The NWT

Caregivers Guide

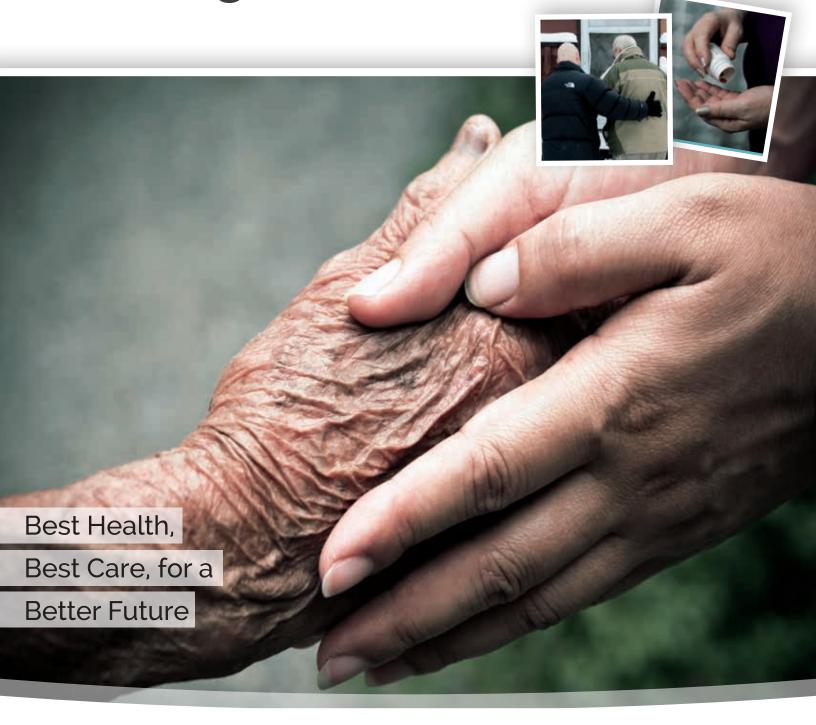


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Introduction

Introduction

The Government of the Northwest Territories Department of Health and Social Services is pleased to share the 2015 *NWT Caregivers Guide(Guide)*, a companion to the *NWT Seniors' Information Handbook*. This Guide is a practical resource for those caring for family, friends or neighbors. The information presented in this Guide is the result of best practice research and feedback from services providers across the NWT.

If you have any comments or suggestions on how to improve this guide, please contact:

Department of Health and Social Services:

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Being a Caregiver

Who are informal caregivers?

Informal caregivers are family members, friends, neighbours or volunteers who provide unpaid care to an individual, which allows them to stay in their home and community, and delays the need for long term care. This is often what individuals and families want, and it is also often the best and most cost effective approach to care.

What do caregivers do?

Every situation is different, but most people need help with one or more of the following:

- Personal care such as: bathing, dressing, and using the bathroom;
- Help around the house such as: cleaning, laundry, meal preparation, and outside work:
- Transportation for appointments, shopping, day programs, socialization etc.; and
- Time spent with family, friends, and community to prevent loneliness.

Some positive things about caregiving include:

- A new relationship with the person you are caring for;
- A sense of purpose, accomplishment and satisfaction;
- Development of new skills and knowledge; and
- Increased compassion.

Practical advice for caregivers

If you are thinking about caring for another person, there are some things you may want to consider before you agree.

- What kind of caregiving help is needed?
- Where will I be providing care?
- How many hours a day can I commit?

Being a Caregiver

- How will I balance caregiving with my other responsibilities?
- Am I physically and emotionally able to provide the care needed?

Caregivers have found it is easier to be a caregiver when they:

- Learn about the person's health condition(s).
- Let the person they care for do as much for themselves as possible.
- Understand the person they care for may have strong feelings about losing their abilities; and that does not mean they don't appreciate your help.
- Keep an up-to-date list of contact information of programs and services.
 - o Many of these can be found in the Seniors' Information Handbook. You can get a copy of the Handbook from your Health Centre, doctor's office, or Homecare program. It can also be found online at: http://www.hss.gov.nt.ca/sites/default/files/seniors_information_handbook.pdf
- Arrange for Home and Community Care services such as Meals on Wheels, Home Support Services, Respite care, and Adult Day Programs.
- Learn what equipment is available to make caregiving easier and safer by talking to Home and Community Care or Rehabilitation Services.
- Learn how to react in an emergency situation by taking a First Aid and Cardiopulmonary Resuscitation (CPR) course.
- Keep the following information about the person they care for handy:
 - o Date of birth:
 - Social insurance number:
 - Health Care Number:
 - Other Health insurance information;
 - Up-to-date list of medications;
 - Personal Directive: and
 - Names and phone numbers of health care providers.

