

## 8 Tips for Caregivers

1. You are your loved one's primary supporter.
2. If you try to provide care at home, try to find a doctor who will visit you there.
3. Make a list of questions you want to ask and give a copy of this list to your doctor or nurse.
4. Take notes during appointments so that you can refer to them later.
5. Arrange for someone to attend doctor's appointments with your loved one if you or your family cannot. Prepare them questions to ask the doctor and have them take notes for you.
6. Keep a journal of all care and treatments. Include in it details of the medications, appointments, names and numbers of the health care team.
7. You may notice changes and symptoms that other members of the health care team do not. Inform other members of the team.
8. After appointments, ask for a summary of what was talked about if you find it helpful.

## After Caregiving Ends

As a caregiver, there can be a natural sense of loss when our caregiving is over. We face the double sorrow of losing a loved one and our purpose or role in their lives. It can be a very difficult time that leaves us feeling lost, lonely, and useless. The first step is to allow and accept our feelings. It is possible that we may feel relief that we don't have to work so hard any longer, and then feel a sense of guilt for feeling such relief. We may be angry with ourselves or someone else for letting us down. All of these are natural reactions. It is important to express our sadness, anger, loneliness and whatever else we may feel.

## Where Can I Find More Information?

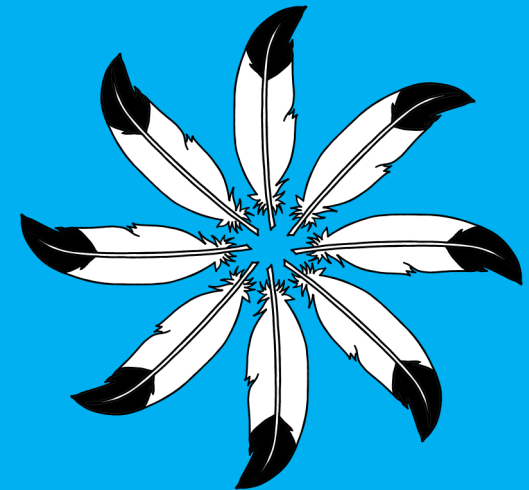
For more information, start by talking to your doctor, nurse, community health representative (CHR), spiritual care providers or any other health care provider.

You may also refer to the **Caring for the Terminally Ill: Honouring the Choices of the People** information booklet made available through your local health representative or at: [http://pubweb.lakeheadu.ca/~eolfn/?page\\_id=199](http://pubweb.lakeheadu.ca/~eolfn/?page_id=199)

This brochure was created by:  
Improving End-of-Life Care in First Nations Communities (EOLFN)  
Centre for Education and Research on Aging & Health (CERAH)  
Lakehead University  
955 Oliver Road | Thunder Bay, ON P7B 5E1  
Tel: (807) 766-7271 Fax: (807) 766-7222  
Web: [www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)  
Email: [eolfn@lakeheadu.ca](mailto:eolfn@lakeheadu.ca)  
Twitter: @EOLFN

Publication of this brochure was made possible through a grant from the Canadian Institutes of Health Research (CIHR). The initial publication was created from a partnership with the Kenora Chiefs Advisory and a financial contribution from the Public Health Agency of Canada (PHAC). The views expressed herein do not necessarily represent the views of the CIHR or PHAC.

# Caring for Someone with a Terminal Illness: Care for the Caregiver



## Taking Care of Yourself

### Understand how this illness affects you

You may struggle with anger, guilt, anxiety, or sadness. You may feel tired and may feel a sense of emptiness wondering why your loved one is suffering or dying and why you are reacting the way you are.

### Practice self care

Eat well, exercise, and get enough rest. Take care of your mental health. This will help your overall health and will also help you provide better care to your loved one. Ask your family and friends for support. They want to help, but may not know how they can help.

### Communicate your needs

It is easy to forget about your own needs when caregiving, such as personal chores, errands, etc.

It is important to talk with your family and friends about ways they can help and ask your doctor or health care provider about available resources.

### Know your Caregiving Needs

Providing care to a loved one can be a complex and challenging process. Here are a few points to keep in mind.

### Navigating the system

Know who does what and how to access services in the health care system.

### Communicating with the care team

When caregiving for an ill person at home, you might feel like your home is “invaded” by a series of strangers who are also providing care. You may feel you are no longer “at home” in your own house.

- Get to know the members of the care team
- Know what each member’s job is
- Ask to have the same care providers in the home so that you are not always getting used to new faces or having to explain your situation over and over again
- Ask to be informed about who will be coming into your home (if your loved one is in a facility, ask about the roles of the various health care providers).

**Respite** is a service for when you need a break in order to re-energize and be able to continue caregiving. Use it when you need to attend to other things in your life such as child care, shopping, your own health care, etc.

### Learn all the aspects of providing care

Operating equipment such as a hospital bed, turning your loved one from side to side, giving fluids, food or medications, or transferring your loved one from a bed to a chair are activities that can add to your stress if you are unsure of how to do them properly. Talk to your health care provider about these things so you feel confident in doing these tasks.

### Financial questions

If you are in the work force, you may need to take time off from work in the form of a vacation or a leave of absence. The Employment Insurance Compassionate Leave plan allows for up to six weeks of partial coverage of earnings. Social work can also assist with financial concerns.

### Legal questions

Talk to your doctor or a legal representative for information on wills, advance care planning, or a power of attorney and when these should be used if your loved one can no longer make their own decisions.

### Understanding Grief

Grief is a natural reaction to illness and loss and is a process of coping. It affects us socially, physically, mentally, emotionally and spiritually. It is a journey which should proceed gently and not be rushed through. While some people grieve privately, others are more open about their grief. The process can last a short time for some, and for others, it can go on for months to years. Grieving may begin before the death actually occurs.

Grief is a uniquely personal experience and can be viewed as involving:

- Accepting the reality of the loss
- Working through the pain of grief
- Adjusting to life without the person
- Emotionally letting go of the person and moving on with life

