

Caring for Someone at Home: Information at a Glance

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For more information on any of these topics,
please visit champlainpalliative.ca

There may be many questions and unfamiliar situations that you have to face when you are caring for someone who is approaching the end of his/her life.

This information can help you answer some of these questions and help you to understand what you might expect. This information is not intended to replace medical advice. If you have specific questions about caring for someone at end-of-life you should ask your healthcare provider(s).

1

Caring for yourself is one of the most important and often most forgotten things you can do as a caregiver. It can be easy to fall into the habit of checking off tasks on your long to-do list, or dropping everything to focus only on your loved one's needs. We encourage you to look after yourself, ask for help, and spend time with the person you are caring for: making memories, sharing stories and enjoying your time together, rather than spending all of your time on "tasks" to get done. The S.T.O.P acronym might help you to remember to do this when you are feeling anxious or overwhelmed.

STOP what you are doing

TAKE a few deep breaths

OBSERVE what's going on with your body, thoughts and emotions

PROCEED with something that will support you in the moment

Adapted from <http://www.mindful.org/stressing-out-stop/>

**STOP – and Remember
to Take Care of Yourself**

2

Caring for someone at home can be challenging. It is important to ask for help from friends, family, neighbours and others. Asking for help doesn't make you selfish or incapable. It means that you are realistic – there is only so much you can do on your own. Even so, many of us are uncomfortable asking for or accepting help. Here are some tips to make it easier:

- Ask a friend or family member to coordinate help for you to plan meal deliveries, rides and visits (potentially using a care coordination website like *LotsaHelpingHands.com* or *TakeThemaMeal.com*).
- Suggest specific tasks. Keep a list of things you need help with so that you are ready to respond when someone offers. For example, “Could you pick up groceries for me?”
- Consider who would want to help with specific activities: someone who loves to cook could make a meal. Maybe your neighbour who loves dogs can walk yours...

Asking for Help and Accepting Help

Confusion can be common for someone with a serious illness. The person may be unable to focus, have memory loss or find it hard to make decisions. They could be confused about the time, place or who they are (or all three). Confusion can be caused by the illness itself, an infection, side-effects of medication, dehydration (because of reduced fluid intake at end-of-life) or other factors.

- You should make sure that the nurse or family doctor is aware of the confusion so that they can help to try to reduce it (e.g. by changing medications).

| Confusion

As the physical needs of the body change, the need for food and drink decreases as does the appetite. People who are approaching the end of their life sometimes feel sick to their stomach (nausea), or have trouble eating or always feel “full.”

- Try offering small amounts of food.
- Feeding with a teaspoon may help.
- Having fresh water and use of a straw may be helpful.
- Premade nutritional shakes may be an option instead of solid foods.

The loss of feeding oneself can be difficult to accept. Offering choices of what to eat or drink allows the person to remain in control of the situation.

| Eating and Drinking

Daily mouth/oral care is very important. If able, the person should continue to brush the teeth, tongue and gums with a soft toothbrush and fluoride toothpaste after meals and at night. If the person you are caring for experiences dry mouth, cracked lips, dry or swollen tongue and thirst it may help to:

- provide sips of water.
- give frequent mouth care.
- use lip balm and/or an alcohol free mouth rinse.

It is important to remember to NEVER use toothpaste or mouth rinses with the person who has swallowing difficulties. A person who is unresponsive/unconscious still needs regular mouth care so that their mouth and lips remain moist (they should be turned on their side when doing mouth care so they do not choke). The nurse or personal support worker can show you how and help you to provide proper mouth care.

As a person approaches the last days of life, you will notice that they sound like they are having trouble breathing or that their breathing changes back and forth; from deep and rapid breathing to slow and shallow breathing with long pauses in between.

Changes in breathing are accompanied by changes in circulation of oxygen in the body – the person’s lips, skin and nails often appear darker and may have a blue or purple tint. Skin may be cool to the touch and look waxy. These are all signs that the body is slowing down.

- Opening a window or using pillows to raise their head, may help the person feel more comfortable.

Changes in breathing/ Shortness of Breath

Noisy breathing, which sounds like a wet rattling or gurgling, is caused by the buildup of saliva and mucus in the throat and chest. Near the end of life, a person's body is not able to clear fluid easily, and this causes a wet or gurgling noise as the breath passes through the vocal cords and fluid. These noises can be upsetting to hear but they do not cause pain or discomfort to the person who is dying.

| Noisy Breathing/Gurgling

As circulation slows, parts of the body (especially the hands, feet and lips) may become pale or bluish. This is normal. The skin may feel clammy and there may be increased perspiration or the skin may feel feverish. You may be unable to feel a strong pulse and the heartbeat may become irregular.

- It may help to keep your loved one dry and covered with a light blanket. It is not necessary to add layers of blankets.

**Physical body/
temperature /pulse**

When someone is spending most of their time in bed it is important to help look after their skin and reposition them in bed. As the skin becomes drier, there is a risk of bedsores on the parts of the body most often in contact with the bed such as the hip(s), buttocks, and heels.

- Using pillows between and under the bony parts of the body or under the lower leg, may help to reduce the pressure on the ankle or the feet.
- Bend the knees, keep the sheets wrinkle free, and try to prevent skin to skin contact.
- If possible, the person in bed should be repositioned every 2 hours, except during the night to allow the person to sleep.

