



HOSPICE PALLIATIVE CARE

*A guide to promote comfort and well-being
in your home at end of life.*

CRJ HOME HEALTH





TABLE OF CONTENTS

2	What is Hospice Palliative Care?
2	Message From CBI Home Health
3	How to Use the Guide
4	Pain
5	Appetite & Fluid Intake
6	Confusion & Forgetfulness
8	Breathing Patterns
10	Bowel & Bladder Function
12	Rest & Sleep
14	Mouth Comfort & Care
16	Skin Colour & Temperature
18	Signs that Death is Approaching
20	Choosing a Health Care Agency
21	Additional Information at Your Fingertips

What is Hospice Palliative Care?

The Canadian Hospice Palliative Care Association defines palliative care as care that aims to relieve suffering and improve the quality of life for persons who are living with, or dying from, advanced illness or who are bereaved.

HOSPICE PALLIATIVE CARE ALSO PROMOTES:

- Autonomy and shared decision-making
- Advance care planning: a process of reflection on values, wishes and beliefs as they relate to preferences for care
- A person- and family-centred approach to care

Message from CBI Home Health

CBI Home Health recognizes that family caregivers are often those that provide ongoing care to loved ones as they experience a journey that leads them to end-of-life. Family caregivers must provide emotional, physical, psychological, spiritual and social support and often do this with little or no experience or information to guide them. They are the key players in providing care when someone wishes to die at home. Canadians prefer to spend their last days in their homes, not in hospitals, long-term care facilities or institutions. Family caregivers deserve great recognition and tools to assist them as they act as the family

caregiver for someone at the end of life. Quality end-of-life care can only be achieved when the dying person – and their family – are provided with the assistance and support that they require and deserve.

This guide brings together information, knowledge and experience for family caregivers caring for loved ones in different levels of Palliative Care. Experiences with the dying will forever impact a person. This guide therefore aims to provide knowledge and insight to make this experience as rewarding and comfortable as possible.



Pain

RECOGNIZING SYMPTOMS / POINTS TO REMEMBER

Everyone expresses pain differently.

- Factors such as worry, fear, boredom or loneliness can make the experience of pain worse.
- Your loved one may: complain of pain, choose not to express the pain or be physically unable to discuss their pain. For these reasons, family caregivers must pay close attention to both verbal cues and non-verbal cues like body language.
- Pain may be at a particular location in the body or a general feeling of not being well.
- No one is more of an expert about the pain than the person who is feeling it, so when your loved one complains of pain or if you recognize signs of pain, try to understand their specific needs.

YOUR LOVED ONE MAY SHOW PAIN BY:

- Appearing pale
- Grimacing
- Holding an affected body part
- Being irritable
- Groaning
- Crying
- Refusing to move or have care done
- Sweating

HOW YOU CAN OFFER COMFORT AND CARE

- Understanding your loved one's pain and supporting their overall health needs can help you to provide comfort.
- Constant pain needs regular pain medication to control it, so give pain medication on schedule even if there is no pain at the time. This will help control the pain and prevent it from returning.
- Plan to give any physical care (such as changing their position) just after a medication has taken effect. Most pain medications will take effect within 30 minutes.

You can provide non-medication comfort measures such as:

- Provide blankets for warmth.
- Distract with soft music, favorite movie, quiet discussion.
- Use gentle touch when providing care.
- Open a window to provide fresh air.
- Give a back rub.
- Keep bed linens tight and wrinkle-free.
- Welcome visitors when your loved one feels up for it.
- Promote relaxation by providing a calm and quiet environment.
- Position your loved one in bed comfortably with pillows.

WHEN TO CALL YOUR HEALTHCARE TEAM

- A new or sudden pain occurs.
- Pain continues after you have given breakthrough medication and other care isn't promoting comfort.
- There is a rapid increase in the intensity of the pain.

