



An information companion
for you and your family

We hug

We laugh

We cry

We love ...

E. Latimer

<u>Table of Contents</u>	<u>Page</u>
Introduction	1
Body and Spirit	1
Changes in Bodily Functions	2
Elimination	2
What about Intravenous Fluids?	3
Breathing	4
Discomfort / Pain	5
Bleeding	6
Eye Care	6
Swelling	6
Temperature and Vital Signs	6
Skin Colour and Coolness	6
Mental-Emotional-Spiritual Changes	7
What a Dying Person May Fear?	7
Saying Good-bye	8
Giving Permission	8
Signs of Approaching Death	9
Some Hints for Caring for Your Loved One	10
Caring for Yourself	10
When Death has Occurred	11
Confirmation of Death	11
Spiritual Care Practitioner	11
Organ / Body Donation	12
Autopsy	12
Choosing and Notifying the Funeral Home	12-13
Frequently Asked Questions	14-15

Introduction

We have had many questions from the persons we care for, and their families, about what they might expect to see and experience as life draws to a close. This booklet will tell you about some of these changes. It is our hope that the following information will:

- Help you understand how the body and spirit prepare for death
- Assist you in knowing what to do or who to ask for assistance in caring for your loved one
- Help you know how to care for yourself during this difficult time
- What you need to know after your loved one has passed

The information included in this booklet is a guide only. We acknowledge that some of the information in this package has been drawn from the Toronto Inpatient Palliative Care Unit committee's "Approaching the End of Life" brochure. Please be sure to ask your Doctor, Nurse, Social Worker or Spiritual Care Practitioner for more information so that your questions are fully answered.

All of your questions are important.

Approaching the End of Life – Some Thoughts for Caregivers

In today's society, it is sometimes difficult for us to realize that death is really a part of life. However, in the face of incurable disease, a time will come when nothing will change the body's progress towards death. When this occurs, and when all treatments aimed at sustaining life are no longer effective, it is appropriate to change the focus of care. Our goals in caring for a dying person and his or her family are to maintain comfort, preserve dignity of the person and offer loving support. Every life is special and unique and so is every death.

Body & Spirit

The physical changes as the body prepares itself for death will, for the most part, be a continuation of what already occurred as the illness has progressed. Your loved one's ability to manage daily routines of living will lessen.

His/her body's normal functions will decrease until they can no longer be maintained. It is impossible to predict when changes will occur or whether some will happen at all. This can be a difficult reality for family members.

The person also may begin to prepare for death emotionally, spiritually and mentally. For example, he/she may need to complete "unfinished business", to resolve conflict, to re-establish or deepen religious connections and to receive permission from a loved one to "let go". Support can come from just listening to these concerns and/or providing assistance to complete "unfinished business". This may help the ill person to have a sense of control of their situation.

It is important that we remember, in spite of advanced illness, people live until the moment of their death. They are part of a family, need to laugh and cry, and usually want to continue living until they die.

Changes in Bodily Functions

Sleeping

The person may spend more time sleeping and may appear to be in an unusual deeper sleep. At times, he/she may be difficult to wake up. This is a normal change as the metabolism slows down and all energy is focused on essential functions such as breathing. Allow your loved one to rest quietly. Plan visits and conversations around awake and alert times.

Encourage friends and family to visit a few at a time and for short periods. Speak to your loved one directly, as you normally would, even though there may be no response. Always assume the ability to hear, as hearing may be the last of the senses to subside. Your quiet presence and gentle touch will be comforting and reassuring.

Food & Fluids

It is important to understand that people approaching the end of their lives respond differently to food and fluids than do healthy persons. At the end of life, it is normal to lose one's appetite.

Most people with advanced diseases lose weight as the illness progresses. It can be very distressing to watch a loved one fade away and to accept that further treatment is not possible in someone so frail.

There are many reasons for a loss of appetite and weight loss. Symptoms like pain, nausea, constipation and shortness of breath take a lot of energy and may reduce the desire to eat and drink. Chemical changes within the body also decrease appetite.

The issue of eating and drinking can be extremely upsetting for family members, and should be discussed with the doctor or nurse if need be.

What Can I Do?

As the body is slowing down, eating and drinking could cause discomfort. Your loved one may find it increasingly difficult to manage food and water.

If your loved one is thirsty, you may offer small sips of fluids as long as he/she is conscious and able to swallow. If your loved one is unable to swallow, you can relieve the thirst and keep the mouth moist by swabbing the mouth with water or artificial saliva.

