

***CARING FOR YOUR  
LOVED ONE AT HOME***

**P.E.I. GUIDELINES FOR MANAGING  
THE EXPECTED HOME DEATH**

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## **Your Home Manual**

This Manual is for you, your family, and your other caregivers to use while you are registered with this Palliative Care Program and Home Care Nursing.

The intent is to help you by providing information and suggestions which will allow you to make sound choices throughout your illness.

The Manual will improve communication and planning around your care. Rather than explaining your situation to every new person, you will be able to refer them to the information already in this binder. Each caregiver will be able to quickly see what has been recommended or ordered for you, and the reasons for any changes that have been made. It will be easier for the whole “team” to work together.

We believe that the more information you and your family have, the better able you will be to decide what is important; what you need and what you want. Having these resources at your fingertips will allow you to make informed choices about your care.

This Manual has several Sections, the care planning and reference sections are identified by different coloured paper. You may find some Sections more interesting and useful to you than others; however, all the material is here for you and your family to look through. If you have any concerns or questions, please do not hesitate to discuss them with your Home Care nurse, Hospice volunteer, physician, or Spiritual caregiver.

## **Introduction:**

One of the most difficult decisions to be made during this time is how and where to provide care.

People often have concerns about the quality of care that can be provided in their home. Sometimes they believe that hospitals are the only place where sick people can receive good care. Other times it's because the family doesn't have the 'resources' they need; enough help, time, physical strength or energy. It could be that they're worried about carrying on for a long period of time. They may think they don't have enough space or the right equipment to set up a sick room.

Many thoughts and emotions may surface. So often people try to ignore death and dying or their own death, yet we all know it is one of the facts of life: we all, one day, will die.

These guidelines are offered to you because the disease/condition with which you are faced is a life-threatening one. Should your choice be to die at home, you and those close to you will need to make additional plans.

It is hoped this information will also encourage you to express your wishes about what you would like to have happen in the event you stop breathing or your heart stops beating. Take time to thoughtfully consider this information and discuss your health care treatment options with your health care professional(s) and family. The freedom to decide one's own destiny is the right of every capable person. This includes the right to accept or refuse health treatments. Many people want to choose their own health care and where they will be cared for because they have definite opinions on how they want to be treated.

The decision to die at home can be a difficult one. Remember to seek information and support from health professionals, trusted family members, friends and/or your spiritual caregiver.

The purpose of these guidelines is:

1. To offer information for the dying person and family in order to manage an expected home death.
2. To help in preparing for an expected home death.
3. To outline the roles and responsibilities of family, friends, health professionals, spiritual care, volunteers and Home Care staff who may be involved in the care and support.
4. To clarify important procedures that need to be considered and decided upon.

## I TERMINOLOGY

An **expected home death** is a situation where:

- an individual chooses to die at home;
- the death is expected and the death occurs in its anticipated sequence;
- the individual is under the direct care of a physician;
- there is no reason to believe that the deceased died under circumstances which requires notification of a Coroner, as per the Coroner's Act, 1988.

**Individual** in these guidelines refers to a person living with a life threatening illness and who is faced with an impending death.

**Family** in the context of these guidelines refers to those closest in knowledge, care and affection to the person. Specifically, it may include:

- family of origin: birth parent(s) and sibling(s);
- family of acquisition: relations by marriage or contract; those persons identified by you as "family";
- family of choice: anyone the person chooses to have closest to them.

**Palliative Care:** "Palliative Care is active, total care provided for a dying person and his or her significant others, living with a progressive, life threatening illness, when they have determined that the main objective of care is providing quality of life and support. Care is provided by a team approach for the dying person and family. Palliative Care neither hastens nor postpones death. It provides relief from pain and other distressing symptoms and includes the psychological, social and spiritual aspects of care. In addition, it offers a support system to help significant others cope during the individual's illness." (P.E.I. Home Care Support Framework Document, April 1996)

**Palliative Home Care Team:** may include the patient, physician, family, nurse, spiritual caregiver, hospice volunteers and others as defined and directed by the dying individual's wishes. The team approach offers supportive care for the dying person and the family.

**Health Care Directive:** There are three basic forms of health care directives - instructional directives, proxy directives (those which name a substitute decision-maker) and the combination of both instructional and proxy. A health care directive document is a document intended to govern the kind of treatment that a competent person will receive if she or he later becomes incompetent.

## **II STATEMENT OF PRINCIPLES**

Every individual has the right to choose to die at home. However, it may be necessary to include a short or long term admission to hospital or to a palliative care unit.

- Decision making for choosing to die at home should be a “shared” decision. It is important to consider what is in the best interest for the palliative patient and family.
- A Home Care palliative patient needs the supervision of his/her physician as well as the support of a palliative home care team.
- The Home Care palliative patient shall have his/her wishes respected regarding care and treatment. The patient’s wishes regarding no active resuscitation will be respected and understood by the completion of a Health Care Directive and/or a Do Not Resuscitate form (see Appendix for sample forms).  
This decision should involve the patient/family/physician(s), nursing, spiritual caregiver, hospice/support workers and others as needed or requested by family.
- The Home Care palliative patient will make choices and decisions regarding his/her treatment until it is determined that he/she is no longer capable. An appointed proxy or substitute decision maker will act on the patient’s behalf during times of incapability.

Expected home deaths are anticipated events and should be under the supervision of an attending physician.

- Police do not need to be called when a death is expected and occurs from natural causes;
- Ambulance services do not need to be called when a death is expected and occurs from natural causes;
- Pronouncement of death may be made by the attending physician (unless prearranged to be a Home Care Registered Nurse or a capable and willing adult designated by the physician).
- The Funeral Home may be called following pronouncement of death. A period of privacy with the deceased for the family should be respected.
- A coroner does not need to be called for an expected death from natural causes, unless there are concerns around the cause of death.

### III     **GUIDELINES**

#### **1.     PLANNING FOR DEATH AT HOME**

Every death is different. It can be a stressful time or one of relative calm.

When an individual chooses to die at home, additional plans are required. Preparation for a death at home can offer positive opportunities for the dying person and family. Specific areas that need to be discussed and considered include:

##### Individual and Family Planning

- Individual and family planning will help to ensure that you are prepared when death is near. It also helps others know what to do and how to manage added responsibilities.
- Discussions with family members and your physician regarding a care setting (eg. hospital or care unit or home) or treatment options (e.g. Health Care Directives);
- Make specific plans for care and support in the home (e.g. hospice, home care, etc.). Should you choose to have Hospice Care or Home Care service, it is best to call and plan for this early. This will allow for good care planning and for a strong relationship to become established.
- Discussions with health care professionals regarding what to expect as death draws near, and at the time of death;
- Making plans for what to do at the time of death;
- Selecting of a funeral home and finalizing related plans.

##### Plan of Care

- Providing good palliative home care requires attention to all details of care. Should you choose to die at home, you and your family may assume roles which may be very different from your usual relationships. It is important to have the support of a family physician and the support of a palliative home care team (see definition).

With good advance planning and sharing of the important/information, the dying persons needs are able to be met. Sometimes there must be commitment to work through changes as they arise. Not all situations can be totally pre-planned.

There are many resources that may assist you and your family in caring and managing an expected home death.

