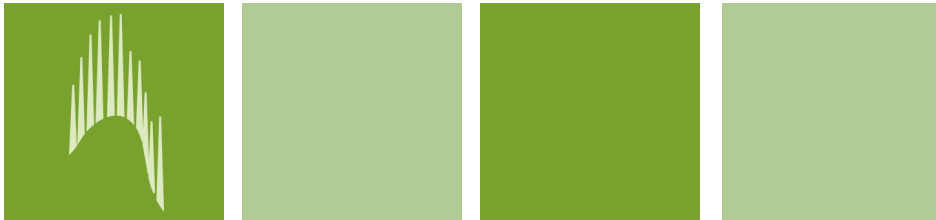




Labrador - Grenfell  
**Health**

**CAREGIVERS:  
YOU ARE IMPORTANT TOO**



Labrador - Grenfell  
**Health**

[www.lghealth.ca](http://www.lghealth.ca)

March 2023



## VERY REWARDING, BUT CAN BE FRUSTRATING

Caregiving can be one of the most rewarding jobs you will ever do, but it can also be frustrating. It's ok to feel frustrated or overwhelmed at times however you should not feel this way long term. Learning coping skills and balance is essential for you to be able to continue caring for your loved one and decrease caregiver burn out. If you don't take care of yourself then you will not be able to help anyone else.

Sometimes becoming the caregiver is a gradual process as your loved one slowly declines. Sometimes the role comes with very little warning when an acute illness occurs and there is very little time to adjust to a dramatic change in care needs. No matter how you became a caregiver the major stressors are the same.



## MY SUPPORT TEAM

In case I become unwell or an emergency arises the following people are able to help.

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Specific care needs: and comforting tips:

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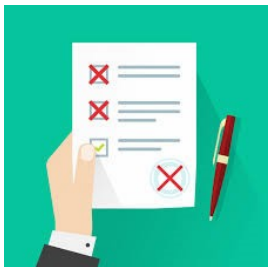
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References:

*Caring for Caregivers - A Handbook for Caregivers. Grenfell Regional Health Services.*

*Guide for Family and Friend Caregivers. SeniorsNL.*

## LEGAL ISSUES



Your care receiver should have an advance health care directive. The earlier this is completed the better as the care receiver is better able to make more decisions for themselves before declining too much.

An advance health care directive can be changed at any time and is not locked in. This dictates the personal care wishes should something happen where they are unable to speak for themselves. This takes away a major stress on the family when this decision has to be made with no input from the person themselves.

An advanced health care directive can be completed with your doctor or social worker at your local hospital. You do not need to be feeling unwell to complete this process.

An enduring power of attorney is also a good idea to have. This allows the care receiver to choose who is legally responsible to make decisions on their behalf should they be unable to do so. This prevents family disagreements and allows the person named the ability to have conversations about the wishes of the individual. This will allow them to make a more informed decision should the need arise.

An enduring power of attorney has to be completed with a lawyer to make it official. Ask your social worker for details.

## A CAREGIVER'S BILL OF RIGHTS

### I HAVE THE RIGHT:

- To take care of my own health, spirit and relationships.
- To seek help from others even though my care-receiver may object.
- To accessible and culturally appropriate services to aid in caring for my care-receiver.
- To get angry, and express other difficult feelings occasionally.
- To accept help that is offered to me by others.
- To receive consideration, affection, forgiveness and acceptance for what I achieve as a caregiver.
- To take pride in what I accomplish and to applaud the courage it has sometimes taken to meet the needs of my relative, partner or friend.
- To protect my individuality and the right to make a life for myself that will sustain me in the time when my care-receiver no longer needs my full time help.
- To expect and demand increased awareness and support to find resources to aid me in caring for my relative, partner or friend.
- To receive appreciation and emotional support for my decision to accept the challenge of providing care.
- To expect family and friends to participate in the care for my relative, partner or friend.

*Reference: Caring for Caregivers - A Handbook for Caregivers. Grenfell Regional Health Services.*

## HOW THE CARE-RECEIVER MAY FEEL

Settling into the roles of caregiver and care-receiver are a huge adjustment and you need to give yourself and each other a break. This is a major change for both of you.

The care-receiver may have feelings of:

- Loss of living life the way they always have in the past.
- Sadness over change of their body.
- Fear of being a burden on family and no longer being able to do activities they could always do for themselves.
- Fear that people will avoid them including friends and family.
- Denial of current condition and lasting effects.
- Fear of being isolated from the outside world.



## HOSPITAL ADMISSIONS

Admissions can be a very worrisome time for you and your care-receiver. Staying Connected with your care-receiver's social worker and care team during admission is helpful.

