



What to Expect When Someone Close to You is Dying

A guide for families and caregivers to help manage the care of loved ones during the last hours or days of living.

**North Simcoe Muskoka Hospice
Palliative Care Network**



NSMHPCN
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Mission:

To support the provision of exceptional hospice palliative care and end-of-life care through partnerships, innovative programs and knowledge exchange.

Vision:

A community where the experience of hospice palliative care and end of life care honours each individual and their choices.

Values:

Respect: We recognize the inherent worth of every person and their choices.

Empathy: We are compassionate collaborative and understanding in our approach.

Inclusivity: We honour and value diversity and promote inclusiveness within our communities.

Integrity: We act with honesty, strong ethical principles and in compliance with provincial standards.

Inclusion:

North Simcoe Muskoka Hospice Palliative Care Network is committed to creating and maintaining an environment free of discrimination. All individuals are treated with respect and dignity, and have equal opportunities.



NOTE FOR CAREGIVERS

We are grateful for the compassion and support you've demonstrated for your loved one during this challenging period.

Should you ever have any worries or questions, please reach out to your healthcare provider, nurse practitioner, or nurse.

TABLE OF CONTENTS

Important Discussions for Advance Care Planning.....	4
Saying Goodbye.....	5
Experiencing an Unexpected Rally.....	5
Pain.....	6
Restlessness and Agitation.....	6
The Care Team.....	7
End-of-Life Sleep Patterns.....	8
Tips on Sleep Patterns.....	9
End of Life Nutrition.....	9
Mouth and Eye Care.....	10
Circulation Changes.....	10
Emotional and Spiritual Changes.....	11
Breathing Changes.....	12
Bowel and Bladder Changes.....	12
When Death is Near.....	13
At the Time of Death.....	14
Self Care.....	15
Important Documents.....	16
Resources.....	17
NSMHPCN Contact Information.....	Back Cover

IMPORTANT DISCUSSIONS FOR ADVANCED CARE PLANNING

Have a conversation with your loved one about their wishes, including the following:

- Body and 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 vs. hospice).
- Funeral wishes, including:
 - where they wish their remains to be buried/cremated
 - hymns/music/pallbearers
 - memorial donations
 - location of documents

Ways to provide comfort to your loved one:

- Keep them company (talk, watch movies, read or just sit with them).
- Listen to their concerns and fears about dying.
- Be willing to reminisce about their life.
- Reassure them that their wishes will be honoured.
- Ask if there is anything you can do.
- Respect their need for privacy.
- Just show up!

SAYING GOODBYE

For many people, saying goodbye is very important. Saying goodbye can happen through conversations, letters, trips, rituals, or sitting together. Some dying individuals are most comfortable with having people around while others prefer privacy and quiet. Sometimes a person will choose the time to pass, 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 emotions that can be healing and release 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.

EXPERIENCING AN UNEXPECTED RALLY

Sometimes when someone is 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, and feelings, as well as the opportunity to say goodbye. Such fluctuations can be unexpected and unnerving for family members, and the duration and frequency are impossible for healthcare 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.

PAIN

Pain does not usually get worse at end of life. Usually, as the person becomes sleepier, moves around less and the body changes, there is often less pain. Your doctor may need to adjust medications to accommodate these changes.

If your loved one can no longer swallow the doctor may need to change the way the medications are given. You may be asked to give the pain medication orally, by placing it against the lining of the mouth or under the tongue where it could be absorbed. The other option for pain control may be by injections using a special setup that uses fewer needles or by an infusion pump that will give them a steady dose of medication. Your doctor or nurse will teach you about that too.

Sometimes you may hear the person moaning. This may happen when you reposition the person from side to side, or when they breathe out. This moaning is not caused by pain. If you see the person's forehead scrunch up or frowning, this could mean they are in pain. In this case, you should give a breakthrough dose of the pain medication as instructed by your healthcare team.

