Guide for Family and Friend Caregivers

SeniorsNL

RESOURCES • INFORMATION • CONNECTION

2024

Dedication

This Guide is dedicated to caregivers of all ages
who provide care – past and present – for
family members, relatives, friends, and neighbors.

Acknowledgements

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Message from Project Chairperson

When people become ill or acquire a disability due to the progression of a chronic illness or other medical and/or social condition they often require support to remain in their homes and communities. Being more dependent on one’s family and friends may change those relationships. A spouse, child, sibling, neighbor, or friend may find that they are now also a caregiver - the person primarily responsible for seeing that another person’s physical, psychological, and social needs are met. Being a caregiver can be rewarding, but can also exhaust a person physically and emotionally, leading to illness and inability to provide adequate care.

Over the years we have heard repeatedly from caregivers that they need access to basic information and practical ideas. This Guide brings together resources to support caregivers to manage common caregiver challenges such as communicating effectively with their care-receiver; organizing day to day schedules, support, and respite services; staying healthy; and coping with grief and bereavement.

Family members who are not caregivers could also use this information to become more aware of the challenges and responsibilities of being a caregiver. We hope that the ideas you find here will help to improve the quality of life for you and the person you care for. We offer this guide with our deepest appreciation for all that you do.

Regards,

Gail

Gail Wideman, PhD
Caregivers Out of Isolation, Volunteer Chair (2007-2012)

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1. Caregiving: An Overview

Caregiving includes a wide range of activities involved in providing support for those who need it. These activities include but are not limited to cleaning, laundry, cooking, household maintenance, yard work, providing transportation, paying bills, banking, personal bathing and toileting, dressing, and arranging medical appointments.

Some caregiving is provided by paid workers, but many caregiving activities are carried out on an informal, unpaid basis by family members, relatives, friends, and volunteers. Indeed, family members continue to be the main (often referred to as essential) source of care and support. Caregivers provide support to a range of individuals, sometimes more than one, including spouses or partners, parents, children, in-laws, relatives, friends, and neighbors.

The Caregivers in Canada Survey released by Statistics Canada in 2018 indicated that 1 in 4 Canadians (aged 15+) provided care to a family member or friend. And 47% of all caregivers reported caring primarily for their parents or parents-in-law.

Unpaid caregiving provided by family and friends has become increasingly recognized as an important role in society. Caregiving reduces the social costs associated with health services and institutionalization. In addition, care recipients benefit when they maintain a positive quality of life by being able to remain at home.

The reality is that Canada is an aging population. At the time of this update 73% of NL’s population is 50 years of age and older. And NL’s population is aging 4x faster than all other provinces/territories in Canada. It is a reality that caregiving by seniors will be on the rise, particularly in provinces where younger family members leave to seek employment opportunities elsewhere, families are having fewer children and people are living longer, placing increasing expectations on seniors as caregivers.

"The greatest discovery of the 20th Century is that
our attitude of mind determines our quality of life, not circumstances."
- William James

Who is a caregiver, and for whom do they care?

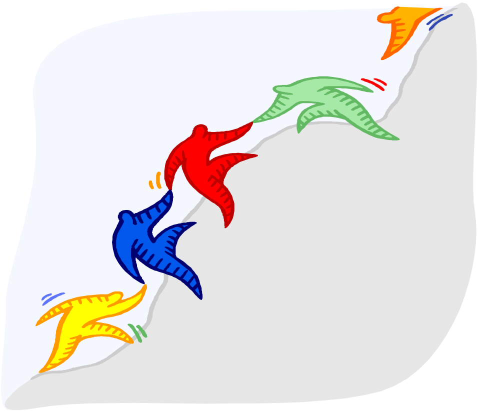
For the purposes of this manual, a caregiver is someone of any age, who provides care to one or more persons whose ability to care for themselves, is restricted.

Caregivers have many different life experiences. They may, for example:

- come from different ethnic backgrounds
- have different religious and spiritual beliefs
- have low, medium, or high incomes
- live in rural or urban areas
- have established careers outside the home
- have spouses and children, grandchildren

A care-receiver is someone of any age who needs assistance as a result of, for example:

- a disability
- failing health that may be related to aging
- an illness
- an impairment
- an injury
- a medical diagnosis



A wise man adapts himself to circumstances
as water shapes itself to the vessel that contains it.
- Chinese Proverb

What does a caregiver do?

Caregivers may provide assistance and support in many different areas including:

- advocating with or on behalf of care-receivers who need support or who are not able to advocate on their own behalf
- coordinating the care plan with family, friends, volunteer programs, medical professionals, counselors and/or paid workers
- dealing with financial and legal affairs: banking, taking care of legal documents, income taxes
- providing emotional support, checking in, visiting
- helping around the house: with housecleaning, laundry, meal preparation, yard/outdoor work
- helping with personal care: bathing, dressing, lifting/transferring, toileting, administering medications
- planning respite support
- researching services and programs that are available locally, provincially, and federally to both caregivers and care-receivers
- driving and/or accompanying the care-receiver to, e.g., medical appointments, shopping, social events
- coordinating a move: to an independent living apartment or facility, a retirement home, a personal care home or a nursing home

You can learn new things at any time in your life
if you're willing to be a beginner.
If you actually learn to like being a beginner, the whole world opens up to you.
- Barbara Sher

The caregiver and care-receiver relationship

The caregiver and care-receiver relationship is different for everyone. The following are some examples.

- It is caring and loving, or
- it is strained and/or relationship.

- The care-receiver communicates his/her needs and is involved in some or all of the care decisions,
- may require support to make decisions, or
- may not be capable of communicating his/her needs, and thus the caregiver or someone else is responsible for making decisions.

- It is a short-term care arrangement:
  "I stayed with my sister for two months after her open-heart surgery – there were some complications, and she lives alone."
- It is a long-term care arrangement:
  "Since the car accident, our adult daughter needs full-time care."

- You and the care-receiver live in the same home.
- The care-receiver lives in his/her own home, an independent living apartment or facility, a personal care home or a nursing home while the caregiver may live in his/her own home:
  "I visit my wife five days a week in the nursing home."

- Long-distance caregiving is the new reality - you may live miles away, or in another province or country:
  "I phone my parents every day from Alberta.
  I visit and do house maintenance in the summer and
  arrange for snow removal and lawn maintenance."

You give but little when you give of your possessions.
It is when you give of yourself that you truly give.
- Khalil Gibran

The caregiver's perspective

"My mother is being looked after the way I want her to be."
(Caregiver)

"I made a promise to my partner,"
(Caregiver)

Caregiving is often a positive and rewarding experience. People step into the role of caregiver for different reasons:

- to fulfill a promise
- because a parent wants to live in the family home
- to make sure a loved one receives the best possible care from family
- not having enough money available to pay for the care needed
- caring for one's elders is a tradition in the family or culture
- wanting to keep someone with a disability at home instead of alternate living arrangements
- caregiver and care-receiver do not want to be separated
- the caregiver feels an obligation
- other family members are not willing or able to make a commitment

It is important to acknowledge the caregiver experience can be stressful. As a caregiver, you may feel:

- **uncertain** about the future
- **anger** towards your situation, or directed at another person
- **anxious** that you do not have much time for friends anymore
- **fear** that you will start to regard the care-receiver as a burden on you and that you will lose patience
- **guilty** for not being able to do everything or for taking a break
- **frustration** with having to give up a job to become a caregiver
- **overwhelmed or exhausted** by caregiving activities, interrupted sleep and having no time for yourself

Give your stress wings and let it fly away.
- Terri Guillemets

The care-receiver's perspective

"For as long as possible, I want to make my own decisions."
(Care-receiver)

The care-receiver is often relieved to have a family member act as a caregiver and may feel supported, safe and loved.

It is important to recognize that the care-receiver may not have accepted his/her reduced independence. The care-receiver may be experiencing:

- denial of his/her condition or its lasting effects
- anger towards his/her life situation, or directed at another person
- anxious that friends will distance themselves
- fear of becoming dependent or guilty because they feel like a burden
- frustration or grief at losing his/her independence
- sadness from a changing self-image

A caregiver may be able to help the care-receiver maintain a sense of control over his/her life. Here are some ideas:

- **ask questions:** What do you need? What are you thinking? What are you feeling? How can I help you? What is your plan? How are you coping? What is the best way to do this?
- **work together:** If possible, work together and look for information about resources and supports that are available. Make a "care plan" together.
- **be honest:** Provide accurate information on the care-receiver's condition, but also share information on positive research with the care-receiver. Be honest about what you can and cannot do.
- **be prepared:** Your care-receiver may express strong emotions.
- **be silent:** Sit quietly and wait for the expression of thoughts, feelings, and needs.
- **celebrate:** Remember and enjoy the good moments. Create memories.
- **listen:** Do your best to understand the meaning of what is said.