Other Considerations:

- Arrange ahead of time if you wish family, friends or spiritual caregiver to be with you during the last few days or hours.
- It is important to get your affairs into order whenever possible. If you make a will, and organize your legal and financial business, this will help family members take care of estate matters after death.  
It is important that you make out a will so that your family is not left with legal issues around the disbursement of your assets. Without a will, your family will have to apply to the Supreme Court of P.E.I. for the right to administer your estate. Your assets will then be determined by law rather than by your wishes.
- Discuss your wishes for any donation of organs with your family physician or Home Care nurse. There are a number of restrictions based on age and cause of death.
- For more information, check with your local Hospice or Home Care office.
- Prearranging your memorial or funeral service can avoid difficult decision-making and emotional stress for family members after your death. The first step is to make an appointment with a funeral director to complete your arrangements. It is helpful to attach a copy of your wishes to your will and give a copy to your family or executor/trix.

Points to Consider:

- Will there be a service?
- Will there be visitation/a wake?
- When will the service be held? > people coming from out-of-town  
> weekday or weekend
- What kind of service? > funeral  
> memorial  
> other
- Where will the service be held? > church, chapel  
> funeral facility  
> home, garden

- Who will facilitate?
  - > minister, rabbi, priest
  - > friend
  - > family members
  
- Burial or Cremation?
  - > If cremation, will remains be buried, scattered or placed in a columbarium?
  
- Other preferences should be arranged with the funeral director, a family member or clergy, e.g. music, readings, important rituals.

### Communication

- You may want to obtain additional information about what to do at the time of death from your family physician or health care professional;
- Begin discussions with your family physician regarding your wishes pertaining to care, particularly around resuscitative interventions;
- A Health Care Directive may be used to communicate your treatment wishes such as resuscitation. Should you choose to prepare a Health Care Directive, an original copy should be kept in your home and a copy carried with you if you are away from the home for any reason (e.g. hospital, travel, etc.);
- Your family physician should also be given a copy of your Health Care Directive and any specific treatment wishes;
- Home Care Nursing Services should receive a copy of the Health Care Directive for your health record file.

## **DEALING WITH PHYSICAL CHANGES - WHAT CAN I EXPECT?**

When people have progressive diseases, their bodies gradually change and become unable to function as they once did. These changes are normal and expected but can be frightening and upsetting if you are not prepared for them to happen. To make this time easier, we have included some information about the kinds of changes patients usually experience as their condition weakens.

Discuss what you observe with your family physician or Home Care nurse. This allows your care team to determine what is causing these symptoms and whether they need to be treated. Sometimes a simple adjustment of medication will be required to remedy the situation. Sometimes introducing a new medication that relaxes the patient will help to lessen any anxiety caused by these changes.

### **Decreasing Appetite**

This is a normal response for seriously ill people. The individual may feel less hungry and thirsty because they are less active and their bodies become unable to process food as they normally would.

It is understandably difficult to watch those you care for eat less than usual. However, it is wise to offer small portions of favourite foods or fluids, and encourage them to eat and drink only as much as they want.

### **You May Notice The Person:**

- Eats very little, is not interested in food or may feel unable to eat.
- Refuses solids and will only drink liquids.
- Loses weight.

### **Comfort Measures:**

- Give nourishing snacks, egg-nogs, soups, ice-cream.
- Serve very small portions of favourite foods that are soft and easy to eat.
- Make mealtime a social occasion.
- Freshen and clean the person's mouth before and after eating.
- If dentures are loose, have them relined or try polygrip.
- If nausea is a problem, tell your Home Care nurse or family physician. Anti-nausea medications can be very helpful.

## **Decreasing Strength:**

This usually occurs gradually over weeks and months, but it can also happen fairly quickly over a matter of days.

As the person gets weaker, you will need to change the way you do things. For example, using equipment such as a walker or wheelchair can provide greater safety and make care in your home easier.

## **You May Notice The Person:**

- Tires more easily and needs to nap often.
- Becomes weary or exhausted after activities that once were easy.
- Becomes short of breath with moving or talking.
- Needs help to walk, bathe, or dress.
- Feels anxious or frustrated by changes in energy and strength.
- Becomes extremely weak and may need to be cared for in bed.

## **Comfort Measures:**

- Ask your Home Care nurse to teach you how to help the patient move more easily.
- Give reassurance. Loss of independence can be upsetting for the person.
- Get a call bell or an intercom for the person to use when help is needed.
- Gently reinforce the need to limit activities and to rest beforehand.

*Talk to your Home Care Nurse about the aids and equipment that can make things easier and safer in your home.*

## **Skin Breakdown**

Sore areas or breaks in the skin can occur if the person has lost weight and has to be in bed for long periods of time.

## **You May Notice The Person:**

- Develops red, sore skin at pressure areas such as the tailbone, elbows, and heels.
- Has broken areas in the skin, itchy areas or rashes.

**Comfort Measures:**

- Change the person's position every four hours. Your Home Care nurse can teach you how to move the person safely and protect yourself as well.
- Use small pillows or padding (such as rolled up towels) to put between knees and to protect other areas from constant contact with bedding.
- Keep skin folds and creases clean by daily sponge baths. Dry thoroughly.
- Use bath oils and lotions to help dry or itchy skin.
- Put extra padding on the bed to cushion the person. Your Home Care nurse can advise you on choices and availability of items.
- Tell your Home Care nurse if you notice any reddened or open areas in the skin. There are a number of protective dressings that can be applied to sensitive skin or open areas that will reduce irritation and provide comfort.

**Changing Levels of Awareness**

Changes in mental functioning may coincide with changes in physical functioning over the course of a progressive illness. The person's ability to think clearly and to respond can be affected.

Sometimes people seem to be confused or to hallucinate. They experience a different reality from ours, often seeing or hearing people who are not physically present.

Changes may be due to a number of things. However, the most common reason for them is that the biochemical substances produced by the disease affect how the brain works. As death approaches, the ability to think and communicate weakens and eventually ceases.

**You May Notice The Person:**

- Becomes restless, excited or irritable at times for no apparent reason.
- Is easily distracted and is unable to follow simple directions, think clearly or communicate.
- Is unable to remember things or recognize familiar people or objects.

- Seems drowsy all the time and falls asleep even when you are talking.
- Is more difficult to arouse or waken.

### **Comfort Measures:**

- Sit quietly to provide a comforting presence.
- Reduce confusion by limiting distractions in the environment, e.g. T.V., radio, visitors.
- Gently bring the person back to reality with reminders about where they are, who you are, what time it is, etc.
- Do not argue if the person's reality is different. Sometimes going along with someone who seems mildly confused allows the situation to pass without upset.
- Quietly listen to the person, who may need to express some thoughts, worries or feelings. Get close, and talk gently.
- Use touch to connect with someone who is unable to respond. Soft music may be relaxing. Assume the person can hear everything on some level.

## **Death at Home**

### **As Death Approaches**

Changes at this stage will vary from person to person, and some of them may be quite disturbing for you. They are usually more difficult for you to watch than for the patient to experience. You may feel anxious, and may want a specific answer about how soon death is likely to occur. Precise predictions are often difficult, but you can expect time will be limited once oral intake or urine output stops, and once there are obvious changes in breathing patterns. The more you understand about what might happen and what you can do about it, the more you will feel able to handle your situation.

### **You May Notice The Person:**

- Is extremely weak.
- Has difficulty swallowing fluids and medications.
- Slips into a coma, which is a sleep-like state, and is unable to respond.
- Has decreased urinary control and output.
- Has irregular breathing with periods when breathing stops for 10 - 30 seconds.
- Has moist or rattling breath sounds.

- Has cool hands and feet which may also appear mottled or patchy in colour.