RESTLESSNESS AND AGITATION

Sometimes your loved one can become very agitated or restless. This is because of the internal changes occurring in your loved one's body, or sometimes from medication side effects. The doctor may prescribe a medication that can be absorbed under the tongue or in the person's cheek. This medication is mildly sedating and should help calm and soothe a restless person. This may need to be administered every hour initially and it may require several tablets before the restlessness stops. Your doctor, nurse practitioner or nurse will teach you how to give the medication. This medication will not harm your loved one, just help to calm them.

THE CARE TEAM

At NSMHPCN we work closely with the other members of your loved ones Care Team to ensure that the best care, education and support is available to you and your loved one.

The Care Team may include the following healthcare professionals:

- Registered Dieticians
- Doctor
- Home Care Case Coordinator
- Nurse Practitioner
- Oncologist
- Pharmacist
- Physiotherapists / Occupational Therapists
- Primary Nurses
- PSW
- Social Workers
- Spiritual and Religious Caregivers / Elder

Remember that your entire Care Team is here to help you. Please never hesitate to talk to any of your Care Team members.

Notes:

END-OF-LIFE SLEEP PATTERNS

Your loved one may feel increasingly weak and tired. Often these changes happen over a few days but occasionally this happens quickly over a few hours.

Your loved one may be spending the majority or all of their time in bed. A hospital bed may be required to make it easier to care for the individual at home. Your healthcare provider may order this for your loved one. Try to keep the person flat with the head of the bed raised up a little. The person may lay partially on their side with the use of pillows. The person's position needs to be changed every two hours (the nurse will help teach you how to reposition your loved one) unless the nurse instructs you otherwise.

To make this time a little easier the nurse may suggest a urine catheter or adult briefs so that the person does not have to leave the bed to go to the toilet. A urine catheter does not cause pain and can be very helpful.

Your loved one may appear to be in a light sleep all of the time and at times can be more awake at night time. In very few cases the patient may be in a coma. Coma should not be feared; it is just a deep sleep and does not cause any pain or distress to your loved one. You do not need to be quiet when around your loved one. Speak in normal voices. However, avoid very loud noises that may startle and disturb the person.

It is important to always talk to your loved one as if they can hear everything. The person may be too weak to respond or not able to speak but will still be able to understand what you say. Tell your loved one what you want to say. Hug, touch, talk and cry; all of these things are important to you and your family, as well as your loved one.

TIPS ON MANAGING CHANGES IN SLEEPING PATTERNS

- Have visitors come by when your loved one is most likely to be alert.
- Avoid arguments in the company of your loved one.
- Avoid over stimulation, as this will be exhausting for all.
- Allow family members to have private time with your loved one.
- Limit how many people are in the room with your loved one.

END-OF-LIFE NUTRITION

At this stage your loved one will eat or drink very little, if at all; often their urge to eat is poor. At this time food and water will not help provide your loved one comfort and it will not change the outcome. If you try to feed someone who is very sleepy the food or water may enter the lungs so be very cautious.

If the person asks for a drink, raise the head of the bed and give them small amounts/sips of fluids. If you hear them cough or have difficulty breathing while giving them fluids, stop immediately.

You and your loved one's care team may consider the use of intravenous fluids (via a needle in the vein). The solutions used are usually just sugar and water and/or salt and water; they do not provide nutrition to your loved one. The intravenous (IV) does not provide comfort and IV fluids may go more into the tissues instead of circulation, worsening or prolonging their suffering. We do not usually recommend using an IV unless there is a special medication that needs to be administered that way.

MOUTH AND EYE CARE

It is important that you help your loved one at this time with mouth care. Often you may find the person is breathing through their mouth and taking in very little fluid. The lining of the mouth and tongue can become quite dry, causing the person some distress. Hourly mouth care will help to provide comfort.

