

Some Thoughts. . . Information for Patients and Families



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As we go through the changes



We hug...We laugh...We cry...We love... E. Latimer

Introduction

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. Our goals in caring for a dying person and his or her family change in order to maintain comfort, preserve dignity, and offer support.



Your doctor or nurse has determined that only a little time remains. We are aware that things have not been easy for you and your family up to this point. We want you to understand that your needs and concerns - and those of your family - are very important to us.

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 the changes and experiences that may occur and often indicate that life is nearing its end.

The information included in this booklet is a guide only. You may have other questions. Please be sure to ask members of your care team for more information or clarification so that your questions are answered to the best of our abilities.

Issues Discussed in This Guide

Page

Introduction	1
List of Issues Discussed in This Guide	2
Body and Spirit	3
Dying People's Fears	3
• Fear of the process of dying	• Fear of the unknown
• Fear of losing control of their lives	• Seeing fear in others
• Fear of leaving loved ones	• Fear that their lives have been meaningless
• Fear of isolation	
Help for the Family	5
The Dying Patient's Bill of Rights	6
Caring for Yourself	7
Changes in Bodily Functions	8
• Weakness	• Bleeding
• Poor Appetite & Weight Loss	• Odours
• Food and Fluids	• Eye Care
• What About Intravenous Fluids?	• Shortness of Breath
• Bladder	• Discomfort/Pain
• Bowel	• Temperature & Vital Signs
• Ostomy	• Skin Colour and Coolness
• Swelling	
Changes in Higher Brain Function	12
• Withdrawal	• Vision-like Experiences
• Disorientation	• Restlessness
Saying Good-Bye	14
Giving Permission	14
Signs of Approaching Death; A Summary	15
Changes in Breathing Pattern; Nearing Death	16
When Will You Know That Death Has Occurred?	17
What To Do When Someone Dies At Home	18
Acknowledgements	19

Body and Spirit

It is important that we remember, in spite of advanced illness, that people live until the moment of their death.

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

Your loved one may also begin to prepare for death emotionally, spiritually and mentally. For example, he/she may need to complete unfinished affairs, resolve disagreements, re-establish or deepen religious connections, or receive permission to "let go". You can provide support by listening to and understanding these concerns, or providing assistance as appropriate. This may help your loved one to maintain a sense of control of his or her situation.

Dying People's Fears

One of the important aspects in caring for a dying loved one is to have some awareness and understanding of his or her thoughts and fears. Being able to share feelings may often bring a feeling of security for a person who is ill, and a sense of closeness for those around him or her.

Thomas Leig described seven fears identified by terminally ill individuals in an address to the Institute on Hospice (Catholic Hospital Association, 1978). They are discussed briefly below. If you need to talk about any of these issues, please ask to speak with any member of your care team.

Fear of the process of dying

People are often concerned about what will happen in their future.

Help for the Family

Fear of losing control of their lives

When people are ill, they often need increasingly more and more help, and become more dependent on others. For example, a father can no longer work; or a child can no longer play with friends.

Fear of leaving loved ones

People facing the end of their lives are concerned about what is going to happen to their families after they are gone.

Fear of isolation

Some people are afraid that they may be alone at the time they die. They want to have people with them, especially those they know and love.

Fear of the unknown

We do not know what to expect as the disease worsens. There is often a fear of suffering. Again, your care team is available to answer your questions.

Seeing fear in others

Sometimes people who are very sick are afraid that they will upset their family members if they talk about their true feelings. We all naturally feel some anxiety and fear. It is often better to share thoughts and feelings. There may be an opportunity for family members to address different issues, so that concerns can be addressed. You may wish to speak to your care team if you are having difficulty speaking with your loved ones.

Fear that their lives have been meaningless

People who are very ill often reflect on how they have lived their lives. What they may need is someone who is willing to listen or comfort them in sadness for those things that cannot be changed. Bringing in familiar objects, looking at photo albums, and arranging for special visitors are some ways to help ill people review and think about their lives. They also benefit from sharing cherished moments, occasions, and accomplishments that are significant for them.

We have provided some suggestions that you may find helpful as you spend time with your loved one. There is no 'recipe' for caring as the end of life approaches. Cultural practices, beliefs, age, past experiences, and previous approaches to hard times all affect how we deal with difficulty. Live day by day: say and do what seems important.

- Accept that people who are seriously ill deserve truth and honesty about their condition.
- Realize that relief from unpleasant symptoms is a right.
- Allow your loved one to be involved 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, and needs to have feelings accepted. You can acknowledge with a nod, or a touch.
- Show your feelings and concerns in your own way and in your own words.
- Be comfortable with silence. It is a natural and meaningful way of communication.
- Help your loved one with his or her physical care if and when you feel comfortable doing so.
- Do not be alarmed if your loved one shares negative feelings with close family or friends.
- As a person nears death, he or she may withdraw and relate to only a few people or even one significant person. Do not think of this as rejection; it is a normal way of coping at this time of life.