Being a Caregiver

Caregiving from a distance

Caring for someone from a distance can be stressful. Here are some ways to help with caregiving when you can't be there:

- Keep regular contact with the person being cared for establish routines for telephone calls, send e-mail messages, photos, or home videos;
- Visit as often as you can to provide relief to the main caregiver; and
- Ask the main caregiver how you can support them e.g. being available to participate in calls with physicians, homecare or social worker.

Taking care of yourself

Caregiving is rewarding, but can also be physically and emotionally demanding. It is normal to sometimes feel overwhelmed or frustrated with the demands of caregiving. In order to look after others, we have to first look after ourselves. Here are some ways to do that:

- Get enough rest;
- Eat well;
- Exercise (it's one of the best stress relievers!):
- Maintain your hobbies and interests;
- Recognize your own mental and physical limits and ask for help from family or friends, the Community Counseling Program, a nurse or doctor, a social worker or call the NWT Help Line (1-800-661-0844);
- Focus on the things you have control over;
- If you are working outside the home and also caregiving, ask your employer what help is available to balance these responsibilities;
- Take breaks if you become impatient, and do something positive for yourself to reduce the tension; and
- Take breaks from caregiving by arranging regular respite it is one of the most important things you can do to take care of yourself!



Arranging for Home and Community Care Services

Home and Community Care services are available to help people remain in their homes and community when they need support and care. To receive Home and Community Care services, the person requiring care must have a valid NWT Health Care card. People can get help with services like:

- home support/personal care;
- nursing care;
- nutrition services;
- palliative care;
- loan of medical equipment; and
- respite care.

Contact your Home Care office or Health Centre to arrange for Home and Community Care services. The Home and Community Care nurse will help you decide what services may help you the most. Phone numbers for your Home Care office or Health Centre can be found in the Telephone Directory of Services in the Seniors' Information Handbook.



What is Respite?

Respite gives caregivers a break from caregiving by having a qualified, responsible person care for your family member or loved one for short periods of time. Respite can happen in the home, in the community, or in a long term care facility. Arranging regular respite is a proven way to help caregivers care for themselves.

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

For more information on how to access respite services, contact Home and Community Care services in your community.

When Caregiving Gets Too Hard

It's normal for caregiving to be stressful at times, but some signs of stress should not be ignored. Below are some questions that can help you decide if caregiving is getting too hard:

- Are you more anxious or worried than is normal for you?
- Do you find yourself "flying off the handle" or worried about your anger?
- Are you often feeling exhausted?
- Are you developing health problems?
- Do you feel alone?
- Is it hard to ask for help?
- Does the responsibility of caregiving just feel "too much"?

If you answered yes to any of these questions, it is important that you talk to someone you trust such as family or friends, an elder, a social worker, nurse or doctor or the Community Counseling Program. There are also supports available over the phone to help you to decide what is best for you and the person you care for:

- NWT Help Line (1-800-661-0844)
- Seniors Information Line (1-800-661-0878)
- Disability Information, Referral and Support Coordinator (1-800-491-8885)

Caregiving Activities:

Personal Care

Personal care means helping with basic day-to-day needs such as getting dressed and using the bathroom. Sometimes this help can be very intimate so it is important to know what the person likes, what they are used to, and how they would like you to help them. Be calm and gentle, do one step at a time, and explain as you go in a way they understand. If the person you care for wants you to stop, respect their wishes and try again later.

Below are things a caregiver can do to make sure the person being cared for feels comfortable and safe, and their privacy is respected. Helping someone with personal care can be made easier and safer by using equipment, especially if the person you care for has a hard time getting around or gets tired easily. The equipment that can be helpful is in **bold** print.

Talk to the Home and Community Care nurse in your community; they can help you get the equipment you need or will organize for an occupational therapist or physiotherapist to help you.