This above all:
to thine own self be true
- William Shakespeare

When caregiving is left to one person

Sometimes, the responsibility for caregiving is left to one person. That person is referred to as the ‘primary’ caregiver. This can happen for different reasons including:

- a parent wants one particular child to care for him/her
- family members who contribute financially feel they are giving enough
- in many cultures women are expected to take on the role of caregiving
- the primary caregiver lacks confidence in asking for help from other family members
- the primary caregiver enjoys the role and is able to cope
- the primary caregiver is not willing to give up control or share tasks even when he/she is exhausted
- family members do not get along, and sharing care duties seems impossible or is not a healthy option
- some family members do not want to be involved or they ignore the situation altogether
- siblings who work outside the home or have children, believe that other family members have more time for caregiving
- members of the family live far apart – in different provinces or countries – and only one person lives with or near the care-receiver

There is only one corner of the universe you can be certain of improving, and that's your own self.
- Aldous Huxley

When caregiving is a team effort

Some families can form a **circle of care** and work together as a team of caregivers. The team may also include friends, neighbours, and co-workers.

How to form a circle of care:

Either:

- the care-receiver takes the lead, calls a meeting and outlines his/her strengths, abilities and care needs; or,
- the care-receiver and caregiver work together and call a meeting to see who is available to meet needs; or,
- the primary caregiver calls a meeting because the care-receiver is not able to do so.

When a circle of care is formed, team members get together to make an overall plan for care. Each person agrees to take on tasks and responsibilities. These responsibilities can change over time. Team members keep in touch by phone, email or in-person meetings.

Every circle of care is different. Examples include:

- members work well together, share tasks, cope with change, and have the time and energy to support the care-receiver
- members struggle with commitments but overcome obstacles to support the care-receiver
- members reduce their commitment or quit the team (e.g., there is family strife, and caregiving is an added stress)
- members include paid support workers, (e.g., homecare workers) or neighbours who volunteer a few hours or are paid to help (e.g., shovel snow)

Out of clutter, find Simplicity. From discord, find Harmony.
In the middle of difficulty lies Opportunity.
- Albert Einstein

Communication is key to providing care

When communicating with the care-receiver:

- Avoid discussing the care-receiver with others as if the care-receiver is not present.
- Be a good listener. No matter how difficult communication may be, people benefit from – and have the right to – frequent and respectful communication with those who care for them.
- Do not ‘talk down’ to the care-receiver.
- Include the care-receiver in decisions impacting him/her, including providing supported decision-making if required or requested.
- Preserve the dignity, respect, and self-esteem of the care-receiver.
- Share activities and pastimes; show the care-receiver you value him/her.
- Treat him/her as you would wish to be treated.

When communicating among family members:

Most families have difficulty communicating about important issues at times. When the health of a care-receiver means a loss of independence and the constant need for care, the chance of emotions running high in families is great.

- Match strengths and capabilities of family members to things that need doing.
- Listen to each other and come to a mutual agreement on plans for the care-receiver.
- Be honest with each other about demands on your time and financial resources.
- Do not give up if it seems you cannot agree. Focus on what is best for the care-receiver and get back on track.
- Be willing to compromise and accept that plans for the care-receiver may change over time.

The first duty of love is to listen.
- Paul Tillich

Caregiver as advocate[1]

Seeking out support, services and good care for your care-receiver means advocating for them. Family members know the care-receiver better than anyone. An advocate wants to make sure that the care-receiver is looked after safely and with dignity. Advocates help make sure the care-receiver receives good care, comfort and treatment.

Tips on being an advocate:

- Understand that the care-receiver is responsible for decisions about his/her own care. The care-receiver should be present as often as possible for all discussions about him/her, and supported decision-making should be available if needed.
- Establish good channels of communication with the health-care team. (This team might include the care-receiver's family doctor, specialized doctors, nurses, dietician, and physiotherapists among others.)
- Provide as much information as possible about the care-receiver to the health-care team (e.g., capabilities, strengths and limitations; likes and dislikes; fears and concerns).
- Discuss issues of pain management with the care-receiver and, together, if possible, relay this to the health-care team.
- Write down the questions you want to discuss with members of the health-care team.
- A caregiver may notice changes and symptoms that other members of the health-care team do not. Communicate these to those health-care professionals.
- Keep a journal of all care and treatments. Include in it details of administration of medications, appointments, the names and contact information of the health-care team. Have it available for meetings with health professionals.

It is one of the most beautiful compensations of life –
that no man can sincerely try to help another
without helping himself.
- Ralph Waldo Emerson

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[1] Adapted from the Canadian Hospice Palliative Care Association.

2. Building Your Support Network

"Friends and neighbours have asked if they can help.
I hate to impose on anyone, but I could really do with the support."
(Caregiver)

A caregiver takes on a host of new roles – from housekeeper and driver to researcher and teacher – and that means many new duties. It is not only okay to ask for help, but also essential.

Family, friends and neighbours will often say, "Let me know if you need help." As a busy caregiver, be sure to take them up on their offer, but provide some guidance. Most people want to help but don't know how. It's important to let them know how they can be of support. It might be cooking a meal, emailing friends to update them about how a loved one is doing or perhaps asking people to plan their visits rather than dropping by unannounced.

Be prepared. Assign tasks. Here are some tips for asking others for help:

- Make a "to do" list of specific chores and who can help with them (see sample worksheet in Appendix 1).
- Ask friends and neighbors what they would like to do.
- Express appreciation for help given.

In life you can never be too kind or too fair;
everyone you meet is carrying a heavy load.
When you go through your day expressing kindness and courtesy to all you meet,
you leave behind a feeling of warmth and good cheer,
and you help alleviate the burdens everyone is struggling with.
- Brian Tracy

Emotional and information support

"I felt so isolated,
like I was the only one who had an ailing father."
(*Caregiver)*

If as a caregiver, you feel isolated, frustrated, or disempowered, find someone to talk with about your feelings. Get support by linking with other caregivers. You can do this by joining a support group, by having a telephone-buddy, or both. Sharing your experiences with others is the best way to fight feelings you may have that you're the only person in the world with these problems. Having someone to share information with, and for mutual support, can help improve your ability to cope with your caregiver responsibilities.

Do a community check to see what circles of support are available, e.g., seniors' groups, family resource centres, public health services. This may be particularly important if you live in a rural area or are part of an immigrant or ethnic community. Find out about support groups that represent the disease or condition affecting your care-receiver (e.g., Alzheimer Society). Some groups meet regularly while others may meet for a limited number of sessions and deal with a specific topic at each one.

Joining a support group offers caregivers an opportunity to:

- share experiences in coping with caregiving responsibilities, dealing with the medical community and other professionals
- explore new ways to solve problems
- exchange information about the disease or condition of your loved one
- share thoughts and ideas without fear of judgment
- overcome feelings of isolation and loneliness
- relieve stress
- provide hope by listening to how others cope in similar situations
- talk, cry, and laugh with people who will not make you feel guilty
- help other caregivers with your suggestions, knowledge and ideas
- learn about community resources available

There are two ways of spreading light –
to be the candle or the mirror that reflects it.
- Edith Wharton

Financial and material support

What can your employer offer you while you are providing care?

- Do you have an Employee Assistance Program (EAP)?
- Does your employer offer flextime, family leave days or other support?
- Are you entitled to benefits or insurance?

What support is available in your community?

Large urban centres can offer more programs and services. In many rural communities neighbours usually help neighbours, and supportive community groups can be available as well. These can be valuable resources for caregivers; but not all caregivers and care-receivers experience this closeness or support. For others, there is a need for privacy. They do not want to share what is happening in their homes with neighbours or seek the support of community groups. Each person and family have to decide what is best for them.

