

Community, Seniors,
Addiction and Mental Health

Before and After an Expected Death in the Home

Information for families of Home Care patients
in a private home or seniors' lodge





©2018 Alberta Health Services, Concurrent Capable Practice Supports.

This work is licensed under a Creative Commons Attribution-Non-commercial-Share Alike 4.0 International license unless otherwise noted. The license does not apply to content for which the Alberta Health Services is not the copyright owner. This material is intended for general information only and is provided on an “as is,” “where is” basis. Although reasonable efforts were made to confirm the accuracy of the information, Alberta Health Services does not make any representation or warranty, express, implied or statutory, as to the accuracy, reliability, completeness, applicability or fitness for a particular purpose of such information.

Support You Can Expect

Preparing for an expected death at home of a family member or someone you know can be an emotional experience. You may not be sure about some of the changes you'll see in their final weeks or hours, or what you need to do after an expected death at home has occurred. The information in this booklet is intended to help guide you through the process of an expected death if you are caring for a child or adult with a life-limiting illness who is receiving home care services (from any team) while living in a private home or a seniors' lodge.

During this difficult time, you are not alone. The Alberta Health Services (AHS) Home Care team is available to help you and your family member throughout this process. They are also there to support you and your family member's healthcare needs and connect you with other healthcare providers and services as appropriate (e.g., the Emergency Medical Services Palliative and End-of-Life Care Assess Treat and Refer Program).

Medical Assistance in Dying is also one type of expected death at home. For additional information, talk to your healthcare team or visit ahs.ca/maid.

The end of this booklet also includes information about other resources that are available as you go through the different stages of preparing for and dealing with an expected death, including grief support.



Key Points

- The Advance Care Planning (ACP) process and the Expected Death in the Home form are important in preparing for an expected death at home.
- Just being present with the person is one of the best ways to offer them comfort and support.
- There are many normal and necessary changes the person may go through in their final days or weeks of life.
- Reach out to people that can support you, such as your Home Care case manager, family members and friends.
- Call the funeral home when you are ready. You **do not** need to call 911, police or ambulance after an expected death at home.
- Talk to your Home Care case manager for information and resources.

More information on these key points will be discussed throughout this booklet.



Preparing for Expected Death in the Home

Advance Care Planning

Advance Care Planning (ACP) is a way to help a person think and talk about and document their wishes for healthcare when they become incapable of consenting to, or refusing treatment or other care.

When a person has a life-limiting illness, it may bring them comfort and peace of mind that you, other family members and the healthcare team understand and respect the kind of medical and personal care they would like to receive. Their personal and medical decisions should be recorded on the proper forms. The forms with this information should be placed in a plastic Green Sleeve located on, or near the fridge that includes:

- completed Goals of Care Designation (GCD) Order
- their Personal Directive (PD)
- the Advance Care Planning (ACP) Goals of Care Tracking Record (where these conversations with healthcare providers are documented)

There is also a guidebook to support patients and families in having advance care planning conversations.

A **Goals of Care Designation (GCD)** is a medical order used to describe and communicate the general aim or focus of care including the preferred location of that care. The person preparing for an expected death at home should have a GCD Order (completed by a physician) that reflects their healthcare preferences. The order should be M1 or M2 (focus on medical interventions without resuscitation) or C1 or C2 (focus on comfort care). If there is no order or the GCD is R1, R2 or R3, (includes resuscitation), first responders may perform CPR if 911 is called before or after the expected death in the home.

A **Personal Directive** (PD) is the legal document in Alberta to appoint an alternate-decision maker (an 'agent') to make healthcare and personal decisions while someone is living but unable to make or communicate their own decisions. If the person preparing for a death at home has a PD, it's important to be aware of who they have selected as their agent as the agent would become responsible for making all the healthcare/personal decisions if the person loses capacity and the PD is enacted.

Talk to your Home Care case manager for more information about these resources or visit [conversationsmatter.ca](https://www.conversationsmatter.ca).

You should also be aware of the person's:

- will and legal contact information
- funeral home pre-arrangements
- cultural or spiritual rituals
- wish to donate their eyes or tissue (please talk to your Home Care case manager for information)
- wish to donate their body for scientific research

Expected Death in the Home form

Your Home Care case manager will work with you to complete the **Expected Death in the Home** form. This form includes steps to take and contact information that may be required for the family after an expected death has occurred. You may find it helpful to keep this information in one place. This also includes information for service providers (e.g., funeral home staff) that come to the home.

