



# Caregiver Resource Guide

Created by

## Caregiver Information and Support

A program of the Saskatoon Council on Aging



2020 College Drive

Saskatoon, Saskatchewan S7N 2W4

Phone: (306) 652-4411

Fax: (306) 652-7525

Website: [www.saskatooncaregiver.ca](http://www.saskatooncaregiver.ca)

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# Information for New Caregivers

An informal caregiver is an unpaid individual who cares for and gives support to a family member, friend or neighbour who is frail, ill or disabled.

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The above definition is broad, as caregiving can take many forms. Both caregiver and care receiver are unique and it is, therefore, very difficult to generalize about what may be required. One thing that virtually all caregivers have in common, though, is that they have had little or no preparation or training for their caregiving duties, and often have no idea who to call or where to go for help. This guide is intended to aid caregivers who reside in the Saskatoon Health Region and it is hoped that it will provide some much needed assistance.

Caregiving can be a stressful job and a contributing factor in the stress felt by many caregivers is the lack of choice they had when thrust into this new role. As you prepare to care for you loved one, consider the options available:

1. Personally caring for your loved one
2. Asking for help from friends and family
3. Asking for help from a professional service

It is not necessary to decide between these, but it is helpful to keep all three in mind as you consider the tasks you face and how you will accomplish them.

**Contact CPAS.** In Saskatoon, Client/Patient Access Services (CPAS) will aid you in sorting out your needs, options, and the professional services available to you and your loved one. CPAS is a department of the Saskatoon Health Region with professionals to help identify appropriate services to meet your needs, assist you in accessing them and staying in touch with you to make sure those needs are met. There is no direct cost to you or your loved one for CPAS services.

## Caregiver Assistance Available in Saskatoon

### **Client/Patient Access Service (CPAS)**

Phone: 306-655-4346

Professional staff at CPAS does a functional assessment of your loved one to determine eligibility for and provide access to:

- Home Care Services
- Volunteer Services
- Meals on Wheels
- Community Day Programs
- Community Services
  
- Long Term Care Services
  - Permanent admission
  - Planned respite
  - Unplanned respite

CPAS also provide information on:

- Personal Care Homes
- Enriched housing options
- Other community resources
- Advance Health Care Directives

**Home Care, Saskatoon Health Region**

201-310 Idylwyld Dr N, Saskatoon, SK S7L 0Z2

Phone: 306-655-4300

Fax: 306-655-4400

- **Eligibility determined by CPAS**
- Nursing services, personal care, respite, volunteer services 306-655-4323
- Case management
- Meal preparation, meals on wheels, home management
- Transportation to medical appointments, for shopping and errands
- Physical & occupational therapy, social work services, and nutritional counseling
- Friendly visiting, security calls
- Community social worker

Fees: Provincial rates; subsidized rates, based on income

**Community Social Work, Saskatoon Health Region**

103 – 310 Idylwyld Drive N, Saskatoon, SK, S7L 0Z2

Phone: 306-655-3400

Fax: 306-655-3430

- Community Services Social Workers provide support to people who are providing emotional support and/or practical assistance to a disabled or chronically ill adult family member or friend.
- Support groups are offered which provide information on topics relevant to caregiving and provide a safe atmosphere to share ideas and concerns and to receive support. They are offered at various times throughout the year. For more information or to register call 306-655-3400.
- Individual counseling is available for issues related to caregiving. To request a referral, contact CPAS intake at 306-655-4346.

There is no fee for social work services or groups.

### **Caregiver Information and Support**

2020 College Drive, Saskatoon, SK S7N 2W4

Phone: 306-652-4411

Fax: 306-652-7525

Website: [www.saskatooncaregiver.ca](http://www.saskatooncaregiver.ca)

Email: [caregiver@sasktel.net](mailto:caregiver@sasktel.net)

- A caregiver drop-in-centre and awareness service is structured to answer many caregiver questions such as “who can I talk to about this?” or “where can I obtain certain health care needs?” and many other common queries.
- Although information and referrals are provided; this is not a counseling service.