The dying person may reach a point where there is no interest in eating or drinking at all. The goals of care are to maintain comfort.

Elimination

Bladder and Bowel

As death approaches, the amount of urine decreases and what is produced is often dark in colour. Bowel movements may become less and not as soft since pain medications affect bowel function. Laxatives and occasionally gentle enemas may be required to provide comfort.

It is common to lose control of the bladder and bowel as muscle control lessens. Absorption pads, briefs or catheters may help keep your loved one dry and avoid skin breakdown.

Ostomy

If a person has an ostomy for urine or stool, the same changes in bowel or bladder function may be noticed. Pouch changes or cleaning may need to be more frequent to promote comfort and freedom from odour. It is common to feel embarrassed by some of these changes so reassurance and loving support are important.

What about Intravenous Fluids?

As death draws near, patients become weaker. They often cannot swallow water or other liquids. Family members sometimes ask about giving water to the patient in other ways. Usually they ask about intravenous (IV) fluids.

The body does not need much water as death draws near. The body is slowing down and is not able to comfortably handle extra water.

Research shows that giving IV fluid during the last stages of life is of little or no benefit to the patient. When the body is slowing down, extra IV fluid may overload the body and may make the patient uncomfortable. Here is how:

- The bladder: more water means more urine. This means using the bedpan or urinal more often. Sometimes a tube (catheter) needs to be placed into the bladder. All of these can be uncomfortable.
- The stomach and bowel: more water may cause nausea and vomiting. A tube may have to be placed into the stomach to lower the pressure of extra fluid in the stomach. This can also be uncomfortable.
- The lungs: extra IV fluid may mean extra fluid in the lungs and increase the accumulation of secretions in the mouth and throat resulting a gurgling or rattling respiration. The patient may find breathing more difficult. Sometimes the accumulated secretions need to be suctioned out. This can be uncomfortable.

Intravenous fluids are not usually recommended.

Dehydration or a slow loss of body water may have a pain-killing effect. This helps the patient to be more comfortable; however, it does give the patient a dry mouth.

Here are some ways to keep your loved one's mouth moist: Ice chips, mouthwashes, or swabbing the inside of the mouth. Please speak to your nurse about what is best for your family member.

Water is such an important part of life. We understand that it is hard to watch as death draws near. Please remember; it is the disease that is taking your family member's life; not the lack of water. Please feel free to talk to any member of the Palliative Care Team about this information.

Breathing

Your loved one may experience some difficulty breathing as the disease progresses and their condition weakens. Breathing may also become rapid due to fever, infection, or changes in kidney function.

Distress from breathlessness may be managed with medications to help open the airways, reduce anxiety, and control fever. As well, your doctor or nurse may suggest oxygen, which can be given at home or in hospital. Sitting the person up with support or leaning him or her forward with arms resting on a table may help. A fan to gently move the air can sometimes lessen the feeling of shortness of breath.

While you may notice that your loved one looks to be working at getting their breath, they may tell you they feel quite comfortable.

As your loved one becomes weaker, you may notice changes in their breathing patterns. You may notice short periods of time when your loved one stops breathing temporarily. There may be repeated cycles of increased deep breaths followed by shallow breathing and then again no breathing for 10-30 seconds or longer.

A slowing in brain activity causes this change in breathing pattern. The amount of time the person stops breathing may become longer. Your loved one will not notice these periods and will not be distressed by them.

Your loved one's breathing may also become noisy. These noises are the result of several things – small amounts of mucous in the throat, the jaw dropping back, or the tongue moving back due to the relaxation of jaw and throat muscles. Sometimes a soft short moaning sound with each breath out may accompany this. We can give a medication with a small needle inserted into the skin or a patch behind the ear that may help to dry up any mucous. It is generally believed that these secretions do not distress the person.

At the time of death, your loved one's breathing will stop. It is also possible that within a few minutes it will seem that he or she is taking short sudden, deep breaths again. These are not true breaths but are the body's final physical release from life. Again, this is quite normal at this point.

We realize that being with your loved one, watching and waiting, can be difficult for family members. However, we believe that the patient does not suffer when these changes in breathing patterns occur.

