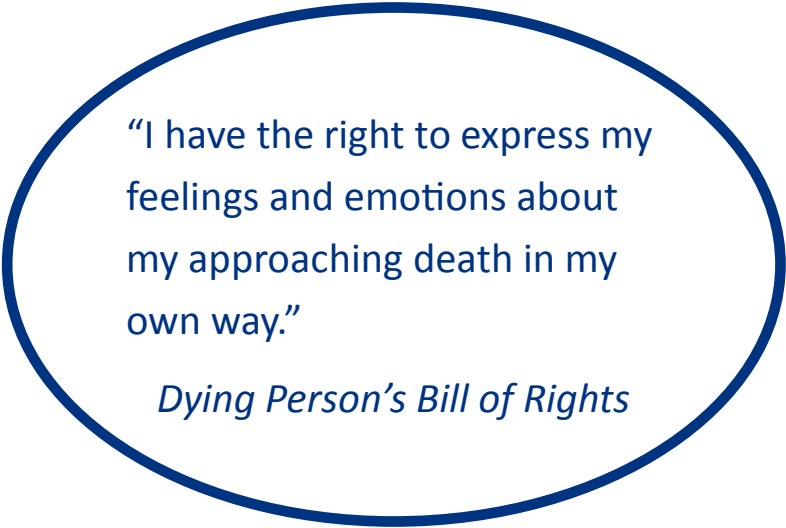


# SUPPORTING A LOVED ONE WHO IS DYING

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WHY IS THIS HAPPENING?  
WHAT CAN I DO?





“I have the right to express my feelings and emotions about my approaching death in my own way.”

*Dying Person's Bill of Rights*

Our thanks to Lori Tinkler, RN and Anke Graenet, RN for their suggestions and to The Township of King for its financial support of the 2009 version of this resource .

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While the term palliative usually means that there will be a progressive decline, and death is expected, all aspects of this care are designed to achieve the best possible quality of life for the dying person during whatever time is left.

## DYING...A MULTI-FACETED PROCESS

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**J**ust as illness affects the entire person, dying too is more than just a physical process; it is also psychological, emotional, social and spiritual.

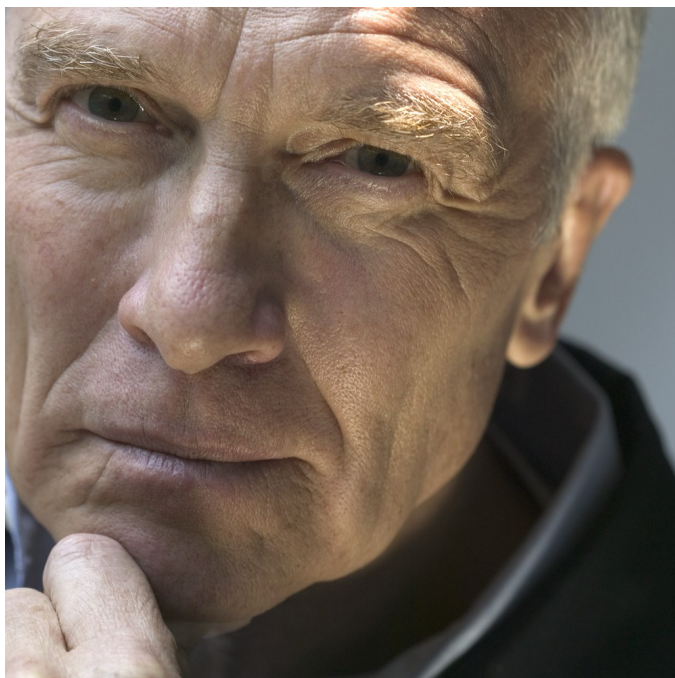
End-of-life (palliative) care aims to alleviate symptoms, reduce pain and provide support for both the dying person and the family in the final stages of illness. It is an approach to care that is responsive to the changing expectations and needs of both the dying person and the family.



Although it is impossible to prepare for the death of a loved one, knowing what and why something is happening can be both reassuring and empowering.

In this booklet you will learn about the expected dying process. This will help you better understand and respond to any physical and emotional changes that occur. It is not intended to replace the advice given to you by your medical providers.

The most important thing to  
be said about end-of-life  
symptoms is that almost all  
of them can be managed.



