# Caregivers' Guide



Practical information for caregivers of older adults



# Table of contents

Introduction
Caregivers
Caregivers who are employed
Contingency planning
Personal care
Quality of life
Physical environment of the older person
Communication
Legal concerns
Services available under the Long-Term Care Program
Preparing for the move to a long-term care facility
End of life care
Financial assistance for caregivers
Conclusion
Additional resources

The Caregivers' Guide is published and distributed by the Department of Social Development PO Box 6000 Fredericton, N.B. E3B 5H1

Printed version: ISBN 978-1-4605-1166-4 PDF version: ISBN 978-1-4605-1167-1

December 2016

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# Introduction

More than eight million Canadians are family caregivers. They are individuals (family members, neighbours, friends and other significant people) who take on the caring role to support someone as he or she ages. With an aging population, it is no longer a question about if someone will assume the role of caregiving; rather it is when. Today, New Brunswickers are living longer and with fewer health issues than in the past; however, most seniors continue to be challenged by at least one chronic disease or condition.

Family caregivers play an important role in helping seniors remain at home. It is well known that seniors prefer to stay in the familiar surroundings of their home for as long as possible, but eventually, they may require help to do so. In many instances, this can be achieved with enhanced supports from the community. These, in turn, may help delay or even avoid the need for more costly forms of long-term care services, such as hospitals, special care homes or nursing homes. It may also lead to better overall health and quality of life for your loved one.

This guide provides information to individuals who are now, or anticipate becoming family caregivers. It provides advice about various aspects of caregiving as well as practical ways caregivers can adapt their lifestyles and living environments to ensure a better quality of life for themselves and the senior for whom they are caring.

Please be advised that all the information in this guide is provided for informational purposes only and is not a substitute for professional medical advice, diagnosis or treatment. It should be noted that programs can change. Details should be obtained directly from the sources mentioned.

Caregivers in the midst of their many day-to-day responsibilities often do not take care of themselves and run the risk of developing health problems and feeling stressed. To help you manage your caregiving responsibilities, we have included information about available services and programs and suggestions about self-care and the importance of building and enlisting the help of a support network.

# Caregivers

# Caregivers who are employed

Balancing work and caregiving responsibilities is a challenge. Many caregivers are also raising children, volunteering, working and more. Employers are recognizing that the struggle to balance work and family commitments has important implications for employee productivity. As a result, more workplaces are promoting family-friendly organizational policies such as flexible work arrangements, family leave, Employee Assistance Programs and educational opportunities. If you are experiencing difficulties balancing work and caregiving responsibilities, ask your employer about what help is available through your workplace.

# Taking care of yourself

The caregiver is a very important person in the life of the care recipient. Providing support can be demanding, requiring time and energy. Many caregivers suffer health problems as a result of the intense physical and emotional demands of looking after someone. As a caregiver, it is essential to look after yourself.

# The personal satisfaction of caregiving can include:

- developing a new relationship with the person for whom you are caring;
- having the opportunity to give back;
- feeling a sense of purpose, accomplishment and satisfaction;
- developing new skills and knowledge;
- increasing understanding and compassion; and
- making new friendships through your support network.

Caregiving is rewarding, but it is normal to have emotions that challenge your effectiveness as a caregiver.

Emotions you may experience include feeling:

- frustrated at your inability to meet all of the older person's needs or to balance your caring roles and personal life;
- resentment about the changing relationship and your new role as a caregiver;



Caregivers are strong and courageous individuals who play an important and invaluable role in society.

- anger and frustration about the physical/mental changes the older person is experiencing;
- guilt about not doing enough or not making the best choices; and
- grief about the loss of your loved one's abilities. You may also grieve the loss of future plans or the relationship you once had with the individual.

As a caregiver, you may feel upset about these feelings. This is a normal reaction. Taking out your frustration on others only adds to your feelings of guilt and loss of control. It also creates tension between you and others. If you find yourself reacting negatively to the person for whom you are caring, take a break and do something positive for yourself.

### Tips:

- Seek options for relief services, such as day activity centres for seniors and respite beds in special care homes and nursing homes.
- Arrange for services such as Meals on Wheels, telephone reassurance calls and safety checks.
- Collaborate with employers to encourage the implementation of more flexible work policies to support family members assisting seniors.
- Help families learn how best to carry out the tasks of caregiving by making information available when needed.

Sometimes care recipients will not want to accept help and prefer to assert their need for independence. They can feel frustrated, too, and they may be grieving over their loss of independence. Respect their choices even if you do not agree with them. Be a patient listener and allow them to express their feelings. This may improve their outlook, and your understanding of the situation may help improve communication. As long as there is no risk of danger to themselves or others, it is important for them to be able to make their decisions wherever possible.

Accept that there are some things you cannot change, so focus on the things you can.

#### Tips:

- Help the care recipient cope with his or her feelings; his or her life is changing, too.
- Instead of focusing on what the care recipient can no longer do, choose to focus on what he or she can still do.
- If the care recipient has a medical condition, learn about it and how you can best care for him or her. This will help you to feel better equipped and allows you to be prepared for changes that may happen over time, so you can be better able to plan for future needs.
- Familiarize yourself with common behavioural changes. Knowing what to expect can help you to cope better.
- There is a difference between "helping" and "doing" adopt an approach that promotes the care recipient's independence whenever possible.

Always make time for yourself, even if it is just an hour or two.

# Take care of your health

#### Tips:

- Get adequate rest, good nutrition and sufficient exercise.
- Trust your abilities and talents.
- Be gentle with yourself and others.
- Take a rest and recharge.
- Try to be aware of your limitations.
- Let go of grievances and grudges.
- Maintain your hobbies and interests.
- Caregiving can be exhausting; do not feel guilty about arranging respite breaks for yourself.
- Do not be afraid to ask for help! If you are feeling overwhelmed, seek advice from a friend, a caregiver support group or a health-care professional who can offer insights, comfort and support to help you cope and get through the transition in your life.
- When friends and family members offer help, welcome their assistance and do not be afraid to be specific about what kind of help you need. It can be as simple as running an errand for you, helping with childcare or even making a casserole to help with meals.
- Community organizations may also provide some of the help you need.

#### Learn to recognize the signs of stress

- Denial.
- Anger.
- Social withdrawal.
- Anxiety/worry.
- Difficulty sleeping.

- Exhaustion.
- Difficulty concentrating.
- Health problems.
- Weight gain or loss.