Discomfort/Pain

Many patients and their loved ones fear pain. They fear experiencing pain at any point during their illness. Some are afraid that their cancer has recurred or is advancing. Others are concerned about addiction or using the strong pain medication too early for fear that if the pain becomes worse, the pain medication will then not be strong enough for when they “really need it”. Because of this, people may end up suffering in pain. This suffering has a negative impact on your health and sense of well-being. Unrelieved pain causes a body to be under constant stress. This can lead to:

- Weight loss
- Rapid heart rate
- High blood pressure
- High blood sugars
- Difficulty passing urine
- Constipation
- Fatigue
- Difficulty concentrating
- Risk of infection
- Slower recovery from an injury (such as a broken bone) or surgery
- Insomnia
- Anxiety/ Depression
- Fear
- Sense of Hopelessness
- Thoughts of suicide

Most pain can be relieved or controlled.

Pain can be controlled by using different medications (analgesics) and by using methods other than medications such as heat, cold, relaxation, massage and distraction. It is important to know that using a combination of these usually best controls pain.

Your doctor will prescribe the appropriate medications for your type of pain. It is important that you take these medications as prescribed by your doctor.

The stronger analgesics such as Codeine, Morphine and Dilaudid can cause side effects. Speak to your team about this.

Living with pain or with someone experiencing pain can be a very difficult and trying time. Pain can cause you to be irritable, withdraw from family and friends and lose interest in your usual activities such as reading, walking and hobbies. It is important to be patient with yourself and your loved one. Realize that you do not need to go through this alone – your health care team is here to help you.

Please feel free to ask questions and find out whom you should call when you are running into difficulties. Remember that pain relief or control is possible.

Bleeding

With cancer, there may be bleeding because of tumor growth into blood vessels or blood may not clot well. Bleeding may be controlled with special materials that aid in clotting.

Eye Care

At points during the final days of life, you may find your loved one asleep with his or her eyes open that may cause the covering of the eye to dry. You may also notice that your loved one is unable to focus or see clearly, as their condition weakens.

Eye drops are available to help maintain the natural moisture to the eye. Your professional caregiver can advise you and show you how to administer these drops.

Swelling

Swelling in the hands and feet is common because of loss of protein and fluids from tissue, or from infection. The swelling usually cannot be treated with medications. Elevating and supporting the limbs may help with some re-absorption of the fluid.

Temperature and Vital signs

Fever is common because the body's temperature regulator is decreasing in its' function. Tumor presence or infection may also cause a fever. You can apply cool cloths to help your loved one feel more comfortable. The doctor will order medication to bring the fever down.

The health care team will not be checking blood pressure and pulse regularly as this will only disturb your loved one's rest; blood pressure and pulse readings are not reliable signs of impending death.

Skin Colour and Coolness

At the end of life, the heart pumps less and blood flow to the organs and limbs will lessen. You may notice blotchiness and cooling of the skin, especially in the arms and legs. The skin may become a pale gray colour, or take on a yellow hue if there is liver failure.

Your loved one will likely not be aware of or troubled by this coolness. They may in fact express a feeling of being too hot as the body's internal temperature is maintained. Soft, light blankets are appropriate. If you wish, loose socks may help. Do not use heating pads or electric blankets as they can cause burns.

Mental, Emotional and Spiritual Changes

Disorientation

Your loved one may seem to be confused about time, place and identity of people. This in no way diminishes how important you are to them. If it is not upsetting to them, frequently tell the person where they are, the day and time and who is in the room. Speak clearly and truthfully and always explain what you are doing.

Withdrawal

Your loved one may seem withdrawn. They are detaching from their surroundings and relationships and are beginning to "let go". Voice and touch are very reassuring. This may be a time to review with them how important they have been to you, how much they are loved, how much they will be missed, and how special their life has been.

Restlessness or Agitation

Sometimes there are neurological changes associated with the dying process. Patients may appear restless and confused, or having hallucinations, jerking movements or even seizures. This does not necessarily indicate that your loved one is in increased pain. Gentle massage, reading to him/her quietly, playing soothing music and calm reassurance can all be comforting.

At times, a medication to relax your loved one may be helpful.

Vision-Like Experiences

Your loved one may "see" or "hear" things, i.e. they may speak to or see people who have already died or they may see places not known or visible to us. This is not usually a hallucination or a drug reaction but rather a preparation for the transition from life to death. Support your loved one by not contradicting, explaining away, belittling or arguing about what they appear to have seen or heard. Listen openly and provide reassurance.

