



## End-of-Life Policy

### 1. PURPOSE

This policy outlines responsibilities of CLBC staff and contracted service providers for the reporting, documenting, and review required following the death of an individual supported by CLBC-funded services. It provides guidance to CLBC staff about end-of-life care for individuals who are dying and bereavement support for members of the individual's family and support network.

### 2. DEFINITIONS

**B.C. Coroners Service:** An agency within the Ministry of Justice governed by the B.C. *Coroners Act*. It investigates unnatural, sudden and unexpected, unexplained or unattended deaths, and has legal authority to compel the production of records and attendance of witnesses.

**End-of-Life Care:** (as defined in *A Provincial Framework for End-of-Life Care*) Clinical and support services appropriate for dying people and their families. The goal of end-of-life care is to provide the best quality of life for dying people and their families.

**Individual:** A person 19 years of age or older who is eligible for CLBC services, as described in the *Eligibility for CLBC Supports and Services* policy.

**Legal Representative:** A Committee of Person (Personal Guardian), a Representative (Personal/Health Care) 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 B.C. can be appointed as Committee, authorized as a Representative, or can either authorize a TSDM or act as a TSDM. Descriptions of the roles and responsibilities of legal representatives are outlined in the CLBC *Role of Formal and Informal Representatives Policy* and included in Appendix Two of this policy.

**Provincial Clinical Consultant:** A B.C.-licensed health care professional who provides consultation on complex health issues and mortalities of individuals with developmental disabilities to interested parties including but not limited to CLBC staff, CLBC-contracted service providers, Ministry of Social Development and Social Inclusion staff, Health Services for Community Living and acute care clinicians, the B.C. Coroners Service, and the Public Guardian and Trustee of B.C.

**Provincial Medical Consultant:** A B.C.-licensed physician who provides consultation on complex health issues and mortalities of individuals with developmental disabilities to

interested parties including but not limited to other physicians, CLBC staff, CLBC-contracted service providers, Ministry of Social Development and Social Inclusion staff, Health Services for Community Living and acute care clinicians, the B.C. Coroners Service, and the Public Guardian and Trustee of B.C.

**Support Network:** Friends, family and/or community members who provide personal support, advocacy and/or help with monitoring services and who have reciprocal relationships with individuals.

### 3. POLICY

CLBC works collaboratively with service providers, individuals, families and/or support network members, legal representatives, and health care providers involved in end-of-life care and service planning to ensure integrated seamless quality care and support is provided in the best interest of the individual and their family and/or support network coping with end-of-life needs.

Service providers are required to report to CLBC all deaths of individuals being supported in a CLBC-funded service. Reporting requirements are outlined in this policy and the CLBC *Critical Incidents Policy*, and are a condition of the service provider's contract. Service providers will:

- Immediately notify CLBC about all deaths of individuals receiving any CLBC-funded service
- Document and submit reports for all deaths of individuals who were receiving CLBC-funded residential services or when their death occurred while they were participating in any CLBC-funded service

CLBC quality service analysts have the responsibility for receiving notifications and reports submitted by service providers when a death occurs and forwarding reports, as outlined in this policy, to ensure a coordinated timely reporting and review response can occur.

The identification, review and analysis of issues, trends and patterns associated with all deaths of individuals who received CLBC-funded services is supported by CLBC in collaboration with the Provincial Clinical Consultant and the Provincial Medical Consultant, and as required, with agencies that have mandatory and /or investigative responsibilities. Review and analysis of these issues, trends and patterns supports CLBC's monitoring approach by identifying concerns that may impact upon the quality of CLBC-funded services.

## 4. PROCEDURES

Appendix One of this policy reviews the following procedures in a table where responsibilities are organized by CLBC regional staff and service provider roles.

### End-of-life care

4.1 Facilitators and analysts collaborate with service providers, individuals, families and/or support network members, legal representatives, and health care providers involved in end-of-life care and service planning. They are familiar with:

- *Appendix 9: End-of-Life Care for Adults with Developmental Disabilities* included in the *Guidelines for Collaborative Service Delivery for Adults with Developmental Disabilities* that outlines their complementary responsibilities for end-of-life health care planning in collaboration with health authority staff; and
- *End-of-Life Guide: Information for CLBC Facilitators and Analysts* that accompanies this policy. The guide provides practice guidance and resource information about end-of-life care.