### More ways to take care of yourself

#### Tips:

- Be realistic about how much you can do.
- Be positive your attitude affects how you feel and the way you approach your caregiving role.
- Accept your feelings in a single day, you may feel content, angry, guilty, happy, sad, embarrassed, afraid and helpless. These feelings may be confusing, but they are normal.
- Remember anger and resentment are often symptoms of exhaustion. Taking time to rest and recharge is not being lazy.
- Reach out to family, friends, health-care professionals or community resources for help.
- Take advantage of relief or respite programs, which provide temporary care while you take a break from caregiving.



An honest conversation can help relieve tension, resolve problems and erase negative feelings.

# **Respite care options**

Relief or respite care can be provided by an informal system of family members or friends. It can also be obtained through the Department of Social Development's Long-Term Care Program:

- Day activity centres for seniors provide caregiver relief, social support and meaningful social/recreational activities in a group setting. There is a daily fee for these services, but it may be subsidized for eligible clients. A small daily fee is charged to cover the cost of snacks and meals.
- Home support services help with daily activities such as personal care (examples: feeding, grooming, bathing), housekeeping and meal preparation. This service could provide you with relief care for personal time or errands or assistance with care needs that you may need support to complete (example: a safe transfer into a bathtub or into a chair). Relief care can be provided to give support to families or caregivers to keep seniors in their homes and delay or prevent placement in residential facilities or hospitals. Temporary relief can be provided in a person's home, a special care home or a nursing home.

Respite care offers you a break and time to relax. Relief staff can provide quality care in your absence. Using respite staff allows you and the care recipient to become familiar with the respite staff and be confident in the care provided.

To access these services under the Long-Term Care Program (see page 27), contact any regional office of the Department of Social Development, 8:30 a.m. – 4:30 p.m., Monday to Friday (closed on statutory holidays):

- Acadian Peninsula: 1-866-441-4149
- Chaleur: 1-866-441-4341
- Edmundston: 1-866-441-4249
- Fredericton: 1-866-444-8838
- Miramichi: 1-866-441-4246
- Moncton: 1-866-426-5191

- Restigouche: 1-866-441-4245
- Saint John: 1-866-441-4340
- For more information:
- Email: sd-ds@gnb.ca
- Web: www.gnb.ca/seniors

Some communities offer senior living facilities to individuals able to live more independently than others but do not want the concerns of maintaining a home. These rental facilities offer access to meals, social activities and events, transportation and housekeeping service. Staff are available for emergency support when required 24 hours a day.

Recognizing one's need for help is a sign of strength in itself.

### Your support network

Learning to accept help is central to self-care for every caregiver. The following are examples that could be included in your support network:

- Family members Listen to each other and come to a mutual agreement on plans for the care recipient. It may be helpful to identify the role for which each family member will take responsibility. Family members who live far away can also help. For more information, see page 8.
- A professional/community team:
  - $\circ\,$  Trained caregivers are ideal for relief care, even if only for an afternoon or evening.
  - $\circ\,$  A home support worker can help with personal care such as bathing and dressing.
  - Community groups such as the Alzheimer Society of Canada, the Canadian Cancer Society, Ability New Brunswick can provide information and services that could help you in many ways.
  - Caregiver support groups are a good way to share experiences and advice with others in a similar situation.
- The Internet is a great source of information, providing links to various organizations and available resources to help you in your caregiving role.
- Assistive devices such as walkers, wheelchairs, raised toilet seats, bedside commodes, shower chairs and grab bars can help you provide care and allow for more independence for the care recipient. See page 19.
- Technology such as Lifeline or Care Link Advantage can help the care recipient live independently and summon help in an emergency.

# How family, friends and neighbours can help

Family, friends and neighbours are important sources of support for caregivers.

#### Tips:

- Take time to listen let the caregiver know you are there to talk if he or she is feeling overwhelmed.
- Be specific with your offers of help. Instead of an open-ended offer such as, "Let me know if you need anything," try a more concrete offer such as, "I am going to the store. Would you like me to pick something up for you?"
- Offer to relieve the caregiver encourage him or her to relax, spend time on a favourite activity or run some errands.
- Provide a change of scenery suggest an outing to the park or a visit to your home that could include the care recipient.
- Choose an activity that everyone will enjoy and arrange a suitable time for the visit.
- Keep in touch a visit, a telephone call, a card, an email or a text can mean a great deal.



- Visits should be relaxed, engaging and not rushed. Be sensitive to the health condition of the care recipient.
- Talk about things the person enjoys, or chat about everyday happenings, the weather, pets, children or grandchildren.
- Stay the course caregiving is often a long journey. Any support you can provide along the way will be appreciated.

#### What you might not know about caregivers

- They often feel alone and isolated from friends and family.
- They are often reluctant to ask for help, even though they may need assistance.
- They sometimes could use help with errands or household tasks.
- They experience stress that can affect their health.
- They need regular breaks from caregiving.
- They often need someone to listen.

# Contingency planning

Planning for contingencies can reduce worries by ensuring that steps are in place in case of a sudden or unexpected change in the health of the care recipient or the caregiver. All those involved will have the satisfaction of knowing that a system is in place that outlines what needs to be done and who will do it. If the care recipient is mentally competent, ask what his or her future care wishes are and make sure they are respected. Do not be afraid to talk about the what-ifs. It is better to plan ahead than react to a crisis.

#### Tips:

- Keep an up-to-date list of contact information of services providers and programs in the care recipient's area.
- With the consent of the care recipient, arrange for programs and services in the community, such as Meals on Wheels; Canadian Red Cross Telephone Reassurance Calls and Wellness Checks; Home Support Services; Respite Care; and day activity Centre programs for seniors.
- Learn all you can about the health condition of the care recipient.
- Keep a personal notebook or journal where information about the care recipient can be recorded and is easily accessible. It helps to keep it available in the same place, perhaps, near the telephone. This will give you peace of mind in knowing all the pertinent information you require is in one place. Remember to keep it updated. Examples of what to include:
  - Full name of the care recipient.
  - $\circ~$  Date of birth.
  - o Social Insurance Number.
  - Medicare number.
  - Health insurance information.
  - Emergency contact numbers.
  - Up-to-date list of medications what they are for, the dosage and when and how they are to be administered.
  - o Names, addresses and telephone numbers of doctors, hospital and clinics.
  - Dates and times of appointments.
  - Schedule of caregiving events (visits from home support worker, Extra Mural nurse, medical appointments, etc.).
  - o Contact information of family and friends involved in your support network.