## PHYSICAL CHANGES THAT OCCUR DURING THE DYING PROCESS

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**D**eath is a natural process as the body's functions begin to shut down. The following physical and emotional signs at end-of-life are described to help you better understand what is happening.

Determining when to discontinue certain aspects of care can mean the difference between comfort or discomfort for the dying person and peace of mind for the family.

Communication between medical providers (nurse and/or doctor) and family is vital. It is the medical providers who will be able to help direct you regarding the best possible comfort measures for your loved one.



It is important to note that all dying experiences are unique and influenced by many factors. Not all of these signs and symptoms will occur with every dying person, nor will they occur in any particular sequence.

"I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals."

*Dying Person's Bill of Rights*

## FOOD AND FLUID INTAKE

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There will come a time when food loses its appeal. Loss of appetite and decrease in thirst are common. This is how the body maintains comfort. The body is beginning to shut down and does not need nourishment. It is important to listen to what the dying person wants and not what you think he/she ought to be wanting.

### WHY IS THIS HAPPENING?

As the physical body progresses through the dying process it loses the ability to digest food effectively. Forcing a dying person to eat when the stomach's ability to digest food is diminished will cause the person to feel bloated.

Likewise forcing fluids or giving intravenous fluid can cause discomfort which may also affect breathing.

The swallowing reflex will also diminish and at some point the dying person will no longer be able to swallow.

### WHAT CAN I DO?

The person may ask for ice chips, popsicles, ice cream or other choice food or beverage, but they may only take a small mouthful.

Listen to, and respect the amounts the dying person wants. Never force food or fluids.

Apply balms and moisture for dry lips and mouth. Small mouthcare sponges can be dipped in a favourite beverage and rubbed on the lips for comfort.



People do not die because they stop eating or drinking, they stop eating and drinking because they are dying. One of the most difficult truths for people to accept is this: in most cases some degree of dehydration will help to keep the dying person more comfortable.

## BREATHING PATTERNS

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Changes in breathing patterns are common and indicate the natural progression towards death.

### WHY IS THIS HAPPENING?

When the person loses the ability to swallow, saliva and secretions may build up in the throat. These secretions can gurgle and crackle and may sound like choking. This causes **no discomfort**.

Breathing often changes to a new pattern of several rapid breaths followed by a period of no breathing. Breathing may stop for 10-30 second periods or there may be rapid, shallow panting.

A moaning sound may occur as the breath passes over the relaxed vocal chords.

When a person is just hours from death, a fairly deep panting pattern emerges. This pattern is driven by the autonomic nervous system after much of the rest of the brain has already shut down.

A final, or “agonal” respiratory pattern is an ineffectual gasping of the mouth with little or no actual intake of air. This occurs very near death.

### WHAT CAN I DO?

Medications may be given to help decrease some of these secretions. It may be helpful to keep the head of the bed elevated (or use pillows) or turn the person to one side and gently wipe away secretions with a moist cloth.

Apply balms and moisture for dry lips and mouth. Small mouth care sponges can be dipped in a favourite beverage and rubbed on the lips for comfort.

Caregivers sometimes mistakenly think this panting pattern indicates recovery rather than approaching death because it is so regular and appears to be effective.



“I have the right to be treated as a living human being until I die.”

*Dying Person's Bill of Rights*

## THE SKIN

---

As death approaches, the skin will likely undergo changes in **colour, texture and temperature.**

### WHY IS THIS HAPPENING?

When a person is dying, the heart gradually slows down. The body temperature can go down by a degree or more. Blood circulation flows to the vital organs not to the extremities. Hands and feet become cool. The face may be pale and the legs may become a purple-mottled colour.

Blood pressure will also gradually lower and blood flow to the hands and feet will decrease.

The skin becomes dry and loose to the touch due to natural dehydration.

There may be swelling of some body parts which can be a sign of fluid imbalance.

### WHAT CAN I DO?

Generally the dying patient is not conscious of being cold even though the body surface may be. Therefore don't misinterpret that the patient feels the cold.

Keep the skin clean and dry. Frequent change of position is helpful if appropriate.

Discuss persistent reddened areas or swelling with your medical provider.

"I have the right to die  
in peace and dignity."

