

7.10 End of Life Care

Policy

The Burnaby Association for Community Inclusion (BACI) is committed to providing compassionate care and comfort to the individuals we serve, living in our staffed homes, who are nearing the end of their life, whose death is anticipated, and who want to remain in their home.

Each aspect of end of life care, up to and including the individual's death, is to be handled sensitively with the aim of ensuring people can die in a dignified, respectful manner, as free from pain and distress as possible, and in accordance with their own wishes.

As per their wishes, the individual will be cared for in their final days in their home. BACI's ability to provide this care is dependent on the employee team's, in collaboration with an interdisciplinary health care team's, appropriate capacity to do so.

If BACI does not have the required capacity, the BACI Manager will work with the individual, their personal support network, and allied organizations (CLBC, Ministry of Health, MCFD) to explore options and set up alternative arrangements in keeping with the individual's needs and preferences.

BACI recognizes that individuals who have a terminal illness and who are at the end of their lives, will require enhanced care, including emotional supports and changes in the roles and responsibilities of those providing their day-to-day care and those who are part of their personal support network. Enhanced care will be supported by developing an End of Life Care Plan. Guided by holding the individual at the centre, the Plan will be developed by the Manager with the input of the employee team, other professional supports (e.g. palliative care practitioners and services, Health Services for Community Living, etc.), and members of their personal support network. The Plan will include information on processes for review, as and when the individual's condition changes. The Plan will place a priority on maintaining the individual's comfort, safety, and management of any pain associated with their condition as much as possible.

The views of the individual's personal support network, including close friends, housemates, relatives, and Legal Representative (when involved), will also be considered in the planning process, though the individual's own views, where stated or known, will always take priority.

As part of preparation for end of life care, the Manager is expected to review all of the late life planning for the individual to ensure that specific details are in place.

Where specific parts of the checklist have not been addressed, the Manager will facilitate processes to involve relevant parties in engaging in this planning.

Policy Outcomes

This policy is intended to ensure that an individual's wishes are the primary focus when they are terminally ill and near the end of their life. At this time:

- They are supported to remain in their homes with competent and compassionate care unless/until their needs can no longer be safely met at home and an alternative setting is required.
- Planning and support for individuals uses a collaborative, values-based and interdisciplinary approach, focusing on quality of life, comfort, and pain management as required.
- Employees are effectively supported and trained to respond to the physical and emotional needs of individuals when providing end of life care.
- Employees understand the reporting, documenting, and reviews required, following the death of an individual.
- There is a commitment to individualized planning throughout the lifespan that is proactive and responsive, taking into consideration the changing support needs at the end of life.

Core Principles

These principles guide the approach to End of Life Care:

- **Preparation is Key to Well-being as People Grow Older** – Early and ongoing planning for later life is widely considered an important predictor of people's health, well-being and quality of life as they age. Successful aging is not measured simply by longevity, but more importantly by the individual's opportunity to engage meaningfully in the areas of their life that are important to them. As individuals prepare for changes in their lives, this focus helps promote practices, adapt supports and explore alternative activities that maintain quality of life.
- **Person Centred Thinking/ Whole Life Planning and Quality of Life** – Person centred thinking focuses on continuously learning and incorporating what is important to the individual for planning and support to adapt fluidly. Quality of life can change dramatically through the aging process. It is essential to use a person centred thinking approach to stay attuned to these changes and avoid putting plans in place based on what the individual previously believed or wanted.
- **Self-Determination and the Opportunity for Choice and Voice** – Central to planning is the individual's voice, in whatever form that it is expressed. The focus is on understanding and ensuring the individual's preferences and what is important to them as their life starts to change.

- **Dignity and Respect** – Promoting equal treatment is key to ensuring individuals are treated with dignity and respect. It is imperative that potential biases, based on the individual’s disability or perceived vulnerability, do not limit:
 - The assessment of an individual’s conditions and their access to treatments, and/or;
 - Their right to be involved in discussions/decisions about their care as they age or approach end of life.
- **Informed Choice** – Promoting self-determination takes the time needed to help individuals and their families receive the information they need. This includes information about both the benefits and risks involved in any decisions made about the individual’s late life planning and end-of-life care.
- **Personal Network/Family Engagement** – Reduced activity coupled with changes in the level of engagement in community can make it harder for individuals to stay connected with loved ones as they, or their loved ones, age. Late life planning should both continue to nurture existing relationships and to continue to broaden these networks for individuals to have a strong circle of people who matter to them. This circle will help provide support and advocacy, as well as having people they know they can count on as they age.

Definitions

End of Life Care: Refers to the supportive and compassionate care provided for people who are dying and for members of their support network. End of life may include a diagnosis of a terminal illness (e.g. end-stage cancer) or a progressive disease which has become palliative in nature. End of life care is not strictly limited to the immediate moments prior to death but can occur over a period of days, weeks and even months, depending upon the unique circumstances for the individual. Care can encompass emotional, physical/health, psychological and spiritual supports, and focuses on comfort and symptom management.

End of Life Plan: Describes and defines the responsibilities associated with supporting an individual regarding at home end of life care. End of life care plans are complementary to the directions provided in a Health Care Plan.

Late Life Planning: Refers to the plans made prior to later life. It considers all aspects of a person’s quality of life, including: health and health care, legal and financial matters, work/community life and retirement, psychological issues, and social roles and resources (Adapted from the American Psychological Association, 2018).

