

The Caregiver's Handbook

Section 1

GETTING ORGANIZED

In this section you will find checklists, plans, charts, and other tools to help you get organized. There is also information on caring for someone with challenging or responsive behaviour, caring for someone when you are a long-distance caregiver, health crisis planning and emergency preparedness, as well as tips on communicating with friends, family, and healthcare providers about your caregiving needs.

The charts, checklists, and schedule of care activities can be downloaded from our website as blank templates.

Help for Unpaid Caregivers
in Nova Scotia


Caregivers
Nova Scotia
for friends and family giving care

www.CaregiversNS.org

Getting Organized

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

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

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

www.CaregiversNS.org/Resources/Handbook

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

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

Developing a Daily Care Plan

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

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

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

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

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

Schedule of Daily Care Activities

Sunday

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

Medications

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

A few tips:

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

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

MEDICATION CHART for: _____ DATE: _____

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

Family doctor's name and telephone number: _____

Name of pharmacy and telephone number: _____

Notes: _____

Meal Planning

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

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

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

Cooking Tips (from Canada's Food Guide):

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

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

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

Preferences: _____

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

The ‘To Do’ List

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

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

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

The ‘To Do’ List:
How Family and Friends Can Help

Tasks	Who Can Help

Communicating with Family, Friends, And Healthcare Providers

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

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

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

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

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

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

Healthcare Providers

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

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

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

Continuing Care

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

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

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

Discharge Planning

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

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

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

Health Crisis Planning and Personal Emergency Preparedness

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

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

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

How do I plan for a health crisis?

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

How do I prepare for an emergency?

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

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

Canadian Red Cross:

1-877-356-3226 | www.redcross.ca/ready

Government of Canada:

www.getprepared.gc.ca

Helping When You Are a Long-Distance Caregiver

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

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

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

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

- **Investigate local services.** Discuss with your care recipient what services may be needed. They may already be aware of local options for home healthcare, meal delivery, or transportation. Ask what you can do to assist them in setting these up.

Caring for Someone with Responsive or Challenging Behaviour

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

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

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

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

- Virginia Bell & David Troxel

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

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

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

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

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

Responsive Behaviour in Alzheimer's Disease⁸

Agitation

Possible causes:

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

Tips that may help:

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

Wandering

Possible causes:

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

Tips that may help:

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

Challenging Behaviour in Autism⁹

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

Possible causes:

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

General tips that may help:¹⁰

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

Support

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

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