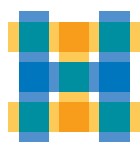


# Approaching the End of Life

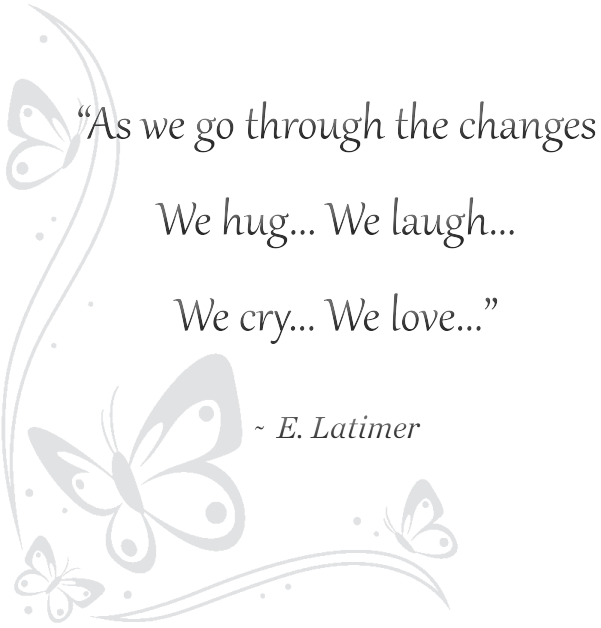


**A GUIDE FOR PATIENTS AND FAMILIES**



**NORTH  
YORK  
GENERAL**

*Making a World  
of Difference*



“As we go through the changes

We hug... We laugh...

We cry... We love...”

*~ E. Latimer*

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*We thank and acknowledge the contributions of our Patient and Family Advisors who partnered in the development of this brochure for all patients and families.*



# Issues discussed in this guide

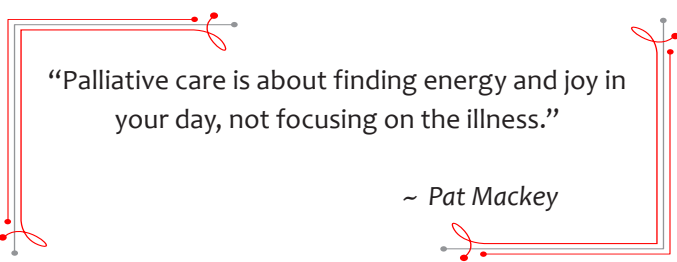
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# Introduction

*This booklet was developed by the Freeman Centre for the Advancement of Palliative Care. Palliative care is a medical specialty that provides care for patients with life-limiting illness. The aim is to provide care that promotes the best quality of life, through relief of pain and other symptoms, help with treatment decisions, and coordination of care. Palliative care can be offered at any stage of illness but this booklet will focus on what you may expect at the end of life.*

*It can be difficult to realize that death is part of life. Sadly, in the face of incurable disease, a time will come when nothing can change the body's progress towards death. The Freeman Centre's goals in caring for a dying person and his or her family are to maintain comfort, preserve dignity, and offer support.*

*We are aware that things have not been easy for you and your family up to this point. We want you to know that your needs and concerns - and those of your family - are very important to us. We have received many questions from patients and families that we care for about what they can expect to see and experience as life draws to a close. This information guide will explain some of the changes that may occur at the end of life. Our hope is that this guide will provide support and reassurance to you and your loved ones.*



“Palliative care is about finding energy and joy in your day, not focusing on the illness.”

~ Pat Mackey

# Caring for your loved one as end of life approaches

Below are suggestions that you may find helpful as you spend time with your loved one. There is no 'recipe' for caring as the end of life approaches. Cultural practices, beliefs, age, past experiences, and previous approaches to hard times all affect how we deal with dying.

