

Living with Dementia



These materials were put together by a group of researchers and practitioners in New Brunswick who work with older adults. Our aim was to help older adults in New Brunswick navigate the complex landscape of information, services, forms, and resources. We hope that you will find this helpful.

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www.stu.ca/aging-in-nb/

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Have you noticed changes in your thinking, memory, or ability to do everyday activities? If so, talk with your family doctor or nurse practitioner and loved ones about your concerns.

Dementia is not a normal part of aging. Here are some of the differences:

NORMAL AGING	DEMENTIA
Getting lost in a new or unfamiliar place.	Getting lost in a familiar place, like your neighborhood or your home.
Missing a monthly payment, every once in a while.	Difficulty taking care of monthly bills. Not able to take care of banking or paying for every day shopping items.
Forgetting some events from a year ago.	Forgetting events from yesterday or the past week. Not able to remember upcoming appointments, even with frequent reminders.
Sometimes forgetting someone's name or what you were talking about.	Having a hard time following a conversation. Often repeating questions or stories. Trouble naming common items or close family members and friends.
Losing things from time to time.	Often misplacing things and not being able to find them, or later finding them in odd places.
Getting the day or date mixed up.	Losing track of time. Being unable to remember the date, season or year.
Being a bit slower to finish a normal task.	Taking a long time or not being able to complete a day-to-day task.

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There are other conditions that can cause symptoms similar to dementia. The following medical issues should be looked into before a diagnosis of dementia can be confirmed:

- Hearing loss
- Medication side effects
- Infection
- Depression or grief
- Delirium

It is important to understand why the changes in your thinking, memory and behaviour are happening. Early detection of dementia is important. Plan a visit to your doctor or nurse practitioner if you think you might be experiencing early signs of dementia.

If you do not have a family doctor or nurse practitioner, you can visit a general walk-in clinic in your area.



Tip: To rule out these other conditions, talk with your doctor or nurse practitioner, have your hearing tested and speak with your pharmacist about your medications.

Preparing to visit your doctor



When you make an appointment, tell the receptionist you have concerns about your thinking and memory. Ask what you can expect during the appointment, how long it will take, and if you can bring someone with you.

Be prepared for the visit! Use the checklist below to note the types of problems you have been having. If possible, note when you first noticed the problem:

PROBLEMS I AM EXPERIENCING	DATE THAT I (OR OTHERS) FIRST NOTICED THE PROBLEM
Attention: Do you often lose your train of thought or become easily distracted?	
Coordination: Do you have trouble using familiar tools (e.g., having a hard time using a common tool such as a screwdriver)?	
Mood: Do you feel low or have no interest in activities that used to be fun?	
Daily activities: Do you have trouble doing daily activities (e.g., making a light snack)?	

PROBLEMS I AM EXPERIENCING	DATE THAT I (OR OTHERS) FIRST NOTICED THE PROBLEM
Planning: Do you have trouble organizing your day or judging the safety of a situation (e.g., Can you explain what to do if there was a fire in your house)?	
Getting lost: Do you often get lost (e.g., when walking or driving)?	
Vision: Do you have trouble seeing or being able to recognize familiar faces?	
Memory: Do your family members get annoyed because you ask the same questions over and over?	
Language: Do you have trouble following instructions that have lots of steps (e.g., following directions like, "After you change your clothes, put your boots on and then meet me in the car.")?	
Walking: Has there been a change in your ability to walk or have you been falling more often?	
Personality and Behaviours: Are you... • Seeing or hearing things that aren't there? • Becoming suspicious of others? • Acting unusual in social situations?	



Tip: Write down a list of questions you have for the doctor or nurse practitioner. Take your questions and the above checklist to your next appointment with them.

Tip: Make a list of all the specialists or other doctors who care for you and take all your medications to your appointments.

At the Doctor's appointment

Ask someone you trust to come with you to your appointment and to take notes. If possible, ask them to help you remember details or make a list about what you have been experiencing. It is important that you speak on your own behalf.

