

Guideline for Patient's Death in the Home Setting – Frequently Asked Questions



Palliative and End of Life Care

Note: This is a living document that will be updated and revised as needed.

Overall

1) What is the scope of this Guideline? Who does it apply to?

- This guideline applies to Provincial Continuing Care Home Care programs, and their health care providers such as:
 - AHS Home Care staff; regulated and unregulated, supporting expected or unexpected death of adult or pediatric patients receiving Home Care services in private homes or lodge.
 - Staff that are contracted by AHS Home Care to provide services in a private home or lodge (e.g., Vendors)
 - Palliative physicians that consider themselves members of medical staff and that are employed by the Home Care program.
- This guideline does not apply to:
 - Family Physicians as they are not employed by AHS Home Care
 - Note: the attending physician, usually the Family Physician, completes the Medical Certificate of Death
 - Staff that have been privately hired by a client or family to provide services or care in a client's home.
 - Staff or caregivers in a private congregate setting or seniors' lodge that are not AHS or AHS contracted health care providers (e.g., staff employed by the lodge). Lodge or Private Supportive Living Facilities may have their own policies and processes for their staff to adhere to when supporting expected/unexpected client death. In settings where there is a mix of AHS/contracted staff and private staff supporting staff, a collaborative approach to care and communication is expected.
 - Life-saving resuscitative actions required for someone who is alive are outside of the scope of this guideline
 - Medical Assistance in Dying events are not within the scope of this guideline

2) Does this Guideline apply to clients on self-managed care?

- Yes and No. Self-Managed Care clients receive Case Management services, and the AHS Case Manager is responsible for ensuring that they follow the elements of the Guideline that pertain to their practice (e.g., establishing ACP; assisting with care planning). However, since the client is privately hiring the employees, they do not follow under the applicability of this Guideline. Therefore, Self-Managed Care Case Managers will only be able to follow all Guideline elements when the death is expected, and may need to provide more in the way of education to the client and privately-hired caregiver on how to manage an unexpected death.

- 3) **Do AHS and Contracted Home Care (HC) staff have a responsibility to follow the policies and procedures of a facility they are working in (e.g., Lodge)?**
- The Patient Death in the Home Guideline has been approved by senior leadership within AHS, and is applicable to AHS Home Care staff and contractors providing care on behalf of AHS. Therefore, the policies and procedures of lodge or congregate setting would not apply to AHS Home Care staff and contractors providing care on behalf of AHS, but to the staff that the lodge or congregate setting employs.

Preparation for Expected Death

- 4) **What if I have questions re: Advance Care Planning/ Goals of Care Designation (ACP/ GCD)?**
- ACP GCD is a provincial policy that is required in all care settings in AHS. Visit www.conversationsmatter.ca for more information, including their policy and procedure (under information for health care providers).
- 5) **How does the Home Care Case Manager (HCCM) communicate the expected death at home and GCD order with the HC contracted health care provider?**
- The guideline states that “The HCCM shall inform members of the patient’s health care team (including contracted health care providers) in the private home or seniors’ lodge of the expected death at home and that the patient has a GCD order.”
 - The HCCM should put this information in the care plan, which is shared with HC contracted health care providers.
 - For patients residing in seniors’ lodges, when consent has been provided by the patient to share relevant health care information with the housing operator/ administrator, the HCCM shall also inform the housing operator/ administrator of the expected death at home and that the patient has a GCD order.
- 6) **Are we allowed to communicate expected death at home and GCD order with privately hired caregivers?**
- Only when consent has been provided by the patient and/or Alternate Decision maker to share relevant health care information with that caregiver.
- 7) **What is the Expected Death in the Home Form?**
- A form completed when a death in the home is expected but has not yet occurred.
 - Provides information for both service providers and family/ next of kin after an expected death at home has occurred.
 - Includes 2 pages – one for service providers (required) and another for family/ next of kin (optional)

