



Kingston  
General  
Hospital

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# Kingston General Hospital

**A Guide to Understanding Death and Dying:**  
Information for Family and Caregivers





## Introduction

Knowing your loved one is close to dying can be painful and difficult. For many of us, death arrives as an unwelcome event. The changes your loved one goes through are often hard to watch. As a family member or caregiver, you may be facing challenges that are unfamiliar to you and can seem overwhelming.

Dying is a different experience for everyone. This is true for the person whose life is ending as well as for the family and caregivers who must let go. However, there are some common things that happen to a person's body, emotions and spirit as death nears. These changes are a normal part of dying. Knowing what to expect can bring you comfort and help you cope with fear and anxiety. When your fear and anxiety are lessened, you may be able to find more meaning in this journey.

This booklet will tell you about the expected changes your loved one may go through. The booklet will also provide suggestions for how you can help comfort your loved one. In addition, there are tips for how to cope and look after yourself and other loved ones during this difficult time.

You can read this booklet all at once or just read the parts you need. Remember, your loved one may not go through all of the changes described in this booklet.

Please speak to your healthcare team if you have any questions or concerns.



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## Changes as Death Approaches

There are some common things that happen to a person's body, emotions and spirit as death nears. These changes do not always move along at the same pace, and will vary from person to person.

The next section will address the physical changes that may occur as death approaches.

### Physical (Body) Changes As Death Nears

There are common physical changes that one can expect as death nears, such as changes in:

- Circulation (blood flow)
- Pain and discomfort
- Swelling
- Intake of food and fluids
- Breathing
- Mouth and lung secretions
- Bladder and bowel function
- The senses (eyes and vision, hearing)
- Confusion and restlessness

These changes occur because the body is slowing down. Things that may seem unusual for a healthy person are normal and expected for a person nearing death.

## Circulation (blood flow)

### What changes can I expect?

- Hands, feet and legs usually get colder to the touch as circulation slows.
- Blood pressure gradually goes down and heart rate gets faster, but weaker.
- Skin may become waxy and pale.
- Fingers, earlobes, lips and nail beds may look bluish or light gray. The healthcare team refers to this as *cyanosis*.
- Purplish or blotchy red-blue coloring on knees or feet is a sign that death is very near. The healthcare team refers to this as *mottling*.

### What can I do to help?

- Add or remove blankets to make your loved one feel more comfortable. A flannel top sheet can be comforting.
- A gentle massage may be soothing.
- It helps to change your loved one's position every 1 ½ to 2 hours. Your nurse will come in to do this regularly. You can help your nurse with this if you like. At least 2 people should perform repositioning.

## **Pain and discomfort:**

### **What changes can I expect?**

- Your loved one may feel pain in different parts of their body.
- There are many medications and other treatments that can be prescribed to help control the pain.
- Medications can be given other ways if your loved one has trouble swallowing.
- Often a small pump is used to deliver medications on a steady and regular basis. The healthcare team may refer to this pump as a *CADD pump*.

### **What can I do to help?**

- It may be difficult to know if your loved one is in pain, especially if they cannot speak. Talk to the healthcare team about what signs of pain you can look for. These signs include:
  - Frowning
  - Moaning
  - Moving around or unable to get comfortable
  - Pulling away when touched
  - Crying out
- If you think your loved one is in pain, explain to your nurse what you see or hear.
- Ask your healthcare team about applying heat or cold, massage therapy or relaxation therapy to try and help control the pain.



## **Swelling:**

### **What changes can I expect?**

- Your loved one may get swelling of the legs or arms. This swelling may cause discomfort.

### **Why is this change happening?**

- Swelling is usually caused by medications, lack of movement, side effects of treatment, or the illness itself.

### **What can I do to help?**

- Try to keep your loved one's arms or legs raised as much as you can.
- Talk to your healthcare team to see if wrapping your loved one's arms or legs will help.

## **Intake of food and fluids**

### **What changes can I expect?**

- The dying person will feel less hungry and thirsty as time goes on. Not eating and drinking is normal.
- Your loved one's mouth may become dry.
- As eating and drinking taper off, there is less fluid buildup and less need to urinate. This natural process promotes comfort for the dying person.
- Your loved one may become drowsy or feel sedated. This is a way of nature taking over to help the dying person feel peaceful.