### **Comfort Measures:**

- Turn and position the person every 4 hours. Your Home Care nurse can instruct you on different moving and positioning techniques.
- If the person is unable to swallow, do not attempt to give fluids - this may cause choking.
- Continue to give pain medications every 4 hours until death. If the person is unable to swallow, these medications will need to be given by suppository or injection. Contact your Home Care nurse or family physician if oral medications are becoming difficult.
- Moisten the mouth with a wet cloth or mouth swabs (e.g. Moistir) and lubricate lips.
- Place protective pads or towelling under the patient's hips, and change when necessary.
- If the breathing sounds moist or 'rattling', medication is available that will ease this.
- Use bed coverings as usual. Even though the skin may feel cool, the person will not be feeling cold.
- Continue talking and touching to let the person know you are there.

### **The Moment of Death**

No matter how much we prepare, no matter what we expect, the moment of death will arrive in its own time and in its own way. The experience of dying is different for every person and for every family. It is important that you do whatever you feel will help during this final stage.

### **You May Notice:**

- There will be no response.
- There will be no breathing or pulse.
- There will be no movement.
- There will be no pain.
- The person's eyes may or may not remain open. Their jaw may be slack.

### **Comfort Measures:**

- Allow your tears and feelings to come.
- Breathe deeply.
- Be in physical contact with others; e.g. hug, hold hands, link arms.
- Gather around the person to send your blessings and love.
- Be with others, in silence or prayer.
- Take whatever time you need.
- Have a warming drink.
- Do whatever feels right for you.

### **AFTER DEATH HAS OCCURRED**

**It is not necessary to call 911, the police or the ambulance.**

The attending physician is responsible for pronouncement of death or may designate the Home Care nurse or a capable and willing adult.

If you have any concerns that an expected death may be unusual or unnatural, you should call the physician immediately.

Having a relative, family member, spiritual caregiver or friend may be very helpful for you at this time. You can take as much time as you need to say your good-byes. You may want to wash and dress the patient, or attend to any rituals that are important in your family.

You may gather family and friends around you, or simply want some quiet time alone.

The **funeral director** you have chosen can be called when you are ready. You may want to assist the funeral home attendants in some way; talk it over with them when they arrive to see what might work best for you.

Individuals and/or family are encouraged to make pre-arrangements with a funeral home for the removal and transportation of the deceased. Once the death has been pronounced, the funeral home may be contacted. There is no rush. You may wish to have some private time with your loved one before calling the funeral home. The funeral home will come to the home to pick up the deceased.

### **REGISTRATION OF DEATH**

The funeral home will obtain the signed Registration of Death and ensure that the Medical Certification of Death section is completed. The attending physician is required to sign the Registration of Death within 48 hours of the death.

## ADDITIONAL CONSIDERATIONS FOLLOWING DEATH

- 1) Contact spiritual caregiver (if desired) Phone: \_\_\_\_\_
- 2) Contact the funeral director during daytime hours to complete arrangements.  
**Funeral Director** \_\_\_\_\_ Phone: \_\_\_\_\_
- 3) Prepare a list of people to be notified. Ask someone to help you with the telephoning.  
**Telephone Helper:** \_\_\_\_\_ Phone: \_\_\_\_\_
- 4) Complete the Vital Statistics Guide on the page that follows and take it to your appointment with the funeral director.
- 5) Contact the Executor/trix of the Will and any lawyers involved.  
**Executor/trix** \_\_\_\_\_ Phone: \_\_\_\_\_  
**Co-executor/trix** \_\_\_\_\_ Phone: \_\_\_\_\_  
**Lawyer:** \_\_\_\_\_ Phone: \_\_\_\_\_
- 6) Notify Canada Pension, insurance companies and Motor Vehicle office. If appropriate, contact utility companies, landlord or mortgage company, land registry, etc. You will most likely require several copies of the Death Certificate to complete arrangements with them. Most benefits are not automatic and must be applied for.

**Bank:** \_\_\_\_\_ Phone: \_\_\_\_\_

**Landlord/mortgage company:** \_\_\_\_\_ Phone: \_\_\_\_\_

**Insurance company:** \_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_ Phone: \_\_\_\_\_

**Canada Pension Office:** \_\_\_\_\_ Phone: \_\_\_\_\_

You will need your own and the deceased Social Insurance Numbers

**Your S.I.N.** \_\_\_\_\_ **Deceased's S.I.N.** \_\_\_\_\_

**Union** \_\_\_\_\_ Phone: \_\_\_\_\_

**Military** \_\_\_\_\_ Phone: \_\_\_\_\_

- 7) Check memberships which have death benefits, e.g. Canadian Automobile Association, Credit Unions, fraternal orders.

\_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_ Phone: \_\_\_\_\_

## IV    **ROLES AND RESPONSIBILITIES**

The following sections provide information regarding your options for care, support of various members of the your palliative home care team and the funeral home.

### **Individual/Family Responsibility:**

- Discuss palliative home care and all possible care options (including a planned home death with or without short-term admission to palliative care unit or hospital) with family members and the family physician.
- Where appropriate, discuss and provide family/close friends/physician with the completion of a Health Care Directive, which includes specific instructions about treatment options (e.g. resuscitative interventions where this is requested . You may wish to complete and sign a Do Not Resuscitate (DNR) form (sample provided in Appendix).
- Participate in the development of a written care plan with the palliative home care team so that everyone is clear about what will happen and family/friends will know what to do as death approaches as well as at the time of death.
- Make pre-arrangements with a funeral home. Such pre-arrangements will normally involve selecting a funeral home and making plans with the funeral director for transportation of your loved one after death.
- Communicate the written care plan to family, friends, and others, such as a spiritual caregiver, so that they may support your decisions and ensure your wishes are respected.

The written care plan should include:

- *who* will pronounce death;
  - *how* the physician can be reached;
  - *what* alternate arrangements have been made should the family physician be unavailable or cannot be reached;
  - *which* funeral home will be called to transport the deceased.
  - comfort measures
- When death occurs, family members/palliative care team should follow the instructions recorded in the care plan.

## **Role of Health Care Professionals**

### **Role of Physician:**

- The attending physician will discuss palliative care option(s), including the option of dying at home;
- The attending physician will provide opportunity for you to discuss treatment/care wishes and any decision regarding resuscitative interventions;
- The attending physician may assist you in the completion of a Do Not Resuscitate form, if you so request.
- The attending physician will direct and supervise your palliative home care, which should include (regular) home visits. Make sure other family members know how to reach the attending physician by telephone.
- The attending physician may assist you to make an early referral to Home Care and/or Hospice for support and services.
- The physician will provide explanation to you about the anticipated physical changes of impending death.
- The attending physician will give family clear instructions on who will be called at the time of death for the pronouncement of death.
- The physician must complete Physician's Medical Certification of Death section of the Registration of Death form within 48 hours and submit to the Department of Health and Social Services, Vital Statistics Division.
- It is the physician's responsibility to inform the coroner and/or the police of the facts and circumstances relating to an unnatural death.
- If the physician finds it necessary to inform the coroner, the body shall remain undisturbed until the coroner otherwise authorizes it.

## **Role of Spiritual Caregiver**

Some families feel embarrassed when they call for spiritual guidance at the last minute to say a loved one is dying or has died. There may often be the feeling of having lost an opportunity to ease a burden through earlier visiting or support in this area. The following are suggested ways that your spiritual care giver may be involved as soon as possible in your family care plan.

If you wish, it can be helpful to involve your spiritual care giver as soon as possible in your home care plan.