You may want to discuss this more with our Spiritual Care Practitioners.

What a Dying Person May Fear?

One of the major factors in caring for a dying loved one is to have some awareness of his or her fears.

Dr. Thomas Leig described seven fears identified by terminally ill individuals in an address to the institute on Hospice (Catholic Hospital Association, 1978)

- **Fear of the process of dying.** People may be concerned about what will happen in their future, for example, whether they will be anxious or frightened, what will happen to their body's appearance.
- **Fear of losing control of their lives.** When people are ill, they may need increasingly more and more help, becoming more dependent on others. This change can make a person feel that usual life routines have been taken from them and raises worries.
- **Fear of leaving loved ones.** Dying persons may be concerned about what is going to happen to their families after they are gone. They also go through the same kinds of processes in dealing with their own dying.

- **Fear of isolation.** We hear about the fear of being alone more often than practically any other fear. Loved ones may be afraid that they could be deserted at the time they die and may want to have someone with them, particularly someone they know and love.
- **Fear of the unknown.** We do not know what to expect as the disease worsens or what will happen after we die. There is often a fear of pain and suffering. If we can make what our loved one is going through less of a mystery, we can bring comfort and lessen anxiety.
- **Fear of seeing fear in the eyes of the caregivers.** Sometimes ill people are afraid that they will upset their family members if they talk about their true feelings. Visible but unexpressed fear is more frightening to loved ones than fears that are discussed openly and candidly between the caregivers and the loved one.
When we as caregivers encounter a dying person, it puts us in touch not only with our own mortality but also with all our own previous losses. We naturally feel some anxiety and fear. It is far better to share that with the person dying so that what we express verbally says the same thing we are expressing non-verbally.
- **Fear that their lives will have been meaningless.** Being ill provides people with an opportunity to reflect on their lives and to come to terms with themselves. It is particularly poignant for those who are dying because this may be their only time to come to terms with their past. They may have to deal with what their lives have been. What they may need is someone who is willing to listen or someone to comfort them for those things that cannot be changed. They may also benefit from sharing cherished moments, occasions, and accomplishments they feel good about.
Cultural practices and beliefs, the age of the ill person, past experiences and previous approaches to hard times all affect how one deals with difficulty. Usually, people want and deserve to be told truthfully and honestly what is happening to them so they can continue to direct their own care and continue to be part of their family.

Saying Good-bye

Saying good-bye is not easy, but can be the final gift of love to your loved one. It may help to achieve closure for both you and your loved one and allow the final release to be possible.

You may want to lie beside your loved one, hold them or take their hand. This is a time to say whatever you want or need to say. It may be "I love you", "Thank you for ...", "I'm sorry for ...". You may want to recall special memories.

Tears are a normal and natural part of saying "Goodbye". Tears do not need to be hidden or apologized for as they express your love and sadness. Consider for yourself that each time you leave your loved one; this may be the last good-bye.

Giving Permission

A dying person may seem to "hold on" in order to be sure that those who are left behind are going to be all right or to say goodbye to someone close to them.

Giving your loved one permission to go, along with reassurance that you will be all right may bring peace and release.

Signs of Approaching Death

For many people there is a sequence of bodily changes that precede death. Not all these symptoms will appear at the same time, or they may not occur. However, knowing that these conditions are part of the dying process, you can start to prepare yourself.

- Possible distancing or withdrawal from family and friends may occur – this is a normal preparation of the person for death.
- Sensation and power of motion as well as reflexes are lost in the legs first and then the arms. Anticipate a need for more physical help to get to the bathroom, then to the commode, then to turn in bed.
- Your loved one will probably eat very little in the last week of life, may forget to swallow, and may need to be reminded of this. Offer small amounts of fluids frequently but do not force the issue.
- Your loved one will sleep more and at times be difficult to awaken. Plan conversation times when he or she seems more alert, keep visiting times short, or just sit quietly at the bedside.
- Your loved one may become confused about time and place or may not recognize familiar persons. This is very difficult for family, but this can be a normal part of the dying process. Speak calmly and naturally to your loved one.
- Your loved one may experience impaired vision. The dying person may turn toward light; therefore, leave a soft light on in the room. He or she may appear to sleep with his or her eyes open. Hearing is the last of the senses to be lost, so never assume he or she cannot hear you. Continue to talk to them, say the things you want to say, even though they may not have the ability to answer.
- Your loved one may become restless, pull at covers or clothing, or have visions of persons or things not present. These symptoms are often a result of a normal decrease in the oxygen circulation to the brain. Provide re-assurance and avoid physical restrictions.
- There may be no urine or bowel movement passed for two to three days before death. Incontinence (loss of control) of urine or bowels is often not a problem. It is important that your loved one is kept clean and dry to prevent skin breakdown.
- As the circulation to arms and legs decreases, there may be purple mottling of the skin and some swelling. It is unlikely that your loved one will complain of feeling cold, so use bed coverings of normal weight, tucked in loosely. Electric blankets should not be used.
- Saliva may collect at the back of the throat and sound like a rattle. This may be difficult for the family to hear, but it is **not uncomfortable**. Like snoring – the sound affects those hearing it not the person snoring. Sometimes raising the head of the bed, or turning him or her to the side can alleviate the sound. The doctor may order medication to reduce secretions.