- Allow your loved one to be involved as much as he or she wishes. Share news, plans and feelings with him or her.
- Listen to what your loved one is saying. He or she may be feeling many emotions, and may need to have these feelings validated. You can acknowledge with a nod or a touch.
- Allow a person who is ill to know the truth about his or her condition if he or she is asking.
- Show your feelings and concerns in your own way and in your own words.
- Be comfortable with silence. It is a natural and meaningful way of communicating.
- Help your loved one with his or her physical care if you feel comfortable doing so.
- Do not be alarmed if your loved one shares negative feelings with close family or friends.
- As a person nears death, he or she may withdraw and relate to only a few people or even one significant person. Do not think of this as rejection; it is an expression of decreasing brain function.

# Dying people's fears

An important aspect of caring for a dying loved one is having an awareness and understanding of his or her thoughts and fears. Being able to share feelings often brings a feeling of security to an ill person and a sense of closeness to those around him or her.

These are some of the most common fears at the end of life (adapted from Theodore Koff ID):

## 1. Fear of the process of dying

People are often concerned about what will happen as they die and the possibility of suffering. You can help to reassure your loved one that their care team will treat symptoms that may arise.

## 2. Fear of losing control of their lives/ being a burden

When people are ill, they need more help and may become increasingly dependent on others. They may also worry about being a burden to family and friends. Encourage your loved one to accept help when offered.

## 3. Fear of leaving loved ones

People facing the end of their lives are concerned about what is going to happen to their families after they are gone. You can help by providing reassurance that you will be “okay.” You can also help by encouraging them to participate in legacy work such as writing cards or letters to loved ones.

## 4. Fear of isolation

Some people are afraid that they will be alone at the time they die. They want to have people with them, especially those they know and love. Others may prefer to be alone and will encourage you to take breaks.

## 5. Fear of the unknown

People do not know what to expect after death has occurred. Even if your loved one is not religious or spiritual, a non-denominational chaplain can help to provide comfort and support.

## **6. Fear of others' reactions**

People who are ill are sometimes afraid that they will upset their family members if they talk about their true feelings. We all naturally feel anxiety and fear and it is usually better to share thoughts and feelings. People can also worry that changes in their appearance will be disturbing. It is helpful if family and friends are told in advance what to expect.

## **7. Fear that their lives have been meaningless**

People who are ill often reflect on how they have lived their lives. What they may need is someone who is willing to listen to or comfort them in sadness for things that cannot be changed. It may be beneficial to bring in familiar objects, look at photos, and arrange for special visitors to help dying people reflect and think about their lives. They may benefit from sharing significant cherished moments, occasions, accomplishments and memories.



## THE DYING PATIENT'S BILL OF RIGHTS

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.
- I have the right not to die alone. I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family in accepting my death.
- I have the right to die in peace and dignity.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face death.

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# Changes to expect at end of life

It is important to remember that, in spite of a serious illness, people live until the moment of death.

As the body prepares itself for death, physical changes will be a continuation of what has already occurred during the illness. The body's normal functions will decrease. Your loved one will need more help with self-care.

Your loved one may also begin to prepare for death emotionally, spiritually and psychologically. For example, he or she may wish to complete unfinished affairs, resolve disagreements, re-establish or deepen religious or spiritual connections, or receive permission to "let go." You can provide support by listening to and understanding these concerns, and providing assistance as appropriate. This may help your loved one to maintain a sense of control over his or her situation.

# Physical changes

## Weakness

Body functions will change as the disease progresses – increasing weakness and tiredness can happen gradually but sometimes happen quickly. At the end of life, it is normal for people to be most comfortable staying in bed. It is useful to have the ability to raise the head and height of the bed when care is provided. A hospital bed can be arranged for home use to assist with this.

Sleepiness may increase to the point that your loved one seems to be in a light sleep all the time, is more wakeful at night, or is in a coma or deep sleep. This is not something to be feared, as it does not mean pain or distress for your dying loved one.