- 8) Who completes the Expected Death in the Home Form?**
- Page 1 (Information for Service Providers) – completed by the HCCM after the patient and family/ next of kin agree to plan for an expected death at home
 - Page 2 (Information for Family/ Next of Kin) – optional; family completes, perhaps with HCCM
- 9) Who uses the Expected Death in the Home form?**
- Page 1 (Information for Service Providers) – funeral homes and other service providers that may come into the home after a death has occurred (EMS, police/ RCMP and/ or Office of the Chief Medical Examiner); provides them with necessary information to know that an expected death at home was planned for
 - Page 2 (Information for Family/ Next of Kin) – family/ next of kin use to determine and follow necessary steps to take after death
- 10) Where should the Expected Death in the Home Form be located?**
- Page 1 (Information for Service Providers) – white copy on home care chart; yellow copy in Green Sleeve
 - Page 2 (Information for Family/ Next of Kin) – patient/ family should place in the Green Sleeve
- 11) Is a GCD required to prepare for an expected death at home?**
- Goals of Care Designation orders of Medical Care (M) or Comfort Care (C) are in line with an expected death at home. However, a patient without a GCD is not excluded from planning an expected death at home. Use the ACP Tracking Record to document why a patient without a GCD is planning for an expected death at home.
- 12) What GCD is required to prepare for an expected death in the home?**
- Due to cultural, logistical and familial reasons, there are rare cases where a patient does not have a GCD, or has an R GCD, that is still accepting of planning for an expected death at home. Goals of Care Designation orders of Medical Care (M) or Comfort Care (C) are in line with an expected death at home. However, a patient without an M or C Goals of Care Designation is not excluded from planning an expected death at home – a patient with an R GCD may still plan for an expected death at home. Use the ACP Tracking Record to document why a patient without an M or C GCD is planning for an expected death at home.

- 13) What if someone doesn't want to have an M or C GCD but wants to have an expected death in the home?**
- Goals of Care Designation orders of Medical Care (M) or Comfort Care (C) are in line with an expected death at home. However, a patient without an M or C Goals of Care Designation is not excluded from planning an expected death at home. Use the ACP Tracking Record to document why a patient without an M or C GCD is planning for an expected death at home.
- 14) Where can I go for more information re: autopsy – if the patient/ family request it?**
- Information from the Office of the Chief Medical Examiner:
 - https://justice.alberta.ca/programs_services/fatality/ocme/Pages/DeathInvestigations.aspx
- 15) Eye and tissue donation need a time of death – how is this handled if it is an expected death and there is no formal pronouncement of death?**
- If not previously discussed with patient and family, eye/ tissue donation is part of the Expected Death in the Home Form discussion.
 - Ideally, the patient and family will have connected with the appropriate eye/ tissue donation program before the death has occurred. Please encourage patients and families to make this contact before an expected death at home. The eye/ tissue donation program can provide guidance regarding this issue.
 - Please emphasize the importance of noting the approximate time of death and need to call the eye/ tissue donation as soon as possible, as there are time requirements for such donations. The family needs to give the best estimate of time of death that they can.

Care After Death – Cardiopulmonary Resuscitation (CPR)

- 16) If the patient is dead, why is CPR being considered?**
- When Home Care health care providers encounter an unwitnessed patient death (patient has no breath and no pulse), decisions may need to be made about attempting resuscitation, as it is not always immediately apparent how long ago the patient died or if they may still benefit from resuscitation.
- 17) Which takes precedence – a Goals of Care Designation Order or a Personal Directive?**
- A GCD is a medical order that is referred to during a crisis when a patient cannot speak for themselves. If a health care provider encountered an unwitnessed death, they would follow the provincial ACP GCD Policy and look to the GCD for direction regarding medical care.
 - The GCD should be in alignment with a Personal Directive, if one exists.

- Personal Directives are not intended to provide medical direction during a crisis.
 - It would not be feasible in an emergency for a health care provider to locate a Personal Directive, see if it had been enacted, read it, contact the ADM and then ask them whether or not to provide CPR. In such a circumstance, this decision needs to be made more quickly based on the GCD order.
- 18) If there is no GCD order and there is a PD, and the PD specifically states no CPR, are we legally able to follow that request?**
- If the Personal Directive has been enacted and the ADM is present, the ADM would provide direction regarding whether or not the patient would prefer to receive CPR.
 - If a health care provider encountered an unwitnessed death, they would follow the provincial ACP GCD Policy and look to the GCD for direction regarding medical care.
 - If there is no GCD, and an ADM is not present, it would not be feasible in an emergency for a health care provider to locate a Personal Directive, read it, contact an ADM and then ask them whether or not to provide CPR. In such a circumstance, this decision needs to be made more quickly. Based on the absence of a GCD order, unless the patient meets criteria for withholding resuscitation, they would receive CPR.
- 19) What if I encounter a patient death where no GCD order is in the home, but ADM/ family state that they had discussion(s) re: GCD excluding CPR?**
- If you can confirm that the concerned individual is the legal alternate decision maker, follow their directions
 - If the concerned individual is another family member (not ADM)
 - Non regulated health care providers - call 911, start CPR
 - Registered Nurses only can get a verbal GCD order from a physician
 - Recorded as such on the GCD order and placed in Green Sleeve
 - That GCD order can then be followed and CPR would not be initiated
 - Physician then has to sign the GCD order
- 20) What if you aren't certified to provide CPR?**
- Even if you are not certified to provide CPR, health care providers may provide CPR with guidance from 911 dispatch
- 21) When deciding whether or not to provide CPR, and the patient has a non R1 GCD, what do I do if the family members want the patient to receive CPR?**
- Following the provincial ACP GCD policy, the GCD order reflects what is medically relevant for the patient, and patient preferences. Discussions should have been had with the patient and family members prior to the GCD order being written and before the patient death has occurred.