No matter where one lives, caregivers and their care-receivers may experience:

- isolation
- transportation problems
- lack of appropriate or sufficient programs
- differences in health-care services that are available

A first step to identifying support is to **do a community assessment**. Identify what resources the community has to offer. Start with places such as the school, hospital or clinic, recreation centre, library, community hall. Speak with your family doctor or public health nurse. Ask about, e.g., caregiver support groups, volunteer services, caregiving literature, a 'meals on wheels' service, medical services, home support services, respite services, assisted living facilities, personal care homes and workers, nursing homes, retirement homes.

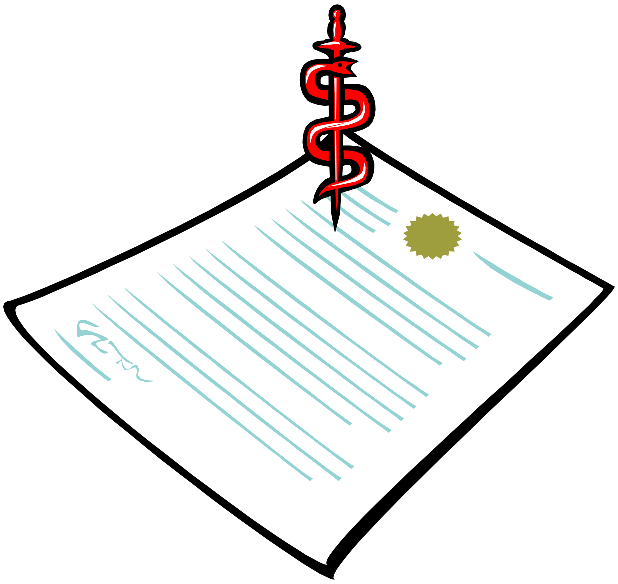
Don't be afraid to give your best to what seemingly are small jobs.
Every time you conquer one it makes you that much stronger.
If you do the little jobs well, the big ones tend to take care of themselves.
- Dale Carnegie

Insurance

Is medical insurance available over and above Newfoundland Labrador's medical program?

Critical Illness Insurance: helps with costs associated with severe illnesses. It may cover illnesses such as cancer, strokes, and coronary surgeries. A number of plans are available. It is a good idea to compare the costs and coverage options offered by several insurance companies to find the coverage best suited to the purchaser's needs.

Long-term Care Insurance: helps offset costs of special medical care required at home or in long-term care facilities. It may include nursing care, home support services, rehabilitation services, and income to cover care received from family members. There are different types of long-term care policies so again, a comparison of different options is helpful.



Kindness gives birth to kindness.
- Sophocles

Home support[2]

There may come a time when as a caregiver, you need extra help in the form of in-home support. The type of home support services received depends on the needs of both you and the care-receiver.

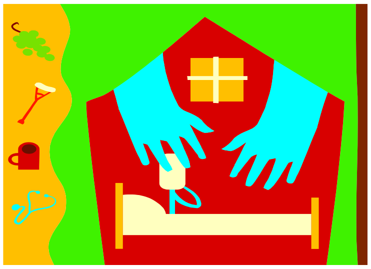
Some of these services include:

- personal care (bathing, dressing, toileting)
- home-making services (light housekeeping, meal preparation)
- day care
- respite care (at home)

To find out what is available, contact your local Regional Health zone office and make an appointment. A nurse or social worker will come to your home to assess needs and help you decide which services best meet those needs.

<u>Home support subsidy</u>

You may qualify for a home support subsidy. A financial assessment is first completed to determine eligibility. Should your care-receiver not qualify for a home support subsidy, the nurse or social worker will provide you with important information to keep in mind when looking for an agency or hiring individuals privately.



We make a living by what we get,
but we make a life by what we give.
- Sir Winston Churchill

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[2] Adapted from: *Seniors Guide to Programs and Services in Newfoundland Labrador*, SeniorsNL, 2013.

Respite services

Respite care refers to different services that may be available to caregivers so they can take a break from their caregiving responsibilities.

Reviewing your needs as a caregiver will help you figure out which respite options to pursue. Ask yourself: “What support do I need most? Is it some free time? Or help with transportation?”

Identifying your care-receiver’s requirements, abilities and preferences will also help you find the right match. Does he/she need assistance with walking or eating? Are social activities or exercise important to him/her?

Types of respite care services:

In-home respite includes informal family support and relief, volunteer or paid companionship, and personal care or skilled health assistance.

In-home services can be a few hours, or overnight, and may be arranged directly or through an agency. They may involve stimulation and companionship for the care-receiver and be provided by family members, friends, neighbours, volunteers of faith-based organizations or paid trained staff from home-care businesses. The latter may be personal care providers (assisting with bathing, dressing, toileting, etc.); homemaker services (assisting with meal preparation, shopping, and housekeeping); or skilled health-care professionals (assisting with medical needs, etc.).

Out-of-home respite can refer to adult day programs or residential respite care. Private and non-profit respite programs may include adult day centres (designed for older adults who can no longer manage independently and may include planned activities to promote well-being). Residential programs in group homes, hospitals, personal care homes and nursing homes may offer temporary care for varying lengths of time including emergency and planned overnight services.

All of us, at certain moments of our lives,
need to take advice and to receive help from other people.
- Alexis Carroll

Hiring a personal care attendant (e.g., home support, respite)

It is critical that personal care attendants have the knowledge and expertise required to provide care and support for the care-receiver. It is equally important that attendants be compatible with the individual for whom they are providing personal services. While many individuals and families turn to home support agencies for the additional support they need, many others choose to hire their own.

If you plan to hire additional help outside an agency, consider what is important to you as you:

- develop a job description
- decide what tasks the employee will perform
- schedule attendant care according to the care-receiver's needs
- decide which personal and skills qualifications the attendant should have
- decide how much money can be afforded for salary
- write advertisements
- screen applications
- interview applicants
- do reference checks
- make a final decision

My first thoughts are that I should not let people down
that I should support them and love them.
- Diana, Princess of Wales

Hospitalization[3]

Hospitalization can be a stressful time for everyone involved. Here are some tips to gain support and help reduce stress.

1. *Contact information:* get the name and number of the head nurse or primary care nurse, in case you want to discuss a problem, get information, or need a referral.

2. *Work with the health professionals:*

Connect with the Social Worker at the hospital to see what programs and services are in place that your care-receiver may be able to avail of.

Speak with the care-receiver's doctor to find out about any rehabilitation services that may be needed. If rehabilitation services are needed, talk with the therapist/s to learn what is involved and how you can help the care-receiver with his/her therapy.

Talk to staff about discharge planning. Make sure all equipment and other items are in place before your care-receiver goes home.

One person caring about another
represents life's greatest value.
- Jim Rohn

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[3] Adapted from: *A Guide for the Caregiver: Information and Resources for Caregivers of Older Adults*. Seniors and Healthy Aging Secretariat, Government of Manitoba.

Long-term care

A person moves from their home to a personal care home or a nursing home for a variety of reasons. The move can be planned, or it can happen unexpectedly, as in the case of an accident or deteriorating health. In some cases, a caregiver is no longer able to care for their family member or friend.

A care-receiver can make the decision that it is time to move. Some family members and professionals make the decision when the care-receiver is not able to or there are no other options.

There are two types of facilities:

Personal care homes[4]

Personal care homes are privately owned and licensed to provide accommodation and care for five or more residents. These are mainly seniors who require minimal to moderate assistance with activities of daily living. Meals are provided in a common area. Staff people are on-site 24 hours a day to provide supervision and routine care, but no on-site medical care is provided. Seniors who choose personal care homes pay the total cost or if on a low income, can be subsidized by Government. For more information contact your Regional Health zone.

Nursing homes (long-term care)[5]

Residents of nursing homes have been assessed by the Department of Health and Community Services as needing higher levels of personal and supervisory care than those living in personal care homes. Nursing homes provide medical care and speech, physical and occupational therapies for those who cannot manage alone but do not need hospitalization. For more information contact your Regional Health zone.

Never believe that a few caring people can’t change the world.
For, indeed, that’s all who ever has.
- Margaret Mead

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[4] Department of Health and Community Services website
[5] Ibid

3. Getting Organized: Making Plans

> *"You have a lot of responsibilities to take over – a lot of professions – cooking, cleaning, medications, personal care, appointments, errands and up through the night"*
> *(Caregiver)*

As a caregiver you have several roles and responsibilities. You've also heard how taking time to care for yourself is important. It may at times seem like a multi-tasking impossibility!

