Information and Resources Clinical Management of Patients Who are Expected to Die at Home

The Information and Resources document does not define, nor should it be interpreted as legal advice. It is not compulsory, unlike a Standard of Practice. The Information and Resources document is dynamic and may be edited or updated for clarity, new developments, or new resources at any time.

Preamble:

The patient and family who wish to plan for an expected death of the patient at home should receive appropriate educational materials and clinical care from the attending physician.

Purpose:

- To ensure that physicians are aware of the central role that they play and the responsibility that they carry in discussing an expected death at home in appropriate circumstances and in facilitating it when requested.

- To ensure that the wishes of patients choosing to die at home are respected and carried out by other parties involved in their care.

- To ensure continuity of care of the terminally ill and support for their care providers during the process of dying within the home environment and during transport to hospital or another facility for palliative or comfort care. Physicians should recognize that continuity of care is particularly important in the transition to an expected death at home and must make every effort to provide ongoing physician care, or to ensure that it is provided.

- To ensure effective communication among all relevant parties so that unintended interventions do not occur, and the patient can die with dignity at home and afterward be transported uneventfully to the destination specified by the funeral director or the lay funeral director or, in the case of tissue donation, to the location specified for that purpose.

Scope:

- This guideline applies to the care of patients who are living in a residential home.

Relevant Issues:

1. Coordination of Care and Arrangements for Expected Death at Home

In coordinating care and making arrangements for the patient's expected death at home, communication between family members, care providers, supporters and others involved in the arrangements after death is of paramount importance. Family members, care providers and supporters may have a wide range of interests, abilities, and resources to offer. There may be dynamics involving the patient's family members and supporters that create barriers to care of the patient. Community resources such as Home Care and Palliative Care serve a very useful purpose, but their involvement may add further complexity.

Some of the parties involved may have legal obligations and/or rights arising from their status as a health care proxy, next of kin, executor, etc. In other instances, the Public Trustee may either be involved, or need to be involved.

The physician should be a resource to all the parties noted above, not only in terms of clinical guidance and information, but often to provide comfort and support. This can be a complicated and challenging role. Clinical skill may be necessary to deal with interpersonal dynamics in these emotionally charged situations. The physician should have a basic understanding of the various roles and legal rights and obligations of the various parties involved. A brief description of some of the roles, rights and obligations of some of the parties that may be involved follows:

2. Anticipating and Preparing for Predictable Clinical Challenges in the Medical Care of the Terminally Ill Person Wishing to Die at Home

The patient with a progressive terminal illness can be expected to undergo a steady decline in functional status, often with a cognitive decline in the final phase. In endeavoring to support the patient and others involved in planning for an expected death at home, anticipating and preparing for specific challenges can often avoid the need for hospitalization.

A critical component of supporting the patient, family and care providers in such circumstances is open discussion about what to expect and what options exist to address challenges as they develop. Such discussion is usually best undertaken proactively, rather than by reacting to a crisis that has developed.

3. Acute Situation Management

Difficulty with symptom management may cause the patient discomfort that requires immediate intervention. The physician should provide clear direction to the *designated caregiver* regarding how to access medical and other relevant services during and after regular hours. Depending on the resources in the patient's community, the options to access required help might include:

- the physician - any physician covering must have access to sufficient information to provide appropriate care or, in the event that the patient has died, to complete the Medical Certificate of Death;

- Home Care or Palliative Care nurse;
- hospital or alternative care facility - the location of the hospital or alternative care facility to which the patient should be taken if medical intervention is required as well as instructions with respect to the nature of transportation should be provided to the *designated caregiver*. Implications of calling 911 or the local 7-digit access number should be discussed.

4. The Child as a Patient

Children should be involved in planning for the end of life in a manner appropriate to their level of understanding. The complex needs of the dying child and the family must be recognized.

5. Pronouncement of Death

The *designated caregiver* must be carefully instructed regarding the dying process and signs of death and the need to communicate to others in an appropriate manner that death has occurred. The task may be made more difficult because of physiological and anatomical changes that may be related to the dying process. Although there is no legal requirement relative to pronouncement of death, the physician should ensure that the *designated caregiver* and others understand to contact the physician or nurse involved in the patient's care if there is any doubt as to whether life has ceased**.** Those in attendance at the time of the patient's death may require support in what is almost always an emotional time. Issues with dying children are particularly complex and often require additional resources, including medical advice.