- Patient preferences, as expressed within a GCD order, are to be followed.
 - Clinicians can locate the GCD order and review it with concerned family members, emphasizing that it reflects the patient/ ADM's most current wishes as well as what is medically relevant for that patient.
- 22) When deciding whether or not to provide CPR, and the patient has a non R1 GCD, what do I do if the Alternate Decision Maker disagrees with the GCD order?**
- Following the provincial ACP GCD policy, the GCD order should be in line with patient (incl. ADM) preferences and a Personal Directive, if one exists.
 - If you can confirm that they are the legal ADM by checking an enacted Personal Directive, follow their instructions.
- 23) When deciding whether or not to provide CPR, what do I do if two family members disagree?**
- Follow the GCD order. The GCD order reflects the patient's wishes, and therefore, it supersedes family disagreements.
- 24) What if a patient has a GCD order excluding CPR, but they died from something other than their life limiting/ life threatening illness (such as trauma)?**
- Remember that in this scenario, the patient has died – they are not alive and still in medical distress. Therefore, follow the GCD order excluding CPR and do not provide CPR.
 - Regardless of GCD, while someone is alive and in medical distress, health care providers would provide appropriate medical interventions. However, after death has occurred, the GCD shall be honoured.

Care After Death – Calling 911/ Police/ Office of the Chief Medical Examiner (OCME)

- 25) How would I determine whether a patient died due to one of the reasons requiring police investigation? What if I'm not sure about the cause of death?**
- If you encounter an unwitnessed patient death, and the patient has a completed Expected Death in the Home Form or a C1 or C2 GCD, and there are no obvious signs that the death occurred due to a suspicious (e.g., violence) or traumatic (e.g., fall) reason:
 - You can assume in good faith that the death occurred as expected
 - Call the funeral home for transportation of the deceased person's body
 - If the death was later reviewed by the OCME and it was determined that it was a suspicious or traumatic death, the person(s) that caused that

- person's death would be held liable, and not the health care provider that called the funeral home for transport of the body
- If you encounter an unwitnessed patient death, and the patient does not have a completed Expected Death in the Home Form or a C1 or C2 GCD order:
 - Err on side of caution and call 911 for police investigation

Care After Death – Other

26) As an HC physician, where/ how do I obtain Medical Certificates of Death?

- Physicians may already have a copy/ copies in their office
- Physicians can order from Alberta Vital Statistics. For more information, please contact Vital Statistics by phone by dialing 310-0000 toll-free, followed by 780-427-7013 or by email at vs@gov.ab.ca
- in certain communities, you may also be able to obtain a copy from the local hospital and funeral homes

27) Can an attending physician (e.g., family physician) sign the Medical Certificate of Death if they have not attended/ seen the patient in the last 14 days?

- Yes, under some circumstances physicians can sign the Medical Certificate of Death if they have not seen the patient in the last 14 days.
- If the deceased person was palliative and being followed by palliative home care or a palliative nurse, the physician can note the date they last consulted with them as the date of last attendance.
- Nursing care acts on behalf and under the direction of the physician. OCME views date patient was “last seen” as the last time nursing staff or physician have seen the patient.
- This information is not formally part of the Fatality Inquiries Act or the Medical Certificate of Death. However, in discussion with OCME, they report having a realistic view that physicians can see all palliative patients within 14 days of their death. In line with this view, they provided the above information.

28) Which deaths do HCCMs need to inform their managers or designate on call at time of incident of?

- Those due to one or more of the following:
 - Reportable incident
 - An unanticipated or normally avoidable outcome that negatively affects a patient's health or quality of life and occurs in the course of health care or has the potential to alter the patient's health status (source: CCHSS 2016).
 - Criteria for a death that is the result of a reportable incident (source: CCHSS 2016) - a patient death caused by:
 - i. error or omission in the provision of Health Care;

