

PREPARING FOR AN EXPECTED DEATH AT HOME



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If you're reading this booklet, you may be preparing for an expected death at home, yours or that of someone you know. Taking the time to prepare for a death at home can be difficult, but it is important. There are many questions to ask and many issues to talk about. That is why we have prepared this booklet for you.

We're hoping that we can give you some of the answers that you're looking for and identify some of the issues you need to talk about. There is a lot of information for you to review. Take your time. Read it slowly and make notes. Most importantly, remember that there are many people who can help you. Family, friends, neighbours and clergy are some of the people you can turn to for support. We encourage you to talk to the people who are close to you. This will give you the support you need and help them to better understand what to expect.

This booklet has two parts. The first section, *What You Should Plan For*, is written for the person who is terminally ill. It offers information and guidance to help the individual and their loved ones plan for the expected death at home. The second section, *Information for Families and Friends*, will help family, friends and others to understand what is happening to their loved one during the last days and hours of life.



WHAT YOU SHOULD PLAN FOR

This section offers information for the person who is terminally ill and who has made the decision to die at home.

Many people are making the choice to die at home. They prefer it to spending their final hours or days in hospital. If you have made this decision, then it's very important for you to take the time to prepare and to let your loved ones know your wishes. Planning gives you the chance to talk with one another about your personal affairs and the arrangements to be made. It's also the chance to share your concerns and feelings.

There are many decisions to make when preparing for an expected death at home.

AGREEMENT WITH DOCTOR, FAMILY AND FRIENDS

Agree with your family doctor and other members of your health care team about what should happen at the time of death. You may also want to talk about your plans and desires with palliative care workers or with Home Care workers. Having a plan will help to reduce anxieties for you and your family. It will also help your family to respect your wishes.

You should also let your physician know if you would like him/her to come to your home at the time of death. He/she doesn't have to come to your house, but your family may wish it. The physician must understand and agree to what you and your family expect. Also, the physician must agree to sign the death certificate to allow the funeral director to prepare the body and to prevent unnecessary responses from emergency personnel.

SPIRITUAL NEEDS

Arrange ahead of time if you wish family, friends, or clergy to be with you during the last few hours or days. Your care team may be able to help you find spiritual resources that are right for you.

PERSONAL AFFAIRS

Make sure your personal affairs are in order. Preparing a will and organizing your legal and financial business will help your family members to take care of your estate. Some people feel that they have no estate to arrange for, but your estate includes pension benefits, insurance policies, and any other income you have. A will is the only way that you can be sure that you, rather than a court, will make decisions about your estate. You can call the Public Legal Education Society, toll- free, at 1-800-665-9779 for more information on making a will.

We also suggest that you ask someone to act on your behalf in case your condition reduces your ability to speak or make decisions. This is called giving them enduring power of attorney.

LIVING WILL

Write a living will. A living will states your wishes about medical care. Even though it is called a will, a living will is not a legal document. It is helpful if you become unable to make your own decisions or to speak and it will help your family and doctor to honour your wishes. If you write a living will, be sure to talk about it with your family and your doctor.

A living will may include a *Do Not Resuscitate* statement, or you may fill out a *Do Not Resuscitate* form separately. Forms are included in the pocket at the back of this booklet.

COMFORT CARE

Talk with your physician, nurses, family, friends and your health care team about comfort care. The people around you will do whatever they can to keep you comfortable.

You should talk with your physician about how much care and what types of treatments are best for you so that they know how you feel and what you want.

MEMORIAL OR FUNERAL PLANS

Make memorial or funeral plans. It can be easier for you and your loved ones if you make plans together. It is helpful to attach a copy of your wishes to your will.

You may wish to think about these questions:

- Will there be a service; what type of service will it be?
- Where will the service be held?
- Who will perform the service?
- Will there be a burial or cremation?
- What are your preferences for special readings or music?

You may also wish to write or talk about some family history information that may help with writing an obituary.

INFORMATION FOR FAMILIES AND FRIENDS

This section is written for the people who are close to the person who has made the choice to die at home. They may be family, friends, caregivers and the clergy.

Changes that occur as a person dies will vary from one person to the next. Some changes may be disturbing. They are usually more difficult for you to watch than for the person to experience.

The more that families and friends understand what is happening, the better you will be able to handle this situation.

As a person is dying, they become extremely weak. Swallowing fluids and taking medication gets harder. Breathing changes: it becomes irregular and may stop at times and it can become noisy. The colour of their hands and feet may be patchy and they may feel cool to touch. The person responds less and less to you.

You can make the person more comfortable by doing some of the following:

- turning them and changing their position
- offering sips of fluids if they can swallow
- moistening their mouth with a wet cloth or with mouth swabs
- continuing to give regular pain medications as ordered by the physician
 - using bed coverings as usual even though they may feel cool
 - talking and touching them so that they are aware that you are by their side.



Another suggestion is that if you find that they can't swallow the medication, let the physician know. Perhaps the medication can be given a different way. Also, if their breathing is noisy or rattling, tell the physician who then may be able to order medication to help make it easier for them.

At the time of death, the person will not respond when you speak to them. They will not breathe or move and will have no pulse. They won't seem to be in pain. Their eyes may be open or closed, and their jaw will relax.

Let the family doctor know that your loved one has died and carry out any other plans or arrangements you have made with the physician. Do not call the police, ambulance, or 911. There is no need to when death has been expected, and if called, they will have to act as if the death is suspicious. Call the funeral director when you are ready. They can arrange to have the doctor sign the death certificate.

No matter how much you prepare for this moment, death arrives in its own time and in its own way. The experience of dying is different for every person and for every family. What is important is to do whatever is felt to be of help during this time. People cope with death in many different ways. Do whatever feels right for you. After your loved one has passed on, take as much time as you need to say your goodbyes.



Many people are ready to help when a family is preparing for an expected death at home. In the pocket at the back of this booklet is a place to keep their names and phone numbers so that you can reach them when you need to. Remember, you are not alone. There are many people who want to and who can help you prepare for an expected death at home.

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 stop me from seeking emergency medical care by paramedics and other medical care that my physician orders before my death.

I understand that my physician will continue to take steps to make me comfortable until my death.

I may change my mind about this at any time.

Signature of patient or responsible party

Date

Witness

Date

Patient's address

Physician DNR Order Form

I hereby order DNR (Do Not Resuscitate) for

_____, who has requested
(name of patient)

this and is competent to make this decision.

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

_____, acting for
(name and relationship to patient)

_____, who has been found
(name of patient)

incompetent.

Physician's signature

Date

Important Telephone Numbers

Family physician: _____

Care team: _____

Clergy: _____

Funeral director: _____

Lawyer: _____

Executor: _____

Bank: _____

Other numbers: _____