Remember to talk to your loved one as if he or she can hear everything. He or she may be too weak to respond, but may be able to hear and understand what you say. Even at this point, it is important to take the time to talk, share, hug, and be with your loved one. Try to avoid loud noises in the room which may be startling or disturbing. We recommend having difficult or upsetting conversations away from the bedside.

## Appetite/ Food and fluid intake

There are many reasons for loss of appetite and weight. This is a normal process and is expected at the end of life. Symptoms like pain, nausea, constipation or shortness of breath may reduce the desire to eat and drink. Chemical changes in the body also decrease appetite. Your loved one may lose weight and become weak because the disease is progressing – not because of lack of food or fluid. It can be especially hard to watch a loved one lose interest in eating and drinking.

People approaching end of life generally do not feel hungry or thirsty. Food and fluid take on a different meaning when end of life is approaching. The focus is now on eating and drinking for pleasure and enjoyment not for nutritional value or extending life.

Our approach to care is to offer food and fluids in small amounts. If your loved one is awake, it is safest to raise his or her head prior to feeding. However, do not force your loved one to eat or drink. Do not offer food or

fluid to your loved one if he or she is too sleepy or not interested in eating or drinking. With time, your loved one will not be able to swallow safely: if he or she coughs after taking fluids, stop immediately, as the fluid may go into the lungs and cause more harm and discomfort.

### **What about mouth care?**

Most ill people complain of their mouth feeling dry. Your loved one may find it comfortable to have the mouth swabbed with water periodically. You can moisten the sponge-tipped swab (see Diagram 1) with water and gently clean and freshen the lining of the mouth, gums and tongue. If your loved one bites down on the swab when you put it into their mouth (a normal reflex reaction), hold onto the stick until he or she relaxes, and then gently remove it. Lip balm or a water-based lubricant can be applied to the lips every hour to keep them moist.



**Diagram 1**  
Mouth swabs

### **What about intravenous fluids?**

Intravenous (IV) fluids do not help to provide comfort at the end of life. IV fluids do not provide nutrition, and do not help to relieve dry mouth or thirst. Additional fluids will not be absorbed at the end-of-life and often start to ‘back up’ in the body causing swelling or increasing difficulty with breathing. As a result, IV fluids cause more harm than benefit and are not recommended at the end of life.

### **Swelling and skin changes**

Swelling in the hands and feet is common because of the loss of protein and fluids from tissue. Remember that this is usually not painful for your loved one. Medications do not typically help to reduce swelling at the end of life.

As your loved one approaches end of life, skin may also feel cooler as the body shuts down. Skin may appear discoloured, pale, and/or blotchy. Skin temperature may change from feeling warm to cool to the touch. These are all normal signs to expect as death nears.

## ***What about temperature and vital sign monitoring?***

Fever is common at the end of life as the body's temperature regulator decreases in function. Tumor presence or infection may also cause fever. The doctor may order medication to bring the fever down. You can apply cool cloths to help your loved one feel more comfortable.

Monitoring blood pressure and pulse is not helpful at this time and may actually disturb your loved one. Changes in these numbers (blood pressure and pulse) do not help to assess for comfort or predict when death will occur.

## **Discomfort/ Pain**

Pain or discomfort is not always present at the end of life. As your loved one's function declines, he or she may become sleepier and move around less. This decrease in activity may actually lead to less discomfort. Sometimes you may hear your loved one moaning. This can happen when you move your loved one from side to side, or when he or she breathes out. This moaning is not necessarily an indication of pain. However, persistent tensing/ wrinkling of the forehead or pointing to a specific part of the body may be a sign of discomfort.

Our aim is to relieve any suffering associated with pain through the use of medications.

## ***What about medication administration?***

There are different ways to administer medications:

(a) orally (by mouth) (b) with fast-absorbing pills under the tongue, and (c) through injection (which includes intravenous and subcutaneous routes). The preferred route is a subcutaneous line using a tiny "butterfly" needle inserted under the skin (see Diagram 2). A small port hangs out of the skin into which medications can be administered with ease. This helps to reduce unnecessary needle sticks.



