



The Caregiver's Handbook



Help for Unpaid Caregivers in Nova Scotia




Caregivers
Nova Scotia
for friends and family giving care
www.CaregiversNS.org



*This resource
is dedicated to all
the unpaid caregivers
in Nova Scotia and across
Canada who give their time
and support to others.*



NOVA SCOTIA

Caregiver's Nova Scotia appreciates the financial support received from the Nova Scotia Department of Health and Wellness, Continuing Care Branch.



The Caregiver's Handbook: Help for Unpaid Caregivers in Nova Scotia

Date: March, 2018

ISBN: 978-0-9689876-7-4

The information provided in this Handbook is intended for broad consumer understanding of topics related to caregiving. This information should not be considered complete nor should it be used in the place of advice or consultation with a trained professional. If you have a health-related problem, we strongly suggest that you visit your healthcare provider, or, in the event of an emergency, contact your local emergency department or urgent care centre.

The information contained in this Handbook should not be viewed as formal legal, medical, or financial advice. This information has been compiled from a variety of sources. Caregivers Nova Scotia or its Directors shall not be responsible for information provided here under any theory of liability or indemnity.

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We would like to thank the Tui'kn Partnership, and the Mi'kmaq Elder and the guardians of the young girl for allowing us to use their photo on the cover.

Finally, we would like to thank Ed MacDormand and Meridian Communications for their work on the design and layout of this Handbook.

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Welcome to the Caregiver's Handbook

This Handbook is the result of years of work done by a dedicated community of individuals. The first edition, published in 2007, was a product of the Healthy Balance Research Program (HBRP), a Canadian Institutes for Health Research funded project of the Atlantic Centre of Excellence for Women's Health at Dalhousie University. The HBRP examined the connections between women's unpaid caregiving and their health and well-being. Over five years, the HBRP brought together university researchers, policy makers, community organizations, and caregivers. Caregivers shared their experiences of difficulties faced when trying to find programs, services, and information. This Handbook was developed in response to those challenges.

Caregivers Nova Scotia was an essential partner in the development of the first edition and is pleased to present this updated version. Every staff member contributed to this new edition with input based on their own experiences as caregivers.

We would like to thank the HBRP and all its funders and participants for their work in creating this tool. We would also like to acknowledge the contributions of each person who reviewed the Handbook and provided valuable feedback during the creation of this third edition. We would also like to thank Stacey Ackroyd, Pam Fancy, Joanne Hussey, and Wendy Turner for their editorial assistance.

In particular, we would like to thank the Nova Scotia Cancer Care Program for their generous funding to produce this version of the Handbook.

We hope this Handbook will further enhance the rewarding aspects of caregiving by helping you to manage some of its challenges and demands. The Handbook is full of many useful tools, tips, and resources intended to help and support you, the caregiver.

Caregivers Nova Scotia Association

We are a not-for-profit, registered charity dedicated to providing recognition and practical supports to friends and family giving unpaid care. Our vision is: “Caregivers are supported as essential partners in care.” Since 1998 we have worked tirelessly to make this vision a reality.

Our services for caregivers take many forms, including confidential, one-on-one telephone support, and peer support groups where caregivers can meet others in similar situations and talk about their experiences. We provide information on provincial and federal programs and services, and deliver educational workshops and topical presentations.

We participate in national conferences and continue to work closely with organizations throughout the province to help each other through referrals, partnerships and consultations. We constantly seek ways to form new partnerships, both locally and at the national level, that will help us to provide caregivers with the resources and information they need. One example of this is working with local pharmacists to deliver the *Safe Medicines for Seniors and Caregivers* workshop. Our continued education and outreach efforts ensure that healthcare professionals, community partners and allies know that we are here to help them help caregivers.

As well, we have been involved in various government task forces and advisory groups to help influence public policy for the benefit of caregivers. Caregivers Nova Scotia also participates in external research projects. Some examples of our research partners include: Mount Saint Vincent University and the Nova Scotia Centre on Aging; the School of Nursing and the School of Occupational Therapy at Dalhousie University; the Dalhousie University Department of Emergency Medicine and the Nova Scotia Health Authority, as well as the Dalhousie University Faculty of Dentistry and the Healthy Populations Institute.



Public Awareness

Our organization launched the first ‘Caregivers Awareness Week’ to recognize and support the many thousands of people providing unpaid care throughout the province. This has evolved into Caregivers Awareness Month, celebrated each May in Nova Scotia. During the month, our staff develop various events and campaigns such as organizing Caregiver Appreciation Teas across the province, setting up informational displays at local libraries, and social media campaigns on Facebook, Twitter, and YouTube.

Our Website

The website is a user-friendly tool that can be used together with this Handbook to assist you in your caregiving journey. It contains up-to-date information and resources for caregivers throughout Nova Scotia, as well as details about our monthly schedule of support groups, educational workshops and presentations. You can also sign up for our bi-annual newsletter and follow us on Facebook.

We have listed our website and contact numbers at the bottom of each page. If you do not have access to the internet or would prefer to speak to someone in person, please call us. We are here to help.

About this Book

As you read the Caregiver's Handbook, you will notice quotations in boxes like this one. These quotations are from caregivers who participated in the Healthy Balance Research Program and those currently supported by Caregivers Nova Scotia.

In some parts of the book, we refer to information from different publications. When you see a number at the end of a sentence, it means the information in that sentence is from the publication with the same number found in the 'References' section at the end of this book.

Several pages provide space for you to reflect on and write about different aspects of caregiving based on your experience. You may find it helpful to do this as you read through, or you may wish to come back to these pages at a later time. This resource is for you, and there is no right or wrong way to use it.

As with any printed publication, some information may become out of date or new information may become available. We encourage you to visit our website or to contact us directly if you have questions about any of the tools, services or organizations included in this Handbook. This will ensure you get the most current information possible. It will also help us to understand your needs and refer you to the right support.

If you are not a caregiver, we hope that *The Caregiver's Handbook* will encourage you to reflect on some of the topics it addresses. We hope this resource helps you to think about the care you may both need and provide, now or in the future, and the ways in which caregiving makes our communities stronger.

Caregivers in Nova Scotia

There are many different kinds of caregivers, and people may define what a caregiver is in different ways.

Caregivers Nova Scotia defines caregiver as a person who gives unpaid care to someone who has a physical or mental health condition, a chronic illness, or who is frail or elderly.

A caregiver may give care to someone at home or in a facility. Some examples of caregivers include adult children who look after parents with a chronic disease, parents who care for children with disabilities, spouses looking after one another, teenagers who help parents after a stroke, and friends or neighbours who take someone to appointments, help with household chores or preparing meals.

We feel strongly that the efforts and commitment of paid care providers such as nurses, physicians, continuing care assistants, physiotherapists, and others should be recognized: their work supports unpaid caregivers and their care recipients in vitally important ways. However, this Handbook is designed especially for family and friends giving unpaid care in Nova Scotia.

Who is a Caregiver?

Thirty-one percent (31%) of Nova Scotians – roughly 290,000 people in this province – give some form of unpaid care to another person with a long-term condition or temporary illness. This is compared to 28% nationally.¹ Nova Scotians, like the rest of Canadians, are living longer and the age of its population continues to rise as baby boomers move into their senior years. This points to a greater need for assistance and care related to aging and other conditions.² It also suggests that the work unpaid caregivers do, and the need to support them, is more critical than ever.

Caregivers live in both rural and urban areas. They include people of diverse racial, cultural, and linguistic backgrounds, different sexual orientations, and persons with disabilities.

Although the number of male caregivers is increasing, in general the number of women in caregiving roles continues to be higher. This difference has been attributed to the type and intensity of the care that women provide.³

Who Is a Care Recipient?

Caregivers in Nova Scotia and across Canada give care to immediate and extended family members, friends, neighbours, co-workers, and others in their communities. Although most caregivers care for an elderly person, many care for children or dependent adults.

Some care for more than one person, and many people receive care from more than one caregiver. Caregivers may care for someone who lives with them or in a long-term care or assisted living facility. But most care for someone who lives in a place of their own.⁴

Young Caregivers

There are many young people who look after parents, siblings, or friends in Nova Scotia due to a chronic illness, disability, or mental health condition. They are an important and growing population of caregivers who need information, recognition, and support just as all caregivers do. Unfortunately, young caregivers are often reluctant to self-identify and therefore remain invisible. As well, many of the existing supports and services in Nova Scotia cannot always address their unique needs.

However, there are health organizations that have online forums and chat communities where young caregivers can connect with others in similar situations. Some have trained caregiver volunteers who can provide one-on-one support over the phone. Details about these organizations can be found in the ‘Information and Support’ section of this Handbook.

When we say ‘young caregivers’ we mean individuals under 19 years of age. Other organizations may define ‘young person’ differently,

for example as under 18, or under 21. Caregivers Nova Scotia is here to help young caregivers in any way we can, no matter their age. Young caregivers are always welcome at any of our support groups and are encouraged to contact us.

What Do Caregivers Do?

Every caregiving situation is different, but most caregivers in Nova Scotia are helping out in at least one of the following areas:

- **Personal Care:** bathing, dressing, lifting and transferring, administering medications
- **Help Around the House:** housecleaning, laundry, meal preparation, yard/outdoor work
- **Transportation and Shopping:** accompanying care recipient to appointments, shopping
- **Coordinating Care:** finding out about available services, arranging appointments and services, negotiating and advocating for the care recipient
- **Psycho-social Support:** checking in by phone, in-person visits (daily, weekly)
- **Financial and Legal Affairs:** banking, taking care of legal documents, income taxes

Caregivers are the invisible backbone of the healthcare system.

Caregivers are indispensable to the lives of the people they care for, and caregivers contribute to society in many other ways.

Financially, caregivers in Canada are estimated to save the healthcare system as much as \$66 billion a year.⁵ In their communities, caregivers do many things in addition to their caregiving tasks. Many are raising children, working in paid employment, volunteering in their community – or all three. In other words, caregivers are a vital part of our society. By supporting them, we can all contribute to stronger and healthier communities.

When Your Caregiving Journey Begins

Many Nova Scotians become caregivers overnight when a friend or family member suddenly becomes ill or is injured. Others take on more and more caregiving tasks gradually as their care recipient's health declines or when other caregivers need a break. Regardless of how it happens, when the need for caregiving arises, there are many things to think about.

Do You Want to Be a Caregiver?

For some of us, there is no time to think about this question. Many people feel that they don't have other options and some feel obliged to provide care.

She said "Can I live with you?", and I said yes. Even though that wasn't what I was prepared for ... I think she asked me because deep down she knew I would say yes and not ... see her go into a hospital or nursing home.

It is important, however, to recognize and respect that every individual should have the right to choose to become a caregiver or not, and how involved they want to be. Taking on the role of caregiver will affect all aspects of your life, so it is important to be as prepared as possible.

Caregiving has kept me connected in a close way with my husband. I see firsthand what he has to deal with ... his appreciation for the smallest of things I do for him always seems to strengthen our love for each other.

Exercise: Consider the Effects of Caregiving

Take a moment to ask yourself how caregiving might affect:

1. My relationship with the person receiving care?

2. My relationship(s) with my partner, my children, my parents, my other family members, and my friends?

3. My health?

4. My career and my job?

5. My social life and leisure activities?

6. My finances?

7. My future?

Exercise: What Role Will You Play?

There are many different caregiving relationships (spousal, parents to children, older or younger children to parents, extended family, or friends). The caregiving experience will be different for everyone. It's important to understand what being a caregiver will mean for you, what you want to do, and what you are able to do.

If possible, it is worthwhile to set boundaries and clarify expectations at the beginning of your caregiving journey, as it can be much harder to do so when you're already deeply involved and committed.