### **Saskatoon Council on Aging Inc.**

2020 College Drive, Saskatoon, SK S7N 2W4

Phone: 306-652-2255

Fax: 306-652-7525

Website: [www.scoa.ca](http://www.scoa.ca)

Email: [admin@scoa.ca](mailto:admin@scoa.ca)

- Resource centre, educational programs, computer lessons, positive aging drop-in program for older adults
- Coming of Age publication published 3x/year
- Pilot projects which promote dignity health and independence of older adults
- Free directories of activities and services

### **Services for Seniors**

103-115-19th Street E, Saskatoon, SK S7K 7Y8

Phone: 306-668-2762

Fax: 306-668-2559

- This is a privately operated, non-profit organization dedicated to providing assistance to seniors living in their homes.
- The agency charges a standard fee of \$14.50/hour, plus a yearly membership fee of \$5. Subsidized rates are available.

Services include:

- Home helper – daily care assistance, letter writing, shopping and errands.
- Yard work – grass cutting, raking, gardening, seasonal yard maintenance, and snow shoveling
- Home maintenance – minor home repairs and improvements, including heavy lifting, packing and moving

Fee: \$5 annual membership, \$14.50/hour for service

# Caregiving Burdens

In attempting to help caregivers prepare for some challenges this new role may present, it is helpful to outline caregiving burdens. Caregiving burdens are problems and concerns that have been recounted by a number of caregivers. The lists are long, but in general fall into two groups – emotional and financial issues.

## **Emotional problems and concerns**

Anxiety, stress, frustration, depression, fear of failure as a caregiver, anger and guilt are all mentioned. All caregivers list at least some of these. Loneliness and social isolation that often result from caregiving responsibilities can produce caregiver burnout. In some cases the caregiver simply gives up. Much of the emotional burden has been attributed to two factors: (1) inability to find answers to their many questions, and (2) lack of support from the existing health care system.

## **Financial problems and concerns**

Because family income often plummets in a caregiving situation, while expenses invariably rise, the financial problems that arise may be devastating. Additional expenses encountered may include medication, special diet, medical equipment and supplies, and respite care. Exceptional expenses occur less frequently, but may include necessary home modifications to accommodate a wheelchair, air conditioning (often vital for MS patients, for example) and a vehicle equipped for a wheel chair. It is obvious that financial problems will tend to create even more emotional burdens.

To counteract these burdens, many caregivers take great comfort in pointing out that there are many rewards in caregiving. They feel a sense of accomplishment in preserving the dignity, and maintaining a quality of life, for the care receiver. It has been shown many times that the bond between caregiver and care receiver is enriched. This most certainly makes the task less a chore and more a “labour of love”

Even with careful preparation before taking on caregiving duties, emotional problems will inevitably be encountered. These are very often due to frustration in trying to get answers to questions or in trying to find a particular agency that can provide assistance. The following sections will provide sources of information for caregivers and lists of organizations, both within and outside the health care system that can be of significant help.

# Getting Organized

Organization can help you strive for a balance between caregiving, other demands for your time, and finding a moment for yourself. Formally identifying what tasks need to be done to provide the best care possible for your loved one is the first step in figuring out how to accomplish them. The exact way you choose to organize things is up to you!

## Developing a Plan

A plan can be as simple as writing down the care your loved one needs and who will provide that care or help. Ideally, your loved one can take the lead in creating this plan, but if they are unable to, be sure to include their opinions, ideas, and preferences as much as possible. Creating a plan during a family meeting or with the help of a healthcare professional may be most appropriate for you situation.

Below are items that your loved one may be able to take care of by themselves or they may need help with. These lists are general so some parts may not apply to your situation and you may think of other things that you do not see here. These lists are meant to help get you started, but not to limit you. Reviewing the caregiving needs occasionally can help make sure both you and your loved one are getting the help you need.

For each of the following items, consider the care receiver's needs. Can your loved one take care of the item themselves, need some form of adaptation or assistance to accomplish it, if you should take care of the item or give that caregiving task to someone else.

### Housekeeping tasks

- Laundry
- Cleaning
- Yard care
- Paring down or organizing
- Managing bills and correspondence
- Home maintenance

### Home Safety and Accessibility

- Access the home from outside
- Move throughout the home safely (are things cluttered? are grab bars or railings needed? is floor slippery or difficult to walk on? Is there adequate lighting, even during the night? etc.)
- Safely reach electrical outlets and light switches
- Use the washroom safely, during the day and the night
- Use the kitchen safely (safely reach items or use appliances, etc)
- Get up safely from chairs and bed

### Social Needs

- Attend social activities or day programs
- Enjoy hobbies
- Participate in religious activities
- Have private time
- Get to and from social activities (Can your loved one safely walk or drive themselves where they need to go or do other arrangements need to be made?)

