

Preparing for Death

A guide for families and caregivers as death approaches



Simcoe Muskoka
Regional Cancer Program



Cancer Care Ontario
Action Cancer Ontario

In this booklet you will learn about:

- Things to consider when a loved one is seriously ill
- Checklist of documents you will need
- Body and spiritual changes as death approaches
- Tips on saying goodbye
- How to take care of yourself as a caregiver

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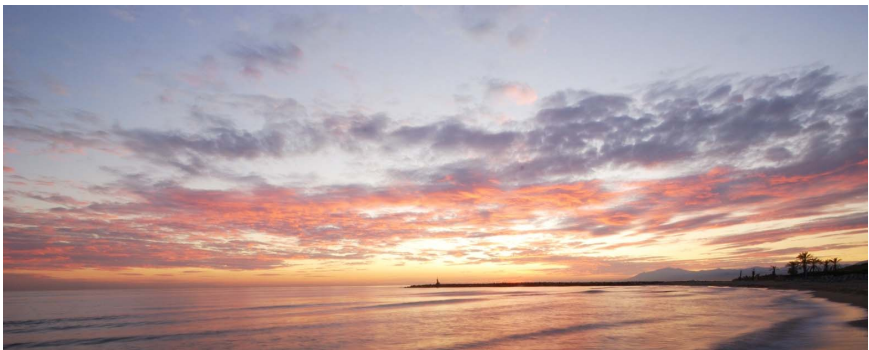
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Things to consider when a loved one is seriously ill

Find out as much as possible about end of life care

Have a conversation with your loved one about their wishes regarding:

- Body or organ donation
- Beliefs, wishes or end of life requests
- Communicate your loved one's wishes to your Care Team
- How and where they want to be cared for at end of life (home versus hospice)
- Funeral wishes including:
 - Where they wish their remains to be buried
 - Hymns/music/pallbearers
 - Memorial donations



Gather the following documents or know the whereabouts of :

- ☐ The will, Power of Attorney documents and Advance Directives
- ☐ Safety deposit box information
- ☐ Important keys to house/car/boat/other real estate (make sure they are labelled)
- ☐ Insurance policies (name, number, amount, beneficiary)
- ☐ Health, accident or burial policies
- ☐ List of all assets including pensions, employee benefit booklets, RRSPs, stocks and bonds
- ☐ List of creditors/debtors
- ☐ Title documents to the house, car, boat, etc.
- ☐ List naming advisors, lawyer, insurance agent, clergy, accountant
- ☐ List of close relatives and friends to contact
- ☐ List of any personal effects or requests not included in the will
- ☐ Credit cards (names and numbers)
- ☐ Bank account passbooks and statements
- ☐ Tax returns for the past 3 years
- ☐ Notarized copy of birth certificate and marriage certificate or separation/divorce papers

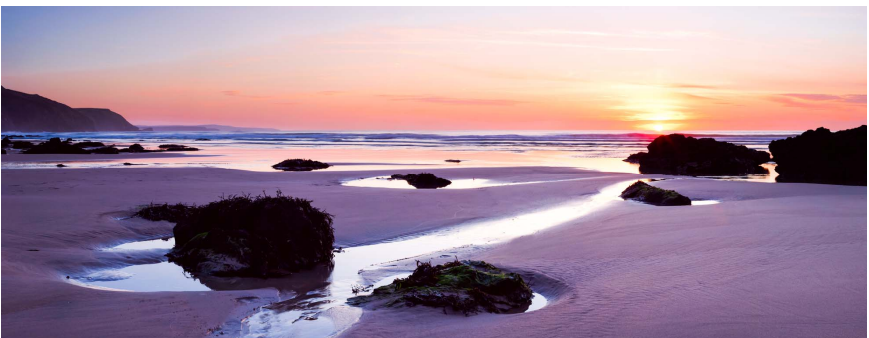
When death is near

No two people experience illness in the same way. However, some generalizations can be made about how an illness affects the body and the physical changes that are present as a person is nearing death. These changes are normal and to be expected. As illness progresses the body's various systems gradually weaken and shut down. Although the changes are presented in the order they usually appear, some variation is common.

When you note changes or have questions or concerns please speak with a Care Team member.

Changes in sleep patterns

A dying person may sleep longer and have difficulty waking at times. There is a notable decrease in energy and day to day functioning. The illness may appear to speed up as weakness quickly leads to further weakness. This decline is often most striking in the last few days of life, where people can change from being fairly independent to sleeping all the time.



Tips on managing changes in your loved one's sleep patterns:

- Plan visits for a time when the person is most wakeful and alert. Sit quietly if the patient is needing to rest.
- Physical touch such as hand holding may be a good way to connect
- Avoid overtiring the person. Limit the number and length of visits.
- Allow family time and private time for final and meaningful connection
- It is comforting for the dying person to know that family is there and supporting one another, sharing fond memories and stories.

Food and fluids at the end of life

It is normal at end of life for there to be little desire for fluids or food. It is a natural part of their body preparing for death. The body cannot use the nutrients in food so family and friends should not be concerned if the person does not eat or drink much. The lack of food at this time does not affect strength or shorten life. Dehydration is a normal part of the dying process and is not the same as thirst.