# **Caregiving from a distance**

Caring for someone from a distance can be just as stressful as or even more stressful than being there. If you are a long-distance caregiver, you help locate and coordinate services or discuss plans with health-care providers and other family members or caregivers.

You may also delegate tasks, monitor the situation and help make decisions.

If you are not the primary caregiver, make yourself available to the person who is.



# There are a number of ways for a long distance caregiver to participate in caregiving:

- Keep regular contact with the care recipient establish routines for telephone calls, send emails, photographs and if possible arrange for Skype or FaceTime visits.
- Visit as often as you can to provide relief to the on-site caregiver.
- Offer to help with financial matters, such as contributing to the purchase of a piece of equipment.
- The use of technologies can offer peace of mind to caregivers who live at a distance. See page 24.

# Personal care

# Bathing

- Be familiar with the routines and preferences of the care recipient – does he or she prefer a shower, a tub bath or a sponge bath.
- Talk to the care recipient ahead of time so he or she knows when the bath is planned.
- Use a calm and gentle manner and proceed slowly. Do one step at a time, talking the care recipient through each one.
- Maintain a feeling of privacy by creating a calming and relaxing ambiance.
- Make sure the bathroom is warm and inviting.
- Test the bath with your elbow for a safe water temperature.
- To prevent burns, you may want to adjust your water heater's settings. The ideal water heater setting is 120°F (49°C).



Personal care is an intimate time. The care recipient may be modest and feel uncomfortable. If you are helping someone with personal care, it is important to plan plenty of time to allow for all necessary activities while following the person's usual routine as much as possible. The most important part of a personal care routine is maintaining dignity and privacy.

- Use a bath chair in the tub or shower stall.
- A hand-held showerhead can make bathing easier.
- Collect all the necessities, including towel, soap, washcloth, razor, shaving cream and skin lotion, and place them within easy reach.
- Give the care recipient the opportunity to participate in his or her care. Hand the bath items out in order of use, if you are required to do so.

# Hair care

- Encourage the care recipient to choose a cut that is attractive but easy to care for.
- Make shampoos part of the regular shower or bath routine. Dry shampoo can be used between hair washings.
- If a care recipient's movement is limited, a device such as shampoo board or a bath visor can make shampooing easier. Check with a beauty salon equipment supplier or go online to obtain one.
- A visit to or from a barber or hairdresser makes any day special.

# Skin care

Attention to basic skin care is essential to good health. Neglect can lead to painful sores that may require medical attention.

- In older adults the skin is thinner, lacks elasticity and can be easily damaged.
- Prevent pressure sores by making sure the care recipient changes positions, sits or lies on a flotation cushion or sheepskin and wears soft fabrics (such as cotton) close to the skin.



- Check the care recipient's skin daily. Look for red skin over bony parts of the body and blue or dark purple patches. Look for any tenderness or broken skin. If a sore is noted, talk to your health-care provider as soon as possible about how to clean, dress or bandage the area.
- Keep skin clean and moisturized. Use body lotion on dry skin, especially on elbows, knees and soles of the feet.
- Use soaps, antiperspirants and perfumes sparingly, and keep hot baths to a minimum because they dry the skin.
- Apply sun screen when planning outdoor activities.
- Special attention is necessary in cases of incontinence. See page 13.

# Foot and nail care

Foot and nail care, including regular inspections for cracks, cuts or ingrown nails are important in overall health and particularly important for people with diabetes.

- When caring for the care recipient's nails, filing is preferable to cutting.
- Keep toe and fingernails filed straight across. If nails are very thick or difficult to trim, consult a professional such as your family physician or call the Extra Mural Program.
- Watch for signs of discomfort or redness on pressure areas of the foot. Sheepskin protectors or foam can be used to take pressure off the area.
- Seek medical attention if foot sores are noted or there is drainage or an odour coming from a foot sore.

# Oral hygiene

Talk to the care recipient ahead of time to let him or her know that it is time to brush his or her teeth. Encourage regular brushing and gentle flossing.

- Use a soft tooth brush with toothpaste.
- If assistance is needed, take a gentle, slow and patient approach, talking the care recipient through each step.
- If the care recipient resists tooth brushing, stop and try again later.
- Depending on the care recipient's ability, you may need to place your hand over his or hers to guide brushing, or stand behind him or her and brush the teeth.
- Dentures should be rinsed after meals and soaked in water overnight. Keeping dentures in the mouth overnight can promote infections.
- If dentures seem uncomfortable, consult a dental professional to find out if they need to be adjusted.

- Make sure that the care recipient gets regular dental check-ups, even if he or she wears complete dentures.
- If you notice any changes in the mouth, such as a broken or damaged teeth, sores, lumps or swollen gums, have them checked by a dentist or a health-care professional.

# **Clothing and footwear**

- · Choose attractive, comfortable, functional and washable clothing.
- Make sure the care recipient has the right clothes for the right activities as well as extra clothes in case something gets soiled.
- Consider buying duplicates of favourite outfits.
- Choose garments with a minimum number of buttons, fasteners and zippers, and make sure these are all easy to reach.
- Large, flat buttons are easier to manage than small round ones.
- Centre-front fasteners are easier to manage than ones on the side or back.
- Clothes with Velcro fastenings can help increase independence with dressing.
- Zippers should have pull-tabs that are easy to grip.
- Choose loose-fitting pants that can easily be pulled up or down.
- Care recipients who sit for long periods or who are confined to wheelchairs can be more comfortable in short jackets, capes and shawls.
- Long T-shirts, night shirts or night gowns may be better for bed wear.
- Choose warm, comfortable shoes with non-slip soles.
- Opt for Velcro fasteners instead of shoe laces.
- Avoid slippers that lack support or are too large they increase the risk of falls.

### **Eating well**

Good nutrition is important at every age. As we age, our dietary needs change. The key to healthy eating is to plan food choices and meals using *Eating Well* with *Canada's Food Guide*.

To order a free guide:

Telephone: 1-866-225-0709
 Email: publications@hc-sc.gc.ca

A registered dietitian can provide advice tailored to the care recipient's nutritional needs. To find a qualified dietitian in your area:

• Web: www.dietitians.ca

# **Physical activity**

Physical activity helps us remain healthy and maintain our bodily functions. When we do not use a part of our body, we risk losing its functional ability. Remember, exercise should never hurt. Ask a physiotherapist what kind of exercise is best for the care recipient. A first step would be to order the *Active NB SeniorsToolkit*.