## **What can I do to help?**

Seeing a loved one lose interest in eating and drinking is often difficult for family because this signals the end of what normally sustains life. You may even feel angry that your loved one is not eating and may interpret this as he or she not wanting to remain alive or that they are “giving up”.

- Let the dying person lead the way. Support your loved one if they make the decision to stop eating or drinking.
- Trust that your loved one is following cues from his or her body and spirit.
- If your loved one is alert and able to swallow, you can offer them ice chips or fluids on a small spoon. Raise the head of their bed before you feed them ice chips or fluids. Stop right away if you hear them coughing.
- If their mouth is dry, you can use swabs or moisture sprays. Your nurse can provide these to you.
- Do not feed or give fluids to your loved one when they are drowsy or sleepy. It may go in to their lungs and cause choking.

## **Mouth and lung secretions**

### **What changes can I expect?**

- Secretions usually thicken and build up in the lungs or at the back of the throat.
- Breathing may sound moist, congested or rattly. This may come and go. The dying person is usually unaware of these changes

### **Why is this change happening?**

- Due to increasing weakness, the person does not have enough muscle strength to cough or clear their own secretions.

### **What can I do to help?**

- Ask the nurse or doctor about medications to dry up the secretions.
- Turn and reposition your loved one every few hours. This can help stop secretion buildup.
- If it is comfortable for your loved one, raise the head of their bed.
- Provide mouth care regularly. Use mouth swabs soaked in water to keep their mouth moist.

## **Breathing**

### **What changes can I expect?**

- There will be changes in the rate, depth and rhythm of your loved one's breathing.
- Your loved one may stop breathing for short periods of time (5-30 seconds). The healthcare team refers to this as periods of *apnea*. These periods will get longer and become more regular as your loved one nears death.
- Sometimes your loved one's breathing might become slow and shallow, then become faster and deeper, then slow down again to a period of apnea. This is a normal pattern of breathing when someone is approaching death. The healthcare team refers to this as *Cheyne-Stokes breathing*.
- These changes are normal and do not mean that the person is short of breath or choking. The dying person is usually unaware of these changes in breathing.

### **What can I do to help?**

- If your loved one is short of breath, try placing a fan nearby. The effect of air moving across the face can help people feel less short of breath.
- Ask the nurse or doctor about medications to manage shortness of breath.
- A calm and quiet environment with soothing conversation or music can be helpful.

## **Bladder and bowel function**

### **What changes can I expect?**

- As your loved one's muscles begin to relax, they may lose control of their bladder and bowel.
- They will urinate less. Their urine may become darker as their kidneys stop working.
- Your healthcare team will make sure your loved one is clean and dry of urine and stool. Your nurse will suggest using disposable pads/briefs.
- The healthcare team may also talk with you about placing a catheter in your loved one. A catheter is a tube gently placed in the bladder to help drain urine. A catheter and disposable pads/briefs will help stop skin breakdown and can provide comfort for your loved one.

### **What can I do to help?**

- Tell your nurse if you think your loved one needs to urinate or have a bowel movement.
- If your loved one has not had a bowel movement in 3 to 4 four days this could cause discomfort. Talk to your nurse about medications that can help with constipation.

## **The senses (eyes and vision, hearing)**

### **What changes can I expect?**

- Your loved one may have a harder time focusing or seeing clearly.
- As your loved one approaches death, his or her eyes and vision may become overactive. This may cause your loved one to withdraw from or push away sights, sounds or people. This is a protective way of toning down the senses, and it is not meant to personally reject you.
- It is normal for your loved one's eyes to be a little open, even when sleeping.

### **What can I do to help?**

- Always assume your loved one can hear even though they are unable to respond. Hearing is usually the last sense a dying person loses.
- Although communication with your loved one becomes more limited, gentle touch is a way you can remain close to him or her.
- Create a comfortable environment using soft light, favourite music playing quietly, storytelling and sharing memories.

## **Confusion and restlessness**

### **What changes can I expect?**

- As a person nears death, changes in mental activity and consciousness can occur.
- Your loved one may start to feel confused, restless or agitated. He or she might try to get out of bed.
- Consciousness may change back and forth between being alert and aware to being in a deep sleep and unresponsive.
- Your loved one may start to see things that are not there. This is called a hallucination.