*Dying Person's Bill of Rights*

The amount of urine and stool will decrease as food and fluid intake lessens. Your loved one may lose control of bladder or bowel function as the muscles begin to relax. As death draws near, total bowel and/or bladder shutdown may be expected.

### **WHY IS THIS HAPPENING?**

Lack of food/fluid intake, decreased physical activity and changes in circulation cause a decrease in bowel and kidney activity.

As the body's organs begin to shut down (a normal part of the dying process), some swelling in the abdomen may be noticed.

### **WHAT CAN I DO?**

There comes a time when one has to consider whether laxatives or enemas are achieving more or less comfort for a person. Your medical provider can help you determine when the time has come to stop worrying about these functions.

Dying people and their caregivers often express a fear of dehydration, yet some degree of dehydration is preferable during the dying process because it generally keeps the person more comfortable.

## SLEEP PATTERNS

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Dying people spend a great deal of time in a sleep/dream state. It may become more difficult to waken your loved one.

### WHY IS THIS HAPPENING?

The normal sleeping pattern during the dying process is virtually identical to the normal sleeping pattern of newborns – off and on, around the clock. Increased time spent sleeping is common and desirable for the dying person's comfort.

Dreams tend to become increasingly vivid during the dying process.

As the amount of oxygen to the body decreases and the organs begin to fail, the dying person may exhibit restlessness, moaning or involuntary movement or twitches. This does not necessarily mean that they are experiencing pain.

### WHAT CAN I DO?

There is no night or day – just dozing off and on, day or night. Gentle touching, stroking and soft words can be a comfort to the dying person even while in this state.

Don't be inclined to blame vivid dreaming on medications and reduce or stop the normal dose.

An increase in restlessness should be reported to your medical provider.

## PAIN & PAIN MANAGEMENT

---

Morphine or a similar narcotic is often prescribed and is very safe when used to control pain. Anti-anxiety medications (ie. Ativan) may help if the dying person appears agitated.

### WHY IS THIS HAPPENING?

It is not unusual for dying persons to experience sensory changes. Sometimes they misperceive a sound or get confused about some physical object in the room.

Dying persons may hear voices that you cannot hear, see things that you cannot see, or feel things that you are unable to touch or feel. Some dying persons can confuse reality.

### WHAT CAN I DO?

Use soft lighting. Reduce confusion by limiting noisy distractions such as television or radio.

Talk calmly and reassuringly. Do not argue if reality is different for the dying person. Sometimes agreeing with someone who is mildly confused allows the situation to pass without creating upset.

Stopping or reducing pain medication leads to higher levels of pain and restlessness which inhibit sleep and lessen comfort.

There is no need to be concerned that your loved one is becoming addicted to narcotics or being overdosed. It's very difficult to overdose from a narcotic you have been routinely taking for pain.

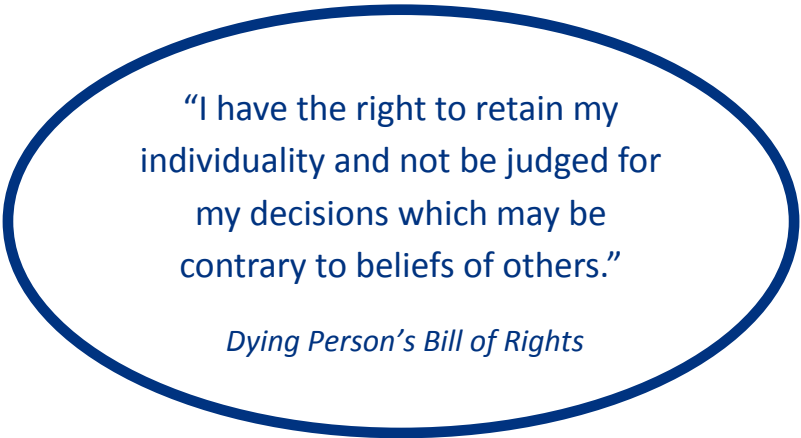
## CHANGES IN LEVELS OF AWARENESS

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**Y**our relationship with the dying person will likely change during the final stages of their illness. As their level of awareness gradually diminishes, the need for your compassion towards them increases. Your role may now be to anticipate and interpret their needs. It is important to know the wishes of the dying person and to respect them.