Bathing

- Get to know what the person prefers, e.g. do they like a shower or a bath?
- If they are shy you can use a sheet or towel to cover them during a bath or shower.
- To prevent burns, make sure the water is not too hot.
- Make sure the room temperature is comfortable.
- Collect everything you need and place within easy reach.
- Showering is easier than taking a bath, especially when you use a bath chair in the tub or shower stall.
- If the person's movement is limited or they use a bath chair, use a **hand-held shower** to make shampooing and bathing easier.
- Use grab bars in the bathtub/shower to give a safe place to hold.
- Use non-skid decals or a suction bath mat in the tub or shower to stop slipping.
- Hand out items in order of use to give the person the opportunity to do what they can by themselves.
- Never leave the person alone.
- Use a non-skid mat beside the tub to stop slipping when getting out of the tub.

Caregiving Activities:

Personal Care

- Dry shampoos can be used between showers for those with who have a hard time getting around or who don't like wet shampooing.
- If the person can't get out of the house, it may be possible to get a hairdresser to come to the house.

Skin, foot and nail care

- Foot care, including regular inspections for redness, cracks, cuts, or ingrown nails is important especially for people with diabetes.
- Learn techniques for foot care from a health professional or have home care provide it.
- Keep finger and toe nails trimmed straight across.
- Check skin for redness or sores and report to your doctor or home care nurse if found.
- Use body lotion on dry skin, especially on elbows, knees and soles of the feet.
- Prevent pressure sores by helping the person you care for change position often. It
 is important to make sure there are no wrinkles in the fabrics the person sits or lays
 on.



Caregiving Activities: Personal Care

Mouth care

- Use a soft tooth brush and toothpaste.
- You can help the person brush their teeth by placing your hand over theirs to guide brushing, or by standing behind them to brush.
- If you notice any changes in the mouth, such as sores, lumps and swollen gums, have them checked by a health professional and/or dentist.
- Dentures should be comfortable, rinsed after meals, and soaked in water overnight. Keeping dentures in the mouth overnight can cause sores and infections.
- Make sure that the person gets regular dental check-ups, even if he or she wears dentures.
- Good mouth care is especially important if the person you are caring for has swallowing difficulties.

Clothing and footwear

- It is important that people get dressed in their regular clothes each day. It helps give structure to the day and can give a sense of wellness.
- Have extra clothes on hand in case something becomes soiled.
- Choose clothes that are easy to put on and take off. E.g. zippers instead of buttons.
- Choose comfortable shoes and slippers that fit well, have good support, and non-slip soles. Choose Velcro fasteners instead of shoe laces.
- If movement is difficult or painful on one side of the body, dress that side first.
- There are lots of tools that can make getting dressed easier. For more information contact your Home care nurse.

Caregiving Activities:

Personal Care

Eating well

- Good nutrition is important at every age.
- As we get older or are unwell we eat less; so it is important that the foods we eat are healthy.
- Health eating includes:
 - Traditional foods, whenever possible;
 - Eating foods from the four food groups on most days grains, proteins, vegetables/fruit and dairy; and
 - Eating more fruits and vegetables and less pre-packaged or sugary food.
- Make sure the person drinks plenty of water in addition to other drinks such as tea or coffee.
- If the individual has medical conditions, what they eat and drink may be even more important. Be sure to talk to their doctor or nurse to see if there is any information you should know.
- If you notice the person is coughing after or during eating, it may be a sign they are having trouble swallowing. Talk to your doctor or nurse.



Caregiving Activities: Personal Care

Physical activity

- Getting enough physical activity is important for all of us to be healthy. When we don't use a part of our body, we risk losing its movement and strength.
- Physical activity should get you to move and breathe a little more than usual.
- Physical activity should not hurt or cause other problems such as dizziness or chest pain.
- Ask a health care provider what kind of physical activity is best for you and the person you are caring for.
- Using a mobility aid such as a cane or walker can help make walking steadier and safer.

Sleep

- Sleep is important for all of us to be healthy. Many things such as medications, stress or depression, pain, and napping can change how much or how well we sleep.
- There are things you can do to get a better sleep:
 - Go to bed and get up at the same time each day;
 - Do some physical activity during the day;
 - Do something relaxing before going to bed;
 - Make sure naps are short e.g. 10-20 minutes; and
 - Limit caffeinated tea, coffee, smoking and alcohol.
- Sleep medications have side effects, so talk to a health care provider before using these medications.
- Side rails on a bed can make turning and getting up from bed easier.
- A **commode** (portable toilet) near the bed can help when using the toilet at night.