### Nutritional Needs

- Get groceries
- Prepare meals
- Eat (Do they need assistance? Are adaptive devices needed?)
- Plan menu and make grocery list
- Meet special dietary needs

### Health Care

- Keep track of medications and their purpose
- Take medications correctly and on time
- Make healthcare appointments
- Get to and from healthcare appointments
- Fill prescriptions
- Keep track of health insurance and coverage information
- Make informed health care decisions
- Implement recommendations of health care professionals

### Personal Care

- Perform oral care
- Get dressed
- Groom hair and nails
- Bath and perform other personal hygiene
- Access and use the washroom

### Care for the Future

- Has health care directives
- Has living will
- Has will
- Has appointed power of attorney
- Manage insurance
- Manage banking and day-to-day finances
- Manage financial planning
- Has expressed or written end of life wishes

When planning all the things that need to be done for your loved one, include plans to meet your need for well-being. Things like:

- Self-care
- Employment and financial needs
- Respite
- Medical needs
- Hobbies
- Time for children, spouse, other family and friends

If there are more demands than you can handle, ask for help or research the kind of support that might be available to you. Asking a family member or your loved one to help you with looking into options is a great way to keep everyone involved, share ideas and work.

You might find a calendar is a useful way to organize your plan. If there are many caregiving duties, the plan may be very detailed, including menu planning and grocery lists as well as a daily routine. Maybe the person you care for needs less assistance or most of their care will be provided by professionals so your plan looks more like a to-do list. In some ways, planning is more important than the plan itself as the process is what identifies where your loved one needs care and how to provide support.

As you identify some of your loved one's needs, you may find it helpful to get some further information, education and/or training. If your loved one is in hospital, ask the professionals working with them to provide you with guidance. Making an appointment with your loved one's physician is another way you may be able to identify caregiving skills that may be helpful. If your loved one has been diagnosed with a specific disease, contacting a local organization that deals with that disease may help you to find the appropriate information (as an example, if the person you care for has diabetes, the Canadian Diabetes Association may be a useful resource)

### **Resources on Caregiving Skills**

#### Canadian Virtual Hospice Caregiving Demonstration Videos

- A series of videos with information for caregivers on different caregiving tasks, like medication administration and providing personal care

<https://www.youtube.com/playlist?list=PL47B0761255A1F993>

#### Family Caregiver Alliance Caregiver College Videos

- A series of videos showing different information and tips for caregivers, like helping loved one in and out of bed

[https://www.youtube.com/playlist?list=PLa1B8idpEiEplIAyH\\_swKvZvTQ9yAKH6t](https://www.youtube.com/playlist?list=PLa1B8idpEiEplIAyH_swKvZvTQ9yAKH6t)

## Creating a Contact List

Create a contact sheet with important or frequently needed phone numbers and addresses. Keep the contact sheet somewhere convenient, like near the phone or on the refrigerator, where it can be found easily by your loved one, you, or anyone else in case of emergency. Some contacts to include are:

- Physician
- Dentist
- Optometrist
- Specialists
- Family Members
- Friends
- Emergency Services

Depending on the care needs of your loved one, contact information for things like transportation services, care aids, or day programs may be helpful to include. If you are a long distance caregiver, you may want to include contact information for neighbors, those with spare keys to your loved one's home, and local emergency services. Contact information for home utilities, repairmen, yard and home maintenance or home security might be valuable if your loved one lives at home, but if they live in a residential facility, contact information for staff or the director may be more appropriate. Make a copy of the list for family members, friends and anyone else who helps care for your loved one (like a care aid or staff at a day program).

## Organizing Health Information

Prepare a health file for your care receiver. A binder, folder, electronic file, or even a shoe box will work for keeping all the information together. Having the information in one place is valuable in a medical emergency, but can also help you get the most out of healthcare appointments and monitor your loved one's health. Helpful information to include is:

- The care receiver's health card number
- Any known allergies
- Updated list of medications and their dosages
- Chronic health issues
- Major surgeries and their dates
- Diagnosis's
- Doctor or other healthcare professionals recommendations
- Immunization record
- Treatment or therapy regimes
- Additional health coverage information
- Health care directives
- Research you, your loved one, family or a health care professional has found about the care receiver's conditions or care needs

## Managing Medications

As a caregiver, you may be managing medications for yourself and the person you care for. It is important to have the following information for each medication:

- Name of medication and the reason it was prescribed
- Correct dosage, including the time and frequency it should be taken
- How to properly take and store the medication
- Possible side effect
- Contraindications and precautions

If you have questions about medications, ask your physician or pharmacist. Do not be afraid to ask questions like how to give the medication to the person you care for or if a pill can be crushed to make swallowing easier. Another resource is the HealthLine, which can be reached by calling 811. The Saskatchewan HealthLine is staffed by health care professionals and is available 24 – hours a day for free.

