Introduction

In today’s society, it is sometimes difficult for us to realize that death is really a part of life; however, in the face of incurable disease, a time will come when nothing will change the body’s progression towards death. When this happens, and when all treatments aimed at sustaining life are no longer effective, it is appropriate to change the focus of care.

Our goals in caring for dying people and their families are to maintain comfort, preserve dignity of the person and offer loving support. It is sometimes said that people die the way they lived. Every life is special and unique. It is important to recognize that all deaths are also distinct to particular people.

We received many questions from those we care for and their families about what they might expect to see and experience as life draws to a close. This booklet will tell you about some changes and experiences that may occur, which often indicate that life is nearing its end.

It is our hope that the following information will help you:

- Understand how the body and spirit prepare for death
- In knowing what to do or who to ask for help in caring for your loved one
- Know how to care for yourself during this difficult time.

The information included in this booklet is a guide only. Be sure to ask your doctor, nurse, social worker or spiritual care provider for more information so your questions are fully answered. **All questions are important.**
**Body and Spirit**

The physical changes as the body prepares itself for death will, for the most part, be a continuation of what has already occurred as the illness has progresses. The ability to manage daily routines of living will decrease. Normal body functions will decrease until they can no longer be maintained. It is impossible to predict when changes will happen, if at all.

This can be a difficult reality for family members. The person also may begin to prepare for death emotionally, spiritually and mentally. For example, he or she may need to complete “unfinished business” to resolve conflict, re-establish or deepen religious connections, or receive permission from a loved one to “let go.”

Support can come from just listening to these concerns and/or providing assistance to complete the “unfinished business.” This may help the ill person have a sense of control of the situation.

**Issues Discussed in this Guide**

- Body and spirit
- Fears of dying people
- Hints for the family
- Caring for yourself
- Foods and fluids
- Bladder
- Bowel
- Ostomy

- Bleeding
- Odour
- Eye care
- Breathing
- Pain
- Swelling
- Temperature and vital signs
- Skin colour and coolness

- Level of awareness: emotional, spiritual, and mental
- Giving permission
- Saying goodbye
- When you will know death has occurred
- What to do when someone dies at home.

**Fears of Dying People**

One of the major factors in caring for a dying loved one is having awareness of any fears. Dr. Thomas Leig has described 7 fears identified by terminally ill individuals in an address to the Institute on Hospice (Catholic Hospital Association, 1978).

**There is a fear...**

...Of the process of dying.

People are often concerned about what will happen in their future, for example, whether they will be anxious or frightened, or what will happen to their bodies’ appearance.

...Of losing control of their lives.

When people are ill, they often need more and more help and become more dependent on others. This change robs people of their usual life routines and raises significant worries. For example, the ill father can no longer provide for the home; the child can no longer play with friends. Hospice Palliative Care supports the idea of dying people and their families having control of life decisions. They can continue to make choices in their relationships and in their lives.

It is important that we remember, in spite of advanced illness, people live until the moment of their death. They are part of a family, need to laugh and cry and usually want to continue living until they die.
There is a fear...

...Of leaving loved ones.
Dying people are concerned about what is going to happen to their families after they are gone. They also go through the same kinds of processes in dealing with their own dying. They are leaving their loved ones and are coming to grips with other losses, such as loss of health, well being, or ability to do activities they enjoy.

...Of isolation.
We hear about the fear of being alone more often than any other. People are afraid they may be deserted when they die. They want to have someone with them, particularly someone they know and love. But even if they cannot have a loved one, they want at least someone near them.

...Of the unknown.
We do not know what to expect as the disease worsens. There is often a fear of suffering physically. If we can make what our loved one is going through less of a mystery, we can bring comfort and lessen anxiety. Knowing how our physical needs may be cared for may be very reassuring. For one thing, we can demonstrate in our care of loved ones that their pain will be taken seriously and treated right away.

...Of seeing fear in the eyes of the caregivers.
Sometimes ill people are afraid they will upset their family if they talk about their true feelings. Visible but unexpressed fear is more frightening to loved ones than fear discussed openly and candidly. When we, as caregivers, encounter a dying person, it puts us in touch not only with our own mortality, but also with our own previous losses. We naturally feel anxiety and fear. But it’s far better to share that with the person so that what we express verbally says the same thing we are expressing non-verbally. This may allow for finishing any unfinished business. You may wish to speak to your professional caregivers if you are having difficulty talking to your loved one.