If you are caring for your loved one at home you can make a solution to assist you with mouth care. Make a solution of 4 cups of water, 1/2 teaspoon of salt and 1 teaspoon of baking soda. Make a new batch each day. Use this solution and a sponge tip swab to clean and freshen the lining of the mouth, tongue and gums. Occasionally your loved one may bite down on the swab, this is a normal reaction to protect the mouth. If this happens, continue to hold the stick and in a few moments, the person will release their bite. As well, use something to protect the lips such as water-based lip balm (petroleum-based lip cream is not recommended when oxygen is in use). The nurse will show you how to provide mouth care.

For relieving dry eyes, purchase some artificial tears from the pharmacy and instill them into the person's eyes about 4 times a day. Your nurse will teach you how to do this.

CIRCULATION CHANGES

As your loved one nears death there will be noticeable changes in their circulation:

- Patchy purple appearance to skin (mottling)
- Fluctuating temperature (skin may feel warm to the touch)
- Hands and feet feel cool
- Clammy skin
- Cold and gray skin (after death)
- Change in nail colour

EMOTIONAL AND SPIRITUAL CHANGES

Your loved one may not be able to recognize familiar people or surroundings. They may also see things that you cannot see. They may pull at their sheets, reach into the air, talk about going home or even seem to be talking to those who have previously died.

As death nears the brain experiences changes the same way the rest of the body does. These changes can often result in some confusion. Strong emotions such as anger and fear may also be expressed. Although not all who are near death will experience confusion or strong emotions, know that they are normal experiences.

- Continue to respond in your usual way.
- Know that your loved one may be trying to figure out how to say goodbye and how to let go.
- Unusual language and/or reverting to primary language or references are not always signs of a problem.
- It is counterproductive to contradict your loved one; refrain from arguing and offer comfort.
- Support your loved one as much as possible.
- If fear or anxiety is evident, please reach out to your Care Team for advice on how to manage the changes your loved one is experiencing.

Notes:

BREATHING CHANGES

It is normal for there to be changes in your loved one's breathing pattern. The most common thing you will see will be short periods of time when the person stops breathing temporarily. This is called apnea. The amount of time the person stops breathing may get longer as they come closer to death. Your loved one will not notice these periods and will not be distressed by them.

At other times, the person's breathing, particularly near death, becomes rapid, deeper and regular. This is due to an acid imbalance in the body and does not cause the person distress.

Oxygen will not help in either of these situations. The person is not lacking oxygen and is not aware of what is happening. There may be certain times when oxygen is appropriate for your loved one and your team will determine if that is the case. Oxygen can prolong the person's dying journey.

Just before death, the person's breathing will slow down, and it may seem like they are gasping. This is again normal and at this point, the person is not aware or in any distress.

BOWEL AND BLADDER CHANGES

If your loved one has stopped eating and is drinking very little, the loss of bowel and bladder control may not be an issue. Decreased urine output and bowel function are completely normal at end of life. A few things to remember are:

- The management of constipation is not considered necessary in the final days of life.
- Adult incontinent or absorbent products may be necessary.
- Talk to a member of your Care Team to see if a catheter is an option.
- In the end the goal is to avoid the skin breakdown that may occur from incontinence and moisture in order to keep your loved one comfortable.

WHEN DEATH IS NEAR

Illness and death are experienced differently by everyone. While death is often feared by many, know that it is a normal and natural process. The body's organ systems gradually weaken and shut down.

As your loved one comes close to the time of dying, you may notice blotchiness and coolness of the arms and legs. The person's eyes will often be open and not blinking. At this time do not worry about the nurse taking your loved one's blood pressure or pulse; they are not reliable signs of impending death. This may be a time when you talk and express your feelings or just sit quietly and be present with your loved one as they make their journey.

Near the time of death (hours to days), you may hear the person gurgle or make snoring-like noises. During this time the person will be extremely drowsy and may not respond at all. 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 the jaw muscles. Sometimes a soft short moaning will occur with each breath out. There is no risk of suffocation or death from a blocked airway. Again, be reassured that your loved one is not in pain and is not in distress.