Caregiving Activities:

Personal Care

Medication

- Make sure that the health care provider knows about the medicine(s) the person you care for is taking. This includes prescriptions and other medications you can buy in the store. This is important because some medications may cause problems when used with others.
- Make sure you know what each medication is for, how it should be taken, and what its side effects may be.
- Make sure medications are kept in a safe place and you check expiry dates.
- It is not safe to throw away medications you do not need. Give them to your nurse or pharmacist.



Caregiving Activities: Personal Care

Going to the bathroom

- Going to the bathroom is a private matter so when people need help they may feel uncomfortable or embarrassed. It is important to respect the person's privacy as much as possible, and to ask them about the best way to help them.
- Some people may need help to clean up after using the bathroom. It is helpful
 to have any personal supplies they may need nearby, e.g. incontinence supplies,
 personal wipes, etc.
- Wash your hands and those of the person you care for after using the bathroom.
 This is important for stopping the spread of infections.
- A raised toilet seat can make it easier to get up and down from the toilet.
- Use grab bars by the toilet to give a safe place to hold.

Two of the most common problems people have with going to the bathroom are:

Constipation (Trouble having a bowel movement)

- Many things can cause constipation including: not enough fiber in the food you eat, not enough exercise, and some medications.
- Bowel movements can often be more regular by eating fresh fruits, vegetables, and whole grains, drinking water and exercising.
- If constipation remains a problem, talk to the individual's health care practitioner or pharmacist.

Incontinence (Trouble holding your bowel or bladder)

 Getting to the bathroom in time can be hard for those who have trouble moving about, who are confined to bed, or whose bedrooms or sitting rooms are far from the bathroom.

Here are some ways to help:

- Place a commode (portable toilet) beside the bed when using the toilet at night.
- Visit the bathroom regularly to avoid rushing to the toilet.
- Place waterproof protective covers on the bed and furniture.
- Use protective underwear liners, absorbent pads or disposable underwear.

Safety Around the Home

Preventing Falls

Falls usually happen because of the combination of several factors. The more "risk" factors that a person has for falling, the greater their chance of falling. Many of the factors that lead to falls can be prevented. Ways to prevent falls include improving mobility, correcting vision problems, and reducing trip and slip hazards in your home or outdoors.

Your Home Care nurse can help you understand the factors that could result in a fall for the person you are caring for, and can also help you complete a home safety check. The Home Care nurse can then help you decide what can be done to decrease the chances of falling, for example, using equipment such as grab bars, or doing exercises to improve strength.

Below is a list of things that can help prevent tripping and slipping at home and outdoors. Equipment that may help is in **bold** writing; your Home Care nurse can give you information on how to get this equipment.

- Use good lighting in the home;
- Use a night light to help to see the way to the bathroom at night;
- Choose comfortable shoes and slippers that fit well, have good support, and nonslip soles;
- Use walking aids (cane, walker) and other equipment for extra safety;



Safety Around the Home

- Try not to use rugs. When they must be used (at the front door or by the bathtub)
 make sure they are non-slip or use double-sided carpet tape to hold the edges
 down to the floor;
- Do not polish floors; it makes them slippery.
- Arrange furniture so it is easy to get around when using a cane, walker or wheelchair;
- Make sure furniture is sturdy and steady so that it won't tip if someone leans on it;
- Avoid using low or soft furniture because it is hard to get in and out of;
- Use lever doorknobs to make it easier to open doors;
- Check that indoor and outdoor stairs are in good condition and are not slippery;
- Arrange to have leaves, snow and ice removed outside on a regular basis;
- Use salt or sand on stairs and sidewalks throughout the winter months;
- Use motion detector lights to light up the path to the main door;



- Ensure there are sturdy **handrails** on both sides of the stairs; and
- Install a **ramp** to the front or side door if it is hard to use the stairs.

Safety Around the Home

Safety with Dementia:

If you are caring for someone with dementia, there are things you can do to make your house safer:

- Remove knobs or install dial guards on the stove;
- Use the self-locking feature or a lock for the oven;
- Keep sharp utensils and small electrical appliances out of sight;
- Keep all cleaning products and detergents locked up and out of reach;
- Use safety latches on cupboards;
- Use an electric, whistling kettle with an automatic shut-off system; and
- Reduce the reflection or glare on shiny floors, windows or mirrors if they cause confusion.