Appetite & Fluid Intake

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

- Loss of appetite, eating nothing or eating very little is a normal part of the dying process.
- It is not painful.
- The intake of foods and fluids will naturally decrease. You may see your loved one have difficulty swallowing, followed by forgetting how to swallow, to then becoming unable to swallow.
- Pushing someone who is dying to eat or drink may cause problems, such as nausea, vomiting, choking or pneumonia.
- Your loved one's body will not digest food as it once did.
- You may notice weight loss. This is a normal result of the decreased appetite as well as your loved one's illness.
- If your loved one is taking in less fluid, you can expect less urine production and the urine may be dark yellow or tea-coloured.

HOW YOU CAN OFFER COMFORT AND CARE

- Encourage your loved one to take small sips and ensure they are sitting up if drinking.
- Gently remind your loved one if they forget to swallow. Sometimes softly stroking the side of the throat will help to stimulate swallowing.
- Provide good mouth and lip care every 2 hours (refer to the mouth-care tab of this guide).
- Ice chips, Popsicles and small amounts of ice cream can be offered. Your loved one may take only a mouthful or two; a taste is often enough.

WHEN TO CALL YOUR HEALTHCARE TEAM

- Uncontrolled nausea and/or vomiting.
- Urine becomes cloudy, foul smelling and/or your loved one complains of pain when urinating; this could indicate a urinary tract infection.
- Coughing or choking on fluids occurs. This could mean that your loved one should no longer take any foods or fluids by mouth.

Confusion & Forgetfulness

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

- As your loved one's illness progresses, their brain may begin to have trouble sending and receiving information correctly.
- They may become confused and not recognize familiar faces or voices.
- They may feel frightened, agitated, or see or feel things that aren't real; these are common reactions.
- These reactions may occur for many reasons, such as changes in oxygen levels to the brain, the disease progression and/or certain medications.
- Your home healthcare team may suggest safety measures for your home, such as bedrails.

HOW YOU CAN OFFER COMFORT AND CARE

- Even when confused, a dying person may feel comforted or relaxed when they hear or are touched by friends and family.
- When talking to your loved one, tell them who you are, and talk calmly, clearly and slowly.
- Always explain what you are doing and why.
- Gently explain what is real and offer reassurance. Do not contradict, belittle or argue about visions.
- If your loved one is scared, remain calm and explain that what they are experiencing is normal.
- Since harm can come easily to a confused person, supervision and guidance are needed.
- Do not leave your loved one alone for long periods.
- Consider providing comfort measures that promote relaxation. You may wish to use warm blankets, provide soft items, give a gentle massage or play their favorite music.

WHEN TO CALL YOUR HEALTHCARE TEAM

- If confusion occurs very suddenly or becomes worse.
- Your loved one becomes violent or very agitated.
- You or your loved one is hurt because of the confusion.
- You are tired and need relief.



Breathing Patterns

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

- It may appear as though your loved one is having trouble breathing. Rest assured that it is common to see rapid, shallow or irregular breathing, and gurgling or rattling sounds may occur.
- You may notice that breathing stops for short periods (5 to 30 seconds). This is a normal response at the end of life.
- Noisy breathing is often caused by saliva that collects in the back of the throat. Although this sounds bad, it does not hurt your loved one.
- These changes in breathing can be frightening for both you and anyone experiencing it. If you know what to expect, it may be less upsetting.

When these breathing changes occur, your loved one gets less oxygen. You may see:

- The skin around the mouth and nail beds may appear blue-tinged.
- There may be large amounts of thick mucus that your loved one can or can't cough up.
- Breathing may be difficult when talking or even resting.

HOW YOU CAN OFFER COMFORT AND CARE

- Your loved one may have less trouble breathing if the surroundings are calm and comfortable.
- Encourage the quiet presence of a family member or friend to help ease the anxiety.
- Elevate your loved one's head or turn them on their side to increase comfort.
- Be sure that any medication prescribed for shortness of breath is taken as directed.
- Open a window for fresh air or consider blowing a fan towards your loved one to improve airflow.
- Remove tight or constrictive clothing and bedding, and use a lightweight blanket.