These questions will help you define your own role:

- Do I want to be a caregiver?

How much care do I want to provide?

- How involved would I like to be in decisions about care?

What does the care recipient want and need?

- What type of care do I want to provide?

What are my skills and resources?

- What types of tasks am I comfortable with and able to do?

What types of tasks am I not comfortable with or unable to do?

- Are there other people who can assist with care, give me a break, and support me in my work? Who are they, and how can they help?

- I live in a different town or province. Can I be a long-distance caregiver? What kind of support can I give?

- How will I feel about myself if I choose to be a caregiver?
How will I feel about myself if I choose not to be a caregiver?

Communicating with Family, Friends, And Healthcare Providers

Now that you have thought about your role as a caregiver, it will be helpful to discuss your ideas and your feelings with family, friends, and others. No matter how long you have been a caregiver, it is important to share your thoughts with those around you so they understand what caregiving means to you.

You might want to bring your family together for coffee, chat with friends over the phone, or consider organizing a meeting of everyone who is helping you.

It may be helpful to think about the following questions before your meeting:⁶

- My care recipient's wishes about their care are important. How do I involve them in these decisions?
- What are your biggest concerns and priorities as you help put together a caregiving plan for someone else?
- How do you think your care recipient and others might react to the conversation?
- How can you explain to your loved one and others why it is important to have this conversation?

You do not have to answer every question in one meeting. The important thing is to start the conversation – and continue it over time – in a way that works for you and your family or wider circle of support. This may also help others see how they can contribute to the care and support you need.

For more information on how to start the conversation with friends and family about care, please contact us.

Healthcare Providers

As a caregiver, you may be unsure how to communicate with your healthcare provider about your role in your care recipient's life.

The skills required to assist your care recipient can be complex, such as administering medications, or lifting and transferring. Your healthcare provider may be the best person to speak to if you have questions or need advice.

It may be helpful to prepare a list of questions, a completed schedule of daily activities, or a 'To Do' List (templates are provided on the following pages) to bring to a future appointment. This will aid the healthcare provider in understanding the nature and extent of the care you give and what your needs as a caregiver are.

Continuing Care

Continuing Care is a branch of the Nova Scotia Department of Health and Wellness. It is responsible for developing programs and services that assist caregivers and their care recipients such as Home Care, the Caregiver Benefit, and Supportive Care, among many others. The Department of Health and Wellness distributes funds to each District Health Authority (DHA), which is responsible for administering and delivering these programs.

Programs and services can only be accessed by calling Continuing Care's toll-free number: 1-800-225-7225. After you select the appropriate menu options, you will be put through to an Intake Worker who will collect basic information about you and your care recipient. This information will be passed on to a Care Coordinator who will call you back and arrange to meet with you. During this meeting you will be assessed regarding your care recipient's and your needs, and the Care Coordinator will talk to you about the outcome of the assessment and what services can be provided. If you are in agreement, services will be set up.

The toll-free number operates every day including weekends, from 8:30 a.m. to 4:30 p.m. If you cannot speak with someone immediately, it is important to leave a message and to follow up in a few days if necessary.

Getting Organized

Most caregivers are trying to balance their caregiving with other responsibilities at work, at home, and in other areas of their life.

... so I ended up doing the cooking, the cleaning, maintaining the finances, doing taxes, the driving, buying the groceries, cooking the meals, doing the yard work, cleaning the basement, mowing the lawn ... plus going to school. I mean at that time I was in high school.

In this section, you will find checklists, plans, and charts – all tools that we hope will help you to get organized and create some time for yourself. Blank copies of the charts, plans, and exercises can be downloaded from our website:

www.CaregiversNS.org/Resources/Handbook

We offer educational workshops such as: *Caregiver Stress Management*, *Safe Medicines for Seniors and Caregivers*, *Advanced Care Planning for Caregivers: Getting Started* and *Brushing Up on Mouth Care*. Other workshops and resources are also in development.

The tools on the following pages are intended to help you in practical and meaningful ways to care for your family member or friend, and for yourself.

Partners In Care Checklist

Step 1 – What are your needs and those of your care recipient? Take an inventory of your skills and the resources available to you both. Are there things that others could do to help you in your role as caregiver or to give you a break from caregiving? What is your care recipient able to do for him/herself?

| ACTIVITIES | WHO CAN HELP? | WHEN / HOW OFTEN? |
|--|---------------|-------------------|
| PERSONAL CARE | | |
| Bathing | | |
| | | |
| Dressing | | |
| | | |
| Eating/feeding | | |
| | | |
| Foot care | | |
| | | |
| Mouth care | | |
| | | |
| Toileting | | |
| | | |
| Lifting/transferring | | |
| | | |
| HELP AROUND THE HOUSE | | |
| Light housekeeping (sweeping/dusting/ meal clean-up) | | |
| | | |
| | | |

| ACTIVITIES | WHO CAN HELP? | WHEN / HOW OFTEN? |
|-------------------------------------|---------------|-------------------|
| Cleaning bathroom and floors | | |
| | | |
| Laundry | | |
| | | |
| Meal planning | | |
| | | |
| Meal preparation | | |
| | | |
| Yard/outdoor work | | |
| | | |
| Care for pets, plants | | |
| | | |
| Check mail | | |
| | | |
| Sort recycling/ Waste disposal | | |
| | | |
| TRANSPORTATION / SHOPPING | | |
| Accompany to appointments | | |
| | | |
| Activities / Social appointments | | |
| | | |
| | | |

| ACTIVITIES | WHO CAN HELP? | WHEN / HOW OFTEN? |
|---|----------------------|--------------------------|
| Take shopping | | |
| Fill prescriptions | | |
| Car maintenance | | |
| Coordinating care | | |
| COORDINATE HOME / HEALTHCARE WORKERS | | |
| Find out about available services | | |
| Arrange appointments | | |
| PSYCHO-SOCIAL SUPPORT | | |
| Check-in by phone | | |
| In-person visits | | |
| Leisure activities | | |
| FINANCIAL / LEGAL AFFAIRS | | |
| Banking, pay bills | | |
| Legal documents | | |
| Income taxes | | |
| NOTES | | |
| | | |
| | | |
| | | |

Step 2 – Once you have developed a list of needs, skills, and resources, you can create a schedule of daily care activities that need to be done and who can help throughout the week.

Schedule of Daily Care Activities

Sunday

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

Medications

If keeping track of medications is one of your caregiving tasks, a medication chart can help. It can serve as a record of all medications taken and as a reminder to take medications on schedule. It is particularly useful for emergency personnel, respite workers, home care workers, or other friends and family who may help you.

A few tips:

- Keep the record up to date with both prescription and non-prescription medications.
- Take the record to all doctors' appointments, emergency department visits, and to the pharmacy each time you pick up a prescription.
- Use only one family doctor and one pharmacy. It will be easier to keep track of your medication and identify any potential risks or harmful drug interactions.
- Ask the pharmacist to set up a blister pack system for you and your care recipient.
- Ask the pharmacist to review each medication with you so you understand when and how to take them, and potential interactions.
- Use the Vial of Life to keep important medication information in your refrigerator. This is essential information for first responders in a life-saving situation (see page 72 for details).
- Find out about the Basic Medication Review Service (BMRS). A medication review takes approximately 20 to 30 minutes to complete and is an insured service under all Pharmacare Programs, except the Under 65 – LTC Program. All other patients may receive this service for a fee. For more information, speak to your pharmacist or visit:
www.pans.ns.ca/manage-my-meds

You can also attend our *Safe Medicines for Seniors and Caregivers* workshop. Please call us for details.

MEDICATION CHART for: _____ DATE: _____

| Name of Medication and Strength | Dosage | When to Take Dose | How to Take Dose | Reason for Taking Medication |
|---------------------------------|--|------------------------|------------------------------------|------------------------------|
| EXAMPLE: Tylenol 200mg | Example: Number of tablets, teaspoons, puffs | 12 p.m., or before bed | With food, or one drop in each eye | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

Family doctor's name and telephone number: _____

Name of pharmacy and telephone number: _____

Notes: _____

Meal Planning

Deciding what to cook can be a daily hassle. For caregivers, it can be even more stressful when combined with other responsibilities. There are many things to think about. Is it healthy? Does anyone have allergies or other dietary restrictions? Do I have the ingredients? How much time do I have? Will there be leftovers?

You may find it helpful to plan meals for a week or more at a time. Here are a few tips to get you started:

1. Collect recipes that work for you and that you and your care recipient enjoy. Look for meals that use ingredients that are **easy to find**, are **affordable**, and are **easy to prepare** (such as slow cooker recipes).

Cooking Tips (from Canada's Food Guide):

- Cook with oils that are low in saturated fats (olive, canola, and soybean oil).
- Choose dark green and orange vegetables as often as possible (broccoli, romaine lettuce, carrots, and sweet potatoes, for example).
- Choose whole grain bread, oatmeal, or whole wheat pasta.
- Eat at least two servings of fish each week.
- Choose lean meats or meat alternatives such as beans, lentils, and tofu.
- Read the 'Nutrition Facts' labels and look for foods that have less fat, sugar, and sodium.

2. Complete the meal planning guide on the next page.
3. Make a grocery list based on the recipes you have chosen for the week.

MEAL PLANNING CHART for: _____
 Allergies/Dietary Restrictions: _____

Preferences: _____

| | Sunday | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday |
|------------------|--------|--------|---------|-----------|----------|--------|----------|
| Breakfast | | | | | | | |
| Snack | | | | | | | |
| Lunch | | | | | | | |
| Snack | | | | | | | |
| Dinner | | | | | | | |

The ‘To Do’ List

Have you ever had a friend or family member ask, “How can I help?” Sometimes people would like to help with caregiving but aren’t sure what they should do. If you have some ideas ahead of time, you can be prepared to take them up on their offer by making a list of tasks they can choose from.

It may be useful to include in your list all the things that you regularly do (or want to do) in a week, for example your employment, housework, caring for children or others, caregiving tasks, or time for yourself. Look over your list to see if there are things that a friend, neighbour, or family member could do for you or that a home care or respite worker might be able to help you with. Write all of these tasks on a separate list, and keep it in a visible place where people who want to help will see what needs to be done. Be sure to include a deadline, if appropriate, and any relevant details. Below are a few examples of activities on your ‘To Do’ list where others could lend a hand. There is a blank list for you to complete on the following page.

| Sample ‘To Do’ List | |
|--|------------------------------|
| Frequent tasks | Occasional tasks |
| Laundry | Car maintenance |
| Sweeping/vacuuming/dusting | Arrange for home maintenance |
| Yard work/snow shoveling | Pay bills and taxes |
| Shopping for groceries | Social activities |
| Cooking and cleaning up after meals | |
| Visit with care recipient | |
| Arrange appointments | |
| Accompany care recipient to appointments | |
| Look into resources or services needed | |

Discharge Planning

There are a number of healthcare professionals who provide support to people who are getting ready to be discharged from hospital. Depending on the hospital or healthcare setting, this may be an administrator, social worker, doctor, nurse, or a patient advocate. If you ask for the ‘Discharge Planner’, you should get to the right person.

Your care recipient, or you as the caregiver, can give the discharge planner important information about your daily activities. Tell them what you and your caregiver can and can’t do, and make your wishes known. Discharge planners often provide information and referrals to other services such as home care, home oxygen, in-home meals programs, or the Victorian Order of Nurses (VON).

