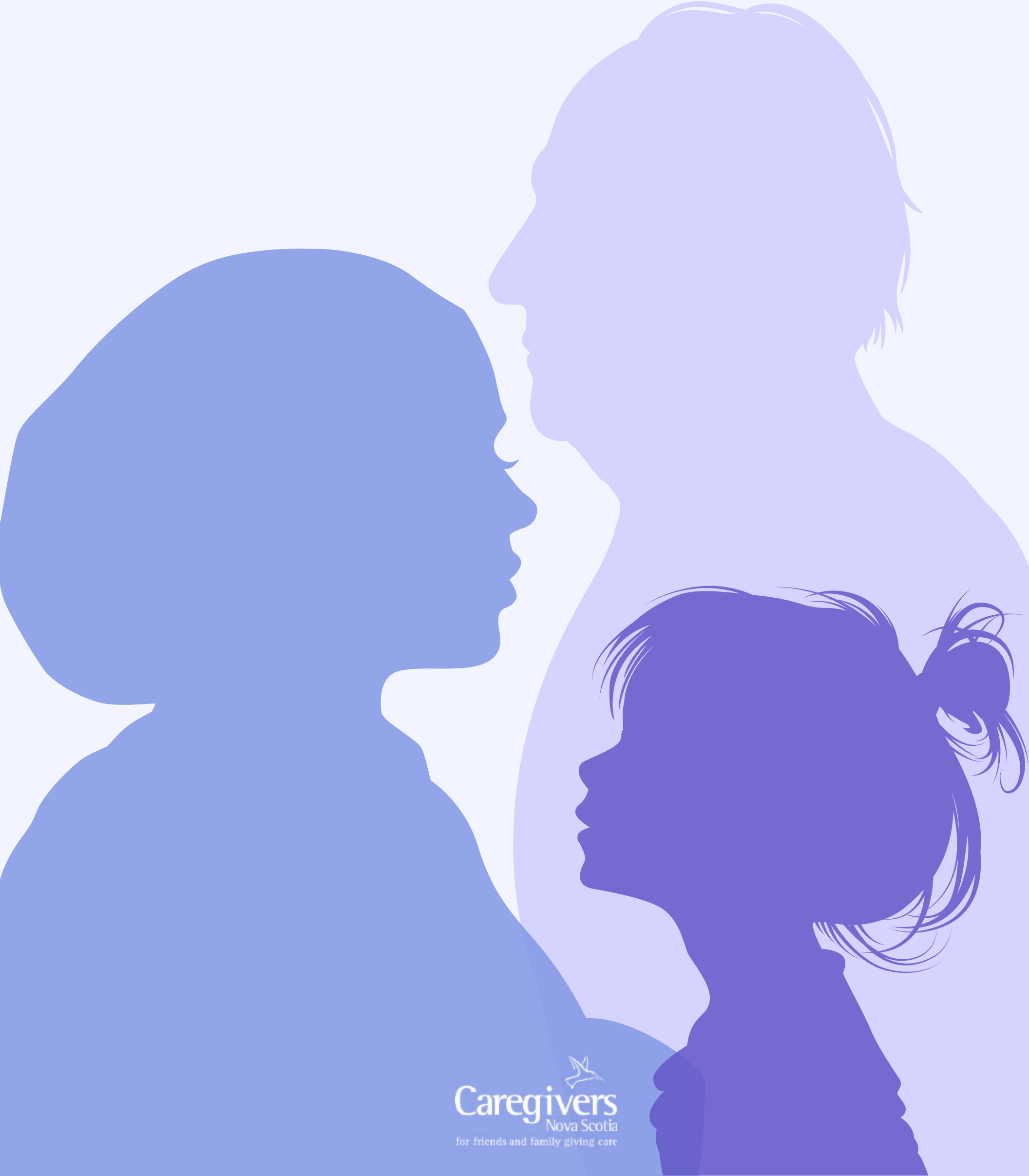
The Caregiver's Handbook

resources • advice • checklists



Caregivers
Nova Scotia
for friends and family giving care

The Caregiver's Handbook

Caring for a Healthy Community

Caregivers Nova Scotia acknowledges that we live and work in Mi'kma'ki, the ancestral and unceded lands of the Mi'kmaq People.

We are continually learning more about how to support and move forward with the work of truth, reconciliation and equity. We recognize that without action, an acknowledgment is empty. It marks the beginning of the work ahead of us, not the end. We are all treaty people.

We also recognize the long-standing history and contributions of African Nova Scotians, who have been a vibrant part of this province for centuries. We acknowledge the strength, resilience, and enduring legacy of African Nova Scotian communities, past and present.

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The Caregiver's Handbook: Help for unpaid caregivers in Nova Scotia

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This Handbook offers general information on topics related to caregiving. This information should not be considered complete, nor should it replace the advice of or a consultation with a trained professional.

If you have a health-related problem, we strongly recommend 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 and/or its Directors shall not be responsible for information provided here under any theory of liability or indemnity.

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Welcome to The Caregiver's Handbook

This Handbook was created with the help of many dedicated people over the years.

The Healthy Balance Research Program (HBRP), a project of the Atlantic Centre of Excellence for Women's Health at Dalhousie University, examined how women's unpaid caregiving impacted their health and wellbeing. Over five years, the HBRP brought together university researchers, policy makers, community organizations and caregivers. Caregivers shared their struggles in finding the right programs, services and information to support their work. In response to these challenges, the first edition of this Handbook was created in 2007.

Caregivers Nova Scotia was an essential partner in the development of the first edition and is pleased to present this updated version. Every member of our team contributed to the new edition, drawing from their own caregiving experiences.

We're grateful to everyone involved in the original project, as well as those who reviewed this edition and shared valuable feedback.

We would like to thank **Petro-Canada CareMakers Foundation** for funding the creation of this edition of the Handbook.

We hope this Handbook will help make your caregiving journey a little easier and maybe a little more rewarding. Inside, you'll find many useful tools, tips and resources to support **you**, the caregiver.

Caregivers Nova Scotia Association

We are a not-for-profit, registered charity that provides recognition and practical support to friends and family giving unpaid care. Our vision is: “Unpaid caregivers are recognized, valued and fully supported as essential partners in care.” Since 1998, we have worked tirelessly to make this vision a reality.

Our support for caregivers comes in many forms. We offer confidential, one-on-one phone and email support, as well as run peer support groups, where caregivers can connect and share their experiences. We provide information on provincial and federal programs and services, and deliver educational workshops and presentations on a variety of topics.

We participate in national conferences and work closely with partners across the province to help each other through referrals, shared resources and consultations. We’re always looking forward to building new partnerships, both locally and nationally, to provide caregivers with the resources and information they need. For example, we’ve teamed up with local pharmacists to deliver a workshop called “Safe Medicines for Seniors and Caregivers”. Through ongoing education and outreach, we make sure healthcare professionals, community partners and allies know that we’re here to help them help caregivers.

We’ve worked in government task forces and advisory groups to help shape public policy that supports caregivers.

We contribute to research, partnering with universities and health organizations. Some of our research partners include: Mount Saint Vincent University, the Nova Scotia Centre on Aging, Dalhousie University, the Department of Seniors and Long-Term Care, McMaster University, Toronto Metropolitan University.

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 and across Canada. During the month, we collaborate with The Canadian Centre for Caregiving Excellence and other Caregiving organizations across Canada to raise awareness about caregivers, their experiences and challenges and advocate for change. During past Caregiver Awareness Months, we hosted caregiver appreciation teas and curated library displays with books recommended by caregivers.

Our website

The website is a user-friendly companion to this Handbook, offering up-to-date information and resources for caregivers across Nova Scotia. You'll also find details about our monthly support groups, educational workshops and presentations. You can also sign up for our bi-annual newsletter and follow us on Facebook to stay connected.

Our website and contact numbers are listed at the bottom of each page. If you don't have internet access or prefer to speak with someone in person, please give us a call — we're here to help.

About this book

Throughout this Handbook, you'll see small numbers at the end of some sentences. These point to sources listed in the 'References' section at the back of the book.

There are several pages where you can reflect and write about different aspects of your caregiving experience. You can fill these out as you go or come back to them later. This resource is here 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. We're happy to give you 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 still hope "The Caregiver's Handbook" encourages you to reflect on some of the topics it addresses, 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

Who is a caregiver?

In Nova Scotia, **one in three** people provides some form of unpaid care to another person with a long-term condition or temporary illness. This is compared to one in four people nationally[1].

Caregivers are essential in supporting the health and wellbeing of others, especially as longer lifespans and an aging population increase the demand for care[2]. While caregiving is commonly associated with age-related issues, care recipients include people of all ages who have a **wide range of needs**, such as medical or mental health conditions, substance use or physical, intellectual or developmental disabilities.

Both caregivers and care recipients include people from **diverse** racial, cultural and linguistic backgrounds, all sexual orientations and persons with disabilities. They live in both rural and urban areas. While the number of male caregivers is rising, women tend to take on caregiving roles more often and provide more hours of care, likely as a result of social and cultural expectations of women[3].

Caregivers provide care to a **wide range of people**, including immediate and extended family members, friends, neighbours, coworkers and others in their communities. Some caregivers support more than one person, and many care recipients rely on multiple caregivers. This care takes place in various settings, including shared homes, in a long-term care or assisted living home or in the recipient's own home[4].

It is important to recognize that caregivers and care recipients from underserved populations, such as those from racial and ethnic minority groups, newcomers, those who live in rural areas or have a low income and members of the 2SLGBTQIA+

community, often face unique challenges and barriers.

Limitations in access to relevant and appropriate healthcare, financial assistance and/or social supports, combined with language barriers, cultural differences and gaps within social systems, can increase the emotional, physical and financial stresses of caregiving and lead to difficulties or hesitancy seeking resources or help[5]. Caregivers Nova Scotia is here to **help all caregivers** in the province, and our support coordinators can help guide you to find appropriate resources for your situation.

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.

Young Caregivers

Young caregivers are people under the age of 24 who look after someone due to a chronic illness, disability, mental health condition or other challenges, such as language barriers.

Compared to their non-caregiving peers, young caregivers often face unique challenges, including balancing caregiving with school or work, social isolation, bullying and a lack of support and recognition due to their age[6].

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.

Young Caregivers Association is the first organization in Canada focusing on the experiences of young caregivers. They've created a Knowledge Centre to help families, educators, healthcare providers and social workers better support young caregivers. It also includes tools and resources to help young caregivers care for their own wellbeing.

Their Powerhouse program teaches young caregivers life and personal development skills, builds confidence and reinforces self-care. The Powerhouse program is offered in-person in Ontario, but their **virtual workshops** are available nationwide.