...That your loved ones’ lives were meaningless.
Being ill gives people an opportunity to reflect on their lives and come to terms with themselves. It is particularly important for those who are dying because this may be their only time to come to terms with their past. They have to deal with what their lives have been.

What they may need is someone who is willing to listen or someone to comfort them in sadness for those things that cannot be changed. They also benefit from sharing cherished moments, occasions and accomplishments they feel good about.

Cultural practices and beliefs, the age of the ill person, past experiences and previous approaches to hard times all affect how difficulties are dealt with. Usually, people want and deserve to be told truthfully and honestly what is happening to them so they can continue to direct their own care and continue to be part of their family. Relief from unpleasant symptoms of their disease is their right.
Hints for the Family

Even though we know dying is part of life, it is still difficult when someone close to us approaches the final stages of living. Below are suggestions that might support you in your caring:

1. Allow loved ones to be part of life as much as they wish. Share news, plans and feelings.
2. Listen to what your loved one is saying. He or she may be feeling many emotions such as anger, depression, loneliness, hope, joy or despair. Everyone needs to have his or her feelings accepted. You can acknowledge with a nod or a touch.
3. Show your concern in your own way and in your own words.
4. Learn to be comfortable with silence. It is natural and often a meaningful way of communication.
5. Do not be afraid to touch your loved one to show your warmth. Let the reaction be your guide.
6. Help your loved one with physical care when you feel comfortable in doing so. Encourage your loved one to do as much as possible for as long as he or she can.
7. Remember, negative feelings are often only expressed to those you love. Your loved one may sometimes express such feelings toward close and trusted people.
8. Live day by day. Say and do what seems important.
9. Provide small things to enhance life, such as favourite foods in small amounts or tapes of loved music. Read a favourite poem or bring a treasured object, flowers or pictures.

Remember, as a person nears death, he or she may withdraw and only relate to a few people or one specific person. This is not rejection, but may be part of your loved one’s way to prepare for death.

Caring for Yourself

Helping to care for the loved one who is dying is physically, mentally, emotionally, spiritually and socially demanding. Your own needs must be met and your well being attended to so you can continue to care for and be supportive to your loved one.

1. The aim should be to do all that we can - not more than we can - to take care of those we love.
2. Know what you can and cannot do. This will help you know where you will need to ask for the help and support of someone else.
3. Adequate sleep and good nutrition are vital. Having healthy snacks and bottled drinks when visiting is recommended. Caffeine and alcohol intake should be kept to a minimum.
4. Time away from the bedside to walk, read, listen to music or sit quietly and think will refresh you and restore your energy.
5. You may wish to keep a journal. Writing may help you express your emotions and sort out your thoughts.
6. Make a list of questions as they arise. Members of the care team can provide answers, guidance or direct you to others who can help.
7. Keep a list of people and phone numbers so that you can easily connect with someone to help and support you (family, friends and professionals).
8. Communicate as openly as possible with your loved one. If you can, this is a time to share memories, tears, laughter, wishes and concerns. Hiding your emotions can be exhausting.
9. Get support from family and friends. They may want to help, but may not be sure what to do. Some may be able to sit with your loved one while you take a break. Ask others to cook, cut the grass, provide rides or babysit.
10. **Ask what other services are available to support you in the community, such as visiting nurses, volunteers, support groups, Hospice services etc. In the hospital, ask a member of the Care team, such as the doctor, nurse, social worker, spiritual care provider, or volunteer.**

### Changes in Bodily Functions

#### Food and Fluids

It is important to understand that people approaching the end of their lives' responses to foods and fluids are different from the responses of healthy people. A small bite or sip is often enough to relieve hunger and thirst when an appetite is much smaller and bodily needs for food are decreased. This loss of interest in food may be more distressing to you than to your loved one.

Most people with advanced cancer and other diseases lose weight as the illness progresses. It can be very hard to watch a loved one fade away; it's also hard to accept that further treatment is not possible in someone so frail. The issue of eating and drinking can be extremely upsetting for family members and should be discussed with the doctor or nurse if need be.

**What causes poor appetite and weight loss?**

There are many reasons for poor appetite and weight loss. Symptoms like pain, nausea, constipation and shortness of breath take a lot of energy and may reduce the desire to eat and drink. Chemical changes within the body also decrease appetite. When cancer is present, your loved one may lose weight and become weak because of the advancement of the disease - not because of the lack of food or fluid. One approach to care is to offer foods and fluids to the person in small amounts and do not expect the person to eat and drink if it's not possible.