It may also be helpful to complete a Discharge Planning Checklist and go over it with the Discharge Planner and your care recipient to ensure the transition is as smooth as possible. You can download a Discharge Planning Checklist from our website at:
www.CaregiversNS.org/Resources

Health Crisis Planning and Personal Emergency Preparedness

A crisis can happen with little or no warning, so it is important that you and your care recipient have a plan and are prepared. Preparing ahead of time for a crisis or emergency situation will help to ease the stress knowing that you will both be safe and supported.

Think about the situations below and whether you have a plan in place should any of them occur:

- There is a sudden deterioration in your care recipient's condition
- You are suddenly unable to provide care (temporarily or permanently)
- Your care recipient wanders away or gets lost
- There is a prolonged power outage (more than 24 hours)
- You or your care recipient must evacuate your home (due to fire or flood)

How do I plan for a health crisis?

There may come a time when your care recipient is unable to express their wishes or you are unable to continue giving care either temporarily or permanently. Preparing legal documents such as a Personal Directive or Enduring Power of Attorney will ensure that future healthcare and financial decisions are carried out according to your or your care recipient's wishes. These documents are explained in more detail in the 'Legal Issues' section of this Handbook.

How do I prepare for an emergency?

If there is a disaster in your area that will affect transportation, power, or other basic essentials, the Canadian Red Cross offers clear, helpful advice on what vulnerable persons and their caregivers can do to stay safe. Both the Red Cross and the Government of Canada's 'Get Prepared' campaign recommend putting together an emergency preparedness kit that allows you to be self-sufficient for 72 hours. The kit contains basic supplies that will help you to get by if you are without power or tap water, including bottled water, canned or

dried food that won't spoil, crank or battery-powered flashlight and radio, and special needs items such as medications or equipment for people with disabilities. For more information:

Canadian Red Cross:
1-877-356-3226 | www.redcross.ca/ready

Government of Canada:
www.getprepared.gc.ca

Emergency Health Services (EHS) Special Patient Program (SPP)

The EHS SPP was developed to maintain the quality of life for people with rare conditions, unique care needs, or those who are receiving palliative care. The program ensures that paramedics know about the patient's special needs—so when EHS is called to help, paramedics will have quick access to the information they need about you or your loved one. Paramedic care follows the clinical policies developed by the Provincial Medical Director of EHS. In some cases, patients may need special care that is not included in EHS practice. The SPP allows you and your health care provider to create an EHS care plan that is right for you. Your health care provider will send your SPP request to EHS.

Depending on the patient's condition, the paramedics may be able to provide care at home, rather than transporting the patient to the Emergency Department. Emergency Department transports can be distressing for patients and families.

To learn more visit:
<https://novascotia.ca/dhw/ehs/palliative-care.asp>

Helping When You Are a Long-Distance Caregiver

My mom lives a distance from me, and lives alone. I go every couple of weeks and stay five or more days. As she ages and needs more care, I really see the need for someone to be with her more. My own mental and physical health prevent me from doing so. I feel so very guilty not being able to do that for her.

Many caregivers face the added challenge of living a distance away from their care recipient. The demands of work and personal family life may mean you're unable to move closer to the person you care for. Living just an hour away can add to feelings of guilt and anxiety, especially as you may be unable to respond to an emergency or regularly assist with daily personal care or household tasks.

However, there are valuable ways you can support your care recipient when you are far away. A few of these are listed below:⁷

- **Schedule regular communication.** A daily phone or video call, or text message, can let your friend or relative know that they're not forgotten and give you peace of mind.
- **Suggest setting up a personal alarm or personal alert service.** The person you care for could wear a personal help button (around their arm or neck). When they press the button, help is called based on their pre-arranged instructions. See pages 68 and 72 for more information on personal alert services and other assistive devices and technologies.
- **Help manage medical and other appointments.** Try to schedule appointments when you'll be in the area, to coincide with those your care recipient already has. Make time to get to know your care recipient's doctors and arrange to be kept up-to-date on all medical issues if possible.

- **Investigate local services.** Discuss with your care recipient what services may be needed. They may already be aware of local options for home healthcare, meal delivery, or transportation. Ask what you can do to assist them in setting these up.
- **Virtual Care Technology:** Some health care providers can include family members who live a great distance away in the patient's visits using virtual care technology. Ask your care recipient's health care providers if this is possible.

Caring for Someone with Responsive or Challenging Behaviour

Challenging or responsive behaviour is often seen in people with brain conditions that affect communication, such as autism or Autism Spectrum Disorder (ASD), Alzheimer's, or other forms of dementia.

The terms 'responsive' and 'challenging' are sometimes used interchangeably to describe behaviour in Alzheimer's Disease and other dementias, as well as in autism or ASDs.

However, 'responsive behaviour' is preferred for persons with dementia. It represents how their actions, words, and gestures are a response that expresses something important related to their personal, social, or physical environment. Their behaviour is the result of changes in the brain that affect memory, judgment, orientation, mood, and behaviour.⁸

Behaviour that we think is strange, unusual or upsetting is often the person's way of coping with a world that is real to him or her.

- Virginia Bell & David Troxel

Autism is described as a neurological disorder and refers to a category of behavioural and developmental issues and challenges. A person with autism may have problems with communication, social skills, motor coordination or attention, or have physical health issues.

In these and other conditions, remember that behaviour has meaning and it is important to try to understand what triggers it. For example, difficulty in processing information, a sudden change in routine, changes in memory function, or feeling tired or hungry can all lead to anxiety or frustration which can trigger a responsive or challenging behaviour.

For many caregivers this behaviour can be upsetting and difficult. However, by learning to understand the meaning and causes

behind the actions, it can be easier to stay calm and manage challenges when they arise.

Below are a few examples of challenging behaviour, their possible causes, and a few tips that may help you to manage them. However, please remember this information is for guidance only. Your care recipient may or may not exhibit the behaviour mentioned, and the triggers may vary from those listed here. Responsive or challenging behaviour may be seen in individuals who have other types of dementia, Autism Spectrum Disorders, or other mental or physical health conditions not covered here. In addition, the most appropriate interventions for your care recipient and you may also be different from those suggested below.

Responsive Behaviour in Alzheimer's Disease⁸

Agitation

Possible causes:

- Environmental (changes to living arrangements, or changes in caregivers or care providers)
- Feeling overwhelmed or confused
- Fear of bathing, unknown surroundings, or having clothes changed
- Feeling hungry, thirsty, or uncomfortable

Tips that may help:

- Redirect person's attention; remain calm and positive.
- Simplify tasks and routines.
- Give options when possible, but only one or two choices to avoid overwhelming.

Wandering

Possible causes:

- Inability to recognize people, places, or objects
- Stress and anxiety
- Desire to fulfill former obligations
- The need to find the bathroom, a special person or a lost object

Tips that may help:

- Encourage movement and exercise to reduce anxiety.
- Remove visual reminders (coat, purse) from sight.
- Help them connect with familiar things (photos, personal items).

Challenging Behaviour in Autism⁹

- Biting, Kicking, Bolting/Wandering, Repetitive Behaviour (hand-flapping or focusing on subjects of special interest)

Possible causes:

- Frustration at not being able to communicate
- Sensory sensitivities to noise, smells, touch, sight
- Lack of structure or changes in routine

General tips that may help:¹⁰

- Be consistent. Creating consistency can help to reinforce learning. Find out what your child's therapists are doing and use these techniques at home.
- Stick to a routine. Create a schedule for your child with regular times for meals, therapy, and bedtime. If you need to change the routine, warn your child in advance.
- Reward good behaviour. Praise your child and be very specific about the behaviour they are being praised for.

Support

The Alzheimer Society of Nova Scotia or Autism Nova Scotia can provide additional resources and support, and we encourage you to contact them (see page 74 for details). Healthcare professionals who have training in understanding challenging or responsive behaviour may also be able to help. Your family doctor can make a referral to a geriatrician, geriatric psychiatrist, or a neurologist. Early intervention services, special education teachers, speech-language pathologists, or child and adolescent mental health specialists can help if you care for someone with autism.

Remember that as a caregiver you are an essential partner in your care recipient's health and well-being. It is important that you work with healthcare and other professionals to find the tools or interventions that work best for your care recipient and you.

Mentally?

Socially?

Spiritually?

Do you feel healthy? What things in your life help to improve your health? What things in your life affect your health negatively?

For many caregivers, the most challenging thing about achieving and maintaining good health is finding balance, especially when they are faced with so many competing demands.

**I feel like I'm a teacher, I'm a daughter, I'm a wife,
I'm a psychologist ... I'm everything.**

Here are a few tips that might help you find a healthy balance.

Managing Stress

We all feel stressed from time to time. In fact, small amounts of stress are beneficial as they may help us to stay alert and focused. Long or intense periods of stress, however, can be extremely hard on your physical and mental health. The Canadian Mental Health Association recommends that everyone take some time to: **think about the level and causes of their stress, talk about it, reduce tension, and prevent future stress.**

For caregivers, these steps are especially important to help prevent 'caregiver burnout'.

Step 1: Check In On Your Stress Level

This quiz may help you to reflect on how you're feeling and to think about the level of stress in your life.

| | Never | Sometimes | Often | Almost Always |
|--|-------|-----------|-------|---------------|
| I find it difficult to balance work, family, and caregiving responsibilities | 0 | 1 | 2 | 3 |
| I have conflicts with my friends, family members, or care recipient | 0 | 1 | 2 | 3 |
| I worry that I am not doing a good job as a caregiver | 0 | 1 | 2 | 3 |
| I feel guilty | 0 | 1 | 2 | 3 |
| I feel anxious | 0 | 1 | 2 | 3 |
| I feel sad and cry periodically | 0 | 1 | 2 | 3 |
| I have problems with sleep | 0 | 1 | 2 | 3 |
| I experience chronic neck or back pain | 0 | 1 | 2 | 3 |
| I have tension headaches | 0 | 1 | 2 | 3 |

Your Score

- 0 - 10 You are probably managing well. Remember that it's still important to think about ways of preventing stress from building up.
- 11 - 15 You may need to seek out some additional support. Try to identify the things that are causing you stress – you may not be able to change all of them, but there may be areas where you can ask for help or make changes to relieve some of your stress.
- 16 -19 You may be experiencing caregiver distress and your responsibilities may already be taking a toll on your physical and emotional well-being. It is important that you talk to your doctor or healthcare professional, a family member, friend, or join a support group to help reduce your level of distress.
- 20 + You may be experiencing caregiver burnout. To protect your physical and mental health, it is important that you talk to your family doctor or healthcare professional today about your stress. You may also want to talk with family or friends, or join a support group.

This quiz and its scoring are meant as a guide to help you reflect on the stress in your life and how you are managing it. It should not be used in place of advice from your doctor or healthcare professional.

Also, keep in mind that your score will change depending on when you take this quiz and where you are in your caregiving journey. If you took this quiz on three different days, you might have three very different scores. Please check back from time to time to see how you are doing.

This quiz was downloaded from www.von.ca and adapted for this Handbook.

Step 2: Figure Out What Causes You Stress

Stressors can range from major life events like changing jobs or the death of a loved one, to long-term worries about your finances or health, to daily hassles like traffic jams or household chores. It may help you to think of the things in your own life that are contributing to your stress level.

Below is a list of things that commonly cause stress:

- Increase in responsibility: caregiving, work or employment
- Changes in your family: marriage, new baby, separation, divorce
- Loss of a partner, family member, or friend
- Personal conflict: with a partner, family members, friends, co-workers, boss, healthcare providers
- Financial concerns: making ends meet, paying debts, planning for the future
- Change in environment: new school, job, community
- Changes in sexual activity: a new partner, lack of desire, sexual health concerns
- Health and physiological changes: injury, illness, pregnancy, menopause
- Drug use, alcoholism, self-harm

There is space for you to write about the stressors in your life on the following page.

What are some of the stressors in your life?

