

Beyond Our Sight

*A Guide to Understanding
Death & Dying*



Perth and Smiths Falls District Hospital
Palliative Care Services

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Acknowledgment

Brockville & District Hospice
Palliative Care Service

Table of Contents

Acknowledgement	2
Table of Contents	3
Introduction	4
Changes	6
Physical	6
Mental	6
Emotional-Social	6
Spiritual	6
Accessing Spiritual and Legal Resources	6
Spiritual Support	6
Legal	6
Principles of dying	7
How to tell if death is near	8
Signs seen as death approaches the Body	8
Circulation	8
Bodily Function	9
Oral Secretions	10
Breathing	10
Elimination	11
The Senses	12
The Mind	13
Mental Changes	13
Emotional-Social Changes	14
Spirituality	14
Your Presence	16
The Surge	16
The Moment of Death	17
Bereavement	18
Multi Faith Prayer Room	18
Resources	19

Introduction

At the Perth and Smiths Falls District Hospital, we promote all aspects of patient care. In creating this booklet, we hope to provide information to help understand the journey that all humans must take someday. We embrace the palliative care philosophy that believes each person is made up of a body, mind and soul. Our focus is comfort oriented care during the final stages of dying. The patient, family, support person or loved one are the focus of care. Family may include anyone who is part of the person's inner support circle.

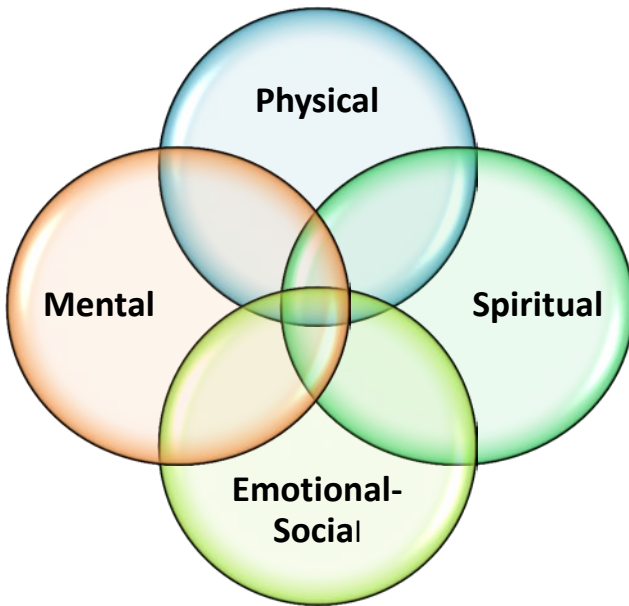
The Palliative Care Team at Perth and Smiths Falls District Hospital includes any or all of the following:

- Patient
- Family, Support Person or Loved One(s)
- Physician(s)
- Nurse(s)
- Palliative Care Consult Nurse(s)
- Minister/Priest/Spiritual Support(s)
- Pharmacist(s)
- Physiotherapist(s)
- Occupational Therapist(s)
- Volunteer(s)
- Speech & Language Therapist(s)
- Dietician(s)
- LHIN (Home and Community Care)

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

Death comes in its own time and in its own way. It is as unique as the individual who is experiencing it. If you have any questions, concerns or just need to speak with someone, please find a member of the Palliative team to assist you, your family and your loved one as you take this incredible and emotional journey. You are not alone!

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.

Changes

Physical

The changes that occur have to do with circulation, bodily functions, 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. This may be one of the most important but difficult ideas to accept.

Mental

This activity may decrease or lose its clarity during the dying process. Periods of restlessness, confusion, increased sleepiness and/or unresponsiveness are examples of changes that may be witnessed.

Emotional-Social

These changes happen as the person detaches from the outside world and pulls inward.

Spiritual

The spiritual dimension is active all throughout the dying process. Spirituality may include, but is not limited to religious faith, personal philosophy, cultural rituals and language.

Accessing Spiritual and Legal Resources

Spiritual Support

If you would like to have spiritual support for your loved one or family, please speak to the Palliative Care Nurse or the Nurse. They may contact the support for you or give the resources to you to do so.

Legal

If the palliative care person is still competent, and has not completed a will or care wishes you may wish to encourage them to contact their lawyer to complete one. The hospital has policies who can witness these documents.

