



We thank all of the families who have contributed to the palliative care education fund. Through this generosity we have been able to educate and send staff to international conferences. We are on the leading edge of palliative care.

## Palliative Care Service

# A GUIDE TO UNDERSTANDING DEATH & DYING



Providence Care  
St. Mary's of the Lake Hospital  
Palliative Care Service  
340 Union Street  
Kingston, ON  
K7L 5A2  
Phone: 613-544-5220  
Fax: 613-544-8558



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For information contact:

Providence Care  
St. Mary's of the Lake Hospital  
Palliative Care Service  
340 Union Street  
Kingston, Ontario  
K7L 5A2

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## *Preface*

It is said that death is a journey. In creating this booklet, we hope to provide step-by-step information, leading you gently, to observe and understand the journey that all humans must take, someday.

For many, death arrives as an unwelcome event. The physical changes that signify the dying of a loved one can be difficult to watch and seemingly impossible to understand. Factor in the mental, spiritual and emotional-social adjustments which may make this event almost overwhelming.

At St. Mary's of the Lake Hospital, we promote all aspects of patient care. When we witness someone approaching death, there are things we may see for the very first time. As a result, we may feel uncomfortable or fearful because we don't know what is happening or why, or what else to expect.

We hope you will find this little book helpful.

breaths. A different and paler color comes over the skin, and facial expression may change.

You might be surprised to know that it is not difficult to see the difference between life and death. Again, trust in the process and that you will know when the time comes.

Shortly after the death occurs, you may wish to hug your loved one, share prayers, silence or memories with gathered family. All of this is helpful for healthy grieving. It is believed that the spirit of the deceased remains in the room until all close family members who need to gather have arrived.

At some moment, you will be aware that it is time to take leave of the body. It is time to take care of yourself and grieve the loss of your loved one.

## *Bereavement*

Grieving is a natural response to loss. It touches the whole person, just as the dying process does. Body, mind and spirit are affected.

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 time back to life.

Many people find grieving to be more difficult than expected, and little understood by those around them. Learn about the grieving process and allow yourself needed physical, emotional and spiritual support. Sharing your grief with others who have experienced a similar loss, in a support group, can be most 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.

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 courageous and timeless gift.

## *The Moment of Death*

When death is very near those close to the person may be feeling many things at one time. Feeling suspended in time, hollow, sad or anxious are some but not nearly all the feelings people describe just before the moment of death. When a parent dies, you remember feeling that you never really knew the meaning of “sad” until then. Realizing it is almost over, one feels a strange blend of anticipation and relief.

By now, many families feel, “it’s time for this to end,” and death may be welcomed as the final comfort. This is natural and rises out of love for the dying person and willingness to let him/her go.

Allow yourself any range and blend of feelings. Express these feelings freely, let the tears flow. And there may be no tears. Remember, everyone grieves differently.

You may want to hug your loved one for a final good-bye, or offer some reassurance that you will be all right after the death occurs. Honor the dying person in your own special way.

The final moment of life may be marked by nothing more than the person simply not taking the next breath. Breaths may be shallow and far apart. They may gently taper off, much like the flickering of a candle flame. There may be a deep sigh or a dramatic sitting forward, followed by a sigh of relief.

There are medical ways to describe the final breath, but there are also poetic ways. Author Elizabeth Bert’s book, *Talk Before Sleep*, tells the story of a woman dying and how it affects her family and friends. In describing the moment of death, one friend imagined the final breath to be nothing less than breathtaking

*“I like to think that she looked out the window one last time the night she died, and saw with a new understanding the placement of the stars. I like to think something incomprehensibly vast and complex moved into her soul at that moment, and that it, not pathology, was what took her breath away.”*

Stay beside your loved one until you’re sure that the next breath is not there. There are ways to confirm death, but you will know by waiting and watching a few minutes to confirm that there are no more

## ACKNOWLEDGEMENTS

This booklet was developed to provide a supportive and educational guide for families as they face the death of a loved one. We hope it will offer information on the dying process and be a source of support to those who are caring for a dying person.

Our philosophy is care for the dying. It is comfort-oriented care offered during the final stages of a terminal illness. At St. Mary’s of the Lake Hospital the patient and family are the focus of care. Family includes anyone who is part of the inner support circle for the dying person.