1. _____
2. _____
3. _____
4. _____
5. _____

Step 3. Talk About It

I have several girlfriends who provide a lot of emotional support for me... they, like the Caregivers' support group sessions, allow me the freedom to express my feelings of anger, resentment, guilt – and to share some of the more humorous aspects of our daily lives.

Friends and family members are often the first people to turn to for support. If there is someone in your life who you think would listen and be supportive, start by calling them or inviting them over for a visit.

Support groups can help you relieve stress, find resources, and reduce feelings of isolation by sharing experiences and information with others. To find an active support group in your area, contact Caregivers Nova Scotia or go to the 'How We Help' section of our website. You can also contact us to find out about our next *Caregiver Stress Management* workshop.

Your family doctor is another person who may be able to help. Tell the doctor about your feelings and ask for advice. You may be referred to a counselor or psychologist.

Your spiritual advisor may also be able to provide counseling, guidance, or advice during times of need.

Step 4: Reduce Tension

Physical activity is a great way to reduce stress, and there is a wealth of medical evidence to support its overall health benefits. Whether you take walks, garden, play a sport, or perform simple stretches, daily physical activity can help to lower blood pressure, strengthen bones, and improve balance, among other things.

Take breaks. Short breaks can be a good way to ease tension, and give you a chance to relax and recharge. You can be creative with what you do depending on the time you have. Here are some suggestions:*

10 minutes

- Make a cup of tea or coffee
- Write in a journal
- Use social media to connect to other caregivers online

15-30 minutes

- Call a friend
- Knit
- Go for a short walk or run
- Follow a guided relaxation exercise

And remember to **laugh**.

He who laughs, lasts!
- Mary Pettibone Poole

On the following page we have included a 15-minute guided relaxation exercise for you to try. This and other relaxation exercises may help you to better cope, and offer a good reason to take a few minutes for yourself each day.

*Adapted from: *Creative Ways to Take Caregiving Breaks*.
www.saintelizabeth.com

Guided Relaxation Exercise

If possible, set aside 15 minutes each day when you are not likely to be interrupted to do this guided relaxation exercise.

Find a place where you feel most comfortable. This could be the bedroom, your favourite chair, or the backyard. Sit comfortably or lay down on your back with your arms resting at your side.

Take a deep breath and exhale slowly. Breathe in through your nose for a slow count of seven, hold your breath for a moment, and breathe out through your mouth for a slow count of seven. Repeat this several times, as you focus only on your breath as it fills your lungs and expands your chest.

As you breathe, focus on the parts of your body where you hold tension. As you inhale, imagine that your breath moves to that area of tension. As you exhale, the tension flows out of your body with your breath. You may want to start by focusing attention on your toes and then working your way up to your knees, legs, lower back, chest, arms, neck, face...breathe in slowly through your nose, and exhale through your mouth as you release the tension in each of these areas.

Now take a moment to scan your body. Repeat the tense and relax exercise a few times for any areas that still feel tense.

Take a few more minutes to breathe in through your nose for a slow count of seven, hold your breath, and breathe out through your mouth for a slow count of seven.

To learn more about guided relaxation or to find additional exercises, try searching the internet by typing 'guided relaxation' into your web browser. There are many websites with a variety of video and audio options available. You can also check your local library or bookstore.

Step 5: Prevent Stress

Keep up with the above activities even when you're feeling less stressed. This will help to prevent stress from building up again. A few other things you can do to prevent stress are:

Educate yourself – about your care recipient's condition and about tasks you may need to carry out. This will help you feel better prepared and less anxious in your role as caregiver.

Make decisions – avoiding decisions causes worry and stress.

Avoid putting things off – make a weekly schedule that includes leisure activities and time for yourself whenever possible.

Delegate – get others to do tasks so that you are not trying to do everything by yourself.

Make your own health a priority – part of being a caregiver means caring for yourself.

For more information on managing stress or other aspects of your mental health, contact:

The Mental Health Association of Nova Scotia

Toll-free: 1 866 227 4642 | www.mentalhealthns.ca

Mental Health Mobile Crisis Team

Toll-free: 1-888-429-8167

Caregivers Nova Scotia

You can speak to one of our Support Coordinators about attending a support group in your area and to find out when our next *Caregiver Stress Management* workshop is offered.

Acknowledging Your Feelings

Guilt, anger, frustration, and grief are all emotions that caregivers may experience, especially if there have been recent changes with your care recipient, or changes at work, with money, in the home, or in other aspects of your life.

It's important to acknowledge your feelings and remember that you're not alone. Keep in mind that approximately one-third of Nova Scotians are caregivers and many of them have the same feelings you do. Try to express your anger in helpful ways, grieve when you need to, and celebrate the happy moments too.

If negative feelings become overwhelming, or you feel depressed or anxious, talk to your doctor, counselor, or another healthcare professional.

Strive for balance, not perfection

Try to set realistic goals. Know your limits and say “no” to taking on more than you can handle.

If you do find yourself with too much to do, ask for help. Asking for and accepting help are important skills, and it is not always easy to do either.

How to Ask

Ask for help with specific tasks. Use the ‘To Do’ List discussed on pages 24 and 25 to give people suggestions about what they can do to support you. Many people are eager to help but are not sure what they can do, so the more specific you are the better.

Take time for yourself

Although this is easier said than done, it is also very important. In the short-term, even a 15-minute break can help you feel refreshed and energized. For more ideas on short breaks, see page 41.



In the long term, take advantage of respite care if possible. You can ask close friends and family members to stay with your care recipient and give you a break. Or you can contact an organization which may provide a few hours of in-home support or provide several days or weeks of facility-based respite care so that you can take a vacation. Try to use respite time to do something for yourself instead of running more errands. Visit with a friend, join a fitness class, or start a new hobby.

Try to organize respite care in advance, so it is there when you need it. This may be challenging depending on demand where you live and on what services are available. Planning in advance will also give your care recipient time to get used to someone else helping out.

For more information on what organizations provide respite care (both public and private), see pages 64 and 65.

Where to Turn

You never know where you'll find help when you need it. Start by browsing through this Handbook. The sections titled 'Services in Nova Scotia' and 'Information and Support' might give you some ideas. You can also contact us.

Turn to family members, friends, neighbours, a local community group, religious organization, or your spiritual advisor.

Find out if your employer offers an Employee Assistance Program (EAP). An EAP can provide you with access to a qualified counseling professional who can help you resolve personal and work-related problems. EAP practitioners act as a link between employees who need assistance and the appropriate source of help. It is a confidential service, accessible to all employees and their dependents. Participation in an EAP is voluntary.

Healthy Eating, Exercise, and Sleep

The following recommendations from Canada's Guide to Healthy Eating and Physical Activity can help you to maintain both your physical and mental health.

Healthy Eating

We know that health is improved by:

- enjoying foods from each of the four food groups
- eating mainly grain products, vegetables, and fruits
- drinking skim, partly-skim, or reduced-fat milk
- baking, broiling, or microwaving food instead of frying it
- eating more peas, beans, and lentils
- snacking on chips and chocolate less often

Physical Activity

You can also improve your health by:

- getting 30-60 minutes of moderate physical activity each day (including things like gardening, housework, and walking)
- choosing a variety of activities
 - for your heart, lungs, and circulatory system (biking, swimming, dancing, brisk walking)
 - to keep your muscles relaxed and your joints mobile (Yoga, Tai Chi, simple stretches)
 - to strengthen muscles and bones and to improve posture (lifting small weights, Pilates)

This doesn't mean you need to work out at the gym for an hour each day. You can build your physical activity through the day in periods of at least 10 minutes each. As a caregiver, some of the activities you do are likely physically demanding. Although these do contribute to your daily physical activities, they may also be stressful. Try to balance these caregiving activities with less stressful types that will also give you a break.

Sleep

Sleep is very important. It allows your body to restore itself and prepare for the next day. When you don't get enough sleep, you might be edgy, less able to deal with stressful situations, and more prone to illness.

The reality is that many people, especially caregivers, do not get eight hours of sleep each night. As a caregiver, you may need to get up during the night to assist your care recipient or you may be anxious that something will happen when they get up on their own, all of which contribute to disturbed sleep.

Below are a few tips on how to improve the quality and quantity of sleep for caregivers:¹²

- Try to maintain a regular sleep-wake schedule.
- Try to take a few minutes every day for exercise and fresh air if possible.
- Try to identify, talk about, and find ways to address worries and concerns before bedtime to help clear the mind for sleep.
- Set up a bedtime routine that lets you unwind before you turn out the light.
- Cut down on caffeine (coffee, tea, chocolate, cola) and nicotine during the day, and especially before bedtime.
- Nap when you can, but try to avoid the late afternoon and evening unless you know you will be awake during the night for your care recipient.
- Minimize nighttime noise or light around you. Remove clocks also, unless you need to set an alarm.
- Have something warm to drink or eat before bed.

Legal Issues

This section offers a brief overview of some of the legal issues that are commonly faced by caregivers and care recipients. It is important to note that the laws are different in each province and territory. The information in this section applies specifically to Nova Scotia, and should not be taken as a substitute for speaking to a lawyer or other legal expert.

Most of the legal documents discussed in this section can be created using blank forms that are available at stationery or drug stores. However, it may be best to get advice from a professional.

In Nova Scotia, there are a few ways to get your legal questions answered, sometimes for little or no cost. We have highlighted the Legal Information Society of Nova Scotia (LISNS) below. They are not the only resource for legal help, but may be a good place to start to find the community legal resources you need in your area.

Finding Legal Information On the Internet or by Phone

The Legal Information Society of Nova Scotia (LISNS) is one place to turn to for help. Their website contains detailed information about each of the topics discussed in this section, and much more.

If you have a question about the law, you can call the Legal Information Line toll-free: 1-800-665-9779 or (902) 455-3135 in Halifax. This is a free service. A counselor will try to answer your question and tell you where to get help with legal problems. Please note: they cannot give legal advice.

Dial-a-Law provides legal information on a taped message service 24 hours a day at: (902) 420-1888. Use the keypad on your phone to select a topic and listen to a recording about a specific area of the law. This is a free service that may help to answer your questions about a particular legal concern. Some topics are also available in

audio format on their website: www.legalinfo.org. Their useful booklet *It's in Your Hands: Legal Information for Seniors and Their Families* is also available to download at: www.legalinfo.org/seniors

Finding a Lawyer

If you have additional questions or concerns about any of the topics in this section, it may be helpful for you to talk to a lawyer. Look for a lawyer who practices in areas like estates, wills, trusts, and elder law. Some lawyers may offer a free or low-rate introductory consultation.

Below are some suggestions on ways to find a lawyer:

- Look in your local phonebook or search online.
- A friend or family member may refer you to a lawyer.
- Your Employee Assistance Plan or union may offer help with finding a lawyer.
- You may qualify for a free 30 minute appointment with a lawyer through Access Legal Help NS, a pilot project of LISNS. To find out more, go to: www.legalinfo.org and click the 'Access Legal Help' logo.

The LISNS Lawyer Referral Service will give you the name and telephone number of a lawyer who will meet with you for 30 minutes for a fixed fee of \$20 plus tax. During this time, you can discuss your situation and get an idea of what your options are and what costs are involved.

Contact LISNS: (902) 455-3135 | Toll-free: 1-800-665-9779

reachAbility's Legal Referral Service connects persons with disabilities to a volunteer lawyer for a free one-hour consultation.

Contact reachAbility: (902) 429-5878 | Toll-free: 1-866-429-5878
www.reachability.org/legal/lrs

Power of Attorney

What is it?