Caregivers Nova Scotia is here to help caregivers in any way we can, **no matter their age**. Young caregivers, their parents and guardians are always 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:** cleaning, laundry, meal preparation, yard/outdoor work.
- **Transportation and shopping:** accompanying care recipient to appointments, grocery shopping, picking up prescriptions and household items.
- **Coordinating care:** finding out about available services, arranging appointments and services, translating and/or interpreting, 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 ways.

Financially, caregivers in Canada are estimated to save the healthcare system as much as **$97.1 billion a year**[7].

In their communities, caregivers do many things in addition to their caregiving tasks. Many are raising children, students, working in paid employment, volunteering in their community – or all four. 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.

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.

Deciding whether or not to become a caregiver can be fluid as your situation changes and/or the care recipient's needs change. It is okay to start out wanting to be a caregiver and then realizing that what the care recipient needs may be beyond your capacity/capabilities.

Exercise: what role will you play?

There are many different caregiving relationships: spousal, parents to children, children to parents, friends or extended family. The caregiving experience will be different for everyone.

It's important to understand what being a caregiver will mean for you, what do 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 role:

1. Do I want to be a caregiver?

2. How much care do I want to provide?

3. How involved do I want to be in decisions about care?

4. What does the care recipient want and need?

5. What type of care do I want to provide? What are my skills and resources?

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

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

8. 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?

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

10. 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?

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?

Communicating with family, friends and healthcare providers

Now that you've had a chance to think about your role as a caregiver, it can be helpful to talk about it with others involved in care. Sharing your thoughts helps them understand what caregiving means to you and how they can support both you and the person you're caring for.

Friends and family

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

During this meeting, you can discuss any thoughts, feelings, ideas and/or concerns you have about caregiving. You can also share what caregiving duties you need help with.

It may be helpful to think about the following questions before your meeting[8]:

- What caregiving needs are there?
- What would be your caregiving role?
- What are your biggest concerns and priorities when it comes to caregiving?
- Are there any gaps in care? What do you need help with? Who can help?
- How will you work together as caregivers?
- How will caregiving change existing dynamics in the family?
- How can you involve the care recipient in decisions about care?

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, your family and a wider circle of support.

These discussions allow others to participate in decision-making, recognize how they can contribute to caregiving and offer the support you need. The conversation can change as your care recipient’s needs change over time.

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

Healthcare providers

You may not know how to talk about your caregiving role with **your healthcare provider**, but it's important.

Caregiving can be physically and emotionally demanding. If you're experiencing signs of burnout, anxiety, trouble sleeping or any physical health concerns, discuss them with your doctor. They can help you manage your health, so you can continue providing care.

At the same time, building a relationship with your **care recipient’s healthcare team**, including doctors, nurses and other specialists, is just as important. Attending appointments when possible and introducing yourself can help improve communication. Ask questions if anything is unclear and don’t hesitate to express concerns about the care your recipient needs.

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

To make the most of appointments, it can be helpful to bring a list of questions, a daily care schedule or a "To-do" list (see templates on the following pages). These tools can help both sets of providers understand the nature and extent of your caregiving responsibilities.

Continuing Care

Nova Scotia Health Continuing Care offers a wide range of programs and services that support caregivers and care recipients of all ages across the province to live at home or return home after a hospital stay. For a list of available programs and services, see **page 63**.

For more information or to make a referral, call Continuing Care's toll-free number: **1-800-225-7225**. If you cannot speak with someone immediately, it is important to leave a message and follow up in a few days if necessary.

If it is determined that Continuing Care may be able to help, a member of the care coordination team will contact you. At that time, they will gather additional information over the phone about your care situation. You may be assessed regarding your care needs and what services you may require.

Getting organized

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

In this section, you will find checklists, plans and charts – all tools that we hope will help you get organized and create some time for yourself.

Blank copies can be downloaded from our website: **www.caregiversns.org/education/handbook/blank-templates**

We offer educational workshops, such as Caregiver Stress Management, Understanding Dementia Behaviours, 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. If there is a workshop you would like to see, please let us know.

The tools on the following pages are intended to help you in practical and meaningful ways to care for your care recipient and yourself.

Checklist: partners in care

Step 1 — What are the needs of your care recipient?
Take an inventory of your skills and the resources available to you. Are there things that others could help you with, to give you a break from caregiving? What is your care recipient able to do for themselves?

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		
Take shopping		

ACTIVITIES	WHO CAN HELP?	WHEN/HOW OFTEN
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		
Leisure activities		
FINANCIAL / LEGAL AFFAIRS		
Banking, pay bills		
Legal documents		
Income taxes		
NOTES		

Checklist: schedule of daily care activities

Step 2 — What are your care recipient's daily care activities? 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.

DAY	CARE ACTIVITY	WHO CAN HELP?
Sunday		
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		

Medications

If you're managing medications, a chart can help you stay organized and on schedule. It is particularly useful for anyone helping with care, from family and friends to emergency personnel, respite and home care workers.

As your care recipient's needs change, some medications may no longer be helpful and could even cause harm, like negative drug interactions, falls, memory issues and hospitalizations. Regular medication reviews with your pharmacist can help prevent these issues.

A few helpful tips:

- Keep an up-to-date list of all prescription and non-prescription medications, vitamins and supplements.
- Bring it to all medical appointments, pharmacy visits and emergency department trips.
- If possible, use only one primary care provider and one pharmacy. It will be easier to keep track of your medication and identify any potential risks or harmful drug interactions.
- You may ask the pharmacist to set up a blister pack system for your care recipient.
- Ask the pharmacist to review each medication with you so you understand when and how to take them and potential interactions.
- Ask your pharmacist about a more in-depth medication review. The Basic Medication Review Service (BMRS) or the more comprehensive Advanced Medication Review Service (AMRS) may be covered for Pharmacare recipients. Those who are not covered by Pharmacare may receive either service for a fee. For more information, speak to your pharmacist or visit: **https://pans.ns.ca/medication-reviews**

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
<u>Examples:</u> Tylenol, 200 mg	<u>Example:</u> number of tablets, teaspoons, puffs	<u>Example:</u> 12 p.m. or before bed	<u>Examples:</u> with food, one drop in each eye	Example: back pain
Vitamin D3, 1000 IU				

Family doctor’s name and phone number: ______________________

Name of the pharmacy and phone number: ______________________

Notes: ______________________

You can download the fillable chart on our website:
https://caregiversns.org/education/handbook/blank-templates/

Meal planning

Deciding what to cook can be a daily hassle. For caregivers, it can be even more stressful as they often have many competing responsibilities.

Planning meals in advance can save time and money, while reducing stress and ensuring you and your care recipient receive proper nutrition. A good meal plan considers dietary needs, personal preferences and medication schedules. You can use the template on the following page to create a meal plan.

A few tips to get you started:

- **Plan ahead:** set aside a dedicated day each week for meal planning and preparation. Collect a list of recipes to have on hand while planning your weekly menu. Once you have decided on your meals, make a grocery list for the week.
- Look for meals that use ingredients that are **easy to find, affordable and easy to prepare** (such as slow cooker, air fryer, or Instant Pot recipes). If you are looking for ideas, Canada's Food Guide offers a collection of healthy recipes online at **https://food-guide.canada.ca/en/recipes**
- **Meal prep:** preparing ingredients or meals in advance can simplify mealtimes, saving time and money while reducing food waste. Meal prepping can involve batch cooking large meals, pre-portioning meals, prepping ingredients and freezing or refrigerating meals to eat later.
- **Reduce cost:** use flyers, apps and coupons to save money on groceries. Buy in bulk and stock up on non-perishables or frozen ingredients when they go on sale. Plan meals around sales or what you already have at home. **See page 72** for more information on where to find help with accessing food.

- **Accommodate eating challenges:** since appetites and eating habits can vary between individuals and change with health conditions, it is important to be flexible. Eating does not need to happen only in three big meals; smaller meals and snacks throughout the day can be just as effective.
- **Consider dietary needs:** be mindful of allergies, food sensitivities and any medications that need to be taken with or without food when planning meals and mealtimes. Try to choose a mix of foods that are high in fibre, protein and healthy fats, and low in saturated fats and added sugars. For more information on nutrition, **see page 48**.
- **Focus on hydration:** food and fluids like herbal teas, low-sugar or diluted fruit juice, broth-based soups, popsicles, fruits and vegetables with high water content (such as watermelon, strawberries, tomatoes or bell peppers) provide hydration beyond just drinking water.

For more information on nutrition, feeding, and more, visit the education section of our website at **https://caregiversns.org/education/nutrition-course/**

MEAL PLANNING CHART for: ______

Allergies/Dietary restrictions: ______

Preferences: ______

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

You can download the fillable chart on our website:
https://caregiversns.org/education/handbook/blank-templates/

To-do list

Has a friend or family member ever asked, “How can I help?” People often want to help with caregiving, but aren’t sure how. Having a list of tasks for them to choose from can make it easier.

Start by making a list of everything you do in a typical week: work, house chores, caregiving, caring for kids or other people, even taking time for yourself. Look over your list. Is there anything a friend, a family member, a neighbour or a home care/respite worker can help with?

Write these tasks on a separate list and keep it somewhere where people who want to help will see (for example, on the fridge or on a table by the front door). Add deadlines, if appropriate, and any relevant details. See an example of activities you can add to your to-do list, as well as a blank list for you to complete on the following page.

Sample activities	
Frequent tasks	**Occasional tasks**
Laundry	Social activities
Grocery shopping	Car maintenance
Arrange appointments	Pay bills and taxes
Visit with care recipient	Arrange for home maintenance
Yard work / snow shoveling	
Sweeping / vacuuming / dusting	
Cooking and cleaning after meals	
Look into resources / services needed	
Accompany care recipient to appointments	

You can download the fillable to-do list on our website: https://caregiversns.org/education/handbook/blank-templates/

TO-DO LIST:
How friends and family can help

Task	Who can help	Deadline	Details

Discharge planning

Several healthcare professionals support people getting ready to be discharged from the hospital. Depending on the hospital or healthcare setting, this may be an administrator, social worker, doctor, nurse or patient advocate. To get to the right person, ask for the **Discharge Planner**.

Discharge planning begins on the day of admission and continues throughout the hospital stay. Both you and your care recipient can share important information with the discharge planner, like your daily activities, what your care recipient can and can't do at home. **Be clear and vocal** about your needs and wishes.

Discharge planners **can connect you with services** like home care, oxygen, meal programs or the Victorian Order of Nurses (VON). Ideally, these services should be arranged before you leave the hospital.

To make the transition smoother, fill in a Discharge Planning Checklist with the discharge planner and your care recipient.