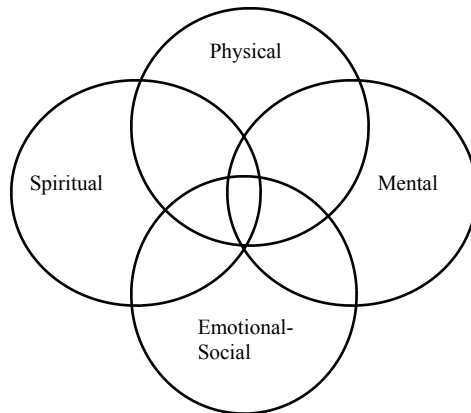
The Palliative team includes:

- The Palliative Care Physicians
- The Palliative Care Unit Nurses
- The Social Worker
- The Physiotherapist
- The Occupational Therapist
- The Clinical Dietitian
- The Speech Language Pathologist
- The Coordinator of In-Hospital Volunteers
- The Volunteers
- The Pharmacist
- The Spiritual Care Team Members
- The Psychologist
- The Recreation Therapist

The team recognizes that terminal illness can be an anxious and frightening time for the dying person and family. Team members are trained to offer help, guidance and comfort.

## Introduction

This booklet is about the changes that occur to the whole person as death nears. The figure below is an example of the interpretation of the whole person: the physical, mental, emotional-social, and spiritual dimensions.



When a person is dying, changes take place in each of these dimensions. These changes may occur at different times and at different rates. The dying process will be a unique experience for each person and each family. We are here to help you along that journey.

The **physical changes** that occur have to do with circulation, metabolism, breathing, lung secretions, elimination and the senses. Essentially, the body is shutting down and what may be abnormal when a person is healthy, is normal and expected during the dying process. For families of a dying person, this may be one of the most important but difficult ideas to accept.

**Mental** activity may decrease or lose its clarity during the dying process. Periods of restlessness, confusion, increased sleepiness or unresponsiveness are among the changes seen here.

The **emotional-social** changes during the dying process often accompany the person's necessary detachment from the outside world and pulling inward as death nears.

**Spirituality** is something we all define and interpret differently. In this booklet, we have attempted to reflect the view that this spiritual dimension is active all through the dying process. Spirituality may include, but is not limited to, religious faith. Your views, language and rituals will be your guide to interpreting this dimension.

## The Vigil

As death approaches, those closest to the dying person may sense that he or she is turning a corner. As this happens, family members may observe more signs of the body shutting down, such as:

- Sleeping most of the time
- Mottling of the skin (purplish discoloration)
- Rattly-sounding breathing
- Rhythmic periods of not breathing (apnea)
- Little or no urine
- Cool, moist skin

As some or all of these physical changes occur, the dying person may seem more withdrawn from the outer world. It is as if the dying person is turning inward, perhaps to save what little life force is left for the final moment of death, of release.

This is what we refer to as the vigil, the time when we realize that we are not in control of the dying process. Death is very near. We can not answer with certainty questions of "How much longer?" During this vigil, we watch, we comfort, we wait. Like birth, death comes in its own way, at its own time.

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."

Likewise, though possibly unable to speak, the dying person may wish to say, "I love you and I don't want to leave, but I need to go. Will you be all right? May I go?" It is comforting for the person to be assured of your love and presence at that moment, and also of your well-being after the death occurs.

Families often wonder if the dying person hears them or is aware of their presence. 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. Why not believe that your best intentions are known by your loved one, whether you're in the room or out of town.

Try to reflect on how you might keep the relationship alive without the physical presence. As you walk closer to the threshold of death, remember what profound gift it is to accompany your loved one. Only courage and love allow one to go this far on the journey.

## THE SPIRIT CONTINUED

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.”

It is not uncommon to see a dying person calling or reaching out to a deceased family member, or to a religious figure. Dying people have been heard to speak of visits from or dreams about those who have died before them. These reports have almost always been comforting to the dying person. *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 witnessing the final stage and those making the passage.

When the final breath is taken, remember that the person dies at just the right moment, whether they are alone or surrounded by others.

The Authors of *Final Gifts* share many examples of dying persons choosing their time to die as a final gift to their loved ones.

No one can explain why or how a dying person may seem to *hold off* or *bring on* the moment of death. Many of us working in palliative care have seen people die just after a close relative arrives from out-of-town or after an anticipated event such as a birthday, family member’s wedding, or holiday.

Likewise, for someone who has been private or independent in life, death may come when everyone steps out of the room for a moment. Sometimes people die at a time that spares certain loved ones from the actual dying event.

The practice of medicine requires an attempt to control and predict all uncertainties. Perhaps one lesson of dying is that we are not so powerful. This is a time to reflect on where our power, our hope, our comfort reside. To do so may ease the stress of trying to control and predict.

You may hope to be present at the moment of death, but allow it to be a hope, not an expectation. Hope is flexible; expectations are rigid. Trust that none of us can control when that final breath will be taken, but if it is your *intention* to be there, that’s what matters.