If the person you care for wanders, there are a few things you can do:

- Plan activities during times they are most likely to wander;
- Have a daily routine;
- Avoid busy places that can be confusing e.g. grocery store;
- Use devices that signal when a door or window is opened; and
- Place outside door locks out of sight (higher or lower).

For more ideas or help, contact Home and Community Care or see the Helpful Resources and Links section of this guide.

Communication

Communication is about talking, listening and understanding. We do this with more than just words; the look on our face, how we use our body, and how we say things. Even when a person does not use words we can figure out what they are saying by watching their face and body.

Health problems such as dementia and hearing loss, as well as some medicines can make communication hard. Here are things that can be done to make it easier:

- Get the person's attention before beginning to speak to them;
- Avoid background noises or distractions that can get in the way of hearing and speaking;
- Speak clearly and slowly and face the person so they can see your face/mouth and hear your words at the same time;
- Speak a bit more loudly but respectfully; don't yell or talk "baby talk";
- If the person has a hearing aid, encourage them to wear it;
- Use simple sentences and words and repeat or say it another way if they don't understand;
- Ask questions one at a time and give the person time to respond;
- Show the person what or who you are talking about, use gestures, pictures, or objects; and
- Include the person you are caring for in the conversation don't talk about them as
 if they are not there.



Planning for the Future

Planning for the future means that plans are in place in case of a sudden or unexpected change for the individual or caregiver. Knowing that a plan is in place can reduce stress and worry. Everyone involved knows what has to be done and who will do it.

People who are being cared for may have concerns about what might happen if they are not able to make decisions. Dealing with these concerns ahead of time can give a person peace of mind. It is important to know that there are many laws that affect decisions about end-of-life, money, property and who will look after a person. For some of these decisions you may need to talk to a lawyer.

The Community Legal Outreach program is operated under the Legal Aid Commission. This program is available to seniors on a scheduled basis to give basic legal advice and in some cases, assist with wills or estate planning. For more information please contact (867) 920-3365.

Here are some ways to put these decisions into writing:

- Creating a power of attorney;
- Creating a personal directive; and
- Making a will.

Power of Attorney

A power of attorney is a legal document that allows us to choose another person to make financial decisions for us while we are living but not able to make these decisions for ourselves. Contact a lawyer or the Community Legal Outreach program to discuss this.

Personal Directive

A personal directive is a legal document that lets you give instructions or choose someone to make decisions about personal matters that are non-financial, such as:

- Medical treatments:
- Where you would like to live;
- Who you would like to live with;
- · Choices about personal activities (recreation, employment or education); and
- Any other personal and legal decisions.

Planning for the Future

This is useful if you have an illness that leaves you unable to make decisions for a few days or the rest of your life. Anyone 19 years of age or older can make a personal directive.

Making a Will

A will is a legal document that expresses a person's wishes regarding the disposal of his or her property upon death. A will may also include special wishes about burial or cremation, and appoint a guardian or custodian for children. In order to be valid, the will must be signed and witnessed according to certain formalities. Contact a lawyer or the Community Legal Outreach program to discuss this.



Trustee and Guardianship

There may come a time when the person you care for can no longer make decisions. In these cases they will need a trusted person appointed to be their legal guardian.

Office of the Public Guardian

The Office of the Public Guardian helps people become legal guardians of individuals 18 years of age and older who, due to injury or circumstance, are unable to make decisions about their personal or health care. Usually a family member will become a legal guardian.

To become a legal guardian people should call the Office of the Public Guardian, who will then arrange to have an assessment completed to determine the need for a guardian. That assessment goes to the courts to decide what kind of decisions the legal guardian may make. These decisions are usually about living arrangements; work; social and recreational activities; education; health care; and day-to-day living matters. The public/private guardian does not make decisions about money. The public/private trustee makes those decisions.

For more information, contact the Office of the Public Guardian at (867) 920-8029.

Office of the Public Trustee

The Public Trustee is a person appointed by the Commissioner of the Northwest Territories who will, in certain circumstances, manage the money, land, and other belongings of people who die or who are incapable of handling their financial affairs.

For more information, contact the Office of the Public Trustee at (867) 873-7464 or Toll-free at 1-866-535-0423.