6. Contact with Funeral Director

Contact with a funeral director must be made prior to the death at home. Where possible, contact with the preferred funeral director should be made early in the planning process. The *designated caregiver* is usually the one responsible for ensuring that the funeral director is contacted following the death of the patient and ensuring that accidental notification of the EMS system does not occur.

7. Documentation

The following documentation will be of assistance to all parties involved in the arrangements for a patient wishing to plan for an expected death at home:

- **Patient Record** - prepared by the attending physician, clearly recording the patient's wish to die at home, together with all relevant information and copies of all documents for reference when the physician is not on call. The patient record should identify the *designated caregiver* by name and provide information on how to contact the *designated caregiver*.

- **End of Life Directive** - include an appropriate Health Care Directive that addresses end of life management such as the one provided on the Manitoba Health Living Will web page that can be found HERE.

- **Five Copies of Notification of Anticipated Death at Home and Direction from the Patient's Physician - Appendix C -** the Notification of Anticipated Death is to be used by the physician assisting in planning for an expected death at home. This notification is intended to have variety of functions:

    1. It acts to notify a funeral director that the patient's body will need to be transported from the home to the appropriate destination.
    2. It helps inform EMS providers of the situation in the event they are called. The notice serves to alert the responders to the presence of an end-of-life directive before attempting resuscitation.
    3. It advises the Office of the Chief Medical Examiner of the anticipated home death. It should be noted again that the completion of a *Notification of Anticipated Death at Home and Direction from the Patient's Physician* - Appendix C does not satisfy the legal requirement to notify the Office of the Chief Medical Examiner of any death occurring in circumstances listed in section 7(9) of **The Fatality Inquiries Act**. (See Appendix C)
    4. A copy is kept in the physician's patient record.
    5. A copy is provided to the dying individual/family to be placed in a prominent and accessible location in the home (e.g. in an envelope on or attached to the refrigerator).

    The *Notification of Anticipated Death at Home and Direction from the Patient's Physician* - Appendix C must clearly state who will complete the Medical Certificate of Death and how to locate that person to complete the Medical Certificate of Death.

Notes:

- The two-page document requiring completion after the death of an individual consists of a Registration of Death (top page) and the Certification of Death, commonly referred to as the Death Certificate (bottom page).

- Most of the Registration of Death (the "top page") is completed by the funeral home, but there is a section where someone signs that a patient has died, and when they have died. This is copied onto the Medical Certificate of Death (the "bottom page") and can be completed by one of several individuals. For example, in a hospital setting, a nurse who was at the bedside at the time of death might complete it. If the death occurs at home, family witnesses the death, and can usually provide a time. The funeral service picks up the body and can provide a date and time for that.

- The second page is the **Medical Certificate of Death.** The Medical Certificate of Death must state the cause of death and be completed by a physician or nurse practitioner, able to provide such information within the required 48 hours after death.

Definitions

Health care proxy - the person who has been appointed and given the power to make health care decisions on behalf of the patient in accordance with the terms of a heath care directive that has been executed by the patient pursuant to **The Health Care Directives Act**.

Next of kin or nearest relative - this term is defined differently for different purposes, but for most purposes in the context of an expected death at home, this person will be the patient's:

a) spouse; unless there is a common-law partner,
b) common-law partner;
c) if no spouse or common-law partner or that person is unavailable or is incompetent;
d) a child at least 18 years of age, or if no child or a child is unavailable;
e) a parent or legal guardian, or if none or that person is unavailable;
f) a sibling at least 18 years of age who is available.

When dealing with the issue of claiming a body under **The Anatomy Act**, and none of the above noted relatives are available, the legislation should be consulted for a complete ranking of preferred persons.

Common-law partner - defined as a person who is not married to the patient but has either cohabited with the patient in a conjugal relationship for at least one year, or is cohabiting with the patient and shares a child with the patient.

Executor - the person appointed by the patient in the patient's will to carry out the directions and requests in the will and to dispose of property according to the provisions of the will after the death of the patient. The executor has the obligation of disposing of the body of the deceased in a dignified and proper manner but is not required to do so in accordance with the expressed wishes of the deceased or the deceased's family.