A Power of Attorney is a legal document that allows you to name a person to make decisions on your behalf about money, assets, debts, and property. These decisions must be made for your benefit. You must be mentally competent (have legal capacity) to give someone Power of Attorney. However, even if you give someone Power of Attorney, *you can still make your own decisions until you become unable to do so.*

Decisions about medical care can also be part of a Power of Attorney or they may be set out separately in a Personal Directive, which is explained in more detail on page 52.

Why is it important?

By law, Nova Scotians aged 19 or older are assumed to be able to make their own decisions. However, an illness or accident can result in losing that ability, making it necessary for someone else to make decisions. This authority comes from you in a Power of Attorney.

How do I make one?

You can get a blank Power of Attorney form online or at stationery or drug stores. These documents are not expensive and may be appropriate in some situations. However, the safest way to make a Power of Attorney is with a lawyer. There are certain situations where you will need to get advice from a lawyer, such as if you own property like a house, a cottage, or a camp, or if you own property outside Nova Scotia. It is also very important to see a lawyer if there might be doubts raised about whether you had legal capacity and made your Power of Attorney voluntarily, by your own free choice.

Even if you write your own Power of Attorney, it is wise to review it with a lawyer.

What if I don't have one?

If you are not able to make decisions because of an illness or injury and you don't have a Power of Attorney, someone must go to court and ask to make decisions on your behalf. This is called **guardianship of the estate**. The person does not have to be a family member, and this court process is more time consuming and expensive than creating a Power of Attorney document by yourself or with a lawyer in advance.

Enduring Power of Attorney

An ordinary Power of Attorney gives another person the authority to make financial and legal decisions for you only while you are mentally competent. An Enduring Power of Attorney takes effect while you are mentally competent, and allows the person you have appointed to continue to make financial or legal decisions if you become mentally incapable.

Advance Care Planning

What is it?

Advance care planning involves thinking about what your preferences are for future health and personal care should you become unable to make decisions about care for yourself. It involves communicating these wishes to friends and family, either verbally or in writing.

Why is it important?

An advance care plan can involve creating a Personal Directive and choosing your Substitute Decision Maker or Delegate. A Delegate will have the legal authority to speak for you if you cannot speak for yourself due to illness or injury. You can write the plan down, or make an audio or video recording. It is also a good idea to provide a doctor with a copy of the plan if it is written; if not, the doctor can record your wishes for you in your medical record.

It may be difficult to have these conversations, but it will help to ease stress for you, your family, and friends knowing that the decisions made for you are what you want.

Personal Directive

What is it?

A Personal Directive allows an individual to specify how personal care decisions will be made, and who will make them, should that individual become incapable of making decisions for him or herself. In a Personal Directive, personal care decisions refer to healthcare, residence, and support services, not financial matters.

Why is it important?

A Personal Directive will give you or your care recipient greater control over future decisions about personal care and who you want to carry them out if you become incapable.

How do I make one?

You can get a Personal Directive at many stationery or drug stores. They are not expensive and may be useful in many situations. However, the safest way to make this document is with a lawyer. You should also talk with your family doctor about who will make your personal care decisions and how to guide them.

You can also find instructions on creating a Personal Directive and download sample forms at: www.novascotia.ca/just/pda

What if I don't have one?

If you don't have a Personal Directive, your nearest relative will often be involved in making medical decisions for you. This may or may not be ideal. Depending on the situation, someone may have to go to court and ask to make personal care decisions on your behalf. This is called **guardianship of the person**. The person does not have to be a family member, and this court process can be time consuming and expensive.

If you want to ensure a particular person, known as a Delegate, has the authority to speak on your behalf, you must name that person in a Personal Directive.

Will

What is it?

A Will spells out how you want to distribute your money and property after your death. You also name your Executor, the person who will carry out your instructions.

Why is it important?

If you are a caregiver, try to make sure your care recipient has an up-to-date Will. Often it is the caregiver who plays a major role in distributing the care recipient's assets after death. This is a difficult and time-consuming task made more complex by the stresses of long-term caregiving. Having a current Will makes the task easier.

How do I make one?

You can get a Will form at many stationery and drug stores. These are not expensive and are appropriate for some situations.

However, the safest way to make a Will is to hire a lawyer. In some cases, you are required to hire a lawyer to advise you through this process (for example, if you own property in a different province or country).

It is also very important to see a lawyer if there are any doubts raised about whether you had legal capacity and made your Will voluntarily, by your own free choice, without being pressured by anyone. Even if you write your own Will, it is wise to review it with a lawyer.

What if I don't have one?

If you don't have a Will, the rules of the province will be used to determine who your property goes to and under what conditions. This is called **disposal of property**. One of your family members will likely be the Administrator - the person who manages your estate if you don't have a Will. You might not agree with the rules or be unhappy with the idea of a certain family member managing your estate. Making a Will is the best way to ensure that your wishes will be respected.

Joint Ownership

When one person is the owner of property or money, that person determines how the property is used or how the money is spent. In the case of joint ownership, more than one person can make these decisions. The two most common forms of joint ownership for caregivers are jointly owning a bank account and jointly owning a home.

Joint bank account

Usually the person named as the owner of a bank account can deposit money and take money out. Exactly what an owner can do is spelled out in their agreement with the bank. Often spouses have a joint account. They both put money in, and they both take money out.

In many families, a parent may invite an adult child to become a joint bank account owner to help with banking in times of illness or if the parent has trouble getting to the bank. In these situations, it is usually only the parent who is putting money into the account and the child can take money out to pay the parent's bills.

Pros and cons

While it is convenient for a caregiver and care recipient to have a joint bank account, there may be pitfalls. Here are a few tips for you and your care recipient:

1. Talk with your bank or credit union. There may be alternatives to having a joint account that will still meet your needs.
2. The care recipient should have complete trust in someone before adding him or her as a joint owner of the care recipient's bank account, as that person will have the right to take out money and use it, even if the care recipient deposited all the money.
3. If you are a caregiver for your parent and you are one of several siblings, you should be aware that your actions are open to scrutiny by the other siblings. Anything you do with the money must be for the benefit of the care recipient.

4. Discuss what is to happen to any money left in the bank account if one of the joint owners dies. For example, if the care recipient dies and has been the only person putting money into the account, will the money go to the surviving owner or pass through the Will? It is best to make your intentions clear to the whole family and to put your intentions in writing.

Home

Owning a major asset such as a home is significant. Generally, the owner can borrow money against it or sell it. There can be more than one owner, but it is the surviving owner of the home who inherits the property.

Many couples own their home together in a special type of ownership called **joint with right of survivorship**. This means that the surviving spouse inherits the home automatically. The transfer of ownership requires less paperwork and is easy and cost effective.

Often a widowed parent will invite an adult child to become a joint owner of the home in which the parent lives. In some cases, there is an understanding that the caregiver will inherit the house in exchange for giving lifetime care to the parent. A care recipient should get legal advice about whether joint ownership of the home is the best option based on his or her goals.

Pros and Cons

In spite of being cost effective and easy, there are some reasons not to own a home jointly:

1. Each owner must sign all documents required to deal with the house. For example, to borrow money against the house or to sell it, the child must agree with the parent's wishes even though the parent may still consider the house to be his or her sole property.
2. The property becomes part of the child's financial affairs, so the home in which the parent lives could become part of a divorce or business bankruptcy of the child.

3. Anyone who owns more than one residence may have to pay extra income tax. If you own a home and are invited by your care recipient to become a joint owner, you should consult a taxation expert before agreeing.

Why is this important for caregivers?

If the goal of joint ownership of assets is to have the caregiver inherit the house, the bank account, or both, make sure this intention is clear to all family members and get legal advice.

Financial Matters

Caregiving can have a significant impact on an individual's financial well-being. For example, both men and women may experience care-related employment consequences such as absenteeism, working fewer hours for pay, or having to leave the labour force. Women (especially those caring for a disabled child), men caring for a spouse, those approaching retirement age, those in poorer health, and those spending more time performing care tasks are especially at risk.¹³

This section offers a brief overview of some of the programs and benefits that may ease the financial burden faced by some caregivers or their care recipients. All programs, benefits, and amounts are current at the time of writing and are subject to change.

Programs and Benefits offered through the Nova Scotia Department of Health and Wellness, Continuing Care Branch

The benefits provided through Continuing Care can help both caregivers and care recipients. A few of these are described below. As mentioned on page 13, each District Health Authority is responsible for implementing and delivering these programs. For this reason, you may find slight differences in what services are available in your area and how they are provided.

Home Care – Nova Scotians can receive nursing services such as dressing changes, catheter care, intravenous therapy, and palliative care and a range of personal care and home support services.

Caregiver Benefit – This program is targeted at low-income care recipients who have a high level of disability or impairment as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive the Caregiver Benefit of \$400 per month.

Supportive Care – This program supports eligible Nova Scotians with cognitive impairments (difficulty thinking, concentrating, remembering) by providing them with \$500 per month for Home Support Services (personal care, respite, meal preparation, household chores, and Adult Day Programs).

For more information on these and other programs and benefits or to set up an assessment, please contact Continuing Care:
Toll free: 1-800-225-7225 | www.novascotia.ca/dhw/ccs

You can also call us or visit our website.

Benefits Offered through Employment Insurance (EI)

Compassionate Care Benefit – Compassionate care benefits are Employment Insurance (EI) benefits paid to people who have to 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 within 26 weeks (six months). A maximum of 26 weeks of compassionate care benefits may be paid to eligible people.

Family Caregiver Benefit for Adults (EI) – allows eligible caregivers to receive up to 15 weeks of financial assistance to provide care or support to a critically ill or injured adult. Caregivers must be family members or someone who is considered to be like family by the person needing care or support.

Family Caregiver Benefit for Children (EI) – This benefit allows eligible caregivers to receive up to 35 weeks of financial assistance to provide care or support to a critically ill or injured child. Caregivers must be family members or someone who is considered to be like family to the child needing care or support.

For more information:

Toll-free: 1.800.206.7218 | www.canada.ca/en/services/benefits/ei

Federal Tax Credits

There are several credits or amounts you can claim on your income tax return to help ease the financial burden on you and your care recipient. Some of these are listed below:

Child Disability Benefit (CDB) – This is a tax-free benefit for families who care for a child under age 18 with a severe and prolonged impairment in physical or mental functions. The CDB is paid monthly to individuals who are eligible for the Canada Child Tax Benefit (CCTB).

Disability Tax Credit – This is a non-refundable tax credit that provides tax relief for individuals who have a severe and prolonged impairment in physical or mental function.

Canada Caregiver Credit (CCC) – If you support a spouse or common-law partner, or a dependent with a physical or mental impairment, the Canada Caregiver Credit (CCC) is a non-refundable tax credit that may be available to you. The CCC combines three previous credits: the caregiver credit, the family caregiver credit, and the credit for infirm dependents age 18 or older.

Medical Expenses Tax Credit – You can claim total eligible medical expenses for yourself, spouse or common-law partner, and your dependent children born in 1996 or later on Line 330 of your tax return.

For more information about these and other tax credits or benefits, contact Canada Revenue Agency:

Toll-free: 1-800-959-8281 | www.cra-arc.gc.ca

Property Tax Rebate for Seniors – Provides an annual rebate on municipal property taxes to help seniors remain at home. Eligible homeowners receive a 50% rebate (up to \$800) based on property taxes paid the previous year. The program is administered by Access Nova Scotia on behalf of the Department of Community Services.

Private Insurance Benefits

Critical Illness Insurance

Critical Illness Insurance pays a lump sum to you if you are diagnosed with a specific illness and survive. This money can help to pay for many things including medical expenses, home healthcare, home modifications, or other therapies or medications. You don't have to get approvals for these items or provide receipts. This type of insurance can benefit you or your care recipient.