**What can I do?**

Your loved one may find it increasingly difficult to manage solid foods and may only want small amounts of soft, puréed foods or liquids. If your loved one is hungry, offer small sips. He or she may try fluids and solids if conscious and able to swallow. If your loved one is unable to swallow, you can relieve thirst and keep his or her mouth moist by swabbing water or artificial saliva. The dying person may start losing interest in eating or drinking. The goals of care focus on comfort.

**What about intravenous fluids?**

It is important to understand that intravenous (IV) fluid is considered active treatment to provide hydration. IV fluids are not food. In end-stage illness, intravenous fluids may not help to prolong quality of life. Fluid that is no longer absorbed well may start to ‘back-up’ in the body and cause swelling, discomfort or increasing difficulty in breathing. Intravenous fluids are not usually recommended.
Bladder
As death approaches, the amount of urine may decrease and be a dark colour. Your loved one may also lose bladder control. A catheter may help keep the person dry and will help avoid discomfort of skin breakdown.

Bowel
Bowel movements may become smaller and less frequent as food intake decreases. Pain medicines also affect bowel function. Laxatives and sometimes a gentle enema may be required to improve comfort. The use of protective pads helps keep your loved one dry and comfortable.

Ostomy
If your loved one has a colostomy, ileostomy, or ileoconduit, the same changes in bowel or bladder functions may be noticed. The person may feel embarrassed by some of these changes in the bowel and bladder function. Reassurance and loving support are important.

Bleeding
With cancer, there may be bleeding because of tumour growth into blood vessels or blood may not clot well. Bleeding may be controlled with special materials that help in clotting.

Odour
Body odour may increase due to infection, breakdown of a tumour (in cancer) or other changes in the body. There are many ways we may be able to help reduce and control odours.

Eye care
During the final days of life you may find your loved one asleep with his or her eyes open. This may cause the eye coverings to dry. Eye drops are available to help maintain natural moisture to the eyes. Your professional caregiver can advise you and show you how to administer these drops. You may also notice that your loved one is unable to focus or see clearly as the condition weakens.

Breathing

Shortness of Breath
Your loved one may experience difficulty breathing as the disease progresses and the condition weakens. Breathing may also become rapid due to fever, infection, or changes in kidney function. Distress from breathlessness can be managed with medicines to help open the airways, reduce anxiety and control fever. As well, your doctor or nurse may suggest oxygen, which can be given at home or in the hospital. Sitting the person up with support or leaning forward with the arms resting on a table may help. A fan to move the air gently can sometimes lessen the feeling of shortness of breath. Your loved one may tell you while catching his or her breath that he or she feels quite comfortable.

Changes in breathing pattern: nearing death
As your loved one becomes weaker, you may notice changes in breathing patterns. You may notice short periods when breathing stops temporarily. There may be repeated cycles of increased deep breaths followed by shallow breathing, then again no breathing for 10 to 30 seconds or longer. A slowing in brain activity causes this change in breathing pattern. The amount of time the person stops breathing may become longer. Your loved one will not notice these periods and will not be distressed by them. The person’s breathing may also become noisy. These noises are the result of several things - small amounts of mucous in the throat, the jaw dropping back or the tongue moving back due to the relaxation of jaw and throat muscles. Sometimes a soft short moaning sound with each exhale may accompany this.
We sometimes give medicine with a small needle inserted into the skin or a patch behind the ear to help dry up any mucous. It is generally believed that these secretions do not distress the person.

When death occurs, your loved one's breathing will stop. It is also possible that within a few minutes it may seem that he or she is taking short sudden, deep breaths again. These are not true breaths. They are the body’s final physical release from life. This is normal at this point.

We realize that being with your loved one, watching and waiting, can be difficult. However, we believe the patient does not suffer when these breathing changes occur.

**Discomfort and Pain**

Pain does not usually worsen at the end of life. As the person becomes more sleepy, moves less and body chemistry changes, the pain may actually be reduced. Your doctor may need to adjust medicines to accommodate these changes.