## Principles

1. **Death** can occur suddenly or as a process over time. The signs of approaching death reflect a slowing down or breaking down of the body. What may be abnormal during life becomes normal during the dying process.
2. **Death is a unique experience** for each person, coming in its own time and way. Someone who has always shared feelings is likely to do so during the dying process. On the other hand, a person who has been stoic, private or independent throughout life, is likely to approach death in this way. Keep in mind that this, like all of the principles suggested in this booklet, varies with the individual.
3. **Dying happens to the whole person**, not just the body. The individual is affected physically, emotionally-socially, mentally and spiritually. All dimensions do not always move along at the same pace.

Sometimes people say, “I’m ready to die, but I guess it’s not that easy.” They may be waiting for their bodies to be ready. Other times, the body moves more quickly toward death, before the person feels ready.

**Remember that pain and suffering, comfort and healing can occur in any or all of the dimensions of a person, not just the body.**

4. **The dying process involves work** as the person gradually lets go. If the body can be made comfortable and pain-free, the person is free to work on matters of the heart in preparation for dying. This work may include completing unfinished business, finding meaning in life, and reflecting on past and present relationships with others.
5. Even though a person is physically dying, the emotional-social and spiritual dimensions have tremendous impact on **growth during the dying process**.

## *Signs Seen As Death Approaches*

### THE BODY

#### CIRCULATION

- Hands, feet and legs usually get colder to the touch as circulation slows.

Keep the person warm with a blanket, but avoid layers of heavy covers or electric blankets. A flannel top sheet may be comforting.

- Blood pressure gradually goes down and heart rate gets faster, but weaker.
- Colour may become waxy and pale and the skin takes on a drawn appearance.
- Fingers, earlobes, lips and nail beds may look bluish or light gray (cyanosis).
- Purplish or blotchy red-blue coloring on knees and/or feet (mottling) is a sign that death is very near.
- A gentle massage may be soothing. The dying person is usually quite sensitive to pressure, therefore, there is a need for gentleness.
- Change his/her position every one and a half or two hours, using at least two people to perform this function.

#### METABOLISM (BODY ENERGY)

The dying person will take less food and liquids as time goes on. When he/she is unable to swallow there is no fluid intake, therefore there is less fluid accumulation and less urine to be eliminated. This natural process promotes more comfort for the patient. Once these fluid changes occur, a natural anaesthetic process happens. The dying patient may be drowsy or feel sedated; this is a way of nature taking over to help the dying person feel very peaceful.

Seeing the person lose interest in eating and drinking is often difficult for the family because this signals the end of what normally sustains life. The family may even feel angry that the loved one is *giving up*, not trying to remain alive.

- Life-Review—looking back at one's life in search of meaning and contributions.
- Closure—saying good-bye to people and places, forgiving and being forgiven, facing regrets.
- Acceptance or coming to terms with ongoing losses and eventual death.

For individual reasons, the dying person may not be willing or able to do these things. Take cues from the person and be available for listening. Share your memories. Find ways to say good-bye, because this will be important for *your* grieving.

### THE SPIRIT

A person's spirituality is very unique and personal. Each person interprets this dimension differently, and the language and rituals used to express it are different for each dying person and family member.

Early in the dying process, the person may face many issues which draw from his or her spiritual dimension, such as:

- The meaning of life, hope, suffering and death.
- Acceptance of ongoing losses and eventual death.
- Grieving those losses.
- Forgiving and being forgiven.

As time passes, it may seem the dying person is letting go of the body and journeying deeper into the spiritual dimension—having one foot in two worlds, the seen and unseen. This becomes most evident closer to the end. Just as a deep underground river flows constantly, it is believed that the spiritual dimension has been active the whole time. So often we are busy focusing on changes in the body, that we miss this very active, often deeply hidden dimension.

It is not unusual for a dying person to speak in metaphors about dying. In *Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying*, the authors Callanan and Keeley refer to the many *gifts* dying people leave their loved ones, the messages and insights they leave in their final moments.

## THE MIND

Changes in the mind can be divided into two areas: mental changes and emotional-social changes.

### MENTAL CHANGES

The dying process (and some terminal illnesses) can cause changes in mental activity and consciousness.

- Restlessness or agitation may be a result of diminished oxygen to the brain, metabolic changes or physical pain.

Quieting and simplifying the environment frequently helps. There are also medications that help soothe the agitation or ease the pain of the dying person.

Keep in mind that the dying person's restlessness may be from working through emotional and spiritual issues before death, and also due to physical changes.

- Occasional or constant confusion may be related to separation from the normal routines of living. It may also be the result of a disease, or the dying process.

Try to keep the person oriented to the surroundings and the people who are present. This will often help prevent feelings of fear or danger in the dying person. Use calm, soothing tones and short phrases when speaking.