Becoming familiar with the Dying Person's Bill of Rights may also help you better understand the needs, wants and desires of the ill person. It is presented on the following page. Please speak to a member of the care team if you have a question or comment.

The Dying Patient's Bill of Rights

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.
- I have the right not to die alone. I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family in accepting my death.
- I have the right to die in peace and dignity.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face death.

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Caring for Yourself

Helping to care for a loved one who is dying is very demanding. You need to try to attend to your own well-being so that you can continue to support your loved one. Some suggestions to help you do this are discussed below:

- Try to do what you can – not more than you can – to take care of those you love.
- Know what you can and cannot do. This will help you know where you will need to ask for the help and support of someone else.
- If you are at home, accept as much help from the CCAC program as can be provided.
- Ask about other services that may be available to support you at home; e.g. visiting nurses, volunteers, support groups, hospice services; etc. If you have insurance with extended health benefits, you may want to ask your doctor whether you qualify for extra nursing help. Other agencies such as Veteran's Affairs may also be able to assist.
- Accept offers of support from 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.
- Try to have adequate sleep and good nutrition. Carry healthy snacks, fruit and bottled drinks when visiting. Caffeine, alcohol and sedatives should be kept to a minimum.
- Try to take time away from the bedside to walk, read, listen to music or just sit quietly and think.
- Keep a journal, if this is helpful for you. Writing may help you express your emotions and sort out your thoughts.
- Keep a list of people and phone numbers so that you can easily connect with someone to help and support you.
- Continue to talk with your loved one. Hiding your emotions is exhausting. If you can, take time to share memories, tears, laughter, wishes and concerns. Remember that even though your loved one may not be as aware or able to respond as he/she becomes weaker, he/she may still be able to hear.
- For support in the hospital ask a member of the health care team.

Changes in Bodily Functions

Weakness

Often body functions change as the disease progresses - weakness and increasing tiredness may happen gradually over time, or sometimes very quickly. It is not unusual for people eventually to be most comfortable staying in bed. A hospital type bed can be arranged for people at home. It is useful to have the ability to raise the head and height of the bed when care is being given.

Similarly, sleepiness may increase to the point that the person may seem to be in a light sleep all the time, may be more wakeful at night, or may be in a coma, or deep sleep. This is not something to be feared, as it does not cause pain or stress.

Remember to talk to your loved one as if he or she can hear everything. He/she may be too weak to respond to what you have said, but will likely hear and understand what you say. It is important to take the time even at this point to 'talk', share, hug and be with your loved one. Try to avoid loud noises which may startle and disturb the person, and lead to distress.

Poor Appetite and Weight Loss

There are many reasons for a loss of appetite and weight loss. Symptoms like pain, nausea, constipation or shortness of breath may reduce the desire to eat and drink. Chemical changes within the body also decrease appetite. If cancer is present, your loved one may lose weight and become weak because of the worsening of the disease - not because of lack of food or fluid.

Food and Fluids

It can be very hard to watch a loved one fade away and especially lose interest in eating and drinking. Actually, people approaching the end of their lives generally do not feel hungry or thirsty.

Our approach to care is to offer fluids and food to the person in small amounts. However, please do not expect your loved one to eat and

drink when he/she is unable, too sleepy or simply does not want to do so. With time, he/she will not be able to swallow safely: if he/she coughs after taking some fluids, stop immediately (as the fluid may go into the lungs).

Many people complain more of their mouth feeling dry. They may be breathing through their mouth or not drinking very much fluid. It is comfortable to have the mouth swabbed with a soda/salt/water solution (4 cups of water (1 litre), 1/2 teaspoon salt and 1 teaspoon baking soda) at room temperature. You can moisten the sponge tipped swab with the solution and gently clean and freshen the lining of the mouth, the gums and the tongue. If the person bites down on the swab when you put it into the mouth (a normal reflex reaction), hold onto the stick until he/she relaxes, then gently remove it. Lip balm or vaseline can be applied to the lips to keep them moist. This care can be given every hour.

What About Intravenous Fluids?

It is important to understand that intravenous (IV) fluid does not help to provide comfort at the end of life. IV fluids do not contain nutrients. In end-stage illness, IV fluids are not well absorbed. Additional fluids often start to 'back up' in the body and cause swelling or increasing difficulty with breathing. As a result, we do not usually recommend IV fluids.

Bladder

As death approaches, the amount of urine may decrease and be a dark colour. Your loved one may also lose his/her ability to control the bladder. A catheter (drainage tube into the bladder) may help keep your loved one dry and will help avoid the discomfort of skin breakdown.