To order this guide:

Telephone: 1-855-550-0552
 Web: www.wellnessnb.ca/seniors

# Constipation

Many things can cause constipation. These include a diet high in refined or processed foods and low in fibre. It can also be caused by a lack of physical activity as well as some prescription drugs and over-the-counter medications. Bowel movements can often be regulated by eating well, increasing dietary fibre intake, drinking at least eight glasses of water every day and exercising regularly.

If constipation remains a problem, consult a health-care professional. A limited course of laxatives may be prescribed, but over-use can sometimes worsen the situation.

### Incontinence

Getting to the bathroom can be difficult for those with limited mobility, or who are confined to bed, or whose bedrooms or sitting rooms are a distance from the bathroom.

### Tips:

- Place a commode beside the bed.
- Visit the bathroom regularly (perhaps every two hours).
- Place waterproof protective covers on the bed and furniture.
- Place waterproof pads and sheets in layers on the bed, so when you remove one layer there is a dry surface underneath.
- Have plenty of clean, dry underwear available.
- Check the care recipient frequently for incontinence.
- Use protective underwear liners or disposable underwear and change as required. Protect the skin from too much moisture. Soiled skin is porous to bacteria and prone to infection and breakdown.

Incontinence is not unusual, especially for seniors and people with various health problems and conditions. The choice of absorbent adult briefs will depend on the care recipient's needs. Many are slip-on and look and feel very much like regular underwear. This can help a person maintain dignity and be comfortable during daily activities.

# **Medication**

Make sure that the doctor and pharmacist know about all the medicines that the care recipient is taking. These include prescribed and over-the-counter drugs including vitamins and herbal dietary supplements. This is important because some medications may cause problems when used with other medications.

Be sure the doctor and pharmacist know of any allergies or adverse reactions the care recipient may have had to any medications.

Make sure you know what each medication is for, how it should be taken and what its potential side effects are. Try to use one pharmacy for all medication needs. This way the pharmacist can keep track of the medications and check for possible interactions.

The care recipient's pharmacist will provide counselling to ensure the prescriptions are appropriate and provide the greatest benefits.

Ask the pharmacist about putting medications in a blister pack to simplify their administration.

Keep medications out of sight and reach of children.

### Sleep

In later life, the need for sleep decreases to about six hours on average. Less time is spent in deep sleep; sleepwaking is more frequent; and there is a tendency to nap during the day.

Many things may interfere with optimal sleep in older adults. Acute and chronic illnesses, side effects of some medications, mental health conditions, sleep disorders and abrupt uncontrollable changes in social and personal life may contribute to sleep difficulties. A first step to better sleep is to know what interferes with it.

Having a regular sleep schedule and getting enough sleep every night are especially important for older adults.

#### Tips:

- Good nutrition and physical activity are associated with good sleep.
- Relaxation techniques can assist with physical and mental relaxation.
- The optimal duration of a nap is 10 to 20 minutes. Otherwise, napping during the day
  may take away from total sleep time at night.
- Create the best possible environment for sleep: a quiet and dark room and comfortable ambient temperature.
- Avoid television and other electronic screens in the bedroom.
- Reduce the intake of stimulants such as caffeine, nicotine and alcohol as much as possible.
- Reduce stressful experiences and worries close to bedtime.
- Ask the pharmacist or doctor about the possible side effects of medications on sleep.

### Visiting the doctor

As caregiver, you may need to advocate on the care recipient's behalf when visiting the doctor. This role may involve asking questions and taking notes on the doctor's instructions during appointments.

#### Tips:

- Remember the care recipient should be included and have a voice on making decisions for his or her treatment.
- Communicating clearly with doctors is crucial. Making regular, scheduled visits with enough time to discuss concerns will help you and the care recipient make the most of every appointment. If there are questions following a visit, contact the doctor's office.
- Bring bottles or vials of prescribed and over-the-counter medications, including dietary and herbal supplements with you to the physician's office.

- Keep a journal with notes about the health of the care recipient. Note any symptoms and changes in the care recipient's health and behaviour, include medications taken and the time at which they are taken, as well as any reactions. Bring these notes to appointments.
- You and the care recipient should keep a list of questions to ask the doctor and be prepared for a follow-up visit if time is limited.

# Hospitalization

Should the care recipient require hospitalization, your involvement can facilitate care and treatment.

### Tips:

- Provide as much information as possible to the doctors and nurses who will be providing care to meet the needs of the care recipient.
- Speak to the manager or primary care nurse to find out the best way to make your comments and/or concerns known.
- Care can be greatly enhanced by the presence of family and/or friends who understand the care recipient's capabilities, strengths and limitations, likes and dislikes, fears and anxieties, and who are capable of advocating on his or her behalf.
- A hospital social worker and discharge planner are available to help with questions, support and counselling.



# Quality of life

Focus on what the care recipient can do and respect his or her desire to remain independent.

Even though the care recipient may have some physical or mental challenges, it is very important to recognize his or her knowledge, strengths and talents and to provide opportunities to engage him or her in meaningful activities with family friends and those around him or her. An individual still needs to feel connected.

#### Tips:

- Help the care recipient choose activities that are enjoyable.
- Choose flexible activities that can be adapted to suit the needs of the care recipient.
- Build on the care recipient's strengths and talents; consider activities that relate to his
  or her accomplishments, interests or hobbies.
- Emphasize the importance of doing things, not the result.
- Help the care recipient create his or her memoirs or story of his or her life experiences and accomplishments.
- Look for activities that make the care recipient feel valued and productive. The care recipient may prefer to only watch or help at first, and may join in later.
- Do not insist on participation. Just watching can be enjoyable for some.
- Feeling a sense of inclusion is important. Plan activities that include interactions with family and friends and where the care recipient feels support and connected to others.

Using a personal tablet can help the care recipient connect with family and friends, send or receive emails or view family photographs.

# Activities that promote quality of life

- Walks or drives.
- Listening to music.
- Singing favourite songs.
- Playing an instrument.
- Dancing.
- Gardening.
- Visiting the park.
- Doing a favourite hobby or pastime (knitting, woodcarving).
- Reminiscing/story telling.

- Going through old photograph albums.
- Reading.
- Playing games (cards, board games, video games).
- Having coffee, tea and conversation.
- Visiting with a pet.
- Visiting with young children.
- Surfing the Internet.
- Watching favourite television shows, movies and videos.