Tips for medication safety:

- Keep medications in the labelled containers they come in to avoid mix ups
- Take only as directed and discuss with your physician before discontinuing a medication
- Set an alarm to remind you when to take medications, especially while you get used to a new routine
- When taking medications that could cause drowsiness or dizziness, be cautious about the activities you engage in. Try to schedule appointments or activities at times when driving or walking is not impacted by such effects.

## Researching Financial Options

As mentioned earlier, caregiving burdens that commonly arise are related to finances. There may be programs, tax benefits, or reimbursements you or the care receiver are eligible for that can ease some financial burdens. Keep things like receipts, tax returns and transaction records organized and stored somewhere safe, but easy for you to access. Filing documents, bills, and receipts as you get them can help to save you the hassle and time of trying to sort things out later.

Some programs require approval before expenses are incurred, while others require you to submit receipts. Because of this, it is valuable to look into the options you have as soon as possible. Take some time to research the tax benefits, programs, or other financial options that are available to you as a caregiver.

### Federal Programs

Service Canada

Phone: 1-800-622-6232

Website: <http://www.servicecanada.gc.ca>

Benefits Calculator: <http://www.canadabenefits.gc.ca/f.1.2c.6.3zardq.5esti.4ns@.jsp?lang=eng>

**Provincial Programs:** Phone: 1-866-221-5200 Website: [www.saskatchewan.ca/live](http://www.saskatchewan.ca/live)

# Healthy at Any Age

Today Canadians are living longer than the generations before them and are faced with many changes as their bodies grow older. While we cannot stop the aging process, we can adapt our lifestyles to promote healthy aging and delay or prevent some of the symptoms.

Health is more than the absence of disease. A state of health includes emotional, physical, mental, and social well-being

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As a caregiver, you have the health of yourself and your loved one to consider. The added work and stress of caregiving puts you at a greater risk of injury and illness, making healthy habits even more important. Some caregivers feel guilty when they prioritize their own health, but it is important to remember that you can provide the best care for your loved one by first caring for yourself.

## **8 Steps for Caregiver Self-Care**

1. **Set goals**, both short-term and long-term, that you wish to accomplish. These can include taking an hour break from caregiving once a week or eating healthier.
2. **Seek solutions** rather than focusing on the problem. If the first solution you try doesn't work, move on to another one. Be creative and take advantage of all of the resources available to you.
3. **Ask for and accept help** before you become exhausted and overwhelmed. Be proactive in taking care of your own welfare.
4. **Eat nutritious food** and limit the amount of junk food and alcohol you consume
5. **Create and stick to an exercise routine**. As a caregiver you may think your time is already limited but consider the exercise you get from everyday activities such as gardening, walking, and household chores. You can also try walking to work or to the grocery store next time.
6. **Learn from your emotions** by recognizing their intensity and when they are taking control of you. Try an activity like writing in a journal or meditating to help process emotions. If you are feeling like your emotions are out of control, speak to a professional.
7. **Take respite**. Respite, a total break from caregiver activities, is not only important but also essential in maintaining a caregiver's ability to carry on, and must be arranged by whatever means available. Family members, friends and neighbours are hopefully available. If not, arrangements must be made through Home Care or another agency, as "time to oneself" is a very necessary part of a caregiver's routine.
8. **Minimize personal stress**. Use strategies to manage stress and when situations are outside of your control, try changing the way you perceive things. The stress you feel is not only a result of caregiving, but also of the way you look at it. Remember that you are not alone!

# Physical Activity

Even though most people know the benefits of staying active, there are many obstacles that prevent them from keeping fit. Some have a fear of injury, illness or feel they have a lack of energy, motivation, time or skill. For others, the cost or location of facilities is an issue, as is the weather. Caregivers have the additional obstacle of finding someone to provide respite care or activities that keep both them and their loved one active.

