CLINICAL PROTOCOL: Actively Dying - Adult - Acute, Long-Term Care, Community Care

AUTHORIZATION: Regional Medical Directors: Medicine, Long-Term Care, Community Care and Palliative Care	**DATE APPROVED:** JUNE 2022	**CURRENT VERSION DATE:** JUNE 2022	**Page** 1 of 10

Version	Date	Comments / Changes
1.0	April 2017	Initial Clinical Protocol Released
2.0	June 2022	• Inclusion of Long-Term Care and Community Care • Resources specific to Indigenous patients • Additional resources for staff/patient education • Updated links • Reformatted appendix

PURPOSE:

To support the care of adults in Acute Care, Long-Term Care (LTC) and Community who are expected to die a natural death in hours to days.

It does not include unexpected deaths or Medical Assistance in Dying (MAiD); however, a person waiting for MAiD should receive the support of this protocol.

1. BACKGROUND

It is expected that the patient and their family have been engaged in a palliative approach to care which may include Advance Care Planning, Serious Illness and Goals of Care Conversations, that has proactively prepared them for this next ‘actively dying’ phase.

According to Phillips, Halcomb & Davidson (2011), it is currently estimated that only 50% of deaths in acute care can be accurately predicted due to the lack of universally accepted and validated criteria. The ability to predict death may also reflect the fluctuating trajectories of people dying from organ failure and the slow dwindling trajectories associated with dementia and frailty. All of these factors make diagnosing dying in these populations a complex and inexact science.

Not all adults in acute, long-term and community care settings have a predictable path to a natural death nor may they demonstrate the signs of approaching death before their dying time. This does not mean the death was unexpected only that the timing is unexpected and the pace they approached death was quicker than expected. It is imperative that we know proactively what a person’s wishes might be with regards to their health care options prior to their death with the implementation of a palliative approach to care and advance care planning.

Over the past few decades, the experience of dying has changed as most people now die with chronic diseases under the care of health professionals. Chronic disease is widespread among older adults with one in three of those aged 80 years and older having at least four chronic conditions, many of which are terminal without cure (Public Health Agency of Canada, 2010). Chronic illness can persist for years so it can be difficult to recognize when palliative care begins (Bern-Klug, 2009). When disease trajectories are not predictable and care staff are not vigilant, there exists the possibility of an unsupported death.

The Leadership Alliance for the Care of Dying People (LACDP) (2014), a broad based coalition of national organizations concerned with ensuring consistent high quality care for people in the last days to hours of life created a new approach to support care of actively dying persons. They identified five priorities that focus on an individualized approach that reflects the needs and preferences of the dying person and their family.

5 Priorities for the last few days or hours

1. The possibility (that a person may die within the next few days or hours) is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes. These are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person and family.
3. The dying person and family are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families are actively explored, respected and met as far as possible.
5. An individual care plan which includes food and drink, symptom control, psychological, social and spiritual support is agreed on, co-ordinated and delivered with compassion
(The Leadership Alliance for the Care of Dying People, 2014).

2. DEFINITIONS

Actively dying: The hours or days preceding imminent death during which time the patient's physiologic functions wane (Bailey & Harman, 2016; Hui et al., 2014). The intent to identify this phase is to neither hasten nor postpone death but to support individuals to live as actively and comfortably as possible until death (Downing, 2006).

Advance Care Planning (ACP): is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness (Sudore et al., 2016). It is important for all members of the team to record ACP conversation outcomes on the Advance Care Planning Record - Form, or equivalent, whether the patient only took a brochure home or engaged in an in depth conversation (Fraser Health, 2015).

Family: Those identified as important to the patient; whoever the person says his or her family is. This may include blood relations, partners, neighbours and/or friends.

Health Care Provider (HCP): includes all professional designations – Physician, Nurses and Allied Health care professionals

Natural Expected Death: Where deterioration to death occurs in its natural sequence but plans may not be in place (British Columbia. Ministry of Health, 2006).