#### Reading is a pleasant and enlightening pastime

Consider these tips to make reading more enjoyable:

- Good lighting.
- Large print.
- Illustrations.
- Reading glasses.
- Audio books and e-readers.

A book support (for use in bed and in chairs).

Those willing to read aloud make it possible for others to enjoy the social connection and as well as the joy of reading.

# Daily household activities

The importance of keeping the care recipient involved in daily household activities cannot be overemphasized. Simple but helpful tasks include:

- Setting or clearing the table.
- Helping with food preparation.
- Drying the dishes.
- Dusting.

- Organizing the recycling bins
- Watering plants or gardening.
- Helping with groceries.
- Collecting the newspaper/mail.

### Outings

Change is as good as a rest, and an outing is a pleasure, especially if it is well planned.

- Allow plenty of time to get ready so you do not feel rushed.
- When spending time outside on sunny days, wear sunscreen, sunglasses and a hat.
- At a restaurant, mention any special dietary requirements when you order.
- Call ahead if you are unsure about the accessibility of a building you plan to visit.
- If you would like to obtain a parking permit for persons having a disability, application forms are available from Service New Brunswick:
  - o Telephone: 1-888-762-8600
  - Web: www.snb.ca

# Spirituality

Many seniors draw comfort and strength from their beliefs, and it is important to support them in their convictions. For example, encourage visits from clergy or pastoral care workers if these are important to the care recipient.

For many people, spirituality fosters hope and provides a foundation for the celebration of life. It can help people find meaning in a difficult situation and achieve a sense of inner peace. Spiritual practices can provide comfort and reassurance as well as encourage acceptance of our mortality.

- Folding laundry.
- Folding grocery bags.
- Caring for a pet (brushing or feeding it).



# Physical environment of the older person

Today's advances in medicine and technology make caring for seniors easier than in the past. Contact the Extra Mural office in your area (telephone number found in the white pages of the telephone book) to talk to an occupational therapist about what home modifications, tools and devices are appropriate for the care recipient.

Many assistive devices are available, explore options online or consult a health-care professional or home health outlet.

Providing physical assistance to others may put you at risk of injury. Being familiar with techniques to prevent injury to yourself or the care recipient is important. You can prevent injuries by learning the correct way to help someone roll over in bed, get up from a chair or move from a wheelchair to a car.

#### **Health care equipment**

Seniors can borrow standard and specialized health equipment free of charge from the Canadian Red Cross Society through the Seniors' Rehabilitative Equipment Program. Available equipment includes hospital beds and mattresses, raised toilet seats, over-bed tables, canes, crutches, wheelchairs, walkers and commodes. To obtain equipment, a written referral must be completed by a New Brunswick physician, nurse, physiotherapist or occupational therapist. All equipment is returned to the Canadian Red Cross Society office when it is no longer required. For further information, contact your nearest Canadian Red Cross Society office.

Explore options online or consult home health outlets for the assistive devices available.

# Options to consider for the home:

#### Bathroom

- Install sturdy grab bars by the toilet and in the bathtub/shower area. Grab bars should be securely attached to studs in the wall. The space between the wall and the bar should not exceed five centimetres (two inches). A space any wider could allow an arm to slip through and cause injury.
- Consider installing a raised toilet seat. You may want to consider getting one with arms to help the care recipient get up from the toilet easily.
- Place a comfortable suction bath mat on the floor of the tub.
- Place a non-skid mat beside the tub.
- Showering is often easier than taking a bath, especially when you place a bath chair in the tub or shower stall.
- A hand-held showerhead offers greater water control and is especially useful for those who sit in the shower.
- If only a bath will do but getting into the tub poses a challenge, investigate what equipment and home adaptation options are available.

#### Bedroom

- If the bedroom is on the second level and access is a problem, convert a downstairs room into a bedroom and bathroom or install a stair lift to access bedrooms on the second level.
- Hospital beds can be raised to make it easier for you to work with the care recipient, or lowered to make it easier to get in and out of bed. They also offer several positioning options and have side rails that can be used for support and safety.
- An adjustable-height commode is useful when the care recipient must urgently go to the bathroom, especially at night.
- A securely installed "trapeze" (suspended triangular device to be grabbed to assist in sitting up or standing) may be useful.
- An adjustable over-the-bed table can be used to hold drinks, snacks, books and crafts.

Make sure smoke detectors in the home are properly installed and working.

#### Entryways

- Consider installing motion detector lights to light up the path to the main door.
- Ensure there are handrails on both sides of the stairs. These should be sturdy, securely attached and in good condition.
- Replace doorknobs with levers.
- For easy access to and from the outdoors, an access ramp may be required.

#### **Floors**

- Avoid deep carpets and scatter rugs; they make walking with a cane or walker or using a wheelchair difficult and dangerous.
- Take care that floors are not slippery.
- Remember a shiny floor can cause confusing reflections.
- Keep floors free of clutter to prevent falls.

#### Furniture

- Arrange furniture for ease of movement when using a cane, walker or wheelchair.
- Make sure furniture is sturdy and steady enough that it will not tip if someone leans on it while sitting or standing.
- Avoid chairs with deep seats.
- Choose synthetic fabrics that can be easily wiped clean.
- Upholstered furniture can be treated with protective spray against spills and stains.
- Place contrasting fabrics on the backs and arms of sofas and chairs to help care recipients with visual impairments.
- Consider replacing lamps that have hard-to-reach switches.
- Use footstools with caution because they can become a fall hazard.

#### **Kitchen**

- If necessary, adjust the stove by removing knobs or installing dial guards so it cannot be used without supervision. Many ovens are equipped with a self-locking feature

   if yours does not have this feature, a lock can be purchased separately.
- Keep sharp utensils and small electrical appliances out of sight.
- Use safety latches on cupboard doors if necessary.
- Keep all cleaning products and detergents locked up and out of reach.
- An electric, whistling kettle with an automatic shut-off system can be a safe choice.
- Purchase a fire extinguisher and place it in a visible area of the kitchen.

#### Fall prevention

- Call the Extra Mural Program for a safety assessment.
- Plan for regular vision and hearing tests.
- Install proper lighting throughout the home.
- Check that stairs are in good condition and are slip resistant. Take the same precautions for outdoor steps.
- Arrange to have leaves, snow and ice removed regularly.
- Use salt or sand throughout the winter. Keep a supply handy near the door.
- Choose proper footwear. See page 12.
- Use walking aids and other safety devices for extra safety.
- Make sure that area rugs are non-slip. If needed, secure them with double-sided carpet tape.