Skin Care and Pressure Sores (Bed Sores)

Constipation is when bowel movements happen less often than they normally do. When someone is constipated they may feel uncomfortable, bloated and may not feel like eating. Contact a health care provider immediately if:

- They have not had a bowel movement within 3 days, or
- They have had ongoing cramps or vomiting, or
- If blood appears in the stool, or
- If they have worsening pain in their stomach.

| Constipation

Decreased food and liquid intake means less output (urine) too. The urine will be darker, thicker and may have a stronger odor. Fecal matter will continue to be produced from cells and bacteria in the body, even if the person eats little or nothing. As death nears, muscles in the body further relax, which can result in the contents of bowels and bladder being released.

Incontinence refers to a person's loss of control over their bladder and bowels. A catheter may be inserted into the urinary bladder. This may be uncomfortable for the person and will restrict their movement. Good hygiene is very important.

- Wash your hands before and after touching the catheter, drainage bag or incontinence garments.
- When the person has a permanent catheter, wash the area where the catheter enters the body at least once a day with soap and water to protect the skin and prevent infection.

| Urination and Incontinence

Restless movements/agitation can often happen when someone has a serious illness. This can be caused by the illness itself, an infection, side-effects of medication, dehydration (because of reduced fluid intake at end-of-life), or other factors.

- Make sure that the nurse or family doctor is aware of the restlessness so that they can help to try to reduce it (e.g. by changing medications).
- Ensure that the person is not at risk of injury.

| Restlessness/agitation

As a person weakens, the number of hours they spend sleeping may increase. Their sleep can be disturbed by the medications they are on or by issues such as pain or difficulty breathing. Often, a person nearing the end of their life can also become “unresponsive” and cannot wake up.

Being alert means that the person is not asleep. Even if they are not asleep, people sometimes begin to withdraw and may appear to be separating themselves from the people and things around them. This could be because they are thinking about their life, memories, people that have already died, beliefs and questions about life and after life...

- Even if the person you are caring for is asleep or withdrawn, you can be a comforting presence at their side.
- Gentle touch and silence can be very meaningful and supportive.
- At times, playing some soft music of their liking may help create a sense of calm.

| Sleep and Withdrawal

Watching someone we love go through the dying process is painful but it can offer a special time to share your thoughts and feelings with them and have open conversations.

- Say what is in your heart, for example I love you, I forgive you, forgive me, thank-you or goodbye.
- Sometimes our loved ones hold on because they can sense that we are not ready to let them go - it is important to give them permission to leave us.

The last sense we lose at end-of-life is our hearing so even if your loved one is unresponsive, they can still hear you.

| **Saying goodbye/Letting Go**

Even if you and your loved one have planned for a death at home, there may be some confusion when it happens. There will be no breathing or pulse. Their eyes may be open or closed.

- Do not call 911.
- Call the health service provider, nurse or care coordinator. The doctor (if not present at the time) will need to sign the death certificate.
- You may want to call other members of the family or a close friend to come and be with you.
- Take your time. When ready, contact the funeral home to assist you with your loved one.

| At Time of Death

The *Champlain Local Health Integration Network (LHIN)*

Home and Community Care (formerly CCAC) provides health care services and supports such as nursing visits or personal support workers. You can self-refer at 1-800-538-0520 or <http://healthcareathome.ca/champlain/en>

Hospices are hubs of support for anyone dealing with a life-limiting illness. They can often help organize visiting volunteers, day hospice, bereavement support and respite for caregivers. You can self-refer to hospice.

Your **family doctor** and other primary care providers form the basis of quality palliative care.

The **Champlain Healthline** provides information about community organizations, supports and hospices that help people caregiving at home www.champlainhealthline.ca.

Palliative Care Specialists: your physician or health care provider can get advice about your care from the Regional Palliative Consultation team or can refer you to specialized palliative care services in the community or at a hospital.

| Who can help provide care?

Where can I get more information?

The *Champlain Hospice Palliative Care Program (CHPCP)* has a number of resources and information about services and supports available in the community:
champlainpalliative.ca.

Please call us if you have any questions or need assistance finding support at **613-683-3779**

The *Canadian Virtual Hospice* has information about everything from symptoms and health concerns to emotional and spiritual health and providing care: virtualhospice.ca.

A Caregiver's Guide: A Handbook About End-of-Life Care, published by the Order of St. Lazarus and the Canadian Hospice Palliative Care Association, may be available to purchase or on loan from your local hospice organization.

NUMBERS TO CALL

PHYSICIAN

Name:

Number:

NURSE/CARE TEAM (DAYTIME)
OR CARE COORDINATOR

Name:

Number:

NURSE/CARE TEAM
(AFTER HOURS)

Name:

Number:

LHIN HOME AND COMMUNITY
CARE

Name:

Number:

SUBSTITUTE
DECISION MAKER

Name:

Number:

EXECUTOR

Name:

Number:

LAWYER

Name:

Number:

CLERGY OR
SPIRITUAL ADVISOR

Name:

Number:

FUNERAL HOME

Name:

Number:

PHARMACY

Name:

Number:

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