This section is about how to make plans to help you get organized, and help you keep on track so you can also make time for yourself.

Daily care plan

As a caregiver, you provide a number of daily personal care needs such as bathing, medications, meal preparation, escorting to medical appointments and researching available programs and services, paying bills and more.

First, assess these needs and take an inventory of your skills and the resources available to you. Who can help you in specific tasks, and when?

Remember, it's important that the care-receiver be asked whenever possible what they want and need. Respect their independence and include them in these daily care decisions.

To help with this task, consult the sample Daily Care Plan in Appendix 1 of this resource guide. Use it to help you organize your daily care needs.

Homes run smoothly when there is a plan.

It's not the load that breaks you down.
It's the way you carry it.
- Lena Horne

Medications[6]

If keeping track of medications is one of your caregiving responsibilities, using a medication chart can help you – as well as any respite worker or family member who may help out in this area of care. The Medication Chart in Appendix 1 may be a helpful guide.

Tips:

- Keep the record up to date with both prescription and non-prescription medications.
- Take the record to all doctors' appointments and to the pharmacy each time you pick up a prescription.
- When possible, use the same pharmacy for all prescriptions. This will help the pharmacist identify potential drug interactions.

Fear can keep us up all night long,
But faith makes one fine pillow.
- Philip Gulley

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[6] Adapted from: IWK Health Centre and Dalhousie University. *The Caregiver's Handbook: A helping hand for families and friends giving care in Nova Scotia*. Healthy Balance Research Program. 2007.

Meal plan[7]

Deciding what to make for supper can be difficult at the best of times. Add this to the other caregiver responsibilities and it can become a real headache. This is especially so if your care-receiver needs a special diet, is allergic to certain foods or you have little time to shop and prepare between other tasks. What to do? Make a plan. Here are some tips:

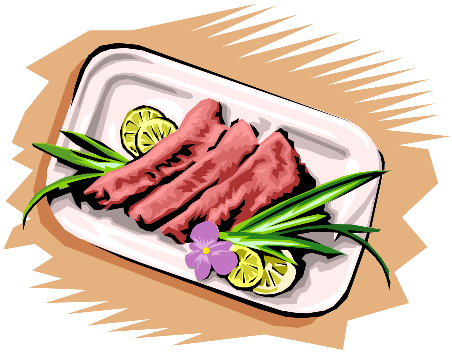
1. Collect recipes that work for you. Look for meals that:

    - use ingredients that are easy to find
    - are affordable
    - can be prepared quickly
    - are healthy

2. Make a grocery list based on the recipes you have chosen for the week.

Having a meal plan on hand will also be helpful to family members and friends who offer to cook for the care-receiver.

There is a sample Meal Planning Worksheet in Appendix 1 of this guide.



The fragrance of what you give
always stays with you.
- Earl Allen

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[7] Ibid.

Emergency plan[8]

An emergency plan is a back-up plan that takes effect should you be unable to care for your care-receiver. Such a plan may become necessary should you:

- become ill
- have other responsibilities that demand your immediate attention
- have difficulty managing the physical, financial, or emotional needs of your care-receiver
- recognize that you need a break from your caregiving responsibilities
- have a personal emergency
- have unforeseen circumstances – such as car trouble or a snowstorm – and cannot see to the needs of your care-receiver

Your back-up emergency plan is a way to help you think about unexpected situations. A well-thought-out plan will decrease your level of stress and put your care-receiver at ease. Perhaps more importantly, a plan gives you the opportunity to consider smaller details that you might not have time to think of later.

Tips:

1. Develop your plan with your care-receiver, partner, or friend and discuss it with emergency contacts and supporters.
2. Keep the plan in a visible location for emergency use.

An Emergency Plan Worksheet is also provided in Appendix 1 for your reference.

Believe it is possible to solve your problem.
Tremendous things happen to the believer.
So believe the answer will come.
It will.
- Norman Vincent Peale

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[8] Adapted from: *Caring for Caregivers: A Handbook for Caregivers*, Grenfell Regional Health Services Health Promotion. 2002.

Emergency alert system

For those care-receivers who live alone or who spend time alone during the day or night, an emergency alert system can provide tremendous relief to both the care-receiver and their caregiver and family members. The systems are used to call for emergency assistance in situations such as a fall or sudden illness. They can potentially save the life of the care-receiver or anyone who uses the system.

For information about emergency alert systems, talk with a Regional Health zone, family physician, pharmacist, or others involved in the medical profession. They can be a valuable source of information or can direct you to suppliers of the systems.

Impossible situations can become possible miracles.
- Robert H. Schuller

4. Finding the Balance: Self-Care

Why self-care is important!

"I made the choice to be a caregiver. But now I have no time
for anything else in my life."
(Caregiver)

Sometimes, caring for the needs of another can feel overwhelming and stressful.

As a caregiver, you may feel guilty about taking time for yourself. Perhaps you feel you have to give all of yourself, all of the time. But doing that can lead to fatigue and make you resentful. It can negatively impact your health, employment, your relationship with the care-receiver and your caregiving abilities.

Taking care of yourself means:

- Knowing your limits. Sometimes, this can mean saying 'no'. Accept that caregiving is challenging, and no one is equipped to do it alone. When you feel you need help, look to family, friends and health-care professionals for support.
- Looking after your physical, mental, spiritual and social health.

Taking care of yourself is not being lazy or selfish! Think of it as recharging your batteries.

Make your own recovery the first priority in your life.
- Alexis Carroll

Acknowledging your feelings

Many caregivers deal with a range of powerful feelings. These feelings are normal and denying them can lead to anxiety and depression. Sometimes, they can get in the way of being an effective caregiver. It is important that they are dealt with. The following are some suggestions for managing your emotions if they are having a negative impact on you and your caregiving duties.

- Don’t be afraid – or too busy – to seek help if negative feelings overwhelm you. Talk to friends and family. Speak with your doctor. Take advantage of counseling programs.
- Keep your perspective. Consider all the positive contributions you are making.
- Take care of your own emotional and physical needs.
- Take time to grieve when you need to but take time to celebrate the happy moments too.
- Try not to take on more than you can handle.
- Use respite care when you need a break.

Have a good cry, wash out your heart.
If you keep it inside, it will tear you apart.
- Dr. Hook

When anger turns to aggression

Angry words, aggressive behavior or violent outbursts are harmful. They can erode the caregiving relationship and are a form of abuse.

A care-receiver may be agitated, exhibit anger about their life situation, or be angry towards family members or friends, including the caregiver. This anger can be occasional and a recent development. Alternatively, there may be a history of violent outbursts.

Anger and aggressive behavior can also happen the other way around. Family members, including the caregiver, may exhibit anger and aggression towards the care-receiver.

As a caregiver, are you being treated badly or abused? Ask yourself:

- Is this behavior new or familiar to me?
- Can the medical diagnosis of the care-receiver cause aggressive behavior?
- Can the prescribed medications cause aggressive behavior?
- What steps and action will I take to stop the aggression or abuse?

As a caregiver, are you acting on your anger or being abusive? Ask yourself:

- What is causing these feelings and behaviors?
- Are there unresolved family issues, life stresses, health problems or medications that are affecting my behavior?
- What steps and actions can I take to stop the anger and abuse?
- Where should I look for help?

Get help - take steps to stop aggressive behaviors and abuse:

- talk to the care-receiver (if appropriate)
- talk to the family doctor or a specialist, including a counselor
- talk to other family members
- talk to a social worker in your Health Region

The opposite of anger is not calmness, its empathy.
- Mehmet Oz

Coping with stress

Do you feel overwhelmed, irritable, or short tempered? You may be unable to focus or complete tasks. You may be unable to eat or are eating too much. Feeling stress in our bodies reminds us to pay attention to what is happening in our life. It is important to take action to reduce or release stress in a healthy way. Here are four steps, a list of additional techniques, and Roger's Anxiety Reducers.

