

Journey Through The End of Life

A guide for family and friends



The Ottawa
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Dedication

“This guide is dedicated to our patients, their loved ones, and the healthcare professionals from whom we have learned so much, as we walk through the end of life journey together.”

Dr. Clara Leigh

This guide was developed by Dr. Clara Leigh as part of her palliative medicine residency project at Bruyère Continuing Care and updated in collaboration with The Ottawa Hospital and the Champlain Hospice Palliative Care Program.

Disclaimer

This guide provides general information and is not intended to replace the advice of a qualified healthcare provider. Please consult your healthcare provider if you have any questions about this information.

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Introduction

There are many changes that occur in the whole person at the end of life. These include changes in body, mind and spirit. Many of these changes are normal when close to death. This guide describes some of the common signs and symptoms observed or experienced at the end of life. Though these changes are common, not everyone is the same. Each experience is unique, just as each person is.

This guide contains information about the end of life and may add to what your healthcare provider has already discussed with you. If you or your loved ones have any cultural or religious needs or customs related to death or dying, please let us know.

There are blank pages at the end of the guide to write down notes or questions you would like to ask at a later time. There is some mystery to death and dying. We may not know the answers to all of your questions, but we will be here to support you through the journey.

This is a difficult time for you. You likely have many questions. Your healthcare team is here to support you and answer your questions.



Loved Ones and Caregivers

Family and Friends

It is possible that many friends and family will want to visit. They may want to say goodbye, share memories, and say things they have never been able to say before. Those who have not visited in a while may not be aware of how much has changed in the dying person. If possible, you may choose to update visitors before their visit and set a time limit for the visit if needed.

The end of life journey affects everyone around the dying person. Sometimes this journey is tiring. It is important to also care for yourself at this time.

A dying person may feel they are a great burden, and knowing that you are taking care of yourself may bring them comfort. Remember to eat and drink regularly and find time to sleep. Take breaks away from the bedside. Go for a walk outside or in the common areas.

Anticipatory Grief

Anticipatory grief refers to the grieving that begins even before a death occurs. The many changes that occur when a loved one's health worsens can lead to many changes for you and your family. These losses can add up and at times feel like it is too much.

Grief can affect you in many ways: how you feel and think and how much energy you have. You may find that you have difficulty making decisions, feel all alone and/or uncertain about the meaning or purpose of your life. You may also feel great joy and love when you share the memories and stories that are special to you and your family.

“Remember, grief is a process, not an event. Be patient and tolerant with yourself. Be compassionate with yourself as you work to relinquish old roles and establish new ones. No, your life isn't the same, but you deserve to go on living while always remembering the one you loved.”

Dr. Alan Wolfelt — Center for Loss and Life Transitions

Grief will likely be a part of your experience. It may be helpful to share your feelings with your friends and family. If you would like to speak to a healthcare professional about your grief, please let a member of your healthcare team know.

Children and Teenagers

Children and teenagers are able to sense when adults are sad or worried even when you try to hide it. It is important to be honest and include children when a loved one is dying. For some children, what they imagine in their minds is worse than what is real. Your healthcare team can offer you advice on how to include children.

Supporting children and teenagers when a family member is dying or has died can be one of the most difficult tasks for adults during this time. You may already be feeling overwhelmed, but despite these worries you can help. Here are a few reminders and suggestions that may support you in your efforts:

- Be honest. Include your children or teenager and don't be afraid to say, "I don't know". Have an open discussion and remind them that there are some things in life that cannot be explained. Some people who may help you answer questions can include your healthcare team, other family members, teachers, and spiritual leaders.
- Use the words dying and dead. Phrases such as "just going to sleep" or "passed away" may confuse a child. Use the appropriate words, such as: "cancer" or "stroke," so that they can understand it is different from having a cold or being sick.
- Assure them they will still be cared for and loved.
- Emphasize that the illness is not anyone's fault. Children often feel responsible for what is happening around them. Some children may believe they accidentally wished or caused the illness to happen or that it is a punishment. Remind them that there is nothing they could have done to cause it, avoid it or cure it.

