FAMILY INFORMATION BOOKLET

End of Life Care

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Disclaimer

This is general information developed by The Ottawa Hospital. It is not intended to replace the advice of a qualified health-care provider. Please consult your health-care provider who will be able to determine the appropriateness of the information for your specific situation.
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Introduction

This booklet has been developed to help you understand what happens when someone is dying and how we provide comfort and support during this time.

You, your family and the health care team have come to an understanding that death will occur shortly and that the goal of care is no longer focused on cure but on minimizing suffering, maximizing quality of life and ensuring a comfortable and dignified death.

As part of these discussions the following have occurred:

• A discussion has taken place regarding cardiopulmonary resuscitation (CPR) and a decision has been made that when diminished breathing and heart function occur, it will be allowed to progress until death occurs. The priority for all concerned (family and healthcare team) will be to maintain comfort and support the patient. Therefore a Do Not Resuscitate (DNR) order has been written in the chart.

We realize that this is a most distressing time for you. This booklet will help to explain what you might expect and how the health care team can work with you to provide care and support at this time.

What is Palliative Care?

Palliative Care is a philosophy of care provided by a team of health care professionals to patients and their families facing life-threatening illnesses. The goals of palliative care are to relieve physical symptoms and provide psychosocial, emotional and spiritual support to ensure the best possible quality of life for a patient who has a life limiting illness.
Who will be providing the care?

The Health Care Team on the unit

The Health Care Team on the unit (physicians, nurses, pharmacists, social work) will continue to provide care and ongoing support.

The Palliative Care Team

The Palliative Care Team (physicians, nurses, social workers, spiritual care) may be asked by the unit team to assist in care. Their role is to provide advice on managing symptoms in addition to providing information and support.

What can family/friends expect?

When death is approaching there are changes that happen in the body which are expected. Knowing what to expect will help you. Not all of these changes always occur, but you might observe the following:

Breathing changes

- Breathing patterns change. Breaths may occur more quickly or more slowly. They may become irregular and shallow. A moaning sound may also occur as the person breathes out. (This does not usually indicate pain.)
- Breathing may stop for up to 45 seconds before starting again. This is a common pattern sometimes called “Cheyne-Stokes” breathing.
- Breathing may sound “rattly” when secretions gather in the throat or upper airway. (This is not uncomfortable for the person.)

Eating and drinking

- Swallowing becomes difficult due to weakness.
- Need for food and fluids decreases. When a body is preparing to die it is perfectly natural that the need for eating and drinking diminishes.
Levels of awareness

People who are very sick have difficulty thinking clearly and responding to their surroundings.
- Anxiety, restlessness and irritability may increase.
- Familiar people or objects may not be recognized.
- Reaching out, seeing and/or calling the name of someone who has died may occur.
- Increasing drowsiness and falling asleep during conversations may occur.
- Eyes may be open or semi-open but the person may not be able to see.
- It is felt that hearing often remains to the end. For this reason we encourage you to continue to speak to your family member.

Skin changes

- Skin may become cooler to the touch, or warm and moist. This is due to the body’s inability to regulate temperature.
- Skin colour may change, for example the hands and feet may become bluish in colour.
- Patients may be aware of the presence of family (voice, touch, etc.) at the bedside even though not able to respond meaningfully.

How will physical symptoms be managed?

The most common symptoms are pain, shortness of breath, agitation or restlessness and secretions in the back of the throat. In most cases these symptoms can be easily managed.

Pain

- Pain is different for everyone.
- Often, a general feeling of not being well is described as pain.
- Worry, fear and loneliness may make things worse.
- There are many ways to help reduce pain for someone who is dying. In the majority of cases pain can be controlled.
Medications

- Someone who has pain all of the time needs regular pain medication to control it.
- Often pain medication needs to be adjusted to find the correct dose to control pain.
- The goal is always to control the pain while minimizing any side effects that may occur.
- Pain medications can be given by mouth, by rectum, by needle or by a patch placed on the skin. This is called the “route” by which medications are given. When a medication is given by a needle, the needle can be placed:
  - into the skin (subcutaneous)
  - into a vein (intravenous)
- The most common way is the subcutaneous route. A tiny needle is placed under the skin and secured by a clear dressing/tape for repeated use. This will reduce the need for frequent injections.
- In some cases a pump is attached to the subcutaneous needle to give the medication continuously.
- The patch is not usually introduced at this time but may be continued if previously used.
- Pain can occur without obvious reason even though regular medications are being given (often referred to as break through pain). For this reason additional doses of pain medication can always be given on an “as needed” (PRN) basis. In addition to regularly scheduled doses of pain medication.
- The team will explain which medications have been ordered and why, which route will be used and what side effects may occur.
- Side effects, if they occur, usually settle within the first 24 to 48 hours.
- Some of the common side effects may include drowsiness, nausea/vomiting, constipation, confusion and occasionally hallucinations.
- These side effects can usually be managed.