Some Hints for Caring for Your Loved One

Even though we know dying is part of life, it is still difficult when someone close to us nears the final stages of living. Below are suggestions that might support you in your caring:

- Allow your loved one to be part of life as much as he or she wishes. Share news, plans and feelings with him or her.
- Listen to what your loved one is saying. He or she may be feeling many emotions such as anger, depression, loneliness, hope, joy or despair. Everyone needs to have his or her feelings accepted. You can acknowledge with a nod, or a touch.
- Show your natural concern in your own way and in your own words.
- Learn to be comfortable with silence. It is natural and often a meaningful way of communication.
- Do not be afraid to touch your loved one to show your warmth, but let his or her reaction be your guide.
- Help your loved one with his or her physical care when you feel comfortable in doing so. Encourage your loved one to do as much as possible for him or herself for as long as they are able.
- Remember, negative feelings are often only expressed to those you love. Your loved one may sometimes express such feelings toward close and trusted persons.
- Live day by day: say and do what seems important.
- Provide small things to enhance life, such as, favorite foods in small amounts or tapes of loved music. Read a favorite poem or bring a treasured object, flowers or pictures.

Remember, as a person nears death, he or she may withdraw and relate to only a few people or even one significant person. This is not rejection, but may be part of your loved one's way to prepare for death.

Caring for Yourself

Helping to care for a loved one who is dying is physically, mentally, emotionally, spiritually, and socially demanding. Your own needs must be met and your well-being attended to so that you can continue to care for and be supportive to your loved one.

- The aim should be to do all that we can – not more than we can – to take care of those we love.
- Know what you can and cannot do. This will help you know where you will need to ask for help and support from someone else.
- Adequate sleep and good nutrition are vital. Carrying healthy snacks, fruit and bottled drinks when visiting is advisable. Caffeine and alcohol intake should be kept to a minimum.

- Time away from the bedside walking, reading, listening to music or just sitting quietly and thinking will refresh you and restore your energy.
- You may wish to keep a journal. Writing may help you express your emotions and sort out your thoughts.
- Make a list of questions as they arise. Members of the care team can provide answers, or guidance, or direct you to others who can help.
- Keep a list of people and phone numbers so that you can easily connect with someone to help and support you, (family, friends and professionals).
- Communicate as openly as possible with your loved one. If you can, this is a time to share memories, tears, laughter, wishes and concerns. Hiding your emotions is exhausting.
- Enlist the support of family and friends. They may want to help but may not be sure what to do. Some may be able to sit with your loved one while you take a break. Ask others to bake, cut the grass, provide rides or do babysitting.
- Ask what other services are available to support you in the community such as visiting nurses, volunteers, support groups, Hospice services and so on. In the hospital, ask members of the Care-team such as the doctor, nurse, social worker, spiritual care practitioner or volunteer.
- There are Ministry programs for paid leave of absences from work to care for a family member who is gravely ill. Please ask your Social worker for more information.

When Death Has Occurred

When death occurs, there is no breathing, no heartbeat (pulse), and no response to calling or touching. There may be some reflex muscle movement for a brief time after death. The eyes may be closed or open and fixed on a certain point. The jaw may be relaxed and the mouth open. Some fluid may seep from the mouth, and there may be loss of urine or stool as muscles relax.