- The spiritual caregiver will assist in the development of a plan of care by participating in discussions with you and your family and other health care professionals.
- The spiritual caregiver will recognize and honour the validity of your personal spiritual beliefs and experiences.
- The spiritual caregiver will discuss with you your wishes for spiritual care and respond appropriately. (ie. Do you wish to have the spiritual caregiver present at the time of death?)
- The spiritual caregiver will outline the spiritual care provided by your faith tradition, ie. visitation, sacraments, services, other rituals.
- The spiritual caregiver will be available to discuss your thoughts related to the end of life and the after death.
- The spiritual caregiver will assist you and your family in making funeral arrangements and planning religious observances following death.

### **Role of Home Care Staff:**

As part of your palliative home care team, the Home Care staff or Hospice volunteer will:

- Participate in discussions with you, family members and the attending physician. They will also assist in the development of a plan of care.
- Review the signs of impending death with family.
- Help ensure that family members understand instructions for what to do as death approaches and at the time of death.
- Confirm with the attending physician the arrangements for who will pronounce death and how/when family members are to initiate contact.

### **Role of the Hospice Volunteer:**

The goal of the volunteer is to provide emotional and spiritual comfort and support and also to help with small physical tasks such as running errands, making phone calls, writing letters, driving patients to appointments, etc. In short, volunteers do whatever they can to enhance the quality of the lives of patient and family and to lighten their burdens.

- They talk and they listen
- They allow the patient to express their feelings - fear, anger, love, hope, etc.
- They help and encourage the patient to pursue as many interests as the patient is able to.
- They comfort patients - brush hair, massage feet and legs, hold hands, etc.
- They play music, read or simply sit with the patient.
- They provide the family with some relief, rest or support.
- They talk, listen and liaise with the family - facilitate communication.
- They pray with the family or patient, if requested.

Following the death of a patient, the hospice volunteer remains in contact with the family during the bereavement for up to one year. This contact is important, especially for a surviving family member who has no other family members living nearby.

### **Role of Funeral Home Director/Staff:**

Advance planning can be most helpful for family members and friends who survive the deceased.

Within a short time following death, family and/or friends may be faced with calling the funeral home for transportation of the deceased and following through with arrangements for a service consistent with the spiritual beliefs of the deceased and the surviving family.

Funeral Directors welcome and encourage inquiries and personal interviews on the part of anyone desiring information on procedures or funeral costs.

### **Responsibilities of Funeral Home Director(s)/Staff**

The Funeral Home Director/staff will:

- Work with you and/or your family to make arrangements for transportation of the deceased, funeral services, and the preferred option for final burial.
- Respond to the call after death has occurred.
- Transport the deceased from the home after death has been pronounced and the family requests it.
- Obtain a copy of the Physician's Medical Certification of Death from the physician, within 48 hours after death has occurred.
- Complete the Registration of Death form and forward to the Vital Statistics Office, Dept. of Health & Social Services, P. O. Box 3000, 35 Douses Road, Montague, P.E.I. C0A 1R0.

## **V    GRIEF**

The section on Grief is to help you deal with the emotions you will experience after the death has occurred. In times of change and uncertainty, it is hard to know what to expect or what is normal. This information may help both you and others understand what is happening and what helps. There is also some information included on children's grief.

For more information on any of our programs, please telephone Island Hospice, Monday to Friday 10:00 a.m. to 2:00 p.m. at 368-4498.

The last section has a list of books which other bereaved people have found helpful.

### **Grief**

When someone important to you dies, your life changes forever and you need to grieve your losses. You will grieve the loss of their physical presence, your shared memories and responsibilities, and all the other things that connected you together. Grief is the process that helps you adjust to these changes in a way that lets you go on with your life.

You may have a wide range of reactions, you may find yourself feeling frightened and overwhelmed; this is quite normal.

You may be tempted to avoid the pain of your grief by not thinking about it, always being busy, or rushing into new relationships. However, the only way to really deal with your grief is to acknowledge, understand, and work through it.

When you are grieving, it helps to know what to expect. The following handouts offer some information about grief and suggestions on how to deal with it. Your experiences may not match everything listed here, but you will probably find a number of similarities. There is also information on children that will give you an introduction to how they grieve and what can help them.

It is important to grieve in your own way and in your own time. While you will get lots of well-intended advice, others can't fully understand your relationship with the person who has died or know how you need to grieve their death.

*Remember: talk about it; take care of your health; trust your intuitions and feelings.*

## **Potential Responses:**

### **To move from denial to acceptance that the loss really has occurred.**

Immediately following a death, there may be a sense of shock, numbness and disbelief that can last minutes or weeks. The person may feel panicked, overwhelmed and experience strong physical reactions. When there has been a lengthy illness, the griever may experience a sense of relief for the person who died and for themselves now that the stresses of caregiving are over. This period allows the person to take information in at a slower rate and to prepare for the adjustments that lie ahead.

### **To acknowledge, experience and work through feelings of hopelessness, yearning, and despair.**

Later, as the numbness wears off, the person may begin to feel the emotional pain of grieving. The intensity of this may surprise and frighten them, but the pain is healthy and can be resolved. The time required for this work will be affected by the quality of the person's support, other losses, preparation for the death, the nature of the relationship with the person who died and their general approach to life.

### **To adjust to a life without the person who died; To re-invest energy in new activities and relationships.**

As grief becomes more resolved, the person will have the energy and desire to re-connect with the world once again. Their loss begins to be seen in perspective and as part of the past.

## **Managing Grief & Loss**

Although there may be some similarities as to how individuals respond to or manage grief, we each will choose our particular path. Some of us may seek consolation and support through close friends and family, others may choose a busy demanding schedule, while others may choose a very private isolating process to heal or deal with grief and loss.

Grief and loss involve a wide range of feelings such as sorrow, painful loneliness, loss and sometimes abandonment, even anger, resentment and guilt. These responses and feelings are normal in all times of stress.

Do not hesitate to reach out to others and to voice your need for their support. Most of your close friends and family want to help and support you, but often feel awkward or do not know how to do so for you.

Having someone just listen, letting you express your feelings, fears and temperament or mood changes helps you work through this very difficult part of your life. This sharing process has helped lessen the pain of grieving and loss for many.

**Crying is a safety valve in times of stress.** Frequently we have been taught not to cry and we feel a need to apologize for crying, thinking we are not coping properly or strongly. In fact, crying can help you share and express your fears and sadness. There seems to be some extra strength that comes from that human connection of crying and sharing.

**Hope is a powerful force that can provide support and comfort** for us through times of stress and worry. You need never give up hope, even though the news is not good. Hope for your loved one may involve physical comfort, emotional calm and a peaceful death. You may treasure some private time together in order to say good-bye and share special memories.

Talking about your hopes and feelings with those who care about you and your loved one also helps them know how you are feeling and thinking.

**The ability to laugh is a great relief from tension.** Never feel guilty or too busy to have moments for light heartedness, a break or a “time out” to regenerate energy and decrease tension.

**Fresh air, taking short walks** can provide you, the caregiver, with some “time-out” to think, refresh, and take care of your own well-being in order to maintain your energy and ability to care and support.

## **Grief..... Emotions**

When someone important to you dies, you grieve. Whenever you have any kind of loss, you need to grieve its disappearance from your life.

Grief means you have many reactions in widely contrasting combinations. These are *healthy responses to loss* and are an important part of the “work” you do to deal with your grief and move on in your life.

You will be very aware of strong, often mixed emotions after a death or loss. These may come and go; like waves washing over you. The intensity of your emotions may be new for you, perhaps frightening or overwhelming.

Some of them may be like the emotions mentioned here, others may be different. You each move through your grief in your own way and at your own pace.

### **In the beginning...**

You may be in *shock*. You are bewildered, literally stunned. "I feel like a spectator in a play. But the drama is about me and the person I loved." You may feel numb all over, almost paralysed in a world of unreality.