Staying active has many benefits. Caregivers who lead physically active lifestyles are more likely to:

- Live longer
- Have decreased levels of stress
- Are less likely to develop cancer, type 2 diabetes, and heart disease
- Have more energy
- Have healthy growth and development
- Are less likely to injure themselves

## Tips for Getting Active

- Try to engage in at least 30 minutes of moderate activity each day – even if you need to start with 10 minute intervals
- Find alternate modes of transportation that promote exercise. Take the stairs instead of the elevator, walk to the grocery store, or try riding your bicycle
- Work out your heart with aerobic exercises like jogging, cycling, dancing, swimming, or brisk walking
- Increase muscle strength and bone mass by lifting weights or doing resistance exercises a few times a week
- Work on flexibility by stretching, doing yoga, Tai chi, golfing or gardening
- Find ways to be active in all seasons. Raking the leaves, shoveling the snow and mowing the lawn all help to keep you active
- Work out with a friend. Having company can help you stick to an exercise plan and has the added benefit of socializing. Try walking with a neighbor or join a community garden
- Don't get discouraged! Every bit of physical activities contributes to you having a more active lifestyle

## Transferring, Lifting, and Repositioning Safely

There may be times when the person you care for needs assistance walking or transferring from one place to another. However, aiding someone to mobilize or reposition can put both the caregiver and care recipient at risk for injury when not done properly. For the safety of your loved one, you must consider your own safety first, before you start to provide assistance. Do not use your body to provide help that could be provided more safely by a walker, grab bar, or other assistive device.

The best way to learn about safe transferring, lifting, and repositioning is from a health care professional like an occupational therapist or physiotherapist. If your loved one is in hospital, you should be provided with some guidance and instruction for safe transferring or lifting before discharge. If you are seeing a

health care professional regularly or Home Care professionals are involved in your loved one's care, ask them to demonstrate safe technique to you. If not, talk to your physician or a nurse at your next appointment.

## Falls

Anyone can fall, but as we age the likelihood of falls increases and, with that, the likelihood of injury. Poor balance, unsafe conditions, reduced vision or hearing, and decreased muscle and bone strength all contribute to falls. Knowing what to do if you fall or witness someone else fall can greatly reduce the physical and psychological consequences. Preventing falls and knowing how to react if you do will help build to confidence and keep you independent.

### Preventing Falls

Assess your surroundings for possible hazards. Helpful hints to keep you on your feet include:

- **Install grab bars and railings** where they are needed. Common places are beside the toilet, along hallways or near the bed
- **Reduce clutter** and keep pathways free obstacles
- **Have adequate lighting** in common areas, hallways, the bathroom, and stairwells
- **Use non-slip rugs** and wipe up any spills right away
- **Store heavy items in lower cupboards** and have a sturdy step stool with a safety rail for reaching items on the top shelf. Store frequently used supplies such in easy-to-reach locations. Don't be afraid to ask for help with tasks that you don't feel comfortable with.
- **Eat nutritious meals** with lots of fruits and vegetables to maintain strength and balance. Skipping meals is dangerous and can cause weakness and dizziness.
- **Make sure you are aware of any possible side effects of prescription drugs** or over-the-counter remedies. If a potential side effect is dizziness or fatigue, adjust your activities so that you are not at risk of falling. It is important to never mix any medication with alcohol.
- **Use assistive devices.** Don't be embarrassed to use safety aids in your daily life. Always wear your glasses and hearing aid and use a walker or cane if needed.
- **Wear suitable footwear.** Shoes with a wide base to prevent any twisting of the foot, non-slip soles and heels of a reasonable height are recommended. A heel cup that wraps around the back of the heel is also very good for supporting the ankle. The mid-sole of the shoe should be firm.
- Most importantly, don't let a fear of falling keep you from doing the things you love! Daily physical activity helps with flexibility and strength. Walking and Tai Chi are two great ways to stay active.

It is helpful to come up with a plan in case of future falls. Make sure that neighbours, friends, and family members are aware of the plan and that someone you trust has a spare house key. Emergency call devices or a cordless phone are useful, particularly if you fall often. Ask someone to call at regular intervals, or find an organization that offers this service.

## **When a Fall Happens**

**If you fall and CAN get up.** The most important thing is to stay calm. Take time to catch your breath and assess if you have any injuries. If you think that you are fine, stand up by following these 5 steps:

1. Lie on your side, bend the leg that is on top and lift yourself onto your elbows or hands.
2. Pull yourself toward an armchair or other sturdy object, then kneel while placing both hands on the chair or object.
3. Place your stronger leg in front, holding on to the chair or object.
4. Stand up.
5. Very carefully, turn and sit down.