It is important to remember that there is pain relief. Our aim is to relieve suffering associated with pain. Some people may have an increase in pain, but we can alter medicines and use other treatments to help. There is no limit in dosages of pain medicines that can be prescribed; there are a number of ways to manage discomfort. Sometimes you may hear your loved one moaning. This may happen when you move the patient from side to side, or when he or she breathes out. This moaning is not necessarily an indication of pain.

Persistent tensing or wrinkling of the forehead or moving the hands to a specific body parts, could be indications that your loved one is experiencing pain. The nurse will give medicine and provide other nursing measures to promote comfort.

**Swelling**

Swelling in the hands and feet is common because of loss of protein and fluids from tissue or infection. The swelling usually cannot be treated with medicines. Elevating and supporting the limbs may help with some re-absorption of the fluid.

**Temperature and vital signs**

Fever is common because the body’s temperature regulator is decreasing in its function. Tumour presence or infection may also cause a fever. Applying cool cloths may help your loved one feel more comfortable. The doctor will order medicine to bring the fever down. The nurse may not continue to take blood pressure and pulse regularly. This may only disturb your loved one's rest. Blood pressure and pulse readings are not reliable signs of impending death.

**Skin colour and coolness**

As your loved one comes very close to the time of dying, you may notice blotchiness and cooling of the skin - especially in the arms and legs. The skin may become a pale gray colour, or have a yellow hue if there is liver failure.

Your loved one will likely not be aware of, or troubled by, this coolness. He or she may actually express feelings of being too hot as the body's internal temperature is maintained. Soft, light blankets or loose socks help. Do not use heating pads or electric blankets.

Let your loved one to rest quietly. Plan visits and when your loved one seems more awake and alert. Staying quietly by the bedside for company is another option. Your loved one may not be able to respond, but will likely know you are there. Encourage friends and family to visit a few at a time for short periods.
Withdrawal

Your loved one may seem unresponsive, withdrawn or in a comatose-like state. His or her eyes may be partially open and not blinking. Your loved one is detaching from the surroundings and relationships and is beginning to “let go.” Voice and touch may be very reassuring to your loved one. This may be a time to review how loved and important he or she is. Tell your loved one how much he or she will be missed and how special life has been.

Always talk to your loved one knowing he or she can hear what you say. He or she may be too weak to respond or may not be able to speak, but will still be able to hear and understand you. Tell your loved one those things you want to say. Hug, touch and cry. All these motions are important to your loved one.

Disorientation

Your loved one may seem confused about time, place and identity, including familiar people. This may be caused by changes as the body prepares for death. This in no way diminishes how important you are to your loved one. If it is not upsetting, remind your loved one who you are, about the surroundings, the day and time and who is in the room. Speak clearly, truthfully and explain what you are doing.

Vision-like Experiences

Your loved one may speak to or see people who have died or see places not known or visible to us. This is not usually considered a hallucination or a drug reaction. It is a preparation for the transition of life to death. It is important not to contradict, explain, belittle or argue about what your loved one appears to have seen or heard. Listen openly and provide reassurance. You may want to affirm your loved one’s experiences. If you have any questions or concerns, please ask a member of your care team.

Level of awareness: emotional-spiritual-mental

Loss of awareness is common as the end of life approaches. Some people enter a “withdrawal” phase. They lose interest in people and things that are happening around them. They may also be confused about time, people, events or become anxious and restless. These changes may be due to the disease, decline of the major body functions or secondary effects from medicines.

Restlessness

Your loved one may appear restless or agitated and may make repetitive motions such as pulling at bed linens or clothing. Restlessness or agitation does not necessarily indicate that your loved one is in increased pain. The doctor and nurse may reassess pain medicine if changes need to be made. Avoid restraining your loved one unless absolutely necessary for safety.

Gentle massage, reading quietly, playing soothing music and calm reassurance can all be comforting. At times, medicine to relax your loved one may help. It is possible your loved one may be restless or agitated if there is something unresolved or unfinished disturbing him or her. The spiritual care provider or social worker may be able to help identify what is happening and what can be done to bring your loved one’s release from tension and fear.
Saying Goodbye
When your loved one is ready to die and you are ready to let go, it is time to say goodbye. Saying goodbye is not easy, but can be the final gift of love to your loved one. It may help achieve closure for both of you and make the final release possible. You may want to lie beside your loved one, hold him or her or clasp hands. Say whatever you want or need to say. It may be “I love you,” “Thank you for...,” or “I’m sorry for...”. You may want to talk about special memories. Tears are a normal and natural part of saying goodbye. You do not need to hide tears or apologize. Tears express love and sadness. Consider that each time you leave your loved one, it may be the last good-bye. If you need more information or would like to talk more about your feelings and concerns, please feel free to approach any member of the care team to help you.