Bowel

Bowel movements may become smaller and less frequent as the intake of food decreases. Medications given for pain also affect bowel

function. Laxatives and sometimes a gentle enema may be required to improve comfort. The use of protective pads helps manage to keep your loved one dry and comfortable.

Ostomy

If your loved one has a colostomy, ileostomy, or ileo-conduit (openings in the bowel or bladder to drain waste away) the same changes in bowel or bladder function may be noticed. Your loved one may feel embarrassed by some of these changes. Reassurance and loving support are important.

Swelling

Swelling in the hands and feet is common because of loss of protein and fluids from tissue. Elevating and supporting the limbs may help with some re-absorption of the fluid.

Bleeding

With cancer, there may be bleeding because of tumour growth into blood vessels, or blood may not clot well. Bleeding may be controlled with special materials (e.g. dressings) that aid in clotting.

Odours

Body odours may increase due to infection, breakdown of tumour (in cancer) and other changes within the body. There are a variety of ways that we may be able to help to reduce and control odours e.g. dressing products, air fresheners.

Eye Care

You may notice, as the body grows weaker, that your loved one does not seem to be able to focus or see as clearly. At times during the final days of life he/she may sleep with his or her eyes open. This may cause the covering of the eye to dry. Eye drops are available to help keep the eye moist. Your professional caregiver can advise you and show you how to administer these drops.

Shortness of Breath

There may be some difficulty in breathing as the disease progresses and the body weakens. Breathing may also become rapid due to fever, infection, or changes in kidney function.

Distress from breathlessness can be managed with :

- various medications to help open the airways, reduce anxiety, and control fever.
- 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.
- a fan to gently move the air to sometimes lessen the feeling of shortness of breath.

You may notice that your loved one seems to be 'working' at getting his or her breath. However, he or she may tell you he or she feels quite comfortable. Changes in breathing patterns are not unusual at this time.

Discomfort/Pain

Pain or discomfort does not usually worsen at the end of life. As the person becomes more sleepy, moves around less and the body's chemistry changes, there may actually be less discomfort. Your doctor may need to adjust medications to accommodate these changes.

It is important to remember that pain usually can be relieved, and our aim is to relieve the suffering associated with pain. Some people may experience increased pain, but we can alter medications and use other treatments to help. There is no limit in dosages of pain medications that can be prescribed. There are a number of ways to manage discomfort - by injection every 4 hours, using pain pills, placing quick absorbing pills against the lining of the mouth or under the tongue, or by using medication delivered by a pump that is attached to a small needle under the skin.

Sometimes you may hear your loved one moaning. This may happen when you move the patient from side to side, or when he or she breathes out. This moaning is not necessarily an indication of pain. However, persistent tensing or wrinkling of the forehead, or moving the hands to a specific part of the body, may be a sign of discomfort. The caregiver will give medication and provide other care to promote comfort.

Temperature and Vital Signs

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

Monitoring blood pressure and pulse is not necessary at this time, and may only disturb your loved one's rest. Changes in vital signs do not help predict when the end of life will occur.

Skin Colour and Coolness

As your loved one comes very close to his or her time of dying, you may notice blotchiness and cooling of the skin, especially in the arms and legs. The skin may become a pale gray colour, or may take on a yellow hue if there is liver failure. Your loved one will likely not be aware of or troubled by this coolness.

Changes in Higher Brain Function

Withdrawal

As a person nears death, he or she may withdraw and relate to only a few people or even one significant person. Do not think of this as rejection; it is a normal way of coping.

Your loved one may seem unresponsive, withdrawn, or in a comatose-

like state. The eyes may be partially open and not blinking. At this point your loved one is becoming less aware of his/her surroundings and is beginning to "let go".

He/she 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. Voice and touch are reassuring. This may be a time to review with your loved one how important he or she has been to you, how much he/she is loved and will be missed, and how special his/her life has been.

Allow your loved one to rest quietly. Plan visits and conversations for times when he or she seems more awake and alert, or remain quietly at the bedside for company. Your loved one may not be able to respond but will likely realize you are there with him or her. Encourage friends and family to visit a few at a time and for short periods.

Disorientation

At times, your loved one may seem to be confused about time, place and identity of people surrounding him or her. Speak clearly and truthfully to him/her, and explain what you are doing.

Vision-like Experiences

Your loved one may speak to or 'see' people who have already died, or they may see things not known or visible to others. They might also make statements about "packing their bags" or "going home." This is not unusual behavior for this time of life. If it is distressing for you, please speak with your care team.

Restlessness

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 experiencing increased pain. However, the doctor and nurse may reassess pain medication to determine if changes need to be made.