Once you are at the appointment with your family doctor or nurse practitioner, let them know if you have hearing loss, vision problems, recent illnesses, periods of grief or struggles with mental health, and if there is a family history of dementia or other diseases.

The appointment will likely involve:

- a) History taking. The doctor will ask about your memory and how you have been making out at home (use the checklist on the previous page).
- b) Physical and neurological exam. The doctor may listen to your heart and lungs. They may also test your reflexes or ask about changes in your strength.
- c) Memory Screening. The doctor may conduct a paper and pen test to assess your memory.
- d) In some cases, the doctor may also order blood tests and other tests, such as an MRI or CT scan, to help confirm the diagnosis or to rule out other diseases.

The appointment may end with the doctor giving you a diagnosis, or they may want to do more tests.

If you are diagnosed with dementia, here are some questions that can be helpful to ask your doctor or nurse practitioner:

- What type of dementia do I have?
- What stage of dementia am I in?
- What kinds of treatments can help (e.g., medications, occupational therapy)?



Tip: Write down the answers or have someone with you who can help you to remember.

After a dementia diagnosis

People can feel many different emotions after receiving a diagnosis of dementia. If you need to talk with someone about your feelings, call the Alzheimer Society of New Brunswick at **1-800-664-8411** or email **info@alzheimernb.ca** and ask about their free services. Even though they are called the “Alzheimer Society,” they have information about all types of dementia.

Next steps:

TALK TO SOMEONE

When you are ready, talk to those you are close to about your diagnosis of dementia and the emotions you are experiencing.

LEARN ABOUT DEMENTIA

There are different kinds of dementia, including Alzheimer’s disease, vascular dementia, fronto-temporal dementia, Lewy-Body dementia and mixed dementia. Learning about the type of dementia you have can help you understand your experience.



Tip for caregivers: It is difficult to watch a person with dementia’s symptoms progress. Knowing about dementia and the various symptoms can help you prepare and build strategies.

The Government of New Brunswick’s Dementia website has answers to many common questions about dementia.

Visit their website at: gnb.ca/dementia.

FIND INFORMATION AND SUPPORT

The Alzheimer Society of New Brunswick offers the First Link program, which focuses on helping you live well with dementia. Although they are called the “Alzheimer Society,” they provide information and supports for all types of dementia.

Contact the Alzheimer Society for more information on these programs or to access free services. Call **1-800-664-8411** or email **info@alzheimernb.ca**.

PLAN FOR THE FUTURE

Dementia is a progressive degenerative disease, which means that the symptoms will get worse. Try to learn about the type of dementia you have, the symptoms you are likely to experience and build strategies to help you manage.

Each person's progression through dementia is unique. It is important to stay independent but equally important to accept others' help. Planning for the future is a way to feel in control. Think about what is important to you and make sure to write down your wishes and talk to family members, friends and your lawyer about your wishes. Here are some things to think about and plan for:

- Driving is a complex skill and eventually you will not be able to drive. See the chapter on "Driving Safety and Aging" for more information.
- You may eventually need help to remain in your home. See the chapter on "Home Support Services" for more information.
- You may need to consider moving into a Long-term Care facility. See the chapter on "Long-Term Care Homes" for more information.
- It is very important that you have a Will and Enduring Powers of Attorney signed before you lose the capacity to make these documents. See the chapter on "Legal Matters" for more information.



Tip: Make a list of family or friends you want to share your diagnosis with. Start with a small group and gradually, as you are comfortable, share your feelings about your diagnosis.

Tip: Tell people how to help you. For example, ask for appointment information to be written down. If an appointment will involve a lot of details, go with a person you trust who can help with complex decisions.

Tip: If you are employed, contact your employer's Human Resources department and ensure you know your rights at work.

Supports for Caregivers

Caregiving can be rewarding but it can also be difficult. It is important to recognize what you can do yourself and when you need help. Be realistic.