You can download the fillable checklist on our website:
https://caregiversns.org/education/handbook/blank-templates/

Checklist: discharge planning

	Care recipient ✓	Caregiver ✓
Preparing and planning ahead		
1. I know who my discharge planner is. • I've talked to the discharge planner and know what I have to do. • My partner, family member or friend will help me, has talked to the planner and knows what to do.		
2. I've made plans for my care after I leave the hospital. • I've made arrangements at my job, if needed. • I've found out about home care services, if needed. • I've set up my home for medical equipment, if needed. • I've found out what services I can get from my provincial health plan or private insurance.		
3. If I'm going to another healthcare setting, I understand why and where I'm going. • I know what type of care I'll be getting. • I know about how long I'll be there.		
The discharge plan		
1. I have received a written discharge plan. • It lists all the medicines I need. • It lists all the health tasks I need to do. • I understand how to perform them. • It lists all doctors or others I may need to call and their numbers. • I agree with the plan. • If I don't agree, I know how to challenge the plan.		
Health concerns		
1. I know what problems to watch for and what to do. • I know which symptoms, side effects or other problems to expect. • I know what to do about these problems. • I know who to call in an emergency.		
2. I understand my medicines. • I know which medicines are new, which I have to stop taking and if any medications' dosages have changed. • I know what each medicine does and why I'm taking it. • I know how and when to take the medicines. • I know what side effects to watch for and who to call for help.		
3. I understand what to do during my recovery. • I know what I can and can't eat. • I know how active I can be. • I've asked about any special instructions.		
Getting help at home		
1. I understand how to use my medical equipment (e.g. walker, oxygen). • I know who to call if I have questions about the equipment.		
2. I know the type of help I'll need. This may include: • Dressing, bathing and using the bathroom • Shopping, cooking and housework • I or my caregiver know how to change bandages or give shots. • I've asked my doctor or nurse what other help I may need.		
3. I know that my health and care may cause stress. • I know the signs of stress and depression. • I know how to manage stress. • I know where to turn for support if needed. • I know that my caregiver may need a break. • My caregiver needs help if they show signs of stress or depression.		

Health crisis planning and personal emergency preparedness

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

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

- Your care recipient's condition became more severe.
- 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 hurricane, 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 and the care recipient's wishes. These documents are explained in more detail in the "**Legal Issues**" section of this handbook.

When a health crisis occurs, it is important to stay calm and assess the situation. If the care recipient is seriously hurt or endangered, **call 911** or take them to the nearest emergency department.

If you are unsure if it is an emergency situation, you can contact a **registered nurse at 811** at any time.

There are some things you can do ahead of time that can be helpful when dealing with emergency health situations:

- Make sure **the house number is clearly visible** from the road so first responders can find it quickly.
- Keep a **folder with important information** about your care recipient, including their condition(s) and an updated list of medications. This can be shared with the first responders, emergency staff or a substitute caregiver.
- If your **care recipient sometimes gets lost**, consider using a GPS tracker, which can be enabled on their phone, a smartwatch or a tracking tile. For more on assistive devices, **see page 70**.
- If your care recipient has a chronic condition, severe allergies or takes life-saving medication, consider utilizing a **medical ID** bracelet, necklace or tag to inform first responders of their condition.
- **Learn about emergency response.** Keep a well-stocked first aid kit and consider training such as First Aid, Psychological First Aid for Caregivers, Naloxone response training and/or other courses that fit your caregiving needs.

How do I prepare for an emergency?

If there is a disaster in your area that affects transportation, power and/or other basic essentials, it may take emergency workers some time to reach you.

You should be prepared to take care of yourself and other members of your household for a minimum of 72 hours.

Here are some tips to help you prepare:

- **Make an emergency plan.** An emergency plan helps everyone in the household know what to do in an emergency, how to contact each other and where to meet.
- **Know where a local comfort shelter is.** If the emergency event warrants it, this type of shelter may open to provide the community with a safe place to charge devices, get a warm drink and access a washroom. These centres are often operated out of local community centres, church halls or fire halls. Ahead of a storm, you may wish to contact your local hall to see if they intend to operate as a comfort center.
- **Vulnerable Persons Registry.** If your care recipient lives at home without 24-hour care, they may qualify for a local Vulnerable Persons Registry. This service helps emergency response teams be more aware of resident needs during large scale emergencies. Contact your local municipality to see if this service is available in your area.
- **Emergency preparedness kit.** Put together an emergency preparedness kit with basic supplies that will help you get by if you are without power or tap water. The kit could include bottled water, canned or dried food that won't spoil, crank or battery-powered flashlight and radio, and care items such as medications or equipment for people with disabilities. For more information on emergency preparedness, visit the websites below.

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 receiving palliative care.

The program ensures that paramedics know about the patient's unique needs and have quick access to the information they need about you or your care recipient.

In some cases, patients may need special care that is not included in EHS standard practice. The SPP allows you and your healthcare provider to create an EHS care plan that is tailored to your healthcare needs. Your healthcare provider will send your SPP request to EHS.

To learn more, visit:
www.novascotia.ca/dhw/ehs/palliative-care.asp

Emergency Health Services (EHS) Ambulance Fee Assistance Program

The program allows users to apply for a payment schedule for ambulance fees. Some people may be able to have the fee waived entirely, depending on their income. Please, apply to this program within 90 days of the date on the bill.

For more information, call the EHS billing office at **902-832-8337** or toll-free at **1-888-280-8884**.

Helping when you are a long-distance caregiver

Some caregivers live far from a person they support, which can make things harder. Work, school and personal life may prevent you from moving closer. Even living just an hour away can add to feelings of guilt and worry, especially if you can't help in an emergency or regularly assist with daily tasks.

There are valuable ways you can support your care recipient when you are far away. Here are some examples[9]:

- **Stay in touch**. A daily phone, video chat or a text message can let your care recipient know that they're not alone and give you peace of mind.
- **Consider a personal alarm or alert service**. A wearable help button (around their arm or neck) allows your care recipient to call for help with one press. The response follows their pre-arranged instructions. See **page 70** for more about personal alert services and other assistive devices and technologies.
- **Use technology**. You can install security cameras, video doorbells, smart locks, light and outlet on/off switches, thermostats and more to access and control from your smartphone. These home devices can help you feel more confident that your care recipient is safe and comfortable.
- **Help with appointments**. If possible, try scheduling appointments for when you'll be nearby so you can attend. Talk with healthcare providers to stay informed on all medical issues.
- **Explore local services**. Discuss with your care recipient what services they might need. They may know some local options for home healthcare, meal delivery or transportation. Offer to help arrange these services.
- **Ask about virtual care**. Some healthcare providers can include long-distance family in appointments using virtual care technology. Check if this option is available.

Caring for someone with expressive behaviours

> **“Behaviour that we think is strange, unusual or upsetting is often the person’s way of coping with a world that is real to [them]”**
>
> - Virginia Bell & David Troxel

The term “**expressive behaviours**" refers to actions, words or gestures used by a person as a way of responding to something happening in their personal, social and/or physical environment.

These behaviours are sometimes labelled as “challenging” or “distressing” behaviours, but the terms “expressive” or “responsive” are preferred. These terms remind us that behaviour is a response to something and a means of expressing or communicating a need.

They shift the focus to the person and what they are expressing, rather than the challenges these behaviours may present. By reframing expressive behaviours as a form of communication, caregivers can explore the underlying reasons for them and respond in a way that meets the person’s needs[10].

Many expressive behaviours are **linked to changes or differences in the brain** that can affect communication, mood, memory or judgement.

These may be related to conditions such as dementia, acquired brain injuries, substance use or withdrawal, autism, mental health conditions like schizophrenia and bipolar disorder, Parkinson’s disease and more[11].

Expressive behaviours **can take many forms**.

A person may frequently move around the area, reach out or hold onto others, act in ways that can harm themselves or others (by biting, scratching, hitting, kicking). They may express sexual desires by touching themselves or undressing in public. They may consume things that aren't safe to eat or drink, repeat certain words, sounds or movements, use strong language or speak in a loud voice.

All behaviour has meaning. While some behaviours may stem from differences in the brain, many are in response to internal or external environmental factors. Identifying these factors can help caregivers support and respond to behaviours appropriately[12].

Potential contributing factors:

Physical factors (internal):
Pain or discomfort from temperature/clothing/assistive equipment (such as wheelchairs), hunger or thirst, needing to use the bathroom, tiredness, altered senses (eyesight, hearing).

Psychological factors (internal):
Depression, anxiety, loneliness, fear, confusion, boredom, lack of purpose.

Environmental factors (external):
Overstimulation/understimulation, clutter, crowds, unfamiliar environment, people and/or routine, lighting that is too bright/too dim[12].

As many behaviours can be linked to physical health problems, it is recommended to have medical check-ups and medication reviews to rule out illness or side-effects as a cause.

Remember, you cannot control someone else's behaviour, but you can control and change how you respond. Try to stay patient, adaptive and compassionate, as what works today may not work tomorrow.

Here are some strategies to support someone with expressive behaviours.

- **Recognize behaviour as communication.** Work to understand what the person is trying to express, instead of taking the behaviour personally.
- **Use a "cheat sheet".** Keep a list of the person's likes, dislikes, routines, and habits to help anyone providing care.
- **Educate.** Make sure everyone providing care knows the person's condition and symptoms. This will help understand their needs and how to address them.
- **Meet basic needs.** Offer food, drink and pain relief. Make sure hearing aids, glasses and/or other assistive devices are available and working.
- **Validate their feelings.** Let them know you are listening and will help meet their needs. Don't argue over false beliefs if they are harmless. Speak slowly, gently and clearly, keep your words simple and brief.
- **Redirect gently.** Use calming distractions, like activities they enjoy or asking for help with simple tasks. For example: offer them something they like to eat, watch a TV show or listen to their favourite music, lead them to a different room or talk about happy memories or their interests.
- **Check their environment.** Keep the space as calm as possible, reduce noise and clutter and adjust lighting if needed.
- **Maintain a consistent daily routine.** Avoid changes to routine and the environment. Support their independence as much as (safely) possible. For example, if unloading the

dishwasher was their usual home task, support them in continuing to do this task, as long as they are able to do it safely.

- **Accept certain behaviours.** If the behaviour is not harmful or distressing, it may be best to accept and accommodate it.

Support

Caregivers Nova Scotia is able to provide support, resources and education regarding expressive behaviours. The staff at CNS are all Dementia Capable Care trained, we have a dementia specialist on staff and we offer an Understanding Dementia Behaviours workshop. Please, contact us for more information on how we can support you.

Condition-specific organizations, such as 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 75** for details).

Healthcare professionals who have training in understanding expressive behaviour can also provide help. Your primary care provider can make a referral to a geriatrician, psychiatrist or a behavioural resource consultant. Early intervention services, special education teachers, speech-language pathologists or child and adolescent mental health specialists can help if you care for a child or young adult with expressive behaviours.