Confirmation of death

The attending physician (or a registered nurse or another physician acting on his/her behalf) will confirm that your family member has died. The physician will complete a "Medical Certificate of Death", which states your family member's name, age, date of death and cause of death. This must be completed before the body is removed from the hospital (This is not the government's official death certificate). Your family member's body will remain in the hospital morgue until you have selected the funeral home. Please ensure these arrangements are made within five (5) business days. The funeral home is responsible for taking care of your loved one from the hospital to the funeral home.

Spiritual Care Practitioner

A Spiritual Care Practitioner (SCP) or your own spiritual leader may be contacted to assist and support you and your family. SCPs are trained and skilled in providing therapeutic grief and bereavement support that is non-denominational, inclusive and compassionate.

Notifying Others

You are encouraged to notify another member of your family, a close friend or a neighbor before you leave the hospital. It is often better to have someone with you when you have just experienced the death of someone who was close to you.

Organ Donation

There are long lists of patients whose lives could be saved by receiving a donated organ such as heart, kidney, liver, lung or pancreas. Other patients could have their lives improved by receiving a donated cornea, long bone graft, or even skin.

In the event of death, family members may be approached by the staff from the Trillium of Gift of Life Network (TGoL) to consider the possibility of organ or tissue transplant.

Donation of the body after death to a medical school

Some people wish to donate their body to a medical school after death. The consent form attached to the person's driver's license and signed by that individual is considered a legal consent. If there is no signed consent the medical school requires written consent from the next of kin. Medical schools accept bodies based on learning needs and may not accept your loved ones. Medical schools do not accept stillborn babies, bodies of those who died of cancer and where autopsies have been performed.

The next of kin can:

(1) Contact the Division of Anatomy as below:

- Request in writing Division of Anatomy (University of Toronto, Room 1156, 1 King's College Circle, Toronto, Ontario M5S 1A8
- Request by telephone Anatomy office 416-978-2692 (0900-1700 hours) and 416-465-7508 (after hours, weekends, holidays)
- Request by email (please include your full mailing address & postal code with request): willedbodyprogram@utoronto.ca

(2) Contact the funeral home for transfer of service authorized by the medical school once acceptance has been received. Transfer care is usually designated to MacKinnon and Bowes Removal Service 416-465-7508.

Autopsy

A physician or nurse may ask you to give permission for an autopsy. An autopsy is the examination of a body to determine the exact cause of death and to increase medical knowledge about the disease or cause of death. This knowledge will be of value in treating future patients and may provide some answers to your doctor and you.

The autopsy will not interfere with plans for an open casket viewing. You can refuse consent for an autopsy, unless it is required for legal purposes as in a case of sudden unexplained death. In such cases, the Coroner has the legal responsibility to order an autopsy. Some results may be available immediately after the autopsy while others may take months. The hospital cannot send you a report of the autopsy findings. To obtain that information, call your family doctor or the doctor who was responsible for the patient's care while in hospital.

Choosing and Notifying the Funeral Home

You may wish to choose a funeral home near your residence, or one whom family or close friends recommend or to contact a specific transporter from your mosque or temple. Your clergy or faith representative can also assist you in that decision. Funeral directors are familiar with the rite and customs of all religions. The funeral home chapel is also available for funeral or memorial services.

Call the funeral home and tell that you would like them to take care of the funeral arrangements and that the body is at the hospital. Please ensure that you know when the body will be released from the hospital, when planning the funeral.

Families without any financial resources for funeral and burial:

Social Service Departments across Ontario provide assistance and payment for burial in cases where the family of the deceased lacks financial resources and/or is already receiving social assistance. Assistance can be obtained through Metro Social Services at your local Social Services Office:

Toronto Client Services 416-392-1666

Durham Social Services 905-428-7400

The person applying for financial assistance should take along the deceased person's Social Insurance number and any bank account statement(s) if they exist.

The funeral home should be advised that you are arranging for financial assistance. Do not sign anything at the funeral home until Social Services have been contacted and instructed you to do so.

Proof of Death Certificates:

In many cases, a "proof of death" document or a Funeral Director's Statement of Death, which is certified with a special seal from the funeral home, must accompany applications for benefits or claims. Upon request, additional copies can be obtained from your funeral director.

Some organizations may require an official death certificate from the Province of Ontario. The official death certificate can only be obtained by applying by fax, mail or in person. There is a fee charged for each certificate.