WHEN TO CALL YOUR HEALTHCARE TEAM

- Your loved one is coughing up thick, yellow-green or bloody mucus.
- They can't get a proper breath and none of the comfort measures is working. (There are medications that can be prescribed to dry secretions and improve your loved one's comfort.)
- Your loved one develops a fever.



Bowel & Bladder Function

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

- As your loved one's illness advances and intake of food and fluids decreases, they will produce less urine and have fewer bowel movements.
- Your home healthcare team will teach you to care for your loved one when they become incontinent (loss of control of the bowel or bladder) to ensure they remain safe and free from infection.
- For managing incontinence an adult brief and protective padding may be used.
- Skin infections, which can be caused by pressure and contact with urine or a bowel movement, is a risk of incontinence. Clean, dry skin is therefore very important.

HOW YOU CAN OFFER COMFORT AND CARE

- Waterproof pads can help keep your loved one comfortable, dry and clean.
- Provide regular skin care.
- Ensure your loved one's position in bed is changed every 2 hours.
- Open windows to ensure fresh airflow throughout the room.

WHEN TO CALL YOUR HEALTHCARE TEAM

- Your loved one is unable to urinate or have a bowel movement, or complains of discomfort when doing so.
- If your loved one has a catheter and you notice leaking around where the tube enters the body.
- The urine becomes cloudy or has an offensive smell, or the person develops a sudden fever. These could indicate a urinary tract infection.
- There is blood in the urine or stool.

Rest & Sleep

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

RESTLESSNESS

- Your loved one may become restless, pull or pick at the sheets, or repeat other movements.

SLEEPINESS AND WITHDRAWAL

- Your loved one may become sleepy and hard to awaken.
- When awake, they may talk very little or not at all.
- They may refuse to see visitors.

FATIGUE

- When someone has a progressive life-threatening illness, they may feel tired without even using energy (such as exercising, working, etc.).
- Your loved one may sleep or rest more often and withdrawal from usual activities.
- Remember that drowsiness is a normal side effect to certain pain medications.
- As death nears, it is normal for your loved one to become weaker and sleep more.



HOW YOU CAN OFFER COMFORT AND CARE

- Speak calmly and softly.
- Provide relaxation through gentle touch, massage, music or a comforting activity like reading.
- Do not talk about your loved one as if they were not present – even if they appear to be in a deep sleep. (Many times people can hear, even though they can't respond.)

When your loved one is very tired, you may want to:

- Reschedule visitors, treatments or activities.
- Suggest calm and relaxing activities.

WHEN TO CALL YOUR HEALTHCARE TEAM

- Your loved one becomes violent or very agitated.
- You or your loved one is hurt because of the restlessness or repetitive movement.
- You are tired and need relief.

Mouth Comfort & Care

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

By helping your loved one maintain a clean mouth, you will increase comfort and prevent mouth complications.

THRUSH (ORAL CANDIDIASIS)

- Thrush occurs commonly in people with advanced illness. Certain medications and treatments such as radiation can increase the risk for thrush.
- Thrush is an infection and needs careful attention.
- Your loved one may complain of a sore mouth, a sore throat, a dry, scratchy throat, hoarseness or problems swallowing.
- When you inspect the mouth, you will see white, curd-like patches on the tongue, roof of the mouth, inside cheeks and lips, and back of the throat.
- Thrush is treated with a medication that is swished in the mouth like a mouthwash, then swallowed.
- If your loved one begins to have problems swallowing, the medication may need to be stopped.
- Thrush can be spread to others. You should avoid kissing your loved one on the lips.

HOW YOU CAN OFFER COMFORT AND CARE

Preventive mouth care is very important. Focus on keeping the mouth clean and moist. These needs will grow as your loved one begins to drink less or in their last days and hours of life.

PROVIDE MOUTH CARE:

- Every 2 hours
- Before and after eating
- Before each dose of medication is taken
- When cleaning the mouth, gently rub along the teeth, gums and tongue

DENTURE CARE

- Clean dentures well at each treatment. If they are not cleaned properly, they can reinfect the mouth.
- Soak the dentures each night in a solution of one part vinegar to four parts water.

LIP CARE

- Put a water-soluble lubricant on the lips, such as a lip moisturizer.