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

Taking care of yourself

> **“Compassion is not just about caring for others; it is also about extending that same kindness and understanding to ourselves.”**
>
> - Unknown

Caregiving can be a meaningful and rewarding way to support your family or give back to someone who has helped you. However, it can also be physically and emotionally demanding. The time and energy caregiving takes can make it challenging to **look after your own health**, even though your wellbeing is just as important.

Being healthy means more than just avoiding getting sick. It includes your physical, mental, social and spiritual wellbeing. Caregiving can affect all of these[2]. Many caregivers report stress, physical pain and injury, poor eating habits, disturbed sleep and depression as a result of their caregiving responsibilities. More time spent caregiving means less time for leisure and social activities, which can result in strained relationships and family conflicts[13].

Checklist: caregiver stress assessment

Answer the following questions by selecting “never,” “sometimes” or “often.”

QUESTION	NEVER	SOMETIMES	OFTEN
Do you have trouble sleeping, such as difficulty falling asleep or waking up at night?			
Are you anxious?			
Have you experienced panic attacks?			
Have you gained or lost weight recently without trying to?			
Have you noticed any changes in your health, like getting sick more often or dealing with issues like headaches, back pain or high blood pressure?			
Do you find yourself reacting strongly to small problems, for example, by crying, getting angry or struggling to control your emotions?			
Do you feel hopeless about your situation?			
Are you finding it hard to balance your caregiving role with career, hobbies or social life?			

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If you answered “sometimes” or “often” to many of these questions, you may need help balancing caregiving and care for your own wellbeing.

See the information on the following pages for information and strategies on managing stress, burnout and wellbeing.

Stress and burnout

The long-term stress of caregiving, especially without enough support and self-care, can lead to **caregiver burnout**.

Everyday stress, which involves heightened emotions like frustration, can often be managed or even help us adapt and solve problems. But when stress continues for a long time, it can become chronic and turn into burnout. This may lead to depression, losing interest in caring for yourself or your care recipient and can hurt both of you.

Burnout builds up over time. **Compassion fatigue**, on the other hand, can happen suddenly after a particularly stressful event. It comes from taking on the pain and stress of the person you are caring for, while also managing your own. You may feel emotionally drained, physically exhausted, not as compassionate for others and unable to care for others like you normally would.

Signs of caregiver burnout include:

- **Physical signs:** body aches, fatigue, headaches, appetite changes, insomnia and frequent illness.
- **Emotional changes:** depression, anxiety, being more quick to anger, social isolation, lack of concentration or motivation.
- Feelings of **anger or resentment** toward care recipient.
- Feeling **helpless or at a loss** of control over your life.
- **Losing interest** in the things you once enjoyed.
- **Neglecting your health** and other needs.

It is important to **recognize the signs** of caregiver burnout and take action if you experience any of them. On the next page, you will find a list of suggestions to help you care for yourself to prevent or address burnout.

- **Figure out what causes your 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 and daily hassles, like traffic jams or household chores. Reflecting on what's causing you stress can help you manage it more effectively.
- **Acknowledge your feelings.** Caregivers often experience anger, frustration, sadness, grief and guilt, especially during major life events. Acknowledge and express your feelings in healthy ways: grieve when you need to and allow yourself to celebrate the happy moments too.
- **Ask for help and support.** Speak with friends and family about how you are feeling and ask for help with some of the day-to-day tasks. Speak to your primary care provider about your symptoms. Speak to a therapist or counsellor or join a support group to share your concerns. Caregivers Nova Scotia offers monthly support groups in all areas of the province as well as a Caregiver Stress Management workshop.
- **Strive for balance, not perfection.** Try to set realistic caregiving goals. Know your limits and say “no” to taking on more than you can handle. If you find yourself with too much to do, ask for help using the “Partners in care” checklist on pages 17-19 and the “To-do list” on page 26. Asking for and accepting help are important skills, and it is not always easy.
- **Educate yourself.** Learn as much as you can about your care recipient’s condition and how their needs are likely to change over time. This will help you plan and prepare for these changes and feel more confident in the care you provide.
- **Make time for self-care.** Although this is easier said than done, it is very important. Make time for yourself and practice self-care through exercise, proper nutrition, sleeping well, doing activities that you enjoy and just taking a quiet moment when you can. In the short-term, even a 15-minute break can help you feel refreshed and energized. For more ideas on short breaks and how to create a self-care plan, see the next pages in this section.

- **Plan for respite care.** Arrange for close friends, family members or a care provider to stay with your care recipient to give you a break. Depending on availability, you may be able to arrange for a few hours of in-home support or 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 a friend, join a fitness class or start a new hobby. Try to plan respite care in advance, if possible, so that it is there when you need it. For more information on what organizations provide respite care (both public and private), see **pages 67-68**.

Self-care

Self-care looks different for everyone, and not all exercises will feel helpful to you. Like trying on new clothes while shopping, you may need to "try on" a few things before finding what fits best. It helps to practice self-care regularly, even when you are feeling fine, so it's easier to do during stressful times. Below are some suggestions to get you started.

- **Journaling.** Journaling helps manage stress while improving self-awareness, communication skills, memory and problem-solving skills. Try journaling every day. If you do not know where to start, you can find journals that include prompts or look for prompts online.
- **Breathing exercises.** Try doing breathing exercises such as the 4-7-8 breathing technique, which involves breathing in for 4 seconds, holding the breath for 7 seconds and exhaling for 8 seconds. This breathing pattern works to reduce anxiety and can help you get to sleep.
- **Self-compassion.** Next time you feel overwhelmed or make a mistake, instead of judging yourself harshly, try speaking as gently and kindly to yourself as you would to a friend. You can say things such as, "You're doing the best you can. I know this is hard right now. I'm here for you."

Practicing this kind of self-talk can help reduce anxiety while acknowledging your feelings.

- **Sensory grounding.** Shift your focus to your senses. Try the 5-4-3-2-1 method by looking around you and listing: 5 things you can see, 4 things you can touch, 3 things you can hear, 2 things you can smell and 1 thing you can taste.

Take short breaks

- **Physical:** go for a walk, run or a bike ride, stretch, do yoga, go to the gym, garden, drink water, eat a healthy snack.
- **Emotional:** cuddle or play with a pet, treat yourself to a cup of tea or coffee, turn off your electronic devices or set them to “do not disturb” for a short time, take a break from reading or watching the news and try to be mindful of the media that you consume and engage with.
- **Spiritual:** follow a guided relaxation or meditation, connect with nature, if you are religious - pray or attend a service.
- **Social:** play a video or board game, connect with other caregivers (in-person, on the phone or virtually), call a friend or a family member just to chat.
- **Environmental:** step outside for some fresh air, get rid of one thing you no longer need or use, light a candle.
- **Creative/leisure:** write, paint, draw, colour, do a crossword or Sudoku, make a collage, knit, crochet, play a musical instrument, listen to music, an audiobook or podcast, read a book, re-watch a favourite movie or catch up on your favourite TV show.

> **“Sometimes the most important thing in a whole day is the rest we take between two breaths.”**
>
> - Etty Hillesum

Exercise: creating a self-care plan

Take a moment to reflect on how you are currently coping with stress. Write down any current strategies you use, and identify if they are healthy or not.

For example, healthy coping strategies could be daily walks or weekly phone calls with a friend, whereas unhealthy coping strategies may look like excessive drinking or being overly self-critical.

What are my healthy self-care strategies?

____

____

What are my unhealthy self-care strategies?

____

____

Take a moment to think of some new self-care activities you would like to try. If you feel stuck, you can refer to the previous pages for some ideas. Try to include **one from each** of the following areas:

Physical self-care: ______________________________
Emotional self-care: ______________________________
Social self-care: ______________________________
Spiritual self-care: ______________________________
Enviromental self-care: ______________________________
Creative/leisure self-care: ______________________________

Having a plan for self-care can make it easier to practice in your daily life. **Choose one or two of your favourite activities** or one or two new ones you would like to try. Then fill out the following statements to create **goals for self-care**:

I will set aside time to ______________________________ once a day.
I will set aside time to ______________________________ once a week.

Exercise: creating a self-care plan

Caregiving can, at times, be very challenging and emotional. Having a plan in place for these moments can help you calm yourself down if/when you feel overwhelmed.

Try the following strategies:

- Practice self-compassion
- Do a breathing exercise
- Practice sensory grounding (5, 4, 3, 2, 1)

When I am overwhelmed, I will: ____________________

Take a moment to reflect: how did your self-care plan work for you?

How did it feel to prioritize your wellbeing?

____

What challenges did you face when making time for self-care?

____

____

What type of self-care was the easiest to commit to?

____

What type of self-care was the hardest to commit to?

____

What exercises were a good fit for you? Why?

____

____

What exercises were not a good fit for you? Why?

____

____

Finding support

You never know where you'll find help when you need it. Start by browsing this handbook. The "Services in Nova Scotia" and "Information and support" sections may give you some ideas. You can also contact us.

When you need support, turn to family members, friends, neighbours, community or a support group, religious organization or your spiritual advisor.

If you are employed, check if your workplace offers an **Employee Assistance Program** (EAP). EAP can connect you with a confidential counsellor or find other supports - both for you and your family. Participation in an EAP is voluntary and confidential.

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

- **Canadian Mental Health Association - Nova Scotia Division.** Toll-free: 1.877.466.6606 | https://novascotia.cmha.ca
- **Nova Scotia Health Mental Health and Addictions Program.** https://mha.nshealth.ca/en
- **Provincial Mental Health and Addictions Crisis Line.** 1-888-429-8167
- **Caregivers Nova Scotia.** Our Support Coordinators can tell you about support groups in your area, when the next Caregiver Stress Management workshop is offered and provide support over the phone and via email.

Healthy eating, physical activity and sleep

The following recommendations from Health Canada can help you maintain both your physical and mental health.

Healthy eating

- Aim for a regular eating routine that includes a balanced variety of nourishing foods.
- Include a variety of vegetables, fruits, whole grains and protein-rich foods, such as lean meats, nuts and lentils.
- Choose fats that support your health: limit saturated fats and fried food.
- If it's helpful, use food labels to make informed nutritional choices.
- Highly processed foods, such as chips and chocolates, can be enjoyed in moderation as a part of a balanced diet.
- Stay hydrated. Limit sugary drinks as they can make you even thirstier and provoke a sugar rush.

Physical activity

Aim for 2.5 hours of physical activity each week. This can include everyday activities, like gardening, housework and walking – it doesn't have to mean going to the gym.

You can build movement into your day in short sessions of at least 10 minutes. As a caregiver, some of your tasks may already be physically demanding. While these count toward your activity, they can also be stressful. Try to balance them with more relaxing movement, like stretching, gentle walking or dancing to your favourite music – something that gives both your body and mind a break.