Communicable disease

If the person is known or suspected to be infected with a communicable disease, your Home Care case manager will tell you how to protect yourself and how to inform others before and after the death has occurred.

As a Person is Dying

No matter how much you prepare for this moment, the experience of caring for someone who is dying is different for every person and for every family. There are many things you can do to help:

- Being present is one of the best ways to offer the person comfort and support.
- Talking when the person wishes or just being silent. Silence is also a powerful way of connecting.
- Writing personal stories and memories in a notebook.
- Laughing together can reduce stress and bring you closer.
- Creating a soothing environment by using a low-intensity light, reading to them, or playing their favorite music.
- Touching them if they wish by giving them a hug, holding their hand or giving them a gentle massage so they are aware that you are by their side.
- Including special traditions or rituals that are meaningful.
- Remembering that although the person may not be responding, they may still be able to hear. Continue talking to them. Be aware of what you are saying when you are near them so that your conversation does not upset them.

Being a caregiver can be rewarding and challenging. It's also important to look after yourself by resting, eating properly, drinking plenty of fluids and asking for help from other family members, friends or your Home Care case manager.

What to expect as a person is dying

Over the last few days or weeks of the person's life you will see changes in them that are normal. You may not see all of the changes listed below and they may not happen in any particular order, but some of these changes include:

- longer sleeping periods
- less eating and drinking
- confusion and restlessness
- rate and depth of breathing may change
- irregular heartbeat
- changes in bowel or bladder control as well as the amount of urine produced
- changes in skin appearance (e.g., bluish grey or blotchy) and/or cooler skin temperature
- muscle twitching
- changes in eyes (e.g., may be more dry)
- elevated temperature

For more information about these changes visit:

myhealth.alberta.ca/palliative-care/resources/final-days

or talk to your Home Care case manager.



After Death

After an expected death at home has occurred, refer to the Expected Death in the Home form for steps to take and contact information. Call your Home Care case manager, palliative care nurse or after hours contact who can help you.

You do not need to call 911, police or ambulance.

If you call 911, Emergency Medical Services (EMS), police/Royal Canadian Mounted Police (RCMP) and/or other medical first responders may come to the home with lights and sirens and will follow the GCD Order in the Green Sleeve. If there is no GCD Order or the GCD is R1, R2 or R3 (including resuscitation) first responders may perform CPR. If the police or RCMP come to the home they may start an investigation into the cause of death. The Expected Death in the Home form would assist them in this investigation.



What you should do when an expected death has occurred at home

- Call your Home Care case manager or after hours contact to let them know of the death and ask for their support if needed.
- Call family members, friends, or your spiritual advisor if you would like someone to be with you.
- Spend as much time with the person who has died as you wish. Remember there is no need to rush. Take time to absorb the reality of the death and to say good-bye.
- Call the funeral home when you are ready. Do not feel that you need to call them immediately after a death has occurred.
- Friends and family who were not present at the time of death may want to see the person.

Give the first page of the Expected Death in the Home form to any service providers (e.g., funeral home staff or healthcare providers) that come into the home. It gives them information that will help them support you.

You may want to share the above information with others that may be in the home at the time of the person's death and ask them to follow these steps.



Resources

Below are additional resources and services that are available:

- AHS Provincial Palliative and End-of-Life Care website: myhealth.alberta.ca/palliative-care
 - AHS Advance Care Planning and Goals of Care Designation: conversationsmatter.ca
 - AHS EMS Palliative and End-of-life Care Assess, Treat and Refer: ahs.ca/info/Page14899.aspx
 - AHS Grief and Bereavement Information and Services: myhealth.alberta.ca/palliative-care/resources/grief-bereavement
- Canadian Virtual Hospice: www.virtualhospice.ca, includes:
 - LivingMyCulture.ca
 - MyGrief.ca
 - KidsGrief.ca
- *A Caregivers Guide: A Handbook About End-of-life Care* (Macmillan et al., 2010. The Canadian Hospice Palliative Care Association: Ottawa ON): www.hospicetoronto.ca/PDF/Acaregivershandbook_CHPCA.pdf
- *Saying Farewell Dying Process Guide* (Alberta Government): www.seniors-housing.alberta.ca/documents/Saying-Farewell-Dying-Process-Guide.pdf
- For 24/7 nurse advice and general health information, call Health Link at 811.