You can learn how to react in an emergency by taking a First Aid and Cardiopulmonary Resuscitation (CPR) and automated external defibrillator (AED) course.

For course offerings in New Brunswick:

St. John Ambulance:

- Telephone: 1-800-563-9998
- Web: www.sja.ca/newbrunswick

**Canadian Red Cross Society:** 

- Telephone: 506-674-6200
- Web: www.redcross.ca/atlantic

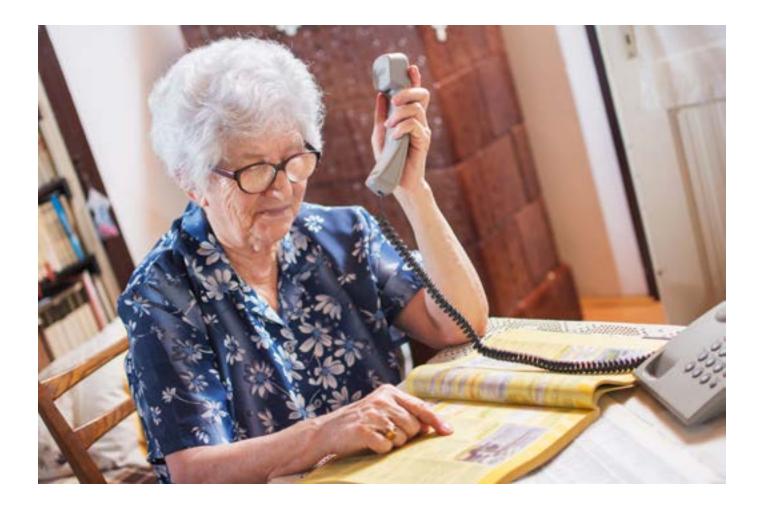
For more information about adapting your physical environment, order a free copy of *The Safe Living Guide*, published by the Public Health Agency of Canada:

- Telephone: 613-952-7606
- Email: seniorspubs@phac-aspc.gc.ca

Some homeowner households may be eligible for a forgivable loan for both disabled accessible modifications and other major repair items (i.e., structural, electrical) to a maximum of \$20,000.

Seniors are eligible for a forgivable loan for minor adaptations to facilitate independent living to a maximum of \$3,500. For more information:

- Telephone: Any Department of Social Development regional office (see page 5)
- Web: www2.gnb.ca/content/dam/gnb/Departments/sd-ds/pdf/Housing/fedprovrepairprog-e.pdf





It's not just about conversation. A touch on the hand, stroking of the hair, a kiss on the cheek, a hug ... says a lot!

# Communication

# **Staying connected**

Continued participation in familiar activities and regular contact with family and friends are extremely important because they provide stimulation and can help maintain independence. Some family members or friends may be reluctant to visit because they no longer know how to communicate with the care recipient. The opportunity for conversations may be limited when the care recipient's ability to express himself or herself becomes compromised. Even though the care recipient may have difficulty communicating, he or she is still aware of his or her surroundings and can still sense the emotional state of others. Even sitting quietly together conveys you care and provides comfort and companionship.

# Conversation

- Listen attentively and try to sense the feelings the care recipient is expressing. You can then respond to the emotional tone of what is being said. For example, "You seem to be upset" or "You look happy today."
- Body language is a useful communication tool. Pay attention to pauses, tone and volume of the voice, gestures, posture and facial expressions.
- Reflect on how you are presenting yourself. Are you tense and frowning, impatient, or calm and reassuring?
- A slow and calm encouraging approach promotes reassurance.
- Use a gentle touch to help convey your message.
- Maintain a normal, adult conversational structure do not use "baby talk" or patronizing language.
- Speak slowly and clearly and allow plenty of time for a response.
- Do not converse with others in front of the care recipient as if he or she is not present. When others are present, remember to always include the care recipient in the conversation.

# **Communication devices**

Communication devices, both simple and sophisticated, can simplify daily activities and are essential in emergencies.

# Consider the following suggestions:

• Invest in a telephone with large numbers and a memory dial feature. A cordless telephone

or cell telephone may be handy for those unable to get to the telephone easily.

- Post large-print emergency and back-up caregiver telephone numbers near the telephone.
- Adjust the telephone volume to an appropriate level.
- A cordless or cell telephone put in a carrying case can be attached to a walker or wheelchair.
- Consider a medical alert or remote monitoring system such as Lifeline or Carelink for a care recipient living alone.
- Talk to your police department if the care recipient might wander away from home. The police can put a plan in place and can react more quickly when they know about the situation.
- The Alzheimer Society has the Medic Alert Safety Home Program that offers an effective way to identify the care recipient who is lost and bring the family back together. Contact your local Alzheimer Society office for more information and to register the care recipient.

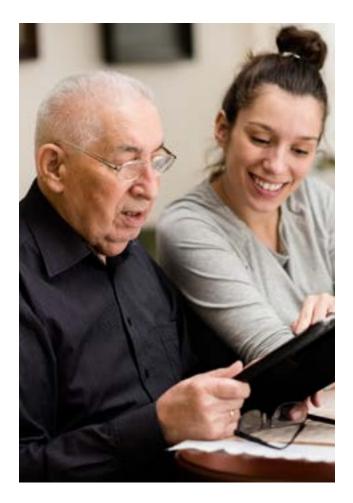
# Independent living with the use of technology

Several technologies are available to help care recipients live independently while providing peace of mind to family members. These are ideal for care recipients who live alone or are alone for long periods, have a medical condition or are at risk of falling. The availability of assistive technology for care recipients is advancing quickly; check online for devices available.

**Medical alert services** allow care recipients to call for help at the touch of a button, ensuring that emergencies are responded to quickly and efficiently. In the event of an emergency, a family member or emergency services are contacted, depending on the care recipient's need. Some medical alert systems can detect falls automatically and activate a call to the proper emergency response system if the care recipient is unable to activate a call for help.

**Monitoring systems** using motion sensors and discrete cameras (optional) allow caregivers to monitor a care recipient's daily activities from a distance to ensure he or she is safe and well. This service can also provide caregivers with instant notifications on selected areas of concern, such as:

- wandering;
- forgetting to take medications;
- sleeping and eating habits;
- absence of activity;
- injuries and other health issues.