Palliative Approach: A palliative approach to care is a holistic, person-centred approach that aims to improve the quality of life of people with chronic life-limiting illnesses throughout their illness trajectory (CIHI, 2018; Lynn & Adamson, 2003; Sawatzky et al., 2017). This is achieved by aligning treatment and care with preferences and goals, by addressing social, psychological and physical concerns, and by supporting a peaceful and dignified death. The principles of palliative care are adopted and integrated into the usual care practices of all healthcare providers, within their scope of practice, in all settings, including LTC, acute care, home care, and primary care (Sawatzky et al., 2017; Thorne, Roberts & Sawatzky, 2016). It is an approach to care for patients and their families that can and should be provided by palliative or non-palliative care specialists.

Palliative Care: The initial concept of palliative care being the terminal phase of an illness is replaced with the perspective that palliative care begins with the diagnosis of a life limiting illness/situation or disease.

> "Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, 2016).

Planned expected home death: Where an individual has chosen to die at home with the support of family and plans have been clearly made and documented beforehand (British Columbia Ministry of Health, 2006).

Patient: Is an overarching term that includes person, patient, client and/or resident.

Total Pain: The multidimensional nature of the palliative patient's pain experience which includes physical, psychological, social, and spiritual domains. The combination of these elements is believed to result in a "total pain" experience that is individualized and specific to each patient's particular situation. The concept of total pain should be used in the assessment and management of pain for palliative patients who are dying (Mehta & Chan, 2008).

3. RELATED RESOURCES

- See Appendices
- Death and Dying: Adult - Social Work Guideline - Clinical Practice Guideline

4. APPLICATION PARAMETERS

Patients can die a natural death in an unexpected time or can recover when expected to die. Therefore, we must identify those who might die and plan for death and at the same time monitor for signs of improvement.

- The patient and their family are the unit of care
- All Indigenous (First nations, Inuit, Metis) patients to be offered Indigenous Cultural Advisor
- The health care team jointly determines if the patient is thought to be in their last days to hours of life
- The whole health care team is responsible for caring for an actively dying person and their family
- The patient must be assessed by the team daily for unmet symptom or care needs
- The patient must be assessed daily for the potential of recovery
- The physician, in collaboration with the interdisciplinary team, terminates the protocol if the patient's health status stabilizes or improves to the point where the patient no longer meets the criteria for actively dying
- **The Actively Dying Adults - Acute & Long-Term Care - Pre-Printed Order must be reviewed two weeks after initiation and reordered or stopped. SBAR (situation, background, assessment, and recommendation) Communication Tool can be used to help communicate with the care team.**
    - **Acute Care** – has a stop order on the Medication Administration Record (MAR) after 2 weeks from initiation
    - **Long-Term Care** – review the resident's condition daily after initiation of Actively Dying Adults - Acute & Long-Term Care - Pre-Printed Order

- The Actively Dying Adults - Community Prescription - Pre-Printed Order (Home and Community only)
    - **Home/Community** – review the need for additional medication or medication changes regularly with the Family Physician

5. ASSESSMENT

According to Chan, Webster & Bowers (2016) in their systematic review on end of life care pathways "the needs of dying people may include but are not limited to; knowing when death is coming, understanding what can be expected, being able to maintain a sense of control and having their wishes given preference, having access to information and excellent care, and having access to spiritual and emotional support as required" (p. 3).

5.1. To determine if a person is Actively Dying

To determine if a person is in the last hours to days of life they must meet all of the following mandatory criteria:

Death	Death is thought to be imminent; anticipated within the next hours to days
Activity	Patient is bedbound, or if the patient has been bedbound there is a deterioration from their usual status
Nutrition	Minimal intake, sips or mouth care only, or there is a deterioration from their usual status

Any team member can bring concerns forward to the team to determine if the patient might be actively dying.

5.2. To determine if a person might recover

Nursing/Physician assessment to determine if there may be another cause for change in condition (such as oral thrush, unmanaged pain, delirium or depression, medications, infections); as long as the treatment aligns with the person's goals of care. The assessment might include:

Physical Status	Determine person's physical status by completing head to toe assessment. Include intake ability and oral assessment.
Laboratory	Review laboratory investigations and medications
Medications	
Delirium	Screen for delirium using Delirium - Hospitalized Adults (Excluding Critical Care, Maternity, Palliative or Hospice Care Areas) - Clinical Practice Guideline (Appendix G) and Confusion Assessment Method (CAM) - Form
Depression	Screen for depression and refer as needed (Appendix H).