WHEN TO CALL YOUR HEALTHCARE TEAM

- If you suspect a thrush infection.
- If you notice any open, bleeding or painful sores or cuts in the mouth.
- If your loved one complains of pain or discomfort in the mouth that isn't improved with the comfort measures.

The following could indicate a sore mouth:

-
- Dry lips, tongue or gums
 - Difficulty swallowing
 - Unpleasant breath odour
 - Red or white sores in their mouth

Skin Colour & Temperature

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

- The skin on the arms and legs becomes cooler to the touch as your loved one approaches the end of life.
- The skin may appear sweaty or oily.
- The skin becomes darker in colour as the body sends most of the blood to the vital organs (e.g., heart, lungs, kidneys, liver).
- The feet and legs may become bluish, mottled (blotchy) and cool to the touch.
- Itchiness may occur. It can be an unpleasant sensation that causes a desire to scratch or rub the skin.

HOW YOU CAN OFFER COMFORT AND CARE

- Check the skin temperature regularly, as it can change frequently.
- If your loved one is sweating, provide clean, dry bedding and clothing.
- Apply skin creams with a water-soluble base 2 to 3 times a day, especially after a bath when the skin is damp, to prevent drying of the skin.
- Choose loose clothing made of a soft fabric.
- Cover your loved one with lightweight bedding.
- Avoid scented and alcohol-based products on the skin.
- Use gentle detergents for laundry.
- Keeping your loved one's nails short and smooth can prevent scratching and breaking the skin.

WHEN TO CALL YOUR HEALTHCARE TEAM

- If itching is bothersome and does not go away or if the skin becomes affected from scratching.
- If an itchy rash develops or becomes worse after creams or ointments have been applied.
- If your loved one has a fever or uncontrollable chills.

Pay Attention to Pressure Areas

- Skin breakdown or pressure sores, if present, can cause discomfort to your loved one.
- Pressure sores usually happen over bony areas (e.g., heels, tailbone, hips, elbows, shoulders).
- Continue to change your loved one's position in bed every 2 hours to relieve pressure on these areas.



Signs that Death is Approaching

RECOGNIZING SYMPTOMS/ POINTS TO REMEMBER

When death is near, the body undergoes changes. If you know what to expect, you may be less anxious when you see these changes happening.

YOU MAY SEE THE FOLLOWING:

- Breathing changes, becoming shallow, quicker or slower.
- Breathing may appear to be difficult, with periods of no breathing.
- You may hear bubbling or rattling sounds in the throat and chest.
- The heartbeat may be irregular.
- Anxiety and restlessness may increase.
- You may see more sleep and less response to you and others around you.
- There is a small quantity of very dark urine or no urine at all.
- There is progressive coldness and purple discoloration, mostly in arms and legs.



HOW YOU CAN OFFER COMFORT AND CARE

- Even if your loved one does not seem to be aware of you during this last stage, your presence is still a comfort.
- Continue to touch and reassure them that you are close by and that you care about them.
- Speak calmly and naturally.
- Provide comfort by keeping your loved one dry and their lips moistened with a lubricant.
- Continue to give pain medications. Anything you can do to promote comfort is important in these last few hours.
- It is likely that your loved one is comforted by knowing that it is okay to let go and die.
- Tell them how much you love them and that they will be missed. It may give them a sense of peace and allow them to let go if they know that you and the people they care about will be okay and together to support one another.
- Repeat comforting words and they will sense your presence and love.
- Your comfort is important: get support from others, friends, professional staff or clergy to help you through this time.

WHEN TO CALL YOUR HEALTHCARE TEAM

- If you need advice, feel frightened or need support of any kind.
- Your loved one has passed away.



At the Time of Death

- Do not call 911.
- Contact the CBI nurse and your family to inform them that your loved one has died. The physician may not come, as the nurse can determine that death has occurred.
- There will be no response, no breathing and no pulse/heartbeat.
- Your loved one's eyes will be fixed in one direction; they may be open or closed.
- There may be loss of bladder and/or bowel control.
- If it would comfort you, contact someone like a sibling or a friend; take all the time you need to be together and share memories about your loved one.
- At a time that is convenient for you, contact the funeral home and they will make arrangements to pick up your loved one's body.
- It's okay to touch your loved one, talk to them, sing to them. This can bring you and those around you comfort.