# Legal concerns

Plan ahead: help the care recipient settle legal and endof-life matters ahead of time. Although everyone should plan ahead, the care recipient and his or her caregivers may have particular concerns about what might happen if he or she loses their ability to make decisions. The Canadian Hospice Palliative Care Association has resources that may help start the delicate conversation on advance care planning and informs the caregiver and the care recipient on a variety of topics that should be considered.

• Web: www.advancecareplanning.ca

Have a full discussion to seek advice from a trusted financial or legal advisor about the care recipient's personal situation and assets.

#### Things to consider when planning:

- Making a will.
- Making funeral arrangements that respect the care recipient's wishes.
- Considering a pre-arranged funeral.
- Creating a power of attorney for financial matters in which the care recipient (as the donor) gives another person (the donee) the authority to handle his or her financial and property matters. (It needs to be an "enduring" power of attorney for the power to continue if the care recipient becomes mentally incompetent.)
- Creating a power of attorney for personal care in which the care recipient, as the donor, gives another person the authority to make his or her personal and health-care decisions when he or she is unable to do so. This other person should be aware of any advance medical directives, health-care treatment or end-of-life decisions that the care recipient has.
- The care recipient can choose as many donees as he or she wants. The care recipient can require donees act together or as alternates. If the care recipient wishes, he or she may choose the same person or persons to act on his or her behalf for financial matters and personal care decisions. Or, the care recipient may choose a different person or persons to handle each of these matters.

Do not delay. Having a power of attorney can give the care recipient peace of mind knowing that if he or she becomes physically disabled or mentally incompetent, he or she has chosen someone able to act on his or her behalf. If the care recipient delays in giving the power, he or she may be unable to do so when he or she needs it.

#### Important documents should be kept in a safe place but where you can easily access them.

For more information and educational pamphlets on legal topics, contact the Public Legal Education and Information Service of New Brunswick (PLEIS-NB). PLEIS-NB is a provincial non-profit organization and a registered charity. Its mandate is to provide the public with information about the law.

PLEIS-NB does not provide individual legal advice, only general information. A range of educational booklets are available, many dealing with topics of particular interest to seniors, such as wills and estate planning, powers of attorney, abuse and neglect, going to a nursing home, and investment fraud. Anyone requiring specific legal advice should consult a lawyer.

- Telephone: 506-453-5369
- Email: pleisnb@web.ca
- Web: www.legal-info-legale.nb.ca



# Services available under the Long-Term Care Program

Care recipients who need help with daily activities (e.g., mobility, bathing, preparing meals) on a long-term basis may be eligible for subsidized services under the Long-Term Care program. These services may be provided in the home, in an adult residential facility or nursing home. All Long-Term Care services are voluntary, and care recipients need to consent to being referred. Referrals to the Department of Social Development can be made by calling the regional office where the care recipient lives.

#### In-home services overview

Home support services can help a care recipient with his or her daily activities such as personal care (e.g., feeding, grooming, bathing), housekeeping and meal preparation in the comfort of his or her home. This service can also be used to offer relief to caregivers. Additional services that have been detailed in this document such as the monitoring system, Meals on Wheels and adult day programs can be subsidized to eligible care recipients as well.

#### Eligibility

A care recipient's eligibility is based on his or her will to be assessed for services that will address his or her unmet needs with respect to personal care, daily activities such as housekeeping and meal preparation as well as various cognitive and behavioural factors.

Cost

Eligibility for a financial subsidy for any of the in-home support services is determined through a financial assessment.

# Adult residential facilities (special care homes and memory care homes)

#### Overview

Special care homes and memory care homes provide supervision and assistance with daily living for people with limitations who can no longer remain in their home. Some special care homes also offer enhanced services to individuals with dementia or a physical frailty and who require help with all aspects of daily life. The Department of Social Development has a complete provincial list of licensed facilities:

• Web: www.gnb.ca/seniors

#### Eligibility

Care recipients are assessed through the Department of Social Development's Long-Term Care Program for eligibility into adult residential facilities.

#### Cost

Care recipients may apply for a subsidy that will aid in the cost of the placement in a residential facility by undergoing a financial assessment. Care recipients will be able to retain a monthly comfort and clothing allowance that they can use to cover expenses associated with clothing, personal items, co-pay for prescription drugs and haircuts.

# Nursing home services

#### Overview

Nursing home services are intended for individuals who are medically stable and who need access to 24- hour nursing care. Services in nursing homes emphasize the resident's physical, social and psychological independence. These services include resident care, resident support, plant and maintenance and general administration. Nursing homes are staffed with registered nurses, licensed practical nurses, resident attendants, dietitians and personnel in laundry, kitchen, activation, rehabilitation, maintenance and administration.

Moving to a long-term care facility can be made easier if the care recipient is included in the decision. You and the care recipient should plan ahead and understand when and why a move to a nursing home is required.

#### Eligibility

The Department of Social Development must approve all admissions to nursing homes. The department will determine the care recipient's eligibility by looking at his or her long-term health care and social needs. Going into a nursing home is voluntary.

#### Costs

If a care recipient can afford to pay his or her nursing home costs (which cover staff room and board), he or she must do so. If a care recipient feels he or she cannot afford the costs, he or she can apply to the Department of Social Development for a subsidy. A care recipient's ability to pay is assessed based on net income. Assets are not included in the calculation of a care recipient's financial contribution. The maximum amount to be paid by nursing home residents may be adjusted from time to time. For up-to-date information about daily costs and nursing home services:

#### • Web: www.gnb.ca/seniors

Most nursing home residents are entitled to receive medications approved under the New Brunswick Prescription Drug Program at no cost. Residents in receipt of assistance from the Department of Social Development are entitled to retain a personal comfort and clothing allowance. This allowance covers expenses associated with personal items, clothing and medications not covered by the New Brunswick Prescription Drug Program and over-the-counter medications not routinely supplied by the nursing home. Residents who are subsidized are also entitled to a health card providing such benefits as eye glasses, hearing aid and other specific health supplies. They are also eligible to access the HST rebate.

# *Preparing for the move to a long-term care facility*

# A difficult decision

A long-term care placement such as a special care home, memory care home or a nursing home is a very difficult decision for families.

Emotions that may arise for family members include the following:

- Guilt, often leading to second thoughts about the decision.
- Relief that the responsibility of providing care is no longer solely on your shoulders.
- Grief, often based on a fear of the unknown.
- Loss of control over decisions about the care recipient's daily care.
- Anxiety about handing over the responsibilities of caregiving to others.
- Concern about the quality of care provided.
- Worry that the care recipient will have difficulty adapting to his or her new home.