5.3. To determine a person's wishes for health care

The team must discuss diagnosis, prognosis and review goals of care with the person, if able, and family and/or to the substitute decision maker. If the patient is competent, they **must** be included in the conversation unless they indicate otherwise. Support for communicating serious illness and having goals of care conversations is available from Bernacki & Block (2015) and Pearce & Ridley (2016).

Advance Care Planning, Serious Illness and Goals of Care Conversations are established through discussions with patient and family and documented on advance care planning record (ACP).

- Refer to the Advance Care Planning Conversation Tools Pulse page for specific conversation guides on:
    a. Advance Care Planning
    b. Serious Illness Conversations
    c. Goals of Care

- Medical Orders for Scope of Treatment (MOST) - Form reviewed and completed to support actively dying pre-printed orders. The patient and family have been informed and aware that the patient's code status is DNR M1 or DNR M2 to meet their comfort needs.

5.4. Symptom Assessment

Assess for symptoms common at end of life. Assessment includes interview, physical assessment, review of medications, psychosocial and environmental factors. Use a standardized symptom assessment approach such as onset, provoking/palliating, region/radiation, severity, treatment, understanding, values (O, P, Q, R, S, T, U and V) for symptom assessment (BC Inter-Professional Palliative Symptom Management Guidelines)

Key areas to assess include:

- Assess for pain and other forms of symptom distress, including total pain (see Appendix I) and determining the effectiveness of medications.
- Assess for dyspnea, nausea, vomiting, restlessness, delirium, secretions and anxiety
- The person might have other symptoms particular to their journey which must be fully assessed

5.5. **Biopsychosocial-Spiritual Support**: It is a collaborative inter-professional team effort to understand the person's and their family's wishes and needs in preparation for death. This may include understanding how to lessen their suffering, what information they need to make informed decisions, how to help them to maintain their dignity and manage their grief. The inter-professional team will involve the medical team (doctors and nurses), and may include a social worker and spiritual health practitioner. A social worker can assess the person and family's psychosocial needs, and based on a mutually agreed upon interventions, provide emotional and/or practical support. The spiritual health practitioner can do a spiritual assessment and, to guide and help the person and family to explore spiritual, emotional, cultural, faith and traditional practices in order to provide spiritual support to them.

All Indigenous (First nations, Inuit, Metis) patients are to be offered an Indigenous Cultural Advisor. Cultural Services can be accessed by contacting the Aboriginal Health Liaison toll-free line at 1-866-766-6960.

Referrals can be made by:

- Individual clients
- Family members
- Friends
- Health professionals

When to call:

- To refer Indigenous clients
- To ask questions regarding any aspect of Aboriginal Health Services

5.6. **Implantable Cardioverter Defibrillator**: Determine if the person has an Implantable Cardioverter Defibrillator (ICD). If it has not been deactivated, follow the Implantable Cardioverter Defibrillator: Deactivation for End of Life Care Planning - Clinical Practice Guideline. If ICDs are not deactivated they can shock the person during their dying phase.

6. INTERVENTION

The top 4 elements identified as important to both patients and families are (Virdun, Luckett, Davidson & Phillips, 2015):

- Effective communication and shared decision making
- Expert care
- Respectful and compassionate care
- Trust and confidence in clinicians

6.1. Initiate orders:

Once the health care team has determined the patient meets the criteria for the actively dying protocol:

	Nurse (Registered Nurse (RN)/ Registered Psychiatric Nurse (RPN)/Licensed Practice Nurse (LPN)	Most Responsible Provider (MRP)
Acute Care and LTC	Initiates the Interprofessional Care Plan for Actively Dying Patients - Form	Initiate the Actively Dying Adults - Acute & Long-Term Care - Pre-Printed Order
Community and Assisted Living	The Community Health Nurse (CHN) reviews the Joint Protocol For Expected/Planned Home Deaths in British Columbia and implements the following: • Notice of Expected Death in the Home form. It is not mandatory that a client have this form in the home to die. If they do not have this form completed a Health Care Professional (CHN), Family Physician (FP), Nurse Practitioner (NP) must go to the home and pronounce that the client has died. • FP/NP completes Actively Dying Adults - Community Prescription - Pre-Printed Order. Support for completing the prescriptions can be found in the Fraser Health Regional Palliative Care Dosing Suggestions for Adult Patients • Use SBAR (situation, background, assessment and recommendation) Communication Tool to communicate about actively dying patient to the FP/NP	