**Diagram 2**  
Subcutaneous  
needle

## **Shortness of breath**

Shortness of breath is not always present at the end of life. Your loved one may experience difficulty breathing as their disease progresses and their

body weakens. You may notice that your loved one seems to be “working” harder at breathing. Changes in breathing patterns are normal and to be expected at this time.

Distress from shortness of breath can be managed with medications (such as morphine and/or relaxants), oxygen, sitting up your loved one, and/or using a fan directed at the face.

### **Bladder changes**

As death approaches for your loved one, the amount of urine output may decrease and be a dark colour. Your loved one may also lose his or her ability to control the bladder. A catheter (drainage tube) may be inserted into the bladder to help keep your loved one dry.

### **Bowel changes**

Bowel movements may become smaller and less frequent as your loved one’s intake of food decreases and the body functions slow down. Pain medications also affect bowel function. Laxatives and sometimes a suppository or enema may be required for comfort. The use of protective pads and briefs will help to keep your loved one dry and comfortable.

If your loved one has a colostomy, ileostomy, or ileo-conduit (openings in the bowel or bladder to drain waste away), the same changes in bowel or bladder function may be noticed.

### **Odours**

Body odours may increase due to infection, breakdown of tumour (in cancer) and other changes in the body. There are a variety of ways to help reduce and control odours like dressing products, air fresheners, and charcoal or kitty litter placed under the bed.

### **Eye care**

You may notice, as the body grows weaker, that your loved one does not focus or see as clearly. At times, during the final days of life, your loved one may sleep with his or her eyes open and this may cause the covering of the eye to become dry. Eye drops or ointments are available to help keep the eyes moist.

# Emotional and mental changes

## Withdrawal

As your loved one nears death, he or she may withdraw and relate to only a few people or even one significant person. Your loved one may seem unresponsive, withdrawn, or in a comatose like state. The eyes may be partially open and not blinking. At this point, your loved one is becoming less aware of his or her surroundings.

He or she may be too weak to speak, but may still be able to hear and understand what you say. At times your loved one may revert back to his or her native language. Familiar voices and touch are reassuring. This may be a time to express to your loved one how important he or she is to you, how much he or she is loved and will be missed, and how special his or her life has been.

Plan visits and conversations for times when he or she seems more awake and alert, or remain quietly at the bedside for company. Your loved one may not be able to respond but will likely realize you are there. Encourage friends and family to visit a few at a time and for short periods.

## Disorientation

At times, your loved one may seem confused about time, place and the identity of people surrounding him or her. Speak clearly and always explain what you are doing.

## Vision-like experiences

Your loved one may speak to or ‘see’ people who have already died or see things not known or visible to others. They may make statements about “packing their bags” or “going home.” This is not unusual behaviour for this time.

## Restlessness

Your loved one may become restless and agitated and make repetitive motions such as pulling at bed linen or clothing. Restlessness or agitation does not indicate that your loved one is experiencing increased pain.

If restlessness does not subside with pain medication, this may be because your loved one’s higher brain function is shutting down. In this situation,

sedative medication will provide comfort. Gentle massage, reading quietly, playing soothing music and calm reassurance may also provide comfort.

## When death is imminent

### Breathing pattern changes and secretions

When death is very close, you may notice differences in breathing pattern. For example, there may be times when your loved one temporarily stops breathing for several seconds. There may be repeated cycles of increased deep breaths followed by shallow breaths and then again no breaths for 10-30 seconds or longer. Again, this is normal at the end of life. Your loved one will not be aware of these changing breathing patterns and will not be distressed by them.

Breathing may also become noisy. This may be the result of saliva collecting in the throat, as swallowing will decrease near the end of life. Sometimes a soft, short moaning sound may accompany each breath out. This is a normal part of dying and does not indicate distress for your loved one. We can give medication to help dry up the saliva or secretions. Suctioning your loved one is not recommended as it can cause more discomfort.