Please speak with your Care Team member regarding any concerns. You can also refer to the brochure *Food and Fluids at the End of Life* for more information.

Spiritual or emotional changes

A dying patient may be unable to recognize familiar people or surroundings. They may see things that you cannot see, pull at their sheets or reach into the air. They may talk about trips or going home. As death nears the brain experiences the same changes as the other systems of the body and there is often some degree of confusion. Strong emotions such as fear or anger may also be expressed at end of life. Although not everyone will experience these responses they are considered normal.

- Continue to respond in your usual way
- Realize that the dying person may be processing important life issues such as life review, saying goodbye and letting go
- Accept that unusual language or references are not always a sign of a problem and may be part of the person's dying experience
- It is not usually productive to contradict the patient. Provide support as much as possible—be a comforting presence
- Sometimes medications are used to settle the patient if confusion or hallucinations are frightening or upsetting to the patient

Speak with your Care Team for advice on how to manage these changes.

Circulation changes

The circulation of the body gradually shuts down which causes the hands and feet to feel cool. The dying person may have a patchy purplish appearance or color on the skin called “mottling”. The heart often beats faster and can make the pulse feel rapid. As the body systems shut down the brain worries less about controlling temperature and the patient’s skin can feel as though they have a fever or feel cool as mentioned above. This is a normal part of the dying process and people do not feel these changes.

Remove blankets or place cool cloths on the person’s forehead if the person is feeling too warm.

Bowel and bladder changes

If the person has stopped eating and drinks very little, loss of bowel or bladder control may not be an issue.

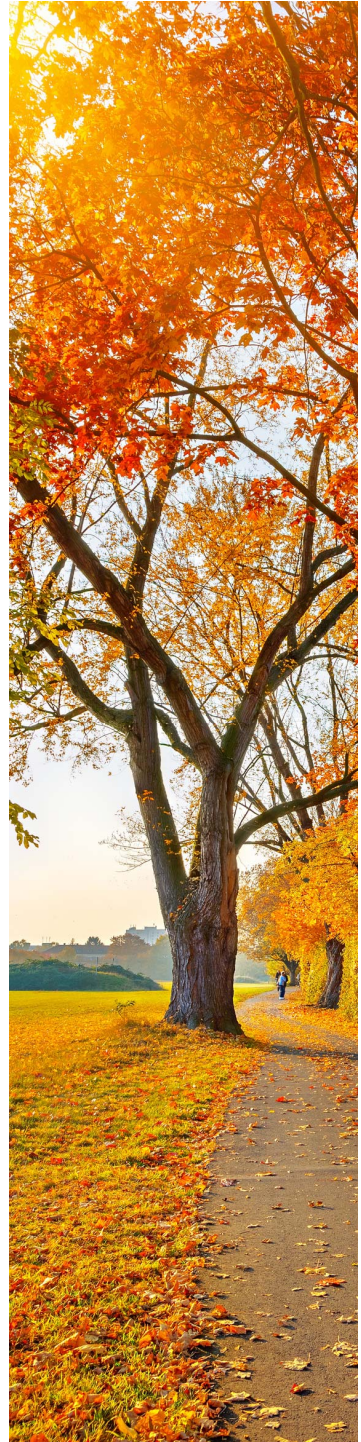
Decreased urine output and bowel function are normal at end of life. Managing constipation is not usually considered necessary in the final week of life or so.

- Adult incontinent or absorbent products may be necessary
- Talk to a member of your Care Team to see if a catheter is an option
- Goal is to avoid skin breakdown that may occur from soiling or moisture

Breathing changes

Changes in breathing are generally the most significant physical changes that give clues to how close someone is to dying. Generally you will see changes in how fast the breathing is (called the *rate*) and how deep the breaths are (may be shallow, deep or normal). You may see changes in the pattern of the breathing and the kinds of muscles used in breathing. This can make it look like it is more strenuous to breathe. There can be an increased amount of secretions or mucous that can build up due to the inability to cough, and some patients may develop an infection.

Rapid shallow breathing may be common and there may be pauses between breaths of 10-30 seconds. Changing breathing patterns are normal and usually the dying person is unaware and untroubled by these changes.



Noisy breathing can sometimes be caused by increased secretions in the lungs. It can be rattling or gurgling and sometimes upsetting for those sitting at the bedside. This is not distressing for the dying person as they are not conscious, just as a sleeping person is not aware that they are snoring.

- Remind yourself to breath normally. Sometimes caregivers temporarily change their breathing pattern as they focus on the dying person's breathing patterns.
- Discuss what you are seeing or hearing with the Care Team. There are medications that can decrease the congestion.
- Request a change in the dying person's position. Sometimes a change in position can aid in their breathing.

Experience an unexpected rally

Sometimes when patients are near death they may rally or experience an improvement in overall alertness which defies expectations. Although temporary, this does allow the family a last opportunity to share thoughts, memories, feelings or the opportunity to say goodbye. Such fluctuations can be unexpected and unnerving for family members, and the duration and frequency are impossible for health care providers to predict.