Try various activities to see what works best for you.
Here are some examples to inspire you:

- For your **heart, lungs and circulatory system**, try brisk walking, cycling, swimming, dancing, hiking. If it is safe for you, challenge yourself to walk or bike short-distance instead of taking a vehicle.
- To **strengthen muscles and bones** and to improve posture, try lifting light weights, squats and push-ups, exercise with resistance bands or pilates.
- To **keep your muscles relaxed and your joints mobile**, try gentle stretching routines, yoga, range-of-motion exercises or Tai Chi.

Sleep

Getting proper sleep is important not only for your health, but also for providing quality care. It helps your body recover and prepare for the next day. Without enough sleep, you might feel irritable, have trouble managing stress and get sick easier.

Many caregivers don’t get eight hours of sleep each night. You may wake up to help your care recipient, feel anxious about their condition or work irregular hours – all affecting your sleep.

Here are some tips on how to improve your sleep[15]:

- Try to maintain a regular sleep-wake schedule.
- Try to take a few minutes every day for exercise and fresh air.
- Try gentle stretches and breathing exercises before bed.
- Write down any worries that make it difficult to sleep.
- Set up a routine to unwind before turning the lights off.
- Cut down on caffeine & nicotine, especially before bedtime.
- Nap when you can, but not in the late afternoon/evening, unless you need to get up at night.
- Create a calming atmosphere around you.

Legal issues

This section gives a brief overview of common legal issues caregivers and care recipients may face. 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 online and 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.

Finding legal Information on the Internet or by phone

The Legal Information Society of Nova Scotia (LISNS) is a charitable organization that provides Nova Scotians with free information about the law. Their website contains detailed information about each of the topics discussed in this section and much more.

If you have a legal question, you can call the Legal Information Line toll-free at **1-800-665-9779** or **902-455-3135** in Halifax. A counsellor will try to answer your question and connect you with a lawyer if necessary. While they cannot give legal advice, they provide free information about the law and help you connect with resources.

Some topics are also available in audio format on their website: **www.legalinfo.org**.

A great place to start is their booklet “It’s in Your Hands: Legal Information for Seniors and Their Families”, available to download at: **https://www.legalinfo.org/wills-and-estates-law/plan-ahead**

Finding a lawyer

If you have more questions or concerns about any of the topics in this section, consider speaking with a lawyer who specializes in wills, estates, trusts or elder law. Some may offer a free or low-rate introductory consultation.

Here are some ways to find a lawyer:

- A friend or family member may refer you to a lawyer.
- You can look in your local phonebook or search online.
- Your Employee Assistance Plan or union may offer help with finding a lawyer.
- The LISNS Lawyer Referral Service will give you the name and telephone number of a lawyer who can meet with you for 30 minutes for a fixed fee of $20 plus tax. During this time, you can discuss your situation, get an idea of what your options are and what costs are involved.

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

Power of attorney

What is it?

A power of attorney (POA) 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**.

Why is it important?

By law, Nova Scotians aged 19 or older are assumed to be able to make their own decisions. This is known as “having capacity”. However, an illness or injury can sometimes take away that ability, which is why it’s important to name someone you trust in a power of attorney, to make decisions on your behalf if you need.

How can I make one?

You can get a blank power of attorney form online or at stationery or drug stores. These forms are inexpensive and may work in some cases.

However, the safest way to make a power of attorney is with a lawyer. If you own property like a house, cottage, camp or land outside Nova Scotia, it can be useful to consult with a lawyer. It’s important to get legal advice if there might be questions about your legal capacity or if you made the power of attorney voluntarily.

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 apply to be named as your **representative** to make decisions on your behalf. The person does not have to be a family member. 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 have capacity. An **enduring** power of attorney makes sure your attorney can act and make decisions if you lose the capacity to manage your property and finances.

You have two choices for when an enduring power of attorney takes effect: as soon as it is signed and witnessed or only if you lose capacity.

LISNS created a **free app** to make an enduring power of attorney: **https://www.legalinfo.org/poa**

Advance care planning

What is it?

Advance care planning means thinking about what kind of health and personal care you would like if you couldn't make decisions for yourself, and sharing these wishes with family and friends, either by talking to them or writing them down.

Why is it important?

As difficult as it is to think about this topic and discuss it with your family, advance planning allows you to have agency when you have no capacity to make decisions. You can be sure that procedures you don't want to go through will not be done to you. At the same time, having a plan set in place will ease stress for your family when your condition worsens. There will be no doubt or conflict within the family over the medical decisions or what you would've wanted.

How do I express my wishes?

You can outline your wishes in a personal directive and choose a 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. Share this plan with your doctor, so it can be reflected in your medical record.

Personal directive

What is it?

Personal Directive is a legal document that lets you name another person, known as a delegate, to make personal care decisions for you when you cannot do so yourself. Beyond choosing a delegate, you can leave instructions for different personal care scenarios. These instructions can be specific or may speak more broadly to your values about personal care and quality of life. In a personal directive, personal care decisions include healthcare, residence and support services, but 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.

How do I make one?

You can get a personal directive at stationery stores, drug stores or online. These options are inexpensive and useful in many cases. However, the safest way to make this document is with a lawyer. Please inform your primary care provider about both your delegate and personal care instructions.

Caregivers Nova Scotia offers an **Advance Care Planning** workshop. Contact us to learn when the next one is hosted.

You can find more **information** on creating a personal directive from the Nova Scotia Hospice Palliative Care Association at: **https://nshpca.ca/advance-care-planning/**

You can find **instructions** on creating a personal directive and download sample forms at: **www.novascotia.ca/just/pda**

LISNS created a **free app** My Personal Directive: **https://www.legalinfo.org/personaldirective**

What if I don’t have one?

If you don’t have a personal directive, your healthcare provider will ask a "statutory decision maker" to make personal care decisions for you. In most cases, it’s your closest relative, which may or may not be ideal.

Depending on the situation, someone may have to go to court and ask to be named your delegate to make personal care decisions on your behalf. The person does not have to be a family member. This court process can be time-consuming and expensive.

Will

What is it?

A will is a legal document that lets you determine how you want to distribute your money and property after your death. You also name your executor, the person who will carry out your final wishes. A will has no legal effect until you die.

Why is it important?

Caregivers often play a major role in distributing the care recipient's assets after their death. This is a difficult and time-consuming task, made even more complex by the stresses of long-term caregiving. To make your job easier, make sure your care recipient has an up-to-date will.

How can I make one?

You can get a will form online or at stationery or drug stores. These forms are inexpensive and may work in some cases.

However, the safest way to make a will is with a lawyer. It's important to get legal advice if there might be questions about your legal capacity or if you made the power of attorney voluntarily.

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

LISNS created a **free app** to make a simple will:
https://www.legalinfo.org/will

What if I don't have one?

If you die without a will, or you have a will but it is not legally valid, your property is distributed to the people considered to be your nearest relatives (Intestate Succession Act). The distribution may be different from what you want, which is why the up-to-date will that outlines your wishes is important.

Joint ownership

What is it?

When one person owns property or money, they have the right to decide how it's used or spent. With joint ownership, two or more people share that right and must make decisions together. For caregivers, joint ownership most commonly involves shared bank accounts or co-owning a home.

Joint bank account

A joint bank account has more than one owner. Each owner can put money in and take money out.

Spouses often share a joint account. In some families, a parent adds an adult child to their account to help with financial matters, like paying bills, especially if the parent is sick or can't get to the bank. Usually, only the parent adds money, and the child helps manage it.

Considerations

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:

- **Talk with your bank.** There may be alternatives to having a joint account that will still meet your needs.
- **Trust is essential.** A joint account owner can take money out at any time, even if they didn't deposit any. Make sure you completely trust the person before adding them.
- **Be open with family.** If you're a caregiver and part of a larger family, your use of a joint account may be closely watched by others. Be sure all spending is clearly for the care recipient's benefit, and keep good records.
- **Discuss what happens if one of the account owners dies.** For example, if the care recipient dies and has been the only person depositing money, 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 like a house is a big responsibility. Generally, the owner can borrow money against it or sell it.

Many couples own their home together as **joint owners with right of survivorship**. This means that when one of the spouses dies, the other inherits the home automatically. In this case, the transfer of ownership is easy, more cost-effective and requires less paperwork.

Sometimes, a widowed parent adds an adult child as a joint owner. This might be part of an informal plan where the child provides care to the parent and, in return, inherits the home. This can be a big decision, so it's best to get legal advice to make sure it fits the parent's goals.

Considerations

While joint ownership is easy and cost-effective, there are some things to keep in mind:

- Both owners must **agree and sign on all major decisions**, like selling the house or using it to borrow money.
- The property becomes **part of the child's financial affairs.** This means it could be affected by divorce assets splitting or business bankruptcy, all while the parent still lives in the house.
- Anyone who owns **more than one residence** may have to pay **extra income tax**. Consult a taxation expert before agreeing to own the house jointly.
- 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 wellbeing.

In fact, **67% of caregivers** in Atlantic Canada have reported experiencing financial hardship as a result of their caregiving responsibilities[16].

Many caregivers miss workdays, reduce their hours or leave their jobs. Out-of-pocket expenses grow, such as travel, household-related expenses or home modifications. As a result, some caregivers use savings or take on new debt.

Some caregivers face more financial stress than others. This includes women (especially those caring for a child with a disability), men caring for a spouse, racialized caregivers, newcomers, people nearing retirement, those in poor health and those spending more time caregiving[17].

This section gives a quick look at programs and benefits that may ease the financial pressure on caregivers or care recipients. Details are current as of writing, but may change over time.

Nova Scotia Health Continuing Care

Continuing Care offers a range of programs and services to help you, or someone you are caring for, live independently at home. For a list of programs and services, see page 64.

To learn more, visit https://www.nshealth.ca/continuing-care (English) or https://www.nshealth.ca/soins-continus (French), or call 1-800-225-7225.

Fact sheets on programs and services caregivers and care recipients may be eligible for: www.novascotia.ca/dhw/ccs/live-well-at-home.asp

Benefits offered through Employment Insurance (EI)

Compassionate Care Benefit – provides up to 26 weeks of compassionate care benefits for caregivers who are caring for a seriously ill family member with a high risk of death within 26 weeks.

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) – 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 call 1-800-206-7218 or visit their website:
www.canada.ca/en/services/benefits/ei

Federal and provincial credits and programs

There are a few credits and benefits you can claim on your income tax return.

Child Disability Benefit (CDB) – a tax-free monthly benefit for families caring for a child under 18 with a serious, long-term physical or mental disability. Parents must qualify for Canada Child Benefit (CCB), and their child must be eligible for the Disability Tax Credit (DTC).