**If you fall and CAN'T get up.** If you feel any pain or discomfort, do not try to get up. Instead try to get help.

1. Call out for help if you think you can be heard
2. If you have an emergency call device or telephone at hand, use it. If you don't, try to slide yourself towards a telephone or a place where you will be heard
3. Make noise with your cane or another object to attract attention
4. Wait for help in the most comfortable position for you. If you can, place a pillow under your head and cover yourself with a piece of clothing or a blanket to stay warm
5. Try to move your joints to ease circulation and prevent stiffness

**If you see someone fall,** do not get them up right away. First assess the person for consciousness and injury. Make sure to reassure the person and let them know what you are doing.

If the individual cannot get up, call for help and administer first aid if you are able to do so. Help the person find a comfortable position and keep them warm using a blanket or article of clothing.

If the individual appears able to get up, proceed with care and follow the steps below:

1. Bring a chair close by. Help the person turn onto their side and bend their upper leg. Then help the person into a semi-seated position.
2. Placing yourself behind the person and getting a firm grip on the hips, help the person to a kneeling position with both hands on the chair.
3. Holding on to the chair, instruct the person to place their stronger leg in front. You may help by guiding his or her leg.
4. With a firm grip on the hips, help the person to stand, then turn and sit on the chair.

## **When to See a Doctor**

Even if a fall appears harmless there could still be after-effects that appear immediately or days after a fall. It is best to see a doctor if there are injuries, dizziness, nausea, headaches, vision problems, overall weakness, a strong or lingering pain, or if there was a loss of consciousness just before or after the fall. A fall may also be caused by medication or a sign of illness. It is a good idea to mention any falls to your doctor as soon as possible.

## **Consequences of a Fall**

Falls are the most common cause of injury among seniors. Physical effects of a fall can be minor, such as bruises and cuts, but can also be severe, ranging from muscle damage to fractures. An individual may also develop pneumonia or blood clots if they are forced to lie on the ground for an extended period of time.

It is important to note the psychological effects of a fall as well. Many people become cautious and, while acknowledging the possibility of a fall is good, becoming consumed by a fear of it can be detrimental. Don't isolate yourself- keep socializing and stay active to maintain strength and balance. Openly discuss your fear of falling with family members or health professionals. Talking about it will help you understand the fear and also let people know how they can help you. Family members can offer to go for a walk once a week with you until you feel comfortable on your own or a physiotherapist can also suggest various rehabilitation exercises.

## **Healthy Eating**

Good nutrition is an essential part of a healthy lifestyle. Other caregiving demands or the special dietary needs of your loved one may make meal preparation more challenging than it used to be. However, eating well is important for caregivers as the work of caring can put their health at risk. A good diet not only provides energy and essential nutrients, but helps to combat stress and stave off illness.

As you make changes, set reasonable goals for improving your diet, breaking any large changes down into stages. As with any new routine, change can take time to master, but planning ahead is a good way to remove some of the stress meal time can present. Making a weekly menu and list of the groceries you'll need for each meal is a great place to start.

A few tips for healthy eating while caregiving

- Eat a variety of food that includes vegetables, fruits, grains, and protein
- Have nutritious food throughout the day to maintain your energy
- Prepare ahead of time. Cut or prepare what food you can in advance to reduce stress around meal time and keep healthy snacks handy
- Keep a bowl of fruit on the counter for quick and easy snacking
- Look for simple recipes that require little preparation time and use nutrient-rich foods
- Ask for help. Have a family member or friend help with groceries or meal preparation

## **Nutritional Considerations for Older Adults**

Poor nutrition affects older adults in a variety of ways. It decreases their ability to digest foods and increases their vulnerability to diseases such as pneumonia, heart disease, stroke and diabetes. It also contributes to the weakening of their bones, which makes them more susceptible to injury.

Many older adults eat alone and this can contribute to unhealthy eating. It is difficult to make meals for one person and this deters a lot of people from taking the time to choose a properly balanced diet.

