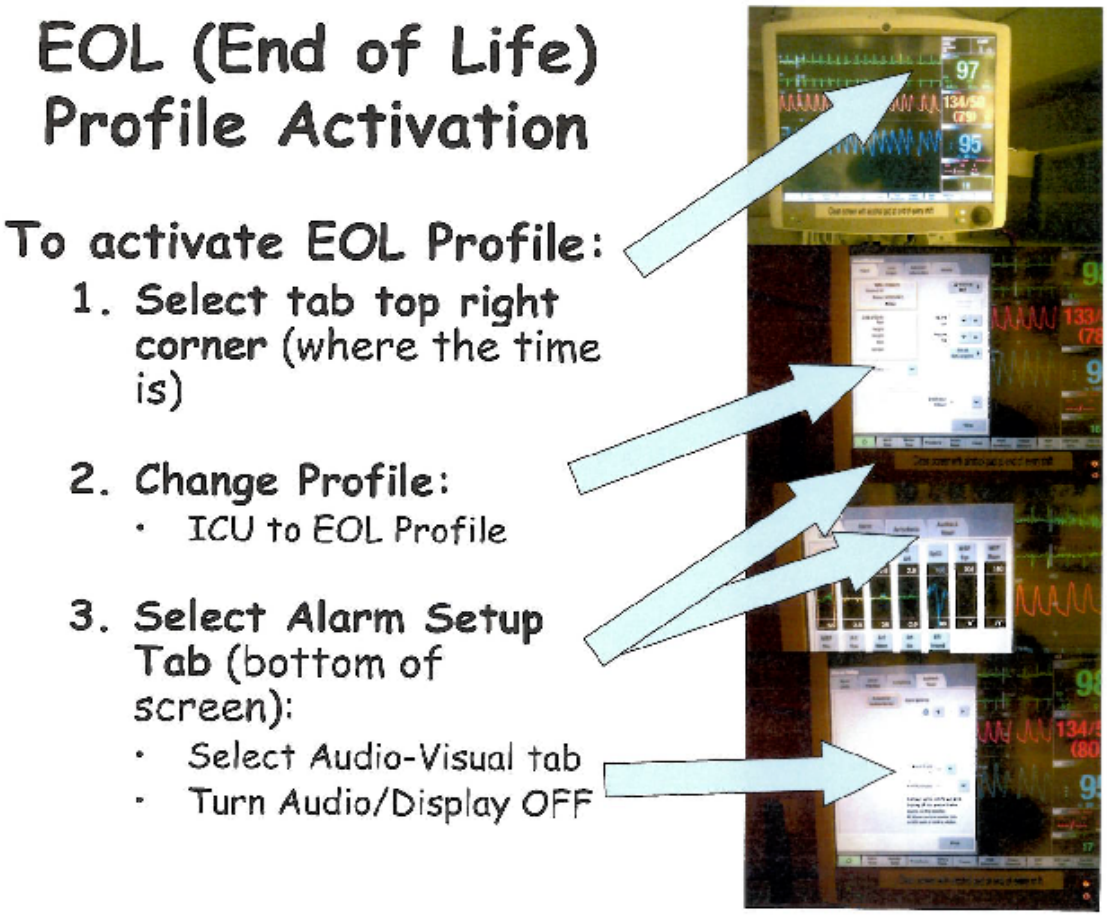
Category	*Sample questions*
Open (i.e., open the door to conversation)	May I ask your faith background?
	Do you have a spiritual or faith preference?
	What helps you through hard times?
Invite (i.e., invite the patient to discuss spiritual needs)	Do you feel that your spiritual health is affecting your physical health?
	Does your spirituality impact the health decisions you make?
	Is there a way in which you would like for me to account for your spirituality in your health care?
	Is there a way in which I or another member of the medical team can provide you with support?
	Are there resources in your faith community that you would like for me to help mobilize on your behalf?

