

25.1 End of Life

End of life planning helps to ensure that individuals continue to live as independently as possible, with the support they need, up to and including a dignified end of life. Thoughtful planning and open communication provide reassurance to the person's loved ones by ensuring the person's wishes are known, that necessary supports are in place, and that expectations and roles are clearly defined.

Definitions

Legal Representative can be a Committee of Person, a Representative, and/or a Temporary Substitute Decision Maker (TSDM) that are involved with health care decision making concerning an individual. The Public Guardian and Trustee of BC can be appointed as Committee, authorized as a Representative, or can authorize a TSDM or act as a TSDM. The roles and responsibilities of legal representatives are outlined in the CLBC Role of Formal and Informal Representatives Policy (see Appendix 2 CLBC's End of Life Policy, referenced below).

End-of-Life Care is the term used for the range of clinical and support services appropriate for people nearing their end of life. The goal of end-of-life care is to ensure the best possible quality of life for people nearing their end of life and their families.

Palliative Care means the specialized care of people who are dying – care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term “palliative care” is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure.

DNR Order – stands for Do Not Resuscitate. A DNR order (or No CPR order) may be deemed appropriate at the end stages of life where CPR would not be beneficial to the individual. Only a physician can place a DNR order. The individual's right to consent is a crucial consideration in determining whether a DNR order is appropriate.

Policy

- (a) Spectrum personnel will be familiar with and will follow the guidelines set forth in Community Living BC's End of Life policy and procedure (referenced below).
- (b) Spectrum will work collaboratively with the individual, family and any professional supports to ensure a coordinated approach to end of life care.
- (c) Spectrum personnel will implement any treatment plans as prescribed. If staff or caregivers are not comfortable with any aspect of the treatment plan or do not feel comfortable providing end of life support, they should speak to the supervisor or HR.
- (d) The rights of the individual and his or her legal representative will be considered paramount. The individual and his or her legal representative will be involved in all decisions regarding end of life care.

Emergency procedure

- (a) If a person stops breathing, goes into an unconscious state or is found deceased, call 911 immediately and administer appropriate emergency First Aid/CPR, unless otherwise directed in writing by the person or the person's legal representative or physician.
 - i. If there is an advanced directive in place (DNR / No CPR Order), follow the steps listed there.
 - ii. Stay with the person until help arrives.
 - iii. Follow the directions of emergency responders.
 - iv. Provide access to the person's profile, care plan, medications and any other pertinent information requested by emergency responders.
 - v. It is not necessary to accompany the person in an ambulance.
- (b) Call the supervisor for further instructions and to let them know what is happening. If you can't get hold of the supervisor, call the Spectrum emergency cell (604) 644-1474.
- (c) The supervisor will contact the next of kin and any professional supports. The supervisor will be the fixed point of contact for the family and professional supports, unless otherwise directed.
- (d) Document what happened on a critical incident report, following the steps outlined in Policy #25: Critical Incident Reporting.
- (e) The Executive Director or designate will contact CLBC and complete a Mortality Information Summary.

Funeral and burial arrangements

- (a) Unless otherwise arranged, the family or designated representative will take the lead on planning the funeral and burial arrangements. See resources below for what assistance is available from the Ministry for burial costs.
- (b) If there is no family or designated representative, Spectrum will coordinate funeral and burial arrangements with the public trustee and the funder.
- (c) With the Executive Director's approval, the Society may contribute to costs associated with funeral and burial arrangements, taking into account the person's funds first then agency funds if required.

Bereavement

Spectrum Society recognizes that the death of a person receiving support can be a very difficult time for staff and caregivers. If needed, we will arrange for grief counselling for teams and personnel can also access individual counselling through the employee assistance plan.

References

CLBC End of Life Policy:

https://www.communitylivingbc.ca/wp-content/uploads/END_OF_LIFE_POL_10_19_2016-1.pdf

A Provincial Framework for End of Life Care:

<https://www.health.gov.bc.ca/library/publications/year/2006/framework.pdf>

Guidelines for Collaborative Service Delivery for Adults with Developmental Disabilities (Appendix 9: End of Life Care for Adults with Developmental Disabilities):

<https://www.health.gov.bc.ca/library/publications/year/2010/Guidelines-collaborative-service-delivery-adults.pdf>

Joint Protocol for Expected / Planned Home Deaths in British Columbia:

https://www2.gov.bc.ca/assets/gov/health-safety/home-community-care/care-options-and-cost/expectedplanned-home-deaths/expected_home_death.pdf

Ministry of Health Advance Care Planning Guide – My Voice: Expressing My Wishes for Future Health Care Treatment:

<http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>

MOST – Medical Orders for Scope of Treatment – A doctor’s order based on advanced care planning conversations that a doctor has with a patient – used by Fraser Health and Interior Health:

<https://www.fraserhealth.ca/health-topics-a-to-z/advance-care-planning/medical-order-for-scope-of-treatment---most#.XAYJJPZFzIV>

Ministry assistance with funeral costs:

<https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/organizational-structure/ministries-organizations/social-development-poverty-reduction/funerals.pdf>