### **Why is this happening?**

- Confusion, restlessness or agitation can be caused by different changes in the body such as lack of oxygen to the brain, organs shutting down, pain or infection.
- Restlessness might also be caused by the dying person working through emotional and spiritual issues before death.

### **What can I do to help?**

- Gently remind your loved one what your name is and who you are, where they are, and who else is in the room. This can help calm fears.
- Speak softly, clearly and in short sentences.
- Ask your nurse or doctor about medications that can help soothe agitation or ease distress.

- Create a quiet and calm environment.
- If your loved one sees something that is not there, comfort them if they are upset.





## Emotional Changes As Death Nears

It is common to have emotional changes as one nears death. This is true for the person who is dying as well as for family and caregivers.

The next section will address emotional changes that might take place for the person nearing death, for family and caregivers, and talking to children about death.

### **For the Person Nearing Death**

As your loved one nears death, changes to their emotions (inner feelings) and relationships can take place. During this time your loved one may be working through important life issues such as:

- Life review- looking back at one's life in search of meaning.
- Closure- saying goodbye to people and places, forgiving and being forgiven, or facing regrets.
- Accepting or coming to terms with ongoing changes and eventual death.

As your loved one's physical condition gradually weakens, talking about these issues may become more difficult. Looking after practical matters or "putting one's affairs in order" can relieve anxiety and reduce fear for the person nearing death. Common practical matters at the end of life include:

- Addressing a Power of Attorney for Personal Care/Health and for Finances
- Talking about advance care directives
- Making a will
- Planning the funeral

### **What can I do to help?**

- Bring familiar things from home for comfort. For example, you can bring blankets, photos and music.
- Try to help your loved one address practical issues that need attention as early as possible.
- Take cues from your loved one and be available for listening. Share your feelings and memories with each other.
- Friends and family may feel uncertain about what to do at the bedside. However, the simple presence of loved ones near the end is usually more important than what is done or said. Families often just go on visiting, reading, laughing and joking, telling stories or watching television. This is quite likely what would most please the person who is dying- knowing that family members are there and supporting each other.
- Offer or ask for forgiveness
- Find ways to say good-bye, this will be important for your grieving. Saying goodbye can happen through words, letters, rituals, or by just being beside and touching your loved one.

## **For Family and Caregivers**

Family and caregivers may feel confused, exhausted and numb at the time of a loved one's death. Planning ahead can ease your stress during your loved one's illness and after their death.

In order to better care for your loved one, you must also care for yourself. Things you can do to care for yourself:

- Try to get enough sleep and eat a well-balanced diet.
- Take a break and do something you enjoy.
- Ask for and accept help from family and friends.
- Find ways to handle updates. Designate a friend to communicate with others.
- Share your feelings with your support network and healthcare providers.
- Understand that it is normal to have changing emotions.
- Ask for a visit from someone from spiritual care or your faith community.
- If you have any questions for the healthcare team, write them down. This will help you remember what to ask when you see them.

Ask to talk to a social worker or chaplain for additional support. They are here to help both adult and child family members and friends.

## Talking to Children about Death and Dying

It is very hard for us as adults to understand and accept that a loved one is dying. It is not surprising then to want to protect our children from feeling these overwhelming emotions. However, it is very important for children to be included when a loved one is dying.

- A child's grief can be eased with open and honest communication about what is happening. Children benefit from simple, direct and truthful information, using as much detail as the child is able to understand.
- Children need to be reassured about their own security. They often worry that they will also die or that their surviving parent will go away.
- When discussing death with children, use words such as died, or "death". Words like "passed away", "sleeping" or "we lost him" can confuse children and lead to misunderstanding.
- Stories such as The Fall of Freddie the Leaf: A Story for All Ages by Leo F. Bascaglia and the Velveteen Rabbit by Margery Williams Bianco are good books to read with children to help them talk about living and dying. *Books are available for loan at the Patient and Family Resource Centre in the hospital. Ask your nurse or social worker about how to access the Resource Centre.*

## **Spiritual Changes As Death Nears**

The next section will address spiritual changes that might take place for your loved one as they approach death.

### **What is spirituality?**

Spirituality may include but is not limited to religious beliefs. A person's spirituality is very unique and personal. The language and rituals used to express it are different for each dying person and family member. Spirituality can be influenced by a person's ethnic or cultural background.