6.2 Completing the Actively Dying Adults - Acute & Long-Term Care - Pre-Printed Order

The health care provider who assesses the person as imminently dying, and communicates to the patient and their family about the patient's diagnosis and prognosis and that comfort care measures have been implemented signs the top section of the pre-printed order (PPO).

- In LTC this may typically be the RN or LPN
- In acute care this would be the MRP

The bottom section is signed by the MRP:

- It indicates that the medications have been individualized to the person's needs by ticking the appropriate medications and calculating the appropriate doses (see back page of PPO for opioid conversion charts)
- Identify which medications can be stopped or if needed changed to another route. Suggestions for aiding in deciding which medications to stop are in Up to Date - Palliative care: The last hours and days of life

6.3 Symptom Management

- Assess patient at least every 4 hours in acute or LTC and daily for home care for unmet symptoms
- Use evidence based guidelines for end of life care to guide symptom management and medication
- Assess regularly for effects and side effects of medications
- Aggressively manage all symptoms causing the patient illness

To provide the most appropriate medication:

- Start with the lowest dose
- Maintain on the lowest effective dose
- Indicate the dose given on the medication record

- If the dose provided is insufficient, such as requiring 3 or more breakthrough doses in a 24 hour period, contact the Physician/Nurse Practitioner for direction
- When switching to another medication and/or changing the route of administration, an equivalent dose of analgesia needs to be calculated and requires Physician/Nurse Practitioner order to adjust (See the back page of the Actively Dying Adults - Acute & Long-Term Care - Pre-Printed Order)
- Oxygen is used for comfort only, monitoring oxygen saturation is not necessary

6.4 Expert care

Initiate the Interprofessional Care Plan for Actively Dying Patients - Form and individualize it in partnership with the patient and family.

6.5 Social Work/Biopsychosocial - Spiritual Interventions

Biopsychosocial interventions provided by social workers are agreed upon, ideally, with the patient and their family, with the goal of overcoming barriers, resolving, and stabilizing and/or bringing meaning to what is causing distress. Some interventions may be tangible or information based, such as requiring information about different systems, benefits or resources that impact a patient and their loved ones and liaison and advocacy for those resources (Fraser Health, Hospice Palliative Care Program Symptom Guidelines, 2016).

Interventions also include communication skills to maximize effective and compassionate care, supportive counselling, participation in family meetings, facilitating adaptation and enhancing coping skills in the management of distress and pain, reframing of hope, providing education related to illness, pain and symptom management such as relaxation techniques, and conflict resolution (Gwyther et al., 2005). Fostering effective communication among members of the interdisciplinary team is another important intervention.

6.6 Spiritual Health Interventions

Members of the inter-professional care team can support Spiritual Health needs through such things as compassionate listening and arranging for patients to connect with appropriate community resources. Spiritual health professionals (SHPs) provide “comprehensive spiritual care and emotional support to patients, families and health care staff” (BC Ministry of Health, 2012), and can respond to patients or family members experiencing spiritual distress or if complex spiritual needs are present. If a Spiritual health professional is not currently involved, a referral would be appropriate. Email spiritual.health@fraserhealth.ca for more information.

6.7 Nutrition and Hydration

Family may not understand that providing nutrition and hydration at this time can cause aspiration and/or fluid overload. Information and support for family is essential, see Education section below.

The traditional practice associated with end of life care is that when interest in food and fluid becomes minimal the individual should not be forced to receive them. If it is important for the person or their family that the person should continue to have fluid (Intravenous (IV) or subcutaneous), assess frequently for symptoms of fluid overload and reduce or stop the infusion if symptoms are seen.

