THE COLLEGE OF PHYSICIANS & SURGEONS OF MANITOBA

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ARRANGEMENTS FOR EXPECTED DEATH AT HOME

When the College replaced the former Statements and Guidelines with the now enacted Bylaw 11, we removed the Guideline for an Expected Death at Home as it was very out of date, especially the clinical components. A working group is looking at pulling together current information for healthcare providers. In the meantime as there have been a number of inquiries we have again uploaded some of the information from the former Guideline, except for the clinical, until a new resource is available. Please be aware that this information is not current but will give you an idea of the forms and agencies to contact to assist you with an expected death at home.

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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. This guideline has been developed through the cooperation of the following participating agencies:

The College of Physicians and Surgeons of Manitoba
Winnipeg Regional Health Authority
Emergency Services Branch, Manitoba Health
Office of the Chief Medical Examiner, Province of Manitoba
Hospice & Palliative Care Manitoba
College of Registered Nurses of Manitoba
Manitoba Funeral Service Association
CancerCare Manitoba
Manitoba Vital Statistics Agency

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, both with respect to care prior to death and arrangements after death.

- 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 their own home and those living in a personal care home.

Relevant Issues:

1. <u>Coordination of Care and Arrangements for Expected Death at Home</u>

In coordinating care and making arrangements for the patient's expected death at home, communication between family members, care providers, supporters and other parties 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:

<u>Health care proxy</u> - 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 **<u>The Health Care Directives Act</u>**.

<u>Next of kin or nearest relative</u> - 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.

A common-law partner is 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. 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 claimants.

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. At common law, 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 licence 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, including the death of a child in any circumstance. A listing of the circumstances in which a person with knowledge of a death must report it to the Office of the Chief Medical Examiner is found in section 7(9) of **The Fatality Inquiries Act**. The medical examiner will 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) - when 911 or the local 7 digit access number is called, representatives from the local or regional EMS system will respond. Any such EMS personnel who attend on the scene may be obliged to commence resuscitation of the patient. Physicians should be aware of the role of the 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 the Regional Health Authorities to provide comfort and support services to individuals and their families facing a terminal illness.

Home Care Program - provincial program administered through the Regional Health Authorities. This community based program provides essential 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 that an expected death at home is managed well and with the least amount of additional stress to the parties involved, it will be 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*. This person (or persons):

1. must be familiar with the patient's needs;
2. be generally accessible to others who might be involved with the patient;
3. will ideally have the support of the patient's friends and relatives;
4. will serve as the point of contact for the physician, and in so doing facilitate communication between the physician and all involved supporters and/or care providers;
5. 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 *designated caregiver* will usually ensure someone is identified to fulfill these and other necessary roles;
6. should be familiar with or at least aware of any involved parties who might have legal standing (e.g. executor) in order to coordinate effectively end of life care and after death arrangements. The *designated caregiver* should also be aware of end of life plans or documents that may have been executed and their location.

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. In some instances this is not possible, and 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.

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. ~~Examples of issues to include in the discussion and other suggestions for clinical management of the care of a patient planning an expected death at home are included in Appendix C.~~

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* has instructed all concerned 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 help to achieve closure. Issues with dying children are particularly complex and often require additional resources. Medical advice is often required.

6. Contact with Funeral Director

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** - either in the form attached as Appendix A or included in an appropriate Health Care Directive that addresses end of life management.
- **5 Copies of Notification of Anticipated Death (Appendix B)** - Appendix B, 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:
    1. notify the funeral director that the patient's body will need to be transported from the home to the appropriate destination;
    2. inform EMS providers, in the event they are called. The notice may serve to alert the responders to look for an end of life directive before attempting resuscitation; and
    3. advise the Office of the Chief Medical Examiner of the anticipated home death. It should be noted that the completion of Appendix B 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**.

In addition to the three copies mentioned above, a copy of the Notification of Anticipated Death should be kept in the physician's file and in a prominent location in the home (e.g. in an envelope attached to the fridge or in a drawer in the bedside table).

- **Medical Certificate of Death - Part 2** - not to be confused with the Death Certificate, the Medical Certificate of Death must state the cause of death, and be completed by a physician able to provide such information within the required 48 hours after death. The Notification of Anticipated Death (Appendix B) must clearly state who will complete the Medical Certificate of Death and how to locate that person to complete the Medical Certificate of Death.

8. Resources

Physicians and their patients wishing to plan for an expected death at home may find the following local website useful:http://palliative.info

REFERENCES:

1. Bruera E, Miller L, McCallion J, Macmillan K, Krefting L, Hanson J. Cognitive failure in patients with terminal cancer: a prospective study. J. Pain Symptom Manage. 1992;7:192-95.
2. Reuben DB, Mor V. Dypsnea in terminally ill cancer patients. Chest 1986;89: 234-36.
3. Muers MF, Round CE. Palliation of symptoms in non-small cell lung cancer: a study by the Yorshire Regional Cancer Organization Thoracic Group. Thorax 1993;48:339-43.
4. Ahmedzai S. Palliation of Respiratory Symptoms, In : Doyle D. Hanks GWC, MacDonald N, editors. Oxford Textbook of Palliative Medicine, 2nd ed. Oxford: Oxford University Press; 1998 p. 583-616.
5. Davis CL. ABC of palliative care. Breathlessness, cough, and other respiratory problems. BMJ 1997;315:931-34.

APPENDIX A

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: _____

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 B

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

To: Local or Regional EMS System: _____

Funeral Director (insert name and address): _____

Office of the Chief Medical Examiner or the RCMP(if death occurs in a location where there is no Office of the Medical Examiner) _____

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: _____

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: _____

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

Printed Name of Physician's Designate: _____

Physician's Designate's Address: _____

Physician's Designate's Phone #: _____ **Fax #:** _____