Your loved one may not respond to you or be able to open his or her eyes. We encourage you to keep talking and touching your loved one as we believe that hearing and touch are the last senses to go. We do realize that being with your loved one and watching and waiting can be difficult. However, we believe that he or she does not suffer as these changes occur. At the time of death, your loved one's breathing will stop.



# Saying goodbye

When your loved one is dying, it is time to say goodbye. Saying goodbye is not easy, but can be a final gift of love and may help to achieve closure for both you and your loved one.

It is believed that the senses of hearing and touch are the last to go. We encourage you to continue talking to your loved one and touching them as you normally would. This is a time to say whatever you want or need to say. It may be “I love you”, “Thank you for ...”, or “I’m sorry for ... .” You may wish to recall special memories.

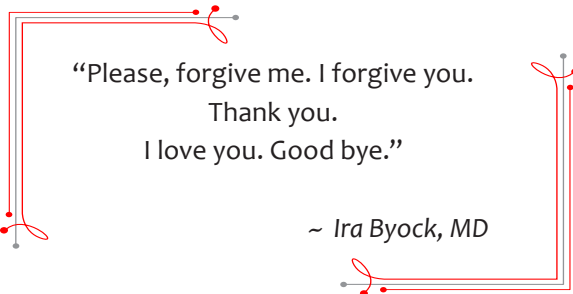
Tears are a normal and natural part of saying goodbye. Tears do not need to be hidden or apologized for as they express both love and sadness.

Consider that each time you leave your loved one, it may be the last goodbye.

# Giving permission

A dying person may seem to “hold on” in order to be sure that those who are left behind are going to be alright or to say goodbye to those who are close to them.

Giving your loved one permission to go, along with reassurance that you will be okay, will bring comfort to your loved one.



# Summary of the signs of approaching death

For many people, there is a sequence of changes that precede death. These changes do not occur at the same time, and some may not occur at all. Knowing that these changes are part of the dying process may help you to feel prepared, and lessen your fear of the unknown at a difficult time.

- 1) Possible distancing or emotional withdrawal from family and friends may occur – this is a normal part of preparation for death.
- 2) Weakness and increased dependency are expected as your loved one approaches the end of life.
- 3) Your loved one will likely eat very little in the last week of life. The safest approach to offering food or fluid is to offer small amounts only when he or she asks and is awake enough to swallow. Do not force your loved one to eat or drink, as this may cause choking and more discomfort.
- 4) Your loved one will sleep more and at times be difficult to waken. Plan conversations for when he or she is 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 members, but is a normal part of the dying process. Speak calmly and naturally to your loved one. Continue talking to him or her and say the things you want to say.
- 6) Your loved one may experience impaired vision. He or she may appear to sleep with his or her eyes open. Hearing is the last of the senses to go. Talk to your loved one and say the things you want to say. Assume that your loved one is able to hear you even if he or she does not respond. Express your love for them.
- 7) Your loved one may become restless, pull at covers or clothing, or have visions of people or objects. Your health care team can provide medication to help with these symptoms. Provide reassurance and avoid physical restraints.

- 8) Loss of control of the bladder or bowel is common near the end of life. Also, there may be a decrease in urine output and bowel movements before death. It is important that your loved one is kept clean and dry to prevent the skin from breaking down.
- 9) As circulation decreases, there may be changes in skin colour or swelling. These signs do not indicate that your loved one is cold, so use bed coverings of normal weight, tucked in loosely. Electric blankets should not be used as your loved one may not be able to communicate if he or she feels warm.
- 10) Saliva may collect at the back of the throat and sometimes makes breathing noisy. These “secretions” are a normal part of dying. It can be difficult for family members to listen to the secretions but is not uncomfortable for your loved one. Sometimes turning your loved one to the side can help. Medications may also be administered to help reduce secretions.