**There is something truly magical about one human being simply “being there” for another. One of the most effective comfort measures to alleviate the fear of dying is the presence of another human being.**

Being present - with understanding, acceptance and respect for your loved one is the true essence of compassion.

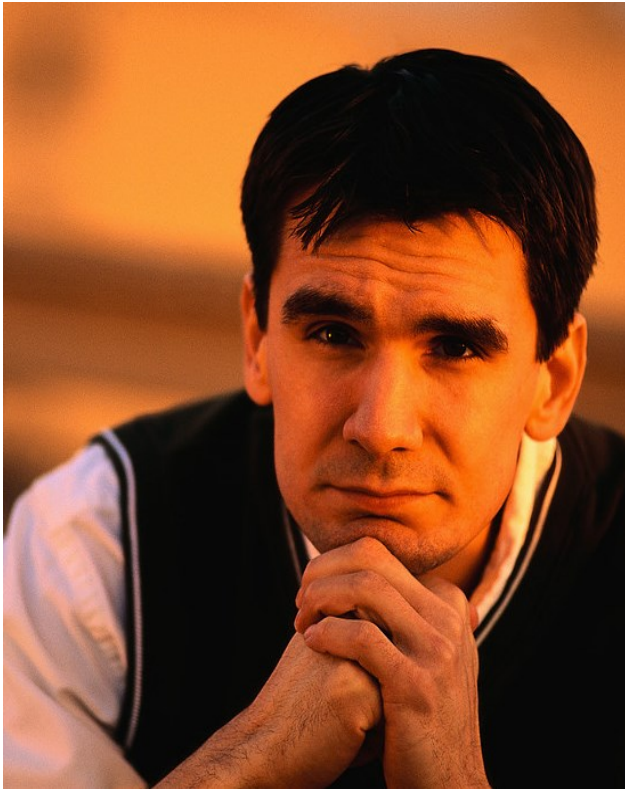


“I have the right to retain my  
individuality and not be judged for  
my decisions which may be  
contrary to beliefs of others.”

*Dying Person's Bill of Rights*



It is not necessarily what you might say or do, but your very presence that makes the difference.



## RESTLESSNESS & CONFUSION

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At times your loved one may become restless, for example, reaching out to unseen objects, pulling at bedclothes or trying to get out of bed. They may speak to people or see places that are not visible to you.

### WHY IS THIS HAPPENING?

Moving about in time/space, and thus being somewhat confused, is a natural and normal aspect of the dying process.

Confusion about time, place and recognition of people, even close family members and friends is common. You may find the dying person is slower to become alert when waking from this deep dream/sleep state. Eyes may appear glazed.

### WHAT CAN I DO?

Touch and silence take on more meaning as words lose their importance. This does not mean that the person does not benefit from hearing your words.

Identify yourself by name to your loved one. Sit with your loved one and reassure them that you are there.

Try not to explain away what the person is saying. Reality may be different for the dying person. Sometimes agreeing with someone who is mildly confused allows the situation to pass without creating upset.

Stopping or reducing pain medication leads to higher levels of pain, restlessness and confusion.

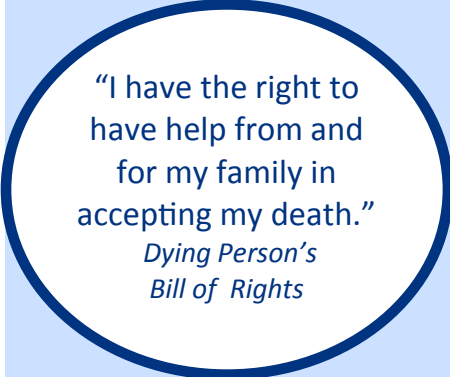
## EMOTIONAL WITHDRAWAL

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Your loved one will become quieter and less interested in physical surroundings. He or she may become withdrawn and less sociable.

### WHY IS THIS HAPPENING?

Advanced illness can affect a person's ability to think clearly and respond to surroundings. As the body dies, brain function is reduced and the dying person is less responsive.



"I have the right to  
have help from and  
for my family in  
accepting my death."

*Dying Person's  
Bill of Rights*

### WHAT CAN I DO?

Identify yourself by name to your loved one. Sit with your loved one and reassure them that you are there.

Hold their hand. Touch can be very comforting.

Speak softly, clearly, and truthfully when you communicate. Speak in present tense (the dying are still living).