### **Why is spirituality important at the end of life?**

For the person nearing death, finding and creating meaning at the end of life with family and friends is often desired. Reflecting on life can provide healing of the mind and spirit and bring peace in the midst of deep grief. When working through important life issues such as life review, saying goodbye and letting go, the dying person reaches inwards to draw on their spiritual dimension.

### **Some things to remember as your loved one approaches death...**

- It may seem that your loved one is letting go of their body and journeying deeper into a spiritual dimension. This becomes more noticeable as death approaches. Just like a deep underground river that flows constantly, the spiritual dimension has been active the whole time.

- Many people believe the messages and insights a dying person leaves in their final moments are gifts for loved ones. It is not unusual for a dying person to speak in metaphors about dying. For example, the dying person may speak about death in terms of travel or a journey (trains, boats and planes). Dying people have been heard to suddenly call out with urgency to “get going, go home, get to the door, find the key, be at the station”.
- Sometimes dying people call or reach out to family members who are deceased. They may also talk about visits from those who have died before them. These reports are usually comforting to the dying person or their family. Rather than deny these descriptions, or correct their reports, try to listen and accept what is being said. This can be a sacred time for those being present as death nears.

### **Spiritual Care at Kingston General Hospital**

Kingston General Hospital makes spiritual care services available to you and your family. Spiritual care helps you cope with your questions and doubts. You do not have to be religious to benefit from spiritual care. Chaplains work closely with your care team. They visit, listen, offer crisis support, ministry and counselling when you are dealing with illness, trauma, end-of-life issues and loss.

To see a chaplain, ask a nurse or a volunteer to call for you, or dial 0 and ask for the chaplain on-call who is available any time, day or night. A chaplain can also help you contact someone from a specific denomination or religion.

The Spiritual Centre is located on Davies 2, across from ICU. The Spiritual Centre is both a healing refuge and a worship space with a variety of holy texts available.

## **The final hours or days: When death is very near**

### **How will I know when death is near?**

As death approaches, you may notice more signs of your loved one's body shutting down, such as:

- Sleeping most of the time
- Purplish discoloration of the skin (mottling)
- Long periods of no breathing (apnea)
- Little or no urine
- Cool, moist skin

### **How much time is left?**

The time when we notice that death is likely very near is what we refer to as “the vigil”. No one can predict exactly when death will occur. However, your healthcare team can inform you about the changes they are noticing.

## **Conversations- can they hear me?**

Families and friends often wonder if the dying person hears them or is aware of their presence.

Though difficult, it may be important to say to the dying person, “I don’t want you to go. I’ll miss you. But it’s all right, you can go” or “we will be fine and you will always be with us in our hearts”. Sometimes it seems as though the dying person needs permission to “let go”...to hear from loved ones that they will be able to carry on, and that it is okay to leave them.

As death nears, it may seem your loved one has already left you. Perhaps the dying person has a more expanded awareness than the physical senses can allow. Whether you’re in the room or out of town why not believe that your best intentions are known by your loved one.

Try to reflect on how you might keep your relationship alive without the physical presence of your loved one. Remember what a profound gift it is to accompany your loved one through this journey.



## **Will I be there for my loved one's moment of death?**

No one can explain why or how a dying person may seem to hold off or bring on the moment of death. Some dying people are most comfortable with having people around while others prefer privacy and quiet. Sometimes a person seems to choose the time to die, perhaps when alone or when particular people are present. People may die at a time that spares or protects certain loved ones from the actual moment of death.

You may hope to be present at the moment of death, but allow it to be a hope, not an expectation. Trust that none of us can control when that final breath will be taken, but if it is your intention to be there, then that is what matters.

## **The Moment of Death**

### **How will I know my loved one has died?**

Usually the most obvious sign that death has occurred is that the person has stopped breathing. You may notice pale or waxy looking skin. Muscles in the face may relax and the jaw may droop. There may be minor muscle twitches that will fade away in a few minutes. There will be no heartbeat. The eyes may be partially closed as this is often the natural resting position. There will be no eye movement.

## **How will I feel at the moment of their death?**

Allow yourself any range and blend of feelings. Express these feelings freely, let the tears flow if they come. For some people, there may be no tears and that is okay. Remember, everyone grieves differently.

You may wish to hug your loved ones, share prayers, silence or memories with gathered family, which can include children. All of this is helpful for healthy grieving.