Advance Care Plan: An Advance Care Plan is a written summary of an adult's wishes or instructions to guide a substitute decision maker if that person is asked by a physician or other health care provider to make a health care treatment decision on behalf of the adult.

Interdisciplinary Team: Allied professionals who provide their expertise and participate in assisting with care planning, medication reviews, and other required supports/treatment for an individual who may have compromised health, a terminal illness, or is receiving palliative care. Team members may include nurses, physicians, pharmacists, physiotherapists, occupational therapists, counsellors, spiritual advisors and others as appropriate to the individual's circumstances and needs.

Palliative Care: Palliative care focuses on the prevention and relief of suffering by means of early identification, assessment and treatment of pain and symptom management, and providing supports to meet other physical, psychosocial, and spiritual needs. The goal of palliative care is to provide comfort and dignity for the individual living with the problems associated with life-threatening illness, as well as support best quality of life for both they and their loved ones. (Adapted from the World Health Organization and Canadian Hospice and Palliative Care Association definitions).

Hospice: Hospices are typically private or not-for-profit organizations who provide palliative and end of life care to individuals, as well as support to their loved ones up to the bereavement phase. Sometimes hospice supports are located in hospitals when a separate facility does not exist. Some hospice supports can also be provided in the home, depending on the community and services offered.

No Cardiopulmonary Resuscitation Decision (No CPR) – Medical Order: Refers to an order that instructs people such as first responders, paramedics, and health care providers not to start CPR on a person's behalf at home or in the community. No CPR is a choice that can be made regarding whether or not cardiopulmonary resuscitation will be initiated in the event of a respiratory and/or cardiac arrest. Individuals who have independent decision-making capacity, may request this. A Medical Order form will be required. This should be done after discussions with their doctor or nurse practitioner.

Medical Orders for Scope of Treatment (MOST): The Medical Orders for Scope of Treatment (or "MOST") form helps care providers honour what is important to the person. A MOST is an official document (Medical Orders). Physicians and other health care professionals use the MOST to relay the treatment wishes and decisions regarding a person's care to others who may be part of the integrated care team. It is a doctor's or nurse practitioner's order based on advance care planning conversations that explore the person's values, goals and the range of beneficial treatments. Once decisions are made, the doctor will record this on the MOST form.

Capacity to Consent to Care: The individual's ability to understand the nature of the illness for which an intervention is proposed, the nature and purpose of the intervention, and its risks and benefits, whether or not the individual receives the intervention. It is necessary that there be no pressure or coercion (real or imagined) placed on the individual or their support network, in making any decisions regarding their consent to care.

Health Care Plan: A Health Care Plan is written by a health care professional who is usually external to the service provider. It is the standard of health care support for which the service provider is accountable. A Health Care Plan guides the service provider, their employees, and other professionals in the care and treatment of an individual with complex care needs.

Delegation of Tasks: Delegable Tasks are tasks that are client-specific and are outside the role description and basic training of an Unregulated Care Provider (an employee providing care that is not regulated by a health care profession). Registered Nurses (RN), Registered Psychiatric Nurses (RPN), Physical Therapists (PT), or Occupational Therapists (OT), are responsible for delegating a professional task to a Service Provider. Delegable tasks are normally performed by a RN, RPN, PT, OT, but under certain circumstances it may be in the best interest of the client to delegate the task to an Unregulated Care Provider (UCP).

The UCP must receive training and demonstrate competence in the performance of the task. A UCP cannot train another UCP on the task. Each UCP performing the task must be trained by the health care professional. The UCP's Supervisor/Coordinator is responsible to ensure the UCP has been trained in the specific task and for ongoing assessment of the UCP's ability to perform the task as taught. The health care professional who delegates the task remains responsible for the determination of client status, care planning, interventions, and evaluation of care until the client no longer requires the task. (Adapted from the Ministry of Health: Personal Assistance Guidelines 2008).

Personal Support Network: Refers to friends, family and/or community members who provide personal support, advocacy, and/or who help with monitoring services, and who have reciprocal relationships with an individual.

Legal Representative: A person or persons who are legally authorized to make decisions on behalf of the individual (e.g. Committee, Representative, Temporary Substitute Decision Maker). There are legal parameters regarding what kind of decisions can be made by different Legal Representatives and their role and responsibilities in carrying out these duties.

Linking Policies:

- 1.1 Vision & Mission Statements
- 1.2 Guiding Principles
- 1.3 Quality Assurance Policy
- 1.8 Code of Ethics
- 2.1 Accessibility Policy
- 2.2 Access to Service Policy
- 3.1 General Health & Safety Policy
- 6.1 Outcomes Management Policy

- 7.1 Individual Support Planning Policy
- 7.2. Personal Service Planning Policy
- 7.3. Individual Support Plans (Care Plans) Policy
- 7.4 Service Transition Policy
- 7.5 Adult & Youth Service Evaluation Policy
- 7.6 Personal Assistance Policy
- 7.9 Late Life Planning Policy
- 7.11 Response to the Death of an Individual Receiving Services Policy
- 8.1 Privacy Protection for Individuals Policy
- 9.1. Rights & Responsibilities of People with Disabilities Policy
- 9.5 Involvement in Decision-Making Policy