In the situation where a person is receiving enteral nutrition (tube feed), it is usually appropriate to either discontinue or reduce the rate. Stopping the enteral nutrition may be recommended by the dietician or nurse but does require a physician order. Whether the tube feed is stopped or titrated down and then stopped, there needs to be a discussion between the patient/SDM, physician, nurse and dietician if available to ensure everyone understands the goal of care for nutrition. There should also be a review of medication given via enteral feeding tube (e.g. G/J-tube) to see if the medications should be switched to the subcutaneous, buccal, sublingual or stopped. If the patient is thought to be recovering, the care team, patient and family/SDM need to have a discussion about restarting the enteral nutrition. The physician is responsible for re-ordering enteral nutrition.

6.8 Communication

- Communication to all members of the care team that the patient is thought to be Actively Dying and the Interprofessional Care Plan for Actively Dying Patients - Form and if needed Actively Dying Adults - Acute & Long-Term Care - Pre-Printed Order has been initiated
- Give room for family to express emotion and ask questions
- Be honest
- Offer bereavement support
- Collaborate with interdisciplinary team members

6.9 Referrals to palliative care program if:

- The primary care team is not able to manage symptoms
- Person has a life expectancy of longer than 48 to 72 hours and may be appropriate for hospice (acute or community care only)
- MRP requires support for writing orders for end of life symptoms or the orders are not managing the symptoms
- Team requires support for other measures to support patient/ family
- Complex biopsychosocial situations if unit social worker and spiritual care practitioner require assistance
- If a resident in LTC requires a palliative consult after exhausting all possible resources, please connect with your local LTC Clinical Nurse Specialist.

7. EDUCATION

Client/Family Education

- Offer and review information in pamphlet which describes symptoms of actively dying and how loved ones can participate in the care of the person dying.
- Use family meetings as a way to convey useful information
- Supporting a Loved One When Death is Near - Booklet
- Eating for Comfort as Health Declines - Pamphlet
- Suggested Books on Bereavement for All Ages - Factsheet

Staff Education

- In-services arranged by unit leaders
- **LearningHub**
  - ○ Hospice Palliative Care Pain Module
  - ○ FHA - Medical Orders for Scope of Treatment (MOST) Online Module
  - ○ FHA - Advanced Care Planning Online Module
- **Clinical Skills**
  - ○ Symptom Management at End of Life

8. DOCUMENTATION

- Use unit and discipline standards to document assessment that person is dying; symptom assessment and management; psychosocial supports and interventions
- Document conversations on what is important to the person and goals of care on the Advance Care Planning Record - Form
- Document level of intervention on Medical Orders for Scope of Treatment (MOST) - Form

9. CLINICAL OUTCOMES

- The individual who is dying will understand and participate in the conversations and decision making as much as they are able to and want to
- The individual dying will be comfortable and their symptoms will be well managed
- The family will understand that their loved one is dying and participate in their care as much as they are able or wish to be
- The staff caring for dying persons will feel confident and competent to support them and their families through the dying process

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11. APPENDICES

Appendix	Resource
Appendix A	Actively Dying Adults - Acute & Long-Term Care - Pre-Printed Order
Appendix B	Actively Dying Adults - Community Prescription - Pre-Printed Order
Appendix C	Discharge Planning Checklist for Complex Patients Requiring Palliative Services at Home - Form
Appendix D	Fraser Health Regional Palliative Care Dosing Suggestions for Adult Patients
Appendix E	Interprofessional Care Plan for Actively Dying Patients - Form
Appendix F	Medical Orders for Scope of Treatment (fillable form) Advance Care Planning Record - Form See Documents in Appendices of: Medical Orders for Scope of Treatment and Advance Care Planning - Clinical Policy
Appendix G	Delirium - Hospitalized Adults (Excluding Critical Care, Maternity, Palliative or Hospice Care Areas) - Clinical Practice Guideline
Appendix H	Geriatric Depression Scale (GDS) - Short Form - Form Cornell Scale for Depression in Dementia - Form Cornell Scale for Depression in Dementia Administration and Scoring Guidelines
Appendix I	Pain Assessment in Advanced Dementia (PAINAD) - Form Iowa Pain Thermometer Preventing and Managing Resident's Pain in Long-Term Care Homes - Clinical Practice Guideline
Appendix J	SBAR Communication Tool