## THINGS TO CONSIDER AS DEATH APPROACHES

When you see these signs that the end is near for your loved one, we encourage you to continue:

- Talking to them
- Telling them you love them
- Reassuring them that you will be OK after their death
- Giving them permission to let go
- Saying goodbye every time you leave the room

# When death occurs

When death occurs, there is no breathing or heartbeat (pulse). There may be some reflex muscle movement in the neck or face 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 leak from the mouth, and there may be loss of urine or stool as muscles relax. After the death, we encourage you to take as much time with your loved one as you need.

A nurse or doctor will “pronounce death” to confirm that your loved one has died. The death certificate must be completed by a physician or nurse practitioner and goes with the body to the funeral home. Official copies of the death certificate can be obtained from the funeral home only after they are certified.

# What to do when someone dies at home

If you are caring for your loved one at home, it is important that you are prepared when death occurs. You may need to know in advance how to turn off equipment or pumps, or how to care for your loved one's body at the time of death.

An expected death at home is not considered an emergency situation. **Do NOT call 911.** Calling 911 initiates emergency services including attendants who perform cardio-pulmonary resuscitation (CPR).

When death occurs, there is no urgency to contact your physician. This can wait until morning (6am or later). This is an opportunity to take private time for yourself and for your family to take private time with your loved one.

Of course, we encourage you to do what is appropriate according to your religious/spiritual customs, beliefs and traditions. You may want to position your loved one on his or her back with some padding under the body in case of bowel or urinary accidents.

When your loved one dies, a health professional (nurse or physician) needs to pronounce death and they will help to prepare the body (e.g. removing medical lines/tubes). The death certificate must be completed by a physician or nurse practitioner and goes with the body to the funeral home.

The funeral home that you have chosen will provide transportation for the body. **Do NOT call an ambulance.** You may want to confirm with funeral home personnel in advance on how to proceed after your loved one has died.

Please notify people (i.e. physician, nurse, personal support worker) who have been assisting with the care of your loved one at home, especially if you are expecting them to visit. Borrowed or rented equipment will be picked up from your home at a later time. Medications can be taken back to your local pharmacy - do not send it to the funeral home. Remember to ask your care team about grief and bereavement supports.

# Summary of end of life symptoms

SYMPTOM	WHY IT HAPPENS	TREATMENT YOUR TEAM MAY SUGGEST
<b>Pain</b>	<ul style="list-style-type: none"> <li>■ May be caused by disease itself (e.g. a tumour or previous treatments)</li> <li>■ Does not usually worsen at end of life</li> <li>■ Not all patients experience pain</li> </ul>	<ul style="list-style-type: none"> <li>■ Opioid medications</li> <li>■ (e.g. Morphine or Hydromorphone)</li> </ul>
<b>Shortness of breath</b>	<ul style="list-style-type: none"> <li>■ May be related to disease, a decrease in lung function or flow of blood to lungs, or back-up of fluid in lungs</li> </ul>	<ul style="list-style-type: none"> <li>■ Changing position (sitting upright)</li> <li>■ Fan/increased oxygen</li> <li>■ Medications (e.g. opioids and/or anti-anxiety)</li> </ul>
<b>Drowsiness or sleepiness</b>	<ul style="list-style-type: none"> <li>■ Related to the dying process and the body's organs shutting down</li> <li>■ Sometimes can be related to medication</li> </ul>	<ul style="list-style-type: none"> <li>■ Saving periods of alertness for quality time with family</li> </ul>
<b>Weakness or tiredness</b>	<ul style="list-style-type: none"> <li>■ Related to the dying process and the body's organs shutting down</li> </ul>	<ul style="list-style-type: none"> <li>■ Energy conservation techniques</li> <li>■ Saving energy for quality time with family</li> </ul>
<b>Lack of appetite</b>	<ul style="list-style-type: none"> <li>■ Occurs when the digestive system receives less blood flow, and when the body shuts down</li> </ul>	<ul style="list-style-type: none"> <li>■ Very normal at end of life</li> <li>■ Focus on feeding for comfort and pleasure, not nutritional benefits</li> <li>■ Do not force your loved one to eat/drink</li> </ul>