For more information, ask your financial advisor or an insurance agent. You can also search the internet to find details of what specific providers offer. Some employers may also offer Critical Illness Insurance as an employee benefit.

Long-Term Care Insurance

The purpose of Long-term Care Insurance is to help pay the costs of care either in a nursing home or at home. It can give families options when choosing what type of care is needed or where that care will be provided.

For more information, ask your financial advisor or an insurance agent. You can also search the internet to find details of what specific providers offer. Some employers may also offer Long-Term Care Insurance as an employee benefit.

Services in Nova Scotia

There are many different services offered to caregivers and care recipients in Nova Scotia. This section offers a brief overview of existing services and their contact information to help you connect with the services you may need or want.

Some of the services listed in this section may be available for free or at a reduced cost depending on your family size or household income.

It's important to remember that navigating your way through the healthcare system and coordinating services for yourself or your care recipient is not easy. You may find yourself disappointed and frustrated with the inflexibility, inconvenience, and lack of availability of many services.

You'll notice from the quotations below that many of the existing services can be extremely helpful or present further challenges.

We found out about home care, and we've been getting that and it's been the greatest.

We have a whole list of [home care workers], oh my goodness... I don't like this idea and Arnold doesn't like it neither because every time we have a new one then we have to explain the whole thing all over again.

Government Services

Services offered by government agencies are often provided for no or low cost to the client. Below is a brief overview of some government agencies that offer services that may be useful for caregivers and care recipients.

Nova Scotia Department of Health and Wellness, Continuing Care Branch

The Continuing Care Branch of the Nova Scotia Department of Health and Wellness provides access to a range of services by distributing funds to each District Health Authority (DHA) in the province.

The DHAs are responsible for implementing and running the services, which include home care, long-term care, respite options, home oxygen, palliative care, self-managed care, and adult protection services.

You can visit the Department of Health and Wellness website for more information on Continuing Care Services. Helpful Fact Sheets which explain each of the benefits and services for which caregivers and care recipients may be eligible are available to download from: www.novascotia.ca/dhw/ccs/live-well-at-home.asp

Nova Scotia Department of Community Services

The Nova Scotia Department of Community Services has two main program areas that coordinate services that may be useful for caregivers:

- **Disability Support Program (DSP)** is a program that provides residential and day programs for adults with intellectual/physical disabilities or long-term mental illness. Residential services include a continuum of options ranging from support to families caring for a family member with a disability in their own home, to full 24-hour residential support.

For more information visit: www.novascotia.ca/coms/disabilities and click on **Disability Support Program**.

- **Housing Nova Scotia** offer programs to help lower-income households, and seniors and persons with disabilities to maintain, acquire, or rent safe, adequate and affordable housing. This Service also offers grants and loans for home repairs, adaptations, and additions.

For more information visit: www.housingns.ca

Nova Scotia Department of Seniors

The Department of Seniors recently partnered with Nova Scotia's 211 service to provide a single entry point that can respond to seniors' issues and concerns. It offers a toll-free information line that allows seniors, as well as concerned family members and friends, to get help in accessing information dealing with government services and programs.

The Department also provides important information and support on Senior Abuse. Their website, www.novascotia/seniors, has details about different community Senior Safety Programs. The section

called 'Understanding Senior Abuse' provides information on how to recognize physical, sexual, emotional, and financial abuse, as well as violations of human rights and neglect, what to do if you suspect abuse, and where to find help.

For information about programs and services available to Nova Scotia seniors: Toll-free: 2-1-1 | www.ns211.ca
Senior Abuse Information and Referral Line: 2-1-1

Veterans Affairs Canada

Veterans Independence Program (VIP) - This national home care program is offered by Veterans Affairs Canada. If you or the person you care for is a veteran, you may qualify for financial assistance to obtain services such as grounds maintenance, housekeeping, personal care services, nutrition services, and health and support services provided by a health professional.

Family Caregiver Relief Benefit (FCRB) - The new FCRB provides eligible veterans with a tax-free lump sum grant. This benefit ensures veterans continue to get the support they need when their family or friend caregivers are temporarily unavailable.

For more information:

Toll-free: 1-866-522-2122 (English) | 1-866-522-2022 (French)
www.vac-acc.gc.ca

Respite, Home Care, and Other Helpful Services

This section provides information on home care, respite and other services such as transportation, meals, and affordable housing options. We begin this section with Respite because, whether or not you have private or publicly funded home care, respite is essential to you as a caregiver and to your care recipient.

Respite can be defined as a reprieve, a short interval of rest, temporary relief, and as an interruption in the intensity of a caregiving activity. It can be a crisis intervention; but ideally, respite is part of a

network of services to support caregivers and their care recipients.¹⁴ Respite can be provided by a variety of people, such as family members, friends, volunteers, or healthcare workers. It can take different forms, such as a coffee with friends while your care recipient participates in an Adult Day Program, or while your child attends a class or activity with a volunteer or respite worker. It also allows care recipients to participate in activities outside their home, and learn new skills.

It can be provided in the home or in a care facility, for varying amounts of time from a few hours to several days or weeks. It is a good idea to try to arrange respite care as far in advance as possible, as it may take time to put the service in place depending on availability and demand in your area.

In Nova Scotia, the Department of Health and Wellness coordinates in-home respite and licensed respite beds in long-term care facilities across the province. Each DHA is responsible for contracting respite services through different agencies within their region. For more information call Continuing Care: 1-800-225-7225

The Department of Community Services also offers help with respite through the Direct Family Support Program. This program provides supports and services, including Enhanced Family Support (EFS), to both children and adults with disabilities who live at home with their families.

Other agencies that offer respite care:

Veterans Affairs Canada

Toll-free: 1-866-522-2122 | www.vac-acc.gc.ca

Victorian Order of Nurses (VON) (See description on page 72.)

(902) 453-5800 | www.von.ca

Private Agencies

Several private agencies also offer respite services.

Caregivers Nova Scotia can answer your questions about who provides respite care and how to access it. Please note we cannot recommend one service provider over another, but we can supply you with a list.

Adult Day Programs

Adult day programs offer care outside the home, usually during regular working hours. Programs are typically held in local hospitals or community centres. The services they provide can vary but may include health monitoring, foot care, hair styling, exercise, information sessions, group outings, and social events.

To find an Adult Day Program in your area, please call us or visit the 'Adult Day Programs' section of our website.

Home Care

Continuing Care provides community-based healthcare services and assistance with activities of daily living to Nova Scotians of all ages who require support to stay in their homes for as long as it is safely possible.

Home care can range from help with daily living tasks and personal care to light housekeeping, nursing services, home oxygen, and palliative care.

If you require an assessment for home care, you must contact Continuing Care. A care coordinator will then arrange for a time to meet with you to complete an assessment. Depending on your family's income and size, there may be a charge for services.

Continuing Care for Aboriginal Peoples

Registered First Nations individuals living on-Reserve in Nova Scotia have access to home-based healthcare and residential care through provincially and federally funded programs.

Eligibility for provincial Continuing Care services depends on whether a person lives on-Reserve and whether they are a Registered Status individual under the Federal Indian Act. Eligibility is assessed by a care coordinator.

Non-Status individuals living off-Reserve can access all Provincial Continuing Care services. Status individuals living off-Reserve can access many Continuing Care services, but there are some exceptions.

Helpful Fact Sheets about Aboriginal Continuing Care services and eligibility requirements are available to download from:
www.novascotia.ca/dhw/ccs/aboriginal-continuing-care.asp

For more information or to apply for home care services, call Continuing Care: 1-800-225-7225

Other Agencies that Offer Home Care

Veterans Affairs Canada

The Veterans Independence Program is a home care program established to help clients remain healthy and independent in their own homes or communities.

See page 64 for more information.

The Victorian Order of Nurses (VON)

See a complete description and contact information for the VON on page 72.

Private agencies

Many private agencies also offer home care services. Please call us or visit our website for more information about home care agencies. Please note we cannot recommend one agency over another, but we can supply you with a list.

Equipment, Assistive Devices and Medical Supplies

Canadian Red Cross in Nova Scotia

The Canadian Red Cross Health Equipment Loan Program (HELP) provides temporary loans of home health and mobility equipment to help individuals recovering from illness or surgery maintain independence and safety in their own homes.

Toll-free: 1-800-418-1111 | www.redcross.ca

Easter Seals Nova Scotia

The Easter Seals Assistive Devices Program helps applicants acquire a wide variety of equipment including wheelchairs and seating inserts, walkers, home safety equipment, communication devices for children, and various orthotic/orthopedic devices.

(902) 453-6000 | www.easterseals.ns.ca

Northwood Intouch

Northwood Intouch is a non-profit organization working in communities across the province. They provide a range of assistive devices such as medical alarms and sensor technologies that help people to live more confidently in their home, knowing that help is always available. The website features a useful video on some of the assistive devices and technologies they offer and how they help.

Toll free: 1-800-461-3346 | www.northwoodintouch.com

Other Agencies that Offer Assistive Devices

Care Alert Canada – When you use their SmartDialer technology, your call for help is always answered by someone you know.

Toll-free: 1-800-661-5481 | www.carealertproducts.com

Medic Alert, Safely Home – When someone with dementia goes missing Medic Alert will bring them safely home.

(902) 422-7961 | www.alzheimer.ca/ns

Philips Lifeline – offers a number of medical alert and medication dispensing services.

Toll-free: 1-800-387-8120 | www.lifeline.ca

Transportation

Access-A-Bus (AAB)

Access-A-Bus (AAB) is a shared ride, door-to-door, public transportation service operated by Halifax Metro Transit. Buses are designed to carry mobility-impaired persons and those unable to utilize the existing conventional Metro Transit service due to cognitive or physical disabilities.

(902) 490-6681 | TTY/TTD: (902) 490-6664
www.halifax.ca/metrotransit

Dial-A-Ride Nova Scotia

Dial-A-Ride provides door-to-door accessible transportation services to all residents. Priority is placed on services to seniors, persons with disabilities and those with transportation barriers to medical appointments, personal errands, business, volunteering and social events.

Pick-up areas: West Hants, Windsor, Hantsport and surrounding areas with service to anywhere in Nova Scotia.

(902) 792-1800 | www.hantscountycan.org

Other local transportation services may exist in your community, such as the VON or your local hospital. On our website we include details of transportation services available throughout the province, as well as a link to the directory of Rural Transportation Association (RTA) member organizations.

BTO Program

The Nova Scotia Department of Health and Wellness Boarding Transportation and Ostomy (BTO) program provides financial help for travel and accommodations for eligible cancer patients. For more information call 1-800-563-8880.

(902) 421-7390 | Toll-free: 1-877-488-7390

What if I have trouble getting to my appointments?

VON Transportation Program

This service provides affordable door-to-door transportation for seniors and adults who need assistance because of a disability living in Halifax Regional Municipality. To register for the VON Transportation program, or if you would like more information please call 902-455-7433.

Accessible Parking

The Registry of Motor Vehicles issues accessible parking plates and permits to qualified individuals with mobility impairments, free of charge. Registry of Motor Vehicles offices are located in most Access Nova Scotia locations.

(902) 424-5200 | Toll-free: 1-800-670-4357 | www.novascotia.ca

Meals

For information on In-Home and Community Meal programs in your area, contact Continuing Care toll-free: 1-800-225-7225

The Nova Scotia Meals Network publishes a directory of meal programs available in different areas, including information about Meals on Wheels, Wheels to Meals, Meals and More, and Frozen Favourites. The directory is available by calling Continuing Care toll-free: 1-800-225-7225

The Positive Aging Directory, published annually by the Department of Seniors, also includes details about meal programs and the contact information for Nova Scotia Meals Network representatives throughout the province. The Directory can be downloaded from the Department of Seniors website: www.novascotia.ca/seniors

Housecleaning and Maintenance

Some agencies that offer home nursing care may also provide some housecleaning and maintenance (see ‘Home Care’ on page 66). Private companies also offer housecleaning services. See ‘House Cleaning’ in your local telephone book, or visit the ‘Resources’ section of our website.