At the end of life, each story is different.

Our professional caregivers not only provide the best possible care to your loved ones, but they also support you and your family with the help you need.

Quality hospice palliative care is achieved when both the dying person and their family are provided with the assistance and support that they require and deserve.

BE SELECTIVE

Choosing a Home Care Agency

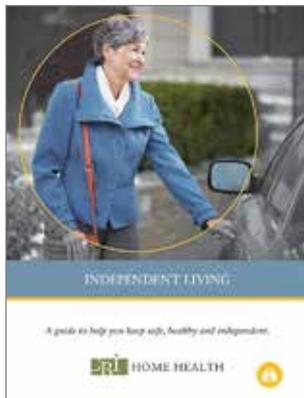
Questions to consider when deciding on a home care provider

- 1 Do I need to be referred by a doctor or hospital?
- 2 Is there a minimum charge?
- 3 How much time must I allow between my request for service and the first home visit?
- 4 Can your agency respond to a request for service on short notice? Is there an extra charge?
- 5 Will the same home care worker be coming every time or will there always be a new caregiver each time?
- 6 What if I need service on a holiday or after normal business hours? Can you provide that?
- 7 Who do I call in case of emergency, even after hours?
- 8 How do you train your home care personnel? Do they have post-secondary education?
- 9 What references do your home care personnel have? Are they insured?
- 10 Do you have home care personnel with specialized training in certain diseases and injuries?
- 11 Will my private insurance company pay the bill?
- 12 How long has the company been in the area?
- 13 Are your healthcare standards accredited for excellence?
- 14 What services do you provide?

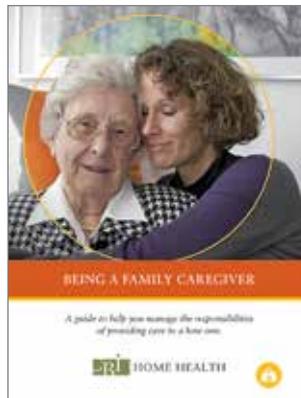
Additional Information at Your Fingertips

CBI Home Health provides a number of valuable resources, free for downloading:

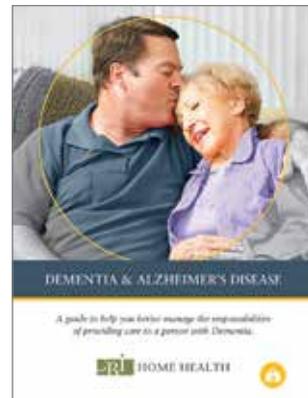
The Independent Living Guide promotes safety and security through a room-by-room assessment.



The Being a Family Caregiver Guide offers you help to manage the responsibilities of providing care to a loved one.



The Dementia & Alzheimer's Disease Guide is a guide to help you better manage the responsibilities of providing care to a person with dementia.



The Hospice Palliative Care Guide promotes comfort and well-being in your home at the end of life.

→ Connect with us on Twitter or Facebook to learn about the experiences of other caregivers just like you.

CBI Home Health FREE GUIDES offer insight on how to live a more independent and healthier lifestyle. Visit www.cbi.ca/homehealth or call us toll-free at 1.800.897.9640 to find out more about our services and how we can support you and your loved ones.

All are available by calling CBI Home Health at 1.800.897.9640 or by visiting www.cbi.ca/homehealth



CBI Home Health offers a variety of compassionate and professional care services that help you live your life.

These include: personal care, house cleaning and meal preparation, nursing, help with medications, advanced foot care provided by a nurse and accompanied visits. Our caregivers are highly trained to help people with Alzheimer's / dementia, diabetes, acquired brain injury and end-of-life care.

1.800.897.9640

SERVING OVER 800 COMMUNITIES ALL ACROSS CANADA