Power of attorney - the person appointed by the patient as the patient's agent with authority to act on behalf of the patient as specified in the document appointing the person as power of attorney. The authority of a power of attorney is usually limited and is automatically revoked on the death of the patient.

Public Trustee - the official guardian in the province. Where a patient is a ward of the Public Trustee, a person other than an officer of the Public Trustee may be authorized in writing by the Public Trustee to give any consent that may be required for that patient's medical treatment.

Legal guardian - where the patient is not legally competent to manage the patient's own affairs due to defect of age, understanding or other disability, the legal guardian is the person who has been given the power and is charged with the duty of taking care of the patient and managing the patient's property and rights. In circumstances involving a child patient, the person will be someone other than the parent and will have been appointed by a court.

Funeral director - a person who owns, controls, operates or manages or is employed by a funeral home or chapel and who takes charge of a dead body for the purposes of burial, cremation or other disposition and holds a license to do so.

Lay funeral director - any person other than a funeral director who takes charge of a dead body for the purpose of burial, cremation, or other disposition.

Vital Statistics Agency - an agency of the provincial government that registers vital events in the province and provides certificates in relation to such events. The death of every person in the province must be registered in accordance with **The Vital Statistics Act**. The Agency requires the personal particulars of a deceased patient which are usually provided by a family member at the request of the funeral director. The attending physician must, within 48 hours of death, determine and document the cause of death and immediately thereafter deliver a Medical Certificate of Death to the Agency.

Office of the Chief Medical Examiner - certain deaths must be reported to the Office of the Chief Medical Examiner. All home deaths require prior notification of the OCME, as prescribed by the Chief Medical Examiner. There are some circumstances that require formal reporting at the time of the individual's death. Examples would be someone who was a child, or someone who died of a workplace injury or an accidental or deliberate overdose of medication, even if receiving palliative care with the goal of a home death, and even if the event occurred sometime previously. A complete listing of the circumstances in which a person with knowledge of a death must report the death to the Office of the Chief Medical Examiner is found in section 7(9) of **The Fatality Inquiries Act**. The list is attached as Appendix C. The medical examiner may request a medical certificate of death from the attending physician if the certificate is not furnished to the Vital Statistics Agency within 48 hours of the death.

Emergency Medical Services (EMS) - The EMS system will respond when contacted for people dying at home. Sometimes this may be a call at a time of panic. Sometimes the goal may be to transfer a patient to a facility. EMS personnel who attend at the scene may be obliged to commence resuscitation of the patient. Physicians should be aware of the role of these service providers and explain the implications of accessing any such service to the patient and those involved in the planning of an expected death at home.

Palliative Care Program - provincial program administered through Shared Health and Regional Service Delivery Organizations to provide comfort and support services to individuals and their families facing a terminal illness.

Home Care Program - provincial program administered through Shared Health and Regional Service Delivery Organizations. This community-based program provides in home supports to individuals who require health services or assistance with activities of daily living to enable them to remain in a community living setting. Services are arranged through Home Care case coordinators.

Designated caregiver - To ensure an expected death at home is managed well and with the least amount of additional stress to the parties involved, it is important for the physician to facilitate communication, cooperation, coordination, and delegation with respect to the many events that must occur. To this end, it may be helpful to have the patient and/or the family and/or other supporters identify a *designated caregiver*. Some of the agencies mentioned above may help in the selection of an appropriate person to act as the *designated caregiver*. It is most helpful if this person (or persons):

1. are familiar with the patient's needs;
2. will generally be accessible to others who might be involved with the patient;
3. will ideally have the support of the patient's family and friends;
4. can serve as the main point of contact for the physician, and in so doing facilitate communication between the physician and all involved supporters and/or care providers;

The designated caregiver should also be aware of end-of-life plans or documents that may have been executed and their location.

The designated caregiver may or may not have other roles, such as care provider, responsibility for funeral arrangements, or even be employed by an agency such as Home Care or Palliative Care Nursing. If not, the physician should encourage the *designated caregiver* to determine, with the family, who should fulfill these and other necessary roles.

The designated caregiver should be strongly encouraged to become aware of any involved parties who might have legal standing (e.g. executor) in order to effectively coordinate end of life care and after death arrangements.