The best position for your loved one is laying on their back with their head slightly elevated, however, if the person appears to be uncomfortable, side lying can also improve the gurgling sound in the throat. Make sure the person is supported by pillows.

The doctor, nurse practitioner or nurse may recommend a small patch "Transderm-V" for behind your loved one's ear, or an injection of medication that will help to dry up the secretions. Oxygen is not helpful in this situation and suctioning the patient almost always causes them a lot of distress.

The most obvious sign that death has occurred is that the person has stopped breathing. You may notice pale or waxy-looking skin. There will be no heartbeat. There may be minor muscle twitches that will fade within a few minutes.

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. Be sure to communicate any wishes or arrangements to your Care Team.

AT THE TIME OF DEATH

Do not panic; do not call 911. There is no need to contact any authority immediately, even the physician.

Express your grief and take your time. Often you will feel quite peaceful and calm especially if you have had the opportunity to deal with your grief around the impending loss before the death.

Spend some time with your loved one before calling the healthcare professional as per the EDITH (Expected Death in the Home) protocol.

When you are ready, call the healthcare professional listed on the EDITH form. If the death occurs in the middle of the night, call the healthcare professional first thing in the morning and they will come as soon as possible. In any case, it may take some time to respond. This should not worry you.

The healthcare professional will complete the EDITH form and then you can call the funeral home.

SELF-CARE

During your role as a caregiver you may find yourself very busy. It is common for caregivers to put everyone else before themselves. It is important to ensure you are taking care of your own health as it can be very difficult to care for others when you have not taken care of yourself.

- Ask for help with the caregiving tasks.
- Accept help or respite when it is offered.
- Gather others who can assist with communicating updates to others.
- Take time to participate in what brings you comfort (reading, walking, drawing).
- Be sure to get enough sleep and eat meals.
- Let others know how you are doing.
- Remember to enjoy the beauty and humour of life.
- Maintain your spiritual and religious practices.
- Talk to your loved one's Care Team, they can connect you with emotional support.

Remember self-care is different for everyone. Do what you feel is right for you; take a nap, sit quietly, cry, and walk.

Notes:

IMPORTANT DOCUMENTS

Gather the following documents (or make note of their location):

- The will, Power of Attorney document and Advance Directives
- Safety deposit box information
- Important keys to house/car/boat/other real estate (labelled)
- Insurance policies (name, number, amount, beneficiary)
- Health, accident or burial policies
- List of all assets including pensions, employee benefit booklet, RRSP's, stocks and bonds
- List of creditors/debtors
- Title documents to the house, car, boat, etc.
- List naming advisors, lawyer, insurance agency, 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/statements
- Tax returns for the past three years
- Notarized copy of birth certificate and marriage certificate or separation/divorce papers

Notes:

RESOURCES

- NSMHPCN..... <https://nsmhpcn.ca>
Virtual Hospice..... www.VirtualHospice.ca
Hospice Palliative Care Ontario.... www.HPCO.ca
Hospice Georgian Triangle..... www.HospiceGeorgianTriangle.com
Hospice Huntsville..... www.HospiceHuntsville.com
Hospice Huronia..... www.HospiceHuronica.ca
Hospice Muskoka..... www.HospiceMuskoka.com
Hospice Orillia..... www.HospiceOrillia.ca
Hospice Simcoe..... www.HospiceSimcoe.ca
Mariposa House Hospice..... www.MariposaHouseHospice.com

Patients, Families & Caregivers



<https://nsmhpcn.ca/patient-family-caregivers/>

Grief & Bereavement



<https://nsmhpcn.ca/grief-bereavement/>

Notes:



North Simcoe Muskoka Hospice Palliative Care Network

169 Front Street South, Orillia, ON L3V 4S8

Tel: (705) 325-0505 Toll Free: (844) 519-2224 Fax: (705) 325-7328

[HTTPS://NSMHPCN.CA](https://NSMHPCN.ca)