There are other ways to help control pain in addition to medications. Some of these include:

- Positioning
- Distraction (music, visitors)
- Massage
- Hot/cold packs
Dyspnea (shortness of breath)

- Dyspnea is the awareness of breathlessness or shortness of breath.
- This happens because either the lungs are not able to take in enough air or they cannot deliver enough oxygen to the bloodstream.
- Dyspnea differs from person to person.
- It may be worsened by anxiety and pain.
- Dyspnea may be a frightening experience for the person and for anyone watching.

There are many ways to help reduce dyspnea. In the majority of cases it can be controlled.

Medications

- Medications used to control pain are also effective for dyspnea.
- Oxygen, by mask or nasal prongs can sometimes be helpful.
- Medications to control the anxiety are also helpful.
- Medications administered via a mask such as ventolin or saline.
- In severe intractable dyspnea, it may be necessary to use medications that cause some sedation to relieve suffering.

Other ways to help reduce shortness of breath include:

- Opening windows to increase air circulation
- Using a fan to blow air across the face
- Relaxation
- Maintaining a calm, quiet atmosphere
- Frequent rest periods between activity
- Doing several activities at a time to allow time for rest periods
- Loose clothing and lightweight sheets/blankets
- Positioning (elevating the head of the bed or sitting up in a chair)

Confusion

- Confusion may involve hearing or seeing things that are not real (hallucinations) particularly at night.
- These symptoms may be due to reduced oxygen levels in the brain as circulation decreases.
Agitation and restlessness

Agitation and restlessness may occur due to many different reasons including:

• Side effects of medications used for other symptoms
• Full bladder
• Constipation
• Infections
• Discomfort
• Unresolved emotional, social or spiritual issues (“unfinished business”)
• Dying process

There may be times when these symptoms are difficult to control due to the underlying cause. In these cases the Palliative Care Team can provide additional information and support.

Medications

Medications often used for confusion, agitation and restlessness include those that reduce anxiety and promote relaxation and/or sedation.

• Medications may be ordered regularly or as needed (PRN).
• Usually they are given subcutaneously but may also be given under the tongue.
• The team will explain which medications have been ordered and what side effects may occur.

Other ways to control these symptoms depend on the underlying cause. Some of these include:

• Reviewing medications.
• Placing a urinary catheter (for full bladder).
• Ensuring the bowel is emptied (for constipation).
• Ensuring pain medications are given appropriately.
• Requesting spiritual support or reviewing unfinished business.
• Reminding the person who you are, where they are.
• Always explaining what you are doing and why.
• Talking slowly using short simple sentences.
• Keeping a quiet, calm environment (touching the person in a gentle manner may help).
• Keeping the room well lit.
• Staying with the person.
• Ensuring safety measures are in place to prevent injury.

**Respiratory secretions**

When a person is dying the muscles in the body weaken reducing the ability to swallow or cough up normal secretions produced in the mouth and airway. The person may be awake or unresponsive. A rattling sound is produced as the person breathes out air from the lungs over these secretions. This is distressing for the family but not for the person who is dying.

**Medications**

Medications used to control this symptom act to dry up or reduce secretions in the throat.

• If you notice secretions developing please notify the nurse so medications can be given.
• Medications are usually given subcutaneously as needed.
• Medications may need to be given regularly if there are a large amount of secretions.

Other methods of managing this symptom include:

• Repositioning to help drain secretions.
• Decreasing or stopping intravenous fluids may be part of the treatment plan.
• *Suctioning will not reduce secretions. It may actually increase them and will cause additional distress.
What can family/friends do?

Visiting
Normal visiting hours are usually from 3 to 8 p.m. When a family member is dying the health care team can ensure that the family can visit at any time. It may be possible to have a cot or reclining chair placed in the room to allow a family member to rest at the bedside.

Practical Information

Parking
Weekly and monthly parking passes can be purchased at the Cashier or Parking/Security. This is at a greatly reduced cost from the daily parking pass. If there are financial worries please ask to speak with the unit social worker.

Cafeteria
Cafeterias/coffee shops and vending machines are available at each campus.

Accommodation
There are options for accommodation nearby the hospital. If this is required please contact the unit social worker.

Helping to provide care
As a family member/friend you are welcome to help to provide care. There may be several ways to do this. You should discuss this with the nurse at the bedside.

Looking after yourself
This is a very stressful time for you. Caring for someone who is dying is hard on you emotionally as well as physically. You may forget to look after yourself.