- Reassure them that they cannot catch the illness.
- Show them you are there to support them and that there are no wrong or bad feelings or thoughts. Children may be sad or angry one minute and play normally the next.
- Explain that it is common to feel a range of emotions and it is important to share them. This can help let children know that it is ok to express themselves.

“If you are old enough to love, you are old enough to grieve.”

Dr. Alan Wolfelt



Last Days to Weeks

In the last days to weeks of life, you may notice changes in your loved one's energy, eating and behavior. All these changes are normal. Some of these changes may already be present but become more obvious during this time.

Weakness and Withdrawal

Many diseases that lead to death first cause a person to become physically weaker. You may have already noticed this. Your loved one may no longer be able to do many routine activities.

As a person gets closer to death even speaking can be tiring. From day to day, energy levels may go up or down. There may be “good days” and “bad days”.

A dying person may gradually withdraw from the world around them, first from the greater community (TV, neighbours and usual interests) and then perhaps from family. This is to help them save what energy they do have and not a reaction to something family or loved ones have done. This is also a natural part of the dying process.

What to do?

Be aware that when the body is weaker, it may take more time to recover. For example, after a busy day, your loved one may spend the next day sleeping.

Continue to visit but adjust activities. For example, use a wheelchair if the person cannot walk long distances. Discuss having time limits for visits. Discuss what type of activities would be most meaningful to your loved one. For ideas on how to adjust to the energy level of your loved one, speak to the members of your healthcare team.

Eating and Drinking

Loss of hunger and loss of thirst are very common in later stages of disease. This can be very distressing to family and friends, who may worry that their loved one is starving or thirsty. This, however, is not the case. Food and fluid will not reverse the dying process.

What to do?

Remember that the person is dying because of the disease and not because he or she is not eating. Offer the dying person food and drinks that they enjoy. Sips and several spoonfuls may be all he or she can handle at one time. Do not force your loved one to eat or drink. This may cause your loved one to have nausea, pain, or other discomfort. Also do not offer food or drink if he or she is not fully awake or has trouble swallowing. Someone who is not fully awake or has trouble swallowing, may struggle with food or drink, or breathe it into the lungs.

Using artificial feeds and IV fluids when someone is dying can cause discomfort and often ends up in the wrong places, like the lungs, or swelling to the hands and feet.

Delirium (Confusion/Restlessness)

You may notice sudden changes in behaviour. There are many different reasons why behavior may change at the end of life. You may find that your loved one forgets where he or she is or what day it is. He or she may see, feel or hear things that are not there. Your loved one may become upset more easily and no longer be able to rest in comfort. He or she may even say things that are hurtful to you or others without being aware of it. Your healthcare professional may call this confusion or restlessness “delirium”. Older frail people who have dementia are more likely to develop delirium. This change is common in the last weeks to days of life.

Common causes of delirium include medications and infections (such as chest or urinary infection). Some causes of delirium are easier to reverse than others.

Sometimes the cause of the delirium cannot be found. People with delirium may become quiet, withdrawn and sleepy or very restless and agitated, or even aggressive.

What to do?

If you notice changes in behavior, please let your healthcare team know. They may be able to find cause for the delirium and correct it. People with delirium may feel frightened and need gentle reassurance. Your team will also be able to use medications for comfort and offer you ways you can help comfort your loved one.



Last Hours to Days

In the last hours to days of life you may see several physical changes. As the body's circulation slows, parts of the body (especially the hands and feet) may lose colour or become bluish. Their arms and legs may become cool to the touch. In addition you may see changes in sleep, energy, and breathing.

Sleep

As a person approaches death, he or she may spend more and more time sleeping. At one point he or she may no longer be awake enough to speak or open his or her eyes. Though no longer strong enough to communicate, your loved one may still be able to hear and to feel the touch of others.

What to do?

Though a dying person might appear to be sleeping, he or she may still be aware of changes in the room. Remember to gently introduce yourself when you arrive and say goodbye when you leave. Even if he or she does not respond, your words may still be heard.

Continue to spend time even if there is very little conversation. Your presence alone can be important and comforting to your loved one. You might read quietly or aloud, visit with other guests, talk or hold hands with your loved one.