You can stay at the bedside to say whatever words seem appropriate or just be with your loved one. There is no harm in touching the person's body and there is no rush to move the body until everyone has had a chance to say goodbye.

At some moment, you will be aware that it is time to take leave of the person's body. Sometimes a family member or friend will leave a letter or keepsake behind with their loved one.

Your loved one's body will remain in the hospital until the funeral home picks him or her up. The doctor will complete a certificate of death. This certificate will go with the body to the funeral home. The funeral home will provide you with copies of the death certificate.

# Grief and Bereavement

## What is grief?

Grieving is a natural response to the death of someone or to a major loss. It can be viewed as a skill (like love) that is learned, nurtured and taught. Grief does not have a beginning or an end. It is a process that continually changes. Grief touches the whole person, just like the dying journey does- your body, mind and spirit are affected.

## Things to remember when you are grieving

In order to accompany your loved one to the end of their journey, you needed information, support and courage. You need the same things now, but for yourself. You are facing another journey now, but this is a journey to a different life without your loved one.

- Many people find grieving more difficult than expected, and may not feel understood by those around them. Allow yourself the necessary physical, emotional and spiritual support.
- Sharing your grief with others who have experienced a similar loss, individually or in a support group, can be very helpful.
- In your grief work, you will discover ways to return to life, while still carrying the memory of your loved one with you. Be kind and patient with yourself. It takes

time and effort. Grieving the death of a loved one is hard work but is a healthy way to process your loss.

Finally, take comfort in the fact that you have braved a difficult journey. Though unable to stop death, you have provided your loved one much needed support, comfort and love. This indeed is a brave and loving act.



## Resources

Ask your nurse or social worker about a list of books for adults and children coping with death and dying. Books are available for loan at the Patient and Family Resource Centre on Burr O.

### Websites

**Canadian Virtual Hospice** 

[www.virtualhospice.ca](http://www.virtualhospice.ca)

**Canadian Hospice Palliative Care Association** 

[www.chpca.net](http://www.chpca.net)

**Southeastern Ontario Palliative & End-of-Life Care Network** 

[www.seopalliativeeolcare.ca](http://www.seopalliativeeolcare.ca)

Click Resources→Patients/Caregivers

### Community organizations

**Bereaved Families of Ontario- Kingston Region** 

Phone: 613-634-1230

Website: [www.bfo-kingston.ca](http://www.bfo-kingston.ca)

## Hospice organizations

Hospice organizations give community supportive care services to individuals and families living with a life-limiting illness or coping with grief and loss. Programs include in home visiting, client day programs and caregiver support.

- **Hospice Kingston**  
Phone: 613-542-5013  
Location: 36 Barrie Street, Kingston  
Website: [www.hospicekingston.ca](http://www.hospicekingston.ca)
- **Hospice Quinte**  
Phone: 613-966-6610  
Location: 225 Dundas Street East, Belleville  
Website: [www.hospice-quinte.ca](http://www.hospice-quinte.ca)
- **Hospice Lennox & Addington**  
Phone: (613) 354-0833  
Location: 91-B Dundas Street East, Napanee  
Website: [www.landahospice.ca](http://www.landahospice.ca)
- **Dignity House Hospice** (serving Lanark County)  
Phone: 613-430-4211  
Location: 125 Gore Street East, Perth,  
Website: [www.dignityhousehospice.ca](http://www.dignityhousehospice.ca)

*There are more volunteer-based hospice organizations across Southeastern Ontario. For more information go to the Southeastern Ontario Palliative and End-of-Life Care Network website [www.seopalliativeeolcare.ca](http://www.seopalliativeeolcare.ca) → click on Service Directory.*

## **Comments, Feedback?**

Contact Patient Education @ 613-549-6666 extension 7987

## **Acknowledgements**

This booklet was adapted with permission from the Providence Care Guide to Death & Dying handbook and developed by an interprofessional team at Kingston General Hospital, including a patient experience advisor, palliative care doctor, advanced practice nurse, social worker, spiritual care advisor, program manager and patient educator.

Photographs courtesy of Cheryl Sutherland.

Author: A joint collaboration: KGH Palliative Care, Social Work, Spiritual Care, and Oncology Patient Education

Created: 11/2013

Revision due: 11/2016