Disability Tax Credit – a non-refundable tax credit for people with a serious, long-term physical or mental disability.

Canada Caregiver Credit (CCC) – a non-refundable tax credit for caregivers who support a spouse, common-law partner or a dependent with a physical or mental impairment.

Medical Expenses Tax Credit – a refund on eligible medical expenses for yourself, spouse or common-law partner and your dependent children who were under the age of 18 at the end of the tax year. Located on line 33099 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 – 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, more information: **https://beta.novascotia.ca/apply-property-tax-rebate-property-tax-rebate-seniors**

Seniors Care Grant - a grant that helps low-income seniors with the cost of household services (lawn care, snow removal, grocery delivery, transportation, small home repairs and phone service), healthcare services (physiotherapy and mental health support, etc.), and home heating.

More information: **https://beta.novascotia.ca/apply-help-household-healthcare-and-home-heating-costs-seniors-care-grant**

Private insurance benefits

Critical Illness Insurance - pays a lump sum if you are diagnosed with a serious illness and survive. You can use this money 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.

Long-term Care Insurance - helps cover the costs of care either in a long-term care home or at home. It gives families options when choosing the type of care and where it can be provided.

To learn more, ask your **financial advisor** or **insurance agent**. You can find details of what specific providers offer online. Some employers may offer these insurances as an employee benefit.

Services in Nova Scotia

There are many different services offered to caregivers and care recipients in Nova Scotia. This section gives a brief overview of existing services with contact information for your convenience.

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

Navigating the healthcare system and coordinating services is not easy. You may feel frustrated by how inconvenient, limited and hard to access some services are.

If you don't see a service you need or want more information about ones that are listed, 211 Nova Scotia can help. They can provide information and referrals to connect you to local community groups, non-profits and government organizations.

Call or text 211 to contact a Community Resource Navigator, or start a live chat at ns.211.ca

Government services

Many services by government agencies are offered for no or low cost. Here are some government agencies that provide services you might find useful.

Nova Scotia Health Continuing Care

Continuing Care offers a range of programs and services that help you or someone you care for live independently at home.

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

- **Home Support Services** help people with bathing, dressing, preparing meals, respite and light housekeeping.
- **Home Support Direct Funding Program** helps eligible Nova Scotians with funding to hire Home Support Services.
- **Nursing Services** are provided at a local clinic, where available, or at home if someone is unable to attend a clinic. This can include IV therapy, catheter care, peritoneal dialysis, wound care and general nursing care. Nursing services require a physician or nurse practitioner order.
- **Caregiver Benefit Program** financially helps eligible low-income caregivers. Those who qualify can receive a benefit of $400 a month.
- **Personal Alert Assistance Program** helps eligible people buy a personal alert device or emergency response service.

For more information, contact **Continuing Care**.
1-800-225-7225 | https://www.nshealth.ca/continuing-care

Nova Scotia Department of Seniors and Long-term Care (SLTC)

SLTC supports the wellbeing of older adults by overseeing long-term care facilities and government-funded home care agencies, funding programs by Continuing Care and connecting seniors to programs and services through the Positive Aging Directory.

The directory is updated yearly; you can get a copy by calling **211** or by visiting novascotia.ca/seniors/directory/partners and filling out a short request form.

Adult Protection and Senior Abuse

The department works with partners to help protect older adults from abuse under the Adult Protection Act and the Protections for Persons in Care Act.

Adult Protection Services help adults at serious risk of self-neglect or abuse who can't protect themselves due to a permanent mental or physical condition. Suspected abuse must be reported to the Department of Seniors and Long-Term Care at **1-800-225-7225**. Call **911** if the person is in immediate danger.

The Protections for Persons in Care Act applies to people aged 16+ in hospitals or licensed care settings. It requires staff to report all allegations of abuse, including physical, emotional, sexual, medical, neglect and theft. Anyone else may report abuse under this Act by calling 1-800-225-7225.

For support and information on senior abuse, visit **www.novascotia.ca/seniors**. You'll find details about community Senior Safety Programs and 'Understanding Senior Abuse' - a section on how to recognize physical, sexual, emotional and financial abuse, violations of human rights and neglect, what to do if you suspect abuse and where to find help.

Nova Scotia Department of Opportunities and Social Development - Disability Support Program (DSP)

The DSP provides residential and day programs for adults with intellectual or physical disabilities, or long-term mental illness. Residential services range from support for families caring for a family member at home to full 24-hour residential support.

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

Veterans Affairs Canada

Veterans Independence Program (VIP) - offers eligible caregivers for veterans financial assistance for services like grounds maintenance, housekeeping, personal care services, nutrition services and health and support services by a health professional.

Caregiver Recognition Benefit (CRB) - a tax-free monthly benefit directly to caregivers of veterans who receive a disability benefit and require high levels of care or supervision due to their service-related health conditions.

For more information, contact **Veteran Affairs Canada:**
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.

Respite can be defined as a short-term relief that gives caregivers a much needed break from their responsibilities. While it can serve as a crisis intervention, ideally it is part of a broader network of support for both caregivers and care recipients[18].

Respite care can be provided by family, friends, volunteers or healthcare workers, and it takes many forms, such as enjoying a coffee with friends while your care recipient attends an Adult Day Program. Respite is **beneficial for care recipients too**: it allows them to participate in activities outside their home and learn new skills.

Respite can be provided **at home or in a care facility**, and may range from a few hours to several days or weeks. It's best to arrange respite care in advance, as setting up respite may take time depending on availability and demand in your area.

In Nova Scotia, **Continuing Care** coordinates access to in-home respite and licensed respite beds in long-term care facilities across the province. A Continuing Care Coordinator will evaluate your caregiving situation and determine if you and your care recipient are eligible for respite care. If you qualify, using **all of the hours you're allotted** can be a valuable way to support both you and your care recipient.

Continuing Care
1-800-225-7225 | www.nshealth.ca/clinics-programs-and-services/respite-and-caregiver-support

The Department of Opportunities and Social Development also offers help with respite through the Disability Support Program. This program provides supports and services, including the Direct Family Support for Children and the Flex Individualized Funding Program, for children and adults with disabilities who live at home with their families.

Other agencies that offer respite care can be found below.

Veterans Affairs Canada
Toll-free: 1-866-522-2122 | www.veterans.gc.ca

RespiteNS
902-446-4995 ext. 24 | www.respitens.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 of private care providers.

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 vary and 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 home care services and assistance with activities of daily living to Nova Scotians of all ages who require support to stay in their homes.

Home care services can help with: bathing, dressing, meal prep, light housekeeping, respite, nursing services and more.

For more information, call **1-800-225-7225**.
A Care Coordinator will provide an assessment. Depending on the income of the caregiver and care recipient, there may be a fee for some services.

Continuing Care for Indigenous Peoples

Indigenous people living in the communities in Nova Scotia may qualify for provincially and federally funded home care. 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.

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

Veterans Affairs Canada created the Veterans Independence Program to help care recipients remain healthy and independent in their own homes or communities. See **page 66** for more information.

The Victorian Order of Nurses (VON) offers a wide range of community healthcare solutions. 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.

1-888-866-2273 (VON-CARE) | www.von.ca

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 of private home care providers.

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 access a variety of equipment, including wheelchairs and seating inserts, walkers, home safety equipment, communication devices for children and orthotic/orthopedic devices.

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

Personal response services usually include a help button worn on the wrist or around the neck. When pressed, it sends an alert for help based on your instructions. It can be life-saving, especially for people who live alone. Personal response services are available through government, non-profit and private providers in Nova Scotia. Contact us to learn more.

Many other organizations provide assistive devices and services. If you would like more information, please contact us.

Please note: while we provide information about the existing services, we cannot recommend one service over another.

Transportation

Access-A-Bus (AAB)

AAB is a shared, door-to-door, public transportation service operated by Halifax Transit. Buses are specifically designed for people who, due to physical or cognitive disabilities, are unable to use the conventional Halifax Transit system. All buses are equipped to accommodate passengers with various mobility needs.

902-490-6999 | www.halifax.ca/access-a-bus

Rural Transportation Association (RTA)

RTA providers throughout the province offer door-to-door transportation services for appointments, shopping, social outings and more. Some providers offer long-term options for daily commutes, such as school or work. The service supports people with accessibility needs, older adults and low-income individuals by offering accessible vehicles at affordable rates.

902-896-8959 | www.ruralrides.ca

Nova Scotia Department of Health Boarding Transportation and Ostomy (BTO) Program

The BTO program provides financial help for travel and accommodations for eligible cancer patients.

For more information, call 1-800-563-8880.

VON Transportation Program

The program provides affordable door-to-door transportation for seniors and adults who need assistance because of a disability. Available in many areas across the province.

To register for the VON Transportation program, or if you would like more information, please call 1-888-866-2273.

Other local transportation services may be available in your area. You can find details about transportation options across the province on our website.

Accessible parking

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

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

Meals

Food banks and meal programs are available in communities across the province.

If you need food, visit ns.211.ca or call 211. They're available 24/7 to help connect you with resources in your community.

You can also use **Feed Nova Scotia**'s Find Food tool below for information on food banks and meal programs: www.feednovascotia.ca/find-food

House cleaning and maintenance

Some agencies that offer home care may also provide house cleaning and maintenance (see “Home Care” on **page 69**). Private companies also offer house cleaning services.

See “House Cleaning” in your local telephone book or visit the “Resources” section of our website.

Housing

The Nova Scotia Provincial Housing Agency (NSPHA) operates and maintains public housing for low-income Nova Scotians. They operate different types of housing across the province, from single-family homes to high-rise apartment buildings.

To learn more or apply for public housing, visit nspha.ca or contact your **local district office**.

Cape Breton Island District
Phone: 902-539-8520
Toll-free: 1-800-565-3135

Metropolitan District
24-hour switchboard: 902-420-6000
Toll-free: 1-800-565-8859

Northern District
Phone: 902-752-1225
Toll-free: 1-833-776-0585

Western District
Phone: 902-681-3179
Toll-free: 1-800-441-0447

Improvements, modifications, adaptations, loans and grants

The Nova Scotia Department of Municipal Affairs and Housing offers loans and grants through Housing Nova Scotia to help lower-income residents fix or adapt their homes so care recipients can stay at home.

They also offer support to eligible renters and homeowners to help with housing costs like rent, mortgage and utilities.

To learn about home repair and adaptation programs, call 1-844-424-5110.

For rent supplement programs, call 1-833-424-7711.

Read more on both: housing.novascotia.ca

Information and support

Caregivers Nova Scotia Association

We focus on empowering caregivers, supporting them and recognizing the important role they play. In this handbook, we've included the services and supports we believe are most relevant to caregivers, but the list is not complete.