Start planning for discharge right away. This allows you extra time to plan and see what changes need to be made.

Will you need different equipment or more help in order for your care-receiver to be discharged? Will the changes in care needs be short term or long term? For example: If the admission was for pneumonia, once recovered your care-receiver can hopefully get back to baseline. Other reasons for admission may lead to long term care changes, such as a surgery or broken hip.

**Home First** is available to help you bring your care-receiver home again with any necessary help. This is a short term plan to help get settled and see how much additional care is needed long term.

There may be community follow up arranged in your home after discharge to check in on progress and assess need for ongoing supports or changes to the care plan.

Talk to the team during admission about any challenges at home prior to admission or any challenges you think may occur once home so plans can be made to help the discharge process go more smoothly, and help make sure supports are in place to return home safely.

## CAREGIVERS ARE ADVOCATES

You are responsible for advocating for your care-receiver, to ensure they receive the best care and support that fits their wishes.

Tips to help make advocating easier:

- Remember that the care-receiver is always responsible for decisions about their own care. They should be present for as many conversations about their care as possible.
- Maintain good communication with all health care team members.
- Provide as much information as possible with the care team about your care-receiver. Things such as tasks still able to complete, fears, limitations, etc. These are all very important for the team to know.
- Discuss pain management with your care-receiver and bring the conversation to your care team as needed.
- Write down questions as they arise and bring them with you to your appointment so you don't forget anything at the time.
- You are in the best position to notice changes or new symptoms in your care-receiver. Be sure to explain any changes to the care team as they are less likely to notice in one short session.
- Keep a list of all care and treatments with dates of symptoms and any medical procedures. Track any new symptoms and if anything seems to make symptoms better or worse.
- Keep lists of medications and appointments with other care members (and who they are). Bring this with you to appointments to reference.

## HOW THE CAREGIVER MAY FEEL

The caregiver may have feelings of:

- Anger over what happened to cause the situation.
- Fear they will not be able to provide the best care.
- Resentment over missing out on family events.
- Sadness over a lost social life.
- Fear they cannot do it alone.
- Concern over what the care-receiver is feeling.
- Denial over how long this will last.
- Overwhelmed with the new tasks and chores on top of an already busy life.
- Guilt for having the above feelings.

Communication is important to share how you feel. You may find you are both worried about similar things and can help to put each other at ease.



## SEEK HELP

Caregiving is not a one person show! Everyone needs help. It may be help with shopping, snow clearing, getting to an appointment, someone to come and visit, someone to sit with your care-receiver so you can go out for a special occasion, or just a listening ear. Sometimes the help is a big ask, other times it is very small.



You may want to go outside and plant flowers in your garden but do not want to leave your care receiver alone inside. Ask someone to come help. You should still plant your flowers or whatever hobby you enjoy.

Many people are happy to help but don't know how. Tell people what it is you need help with and they may be more than ready to give you a hand.



## TALK WITH ANOTHER CAREGIVER

The common saying of no one else knows how it feels can ring true for caregivers. Who better to understand what you are feeling than another caregiver? Find a another caregiver and be each other's support buddy. It can be someone you call or someone you meet up with for coffee and a chat. Not every caregiver experience is the same but you can relate to each other and be honest about your feelings and fears.

This type of support can help you:

- Learn about your care-receiver's condition and possible progression
- Decrease your loneliness
- Brainstorm solutions/problem solve
- Relieve stress (sometimes you need to just vent)
- Have a chance to laugh or cry about your situation and not be judged for how you are coping
- Compare resources available
- Help someone else by returning the favor and being their support system as well

There are numerous online support groups on social media. You can search different ways. Try caregiver support groups or add the condition your care-receiver is living with in front of your search for more specific groups.

## CAREGIVING IS NOT PARENTING

Being a caregiver is not the same as being a parent, even if you are caring for your child. Your care-receiver has choices and is in charge of all final decisions regarding their care.

As a caregiver you are not in charge the same way a parent would be and the relationship dynamic is different.

Your care-receiver may be a parent, spouse, family member, or friend. That relationship still is important even though there is an extra role.

Seek professional help if you need to cope with these role changes. Feeling overwhelmed at times is normal but don't let it consume you.



Sometimes your care receiver is a very private person and do not want other people in their personal area. However, it is ok to have a true conversation with your care-receiver if you need a break. Tell them how you feel and see if you can both make a plan moving forward.

Smaller communities can pose more challenges as there are less resources to call on for help. If you need additional help please reach out to a member of your healthcare team or a local social worker to see what help is in your area.