You don't want to believe it. "It's a bad dream. When I wake up, I'll find it really didn't happen." *Denial* is when you secretly think or pretend your loved one will return and life will go on as before. It is so strange. You feel as if the death has not really occurred, even though you know it has. Many people need time before they can face the harsh truth. It is so hard to realize that in your lifetime you will never see or touch the person again.

*Panic* may set in. "What will happen to me?" "I'll never make it alone." "Why can't I get hold of myself?" You feel like you are losing control, panicking over things you used to do with confidence. "If only I could run away, somewhere, anywhere!"

### **Later...**

Emotional pain often brings *physical distress*. For example, inside your chest you may feel a sharp pain, as if a jagged rock is pressed against your ribs. You collapse, exhausted, into bed but cannot sleep. Food may have little taste for you. You eat only because you think you should. Or else, you just cannot stop eating. Your stomach may be tied in knots. Your back may be hurting. The pain is not imagined, it is real. Your body is feeling your emotional loss.

Many people become *angry* when someone close to them dies. "Why me?" "Why my beloved?" "What did I do to deserve this?" Hostility is one of the most difficult emotions to handle. Many of us are taught as children that anger is an unacceptable feeling and we learn to hold it inside from a very early age. But feelings of rage do not magically go away.

Expressing your anger helps you to release your anguish and your frustrations. A life that is so precious to you has been taken away and there is nothing you can do about it. Resentment is a normal part of the grief process.

You may feel *guilty* or angry with yourself. You keep asking yourself: “If only I had spent more time with my beloved, if only I had been more understanding, if only I had called the doctor sooner, if only I had done this, if only I had done that...”

Know that this is a common feeling that may soften when you are able to remember what you did achieve. Remember that this is now in the past and guilt will not bring the dead person back to you.

Guilt may result in *depression*. You may feel alone, naked, unprotected. There could be a sickening feeling of going down, down, down. You may feel overwhelmed and drained. “Nothing matters any more. Nothing. Life will never be worth living...Am I crazy?”

Of course not, but give yourself time... time to be hurt, to grieve, to cry, to scream, to “be crazy.”

### **Finally...**

Your emotions will become less intense, less overwhelming and more hopeful. As you are ready, you will begin to reinvest your energy in the outside world and will start to feel like a “normal” human being again.

### **Grief.....Looking After Your Health**

When you are grieving, it is important to look after your physical, as well as emotional, well-being. This is often forgotten or ignored when you are under stress and can have a great influence on your emotional healing after a major loss.

Both your eating and sleeping patterns may change, as well as your general health. The following information is intended to help you find ways to take care of your physical health while you are grieving. Remember, everyone’s needs are different.

## Sleep

### Reactions

Your sleep patterns will probably change during grief. While most people have trouble sleeping, some do sleep more. Dreams and nightmares are also part of the grieving process, a way of working through concerns and feelings.

### Suggestions:

- Go to bed and get up at the same time every day, even on weekends. Only use your bedroom for sleeping at night; nap elsewhere.
- Keep the room temperature warm, rather than hot or cold.
- Drink only herbal teas or decaffeinated beverages for at least five hours before bed-time. Soft drinks, coffee, tea, cocoa, chocolate, and anacin all contain caffeine.
- Exercise daily, but not close to bedtime.
- Even though alcohol, cigarettes and heavy meals may make you feel sleepy, they can cause insomnia. Once they are out of your system, you wake up.
- Sleeping pills can be used occasionally to help break the pattern, but remember your insomnia will pass.
- Discuss any anxieties with an understanding friend or family member or write them down in a journal. Counselling will help you deal with ongoing grief difficulties.
- Don't keep busy right up to bedtime, take 30 minutes to prepare and unwind. Hot milk contains an amino acid that helps induce sleep. A warm bath can be soothing. Reading a 'light' book can give you something else to think about. Relaxation exercises or listening to gentle music also helps prepare you for sleep; watching television in bed will not.
- A prime cause of insomnia is the fear that you won't get to sleep; tell yourself you will have a good, restful sleep.
- Try curling up with a pillow or soft stuffed animal, lie on your side with a pillow behind your back, use earplugs or a pillow over your exposed ear to block out sounds.
- Don't try to force sleep. Use mind games (count sheep, recall a pleasant time, plan a trip, plot a novel). If unsuccessful after 30 minutes, get up and do something pleasant and relaxing.
- If the bedroom has too many memories, sleep temporarily in another room, rearrange furniture or redecorate, sleep on your partner's side of the bed.

## Eating

### Reactions

Your appetite and eating patterns may change during grief. You could have no appetite at all or could be constantly hungry. Food may be tasteless. Mealtimes can be difficult: the 'empty chair' reminds you that the person is no longer here, enjoying food without them leaves you feeling guilty, etc.

Poor nutrition can result in headaches, digestive problems, feeling fatigued or rundown.

### Suggestions

- If eating alone is difficult, try changing where you eat or where you sit at the table. Do not choose this time to go on a diet, but do pay close attention to what you eat and drink.
- Breakfast is important because it produces the energy you need to face the day's tasks. Good breakfast foods are high in protein and low in sugar - milk, yogurt, whole grain cereal, breads, lean meat, eggs.
- While protein enhances your energy and concentration level, high sugar intake causes fatigue and too many fatty foods can create serious health problems.
  - Limit fatty meats and eat more chicken and fish.
  - Use 2% or skim milk, margarine and polyunsaturated oils.
  - Use low fat cooking methods (steaming, broiling and poaching).
  - Eat vegetables, fruit, breads, rather than candy or baked goods.
  - Choose packaged and restaurant foods carefully, as they can be high in fat and sugar.
- Keep healthy snacks available, especially if you find yourself eating a lot. Try the following foods:

- dried or fresh fruits	- popcorn
- fig newtons	- granola
- orange juice	- fresh vegetables

## General Health

### Reactions

You will have several different physical reactions to grief and it is important to understand what is happening. You are also *high risk* for illness, so have regular check-ups and consult your physician about any problems.

### Suggestions

- Be careful about driving; poor concentration and 'blinking out' can make it hazardous.
- Poor nutrition leaves you susceptible to disease, as well as weakened bone and muscle strength.
- Poor energy is to be expected. Give yourself permission to slow down and let go of some responsibilities for a time.
- Regular exercise is essential; even a walk around the block helps.
- Be careful with drugs and alcohol. Grief is not treated with medications, as they tend to mask rather than deal with the pain. Alcohol is a depressant.
- Palpitations, digestive problems, chest pains, shortness of breath may be experienced and it is important to contact your doctor should any of these symptoms occur.
- Remember, grief affects all of you and it is important to take care of your body, as well as your mind.

## **Children's Grief... Introduction**

Children grieve differently than adults. Their understanding of and ability to deal with death is determined by their age, development and the intensity of the experience. Children tend to grieve off and on, rather than continuously all the time. They often express their thoughts and feelings through their behaviour rather than in words. As they grow older and are able to understand death in new ways, children need to grieve a death or loss again and again.

### **How children deal with their grief will depend on a number of things:**

- Developmental level, age, gender.
- General life experiences, as well as other losses.
- Individual personality and coping style.
- Family attitudes about death and grief.
- Cultural background and home environment.
- Family communication.
- Grieving styles of the adults around them.
- Availability of support.
- Relationship with the person who died (as seen by the child)
- The kind of death; e.g. sudden, lengthy, expected, peaceful.
- The preparation for the death; e.g. having clear information, enough time for grieving and being included in plans and events.