If you're unsure which organization to contact or want to talk to someone about a service and how it might help, please contact us. We'll be happy to connect you with the right support for your situation.

902-421-7390 | Toll-free: 1-877-488-7390
www.caregiversns.org | info@caregiversns.org

211

Dialing 211 connects you to the community and social services across the province, regardless of where you're located. You can also visit: www.ns.211.ca

988 Suicide Crisis Helpline

This free helpline offers live support for anyone who is thinking about suicide or worried about someone. It's accessible across Canada by phone and text. If 988 doesn't work, call 1-833-456-4566. Visit 988.ca for more information.

811

811 connects you to non-emergency health information and services. A Registered Nurse will give you the advice and information you need. If you are hearing-impaired, call 7-1-1 (TTY). If dialing 811 doesn't work, dial 1-866-770-7763. You can also visit their website: https://811.novascotia.ca/

Nova Scotia Health

Nova Scotia Health offers a variety of education resources, services and supports for patients and their caregivers.
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.

ALS Society of New Brunswick & Nova Scotia
902-454-3636 | Toll-free: 1-866-625-7257 | www.alsnbns.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
Toll-free: 1-877-544-4495 | www.autismnovascotia.ca

Brain Injury Association of Nova Scotia
Toll-free: 1-833-452-7246 | www.braininjuryns.com

Canadian Cancer Society
TTY 1-866-786-3934 | Toll-free: 1-800-639-0222 | www.cancer.ca

Canadian Mental Health Association
Toll-free: 1-877-466-6606 | www.novascotia.cmha.ca

Canadian National Institute for the Blind (CNIB)
902-453-1480 | Toll-free: 1-800-563-2642 | www.cnib.ca

Craig's Cause Pancreatic Cancer Society
Toll-free: 1-877-212-9582 | www.craigscause.ca

Cystic Fibrosis Canada – Atlantic Region
Toll-free: 1-800-378-2233 | www.cysticfibrosis.ca/atlantic-canada

Diabetes Canada, NS Regional Office
902-453-4232 | Toll-free: 1-800-226-8464 | www.diabetes.ca

Health Equity Alliance of Nova Scotia
902-425-4882 | Toll-free: 1-800-566-2437 | www.healns.ca

Heart and Stroke Foundation Nova Scotia
Toll-free: 1-888-473-4636 | www.heartandstroke.ns.ca

Hope for Mental Health
902-465-2601 | hope4mentalhealth.ca

Huntington Society of Canada
Toll-free: 1-800-998-7398 | www.huntingtonsociety.ca

LungNSPEI
902-443-8141 | www.lungnspei.ca

March of Dimes After Stroke Program
1-800-263-3463 | www.afterstroke.ca

MS Canada
902-468-8230 | Toll-free: 1-800-268-7582 | mscanada.ca

Muscular Dystrophy Canada – Atlantic Canada Region
1-800-567-2873 | www.muscle.ca

Nova Scotia Cancer Care Program
Toll-free: 1-866-599-2267 | www.nscancercare.ca

Nova Scotia Hospice Palliative Care Association
782-321-9181 | www.nshpca.ca

Parkinson Society Nova Scotia
902-404-0792 | www.parkinsonsocietynovascotia.com

Prostate Cancer Canada Atlantic Region
Toll-free: 1-888-939-3333 | www.prostatecancer.ca

Society of Deaf and Hard of Hearing Nova Scotians
Halifax and mainland (Voice/TTY): 902-422-7130 |
Cape Breton (Voice/TTY): 902-564-0003 | www.sdhhns.org

Support Groups

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

Accessing healthcare

Access to medical care in Nova Scotia has changed recently.

As always, if you or the person you care for is experiencing a potentially life-threatening emergency, call **911** or go to your nearest emergency department. The 24-hour mental health crisis line is available at **1-888-429-8167**, suicide crisis line - at **988**.

For non-urgent health concerns, contact your primary care provider. If your provider is not available or you do not have one, there are other services available to help you.

811

Call 811 to speak with a registered nurse for healthcare advice, general information about your health concerns and services that are available in your area. This service is available 24/7 and in over 125 languages. You can find information on more than 500 health topics at 811.novascotia.ca.

Need a Family Practice Registry

The Registry connects Nova Scotians who do not have a primary care provider with a family practice. Add your name to the registry at needafamilypractice.nshealth.ca or call 811.

VirtualCareNS

VirtualCareNS allows Nova Scotians to connect to a primary care provider online through their computer or mobile device.

If you're on the Need a Family Practice Registry, the service is free. If you already have a primary care provider, you get two free virtual care visits through Maple per year.
Your local library may help you access VirtualCareNS.

For more information, visit virtualcarens.ca.

Community Pharmacies

Community pharmacists are able to provide a range of healthcare services, including assessing and prescribing for some minor ailments, such as skin conditions, tick bites and urinary tract infections. They can also renew some prescriptions and are authorized to prescribe and inject some vaccines and medications.

To find a pharmacy near you, visit pans.ns.ca/find

Urgent Treatment Centres

These centres treat urgent but not life-threatening medical issues. Unlike emergency, these centres do not receive ambulances and see patients by appointment only.

Learn more at: nshealth.ca/urgenttreatmentcentre

HealthyNS.ca

This website offers free online wellness sessions led by healthcare professionals, plus reliable info on healthy living. Anyone can sign up, no referral needed. Visit: healthyns.ca

YourHealthNS

YourHealthNS allows you to view your health records, navigate health and wellness information, book services like blood tests, flu shots and x-rays, and discover care options from your mobile phone or computer.

Download the YourHealthNS app or visit www.yourhealthns.ca

For more information on these services or to see what options are available in your area, visit **www.nshealth.ca/wheretogoforhealthcare** or contact 211.

Additional resources

Some agencies offer information, programs or services tailored for specific communities. If you or your care recipient identifies with a particular cultural background or is a part of a visible minority, the organizations below can be helpful. This list is not exhaustive.

Indigenous

Each First Nations community has a health centre providing primary care services to the community.

For contact information and more, visit:
https://mha.nshealth.ca/en/topics/group-identity/first-nations-indigenous

Mi'kmaw Native Friendship Society
902-420-1576 | www.mymnfc.com

Native Council of Nova Scotia
902-895-1523 | Toll-free: 1-800-565-4372 | www.ncns.ca

24-Hour Residential Schools Crisis Line
1-866-925-4419

Hope for Wellness Helpline
Available 24/7 by phone at 1-855-242-3310 or by chat at www.hopeforwellness.ca

Tajikeimɨk
Representatives from all 13 Mi’kmaw First Nations, including Grand Council, Chiefs and Health Directors, are working together to build and transform the health and wellness system to better serve Mi’kmaw communities now and into the future.

Toll-free: 1-833-884-8254 | www.mhwns.ca

Nuji-Apoqnmuet (Mi’kmaw Patient Helpers) Team
Provides support to Mi'kmaw and Indigenous community members and their families while they are accessing health services in a hospital.

1-833-884-8254 | https://mhwns.ca/programs/nuji-apoqnmuet-team

Tui’kn Partnership
Health partnership of the five Cape Breton First Nations. This initiative seeks to achieve a model of primary healthcare that is holistic, multi-disciplinary, comprehensive and supportive of the vision of improved health and quality of life in First Nations communities.

902-564 6466 ext. 2810 | www.tuikn.ca

Union of Nova Scotia Mi’kmaq Mental Wellness Team
The Team offers wellness services for First Nations people of all ages in the five Unama’ki communities and Paqtnkek (Antigonish County). They provide care directly and work with community and provincial groups to improve access to other wellness services.

902-539-4107 | www.unsm.org/dept/mental-wellness

Acadian or Francophone

En 2022, la FFANE, en collaboration avec la CNS et d'autres partenaires, a publié une traduction française de ce manuel.

Contactez-nous pour demander une copie par courrier ou une version numérique peut être trouvée sur notre site web: https://caregiversns.org/francais/manuel-du-soignant

La Fédération Acadienne de la Nouvelle-Écosse (FANE)
902-433-2088 | www.acadiene.ca

La Federation des Femmes Acadiennes de la Nouvelle-Ecosse (FFANE)
902-433-2088 | www.ffane.ca

L'Office des affaires acadienne/Office of Acadian Affairs
Toll-free: 1-866-382-5811 | acadien.novascotia.ca

Réseau Santé - Nouvelle-Écosse
902-222-5871 | www.reseausantene.ca

African/Black Nova Scotian

Association of Black Social Workers
902-407-8809 | 1-855-732-1253 | www.nsabsw.ca

The Health Association of African Canadians
902-405-4222 | haac.ca

Office of African Nova Scotian Affairs
902-424-5555 | Toll-free: 1-866-580-2672 | ansa.novascotia.ca

Nova Scotia Brotherhood Initiative
902-434-0824 | www.nshealth.ca/clinics-programs-and-services/nova-scotia-brotherhood-initiative-nsbi

Nova Scotia Sisterhood
902-399-5473 | https://www.nshealth.ca/clinics-programs-and-services/nova-scotia-sisterhood

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.

Contact your Cancer Patient Navigator:
toll-free 1-866-524-1234 | www.nscancercare.ca

Family Resource Centres

Family Resource Centres across the province can be excellent sources of information and support. There are many centres across Nova Scotia, each offering a range of services to its surrounding community.

To find the Family Resource Centre nearest to you, visit the Nova Scotia Association of Family Resource Programs at www.nsfrp.ca or contact **211**.

2SLGBTQIA+

2SLGBTQIA+ Health Guide - Nova Scotia Health

https://library.nshealth.ca/LGBTQ/About

prideHealth

prideHealth is a partnership of Capital Health and the IWK Health Centre. It supports 2SLGBTQIA+ people by improving their access to safe, coordinated, comprehensive and culturally appropriate primary health care.

902-487-0470 | www.cdha.nshealth.ca/pridehealth

SUGAR Health

Connects the 2SLGBTQIA+ community to essential sexual, gender and reproductive (SGR) healthcare, forges links between healthcare providers and clients and empowers practitioners with resources to elevate their SGR services.

1-888-299-2066 | www.sugarhealth.ca

The Youth Project

A non-profit organization that provides support, education, resources and social services for youth across Nova Scotia around sexual orientation and gender identity.

902-429-5429 | https://youthproject.ns.ca

Immigrant or Newcomer

Immigrant Services Association of Nova Scotia (ISANS)

An agency providing settlement and integration services to newcomers to Nova Scotia.
902-423-3607 | Toll-free: 1–866-431-6472 | www.isans.ca

Association of Translators and Interpreters of Nova Scotia

Maintains an online directory of translation and interpretation services offered by members of the association. Member of the Canadian Translators, Terminologists and Interpreters Council.
https://www.atins.org

Persons with disabilities

Accessibility Directorate

Responsible for administering the Accessibility Act and advancing disability issues within government. The Accessibility Directorate works collaboratively with individuals with disabilities, municipalities, businesses, post-secondary institutions and others to achieve the goal of an accessible Nova Scotia by 2030.