See Practice Section (6.2) of this policy for additional information about the role of CLBC staff regarding end-of-life care.

4.2 Facilitators and analysts comply with the *CLBC Role of Formal and Informal Representatives Policy* that outlines the decision-making roles of legal representatives and the parameters of supportive relationships that CLBC staff, service providers, and families have with an individual.

4.3 Analysts have additional responsibilities when an individual lives in a directly-contracted home share. Analysts:

- Provide information to home sharing providers about their responsibility to notify CLBC when an individual has been deemed palliative by a physician;
- When notified an individual has been deemed palliative by a physician, confirm with home share providers that end-of-life care and service planning is occurring; and
- Request facilitators to assist with end-of-life care planning and service coordination when additional support is required.

4.4 Directly-contracted home sharing providers notify CLBC when an individual has been deemed palliative by a physician.

4.5 Facilitators, when requested by analysts, assist directly-contracted home share providers with end-of-life care planning and service coordination.

### Notification of all deaths of individuals who received CLBC-funded services

4.6 Analysts provide information to service providers about their responsibility to immediately notify their CLBC liaison analyst about all deaths.

4.7 Service providers immediately contact their CLBC liaison analyst when a death occurs including when the service provider is aware of a death that occurred when the individual was not in attendance at the CLBC-funded service.

When a death occurs outside of normal CLBC working hours, the service provider is to contact the Ministry of Children and Family Development (MCFD) [After Hours](#).

4.8 Facilitators, upon being notified about a death, immediately contact:

- Community Planning & Development Manager; and
- Liaison analyst for the service provider who provided service to the deceased individual.

4.9 Analysts, upon being notified about a death, are responsible to immediately contact:

- Quality Service Manager;
- Director, Regional Operations;
- Other involved CLBC staff (e.g. facilitator); and
- Provincial Clinical Consultant and the CLBC staff designated to receive mortality notifications by completing a *Notification of Death* form and submitting it by e-mail via the Outlook *CLBC Mortality Notifications* distribution list.

4.10 Residential service providers notify family members and legal decision makers about the death of an individual residing in a CLBC-funded residential service. Following a death, residential service providers:

- Immediately notify or confirm that the family and when involved, legal representative, have been notified about the death; and
- Notify a Committee of Estate or other legal decision maker that has been involved with managing the individual's financial and legal affairs.

See Practice Section (6.5) of this policy for additional information about notification to family members and legal decision makers.

#### **Notification of sudden and unexpected deaths of individuals**

4.11 Service providers immediately contact 911 for an ambulance and local police when an unnatural, sudden and unexpected, unexplained or unattended death of an individual occurred while in attendance at the CLBC-funded service. See Practice Section (6.4) of this policy for additional information.

#### **Reporting of deaths of individuals who were receiving CLBC-funded residential services or when their death occurred while they were participating in a CLBC-funded service**

4.12 Analysts provide information to service providers about their responsibility to document and submit reports following deaths.

4.13 Service providers submit reports about deaths as follows:

- Within 24 hours of a death, complete the service provider section of the CLBC *Mortality Information Summary* form and submit it to the CLBC liaison analyst. When the death occurs on a weekend or a statutory holiday, the CLBC *Mortality Information Summary* form is submitted by 8:30 a.m. on the next business day; and
- Submit critical incident reports as outlined in the CLBC *Critical Incidents Policy*.

When more than one service provider is under contract to provide services to the individual, the reports are submitted by the service provider whose funded services the individual was participating in when the death occurred. If the individual lived in a residential service and was not participating in another funded service when the death occurred, the residential service provider will submit the reports.

**4.14** Analysts, upon receipt of a CLBC *Mortality Information Summary* form, will respond as follows:

- Within 12 hours, complete the CLBC section of the *Mortality Information Summary* form and submit it to:
  - The CLBC staff and the Provincial Clinical Consultant designated to receive mortality notifications by e-mail via the Outlook *CLBC Mortality Notifications* distribution list;
  - Quality Service Manager; and
  - Director, Regional Operations.
- Comply with procedures outlined in the CLBC *Critical Incidents Policy*.