Children are certainly aware of death. Listen to their songs and nursery rhymes. Watch the games they play, read their comic books or watch Saturday morning cartoons and you will realize how often children are exposed to death. Unfortunately, the portrayal of death is often based on fantasy rather than fact and this may be very confusing for children. For example, actors die in one show and reappear in another; death scenes are rarely true to life.

Children have different ideas about death at the different ages and stages of their development. Each stage builds on the one before, making it important to give children more information and opportunities to learn about death as they get older.

Remember, guidelines are just that; children are individuals and their ability to understand and grieve this death will vary from one to another.

## **Children's Concept of Death\***

Children should be allowed to share in grief and attend the funeral, wake, etc., but only if they want to. They might feel angry at being abandoned, scared of being alone, confused, or guilty that they might have caused the death. You can help by answering questions honestly, helping them to express emotions and reassuring them that it is okay, and being patient if they bring up the subject of death again and again. It is a good idea to prepare children before a loved one dies. Talk about the subject naturally.

## **Children's Grief... Ways to Help**

### **Be calm.**

- Crying is fine, hysterics are frightening.

### **Explain the situation clearly in language they'll understand.**

- Give simple, honest explanations about the death.
- Use words like 'dead' or 'buried' rather than 'passed away' or 'interred'.

### **Sit down and really listen to their questions and fears.**

- Physical touch may also be comforting.
- Don't assume you know what they mean or want to know.... ask.

### **Don't overprotect or try to make it better.**

- Allow them to experience sad feelings.

### **Set the stage for ongoing discussions about the person who died, the death itself, feelings, changes, etc.**

- Give only the amount of information children can handle.
- Be prepared to go over things many times.

### **Explain what will happen now; e.g. viewing, funeral, cremation.**

- Include children in planning and activities as much as possible.
- Allow them to decide how/if they want to be involved.

### **Give some information about grief and what they may expect.**

- Let children see you grieve so they know it's alright.

\* Island Hospice Association Volunteer Training Manual, Feb. 1999, page 63

**Keep to your routine and avoid changes as much as possible.**

- Bed times and chores.
- Return to activities and school as children are ready.

**Encourage remembering, rituals and traditions.**

- Don't avoid special family events but plan ways to deal with them.
- Do some of your remembering out loud.

## VI

### **Care Planning/Journal Section Guidelines for Managing the Care of a Dying Person at Home**

#### **Purpose:**

This next section is intended for your personal notes and reference.

There are several items included here that you may or may not need or want to use. However, samples are provided for your information or discussion purposes.

In addition, there are sections to record telephone numbers, contact names, questions, or record observations for health professional updates.

#### Outline

**Section I** Family Support Information

- Providing Basic In-Home Caring
- Safety and Comfort Considerations

**Section II** Contact names, Telephone numbers

**Section III** Patient and Family Journal

**Section IV** Instructions for Care

**Appendix** Sample forms - Health Care Directives  
- Do Not Resuscitate  
Definition of Terms  
Reading List  
Resource/Reading Reference List

## Section I

### Providing Basic In-Home Caring

**Everyday, basic activities** must go on. Maintaining a regular schedule, including meals, is a very important aspect for both the palliative care patient and the caregivers and family involved.

**Hand and foot massages can be comforting** for both caregiver and the patient. A mildly scented or favorite lotion can help add relaxation and peace for some. For some, a nail manicure and polish can provide a real emotional lift.

**In-home hairdressing** services can be available and also help brighten the person and others who care or visit.

Ask the **Home Care nurses to teach you how to do mouth care** for your loved one. This is easy to do and is very refreshing for a sick person.

**Tapes of favorite music, radio or t.v. shows** can be arranged to brighten up a quiet day. Also, **tapes from family or friends away** can be comforting for you and your loved one and can be replayed and enjoyed.

**Listening to, remembering and encouraging** your loved one is powerful communication at a time of illness, palliation, or near death. Sharing silence, reading old or recent letters helps put the right words together for some.

**Touch is a powerful way of saying “I’m here”**. It communicates caring and strength. Touch can be hands on care, massage, a hug, holding a loved ones hand or arm while sitting quietly, or stroking hair or face gently.

When planning for a loved one to receive palliative care or to die at home, consider with that person **where to place the bed**. Some people like to see outdoors, others like to be close to activity, while others prefer quiet and privacy.

**Alcohol should be used in moderation** at this time. Although it may seem to help us relax, alcohol can also exaggerate feelings of sadness, grief and loss of control.

**Periods of proper rest and sleep is essential** for a caregiver to maintain personal energy and wellbeing. If you are having trouble sleeping, speak to your family doctor for suggestions. Also, a few minutes in a warm bath, a warm drink such as milk, hot chocolate, ovaltine, etc. can help relax and encourage sleep.

**An answering machine or a “telephone person”** can assist you to deal with an increased number of well-meaning friends calling in the evening or at a very busy or low time of your day. A “fan-out” system shared by family members can keep others informed about day-to-day progress or changes in your loved ones condition.

## **Safety and Comfort Considerations**

This page relates to noting issues regarding comfort and safety when planning and supporting a death at home.

### **Fire Prevention & Safety**

- 1) Sometimes additional electrical equipment will require specific safety precautions, e.g. heavy duty grounded extension cords.
- 2) The Fire Department in your community will provide an on-site safety check visit if requested.
- 3) When an individual may be drowsy due to medication, or less able to manage to smoke independently, smoking in bed is very dangerous and must be carefully monitored.
- 4) A communication plan with your Fire Department to provide awareness of special circumstances in your home in the event that a call for assistance or fire should occur.
- 5) The use of electric blankets and/or heating pads are not advised for use for dying patients. Spills, dampness or sitting on the blankets can cause hot spots, cracks and there is a real possibility of causing a skin burn or irritation.













## Acknowledgements

The P.E.I. Palliative Care Task Group 1998/99 (for the Management of Home Deaths) would like to acknowledge that in the process of developing policy and the associated guidelines for Home Care to Hospice/Palliative care, much has been learned from other provinces.

In particular, information and documents were reviewed from the following jurisdictions:

1. British Columbia: Ministry of Health, Ministry Responsible for Seniors, Joint Protocol for the Management of Planned Home Deaths, February 1996.
2. Calgary, Alberta: Tom Baker's Cancer Centre, Dept. of Nursing, Community Resources Manual, Expected Death in the Home, October 1996
3. New Brunswick Extra Mural Hospital, Patient Care Manual - Death in the Home, Patient Death - Expected.
4. Saskatchewan Health, Community Care Branch, Policy on Pronouncement of Death.
5. P.E.I. Vital Statistics - Draft Registration of Death & Burial Permit - outline of process.
6. Capital Regions Health of Victoria, B.C., Policy & Procedures - Pronouncement of Death in the Home by CRD Home Care Nurses, February 1997.
7. Victoria Hospice Society, Victoria, B.C.
8. Nova Scotia Department of Health, Home Care Nova Scotia  
*Draft* - Physician DNR Order Form  
*Draft* - Do Not Resuscitate (DNR) Form
9. Maine Emergency Medical Services, Physician Instruction for Maine EMS Comfort Care/DNR Program, Background, Instructions, 1994.

# **APPENDIX**



## Personal Health Care Chart

Write your choice in the space provided below each section. Please date, sign and obtain signatures of your proxies and physician.