Step 1: Identify the causes

- Are you feeling isolated from friends?
- Are you pressured by financial decisions and don't have enough money?
- Are there other problems with children, marriage, employment, or health? What are they?
- Do you experience multiple demands on your time, energy, or money? What are they?
- Do you feel anger and resentment towards others?
- Do you feel a lack of understanding about the care-receiver's mental or physical condition?
- Do you feel a loss of freedom, a sense of being 'trapped'?
- Do you feel that other family members have negative attitudes with which you have trouble working?
- Do you feel your responsibilities conflict? Which ones?
- Do you have difficulty meeting your care-receiver's physical or emotional needs?
- Does your care-receiver place unrealistic demands and expectations on you?
- Is there a difference in expectations among your family, your boss, your spouse/parent/friend? What are they?
- Is there disagreement among family members?
- Is there a lack of open communication?
- Is there an observable deterioration with your care-receiver that is difficult to watch happen?

The greatest weapon against stress
is the ability to choose one thought over another.
- William Jones

Step 2: Talk about your feelings

"You don't have to carry your burdens. Vent your feelings.
You need someone to listen."
(Caregiver)

Approach your family doctor for advice. You may get a referral to a counselor.

Talk with friends or family members.

See your spiritual advisor.

Find another caregiver or support group to talk with to share concerns and experiences.

Strength means recognizing that it is impossible
to be strong all the time.
- Sally Franser

Step 3: Reduce tension

It can be difficult, but it is important to take even a short break every day to keep your batteries recharged. Physical activity is a great stressbuster. Take a brisk walk or do a few simple stretches.

Try to build in time for social activities and community events. You will benefit from a change of scenery and socializing. Maintain hobbies and interests you enjoy. Maintain ties to your friends, even if it means just a phone call.

Writing down your experiences or challenges in a journal can be an outlet for your feelings and may help you find solutions.

Once you make a decision,
the universe conspires to make it happen.
- Ralph Waldo Emerson

Step 4: Guided relaxation[9]

Guided relaxation exercises can help reduce tension and stress.

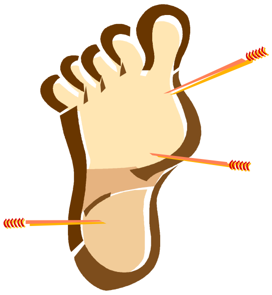
Find a place where you are comfortable and not going to be interrupted. Lie down on your back with your arms resting at your side.

Close your eyes, and take a deep breath in through your nose, holding it for several seconds. Slowly exhale through your mouth. Repeat this several times, just focusing on your breath as you fill your lungs and empty them completely.

Focus on parts of your body where you hold tension. As you inhale, imagine your breath moving to that area of tension. As you exhale, visualize the tension flowing out with your breath.

Now practice tensing and relaxing each part of your body. Start by focusing on your toes. Tense them as you inhale and hold your breath for a few seconds. As you exhale, allow the tension in your toes to melt away. Next, focus on your lower legs, tensing them as you inhale; releasing the tension as you exhale.

Continue to move up your body – through your knees, thighs, buttocks, abdomen, lower back, chest, shoulders, neck, arms, hands, face...each time breathe in slowly through your nose, tense that part of the body, hold your breath, then let the tension be released as you slowly exhale.



The more tranquil a man becomes, the greater is his success,
his influence, his power for good.
Calmness of mind is one of the beautiful jewels of wisdom.
- James Allen

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[9] Adapted from: IWK Health Centre and Dalhousie University. *The Caregiver's Handbook: A helping hand for families and friends giving care in Nova Scotia*. Healthy Balance Research Program. 2007.

Step 5: Additional techniques

1. Make every day into an adventure!
2. Be compassionate with yourself.
3. Relax. Take a few deep breaths. Ahhh!
4. Exercise more, walk more, move more.
5. Whistle. Hum a tune. Sing!
6. Take time off if you need it.
7. Hug your loved ones.
8. Let some chores go. Do them when you have the energy.
9. Write down things so you don't forget.
10. Calm with aromatherapy, a scented candle, incense…
11. Bake a cake, some cookies or muffins
12. Do something every day that makes you happy.
13. Try massaging your feet.
14. Warm your hands. Running them under warm water or rubbing them together quickly will open blood vessels and send your brain a signal to relax.
15. Accept that everyone is different.
16. Eat dinner with loved ones when you can.
17. Laugh more.

The most wasted of all days is one without laughter.
- e. e. cummings

Roger's anxiety reducers[10]
(What we can do on the inside)

"The following is a list of things that I read about recently that help to reduce anxiety, and I hope that they might be of some help to you on your journey.

All the best, Roger."

1. Ask yourself: "Do I need this anxiety right now? Is it necessary? Is this anxiety actually making me more alert, and therefore helping me to get through my day?"

2. Accept it. Sometimes the best thing to do is to become aware of anxiety. Let it know that you are aware of it.

3. Take a big picture leap. "Will I feel this way in a year, a month?" Are you worrying excessively about something that is really not that significant in the larger scheme of things? Will your worrying or your dread get you anywhere?

4. Plan how to reward yourself when the anxiety is over.

5. Personal mantras. When overwhelmed, feel free to repeat a personal mantra. Some examples are:
   - I am determined and strong.
   - I can conquer all obstacles.
   - I will get through this.
   - I am confident.

6. Keep relaxation items around - stress balls, massagers (some people have rolling pins that they massage their feet on), worry stones, crystals - whatever works for you.

There are some things you learn best in calm,
and some in storm.
- Willa Cather

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[10] Roger Baggs is a mental health advocate living in St. John's, NL.

Taking care of your physical health

It is easy to neglect your own nutritional and sleeping needs when caring for the needs of another. Staying healthy by eating well can help you manage stress more effectively. Sleep is important also, as it allows your body to restore itself. Physical activity, too, keeps your body and mind fit and better able to cope.

Eating well (with Canada's Guide) recommends:

- enjoying foods from each of the four food groups
- eating mainly whole grain products, vegetables, and fruits
- drinking reduced-fat milk
- baking, broiling or microwaving food instead of frying
- eating more peas, beans and lentils
- reducing chips and chocolate snacks

Getting a good night's sleep:

- develop a regular routine; try to go to bed and wake up around the same time each day
- have a relaxing bath or read a book before bed
- avoid strenuous activity close to bedtime

Staying active:

- Physical activity is more than just playing sports. It can include everyday things like walking the dog, digging in the garden and raking the leaves.
- Check out the tips for Physical Activity and Your Health at https://www.canada.ca/en/public-health/services/being-active/physical-activity-your-health.html

Don't let your mind bully your body into believing;
it must carry the burden of its worries.
- Astrid Alauda

Mental health and addictions

Coping with a stressful situation can lead to dealing with such emotions or ‘stressors’ by turning to drugs and alcohol. If caregivers feel at risk of this, support is available to individuals as well as families. It can be obtained from nurses, social workers, and addiction counselors in each Regional Health zone.

Addictions services can also provide information about local self-help groups such as Alcoholics Anonymous, Narcotics Anonymous, and Gamblers Anonymous.

Help is also available 24 hours a day. The province’s *Mental Health Crisis Line* can be reached through the **811 Health Line**.

When you feel like falling down, don’t give up.
Try again.
- Samantha Smile

Reflections for caregivers

Whether new to the role of caregiving or not, as a caregiver you are giving lots of time and energy to another person. It is important for you to maintain balance and perspective, and remember to:

- accept help that is offered to you by others
- acknowledge or talk about the joys and challenges of caregiving
- express difficult feelings to a friend or professional; don’t let feelings “bottle up” inside
- protect your individuality, and make a life for yourself that will sustain you when your care-receiver no longer needs your full-time help
- accept appreciation and emotional support for your decision to be a caregiver
- accept consideration, affection, forgiveness and acceptance for what you achieve as a caregiver
- recognize when the workload or stress is too much (and have a back-up plan)
- seek help from others and take time for yourself, even if your care-receiver does not want you to
- take care of your health, spirit, and relationships
- take pride in what you accomplish and applaud the courage it has sometimes taken to meet the needs of your relative, partner or friend

You cannot tailor your situation in life,
But you can tailor-make your attitudes to fit those situations.
- Zig Zigler

5. Legal Issues

As a caregiver you may be faced with several legal and financial issues of your care-receiver. Some of your legal questions may be answered at little or no cost to you by contacting the Public Legal Information Association of Newfoundland Labrador (PLIAN). This not-for-profit organization can be contacted toll-free at: 1-888-660-7788, 1-709-722-2643 or by email, info@publiclegalinfo.com

Powers of Attorney

A Power of Attorney is a written document that allows an individual (e.g., your care-receiver) to name a person to make decisions on their behalf about money, assets, debts, and property. The Power of Attorney can be for a specific purpose, or a specific time period, or it can be very general. If an individual becomes legally incapacitated, the Power of Attorney is no longer valid.