**4.15** Analysts, when notified about a death of an individual who was receiving individualized funding, will:

- Determine if the person who was authorized as the individual's agent is a family member and is able to complete the *Mortality Information Summary* form within 24 hours of the death;
- Complete the *Mortality Information Summary* form when the agent is a family member and unable to complete the form within 24 hours of the death; and
- Within 36 hours following a death, submit the *Mortality Information Summary* form to the CLBC staff and the Provincial Clinical Consultant designated to receive mortality notifications by e-mail via the Outlook *CLBC Mortality Notifications* distribution list.

See Practice Section (6.6) of this policy for additional information about completing *Mortality Information Summary* forms involving deaths where the person who was authorized as the agent is a family member.

### **Investigations and reviews of deaths of individuals who received CLBC-funded services**

**4.16** CLBC staff comply with requests:

- For information from the Provincial Clinical Consultant and Provincial Medical Consultant; and

- From law enforcement officers or agencies that have regulatory and/or investigative mandated responsibilities such as the B.C. Coroners Service to assist with a formal investigation and review.

4.17 Service providers comply with requests:

- For information from the Provincial Clinical Consultant and Provincial Medical Consultant; and
- From law enforcement officers or agencies that have regulatory and/or investigative mandated responsibilities such as the B.C. Coroners Service to assist with a formal investigation and review.

### **Tracking System**

4.18 The CLBC Manager of Quality Assurance, in collaboration with the Provincial Clinical Consultant and the Provincial Medical Consultant, maintains a central data base for the systematic tracking of all deaths of individuals who received CLBC-funded services.

### **Bereavement Support**

4.19 Facilitators and analysts may provide information to families and/or support network members and service providers about community resources that provide bereavement support. See Practice Section (6.7) of this policy for additional information about the role of CLBC staff regarding bereavement support information.

## **5. DOCUMENTATION**

### **End-of-life care for individuals who are deemed palliative by a Physician**

5.1 When notified about an individual who has been deemed palliative by a physician, a “Health Note” in PARIS is completed that summarizes the end-of-life care and service planning being carried out.

- Facilitators complete the “Health Note” when providing planning support with end-of-life care and service coordination.
- Analysts complete the “Health Note” when facilitators are not providing planning support.

### **Following all Deaths**

5.2 A “Mortality Note” is completed in PARIS by the analyst and/or facilitator and can include information about:

- Actions that have been/will be taken following a death including notification to a family member and, when involved, to a legal representative and/or a legal decision maker that has been involved with managing the individual’s financial and legal affairs
- Bereavement support community resources that have been provided to family, a support network member, or a service provider
- Funeral/memorial arrangements

- Administration of the individual's estate (see *End-of-Life Guide: Information for CLBC Facilitators and Analysts*)

5.3 Analysts ensure copies of both the *Notification of Death* form and the *Mortality Information Summary* report are stored in the individual's PARIS file in the Individual Site (SharePoint).

5.4 Analysts ensure printed copies of the *Mortality Information Summary* report are placed in the service provider's CLBC record.

5.5 Quality Service Manager/ designate or Community Planning & Development Manager/ designate change the individual's PARIS file status to "Deceased". Completing the status change enters and confirms the date of death in the "Additional Details" form in the Central Index.

## 6. PRACTICE

The *End-of-Life Guide: Information for CLBC Facilitators and Analysts* accompanies this policy to provide supplementary information related to the following practices.

6.1 Planning for future health care, including end-of-life care decisions, can be addressed well in advance of when an individual is deemed palliative by a physician and requires end-of-life care. The B.C. Ministry of Health describes "advance care planning" as a "process by which a capable adult talks over their beliefs, values and wishes for health care with their close family/friend(s) and a health care provider in advance of a time when they may be incapable of deciding for themselves". A person is considered capable of making their own health care decisions, including end-of-life health care, unless deemed incapable of making a specific health care decision by a health care provider or full decision making has been assigned by the court to a Committee of the Person (Personal Guardian).

"Advance care planning" needs should always be considered when an individual develops a serious or life threatening illness or has increasing complex care needs as they get older. A discussion about the need for "advance care planning" can occur as part of a review of an individual's increasing health needs due to aging or illness.