Health Care

When the person you care for can still make their own decisions it is important to talk to them about whether they want your help when they receive healthcare services. If the person you care for wants your help, here are a few tips:

- Be ready to take notes and help with asking questions;
- Ask the person what they want to talk about during the appointment and make a list of questions to ask the healthcare provider;
- Help the person be ready to talk about symptoms and changes in their health;
- If there is not enough time to discuss all concerns, be prepared to make a followup appointment;
- Bring all medications to the appointment;
- Tell the healthcare provider about medication allergies and reactions; and
- Be prepared for follow-up because the healthcare provider may suggest other care providers that can answer questions or provide support.

Long Term Care within the Northwest Territories (NWT)

If you can no longer care for the person at home, you will need to discuss with the person if they want to apply for long term care.

- Long term care is for people who need high levels of personal care throughout the day and are no longer able to live on their own or with family.
- Long term care is a place where professional caregivers are available 24 hours a
 day to support people with personal care, medication, meals, laundry and social
 and recreational activities.
- Contact your local Homecare Office or Health Centre to complete your long term care application.

Recognize it can be a difficult and emotional decision for the person and the caregiver to choose to apply for long term care. This is a very important decision.

Health Care

Here are some steps to help you learn about long term care and how you can continue to be involved in the life of the person you care for:

- Talk with the Director or Manager of the long term care facility near you to better understand their roles and responsibilities;
- Provide a list of services the person you care for will need; and review which services are available within the long term care facility and which need to be accessed through the community; and
- Ask about a family/resident council and how you can be involved.



Helpful Resources and Links

Your local Health Centre or Homecare office can provide support and information about your caregiving concerns. Below are some useful links to care-giving resources:

1. Dementia

This link provides useful information on caring for a person with dementia. This link also provides good ideas for self-care.

http://www.alz.org/care/

2. Fall Prevention

This link provides a check list to help you identify and fix falling dangers . http://www.cdc.gov/HomeandRecreationalSafety/pubs/English/booklet_Eng_desktop-a.pdf

3. Medication

This link provides information about using medications safely. http://www.healthunit.org/adults/resources/Knowledge_is_the_Best_Medicine.pdf

4. Nutrition

Healthy eating information for northern residents:

http://www.nutritionnorthcanada-nwt.ca

Useful tools for healthy eating:

http://www.dietitians.ca/Your-Health.aspx

http://www.healthyalberta.com/HealthyEating/foodchecker.htm

http://choosenwt.com/wp-content/uploads/2014/11/

HealthyEatingWeightManagementGuideweb.pdf

Healthy eating toolbox:

http://www.hc-sc.gc.ca/fn-an/nutrition/part/tb-bo/index-eng.php

http://www.eatrightontario.ca/en/MenuPlanner.aspx#

5. NWT Programs and Services:

Contact information for programs and services can be found in the Seniors' Information Handbook. You can get a copy of the Handbook from your Health Centre or doctor's office. You can also find an electronic copy online at: http://www.hss.gov.nt.ca/sites/default/files/seniors_information_handbook.pdf

Helpful Resources and Links

6. Physical Activity

Choose NWT - Canadian Physical Activity Guidelines

http://choosenwt.com/wp-content/uploads/2013/12/PA-CSEP-InfoSheets-ENG_NWT_Nov2013.pdf

Choose NWT - NWT Physical Activity Toolkit

http://choosenwt.com/wp-content/uploads/2013/12/nwt-physical-activity-toolkit.pdf

7. Planning for the Future

This link provides information about the role of a power of attorney. http://www.justice.gov.nt.ca/pdf/PublicTrustee/making_pa.pdf

More information about personal directives and a sample can be found at: http://www.hss.gov.nt.ca/publications/brochures-fact-sheets/personal-directives-choosing-future

More information about wills can be found at: http://www.justice.gov.nt.ca/pdf/
PublicTrustee/Questions_about_Wills.pdf

8. Respite

This link provides information on how to access respite services in the NWT: http://www.hss.gov.nt.ca/sites/default/files/home_care_in_your_community.pdf

9. Caregiving and Self-Care

These links provides practical information about being a caregiver and self-care: http://caregiverconsortium.org/pdfs/ResilientCaregiver2014.pdf
http://www.saintelizabeth.com/Caring-for-Family.aspx