Appendix G: BC Transplant GIVE trigger



Appendix H: Enabling EOL Profile on bedside Monitor

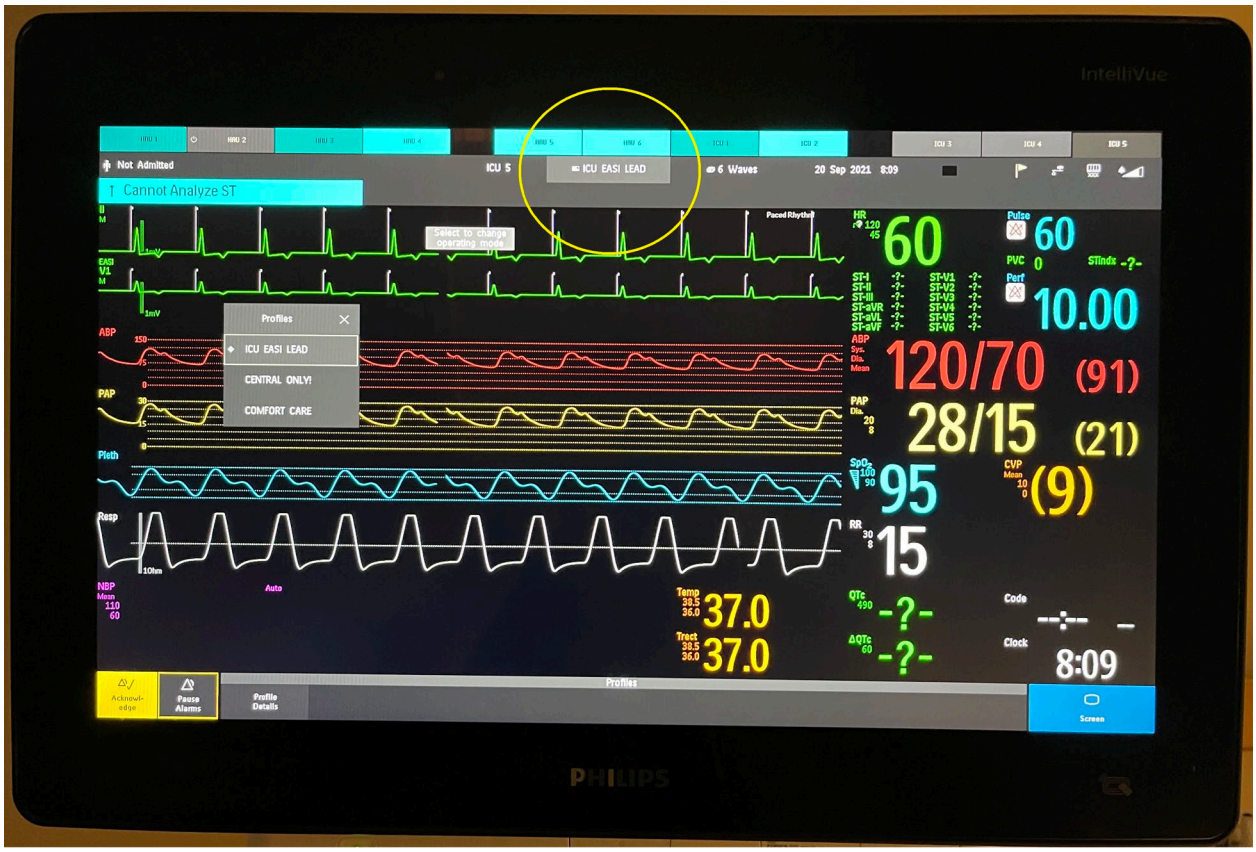
VGH ICU/HAU



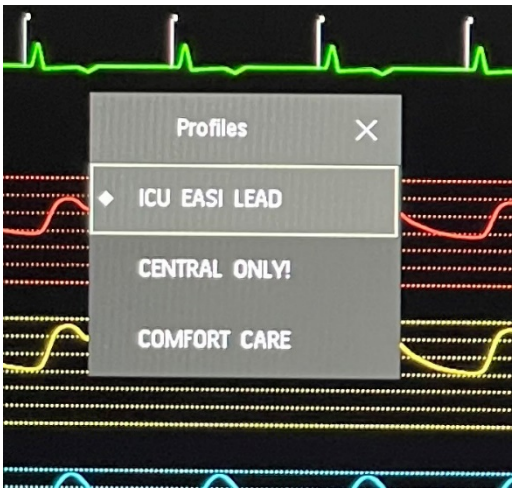
Richmond ICU:

When patient passing imminently (expected within hours), the bedside practitioner may adjust the monitoring equipment for end of life as needed.