TTY: 1-877-996-2667 | Toll-free: 1-800-565-8280 |
www.novascotia.ca/accessibility

Inclusion NS

A provincial non-profit, supporting people with intellectual disabilities to live full and inclusive lives in the community.

902-469-1174 | Toll-free: 1-844-469-1174 | www.inclusionns.ca

Nova Scotia League for Equal Opportunities

A provincial consumer organization that provides information and referrals to all Nova Scotians regarding disability issues.

TTY: 902-455-6942 | Toll-free: 1-866-696-7536 |
https://www.nsleo.com/

DIRECTIONS Council

A not-for-profit supporting people with disabilities through its 32 member agencies throughout Nova Scotia. They promote employment and inclusion of persons with disabilities in their communities.

902-466-2220 | www.directionscouncil.org

reachAbility

reachAbility provides supportive and accessible programs that build capacity for inclusion and equalize the playing field for people facing barriers. Their programs, camps and events are free to all clients.

Phone/TTY: 902-429-5878 | www.reachability.org

The Nova Scotia Residential Agencies Association (NSRAA)

NSRAA is a coalition of not-for-profits providing community-based residential support options to people with disabilities in Nova Scotia. https://nsraa.ca

Seniors

Canadian Association of Retired Persons (CARP)

CARP is a national non-profit advocating for Canadians as they age, especially focusing on healthcare and financial security.

902-495-8284| www.carp.ca

Aging Well Nova Scotia (formerly Community Links)

Aging Well Nova Scotia works in collaboration with senior-serving organizations to promote and support age-friendly, inclusive communities and to ensure older Nova Scotians are connected and valued.

902-422-0914 | Toll-free: 1-855-253-9355 | www.agingwellns.ca

Seniors' Advisory Council of Nova Scotia

An independent advisory body made up of nine organizations dedicated to improving the wellbeing of Nova Scotian seniors.

https://novascotia.ca/seniors/groupIX.asp

Seniors Connect NS

A free, phone-based recreation program offering group programs that make it safe and easy for seniors to participate in interesting activities, meet new people and make meaningful connections – all from the comfort of home.

902-410-7092 | https://www.seniorsconnectns.ca

We Are Young

A non-profit organization that works with sponsors, volunteers and its community to grant unfulfilled wishes to seniors.

902-701-8848 | https://weareyoung.ca

Young Caregivers

Young Caregivers Association

A non-profit based in Ontario with a mission to see a Canada where Young Caregivers and their families are recognized, supported and empowered to achieve their full potential.

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

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

When things change

Your role as a caregiver may change over time.

Sometimes, changes happen gradually, as a care recipient becomes healthier and no longer requires care.

Other times, 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 daily activities without assistance. When this happens, it may be time to consider home care services or explore assisted living or long-term care.

Your regular routine might shift. Health challenges, whether physical or mental, can make it difficult for you and your care recipient to participate in activities you once did.

In some cases, changes happen abruptly when palliative care becomes necessary.

In any of these times of transition, your role as a caregiver can be challenging. You may experience a range of feelings: grief, anger, sadness, confusion and relief are just a few examples. Change and shifting responsibilities can add to your stress.

We're here to help. 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.

Hospice and palliative care resources

Nova Scotia Hospice Palliative Care Association
902-818-9139 | https://nshpca.ca/

Nova Scotia Health - Palliative Care
https://library.nshealth.ca/Palliativecare

Canadian Virtual Hospice

This organization has an excellent series of caregiving demonstration videos, covering daily tasks like helping with movement, administering medications and personal hygiene.

www.virtualhospice.ca

Dying with Dignity

This charity empowers Canadians and defends their end-of-life rights so they can navigate the dying process in a way that reflects their values and wishes.

1-800-495-6156 | www.dyingwithdignity.ca

Medical Assistance in Dying (MAiD)

It's a legal process allowing individuals with specific serious conditions to receive assistance from a medical practitioner in ending their life. A person seeking MAiD must meet a number of criteria.

1-833-903-6243 | maid@nshealth.ca | www.nshealth.ca/about-us/medical-assistance-dying

Grief

While many people associate grief with the death of a loved one, it can happen at any point in the caregiving journey.

Often, grief begins with **transitions in caregiving**. For example, when the care recipient gets a serious diagnosis or moves to a long-term facility, the role shift may feel like a loss. Health challenges can make it difficult to enjoy routine activities you once shared, and you may grieve the sense of closeness these moments provided. Memory or behavioural changes due to conditions like dementia, cancer or a brain injury can affect how you connect with the person. Divorce, separation and long-distance caregiving may create an emotional distance. These shifts can leave you feeling a sense of loss, even though the person is still alive.

This kind of grief can take different forms. **Anticipatory grief** can occur when your care recipient's health is gradually declining or when you're preparing for the possibility of their death. You may feel sorrow, anxiety or helplessness as you watch them change over time. Another form, known as **ambiguous loss**, is experienced when there is no clear sense of closure. It can happen when someone is physically present, but emotionally or cognitively changed. For example, when a care recipient progresses to the moderate stages of dementia and their memory changes become more significant, a caregiver might grieve the loss of the person the care recipient used to be. This kind of grief can be just as painful as grieving someone who has died.

> **"Grief is like the ocean; it comes in waves, ebbing and flowing. Sometimes the water is calm, and sometimes it is overwhelming. All we can do is learn to swim."**
>
> \- Vicki Harrison

It is important to remember that any emotions you experience during your caregiving journey, including grief, are completely normal. Give yourself permission to grieve, laugh, be angry, or cry. You may need extra support from family and friends during these times, as well as from your doctor, a counsellor, your religious organization or a grief support group.

To find a support group in your area, visit **https://caregiversns.org/how-we-help/peer-support-groups/** and choose your region.

See more bereavement resources here: **https://caregiversns.org/resources/peolc/grief-and-bereavement-resources/**

Exercise: after caregiving

When your caregiving role ends, there are a lot of emotions to process and things to think about. You might be considering big life changes – returning to full-time job, moving to another house, starting a family or retiring.

This may be a good time to reflect on your caregiving. Here are a few prompts to help you.

1. Since becoming a caregiver, what new skills have you developed? How do these skills help you in your personal or professional life?

2. How have your interests changed since you became a caregiver?

3. What have you learned about yourself?

4. What have you learned about people around you - friends, family members, neighbours or your community? Have any relationships changed because of caregiving?

Being an advocate

If you've ever requested a service or information for your care recipient, taken time to educate others about caregiving or spoken with a local politician about caregiving issues, you've helped to give a voice to both your care recipient and other caregivers. People who do this are often called advocates.

> **"Never believe that a few caring people can't change the world. For, indeed, that's all who ever have."**
>
> - Margaret Mead

Advocating for yourself

As a caregiver, you'll often find yourself advocating for your care recipient. You may need to become familiar with a health insurance policy, request a suitable housing option or suggest ways to improve existing services.

Don't forget to speak up for yourself; you deserve support, too. Service providers need to hear from caregivers like you to meet your needs better.

If you're not comfortable with this role, that's okay. Sometimes the best way to advocate is to simply ask for help. If you know someone who's good at speaking up, ask them to support you. A family member could come with you to appointments or help you figure out how to handle concerns with your employer or healthcare provider.

Advocating for others

One way to support other caregivers is by sharing your experiences with people in your community.

You can also talk to your local Member of the Legislative Assembly (MLA) or your Member of Parliament (MP) about caregiving. Let them know how existing programs and services helped you and where they can be improved.

Your voice can help bring positive change. The first step toward better support is being heard.

Contact your MLA:
902-424-4661 | www.nslegislature.ca

Contact your MP:
1-866-599-4999 | www.ourcommons.ca

Advocating for others

There are organizations that work to influence public policy on behalf of all caregivers. Here are a few of them.

Caregivers Nova Scotia Association

Caregivers Nova Scotia is dedicated to providing recognition and practical support to friends and family giving care.
We participate in various government task forces, advisory groups and research to help influence public policy for caregivers.

For more information on how we advocate, please contact us.

Canadian Centre for Caregiving Excellence (CCCE)

The CCCE supports and empowers caregivers and care providers, advocates for the National Caregiving strategy and initiates research about caregiving.

416-322-5928 | www.canadiancaregiving.org

Checklist: information about you and your care recipient

Filling out this page can make it easier to find the information when you need it.

About you

Name: ______________________________

Address: ______________________________

Mobile phone: ______________________________

Work/home phone: ______________________________

Health card number: ______________________________

Family doctor: ______________________________

Pharmacy: ______________________________

Health Insurance company: ______________________________

Policy number: ______________________________

About your care recipient

Name: ______________________________

Address: ______________________________

Mobile phone: ______________________________

Work/home phone: ______________________________

Health card number: ______________________________

Family doctor: ______________________________

Pharmacy: ______________________________

Health Insurance company:

Policy number: ______________________________

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

Checklist: frequently called numbers

Useful numbers

Keep this list somewhere you can find it easily,

Family doctor: ____________________

Health insurance: ____________________

Local hospital: ____________________

Pharmacy: ____________________

Lawyer: ____________________

Care provider: ____________________

Caregivers Nova Scotia: ____________________

Other numbers:

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Glossary

Activities of daily living (ADLs) - 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 end-of-life care. 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 their death.

Assistive devices - items that make daily activities easier 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 member, 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 and provide care to all age groups. Also called: carer, unpaid caregiver.

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

Caregiver distress - a state when a caregiver is no longer able to continue with caring activities and expresses feelings of distress, anger or depression due to the physical, psychological and financial demands of caregiving.

Enduring Power of Attorney - a document that 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.

Expressive behaviour - a term that refers to how actions, words and gestures are a response that expresses something important about someone's personal, social or physical environment. Also called: responsive behaviour.

Instrumental Activities of Daily Living (IADL) - the daily tasks someone does to take care of themselves and their home. These are more complex than ADLs and include things like managing finances, shopping, meal preparation and cooking, housekeeping, transportation and using the phone.

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.

Substitute decision maker - the person you choose to make medical decisions on your behalf in the advanced care plan. This can be anyone you trust and who is capable of honouring and carrying out your wishes. Also called: a delegate.

Young caregiver - an individual under 24 years old who gives unpaid care and support to parents, grandparents, siblings or friends due to a chronic illness, disability, mental health condition or other challenges, such as language barriers.

Notes

www.caregiversns.org

The Caregiver's Handbook

resources • advice • checklists

www.caregiversns.org