Continue to work with your team to ensure your loved one's comfort. When someone who is dying is not able to speak of pain or discomfort, you can still detect it. Tension in the body, especially the face, may indicate discomfort. A relaxed face usually means that your loved one is comfortable.

Changes in Energy

You may have watched your loved one's body become weaker and have found your loved one sleeping more often. You may have also noticed his or her energy levels go up and down from day to day or even from moment to moment.

He or she may have moments with more energy and then quickly become very tired or may be awake for only seconds before falling asleep again. Occasionally, you may see a surge of energy before death.

What to do?

Moments of increased energy can be precious. Treasure them. They can be gifts of time to share important or simple things together. Also watch out for words or signs of discomfort. Please tell a member of your healthcare team if you feel your loved one has discomfort or pain.

Breathing

Near the end of life, you may notice that your loved one's breathing changes. The breathing may become irregular. He or she may breathe in and out more quickly at times and more slowly at other times. Breathing may also stop for periods lasting 20 to 60 seconds and then start again. These moments of not breathing may be called periods of "apnea" by your healthcare professional.

What to do?

These changes in breathing are normal in someone close to death. Be aware that these changes do not cause discomfort in your loved one.

Noisy Breathing

In addition to changes in the breathing pattern, you may find that your loved one's breathing becomes noisier or gurgling.

It may have a sighing or a “wet” sound. Near the end of life, the vocal cords are very relaxed. The mouth still produces saliva, but your loved one may not be able to swallow it or clear it, and it sits in back of the throat. These sounds are made as air passes through the vocal cords and saliva in the throat. Noisy breathing may be very upsetting to those who hear it, but it does not mean your loved one is uncomfortable.

What to do?

Your loved one’s breathing may be quieter with his or her whole body turned to the side. Your healthcare team may be able to give medications to decrease the amount of saliva, but even with medication the breathing may still be noisy.

Remember the gurgling noise does not cause discomfort. Suctioning can cause discomfort and is usually avoided. Suctioning may not help stop the noise and may make the saliva worse.

Speaking from the Heart

Caring for someone at the end of life can be very emotional. There may be things that you have not said that you want to say.

What to do?

Do not wait to say what you must. Speak from your heart. Remember and share the meaningful memories you have of your loved one. Take the time to say goodbye. It can be a comfort to your loved one to hear these things.

It may also be helpful for you in your grieving process. Also remember, that your presence at the bedside speaks to the person dying when words are too hard or not enough.



At the Time of Death

No one can predict exactly when the moment of death will be. Your loved one may die when you are present or when he or she is alone. You may want to be present at the time of death, but it is okay not to be. When death occurs the person will stop breathing. It is normal for the eyes to stay open and the mouth and chin to fall relaxed. Parts of your loved one's body closest to the chest may stay warm to touch for some time after death. The skin may appear paler.

What to do?

You may have many reactions to the moment of death of your loved one. It is normal to feel shocked, to cry, to sit quietly, or even to feel relieved for your loved one.

You may wish to stay with your loved one for a time. When you are ready, you can let the nearest member of your healthcare team know.

Summary

Loved Ones and Caregivers

- Friends and family go through the end of life journey too, and need support
- Children should be included

Last Days to Weeks

- Withdrawal from the outside world
- Progressing weakness
- Decline in eating and drinking
- Possible delirium

Last Hours to Days

- Physical changes including colour and warmth of arms and legs
- Increasing amount of time sleeping
- Changes in energy
- Breathing rate and pattern will change
- Noisy breathing may begin
- At the time of death you may wish to stay with your loved one for a time

Resources

An online version of this booklet can be found under the heading “For Caregivers & Patients” on the Champlain Hospice Palliative Care website at www.champlainpalliative.ca

Booklet

A Caregiver’s Guide: A Handbook About End-Of-Life Care
Available through the Canadian Hospice Palliative Care Association www.chpca.net or check with your local hospice organization.

Websites

Champlain Hospice Palliative Care Program
www.champlainpalliative.ca

Virtual Hospice
www.virtualhospice.ca

Volunteers

For more information about volunteers, speak with your healthcare team.