If restlessness does not ease with giving pain medication the reason is likely due to shutting down of higher brain function. Giving sedative medication will provide comfort in this situation.

It is possible your loved one may be restless or agitated if there is something unresolved or unfinished that is disturbing him or her. A member of your health care team may be able to help you identify what is happening and what can be done to ease your loved one. Gentle massage, reading quietly to him or her, playing soothing music and calm reassurance may also provide comfort.

Saying Good-bye

When your loved one is ready to die and you are ready to let them go, it is time say goodbye. Saying good-bye is not easy, but can be a final gift of love. It may help to achieve closure for both you and your loved one, and allow for a final release.

You may want to lie beside your loved one, hold him or her or take his or her 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 may be the last good-bye. If you need more information or would like to talk more about your feelings and concerns, please feel free to approach any member of the care team.

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: A Summary

For many people, there is a sequence of changes that precede death. These changes do not occur at the same time, and some may never happen. However, knowing that these conditions are part of the dying process may help you be prepared, and lessen the fear of the unknown at a difficult time.

- 1) Possible distancing or withdrawal from family and friends may occur - this is a normal part of preparation for death.
- 2) 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.
- 3) 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. Eventually, he/she will become too weak to swallow. Trying to take fluids at this time may result in choking.
- 4) Your loved one will sleep more and at times be difficult to awaken. Plan conversation times for when he or she seems more alert, keep visiting times short, or sit quietly at the bedside.
- 5) 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. Do not assume he or she cannot hear you. Continue to talk to him/her, say the things you want to say, even though they may not have the ability to answer.

6) 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; do not assume that your loved one is unable to hear you-he/she is not able to respond.

7) Your loved one may become restless, pull at covers or clothing, or have visions of persons or things not present. Provide reassurance and avoid physical restrictions.

8) 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.

9) As the circulation to arms and legs decreases, there may be purple blotchiness or 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.

10) Saliva may collect at the back of the throat and sometimes makes the breathing sound noisy. This may be difficult for the family to hear, but it is not uncomfortable for your loved one. 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 help reduce secretions.

Changes in Breathing Pattern: Nearing Death

As your loved one becomes weaker, you may notice other differences in the breathing pattern. A slowing in brain activity causes this change. For example, there may be short periods of time when your loved one temporarily stops breathing for a few to several seconds. Or, there may be repeated cycles of increased deep breaths followed by shallow breaths and then again no breaths for 10-30 seconds or

longer. Again, this is not unusual. Your loved one will not be aware of these breathing patterns and will not be distressed by them.

Breathing may also become noisy. This may be the result of several things – small amounts of mucous in the throat, the jaw dropping back as the body weakens, 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. It is generally believed that these secretions do not distress the person.

We sometimes give a medication with a small needle inserted into the skin or a patch behind the ear (called Transderm V) that may help to dry up any mucous. These medications may cause increased sleepiness. Applying oxygen will not help at this time of life.

At the time of death, your loved one's breathing will stop. It is also possible that within a few minutes it may 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 time.

We do realize that being with your loved one, and watching and waiting, can be difficult. However, we believe that he/she does not suffer as these changes in breathing patterns occur.

When Will You Know That 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 in the neck or face 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. A nurse or doctor will "pronounce" or confirm that your loved one has died.

After the death, we encourage you to take as much time with your loved one as you need. If you would like to spend private time alone with your loved one, please arrange this with your care team.

What To Do When Someone Dies At Home?

If you are caring for your loved one at home, it is important that we help you to prepare yourself for what to do when the death happens. You may want to know in advance how to turn off any equipment or pumps, or how to care for your loved one's body at the time.

Please understand that an expected death at home is not considered an emergency situation. **Do not call 911**, since calling 911 initiates emergency services, including attendants performing cardio-pulmonary resuscitation (CPR).

When the death has occurred, there is no real urgency to immediately contact your physician or funeral director, especially during the night. This can wait until morning (6A.M.). However, we encourage you to do what is appropriate given religious customs, etc. at the time. You may want to position your loved one on his or her back with some padding under the body in case of bowel or urinary accidents. There is an opportunity to take private time for yourself and your family to be with your loved one.

The physician will come to your home to pronounce death and complete the Death Certificate. This form must be signed before the body can be transferred. When he/she visits, the physician can also assist with removing any pieces of equipment.

The funeral home that you have chosen will provide transportation for the body. Do not call an ambulance. You may want to confirm with funeral home personnel in advance on how to proceed after your loved one has died.

Please notify people who have been assisting with care, especially if

you are expecting them to visit, i.e. physician, nurse, personal support worker. Lent equipment will be picked up from your home later - please do not send it to the funeral home.

It is our hope that the information in this booklet will provide support and reassurance for patients and their caregivers and families across the city.

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