Options available to you:

- (1) Download and complete the [Request for Death Certificate application](#).
- (2) You can apply in-person at the Service Ontario Centre: 47 Sheppard Avenue East, unit 417, 4th Floor, Toronto, ON, M2N 5N1
- (3) You can apply by mail to Service Ontario, 189 Red River Road, PO Box 4600, Thunder Bay, ON, P7B 6L8
- (4) You can apply by fax by sending completed applications to: 1-807-343-7459.

Frequently Asked Questions

What Causes Poor Appetite and Weight Loss?

Symptoms like pain, nausea, constipation and shortness of breath take a lot of energy and may reduce the desire to eat and drink. It is normal for patients with advanced diseases or those who are dying to lose their appetite and lose weight; this does not increase their suffering.

My mother can no longer eat or drink. Why don't you start an IV?

The body does not need much water as death draws near. The body is slowing down and is not able to handle extra water. Research shows that giving IV fluid during the last stages of life is of little or no benefit to the patient. When the body is slowing down, extra IV fluid may make the patient uncomfortable. More fluid may cause nausea and vomiting, increased fluid in the lungs and secretions. The patient may find breathing harder. Sometimes the accumulated secretions need to be suctioned out. This can be uncomfortable.

Why is my family member getting laxatives/enemas?

Medications given for pain also affect bowel function. Laxatives and sometimes a gentle enema may be required to improve comfort.

Why does my dad sleep with his eyes open?

As patients lose weight and get weaker, the eyelids become relaxed and often stay open even when asleep. The eyes may become dry and look uncomfortable. Eye drops are available to help maintain the natural moisture to the eye. You can apply warm cloth to your Dad's eyes and apply eye drops to keep his eyes moist.

Why is mom's breathing noisy?

These noises are the result of several things – accumulation of mucous in the mouth and throat, the jaw dropping back, or the tongue moving back due to the relaxation of jaw and throat muscles. A gurgling sound or a soft moaning sound may be heard on respirations. Sometimes repositioning may help, or a medication can be injected through a small needle or a patch be put behind the ear to help dry up the secretions. Suctioning is not advised unless it is necessary because it causes great discomfort to the patient. It is generally believed that these secretions do not distress the person. Like snoring – the sound affects those hearing it not the person snoring.

My Sister is unable to communicate any longer, how do I know that my family member is not experiencing pain?

There are verbal and non-verbal "cues" that your loved one demonstrates when they are experiencing pain. Although they are not able to directly tell us that they have pain, nurses watch for these "cues". Some examples are facial grimacing, moaning during turning and agitation.

My loved one's feet and hands are swollen, what can I do to help?

The swelling usually cannot be treated with medications. Elevating and supporting the limbs may help with some re-absorption of the fluid. Although the swelling may not resolve, this ensures comfort for your loved one.

Why is the nurse not taking my father’s vital signs more frequently?

Taking blood pressure and pulse regularly will only disturb your loved one's rest. Moreover, blood pressure and pulse readings are not reliable signs for impending death.

Why do my brother’s legs feel cold?

When approaching end of life, circulation to arms and legs decreases. Skin color may change to purple mottling and is cool to touch. Your loved one will likely not be aware of or troubled by this coolness. Light blankets are appropriate. If you wish, loose socks may help. Do not use heating pads or electric blankets they may cause burns.

My mother is no longer communicating with us; can she hear us when we talk to her?

Voice and touch may be very reassuring to them. This may be a time to review with your loved one how important he or she has been to you, how much they are loved and will be missed, and how special their life has been.

Always talk to your loved one knowing he or she can hear everything you say.

They may be too weak to respond or may not be able to speak, but will still be able to hear and understand what you say. Tell your loved one those things you want to say.

Hug, touch and cry – all of these are important to you and your family, as well as to your loved one.

Why is my father confused?

Your loved one may seem to be confused about time, place and identity of people surrounding him or her, including familiar people. This may be due, in part, to changes as the body prepares for death, but in no way diminishes how important you are to that person.

Why is my father restless and agitated?

Sometimes there are neurological changes associated with the dying process. Your loved one may appear restless and agitated and may make repetitive motions such as pulling at bed linen or clothing. Restlessness or agitation does not necessarily indicate that your loved one is in increased pain. Gentle massage, reading to him or her quietly, playing soothing music and calm reassurance can all be comforting. At times, a medication to relax your loved one may be helpful.

The Palliative Team at SHN hopes
this information companion for you and your family
has been helpful in guiding and supporting you through
your journey.

Please ask us questions and tell us your concerns.
You and your family are our priority.