There is a special document called an Enduring Power of Attorney which can be completed by individuals who want to name someone to make decisions on their behalf in the event they become legally incapacitated, or legally unable to make their own decisions.

Decisions about medical care can also be part of a Power of Attorney, or they may be part of an Advance Health Care Directive.

If we did all the things we are capable of,
we would astound ourselves.
- Thomas Edison

Advance Health Care Directive[11]

An Advance Health Care Directive is a document that allows individuals to give instructions about their future medical care and/or designate an individual(s) to make health-care decisions for them should they no longer be able to do so themselves.

The Advance Health Care Directive only comes into effect when:

- the individual does not have the capacity to make his/her own health-care decisions, or
- the individual is incapable of communicating these decisions. (This could be a result of, for example, advanced Alzheimer's disease or other form of dementia or due to loss of consciousness related to an accident.)

Everyone should consider making an Advance Health Care Directive while still healthy and emotionally in control.

Every exit is an entry somewhere.
- Tom Stoppard

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[11] *Seniors and the Law in Newfoundland Labrador*. Public Legal Information Association of Newfoundland Labrador. 2011.

Wills

A will is a legal document that explains what an individual wants done with the things they own (their estate) after they die.

In Newfoundland Labrador a law called the Wills Act sets out the legal requirements for making a valid will. If you are a family caregiver, it would be a good idea to encourage the person you are caring for to have an up-to-date and valid will.

Individuals can also name a person to make sure the terms of the will are carried out. That person is called the Executor of the will. Often it is the caregiver who has the complex and time-consuming task of ensuring property is distributed according to the will. Planning in advance can help ease this process.

Although it is not necessary, when making a will it is a good idea to consult with a lawyer to make sure that all of the requirements are met. For example:

- A will must be in writing (e.g., typed or written by hand) and signed by the individual to be valid.
- A video or audio recording is not considered a valid will.
- The person making the will must be at least 17 years of age.
- The person who makes a will must be free from the pressure of other people.
- The person must have capacity (e.g., understand what they are writing/doing).
- It is mandatory that two people witness signing of the will; and it is not a good idea to have a beneficiary, or a spouse, be a witness. If a beneficiary or spouse is chosen as executor of the will, he/she cannot witness the document.

The real secret of happiness is not what you have or what you receive,
it's what you share.
Source Unknown

6. End-of-Life Care

"I was constantly adjusting. Why?
Because my husband's condition kept changing.
Just when we settled into a routine, the routine changed."
(Caregiver)

The role of the caregiver is constantly changing. The care-receiver may become healthier and no longer need extensive care or their condition may worsen, and they may need to move into a long-term care facility. Sometimes change comes quickly, and a care-receiver passes away.

As your caregiving role changes, you may take on new or additional responsibilities such as hiring a home support worker or researching palliative care services. Throughout the journey, you'll also be an advocate for your care-receiver, making sure his/her wishes are respected, dignity maintained, comfort addressed, and treatment arranged.

You will likely develop new skills, such as learning about legal and financial matters. This section will help you navigate some of these changes.

Navigating End-of-Life care

Changes in the health of your care-receiver may signal the need for you to plan their end-of-life care. This may mean understanding a new set of health-care systems such as hospitalization, long-term care and palliative care.

These changes may bring another wave of mixed emotions: grief, sadness and possibly relief. Take stock of your feelings about, and experience with caregiving:

- What new skills and interests have I developed?
- Am I taking care of my emotional and physical health?
- Has my relationship with family and friends changed?

I think that wherever your journey takes you,
there are new gods waiting there, with divine patience – and laughter.
- Susan M. Watkins

Palliative Care[12]

Palliative care is sometimes called hospice palliative care or end-of-life care. It is an approach to caring for individuals who are living with a life-threatening illness, whether they are young or old.

Palliative care is about achieving comfort and good quality of life while ensuring respect for the person who is nearing death.

Palliative care takes care of different aspects of end-of-life care by:

- managing pain and other symptoms
- providing the care-receiver with social, psychological, cultural, emotional, spiritual and practical support
- supporting caregivers
- providing support for bereavement

Some people want to die at home. End-of-life-care can take place in a home setting, a hospital, or a long-term care facility such as a nursing home or a hospice.

Who provides palliative care services?

A team of care workers usually provides palliative and end-of-life care services. The team may include nurses, physicians, social workers, spiritual advisors, bereavement support workers, trained volunteers, and informal caregivers such as family members, who work to meet the needs of the patient, family and loved ones.

For information on palliative care services in your area, contact your Regional Health zone.

"Seeing death as the end of life is like seeing the horizon as the end of the ocean." - David Searls

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[12] Adapted from: *Palliative and End-of-Life Care*. Health Canada at http://healthycanadians.gc.ca/health-system-systeme-sante/services/palliative-pallatifs/index-eng.php

Bereavement and Grieving[13]

Grief is the range of physical and emotional feelings we sometimes have when faced with or waiting for, the loss of a loved one. Examples might be the grief a wife feels when her husband passes away or that which a husband feels as he watches his wife go through the stages of Alzheimer's disease.

When you are grieving you may be unable to eat, have trouble sleeping, have panic attacks, or experience depression.

Bereavement is the state of suffering a loss. During this time, there are four stages of grieving:

- accepting the reality of the loss
- experiencing emotional pain and/or anger
- adjusting to living without the loved one
- letting go

Each person is different. There is no set time for how long grieving will or should last. To help you deal with your grief, you might consider connecting with your church, social worker, or pastoral care coordinator within your Regional Health zone.

While we may not be able to control all that happens to us,
we can control what happens inside us.
- Benjamin Franklin

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[13] Adapted from: *Community Respite Through Neighbours Helping Neighbours: A Training Guide*, Victorian Order of Nurses for Canada. 2009; and *Living Lessons: A Guide for Caregivers*. Canadian Hospice Palliative Care Association and the GlaxoSmith Kline Foundation. 2002.

APPENDIX 1:

PROGRAMS AND SERVICES

Government of Newfoundland Labrador: Newfoundland Labrador Housing

a. Provincial Home Repair Program (PHRP)

Through Newfoundland and Labrador Housing Corporation (NLHC), PHRP is designed to provide funding to assist homeowners with low income who require repairs to their homes that bring dwellings up to minimum fire and life safety standards.

For applicants who require accessibility changes, please apply under the Home Modification Program (HMP).

Who is eligible:

- Homeowners with low income (an annual household income of $32,500 or less) requiring repairs to their dwellings.
- Except in the case of emergency PHRP, the client must have owned and occupied the property for a minimum of five (5) years.
- There is a lifetime assistance cap of $12,500.
- Application for a second project can be submitted after seven (7) years.

What types of repairs are eligible:

- Repairs necessary to maintain a dwelling for continuous safe occupancy.
- This may include improvements in basic heating, electrical and plumbing services; repair deteriorated structures, foundations, windows, doors, roofing or siding; replace oil tank

Financing includes forgivable and repayable loans

- Funding is limited to the costs associated with repairs.

Client Selection/Delivery Process:

- Priority will be given to first-time applicants.
- Emergencies are also treated as a priority.

b. Home Modification Program (HMP)

Through Newfoundland and Labrador Housing Corporation (NLHC), HMP is designed to provide funding to assist homeowners, with low-to-moderate income, who require accessibility changes to their residences. The goal is to enable individuals to remain in their own homes for a longer period.

Who is eligible:

- Homeowners with low-to-moderate income ($46,500 or less) requiring accessibility modifications to their homes – including persons with disabilities and not limited to 65 years of age and over.
- Occupational Therapist's report is required clearly indicating whether modifications are non-urgent or urgent:
  - Urgent modifications are required for the client to return/remain home.
  - Where extenuating circumstances exist, and at the discretion of NLHC, a report prepared by a qualified medical professional other than an Occupational Therapist may be accepted.

What types of repairs are eligible:

- Installation of a ramp; widened doorways/halls to increase space for wheelchairs
- Handrails, lowered counter and workspace in the kitchen
- Roll/walk-in showers, bathtub grab bars; and seats.