Often, the identity of the person best suited to be the *designated caregiver* will be clear from the outset. If such is not the case, early in the planning process, the physician should consider urging the family, care providers or supporters to identify such an individual, or at minimum to identify a person to serve as the point of contact for the physician. Whether a designated caregiver has been identified or not, the physician will necessarily have to deal with numerous individuals as the need arises. This can be difficult, and it may be helpful to seek additional help from various community resources such as Home Care or Palliative Care.

APPENDIX A

Deaths that require an inquiry by reporting to a Medical Examiner from the Fatality Inquiries Act

Deaths that require an inquiry

7.1(1) An inquiry into a death is to be conducted under section 7.3 if it appears that the death occurred

(a) due to accident;

(b) by suicide or homicide;

(c) suddenly and unexpectedly when the deceased appeared to be in good health;

(d) due to poisoning;

(e) due to a contagious disease that is a threat to public health;

(f) during pregnancy, or following pregnancy in circumstances that might reasonably be related to pregnancy;

(g) in any of the following circumstances:

(i) during surgery or the performance of an invasive medical procedure,

(ii) within 10 days after surgery or the performance of an invasive medical procedure,

(iii) while the deceased was under anaesthesia;

(h) within 24 hours after the deceased attends at a hospital seeking admission;

(i) while the deceased is in the custody of a peace officer or as the result of the use of force by a peace officer who was acting in the course of duty;

(j) as the result of

(i) contracting a disease or condition,

(ii) sustaining an injury, or

(iii) exposure to a toxic substance,

at the deceased's current or former place of employment or business;

(k) while the deceased is a resident in a facility under *The Mental Health Act* or a developmental centre under *The Vulnerable Persons Living with a Mental Disability Act*;

(l) while the deceased is imprisoned or detained in a correctional facility, jail or penitentiary;

(m) when the deceased is a child;

(n) in a prescribed type or class of facility or institution; or

(o) in prescribed circumstances.

Interpretation: suicide and homicide

7.1(2) For the purpose of clause (1)(b), the terms "suicide" and "homicide" do not include a death that is a result of the provision of medical assistance in dying as defined in section 241.1 of the *Criminal Code* (Canada).

***Appendix B* and *Appendix C* located on the following pages may also be downloaded for your use here.**

APPENDIX B

END OF LIFE DIRECTIVE

(display prominently)

I, _____, do not want any resuscitative measures for
(insert patient's name)

_____.
(insert "myself", or name of child if for a child less than 16)

PATIENT INFORMATION:

Full Name: _____

Date of Birth (month in words): _____

Address: _____

City: _____ Prov _____ Postal Code _____

PATIENT'S SIGNATURE: _____
(if the patient is a child less than 16 years old, a parent or the legal guardian of the patient should sign; if the patient is otherwise not legally competent, the legal guardian or health care proxy should sign on the patient's behalf)

_____
(printed name, if signed by patient's parent, guardian or proxy)

WITNESS' SIGNATURE: _____
(witness must be 18 years of age or older)

Witness' printed name: _____

Date of patient's and witness' signature (month in words): _____

Name of attending physician: _____

Address: _____ **Phone #:** _____

Physician's signature (optional): _____

Date of physician's signature (month in words): _____

APPENDIX C

NOTIFICATION OF ANTICIPATED DEATH AT HOME AND DIRECTION FROM THE PATIENT'S PHYSICIAN

To: **Local or Regional EMS System:** _____

Funeral Director (name and address): _____

_____

Office of the Chief Medical Examiner _____

Or if in Rural area the RCMP _____

Physician's file _____

Prominent location in the patient's home _____

This notice is being sent to the recipients listed above in anticipation of the death at home of my patient. The personal particulars of my patient are as follows:

Given Names: _____ **Surname**: _____

Sex: _____ **Date of Birth** (month in words): _____

Address: _____ City _____ Prov _____ PC _____

Manitoba Health Number: _____

As attending physician, I or my designate will be responsible for completing the Medical Certificate of Death within the required 48 hours.

Printed Name of Physician: _____

Physician's Signature: _____

Address: _____ City _____ Prov _____ PC _____

Phone #: _____ **Fax #:** _____