Affordable Housing

The Nova Scotia Department of Community Services provides a variety of affordable housing programs that are available through Housing Nova Scotia. These include rental housing programs for seniors and families with low or fixed incomes.

Improvements, modifications, and adaptations

Housing Nova Scotia also offers specific housing programs for Seniors, as well as several grant and loan programs to help lower income Nova Scotians maintain, repair, or modify their homes to accommodate the needs of care recipients so they can remain in their homes.

For more information on these programs and to see if you qualify for the grant and loan programs, please visit the Housing Nova Scotia website: www.housingns.ca.

You can also contact the Housing Nova Scotia Office in your area:

| | |
|----------------------|---------------------------|
| Eastern Region | Toll free: 1-800-567-2135 |
| Northern Region | Toll free: 1-800-933-2101 |
| Halifax Metro Region | Toll free: 1-800-774-5130 |
| Western Region | Toll free: 1-800-278-2144 |

Other Programs and Services

The Victorian Order of Nurses (VON)

The VON is a not-for-profit, national healthcare organization and registered charity offering a wide range of community healthcare solutions 24 hours a day, seven days a week. Their home healthcare services include palliative care, pediatric services, dialysis, foot care, and more. Other support services may include personal care, light housekeeping, meal preparation, and respite care.

For more information: 1-888-866-2273 (VON-CARE) | www.von.ca

Personal Response Services

A personal response service usually consists of a personal help button worn around the wrist or neck. When the button is pressed, help is summoned based on your pre-arranged instructions. A personal response service can be life-saving and is especially important for people who live alone. There are government, not-for-profit, and private organizations that offer a personal response service in Nova Scotia. To find out more, contact Caregivers Nova Scotia.

Vial of Life

The Vial of Life provides emergency medical personnel with vital and perhaps life-saving medical information about you if they are called to your home and find you unconscious or very ill. The vial is a small plastic container which holds a specially designed form on which you record information such as your name, health card number, medical history, doctor's name and phone number, and a contact person. The vial is kept inside your fridge and a Vial of Life sticker is placed on the outside of your fridge to alert emergency personnel that vital medical information is available. Thanks to the efforts of local sponsors, the Vial of Life kits are available free of charge in many communities. To find out the contact in your area, call the Department of Seniors toll-free: 1-800-670-0065

Information and Support

Caregivers Nova Scotia Association

Our focus is on empowering caregivers, supporting their efforts, and on recognizing the invaluable contribution they make both to those in need and to society in general. In this Handbook we have made every effort to include the types of services and support that we feel are most relevant to caregivers, however, this list is not exhaustive.

If you are still unsure which organization to call, or would just like to speak to someone to help you understand a service and how it may help, please contact us. One of our Support Coordinators will be happy to speak with you and connect you with the right healthcare and community supports based on your situation.

(902) 421-7390 | Toll free: 1-877-488-7390
www.CaregiversNS.org | Info@CaregiversNS.org

211

When you dial 211, you can easily and quickly connect to the community and social services you need throughout the province, regardless of where you're located. You can also visit their website: www.ns.211.ca

811

When you dial 811 you will have access to non-emergency health information and services. A Registered Nurse will give you the advice and information you need and provide reassurance concerning all kinds of general health issues and questions. If you are hearing-impaired, call 7-1-1 (TTY). You can also visit their website: www.811.novascotia.ca

Nova Scotia Health Authority (NSHA)

The NSHA offers a wide variety of patient and caregiver education resources, services and supports for patients and families. Website: www.nshealth.ca

Health Organizations

Several non-profit organizations provide support and information about specific health-related conditions. We have listed a number of them here.

AIDS Coalition of Nova Scotia

(902) 425-4882 | Toll-free: 1-800-566-2437
www.acns.ns.ca

ALS Society of Nova Scotia

(902) 454-3636 | Toll-free: 1-866-625-7257 | www.alsns.ca

Alzheimer Society of Nova Scotia

(902) 422-7961 | Toll-free: 1-800-611-6345 | www.alzheimer.ca/ns

The Arthritis Society, Nova Scotia Division

(902) 429-7025 | Toll-free: 1-800-321-1433
www.arthritis.ca/NS

Autism Nova Scotia

(902) 446-4995 | Toll-free: 1-877-544-4495 | www.autismnovascotia.ca

Brain Injury Association of Nova Scotia

Tel: (902) 473-7301 | Halifax Chapter: (902) 473-7303
www.braininjuryns.com

Canadian Cancer Society

TTY 1-866-786-3934 | Toll-free: 1-888-939-3333 | www.cancer.ca

Canadian Mental Health Association

(902) 466-6600 | Toll Free: 1-877-466-6606
www.novascotia.cmha.ca

Canadian National Institute for the Blind (CNIB)

Toll-free: 1-800-563-2642 | www.cnib.ca

Craig's Cause Pancreatic Cancer Society

www.craigsc ause.ca

Cystic Fibrosis Canada – Atlantic Region

(902) 425-2462 | www.cysticfibrosis.ca/atlantic-canada

Diabetes Canada, NS Regional Office

(902) 453-4232 | Toll-free: 1-800-326-7712 | www.diabetes.ca

Heart and Stroke Foundation Nova Scotia

(902) 423-7530 | Toll-free: 1-800-423-4432

www.heartandstroke.ns.ca

Hepatitis Outreach Society of Nova Scotia (HepNS)

(902) 420-1767 | Toll-free: 1-800-521-0572 | www.hepns.ca

Huntington Society of Canada

(902) 446-4803 | Toll-free: 1-800-998-7398

www.huntingtonsociety.ca

Lung Association Nova Scotia

(902) 443-8141 | Toll-free: 1-888-566-5864 | www.lung.ca

Multiple Sclerosis Society

Toll-free: 1-800-268-7582 | www.mssociety.ca

Muscular Dystrophy Canada – Atlantic Canada Region

(902) 429-6322 | Toll-free: 1-800-884-6322

www.muscle.ca/about-us/regions/atlantic-canada

Nova Scotia Cancer Care Program

(902) 473-4645 | Toll free: 1-866-599-2267 | www.nscancercare.ca

Parkinson Society Maritime Region

(902) 422-3656 | Toll-free: 1-800-663-2468

www.parkinsonmaritimes.ca

Prostate Cancer Canada Atlantic Region

(902) 420-1444 | Toll-free: 1-855-420-1444

www.prostatecancer.ca

Schizophrenia Society of Nova Scotia

(902) 465-2601 | Toll-free: 1-800-465-2601

www.ssns.ca

Support Groups – Many of these organizations also run support groups for care recipients and caregivers. Contact the organization directly for more information.

Other Resources

Some agencies offer information, programs, or services for specific groups. Below is a list of organizations which may be helpful to you if you or your care recipient are of a specific ethnic or cultural background, or if you are a member of a visible minority. We have attempted to include organizations that may provide supports most relevant to caregivers, but this list is not exhaustive.

Aboriginal

Eskasoni Community Health Centre

(902) 379-3200 | www.eskasonihealth.ca

Native Council of Nova Scotia

(902) 895-1523 | Toll-free: 1-800-565-4372 | www.ncns.ca

Tui'kn Partnership

Funded by Health Canada's Primary Health Care Transition Fund, the five First Nations Bands in Cape Breton have embarked upon an historic partnership – the Tui'kn (Dw-ee-gun) Initiative.

The Initiative seeks to achieve a model of primary health care that is holistic, multi-disciplinary, comprehensive, and supportive of the vision of improved health and quality of life in our communities.

(902) 564 6466 ext. 282 | www.tuikn.ca

Acadian or Francophone

La Fédération Acadienne de la Nouvelle-Écosse

(902) 433-0065 | www.acadienne.ca

L'Office des affaires acadienne/Office of Acadian Affairs

(902) 424-0497 | Toll-free: 1-866-382-5811

www.novascotia.ca/acadian

Réseau Santé - Nouvelle-Écosse

(902) 222-5871 | www.reseausantene.ca

African Canadian

African Diaspora Association of the Maritimes

(902) 404-3670 | www.adamns.ca

Office of African Nova Scotian Affairs

(902) 424-5555 | Toll-free: 1-866-580-2672 (ANSA)

www.ansa.novascotia.ca

Cancer Patient Navigator

Cancer Patient Navigators are oncology nurses who work with you, your family and your cancer care team throughout your treatment and follow up care. You can contact your Cancer Patient Navigator by calling toll free 1-866-524-1234 or go to www.nscancercare.ca for more information.

Family Resource Centres

Family Resource Centres across the province can be excellent sources of information and support. There are 38 centres in Nova Scotia, each offering a range of services to its surrounding community. To find the Family Resource Centre nearest you, contact the Nova Scotia Council for the Family:

(902) 422-1316 | www.nscouncilfamily.org

Gay, Lesbian, Bisexual, Transgender, Intersex, Queer (GLBTIQ)

prideHealth

prideHealth is a partnership of Capital Health and the IWK Health Centre. It provides safe and accessible primary health care services for people who are gay, lesbian, bisexual, transgender, intersex, and queer (GLBTIQ).

(902) 473-1433 | www.cdha.nshealth.ca/pridehealth

Immigrant or Newcomer

Immigrant Services Association of Nova Scotia (ISANS)

(902) 423-3607 | www.isans.ca

Nova Scotia Interpreting Services

Patients can request an interpreter in advance when making an appointment, or can ask for assistance once they have arrived at the doctor's office or hospital. Generally, interpreting services are provided by hospitals at no charge to patients when attending appointments in Capital District Health Authority or the IWK. Other organizations may also cover the cost of interpreting.

(902) 425-6604 | www.interpretingservices.ca

Persons with Disabilities

Nova Scotia Disabled Persons Commission

The Nova Scotia Disabled Persons Commission (DPC) gives people with disabilities living in Nova Scotia a way to participate in the provincial government policy-making process.

TTY: 1-877-996-9954 | Toll-free: 1-800-565-8280
www.disability.novascotia.ca

Nova Scotia League for Equal Opportunities

A provincial consumer organization that provides information and referral services to all Nova Scotians regarding disability issues and available programs and services.

TTY: (902) 455-6942 | Toll-free: 1-866-696-7536
www.novascotialeo.org

reachAbility

reachAbility provides accessible opportunities for persons of all abilities. Their programs, camps, and events are free to all clients.

Tel/TTY: (902) 429-5878 | Toll-free/TTY: 1-866-429-5878
www.reachability.org

Seniors

Canadian Association of Retired Persons (CARP)

Toll-free: 1-888-363-2279 | www.carp.ca

Community Links

A province-wide organization that promotes age-friendly communities and quality of life for Nova Scotia seniors through community development and volunteer action.

(902) 422-0914 | Toll-free: 1-855-253-9355
www.nscommunitylinks.ca

Group of IX Seniors' Advisory Council of Nova Scotia

An independent advisory body made up of nine organizations dedicated to improving the well-being of Nova Scotia seniors.

www.novascotia.ca/seniors

We are Young

The We Are Young Association is a non-profit organization that works with sponsors, volunteers, and its community to grant un-fulfilled wishes to elders living in the province of Nova Scotia.

For more information visit <https://weareyoung.ca/>

Young Caregivers

Young Carers Initiative

The Young Carers Initiative (YCI) is a non-profit agency based in Niagara Centre, Ontario, with a mission to promote the well-being of Young Carers, their families, and their community partners.