Principles of Dying

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.
2. ***Death is a unique experience*** 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, vary 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.
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 may be enhanced.

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 towards death, before the person feels ready.

Remember that pain and suffering, comfort and healing can occur in all of the dimensions of a person.

How to Tell if Death is Near

- Decreasing appetite
- Sleeping more
- Becoming less social
- Changing vital signs
- Changing toilet habits
- Weakening muscles
- Changing body temperature
- Experiencing confusion at times

Signs Seen As Death Approaches The Body

Circulation

- Hands, feet and legs usually get colder to the touch as circulation slows
- Skin 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 colouring on knees and/or feet (mottling) can be a sign that death is near
- The person's position should be changed regularly using at least two people to perform this function
- The person should be kept warm with a blanket, but avoid layers of heavy covers or electric blankets. A warmed flannel top sheet may be comforting.

Gentle massage may be soothing. The person is usually quite sensitive to pressure therefore, there is a need for gentleness.

Bodily Functions

The person may:

- Take less food and liquids as time goes on. As the person becomes unable to swallow there is no intake of food and as a result less urine to be eliminated. This natural process promotes more comfort for the patient. Once these fluid changes occur, a natural anesthetic process happens.
- Be drowsy, feeling sedated with a sense of peace.
- Loss of interest in eating and drinking. This 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, and not trying to remain alive.
- Not want food or fluids. Forcing food and fluids may cause nausea, vomiting, choking or other problems.
- Realize that they are moving through the dying process. Trust that the person is following cues from their body.

As eating and drinking tapers off, the body naturally becomes dehydrated. When this occurs, the 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.

If the person can swallow, ice chips or fluid 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 small spray bottle can provide a fine mist of water to the mouth).

Fluctuations in the body, such as increased/decreased heart rate, breathing and/or body temperature may or may not occur at times.

Medications are often given as a comfort measure.

Oral Secretions

There are changes that show the physical body is losing its ability to maintain itself:

- Congestion can also occur with a rattling sound (in the lungs and) upper throat. There may be coughing with this but generally nothing is brought up.
- Suctioning usually only increases the secretions and causes discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe their mouth with a moist cloth. All of these breathing changes and congestion have a tendency to come and go. Medications are often given as a comfort measure.
- Swallowing may become difficult with the loss of the gag reflex.

Breathing

Because of circulation and bodily function changes, changes in breathing occur. Alterations in breathing occur due to changes in bodily function and circulation

- 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.

Elimination

The kidneys and bowels will 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.

Bowel movements become less frequent and not having one for three to four days may become uncomfortable.

Medications might be helpful.

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 person's dignity.

The person will occasionally lose control of bowel and bladder function at the end as muscles relax.

The Senses

The senses are what connect a person to the outside world.

The senses may become overactive or underactive.

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

Sometimes the senses are overactive, and normal stimulation becomes very abrasive. Such things as bright lights, loud or persistent sounds or strong odours may be very upsetting. As a defense against this physical condition, the person may withdraw from sounds or people. 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 Nurse. There are also medications which might be soothing during this time.

A comfortable environment can be created using indirect light, favourite music played softly, storytelling, and/or sharing memories. All of these actions can help create a comforting setting.

The Mind

Changes in the mind can be divided into two areas: Mental Changes and Emotional-Social Changes.

Mental Changes

Changes can occur in mental activity and consciousness.

Anxiety, confusion or agitation may be a result of diminished oxygen to the brain, bodily changes and/or physical pain.

Toning down the environment frequently helps. There are also medications that help soothe the agitation or ease the pain of the person.

Try to keep the patient oriented to the surroundings if this is not upsetting. This will often help prevent feelings of fear or danger in the person. Use calm, soothing tones and short phrases when speaking.

The person may be sleepy and their level of consciousness may vary. Always assume that the person is able to hear you, and at some level knows you are present.

Emotional-Social Changes

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

For individual reasons, the person may find this difficult especially if the family is unable to help, encourage them to listen. Find ways to share memories and say good-bye as this will be important for grieving.

Such topics may include:

- 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.

Spirituality

A person's spirituality is very unique and personal. Each person interprets this dimension differently including the language and cultural rituals used to express it.