• It is very important that you eat properly, even when it seems you are too tired or too busy.
• Make time for some exercise and relaxation away from the bedside.
• Try to get enough rest/sleep.
• Take time off from work if possible. (The Compassionate Care Benefits Program established by the government can help with this.) If you have questions please contact the unit social worker.
• Set aside time for others in your life.
• Allow yourself to express your feelings (crying, laughing, anger, frustration).
• Talk to a friend.
• Nourish your spirit in whatever way comforts you.
• Enlist a family member/friend to assist you with practical matters (i.e. contact funeral home) as well as day-to-day errands (i.e. groceries, housekeeping, etc.).

How can the family talk to children about death?

• As soon as you can, be open and honest with your children.
• Tell all of your children at the same time, even if there is an age gap. The younger ones may not have the same level of understanding as the older ones, but they will feel included. Explain to children that the person is dying. Avoid using words such as gone to sleep or gone to heaven. Using such terms may cause children to become frightened of falling asleep. When the children know there are no secrets, they will be better able to trust the adults caring for them.
• Prepare children for what changes they may see (i.e. medical equipment, individual’s appearance) and allow them the choice to visit or not.
• Discuss the fact that the person is dying when it is happening. Probably the hardest thing for everyone will then be in the open and no one will have to be on guard. Ask the unit social worker for advice on when and how to do this.
• Involve your children in what is happening so they feel included.
• Keep children informed about the plans for them, their sick parent and their healthy parent over the next while. Avoid surprises whenever possible.
• There are many books available for children and teens to help them understand and cope at this time. Please see the list in this booklet or ask the unit social worker for help with this.
What needs to be done to make funeral arrangements?

Arrangements after a death are emotional tasks that are often done when you are least able to think about such decisions. Some people choose to make arrangements in advance. Then, at death, there is time to visit with family and begin mourning without worrying about funeral details. For other people, making arrangements in advance is too difficult and they prefer to spend the time with their loved one. There is no correct or incorrect way to do the planning.

What is Grief?

Grief

• Is a normal reaction to a death or loss in a person’s life.
• Can be hard, stressful and tiring, but it is not an illness.
• Helps us to adjust to a new life without the person who died.

How does grief affect people?

All people grieve differently. Most people will feel shock and numb in the beginning. Strange and painful thoughts and feelings may follow:

• Thoughts of confusion, disbelief, and wondering if this is just a dream.
• Feelings of sadness, anger, guilt, loneliness, bitterness, fear, edginess, nervousness, short temperedness, and lack of confidence.

People who are grieving may

• Cry a lot
• Blame others
• Withdraw from their normal activities
• Have upset stomachs and headaches
• Have problems sleeping, resting, eating or doing small tasks
• Have no energy
• Feel they have the same problems as the person who has died.

**People who are grieving find that**
• Grief goes on much longer than they imagined.
• There are no quick fixes or ways to grieve.
• Each person has to work through his or her grief and in his or her own way. It is not easy for others to help.
• Grief lessens with time.
• Grief helps the person to deal with the death.

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**Children and grief**

**What about children and grief?**
Children grieve but not always like adults. Their understanding, the way they react and what helps them vary with age. Children of all ages sense sadness, feel loss and pain, fear death and being left alone. Some children may feel guilt for what has happened.

**Children**

• From infant to 2 ½ years cannot understand that death is forever. Sense loss and change but cannot understand the impact or verbalize the insecurity or discomfort they feel. May act out and cling to parent. May have changes in sleeping and eating patterns.
• 2 ½ to 5 years may believe they caused the illness, they cannot express the anxiety of separation and do not understand the finality of death. They may regress in behaviour. May be angry one minute and then play normally the next.
• 5 to 8 years have some understanding but very concrete in questions they ask. May be angry about what has happened and then feel guilty that they are not sick and they want to play.
• 8 to 12 years may manage normal activities better but wants to be grown up and may hide feelings such as anger, crying. They may blame themselves for the illness and feel it is their fault. May want specific information about the illness and the hospital care.
What will help children with grief?

- Being honest and giving answers in words they understand.
- Having someone listen to what they are really saying.
- Being part of what is happening.
- Being told the truth and given lots of support.
- Knowing they are loved and will be cared for, that their thoughts and feelings are good and normal and it is OK to cry.
- Being honest and giving answers in words they understand.
- Being told that illness does not always lead to death.
- Knowing that others understand and it is good to show their feelings by talking, drawing, painting, poetry, puppets, play and music.
- Adults who show and admit their feelings and cry with their children help the children to accept and understand death.
- Making them aware that they didn’t cause the illness and also that the illness is not contagious.