Giving Permission
A dying person may seem to “hold on” to be sure that those who are left behind are going to be all right or to say goodbye to someone close. Giving your loved one permission to go, along with reassurance that you will be all right may bring peace and release.

When will I know death has occurred?
When death occurs there is no breathing, heartbeat (pulse) or response to calling or touching. There may be some reflex muscle movement for a brief time after death. The eyes may be open or closed and fixed on a certain point. The jaw may be relaxed and the mouth open. Some fluid may seep from the mouth and there may be loss of urine or stool as muscles relax. A nurse or doctor will “pronounce” or confirm that your loved one has died.

If you need time alone with your loved one, let the care team know. It is at this time you may wish to call a friend or family member for support. Your health care team is here for you. Let them know what you need.

Signs of Approaching Death: a Summary
For many people, there is a sequence of bodily changes before death. Not all symptoms will appear at the same time; some may never appear. However, knowing these conditions are part of the dying process, can help you prepare yourself.

1. Possible distancing or withdrawal from family and friends may occur. This is normal for the dying person.
2. Sensation and power of motion as well as reflexes are lost in the legs first, then the arms. Prepare for more physical help to get to the bathroom, the commode, then to bed.
3. Your loved one will probably eat very little in the last week of life, may forget to swallow and need to be reminded. Offer small amounts of fluids frequently, without forcing.
4. Your loved one will sleep more and at times be difficult to awaken. Plan conversations when he or she seems more alert, keep visiting times short or sit quietly at the bedside.
5. Your loved one may become confused about time and place or may not recognize familiar people. This is very difficult for family, but can be a normal part of the dying process. Speak calmly and naturally to your loved one.
6. Your loved one may experience impaired vision. He or she may turn to light. Leave a soft light on in the room. Your loved one may sleep with open eyes. Hearing is
the last sense lost; never assume your loved one cannot hear you. Continue talking to your loved one. Say what you want to say, even if he or she does not answer.

7. Your loved one may become restless, pull at covers or clothing, or have visions of people or things. These symptoms often result from a normal decrease in oxygen to the brain. Provide reassurance and avoid physical restrictions.

8. There may be no urine or bowel movement passed for 2 to 3 days before death. Incontinence of the bladder or bowels is often not a problem. It is important that your loved one is kept clean and dry to prevent skin breakdown.

9. As circulation to arms and legs decreases, purple mottling may appear on the skin and swelling. It is not uncomfortable for your loved one. It is unlikely your loved one will complain of feeling cold. Use normal bed covers tucked in loosely. Electric blankets should not be used.

10. Saliva may collect behind the throat with a rattling sound. This may be difficult for family to hear, but is not uncomfortable for your loved one. Raising the head of the bed, or turning him or her to the side can alleviate the sound. The doctor may order medicine to reduce secretions.

What to Do if Your Loved One Dies at Home

To avoid panicking, prepare yourself for what you will do when your loved one dies.

When death is expected to happen at home, it is not an emergency. Do not call 9-1-1. Calling 9-1-1 initiates emergency services, requiring cardio-pulmonary resuscitation (CPR).

It is important to prepare in advance and discuss actions to take with your community doctor or nurse. He or she will inform you who to contact and what to do if death happens during the night. It is not important to contact the doctor or funeral director right away.

You may want to position your loved one on the back with some padding under the body in case of bowel or urinary accidents. You may want to know in advance how to turn off any equipment or pumps. The doctor can help with removing any equipment. Loaned equipment will be picked up from your home later. Do not send it to the funeral home.

The doctor will come to your home to pronounce death and complete the Death Certificate. This form must be completed before your loved one’s body can be transferred. The funeral home will provide the transportation. You may want to confirm in advance how to proceed after your loved one has died. Do not call an ambulance for transportation only.

Please notify people who have been helping with care, especially if you are expecting them to visit (such as, the doctor, nurse or personal support worker).

Take time for yourself and your family.
We hug

We laugh

We cry

We love

E. Latimer
Important Phone Numbers

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It is our hope that this will provide support to caregivers across the city.