Take care of yourself

Maintain your own health and wellness so you can remain a caregiver for someone else.

Recognize burnout

- Are you feeling angry, withdrawn, anxious, or exhausted?
- Are you having trouble sleeping or concentrating?
- Have you gained or lost a lot of weight lately?

These can all be signs of stress. Take care of yourself by reaching out to friends and family to talk about your feelings and ask for help.

Build a Support network

- Make a list of people you can rely on for help and note what kinds of tasks they can do (e.g., preparing meals, driving, running errands, picking up groceries).
- Ask in your community about people who can help drive you or the person you are caring for to appointments.
- Have a list of friends who are available to chat on the phone. Keep their phone numbers close by.
- Talk with people who add humour to your day, or who can share a joke and help you remain positive.
- Ask friends or family members to make a meal for you or the person you care for.
- Look for services to help with the care work of cooking and cleaning (see the chapter on “Home Support Services.”).
- Talk to your employer about potential accommodations and supports. This could include things like working from home, extended lunches, flexible hours, etc.



Tip for caregivers: Follow up with your regular medical and dentist appointments. Don't let your appointments get lost in the business of caring for others.

Tip for caregivers: Tell people when you are feeling overwhelmed! Talk to friends and family. You can call **1-866-355-5550** to access free mental health support 24/7. Visit socialsupportsnb.ca/healthcare for more resources.

Tip for caregivers: The Alzheimer Society of NB offers free counselling services and support groups for caregivers, family, and friends of people living with dementia. Visit <https://alzheimer.ca/nb/en> or call **1-800-664-8411**.

Think About Using Home Respite or Relief Care

Respite or relief care is a service that gives short-term breaks to caregivers. This can be during the day or overnight.

You can apply for respite care through the Department of Social Development's Long Term Care Program. For more information, call **1-833-733-7835**, visit socialsupportsnb.ca/LTC or Google "Social Supports NB Long Term Care Program."

The following are common respite/relief care services (also see the chapter on "Home Support Services" for more information on each of these):

Medical Alert Systems: These tools can help ease the anxiety of caregivers who cannot be with the person they are caring for all the time. Medical Alert Systems allow individuals to call for help in an emergency. Some services also offer automatic fall detection, motion sensors, or medication reminders. For more information:

- **Carelink Advantage** – Visit <https://carelinkadvantage.ca/>, Google "carelink advantage," or call **1-866-876-7401**.
- **Lifeline** – visit <https://www.lifeline.ca/en/>, Google "Lifeline Medical Alert Canada," or call **1-866-729-0532**.
- **Caretrak** – Visit <https://www.caretrak.ca/>, Google "caretrak," or call **1-855-333-3381**.
- **Telus LivingWell Companion** – Visit <https://www.telus.com/en/personal-health/livingwell-companion>, Google "telus living well," or call **1-855-724-0031**.

Meals on Wheels: This service provides hot, nutritious, and affordable ready-made meals. To find out if there are services in your area and for more information, call **2-1-1**, visit <https://socialsupportsnb.ca/en/program/meals-wheels> , or Google “Meals on Wheels NB”.

Adult Day Centers: Adult Day Centers offer a safe and supervised setting outside of the home. (See chapter on “Home Support Services” for more information.)

Home Support Services: Home support services may be able to help with a variety of daily activities like cooking, bathing, and cleaning. (See chapter on “Home Support Services” for more information).

Special Care or Nursing Home Respite: Some special care or nursing homes offer short-term respite care for caregivers. Cost and availability vary by location. Visit nb.211.ca online or call **2-1-1** for a list of special care or nursing homes in your area. For more information, see socialsupportsnb.ca/ltc.



Financial Tip: Do you need help paying for respite care services? Call the Department of Social Development at **1-833-733-7835** or try their online Financial Help Calculator to see if you qualify for financial help at [Socialsupportsnb.ca/financialhelpcalculator](https://socialsupportsnb.ca/financialhelpcalculator).