Children’s books on grief, dying and death

- **Ages 3 to 8**
  - Blow me a Kiss, Miss Lilly (Nancy White Carlstrom 1990) – Harper and Row Publishing
  - You Hold me and I’ll Hold You (Jo Carson – 1992) – Orchard Books
  - I’ll Always Love You (Hans Wilhelm -1985) – Crown Publisher’s Inc
- **Ages 4 to 9**
  - The Fall of Freddie the Leaf: A Story of Life for All Ages (Leo Buscaglia – 1982) – Holt, Rinehart and Winston
  - Lifetimes: A Beautiful Way to Explain Death to Children (Brian and Ingpen Mellonie) – Bantam Books
  - Gentle Willow (Joyce Mills – 2003)
- **Ages 8 to 11**
  - Children Also Grieve (Linda Goldman)
  - Sadakko and the Thousand Paper Cranes (Eleanor Coerr – 1977) – G.P. Putnam’s Sons
What resources or supports are there?

Social Workers
Each hospital unit has a unit social worker who is trained to help families deal with these difficult situations. The nurse can make a referral to the social worker for you.

Spiritual Care
The hospital has a spiritual care service that can provide access to a hospital chaplain of any faith should you require such support. The nurse can contact the spiritual care service for you. If you have a spiritual support person (priest, minister, rabbi, imam, etc.) from your own community, he/she can be contacted and visits arranged.

Bereavement
Grieving and bereavement are normal processes that take place after the death of a loved one. Sometimes family members may require additional support. There are many organizations in our community that provide such support. A listing of these services if found below.

Community Resources available to bereaved family members and friends
Bereaved Families of Ontario ................................. 613-567-4278
Catholic Family Services ........................................ 613-233-8478
Distress Centre—Ottawa and Region ......................... 613-238-3311
Entraide-Deuil de l'Outaouais .................................. 613-770-4814
Family Services Centre of Ottawa-Carleton ................. 613-725-3601
Jewish Family Services ........................................... 613-722-2225
Mental Health Crisis Team ..................................... 613-722-6914
Ottawa Baffin Program ........................................... 613-523-7822
Public Guardian and Trustee .................................. 613-241-1202
St. Paul University (Counselling Centre) .................... 613-782-3022
Survivors of Suicide .............................................................. 613-737-7791
Tel-Aide Outaouais .............................................................. 613-741-6433

The Compassionate Friends:

   Nepean Chapter .............................................................. 613-692-4521
   Kinburn Chapter .............................................................. 613-832-1007
   Ottawa East Chapter ......................................................... 613-841-9504
   Chelsea (Québec) Chapter .................................................. 819-243-7861
   Perth Chapter ................................................................. 613-267-7171

Your Employee Assistance Program

**Canadian Virtual Hospice**

The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators. It can be accessed at www.virtualhospice.ca.
What else do I need to know?

In addition to the funeral there are other administrative details the family will need to attend to. The following is a listing of various agencies you may need to contact.

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### Checklist of people/organizations to be notified on the death of a loved one

#### Lawyer/Legal Aid

The Lawyer will assist the executor fulfill the terms of the Will and arrange probate. This may not be necessary if it is a simple estate settlement and the executor is informed.

#### Banks/Credit Unions

The deceased's bank(s) should be contacted and provided with Proof of Death Certificate so that the accounts may be closed. The manager or accountant will assist regarding safety deposit boxes.

#### Employer/Union

As well as pension plans, many companies have life insurance coverage as part of their employee benefit package.

### Other Life insurance companies or private pension plans

#### Canada Pension Plan

300 Laurier Ave. West, Level M2, Ottawa, ON, K1A 0M7

A lump sum death benefit may be paid to the estate. In addition, surviving spouse and dependent children may be eligible for a monthly pension. Application has to be made. Call the 1-800 number to set up an appointment.

#### Old Age Security

300 Laurier Ave. West, Level M2, Ottawa, ON, K1A 0M7

The estate is entitled to a cheque for the month in which the individual died.
Ontario Health Insurance Plan (OHIP)  
75 Albert St., Ottawa, ON, K1P 5Y9  
783-4400  
Notify in writing of the death, including a copy of the death certificate and the health insurance card.

Credit Card companies  
i.e. Mastercard, Visa, Sears, The Bay, etc.

Ministry of Transportation  
If the deceased person owned a car. Also the automobile insurance company.

Cancel deliveries, service calls, subscriptions, appointments, etc. on behalf of the deceased.

Department of Veteran’s Affairs  
If the deceased was a veteran of the Canadian Armed Forces you may be eligible for some type of dependents' benefits in addition to death benefits. (1-866-522-2122).

Fraternal organizations/service clubs to which the deceased belonged.

Revenue Canada  
Income tax return for the deceased must be filed by April 30th of the year following death.

Please Note:

The Ottawa Hospital provides the above guidelines for your convenience. They may not cover all sources from which you may obtain benefits or with which your involvement may be required.
Questions to ask the health care team