While daily care shifts to the long-term care facility, caregiving does not end. Family members will still play an important role by providing emotional support and becoming advocates for the care recipient.

#### Tips:

- Get to know facility staff and the director of nursing.
- Develop a positive relationship with staff at the home.
- Determine what role you may share in the delivery of care.
- Find out whether there is a family council or advocacy group.
- Join a family caregivers' support group.
- Familiarize yourself with the home's policies and activities.

### Adjusting to the new situation

It will take time for you and the care recipient to adjust. Keep in mind that there is no "ideal" number of times to visit during this period. For some, the strain of caregiving has been such that he or she needs a rest during the first few weeks after the move. Other care givers may want to visit as often as possible.

Stay connected; visit as often as you want and stay for as long as you feel comfortable. The important thing is to make each visit – no matter the length or the frequency – as full and rewarding as possible for the both of you.

The care recipient will also need some time to adjust to his or her new environment. Be patient as he or she settles in. For some, this may take weeks or months; for others, it may be less. Do not hesitate to communicate closely with the staff during this period.

Sometimes, the care recipient adjusts quite well to his or her new surroundings. This may leave you with mixed emotions – while you feel happy that the care recipient is doing so well, you may also feel slightly rejected if he or she seems more content in the facility than at home. These feelings are perfectly natural.

# Practical information for caregivers of older adults

You have not lost your role as caregiver. You are now sharing the responsibility of care with others. An advantage of having outside care is that you can focus your time and energy on providing the care recipient with a sense of love and belonging that no one else can give.



# End of life care

**End of life or palliative care** is health care for people (of any age) and their families who are living with a life-limiting illness, usually at an advanced stage. The goal of palliative care is to manage physical symptoms and provide social, emotional and spiritual support for patients and their families throughout the illness. In some cases, a physician may suggest the option of palliative care either in hospital or at home delivered by the Extra Mural Program.

While providing comfort and dignity is important at all times and is especially important during end-of-life care. Decisions will need to be made throughout the late stage of life. These decisions may be difficult, and you may feel uncomfortable making them.

Some care recipients may have set out advance medical directives to help family members carry out his or her wishes in terms treatment and end-of-life decisions. If these wishes have not been communicated and are not in place through a power of attorney for personal care, respecting the expressed wishes of the care recipient should guide all end-of-life care decisions. If these wishes have not been communicated, knowing the care recipient's values and beliefs can help you make a decision that would most closely resemble one that the person would make if capable of doing so. A guiding principle is to uphold the dignity, privacy and safety of the care recipient.

If plans have not been made, or if there are disagreements among family members, you may want to consider asking a third party – such as a member of the health-care team, counsellor or clergy.

# Financial assistance for caregivers

Although some employers offer flexible work arrangements, the responsibilities of caregiving can still disrupt a caregiver's work life. In addition, many caregivers are paying out-of-pocket expenses to care for the care recipient.

As a caregiver, you may be eligible for assistance from the Government of Canada. Service Canada has prepared a list to help you prepare for this role.

#### 1. Apply for Employment Insurance Compassionate Care Benefits

Employment Insurance (EI) provides Compassionate Care Benefits to persons who have to be away from work temporarily to provide care or support to a family member who is gravely ill with a significant risk of death. You can apply for El online or in person at a Service Canada Centre. You should apply as soon as you stop working, even if you receive or will receive money when you become unemployed.

Self-employed persons who register for EI may also be eligible to receive Compassionate Care Benefits.

#### 2. Claim the caregiver amount on your income tax return

You can claim the caregiver amount tax credit if you lived with a dependant who was one of the following individuals:

- you or your spouse or common-law partner's child or grandchild; or
- you or your spouse or common-law partner's brother, sister, niece, nephew, aunt, uncle, parent or grandparent living in Canada;
- other criteria may apply.

#### 3. Take care of yourself while taking care of others

The *Self-Care for Caregivers Guide* from the Public Health Agency of Canada provides information about taking care of yourself in demanding times.

• Web: www.phac-aspc.gc.ca

#### 4. Explore live-in caregiver options

The Live-in Caregiver Program for employers and caregivers abroad allows professional caregivers to work in Canada. Caregivers are individuals who are qualified to work without supervision in a private household providing care for children, elderly persons or persons with disabilities. Live-in caregivers must live in the private home where they work in Canada.

Application information for the program is available from the federal Department of Immigration, Refugees and Citizenship (formerly known as Citizenship and Immigration Canada):

• Web: www.cic.gc.ca

# Conclusion

With the growing emphasis on independent living, caregivers will continue to play a critical role in helping care recipients remain in their homes for as long as possible. In many cases, a little help from family and neighbours is all that is needed for a care recipient to continue living independently in his or her community. It can be as simple as providing transportation to and from an appointment, shovelling snow, mowing the lawn or running an errand.

We hope the information and suggestions in this guide are useful to you and your family in providing care for a loved one. For information about services and programs available for seniors in New Brunswick and how to access them, contact the Seniors Information Line, 8:30 a.m. – 4:30 p.m., Monday through Friday:

• Telephone: 1-855-550-0552

As helpful as it may be, written material is no substitute for an understanding listener, so remember to reach out to family, friends, professionals and support groups for help. Remember that you are not alone; you have the right to ask questions and to ask for help.

# Additional resources

Websites and contacts that provide information and helpful tips for informal caregivers include:

Department of Social Development

- Telephone:
  - o Acadian Peninsula: 1-866-441-4149
  - o Chaleur: 1-866-441-4341
  - o Edmundston: 1-866-441-4249
  - o Fredericton: 1-866-444-8838
  - o Saint John: 1-866-441-4340
  - o Miramichi: 1-866-441-4246
  - Moncton: 1-866-426-5191
  - o Restigouche: 1-866-441-4245
- Web: www.gnb.ca/seniors

Government of Canada – Information for Caregivers:

- Telephone: 1-800-622-6232
- Web: www.seniors.gc.ca

Alzheimer Society New Brunswick:

- Telephone: 1-800-664-8411
- Web: www.alzheimer.ca/en/nb

Elizz – Online caregiver resource centre:

- Telephone: 1-855-275-3549
- Web: www.elizz.com

Canadian Red Cross Society:

- Telephone: 1-800-588-4881
- Email: az-communityhealth@redcross.ca