Visit www.powerhouseproject.ca to find resources and links to information for young caregivers.

Certain health organizations in Nova Scotia may also have supports for young caregivers. Check with the individual organization directly or contact us.

When Things Change

As a caregiver, your role may change over the course of your journey. Sometimes changes happen gradually as a care recipient becomes healthier and no longer requires care. Sometimes, due to a progressive illness or frailty, your care recipient may become more dependent on you: they may no longer be able to drive or perform activities of daily living without assistance. When this happens, it may be necessary to talk about home care services, or the possibility of assisted living or long-term care.

You may experience the loss of a regular routine. You and your care recipient may no longer be able to participate in activities you once did due to a physical or mental health impairment.

Other times, changes can happen abruptly when a care recipient requires palliative care.

In any of these times of transition, your role as a caregiver can be challenging. Transitions will likely involve mixed emotions – grief, anger, sadness, confusion, and relief are just a few examples. Change and shifting responsibilities can also increase stress levels.

Please contact Caregivers Nova Scotia for more information and tips on how to speak with your care recipient about bringing additional care services into the home, transitioning to long-term care, or hospice care.

More information on hospice and palliative care can be found by contacting:

Nova Scotia Hospice Palliative Care Association

(902) 818-9139 | www.nshpca.ca

Living Lessons

www.living-lessons.org

Nova Scotia Health Authority - Palliative Care

<https://library.nshealth.ca/palliative>

Canadian Virtual Hospice

www.virtualhospice.ca

Canadian Virtual Hospice provides an excellent series of Caregiving Demonstration videos. These are short videos on how to perform daily caregiving tasks such as: helping with movement, administering medications, and personal hygiene. Please visit their website for more information.

Medical Aid in Dying (MAiD)

<http://www.nshealth.ca/about-us/medical-assistance-dying>

MAiD is when a doctor or nurse practitioner (NP) gives a drug to a person, at their request, that intentionally causes their death. A person seeking MAiD must meet a number of criteria to access MAiD.

Grief

Grief is commonly experienced by caregivers during times of transition, but it can also be felt at many points during a caregiver's journey. It can refer to the sadness felt when a loved one passes away, but it can also occur when your responsibilities change, such as when your care recipient moves into a long-term care facility. It is also common to grieve if your relationship with your care recipient changes. You may find you are no longer able to engage in the activities you once did due to physical limitations. A divorce or separation, or memory or behavioural changes due to Alzheimer's disease or other forms of dementia may contribute to this loss. Caregivers (and care recipients) may grieve these changes without recognizing that they are doing so.

Grieving can also begin long before a person passes away. This is often referred to as 'anticipatory grief'.

As her dementia progresses, the mother I knew is gradually slipping away.

It is important to remember that grief and other emotions are normal. Give yourself permission to grieve, to laugh, to be angry, and to cry. You may need extra support from family and friends during these times. You may also want to seek support from your doctor, a counselor, your local religious organization, or a grief and bereavement support group.

To find an active peer support group in your area, contact Caregivers Nova Scotia. You can also visit the 'Grief and Bereavement' section of our website where you will find information, articles, and resource guides on understanding and coping with grief.

Having a Voice - Being an Advocate

If you have ever requested a service or information for your care recipient, taken time to educate others about caregiving, or talked to a local politician about issues related to caregiving, then you have helped give your care recipient a voice, as well as other caregivers like you. People who help in this way are also referred to as advocates.

**Speaking up for those we love and care about
gives us a special voice.
What we have to say is personal.
It has been experienced and is our truth.**

Advocating for your care recipient and for yourself

You will likely find yourself advocating for your care recipient on many occasions. You may need to become familiar with a health insurance policy, request a suitable housing option, or suggest changes to improve existing services.

Don't forget to speak up for yourself. As a caregiver, you also deserve to have the support that you need, and service providers need to hear from you so that they can better meet your needs and the needs of other caregivers.

Not everyone feels comfortable in an advocacy role. Sometimes the best thing you can do to advocate for yourself and for others is to ask for help. If you know someone who has a knack for speaking up and getting people's attention, ask that person if she or he would help you. Perhaps another family member could accompany you and your care recipient to appointments or give you some advice on how to address issues with your employer or healthcare provider.

Strengthening the Voice of All Caregivers

You can support all caregivers by talking to people in your community about your experience. You can also help to work toward positive change by talking about caregiving with your Member of the Legislative Assembly (MLA) or your Member of Parliament (MP). Tell your MLA or MP about your experiences of caregiving. Describe how existing programs and services have helped you and how they might be improved to better serve all caregivers. The first step toward better support is being heard.

Contact information for your MLA is available at:
(902) 424-4661 | www.nslegislature.ca

Contact information for your MP is available at:
Toll-free: 1-866-599-4999 | www.parl.gc.ca

Policies for Caregivers

There are also organizations that work to influence public policy on behalf of all caregivers:

Caregivers Nova Scotia Association

Caregivers Nova Scotia is dedicated to providing recognition and practical supports to friends and family giving care. We also participate in various government Task Forces and Advisory Groups, and research to help influence public policy for the benefit of caregivers.

For more information on how we help in this way, please contact us.

Information About You and Your Care Recipient

It may be helpful for you to complete this page so that you have easy access to this information when you need it. Sometimes having this list by the phone is useful.

About you

Name:

Address:

Home Phone:

Work Phone:

Mobile Phone:

Health Card Number:

Family Doctor:

Pharmacy:

Health Insurance Company:

Policy Number:

About your care recipient

Name:

Address:

Home Phone:

Work Phone:

Mobile Phone:

Health Card Number:

Family Doctor:

Pharmacy:

Health Insurance Company:

Policy Number:

EMERGENCY (Ambulance, Police, Fire): 9-1-1

Frequently Called Numbers

(Keep near the phone or somewhere that it is easily accessible.)

Organization:

Local Hospital:

Pharmacy:

Doctor:

Lawyer:

Health Insurance:

Caregivers Nova Scotia:

Notes:

Other Services

Organization:

Contact:

Name:

Address:

Phone:

Email:

Website:

Notes:

References

1. Sinha, M. (2013). Portrait of Caregivers, 2012. *Spotlight on Canadians: Results from the General Social Survey*. No. 1. September. Statistics Canada Catalogue No.89-652-X.
2. Turcotte, M. (2013). *Family Caregiving: What Are the Consequences? Insights on Canadian Society*. Statistics Canada Catalogue No. 75006-X.
3. Keefe, J.(2011). *Supporting Caregivers and Caregiving in an Aging Canada*. IRPP Study No.23. Montréal: Institute for Research on Public Policy.
4. Keefe, J., Hawkins, G., & Fancey, P. (2006). *A Portrait of Unpaid Care in Nova Scotia*. Retrieved from: www.dal.ca/diffAtlantic-Centre-of-Excellence-for-Womens-Health/projects-and-publications/healthy-balance-women-unpaid-caregiving-research.html
5. Fast, J. (2016, January 21). We need to start caring for caregivers. *thestar.com*. Retrieved from <https://www.thestar.com>
6. American Association of Retired Persons (2010). *Prepare to care: A planning guide for families*. Retrieved from: www.aarp.org/foundation/preparetocare
7. National Institutes on Aging (2010). *So Far Away...20 Questions and Answers About Long-Distance Caregiving*. Retrieved from: www.nia.nih.gov/health
8. Alzheimer Knowledge Exchange, Alzheimer Society Ontario, Behaviour Supports Ontario (2013). *Shifting Focus. A Guide to Understanding Dementia Behaviour*. Retrieved from: www.alzheimer.ca/en/ns/About-dementia/Understanding-behaviour
9. Autism Nova Scotia (2011). *Autism Information & Resource Kit. For Newly Diagnosed Families*. Nova Scotia: published by the author.
10. Helpguide.org (2013). *Helping Children with Autism. Autism Treatment Strategies and Parenting Tips*. Retrieved from: http://www.helpguide.org/mental/autism_help.htm

11. Gahagan, J., Loppie, C., MacLellan, M., Rehman, L., Side, K. (2004). *Caregiver Resilience and the Quest for Balance: A Report on Findings from Focus Groups*. Retrieved from: www.dal.ca/diff/Atlantic-Centre-of-Excellence-for-Womens-Health/projects-and-publications/healthy-balance-women-unpaid-caregiving/research.html
12. Canadian Virtual Hospice (2011). *Sleep and Caregivers*. Retrieved from: <http://www.virtualhospice.ca/>
13. Fast, J., Dosman, D., Lero, D., and Lucas S. (2013). *The Intersection of Caregiving and Employment Across the Life Course: Final Report*. Edmonton. University of Alberta, Research on Aging, Policies and Practices.
14. Canadian Healthcare Association (2012). *Respite Care in Canada*. Ottawa: published by the author.
15. Canadian Institute for Health Information (2010). *Supporting Informal Caregivers – The Heart of Home Care*. Retrieved from https://secure.cihi.ca/free_products/Caregiver-Distress_AIB_2010_EN.pdf

Glossary

Term Definition

Activities of Daily Living (ADL) Refers to daily self-care activities within an individual's residence or in outdoor environments such as bathing, toileting, feeding, dressing, functional mobility, and personal hygiene.

Advance Care Plan A document that sets out your wishes for care at the end of life. It involves choosing one or more persons to represent you if you cannot speak for yourself due to illness or injury. It will only be used if you become unable to speak for yourself.

Anticipatory Grief The process of grieving the loss of a person before death.

Assistive Devices Items that ease the strains of daily activities at home, at work, or during leisure activities and help you and your care recipient to feel safe and secure. They include medical equipment, personal alarms, mobility aids, information technologies or practical aids. Also called **Assistive Technologies**.

Care Provider A person who provides care and receives a salary or wage for their time, such as a continuing care assistant/home support worker, physician, nurse, physiotherapist, etc.

Care Recipient A person who receives care from an unpaid caregiver or paid care provider either at home or in a facility.

Caregiver A family, friend or neighbour who gives unpaid care and support to someone who has a physical or mental health condition, is chronically ill, frail, or elderly. Caregivers range in age from youth to seniors, and provide care to all age groups and in palliative situations. Also called **Carer**.

Caregiver Burnout Caregiver burnout is a state of physical, emotional, and mental exhaustion. Burnout can occur when caregivers don't get the help they need or if they try to do more than they are able.

Caregiver Distress When a caregiver is no longer able to continue in caring activities and expresses feelings of distress, anger, or depression due to the physical, psychological, and financial demands of caregiving.¹⁵

Enduring Power of Attorney An Enduring Power of Attorney lets one person give another person authority to act on their behalf. More specifically, it will remain in force if the person who has granted the authority becomes mentally incompetent.

Respite A reprieve, a short interval of rest, temporary relief, and an interruption in the intensity of a caregiving activity. Respite can also refer to a break for care recipients, and can be provided at home or in a facility.

Responsive Behaviour A term that refers to how actions, words and gestures are a response that express something important about someone's personal, social or physical environment. Also called **Challenging Behaviour**.

Substitute Decision Maker This is the person you choose, as part of your advanced care plan, to make medical decisions on your behalf. This can be anyone you trust and who is capable of honouring and carrying out your wishes. Also called a **Delegate**.

Unpaid Caregiver Someone who gives care to another person, but does not receive a salary or wage for their time. See definition of **Caregiver** above.

Young Caregiver An individual under 19 years of age who gives unpaid care and support to someone who has a physical or mental health condition, is chronically ill, frail, or elderly. Also called **Young Carer**.





The Caregiver's Handbook

Help for Unpaid Caregivers
in Nova Scotia