Take advantage of the opportunity to be together and supportive. Speak with your Care Team if you have any questions or concerns.

Saying goodbye

For many people, saying goodbye is very important. Some forms of saying goodbye happen through conversations, letters, trips, rituals or by just being together. Some dying people are most comfortable with having people around while others prefer privacy and quiet. Sometimes a person seems to choose the time to die, perhaps when alone or when particular people are present.

- Talk about shared experiences. Offer and receive love and support.
- Offer or ask for forgiveness
- Tears and crying are natural and a healing release of sadness
- Provide reassurance to the dying person that you and the family will be okay
- Discuss any last minute wishes
- Speak with your Care Team regarding any rituals, wishes, beliefs or ceremonies that you would like to perform in the hospital



At the time of death

Usually the most obvious sign that death has occurred is that the person has stopped breathing. You may notice pale or waxy looking skin. Muscles in the face may relax and the jaw may droop. There may be minor muscle twitches that will fade away in a few minutes. There will be no heart beat. The eyes may be partially closed as this is often the natural resting position. There will be no eye movement.

You may wish to stay at the bedside to say whatever words seem appropriate or just be with your loved one.

There is no harm in touching the person's body and there is no rush to move the body until everyone has had a chance to say goodbye.

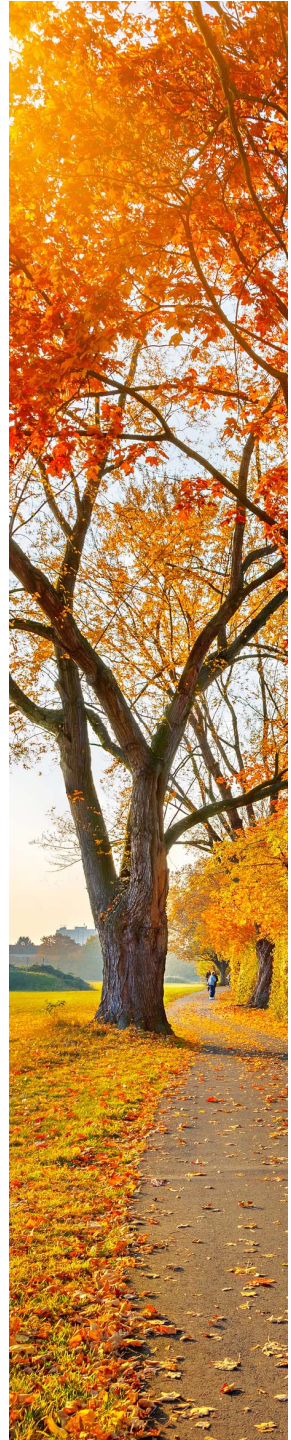
Communicate any wishes or arrangements to your Care Team.

Don't forget about you— self care suggestions

At this time you may find yourself very busy being the caregiver, so much so that you are not looking after your own health. It can be very difficult to care for another when you do not care for yourself.

- Ask for and accept help with caregiving and other household tasks.

- Find ways to handle updates. Designate a friend to communicate with others.
- Notice and participate in what gives you comfort or pleasure (time with others, reading, walk with nature)
- Remember to eat and sleep
- Let others know how you are doing. Communicate needs and wants.
- Don't ignore the beauty and humor of life
- Share stories and memories
- Do anything that feels like self care (nap, sit quietly, cry) and maintain your spiritual and religious practices
- Remember that everyone including you is doing their very best
- Talk to our Social Work team for additional support. Our Social Workers are here to help both adult and child family members or those who are close to the patient.



Your Care Team

At the Simcoe Muskoka Regional Cancer Centre, the care provided by our staff is tailored to the needs of each individual patient and caregiver. The staff at the Cancer Centre will work together to provide the best care, education and support that's just right for you.

Your Care Team may include the following health care professionals:

Oncologists are doctors who are specialized in treating cancer. Oncology further specialize in specific ways to treat cancers, such as:

- **Surgical Oncologists/General Surgeons.** These doctors perform surgical procedures related to cancer such as biopsies and removal of lumps or tumours.
- **Medical Oncologists** are doctors who treat cancer using medications, such as chemotherapy.
- **Radiation Oncologists** are doctors who treat cancer with radiation treatment.

Primary Nurses will work with your Oncologist to help you and your family identify your individual needs and make decisions about your care.

Clinical Dietitians can help you with eating problems, weight changes, special diets and the use of nutritional supplements.

Physiotherapists & Occupational Therapists can help with proper exercise and safe mobility for cancer patients while in hospital. They can recommend the right walker or other equipment for home use. They can also assess the needs of patients on bedrest to reduce physical pain and discomfort.

Social Workers can help you and your family cope with changes due to cancer and treatment and they can help you access community support services.

Spiritual and Religious Caregivers are available to meet with you and your family members when you are dealing with spiritual and emotional issues.

You can talk to any member of your Care Team if you have any questions or concerns. **Remember, we're all here for you!**

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