Financing includes forgivable and repayable loans

- Funding is limited to the costs associated with repairs.

c. Home Energy Savings Program (HESP) for Oil and Electricity *(replaces the Residential Energy Efficiency Program - REEP).*

A provincial initiative designed to assist households that use oil or electricity heat in making energy efficient retrofits to their homes to improve affordability and reduce greenhouse gas emissions that contribute to climate change.

Newfoundland and Labrador Housing Corporation (NLHC) will provide a pre- and post-energy evaluation to determine the best possible solutions for energy efficiency. The post-energy evaluation will be required to confirm that identified work was completed.

Examples of some repairs/upgrades that will create energy efficiency include basement and attic insulation, and draft-proofing.

Heat Pumps are potentially eligible as an energy upgrade under this program.

- Requires an NL Housing Engineering Technician to do an on-site evaluation of the home to determine what the best investment is with the rebate for the home - in terms of energy reduction and savings.
- Although a heat pump may be eligible, the technician will make a list of prioritized recommendations and increasing attic or basement insulation levels, or air sealing may be considered the best first step instead of adding heat pumps.
- Recommendations are house specific.

Who is eligible:

- Homeowners with incomes of $32,500 or less per year.
- The dwelling must be your primary residence.
- For owners of single, row and semi-detached housing, assistance is available in the form of a grant up to $5,000 per unit.
- NOTE: Condo owners are not eligible for HESP assistance.
- You will need to provide proof of annual electricity or oil consumption, proof of home ownership and consent to allow NLHC to receive income information from Canada Revenue Agency.
- NOTE: If you have already received HESP assistance you are not eligible to apply.

Government of Newfoundland and Labrador: Newfoundland Power and Newfoundland and Labrador Hydro

d. takeCHARGE

takeCHARGE brings energy efficiency awareness and rebate programs to everyone in Newfoundland and Labrador. https://takechargenl.ca/

Government of Newfoundland Labrador: Department of Finance

e. Seniors' Benefit and Income Supplement

These benefits are refundable tax credits that may be paid to low income individuals, seniors and families. A refundable tax credit is an amount paid even if there is no tax payable. The benefits are paid to those eligible in quarterly installments in January, April, July and October. No application for the benefits is required. However, eligible individuals must ensure their annual income tax return is filed in order to receive the benefits. Eligibility will be based on family net income from the previous year.

A calculator to help find out the amount of your benefit can be found at: http://www.fin.gov.nl.ca/fin/tax_programs_incentives/personal/calculator.html

Government of Newfoundland Labrador: Department of Health and Community Services

Some of these programs may differ from health region to health region. It is a good idea to call your Regional Health zone office for information about the services offered by the Department.

f. Community/Home Support Program

The Program is designed to promote, maintain, or enhance an individual's well-being in his/her home. Eligibility is based on a financial and a personal care needs assessment. Home support services may be either purchased privately by an individual or subsidized from public funds to a maximum financial ceiling. To apply for subsidized home support, contact Community Supports in your Regional Health zone.

g. Short-term Home Care Services (when discharged from hospital)

Short-term home care services include community home support, nursing visits, some medications, and equipment and/or supplies. They are provided to individuals with an injury or acute illness to support their recuperation in their own homes. Eligibility is determined by needs assessment, and services are provided free-of-charge for two weeks. Services may vary from one region to another depending on priorities, the availability of human resources, and the needs of the clients. It is recommended that you discuss this with the hospital Social Worker before being discharged.

h. Adult Day Programs

Adult Day Programs allow people to live at home while attending a program offered in the community. These programs offer safe and supportive environments and may provide personal care, physiotherapy, socialization, and/or a meal. For programs run through a Regional Health zone, individuals need to be assessed and may be waitlisted for this service, as space is limited. For programs run through a Retirement Residence contact is direct to the facility. Some people may have home support services in addition to attending a day program.

i. Palliative Care

Palliative Care services are offered for all clients with a life limiting illness

- Services are available in the home and in community clinic settings from community care nurses and social workers
- Goal is to improve quality of life by providing relief from disease symptoms such as pain, nausea or stress

End of Life Care at Home

- When an individual has reached the final stages of their life, additional services are available to provide comfort and support to the patient and their family in their own home, such as:
    - Home visits, symptom treatment, equipment and other supplies needed for care (such as a hospital bed), personal care for the patient, household management needs, respite for the main caregiver, medications
- Accessing End of Life Care Assessment for end-of-life care at home can be done in the hospital by staff in consultation with other members of the care team or in the community by nurses or other professional staff.
- Approval for this service may depend on a number of factors, including:
    - All treatment aimed at a cure has been completed and death is imminent
    - Client is aware that death is near and wishes to be at home
    - A physician or nurse is available to provide end of life support to the individual in the comfort of their own home
    - Caregiver or family is able and willing to help care for the client at home

j. Paid Family Caregiving Option

This program is available for seniors and adults with disabilities to pay a family member for approved home support.

Eligibility:

- Be a new or current client for one of the Home Support Programs
- Have a long-term need for a home support subsidy
- Meet the clinical and financial assessment for service
- Have a clinical assessment that indicates a care need for personal care/behavioural support and that care can be appropriately provided by a family member
- Agree to the financial contribution, if any, as indicated by the financial assessment
- Individuals who are eligible to be paid to provide care under the Paid Family Caregiving Option are: parents, children, siblings, grandparents, grandchildren and relatives residing in the same home, *excluding spouses and common law partners.*

k. Newfoundland and Labrador Prescription Drug Program (NLPDP)

NLPDP provides financial assistance for the purchase of eligible prescription medications for those who reside in the province. There are five main plans under the program, including the 65Plus Plan.

- The 65Plus Plan provides coverage of eligible prescription drugs to residents 65 years of age and older who receive Old Age Security Benefits (OAS) and the Guaranteed Income Supplement (GIS).
- Beneficiaries will be responsible for payment of the dispensing fee up to a maximum of $6.
- Those who qualify for a drug card under the 65Plus Plan also qualify for the Ostomy Subsidy Program. The program will reimburse 75% of the retail cost of benefit ostomy items.

NOTE: Seniors who are receiving subsidized home care through a Regional Health zone, or in a Personal Care Home with a subsidy, are eligible for the Foundation Plan which offers the most benefits. Call NLPDP for details.

l. Medical Transportation Assistance Program (MTAP)

MCP beneficiaries required to travel for specialized insured medical services may be eligible to apply for financial assistance under MTAP for:

- Airfare (and related eligible taxi fares)

- Private vehicle usage (after a 500 kilometres/year deductible)
- Purchased registered accommodations (and related meal allowance)
- Private accommodation benefit and meal allowance
- Busing and use of ferries based on program criteria (deductibles may apply).

For out of province travel, the referring physician must complete an application in full and all applicants must complete and submit a Direct Deposit Form.

Applicants are encouraged to apply to the MTAP two months prior to the confirmed scheduled appointment/consultation date(s) and must pay medical travel costs upfront and make a claim for allowable expenses to the department.

m. Special Assistance Program

The Special Assistance Program is a provincial program which provides basic medical supplies (such as dressings, catheters and incontinence supplies), oxygen, orthotics (such as braces and burn garments) and equipment (such as wheelchairs, walkers and commodes) to assist with activities of daily living for individuals living in the community. The person must meet the eligibility criteria for the program. For more information on accessing this service contact your Regional Health zone.

n. Personal Care/Nursing Homes

When people need more help than can be provided through home support services, they may need to consider admission to a Personal Care home or a Nursing home.

Personal Care homes are privately owned and operated residential homes for seniors and older adults who need assistance with daily living. Individuals who are admitted to personal care homes do not require on-site health or nursing services but may require the service of a visiting professional. These homes are licensed by the regional health authorities.

Nursing homes are for people who need nursing care as well as a higher level of personal and supervisory care than that provided by a personal care home.

There is a single-entry system for admission to personal care or nursing homes. Contact should be made with your Regional Health zone (Community

Supports) and arrangements will be made for a home visit to assess the person's needs and the level of care required. A financial assessment will also be done.

o. Protective Community Residences (PCR)

Protective Community Residences are specially designed and staffed homes that provide a unique, home-like, residential care option for persons with mild-to-moderate dementia. PCR's fall under the LTC (Long Term Care) umbrella but operate independently. They are a separate option from Personal Care Home and Nursing Home.

Admission is based on assessment by staff of regional health authorities. A financial assessment is also conducted to determine if and how much the individual must pay. For more information, contact your regional health zone.