Early in the dying process, the person may face many issues which draw from their 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.

For example, the person may speak about death in terms of travel or a journey (trains, boats, planes). People have been heard to suddenly call out with urgency to “get going, go home, get to the door, find the key, and be at the station.”

It is not uncommon to see a person calling or reaching out to a deceased family member(s), support person(s), important person(s) or religious/cultural figure(s). People have been heard to speak of visits or dreams about those who have died before them. 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 stages and those making the journey.

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

No one can explain why or how a 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 special person arrives or after an anticipated special event.

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. If it is your intention to be there that’s what matters.

Your Presence

Though difficult, it may be important to say to the person, “I don’t want you to go. I’ll miss you. But it’s all right for you to go.”

Likewise, though possibly unable to speak, the person may wish to say “I love you and I don’t want you to leave, but I need you 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 person hears them or is aware of their presence. As death nears it may seem your loved one has already left you. Perhaps the person has a more expanded awareness than the physical senses can allow. Believe that your best intentions are known by your loved one.

The Surge

The last couple of days prior to death can sometimes surprise family members. Your loved one may have a surge of energy as they get closer to death.

This is a very small amount of energy, but it is significant and seems like a remarkable improvement. This can be deceptive to both health care providers and family. Everyone is preparing for death and instead the person appears better. This period does not last long and death commonly comes in a day or two.

The Moment of Death

As death approaches the family may experience a variety of feelings, including a blend of sadness, anticipation and/or relief.

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

Allow yourself any variety of feelings. Express these feelings/emotions freely. 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. Honour the person in your own special way.

Breaths may be shallow and far apart. The final moment of life may be marked by nothing more than the person simply not taking the next breath.

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.

When death occurs you may wish to say good bye in your own way.

It is now time to take care of yourself and grieve the loss of your loved one.

Bereavement

Many people find grieving to be more difficult than expected. It would be helpful for you to learn about the grieving process. Allow yourself needed physical, emotional and spiritual support. It may be helpful to share your grief with those who have experienced a similar loss or in a support group.

In your grief work, you will discover ways to return to your normal 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 endured 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.

Multi Faith Prayer Room

A Multi-Faith Prayer room is available at each hospital site. You can locate the Multi-Faith Prayer room on the main floor. All are welcome to use this quiet space for a time of reflection or prayer.

Resources

The PSFDH Palliative Care Nurse can be reached at:

613-283-2330 Ext. 2180

613-267-1500 Ext. 2180

Palliativecare@psfdh.on.ca

You can also call the phone numbers listed above and press zero.

This will connect you to the PSFDH Registration/Switchboard, who can page Palliative Care for you.

If you require Bereavement Peer Support Services, you can contact the any of the following:

Community Home Support of Lanark County (CHSLC)

Perth Location

40 Sunset Blvd Suite 100

Perth, ON K7 3C6

613-267-6400

<https://www.chslc.ca/>

Smiths Falls Location

2 Gould St

Smiths Falls, ON K7A 2H9

613-283-6745

<https://www.chslc.ca/>

Hospice Care Ottawa – Ruddy-Shenkman Hospice

Kanata location

110 McCurdy Drive

Kanata, ON K2L 2Z6

Tel: 613.591.6002

<https://www.hospicecareottawa.ca/>

Bereaved Families of Ontario

Ottawa Region

303-211 Bronson Avenue

Ottawa K1R 6H5

613.567.4278

office@bfo-ottawa.org

Kingston Region

14-993 Princess Street

Kingston K7L 1H3

613.634.1230

bfo@kingston.net

Many other support groups are available. If you would like more information on these groups, please consult with the Palliative Care Nurse.

I Am Standing Upon the Seashore

I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength. I stand and watch her until at length she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

When someone at my side says: "There, she is gone!"

"Gone where?"

"Gone from my sight. That is all"

She is just as large in mast and hull and spar as she was when she left my side and she is just as able to bear her load of living freight to her destined port. Here diminished size is in me, not in her.

And just the moment when someone at my side says, "There, she is gone!" there are other eyes watching her coming, and other voices ready to take up the glad shout:

"Here she comes" Written by Henry Van Dyke.