SYMPTOM	WHY IT HAPPENS	TREATMENT YOUR TEAM MAY SUGGEST
<b>Restlessness, agitation and/or confusion</b>	<ul style="list-style-type: none"> <li>■ Occurs when metabolic changes affect brain function</li> <li>■ Often mistaken for pain (your health care provider will help you to determine which symptom it is)</li> </ul>	<ul style="list-style-type: none"> <li>■ Calming environment</li> <li>■ Providing reassurance</li> <li>■ Antipsychotic medications (e.g. Haldol, Nozinan)</li> </ul>
<b>Secretions</b>	<ul style="list-style-type: none"> <li>■ Occurs when swallowing becomes more difficult</li> <li>■ This is not distressing for your loved one but can be difficult to listen to</li> </ul>	<ul style="list-style-type: none"> <li>■ Repositioning</li> <li>■ Anticholinergic medications (e.g. Scopolamine or Gylcopyrolate)</li> </ul>
<b>Swelling</b>	<ul style="list-style-type: none"> <li>■ Occurs when the body is no longer processing food and fluid normally</li> <li>■ Usually this is not distressing for the patient</li> </ul>	<ul style="list-style-type: none"> <li>■ Stopping artificial hydration or nutrition</li> <li>■ Focus on feeding for comfort and pleasure, and nutritional benefits</li> </ul>

# Caring for yourself

Caring for a dying loved one is demanding. Try to attend to your own wellbeing so that you can continue to support your loved one. Allow yourself to be family first and caregiver second. Here are suggestions to help:

- Keep a list of people and phone numbers so that you can easily connect with someone to help and support you.
- Do what you can – but not more than you can – to take care of those you love.
- Know what you can and cannot do. This will help you to know when you need to ask for help and support.
- If you are at home, accept as much help as offered.
  - Explore other publicly or privately funded services that are available to support you at home (e.g. visiting nurses, volunteers, support groups, hospice services, etc.).
  - Accept support offered by 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 bring you food, cut the grass, help with transportation or babysit.
- Try to take time away from the bedside to take care of yourself.
- Keep a journal if this is helpful. Writing may help you to express your emotions and sort out your thoughts.
- When “all is said and done” it is very common that you may wish for death of your loved one to come sooner.

Continue to talk with your loved one. Hiding your emotions is exhausting. If you can, take time to share memories, tears, laughter, hopes and concerns. Remember that even though your loved one may not be as aware or able to respond, he or she may still be able to hear you.

Think about funeral planning and grief and bereavement support before your loved one dies. It can be more difficult to plan and make decisions after death occurs. Please feel free to ask the team for more information about this.



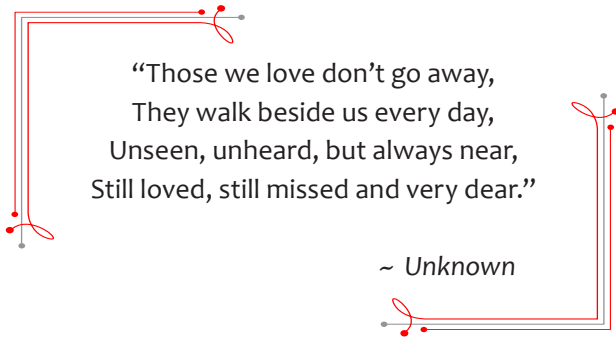
# Grief & bereavement

Everyone grieves in their own way. Some people may feel relief after their loved one dies. If you feel like you need support beyond your friends and family, reach out to your health care team, family physician and/or your spiritual/ religious advisor.

## Memorial service

North York General Hospital holds a semi-annual Multifaith Memorial Service at the General Site. This ceremony is open to all families, visitors, staff, physicians and volunteers who have lost a loved one. The intention of the memorial service is to contribute to healing in a positive and meaningful way.

For more information, contact 416.756.6311.





# Notes

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