Government of Canada – Canada Revenue Agency

p. Canada Caregiver Credit

The Canada Caregiver Credit (CCC) is a non-refundable tax credit that may be available to you if you support your spouse or common-law partner with a physical or mental impairment.

It may also be available for one or more of the following individuals if they depend on you for support because of a physical or mental impairment:

- Your (or your spouse's or common-law partner's) child or grandchild
- Your (or your spouse's or common-law partner's) parent, grandparent, brother, sister, uncle, aunt, niece, or nephew (if they resided in Canada at any time in the year)
- An individual is considered to depend on you for support if they rely on you to regularly, and consistently, provide them with some or all the basic necessities of life, such as food, shelter and clothing.

Government of Canada – Employment Insurance

q. Compassionate Care Benefits

Compassionate care benefits are Employment Insurance (EI) benefits* paid to people who must be away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death. A maximum of 26 weeks of compassionate care benefits may be paid to eligible people.

Care or support of a family member means:

- providing psychological or emotional support; or
- arranging for care by a third party; or
- directly providing or participating in the care.

You can receive compassionate care benefits for a variety of family members - both yours and those of your spouse or common-law partner.

* Employment Insurance benefits require 600 insurable hours over the last 52 weeks.

r. Family Caregiver Benefit for Adults

Through Employment Insurance, Service Canada, you could receive financial assistance benefits to help you take time away from work to provide care or support to a critically ill or injured adult 18+ or someone needing end-of-life care. The weeks of benefits can be shared by eligible caregivers, either at the same time or one after another. Caregivers must be family members or someone who is considered to be like family by the person needing care or support.

Government of Canada – Service Canada

s. Canadian Pension Plan Retirement Pension (CPP)

The CPP provides a monthly benefit paid to seniors who have made at least one valid contribution to the Plan. You can claim full CPP if you are the age of 65 or older. However, you can receive it by the age of 60 with a deduction, and 70 with an increase. For more information on the CPP and other related benefits (post-retirement benefit, disability benefits, survivor benefits, pension sharing, credit splitting for divorced or separated couples, death benefit, child rearing provision), contact a Service Canada office.

t. Old Age Security (OAS) Pension

The Old Age Security program is the Government of Canada's largest pension program. It is funded out of the general revenues of the Government of Canada, which means that you do not pay into it directly.

The Old Age Security (OAS) pension is a monthly payment available to seniors aged 65 and older who meet the Canadian legal status and residence requirements. You may need to apply to receive it.

In addition to the OAS pension, there are three types of OAS benefits:

- Guaranteed Income Supplement (also see v. below)
  If you live in Canada and you have a low income, this monthly non-taxable benefit can be added to your OAS pension.
- Allowance
  If you are 60 to 64 years of age and your spouse or common-law partner is receiving the OAS pension and is eligible for the Guaranteed Income Supplement (GIS), you might be eligible to receive this benefit.
- Allowance for the Survivor
  If you are 60 to 64 years of age and you are widowed, you might be eligible to receive this benefit.

u. Guaranteed Income Supplement (GIS)

The GIS provides additional financial assistance (in addition to the OAS) to low-income seniors at least 65 years of age and living in Canada.

Government of Canada – Veterans Affairs Canada

v. Veteran’s Affairs Canada programs

Allowance (WVA)
The War Veterans Allowance provides monthly financial assistance to help low-income Veterans, or their survivors, meet their basic needs. The amount provided is based on income, marital status and if the veteran has any dependents.

Assistance Fund – The fund provides grants of up to $1,000 (per calendar year) to help pay for a genuine emergency situation that affects your health and/or safety

Assistance Service - Provides psychological support. It is available 24 hours a day, 365 days a year to Veterans, former RCMP members, their family members or caregivers. The service is available free of charge.

Caregiver Recognition Benefit - This benefit simplifies how Veterans Affairs Canada (VAC) recognizes and supports caregivers:

- $1000 monthly, tax-free benefit directly to caregivers
- No time limit to apply
- Recognition of caregiver's support to Veterans

Emergency Fund - Quick access to eligible Veterans and their families who are facing an urgent or unexpected situation that puts them and their well-being at risk. It is a short-term solution for an urgent situation. Veterans Affairs will work with them to find long term plan that supports their health and well-being and improves their financial stability. The emergency fund covers essentials, such as: food, clothing, rent, mortgage, medical care/expenses, and expenses required to maintain safety and shelter.

Funeral and Burial Assistance - Ensures that eligible Veterans receive dignified funeral and burial services. The Last Post Fund (LPF), a non-profit organization, delivers the program on behalf of Veterans Affairs Canada. To be eligible for the program, Veterans must meet both military and financial criteria.

Health Care Benefits – from hearing aids and prescription drugs to dental and vision care.

Independence - helps you remain independent and self-sufficient in your home and your community. Depending on your circumstances and health needs you may qualify for financial assistance to obtain services such as grounds maintenance; housekeeping; personal care; and/or access to nutrition, health and support services provided by a health professional. VIP does not replace other federal, provincial or municipal programs. Instead, its role is to complement existing programs to help meet your needs.

Long Term Care - Financial support from Veterans Affairs Canada may be available when you have been admitted to 24-hour care in a community bed (available to any provincial resident) or contract bed (only available to Second World War or Korean War Veterans).

Rehabilitation - can improve health and help adjustment to life at home, in community or at work (Vocational Rehabilitation). Depending on the circumstances and needs, it may include treatment and therapies to overcome or cope with a service-related illness or injury.
The vocational rehabilitation component of provides skills development, education or training and other supports to help the veteran or spouse (depending on health) with vocational assistance.

Treatment - If you qualify for the Treatment Benefits program, you will receive a VAC healthcare card. This healthcare card provides coverage for such things as home health or hospital services, nursing services, appointments with specialists (such as physiotherapists, audiologists, and mental health providers), medical equipment, prosthetics, and prescriptions. The extent of your coverage will depend on a number of factors, including how you qualified, your health needs and your individual circumstances.

Important Contact Information

Do you have any questions about anything in this guide?

Reach out to SeniorsNL.

Telephone:
709-737-2333 (St. John's and Area)
1-800-563-5599 (toll-free within NL)

Email: info@seniorsnl.ca

Contact Us form: www.seniorsnl.ca

Social Media:
https://www.facebook.com/SeniorsNL
https://twitter.com/SeniorsNL

SeniorsNL

RESOURCES • INFORMATION • CONNECTION

APPENDIX 2:

WORKSHEETS

TO DO: Chores

Date	Time	Meals	Laundry	House-cleaning	Outside chores	Shopping	Driving, errands	Research
		Name	Name	Name	Name	Name	Name	Name
1								
2								
3								
4								
5								
6								
7								
8								
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13								
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31								

COMMUNITY SERVICES

Service	Address	Phone number
Hospital		
Clinic		
Ambulance		
Regional Health Zone		
Public Health Nurse		
Home care agency		
Respite care		
Police		
Fire		
Church Minister		
Family Resource Centre		
Seniors Centre		
Accessible transportation		
Disabled parking Placard		
Funeral Home		

There are many services and organizations, perhaps some in your own community, which may be able to provide useful information and supports. These include caregiver support groups, disability organizations (e.g., Alzheimer's disease, hearing, vision); women's groups; immigrant organizations; LGBTQ2+. Use the spaces in the form above to add these for easy reference.

DAILY CARE PLAN

Date	Toileting	Bathing	Dressing	Change bed linens	Medications	Appointments, e.g., doctor
	Name	Name	Name	Name	Name	Name
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						
16						
17						
18						
19						
20						
21						
22						
23						
24						
25						
26						
27						
28						
29						
30						

MEDICATION CHART
Month: __________

Date	Name of Medicine	Dosage	When to take, e.g., bedtime	How to take e.g., empty stomach	Time taken (note each time taken)
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					
21					
22					
23					
24					
25					
26					
27					
28					
29					
30					
31					

MEAL PLAN

Day	Breakfast	Lunch	Dinner	Items needed	Who will prepare
Sunday					
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					

EMERGENCY PLAN

Names of persons who can help in case of emergency or at the last minute	**Phone number**	**Length of time they can give, e.g., number of hours, mornings, afternoons, overnight, day/s of week**	**Task, e.g., company, meals, medications, toileting, bathing**

APPENDIX 3:

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