Don't be afraid of silences: simply be present, open-minded and accepting. Sometimes words are necessary and sometimes silent awareness is more important.

Limiting the number of visitors to those significant to the dying person may be appropriate at this time.

Many find it comforting to engage in familiar rituals and/or prayers. Rituals that are meaningful to the patient are often effective.

## LAPSING INTO A COMA

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Most often before death, people will lapse into a coma. A coma is a deep state of consciousness in which a person cannot be aroused. All evidence suggests that people in a coma still hear what is said even when they no longer respond.

### WHY IS THIS HAPPENING?

Because the central nervous system is directly impacted by the dying process, it too begins to shut down.

### WHAT CAN I DO?

Always act as if the dying person is aware of what is going on and is able to hear and understand voices. Hearing is one of the last senses to lapse before death.

Reading aloud from a favourite book (i.e. religious text, newspaper, poetry) may be soothing.

**“I have the right  
to not die alone.”**

*Dying Person’s Bill of Rights*

People die in their own time.

Sometimes it seems to be taking longer than you anticipated. Perhaps the dying person is more in charge than we understand.

We may expect ourselves to be present at the time of death, but can't always control this.



Stay rested, eat properly. Know what refreshes you and take the time to do so.

## WHAT ABOUT ME?

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The experience of providing supportive care for someone approaching death can affect every aspect of your life. It is a time of strong emotions. Feelings such as guilt, anger, frustration or sadness are common among people who are supporting a person as death approaches. Often the person providing support will become exhausted, and perhaps feel helpless. This is normal.

### WHY IS THIS HAPPENING?

Normal family routines will be disrupted and you may feel you have lost your ability to concentrate. Due to emotional and physical exhaustion, uncertainty and helplessness, you may wish for “things to be over”. Be assured that you are not alone in these feelings. This is often expressed by loved ones.

### WHAT CAN I DO?

Keep information about care needs and people to call in a single notebook.

Prepare a list of people to call near or at the time of death.

Take regular breaks. Caregiving is not a ‘solo act’. Involve other family members or professionals in providing support. Asking for help is not a sign of weakness or an admission of failure.

Smiles and laughter among family members and friends can ease tension.

Attend to your own cultural, emotional and spiritual needs.

## **TOUGH QUESTIONS...**

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### **DO YOU WANT YOUR LOVED ONE TO RECEIVE ARTIFICIAL NUTRITION AND/OR HYDRATION?**

This means whether or not to have tube feeding or intravenous fluids. This may prolong life for a few days but not necessarily make the dying person comfortable.

### **IS A “DO NOT RESUSCITATE” (DNR) IN PLACE?**

A DNR order is a written order (witnessed by a doctor or nurse) stating that resuscitation should not be attempted in the event of cardiac or respiratory arrest. Keep this directive in a readily accessible place. You will need to tell people who sit with or provide nursing care that a DNR is in place. The DNR applies to home, ambulance and in hospital.

### **HAVE YOU DEVELOPED A PLAN WITH YOUR MEDICAL TEAM (NURSE AND/OR DOCTOR) ABOUT WHO IS TO BE CONTACTED AT THE TIME OF DEATH?**

The doctor is not always required to come when an expected home death occurs. Prior arrangements can be made with your CCAC case manager or visiting palliative nurse.

### **HAVE YOU MADE FUNERAL ARRANGEMENTS?**

If you have not already done so, you should consider making funeral arrangements with a funeral home and tell them that a death is expected.

### **DO YOU HAVE SPECIAL REQUESTS FOR PASTORAL CARE, OR FOR SPECIAL CULTURAL OR RELIGIOUS RITUALS TO BE OBSERVED?**

People vary greatly in their beliefs. A spiritual advisor can provide support to both the dying person and the family. You should consider calling to let them know that a death is expected.



## **HAVE YOU CONSIDERED WHAT YOU MIGHT DO IF YOU OR YOUR LOVED ONE HAS A CHANGE OF MIND ABOUT A PLANNED HOME DEATH?**

If there is a change of plans regarding a home death, your medical provider can assist with appropriate placement. This in no way should be considered a failure. Explain to the dying person the decision to move them. You can still help provide support in a hospice, hospital or nursing home.