1) **Touch "ICU EASI LEAD" profile option identified by yellow circle in picture below on the bedside monitor:**

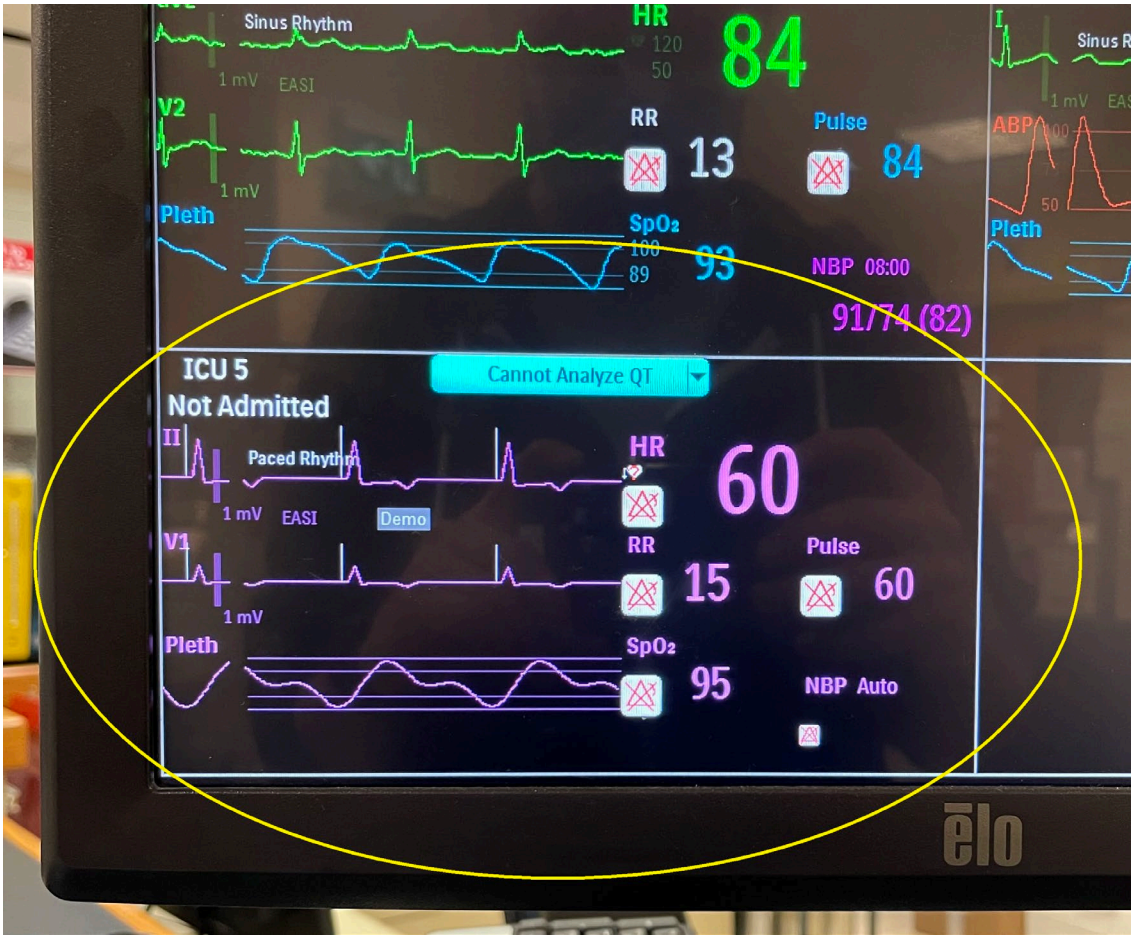


2) This provides the following 3 options for the user to select. Each Profile affects bedside screen display <u>and</u> alarm settings:



Profile	Bedside		Central Monitoring (Nursing Station)	
	Screen	Alarm Settings	Screen	Alarm Settings
ICU EASI Lead	ON	ON	ON	ON
Central Only!	OFF	OFF	ON	ON
Comfort Care	OFF	**ALL OFF**	ON**	**ALL OFF**

3) **When the "Comfort Care" profile is activated – only central monitoring is visible and display colour is changed to PURPLE per image below:



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Owners: *(optional)*	VCH
	Developer Lead: • Clinical Nurse Specialist, Intensive Care Unit, Vancouver General, VCH **Development Team Members** • Clinical Nurse Educator, Intensive Care Unit, Vancouver General • Clinical Nurse Educator, Intensive Care Unit, Vancouver General • Clinical Nurse Educator, Intensive Care Unit, Vancouver General