If my condition is <b>Reversible</b>			If my condition is <b>Irreversible</b>		
<b>Life Threatening Illness</b>	<b>Cardiac Arrest</b>	<b>Feeding</b>	<b>Life Threatening Illness</b>	<b>Cardiac Arrest</b>	<b>Feeding</b>
Palliative Limited Surgical Intensive	No CPR CPR	Basic Supplemental Intravenous Tube	Palliative Limited Surgical Intensive	No CPR CPR	Basic Supplemental Intravenous Tube
Date: _____		Name: _____		Proxy # 1: _____	
				Proxy # 2: _____	
				Physician: _____	
<b>Date of next review should be once a year, after an illness, or if there is any change in health.</b>					
Date: _____		Name: _____		Proxy # 1: _____	
				Proxy # 2: _____	
				Physician: _____	
Date: _____		Name: _____		Proxy # 1: _____	
				Proxy # 2: _____	
				Physician: _____	

### PERSONAL STATEMENT

I would consider an irreversible condition to be any condition

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I would agree to the following procedures: (Write YES or NO)

Post Mortem: \_\_\_\_\_ Blood Transfusion: \_\_\_\_\_

Cremation: \_\_\_\_\_ Organ Donation: \_\_\_\_\_

## DEFINITION OF TERMS USED IN THIS DIRECTIVE

**Reversible Condition:** Condition that may be cured without any remaining disability; e.g. pneumonia, bleeding ulcers.

**Irreversible Condition:** Condition that will leave lasting disabilities; e.g. multiple sclerosis, stroke, severe head injury, Alzheimer's disease.

**Proxy:** A person who acts for another in health care decision making, also called a Patient Advocate, Health Care Advocate or Medical Agent in different states and provinces.

### Feeding

**Basic Feeding:** Spoon feed with regular diet. Give all fluids by mouth that can be tolerated, but make no attempt to feed by special diets, intravenous fluids or tubes.

**Supplemental:** Give supplements or special diets, for example, high calorie, fat or protein supplements.

**Intravenous:** Give nutrients (water, salt, carbohydrate, protein and fat) by intravenous infusions.

**Tubes:** Use tube feeding. There are two main types:

**Nasogastric Tube:** a soft plastic tube passed through the nose or mouth into the stomach.

**Gastrostomy Tube:** a soft plastic tube passed directly into stomach through the skin over the abdomen.

### Cardiac Arrest (CPR)

**No CPR:** Make no attempt to resuscitate.

**CPR:** Use cardiac massage with mouth-to-mouth breathing; may also include intravenous lines, electric shocks to the heart (defibrillators), tubes in throat to lungs (endotracheal tubes).

### **Palliative Care**

- keep me warm, dry, and pain free
- do not transfer to hospital unless absolutely necessary
- only give measures that enhance comfort or minimize pain, e.g. Morphine for pain
- intravenous line started only if it improves comfort; e.g. for dehydration
- no x-rays, blood tests or antibiotics unless they are given to improve comfort

### **Limited Care (includes Palliative)**

- may or may not transfer to hospital
- intravenous therapy may be appropriate
- antibiotics should be used sparingly
- a trial of appropriate drugs may be used
- no invasive procedures; e.g. surgery
- do not transfer to Intensive Care Unit

### **Surgical Care (includes Limited)**

- transfer to acute care hospital (where patient may be evaluated)
- emergency surgery if necessary
- do not admit to Intensive Care Unit
- do not ventilate (except during and after surgery); i.e. tube down throat and connected with machine

### **Intensive Care (includes Surgical)**

- transfer to acute care hospital without hesitation
- admit to Intensive Care Unit if necessary
- ventilate patient if necessary
- insert central line; i.e. main arteries for fluids when other veins collapse
- provide surgery, biopsies, all life-support systems and transplant surgery
- do everything possible to maintain life

## DO NOT RESUSCITATE

Patients who know they have a terminal illness or who are considered at the natural end of their lives can request beforehand that no active resuscitation be started on their behalf if they are dying. This should be done after discussions with their doctor. "No active resuscitation" is defined as no cardiopulmonary resuscitation in the event of a respiratory and/or cardiac arrest.

This form is provided to you and/or your next of kin by your doctor to allow you to clearly state that you do not want active resuscitation to be given to you in circumstances where you can no longer make the decision for yourself. It instructs people such as ambulance attendants and emergency room personnel not to start active resuscitation on your behalf whether you are at home, in the community, or in a long term care facility. The personal information collected on this form assists the health professionals noted above to carry out your wishes. If you have any questions about the collection of this information contact the Director, Acute Care Division, P. O. Box 2000, 16 Garfield St. Charlottetown, P.E.I. Phone: 368-6132

If you change your wishes about this matter, then please inform your doctor and community nurse and tear up the form.

<b>PATIENT INFORMATION</b>	<table style="width: 100%; border: none;"> <tr> <td style="width: 60%; border: none;"><b>SURNAME (YY/MM/DD)</b></td> <td style="width: 40%; border: none;"><b>BIRTH DATE</b></td> </tr> <tr> <td colspan="2" style="border: none; text-align: center;">_____</td> </tr> <tr> <td colspan="2" style="border: none;"><b>GIVEN NAMES</b></td> </tr> <tr> <td colspan="2" style="border: none; text-align: center;">_____</td> </tr> <tr> <td style="border: none;"><b>ADDRESS</b></td> <td style="border: none;"><b>TELEPHONE NUMBER</b></td> </tr> <tr> <td colspan="2" style="border: none; text-align: center;">_____</td> </tr> </table>	<b>SURNAME (YY/MM/DD)</b>	<b>BIRTH DATE</b>	_____		<b>GIVEN NAMES</b>		_____		<b>ADDRESS</b>	<b>TELEPHONE NUMBER</b>	_____	
<b>SURNAME (YY/MM/DD)</b>	<b>BIRTH DATE</b>												
_____													
<b>GIVEN NAMES</b>													
_____													
<b>ADDRESS</b>	<b>TELEPHONE NUMBER</b>												
_____													
<b>SIGNED BY THE PATIENT</b>	<p>I, _____ (patient's name in full) understand and accept that I have been diagnosed as having a terminal illness or am considered to be at the natural end of my life and that my care is to include support and comfort only and that no active resuscitation is to be undertaken. I have requested that in the event of a respiratory and/or cardiac arrest, no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in one year.</p> <p style="text-align: center;">_____</p> <p style="display: flex; justify-content: space-between;"><span>Patient's signature</span><span>Date</span></p>												
<b>SIGNED BY THE AUTHORIZED REPRESENTATIVE OF THE PATIENT (Where the patient is unable to sign because of incompetency)</b>	<p>I, _____ (the authorized representative of the patient) _____ (patient's name in full) understand and accept that care is to include support and comfort only and that no active resuscitation is to be undertaken. I have requested that in the event of a respiratory and/or cardiac arrest, no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in one year.</p> <p style="text-align: center;">_____</p> <p style="display: flex; justify-content: space-between;"><span>Signature of Authorized Representative of Patient</span><span>Date</span><span>Signature of Witness</span></p> <p style="text-align: center;">_____</p> <p style="display: flex; justify-content: space-between;"><span>Relationship of the Authorized Representative to the Patient</span><span>Witness (In print)</span></p>												

**DO NOT  
RESUSCITATE  
ORDER**

The above identified patient has been diagnosed as having a terminal illness, or is considered to be near the natural end of their life. I have discussed the prognosis of this illness, the life expectancy, the persons wishes and the treatment options with the patient/patient's next of kin . Based on this, I order that in the event of a respiratory and/or cardiac arrest no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in one year.