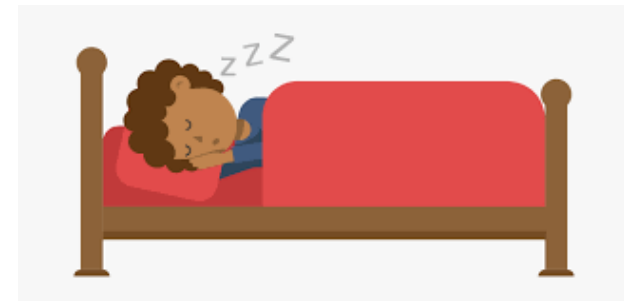
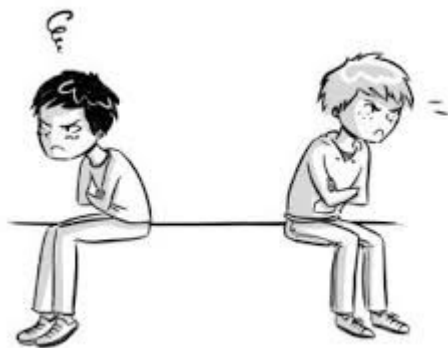


## FAMILY TENSIONS

Changes in care needs often lead to increased family tensions. The primary caregiver is usually only one family member.

- Some family members who contribute financially feel that is their share
- Family away feel their hands are tied
- Family who are working full time feel it is the retired persons responsibility
- Family with younger families are busy and don't have time to commit to helping
- Some family members are in denial or those away do not realize the true situation
- Disagreements arise over best care options
- Some family members are more vocal than others

- Sports. Playing yourself or watch in person or on TV.
- Laugh. At yourself, at a funny video, or just start laughing at nothing. Sounds odd but try it, you'll feel better after a good laugh.
- Take a bubble bath. Sit back in the tub with some music, a good book, or just you. Buy a pillow for more comfort. Let the tension melt away with the warm water.
- Get a massage.
- Eat well and sleep well. It's very important to fuel your body or you will feel drained all the time.
- Do something every day that makes you happy!





## IDEAS TO HELP MANAGE STRESS

Here is a list of suggestions to get you started. Identify the activities you enjoy most. Find a way to unwind, even if it is only for a little while.

- Write in a journal. It's a great way to get your feelings and frustrations out.
- Exercise. Walk, bike, swim, ski, snowshoe, take an exercise class (in person or online).
- Listen to music. Sit back and relax or turn it up and dance!
- Hobbies (i.e. painting, woodworking, baking, etc). Spend time doing the things you enjoy.
- Movie night. Pick at least one night a week to sit back and watch a movie. Pop some popcorn, open a bag of chips, and invite a friend.
- Eat out once or twice a month. Pick different restaurants or your favorite. Take a friend or family member with you and enjoy a change of scenery.



If you are the primary caregiver, speak to your family about what the care needs are and where help is needed. When they are not living with the care-receiver it is easy to misunderstand the needs.

If you are a family member of a primary caregiver, ask them if they need help and offer to give them a break.



## 10 COMMANDMENTS FOR CAREGIVERS



- Don't let your parent, partner or friend overshadow your life. Be both loving and firm. Help your care-receiver remain in charge of their life.
- Help your care-receiver do as much as possible for themselves.
- Don't feel guilty for not doing everything and acknowledge that you cannot do everything.
- Try to understand what it means to be ill or to get old and lose independence.
- Value the time that you spend with your partner, parent or friend.
- Help your care-receiver appreciate what they can still do for themselves as well as accept help if it is needed.
- Keep a sense of humor although your day may have been frustrating or challenging.
- Make your partner, parent, or friend feel good about themselves.
- Don't let yourself become burned out. Be good to yourself and remember to take care of your own needs too.

*Author Unknown*

## SIGNS YOU ARE ON THE EDGE OF BURNOUT

- You always feel fatigued and lack energy.
- You don't sleep well and wake up constantly throughout the night.
- You usually feel ill.
- You have unintentional weight gain/loss.
- You have muscle aches and/or headaches often.
- You feel sad or depressed most of the time.
- You never consider your own health needs.
- You no longer spend time with your family and friends.
- You gave up hobbies and activities you use to enjoy.
- You get overly annoyed with small daily issues and feel they are bigger problems.
- You cry easily and/or frequently.
- You have a quick temper which is different for you.

If some of these describe how you are feeling you need to ask for help. Remember, you also need to care for yourself. Look after yourself mentally, socially, physically and spiritually. Recharge your batteries!