Facilitators may be involved in discussions about the need for "advance care planning" with an individual living in their family home, their family, and support network members. When the individual could benefit from "advanced care planning", facilitators can assist the individual and their family to initiate the process with a health care provider.

Analysts may be involved in discussions about the need for "advance care planning" with a directly-contracted home sharing provider and an individual. When the individual can benefit from "advanced care planning" and their family cannot assist them, support is provided by CLBC staff. Analysts involve facilitators in the planning process with the individual, their home share provider, and a health care provider.

**6.2** CLBC staff may provide planning support or assistance with service coordination to families, individuals and/or service providers who are involved in end-of-life care and service planning. Residential service providers or families are usually the primary point of contact for health care providers involved in end-of-life health care. Facilitators offer assistance to individuals and their families in situations where families can benefit from support. As outlined in this policy, analysts have additional responsibilities with directly-contracted home sharing providers. Analysts request facilitators to assist with end-of-life care planning and service coordination when additional support is required.

**6.3** Family members of an individual residing in a residential service, who is deemed palliative by a physician, should be notified that the individual has been deemed palliative unless the circumstances indicate that the individual does not wish to have contact with their family. A discussion can occur with the individual about how they would like their family to be informed.

**6.4** In situations where the service provider is uncertain about whether a death is considered unnatural, sudden and unexpected, unexplained or unattended, 911 should be immediately called who can then advise if the ambulance and local police need to respond. When a planned expected natural death occurs at home in accordance with the *Joint Protocol for Expected/Planned Home Deaths in British Columbia*, the ambulance and the police do not need to be called. The *Joint Protocol for Expected/Planned Home Deaths in British Columbia* states what must be done at time of death including who to call.

**6.5** Following a death, family members of an individual who resided in a CLBC-funded residential service are notified in a manner that is sensitive to their loss and reflects the type of relationship they have had with their deceased family member, the service provider, and CLBC staff. In situations where it is unclear if the residential service provider is the most appropriate person to notify the family and/or a legal decision maker, the facilitator and analyst can work together in a timely way with the residential service provider and health care professional (e.g., family doctor, nurse) to determine who should be responsible for notification and how it should be done.

**6.6** In individualized funding situations where the person who was authorized as the agent is a family member, it may be unrealistic and insensitive to expect them to complete a *Mortality Information Summary* form within 24 hours following the death. The analyst should complete the form to the best of their ability, based on the information that has been provided to them about the circumstances of the death. Additional information can be gathered at a later date, as needed.

**6.7** Information about community resources that provide bereavement support can be provided by health care providers, community agencies, or obtained by service providers. CLBC staff involvement is usually only limited to situations where facilitators provide community resource information to families as needed or where analysts provide community resource information to directly-contracted home sharing providers as needed.



**6.8** Family members and/or residential service providers usually assume responsibilities following the death of an individual that they cared for, such as making funeral arrangements. Service providers can work with families to determine who should take the lead in completing tasks. CLBC staff can provide resource information and support, as needed.

**6.9** Other CLBC-contracted service providers and government agencies (e.g. Ministry of Social Development and Social Inclusion) that have provided services to an individual and are not aware of their death, require notification. For individuals who were receiving CLBC-funded residential services, the analyst can work with the residential service provider and other CLBC staff (liaison analyst for other service providers) to ensure that all other CLBC-contracted service providers and government agencies that the individual was receiving services from have been informed.

## **7. REFERENCES**

### **CLBC:**

Critical Incidents Policy

Eligibility for CLBC Supports and Services Policy

End-of-Life Guide: Information for CLBC Facilitators and Analysts

End-of-Life Policy: Questions & Answers

Role of Formal and Informal Representatives Policy

### **B.C. Government References:**

A Provincial Framework for End-of-Life Care

Guidelines for Collaborative Service Delivery for Adults with Developmental Disabilities,

Appendix 9: End-of-Life Care for Adults with Developmental Disabilities

Joint Protocol for Expected/Planned Home Deaths in British Columbia

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

### **Legislation:**

B.C. Coroners Act

**APPENDIX ONE: END-OF-LIFE POLICY Procedures and Practice**

**APPENDIX TWO: LEGAL REPRESENTATIVES ROLES and RESPONSIBILITIES**