- Levels of consciousness (being alert and aware) vary.

The dying person may be sleepy, but able to be awakened and have awareness of the surroundings.

The senses may be dulled, and there may be little awareness of what is happening in the environment.

Sleep may be so deep that the dying person cannot be awakened and is unresponsive. *Always assume that the person hears you, and at some level knows you are present.*

### EMOTIONAL-SOCIAL CHANGES

During the dying process, changes affecting a person's inner feelings and interpersonal relationships may take place. As early as possible, try to address any emotional, social or spiritual issues that need attention. As the person's physical condition gradually weakens, discussion about such topics may become difficult. These may include:

Let the dying person lead the way. Trust that the person who is dying is following cues from his or her own body, and is moving with the dying process.

Loved ones might also be watchful of the person who forces himself to eat for the sake of the family, but is losing the physical ability to do so safely.

### DEHYDRATION (LOSS OF FLUID)

- As eating and drinking taper off, the body naturally becomes dehydrated. When this occurs, the dying person becomes sleepier and may be less aware of pain or discomfort. This is a normal part of the dying process and there are ways to keep the person comfortable throughout this time.

Forcing food and fluids when a person doesn't want them, or can't digest them properly, may cause nausea, vomiting, choking or other problems.

If the person can swallow, ice chips or fluids on a small spoon will generally satisfy thirst; be sure the head is raised to avoid accidental choking.

Swabbing the mouth with cool water is another comfort measure. Use of a spray bottle or atomizer can provide a fine mist of water to the mouth.

- Fever may or may not occur, but is common nearer to death.

Medications are often given to *take the edge off* the fever, but they rarely eliminate it altogether at this stage. Again, such care is a comfort measure.

### MOUTH AND LUNG SECRETIONS

Because of the natural processes of dehydration and increasing weakness to effectively cough...

- Secretions usually thicken and build up in the lungs and/or the back of the throat.
- Breathing may sound moist, congested or rattly. This may come and go, and is rarely of bother to the dying person closer to the time of death. By this point, the person is barely responsive and generally unaware of discomfort.

## **MOUTH AND LUNG SECRETIONS CONT'D**

Secretions can best be managed with:

- Medications
- Turning and positioning the person every few hours
- Keeping the head of the bed up
- Frequent mouth care

These measures will help to stop pooling of the secretions and will allow gravity to assist with drainage.

Often, the rattling sound will suddenly stop on its own. Deep suction is usually not helpful and may increase the secretions or make the person uncomfortable.

## **BREATHING**

Because of circulation and metabolic changes, there is sometimes a buildup of bodily waste products that commonly cause...

- Changes in the rate, depth and rhythm of breathing.
- Periods of not breathing for 5-30 seconds (apnea).
- A distinct pattern of breathing that is rhythmically slow and shallow, then becoming faster and deeper, then slowing down again to 10-20 seconds of apnea.

Remember, these signs reflect metabolic changes, not shortness-of-breath or air hunger. The dying person is generally not aware or distressed by these changes in breathing. Although you may feel short-of-breath watching, the dying person is not likely to experience this as suffocation.

## **ELIMINATION**

Because the kidneys and bowels eventually stop working...

- There is less urine and it is darker in colour.

A catheter may be placed in the bladder as a comfort measure if there is a concern about skin breakdown or inability to empty the bladder.

- Bowel movements become less frequent, but not having one for three to four days could become uncomfortable.

Discuss this with the palliative care nurse, because medications might be helpful.

- The dying person will usually lose control of bowel and bladder function (incontinence) as muscles in that area begin to relax.

It is very important to keep the person clean and dry of urine and stool. The use of a catheter and incontinence pads will help prevent skin breakdown as well as maintain the dying person's dignity.

## **THE SENSES**

The senses are what bind a person to the outside world. During the dying process, the senses may be overactive or underactive.

- Eyesight may become blurred.
- Always assume the dying person can hear, even though unable to respond. This is usually the last sense to be lost.
- Although verbal and nonverbal communication become more limited, gentle touch is an effective way to remain close to your loved one.

Sometimes the dying person's senses are overactive, and normal stimulation becomes very abrasive. Such things as bright lights, loud or persistent sounds or strong odors may be very upsetting. As a defense against this physical condition, the dying person may withdraw from or even push away sights, sounds or people. Remember, this is a protective way of toning down the senses, and it is not meant to personally reject a loved one. If this seems to be happening, discuss it with the hospice nurse. There are also medications which might be soothing during this time. A comfortable environment can be created for the dying person. Indirect light, favourite music played softly, storytelling, sharing memories all help to create a comforting setting.