Older adults have unique dietary requirements. They require fewer calories but more nutrients and should try to:

- Eat grain products that provide energy and fibre. Try using brown rice in soups, having a bran muffin for a snack, or eating a bowl of oatmeal for breakfast.
- Eat dairy products and other calcium rich foods to promote healthy bones. Add milk instead of water when making canned soup, enjoy low-fat pudding for dessert, and try cheese or almonds as a snack.
- Choose lean meat and lower fat products. Poultry, fish, and seafood are healthy choices. For those who prefer meatless meals choose eggs, tofu, peanut butter, beans, or lentils.
- Fruits and vegetables are good for preventing respiratory disease, vision loss, and types of cancer. Sprinkle fruit in your cereal, make a vegetable stir-fry, splurge on real fruit juice, and instead of eating candy as a snack try a handful of dried fruit.

### **Resources to Support Healthy Eating**

#### **Canada's Food Guide**

Phone: 1-800-926-9105

Website: <http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>

- has information about the types and amounts of food suggested for healthy eating

#### **CHEP Good Food Inc.**

Phone: 306-655-4575

Website: [www.chep.org](http://www.chep.org)

Grocery stores with quality stock are not always easily accessible and the price of fresh fruits and vegetables tends to be more expensive. In Saskatoon, CHEP Good Food Inc. is a community organization with programs to make healthy, fresh produce available at affordable prices. CHEP purchases local and wholesale produce and distributes it at neighborhood locations all over Saskatoon.

- Good Food Box program
- Seniors Markets are pop up stores in some seniors complexes selling produce and eggs

Fee: ranges based on product

#### **GLWD's Nutrition Tips for Caregivers**

Website: <https://www.glwd.org/nutrition/publications.jsp>

- Dietary information for caregivers in general and for specific conditions
- Food safety tips for at home
- Nutritional information for end of life care

For additional nutritional information for those living with specific health concerns:

<https://www.glwd.org/nutrition/illness.jsp>

## Oral Health

Oral health care is a responsibility held by an individual until an accident, an illness, or simply ageing, places this responsibility into the hands of a caregiver. Daily oral care is vital to maintaining teeth and gums, but seeking professional dental care is also important. Medications, dietary alterations, and change in health status can contribute to tooth decay, dry mouth or infections. This can be done at their dentist's office or through the services of a mobile dental service. Mobile services will bring professional dental care to the ageing or vulnerable individual who has become somewhat dependent on others for daily care.

A dental professional should be notified of any changes in health status. As the caregiver, you can request a dental assessment/examination in order to formulate a plan for the daily and preventative care needed. An oral health maintenance protocol will be recommended to allow maximum preventive care for this vulnerable individual. Most of the time the dental treatment recommended is simple, inexpensive and easy to deliver.

Dental health and medical health are related. Many medical illnesses have been shown to have a relationship with deteriorating teeth and gums. Research has established links between dental disease and strokes, heart attacks, poor diabetes control, prosthesis problems and aggressive behaviour. Aspiration Pneumonia, the #1 reason long term care residents have to seek emergency medical care, has been linked to high levels of dental plaque and dental disease.

To contact a dental team that may be able to assist your loved one please look at the Directory of Services with SCOA, contact the College of Dental Surgeons of Saskatchewan at 306-244-5072, or contact your own personal dental team member.

## Getting a Good Rest

When life is hectic, stressful or hard it can be difficult to sleep. If your caregiving responsibilities extend overnight, you may have even more challenges to getting enough rest. Sleep, like eating well, can help you stay healthy and combat the stress of caregiving.

### Tips for getting enough rest

- Limit the amount of caffeine, nicotine and alcohol you consume. Avoid drinking coffee, tea or other energy drinks in the latter half of the day all together
- Get some exercise during the day. Physical activity promotes good rest
- Write in a journal, meditate or talk with someone you trust to help let go of the day's events before you try to sleep.
- Turn off the TV, computer, tablet, phone or other screens before getting into bed. Ideally, give yourself a couple hours before bed of screen-free time
- Take a nap. If you caregive 24/7, try napping while the person you care for naps, is at a day program or has someone else over for a visit
- Keeping the hallway and bathroom well-lit at night may help to prevent wandering, confusion or falls for the person you care for and minimize the number of disruptions to your sleep

If you are still not getting enough rest, it may be time to talk to your physician or look into respite. Having someone else care for your loved one for a night – or even better a few nights – each week may be the best way to help you maintain your health and provide the best possible care you can. Ask for help before you are exhausted and organizing respite becomes another task that contributes to feeling overwhelmed.

## Managing Stress

As mentioned before, in addition to providing care to another person, a caregiver must also care for themselves. This necessity requires minimizing stress and related problems. Stress is a normal reaction. Understanding its effects will help you recognize it and reduce some of the problems that stress can cause.