- ii. error or omission in the provision of accommodation services;
 - iii. equipment malfunction or error in operation;
 - iv. accommodation grounds or equipment in disrepair or unsafe;
 - v. assault/aggression.
 - Notifiable death according to Fatality Inquiries Act
 - See Guideline for Patient's Death in the Home Care Setting or Fatality Inquiries Act for more information
 - Implications for media
 - Family concerns/ complaints
 - Threats to report to government
- 29) Which deaths would a manager need to inform a director of?**
- Those deaths with one or more of the following:
 - Implications for media
 - Family concerns/ complaints
 - Threats to report to government
 - Level 3 and 4 reportable incidents (defined on reportable incident report)
- 30) What do you do if you are aware that the patient has a communicable disease?**
- Before the death occurs
 - Document the presence of the communicable disease(s) in the health record;
 - If the patient is preparing for an expected death at home, also document the presence of the communicable disease(s) on the Expected Death in the Home form;
 - Provide information to the alternate decision maker (ADM) and/or family regarding infection control measures;
 - In case the expected death occurs with no health care provider present (and no health care provider would then arrive on scene afterwards), inform the family of the following:
 - Instruct the family/next of kin to inform the person(s) handling the deceased patient; and
 - Inform the family/next of kin that deceased patients who die while infected with a Schedule 1 or 2 communicable disease should not be removed from the room in which the expected death occurred unless the person handling the body is informed of the infection.
 - If a Home Care health care provider is present for a death or encounters an unwitnessed death
 - They would follow standard infection control measures as needed, including the use of Personal Protective Equipment, as necessary.
 - If the patient was known to be infected with Schedule 1 or 2 communicable disease:

- The health care provider shall inform all service providers (e.g., funeral home, police) that come into contact with the deceased person's body of the disease.
 - It is those other service providers' responsibility to handle the body in accordance with the Public Health Act.
- For patients with a Schedule 1 communicable disease, contact with the body is as limited as practically possible

31) How much info do you give police/ OCME from patient chart?

- If requested, Home Care health care providers shall assist the OCME, including the police or RCMP (who act on behalf of the OCME) with access to and copies of the patient's health record.
- If the whole health record is requested, the Home Care Manager (or designate) is responsible for arranging access and copy of the record.
- Note: A Medical Examiner appointed under the Fatality Inquiries Act is entitled to inspect and make copies of any diagnosis, record or information relating to a deceased patient.
- Health care providers are encouraged to consult AHS Information & Privacy department if they need guidance regarding: 1) whether they have an obligation to disclose patient information given the particular circumstances and 2) how much information to disclose.

32) What do you do if the deceased patient has an Implantable cardioverter defibrillator (ICD)?

- ICDs are usually turned off before an expected death.
- After death, the ICD won't send shocks anymore. The device works based on sensing a heartbeat; if there is no heartbeat, the device will not operate.
- If not turned off before a death occurs, the funeral home should handle turning off the ICD.
- If you are unsure of what to do, call your supervisor/ manager.

33) Who should staff contact if there is no family/ next of kin/ guardian?

- Many, but not all, funeral homes will accept a deceased person's body if that person has no family/ next of kin/ guardian.
- Some, but not all zones and cities/ towns have a list of such funeral homes. If you do not know whether or not your area has such a list, ask your supervisor/ manager. If you do have access to such a list, refer to that list and call funeral homes in a rotating order (so all those listed have an equal opportunity to be called).
- If you do not have access to such a list, call a local funeral home to ask if they will pick up the deceased person's body in this instance
- If that funeral home will not pick up the deceased person's body, call another funeral home (if there is one available)

- Contact your Manager for direction if you cannot locate a funeral home that will transport the deceased person's body.
 - This fact should be picked up on in previous discussions with the patient, and some preparatory work to pre-select an appropriate funeral home with the patient should be done.
- 34) Is formal pronouncement of expected deaths in a private home or seniors' lodge required?**
- There is no legislative requirement for pronouncement of expected deaths in these care settings.
- 35) Is formal pronouncement of unexpected deaths in a private home or seniors' lodge required?**
- There is no legislative requirement for pronouncement of unexpected deaths in these care settings. EMS/ police/ RCMP are called in these instances, and it would be their call as to whether or not pronouncement is necessary.
- 36) Is formal pronouncement of expected pediatric deaths in a private home required? Unexpected pediatric deaths?**
- As above, there is no legislative requirement for pronouncement of death.
 - Where a child who is under the guardianship or custody of the Director of Child, Youth, and Family Enhancement dies, that Director (not Home Care health care providers) must notify the Medical Examiner.
- 37) Are there any requirements for seniors' lodges to call police/ RCMP for all deaths?**
- There are no legal requirements for seniors' lodges to call police/ RCMP for every death that occurs at their sites.
 - Seniors' lodges may have policies or procedures directing them to call police/ RCMP for all deaths.
 - Seniors' lodges shall call police/ RCMP for notifiable deaths that require police investigation (see algorithm for health care professionals and section 5.1.c.ii on page 8 of the guideline)
- 38) Can the Home Care Case Manager fax the completed 1st page (for service providers) of the Expected Death in the Home Form to a funeral home before death has occurred (as a heads up)?**
- This is not the role of the Home Care Case Manager. The document belongs to the patient/ family. If desired, the patient/ family can send the Expected Death in the Home Form to the funeral home before an expected death has occurred.