\_\_\_\_\_  
Attending Physician's Name (in print)

\_\_\_\_\_  
Alternate Physician's Name (in print)

\_\_\_\_\_  
Attending Physician's Address

\_\_\_\_\_  
Phone Number

\_\_\_\_\_  
Alternate Physician's Phone Number

\_\_\_\_\_  
Attending Physician's Signature

\_\_\_\_\_  
Date

White Copy - To Patient

Yellow Copy - To attending Physician

Pink Copy - Community Home Care Nursing Services (if patient in care)

**Prince Edward Island  
Home Care Support Program**

**Physician DNR Order Form**

I hereby order DNR (Do Not Resuscitate) for \_\_\_\_\_ (Client),  
who has requested this and is competent to make this decision.

I hereby order DNR (Do Not Resuscitate) as requested by:

Name: \_\_\_\_\_

Relationship to client: \_\_\_\_\_

acting for (name of client): \_\_\_\_\_

who has been found incompetent.

\_\_\_\_\_  
Physician signature

\_\_\_\_\_  
Date

**Prince Edward Island  
Home Care Support Program**

**Do Not Resuscitate (DNR) Form**

I understand the definition of **Do Not Resuscitate (DNR)**. If my heart stops beating, or if I stop breathing, **no medical treatment will be started or continued.**

I understand that this decision will not prevent me from obtaining emergency medical care by paramedics and other medical care at the direction of my physician prior to my death.

I understand that my physician will continue to take steps to assure my comfort until my death.

I may revoke this request at any time.

\_\_\_\_\_  
Client Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Substitute Decision Maker

\_\_\_\_\_  
Date

\_\_\_\_\_  
Client Address

## Reading List

The following list gives only a few of the many books written by and for grieving people. You will find that some are helpful to you while others aren't. Your local library and bookstore should have a good selection of books on bereavement. Not all suggested references below will be available at all locations.

### **For Adults**

*Beyond Grief*, Carol Staudacher, New Harbinger Publisher, Oakland, Calif., 1987.

This book has good general information about the grief process. It talks about issues commonly faced by grieving people and gives practical advice for coping, including how to get help. How people respond to different types of loss, (for example, death of a child or suicide) is discussed.

*Giving Sorrow Words*, C. Lightner and N. Hathaway, Warner Books, Inc., New York, 1990.

*Grieving: How to Go on Living When Someone You Love Dies*, Theresa Rando, Lexington Books, 1988.

*Living and Working with Bereavement, Guide for Widowed Men and Women*, Elsie Palmer and Jill Watt, Detselig Enterprises Ltd., 1987.  
An easy-to-read, helpful guide covering patient care, legal and estate issues, emotional aspects etc. This book includes "information forms" to help organize yourself.

*Men and Grief*, Carol Staudacher, Her Harbinger Publications, Oakland, Calif., 1991.

This book talks about the particular ways in which men grieve, the issues and challenges that they face. It offers suggestions on how to work through grief.

*The Courage to Grieve*, Judy Tatelbaum, Lippincott and Crowell, 1980.

*When Bad Things Happen to Good People*, Harold S. Kushner, Schocken Books, New York, 1981.

*When Parents Die*, E. Meyers, Penguin Books, Middlesex, England.

*Why Her Why Now*, Lon Elmer, Signal Elm Press, Seattle, Washington, 1987.

## **For Children**

### **Ages 2-5**

*Lifetimes*, R. Ingpen and M. Gryan.

A simple story of beginnings, endings and lifetimes of plants, animals and people. Sensitive done.

*Nana Upstairs and Nana Downstairs*, Tomie de Paopla

A young boy's special relationships with his two grandmothers and his feelings when they die.

### **Ages 6-8**

*Badger's Parting Gifts*, Susan Varley

A badger dies after a long life. His friends are sad, but remember the things he taught them.

*I Had a Friend Named Peter: Talking to Children About the Death of a Friend*, Janice Cohn.

Betsy's friend Peter dies suddenly and her questions about why and what will happen to him now are answered by her parents and a schoolteacher.

*The Tenth Good Thing About Barney*, Judith Viorst

When his cat dies, a boy tries to remember ten good things about him.

### **Ages 9 - 12**

*A Summer to Die*, Lois Lowry

After moving to the country, Molly becomes ill. Her sister Meg, and her parents must deal with her impending death.

*A Taste of Blackberries*, Doris Smith

A boy describes his special friendship with Jamie. Good exploration of his feelings when Jamie suddenly dies.

*How It Feels When a Parent Dies*, Jill Krementz, A.A. Knopf, 1988.

*Learning to Say Good-bye*, Edna LeShan.

Addresses the many questions and feelings a child has when a parent is sick and dies.

## **Adolescents**

*A Death in the Family*, J. Agee

*I Heard the Owl Call My Name*, Margaret Craven, Doubleday, New York, 1973.

*With You & Without You*, A.M. Martin, Scholastic Inc: Toronto, 1986.

## **Parents and Caregivers**

*Childhood and Death*, Charles Corr & Hannelore Wass. eds.

A comprehensive book about children and death; gives information and addresses issues.

*Explaining Death to Children*, Earl Grollman.

Assorted articles regarding children and death; shows a deep concern for the child.

*How Do We Tell The Children?* Dan Schaefer & Christine Lyons.

"A parent's guide to helping children understand and cope when someone dies." Mr. Schaefer work with children as a funeral director.

## Resource/Reading Reference List

### Acts

- ▶ P.E.I. Chief Coroners Act, 1988
- ▶ P.E.I. Vital Statistics Act, Draft Revision, 1998
- ▶ P.E.I. Consent to Treatment/Advance Directives Act, 1996
- ▶ P.E.I. Home Care Framework Document, April 1996  
Copies of these Acts are available from Island Information Service, 1st Floor Jones Bldg., Charlottetown

### Articles

- ▶ *An Assessment of Open Communication Between People with Terminal Cancer, Caring Relatives, and Others During Home Care*, John Hinton, Journal of Palliative Care 14:3/1998; 15-23
- ▶ *Psychosocial Needs of Patients and Families*, Mary L.S. Vachon, Journal of Palliative Care 14:3/1998; 49-56
- ▶ *Closure of an In-Hospital Palliative Home Care Service*, Carmelita McNeil, Susan Britton, Nelleke Nieuwendijk, and Kathleen Rasmussen, Journal of Palliative Care 14:3;1998; 84-90
- ▶ *The Dorothy Ley Hospice Day Respite Program*, Judith Filman and Thelma Martin, Journal of Palliative Care 14:3/1998; 94-97
- ▶ *Death at Home: Challenges for Families and Directions for the Future*, Kelli Stajduhar and Betty Davies, Journal of Palliative Care 14:3/1998; 8-14

### Resources & Information Sharing:

- ▶ Island Hospice Association Volunteer Training Manual, February 1999  
Provincial office: 5 Brighton Road, Charlottetown, PEI C1A 8T6  
Phone: 902-368-4498 Fax: 902-368-5946
- ▶ Victoria Hospice Society Bereavement Information Package, August 1995  
Society office: 1900 Fort St., Victoria, B.C. V8R 1J8  
Phone: 604-370-8716 Fax: 604-370-8625

- ▶ Canadian Cancer Society, P.E.I. Division  
1 Rochford St., Ste. 1, Charlottetown, PEI C1A 9L2  
Phone: 902-566-4007 Fax: 604-370-8625
  
- ▶ Marguerite House- Sister Doreen Walsh, Sister Alice Long  
Phone: 902-894-4529
  
- ▶ Belvedere Funeral Home - Faye Doucette  
175 Belvedere Ave., Charlottetown, PEI C1A 2Y9  
Phone:(toll free-1-888-628-1881) Fax:902-892-9048