### **TIPS FOR PROVIDING SUPPORT IN A HOSPICE OR HOSPITAL SETTING**

Be with the person during the move.

Take meaningful objects from home to help make the surroundings familiar.

Continue to stay involved with the person's care either by helping make decisions or by helping with simple tasks.

You might find it helpful to have a visitor log book. It will keep you aware of who is visiting and may encourage meaningful conversation with your loved one.

Find out about parking, after-hours visiting, meals & nourishment for family.

Ask for comfortable sleeping arrangements if you wish to spend the night.



## WHEN DEATH OCCURS

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**F**amily members are rarely ready to see a loved one die – as much as you think you’re ready, you’re usually not.

### WHAT YOU NEED TO KNOW:

At the time of death, body functions stop.

There will be no response, no breathing and no pulse.

The eyes will be fixed in one direction; they may be open or closed.

The jaws will relax and mouth may be open slightly.

There may be loss of control of bladder or bowels.

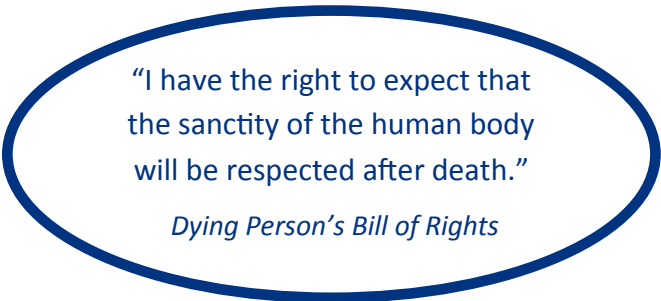
The skin will become cold and waxy.

**Once death has occurred, you may feel an urgency to “do something” but there is no rush.**

Spend as much time with your loved one as you wish. Take time to say goodbye.

Be supportive of anyone who chooses to hug or caress the person. (These are normal ways of working through the finality of death.)

As previously arranged (see page 20), call your visiting palliative nurse or doctor to let them know that death has occurred.



“I have the right to expect that the sanctity of the human body will be respected after death.”

*Dying Person’s Bill of Rights*

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## LINKS & RESOURCES

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<b>Advance Care Planning</b>	<a href="http://www.advancecareplanning.ca">www.advancecareplanning.ca</a>
<b>Community Care Access Centres (CCAC)</b>	<a href="http://www.ccac-ont.ca">www.ccac-ont.ca</a> Richmond Hill 905-763-9928 Newmarket 905-895-1240
<b>Cancer Resource Centre</b>	<a href="http://www.cancerresourcecentre.com">www.cancerresourcecentre.com</a>
<b>Dying with Dignity</b> Living wills and durable power of attorney for healthcare	<a href="http://www.dyingwithdignity.ca">www.dyingwithdignity.ca</a>
<b>Find Your Hospice</b>	<a href="http://www.findyourhospice.ca">www.findyourhospice.ca</a>
<b>Hospice Palliative Care Ontario</b>	<a href="http://www.hpco.ca">www.hpco.ca</a>
<b>Canadian Virtual Hospice</b>	<a href="http://www.virtualhospice.ca">www.virtualhospice.ca</a>
<b>Canadian Hospice Palliative Care Association</b>	<a href="http://www.chpca.net">www.chpca.net</a>
<b>Bereaved Families of Ontario York Region</b>	<a href="http://www.bfoyr.com">www.bfoyr.com</a> 905-898-6265
<b>Helpguide</b>	<a href="http://www.helpguide.org">www.helpguide.org</a>
<b>Losing Our Parents</b>	<a href="http://www.losingourparents.com">www.losingourparents.com</a>
<b>Center for Loss &amp; Life Transition</b>	<a href="http://www.centerforloss.com">www.centerforloss.com</a>
<b>Hospice Palliative Care Teams for the Central LHIN</b>	<a href="http://www.centralhcnetwork.ca/hpc/hpcteam">www.centralhcnetwork.ca/hpc/hpcteam</a>

# NOTES

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## NOTES

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Hospice King-Aurora first prepared this booklet in 2009 for those in our community caring for a dying person. A few updates have been added to this 2013 edition.

**Hospice King-Aurora** offers specialized services and support to those living with life-threatening illness, the people who care for them and those who are bereaved. We're here to help.

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**Care ♥ Compassion ♥ Support**