Stress management is not easy, but following a few recommended routines can be very helpful. First, recognize one's personal stress symptoms. Short temper, fatigue and difficulty in making decisions are all signs that one is approaching serious stress. Once this is recognized, it is then possible to develop a plan. This often requires a break from caregiving duties, during which it is helpful to talk about these duties with someone, and even to write about them.

**Educate yourself.** Learn about the medical condition of the person you care for and about being a caregiver. If the person you care for has been diagnosed with a disease, find out about the disease progression and what changes are anticipated. An understanding of what to expect can reduce the stress you experience now and later.

**Start each day with a well-organized schedule.** This may reduce the potential for stressful situations. Many caregivers prepare, in writing, a plan for that particular day. Include care for yourself in the schedule as self-care is one of the most important, and yet frequently neglected, tasks for caregivers. Obviously, changes may be required to meet specific situations, but it nevertheless provides some stability to their day.

**Make lists.** By preparing a list of all the responsibilities involved in caregiving, you enable yourself to prioritize, be organized and be prepared to share the work of caregiving with others. It can be difficult to ask for help, but having a list of what needs to be accomplished can help you identify the places you need assistance and where others can contribute. Even if it is only for groceries, having a list can make it easier to hand off a task to someone else.

**Take time-outs.** An essential element both in preventing stress and relieving it is taking time-out, even if just for a few minutes. Time-out must be a part of the caregiver's schedule and can generally be accommodated while the care receiver is resting or participating in an activity. However, a time-out must be a respite from caregiving duties, not just a time to do normal household activities. In other words, take a complete break and a bit of relaxation.

**Schedule respite and do it before you start to feel burnt out.** Some caregivers experience guilt for needing or wanting respite, it can be helpful to remember that a bit of time apart often benefits both of you and your relationship with one another.

**Visit with someone who listens to you.** Other means of dealing with stress include contact with others; particularly, if possible, with other caregivers. While few full time caregivers can find much time to attend support groups, contact by telephone is a great way to share problems. In so doing, discover that others are experiencing the same stresses and frustrations. This will often help to relieve the feelings of isolation and loneliness so often experienced by caregivers.

## Caregiver Burnout

Older caregivers and caregivers who are juggling multiple responsibilities simultaneously, such as children or jobs, have greater health risks than those in their situation who are not caregivers. They have a higher chance of experiencing chronic illness, depression, and a decline in quality of life. Sleep deprivation, poor or irregular eating and exercise habits, a failure to rest even when ill, and a tendency to postpone important medical appointments are all factors. Some people may also turn to substances such as alcohol to deal with the stressors of caregiving.

Recognize the following signs of caregiver burnout (which can also indicate the onset of depression):

- Denial about the loved ones condition
- Inability to ask for help
- Anger directed at the affected person: 'If he asks me that question again I'll scream.'
- Losing touch with friends and not participating in favourite activities
- Anxiety about the future and difficulty facing another day
- Feeling sad, tearful, helpless and out of control
- Exhaustion and difficulty completing daily tasks
- Difficulty sleeping and trouble concentrating

## **How to prevent Caregiver Burnout**

- Research and understand the disease(s) you face so you know what to expect as your loved one's condition progresses
- Plan early to find ways to support yourself and to stay healthy through diet, exercise, vitamins and supplements, yoga or meditation. Try to get enough rest. Avoid making promises you may be unable to keep
- Reserve time for yourself – take time off to pursue some interest or hobby
- Investigate and use respite service possibilities. Take advantage of offers of help from family, friends and community agencies. Define the help you need making a list of tasks that others can perform when they offer to help
- Be patient with yourself; recognize that some days are going to be more difficult than others.
- Have at least one person to confide in, who can give you support and to whom you can provide support as well through a mutual relationship
- Realize that there may be a time when you are unable to continue care for your loved one at home and that you need not feel guilty about this

## **What to do if you are experiencing Caregiver Burnout**

- Talk to someone about how you are feeling
- Ask for help from friends, relatives, and neighbors
- Contact Caregiver Information and Support at 306-652-4411 for information or referral to other community resources
- Contact CPAS for planned or unplanned respite care at 306-655-4346
- Contact the Saskatoon Health Region to join a caregiver support group or to obtain information about monthly caregiver drop-in group, call 306-655-3400
- For individual counselling contact CPAS at 306-655-4346 and ask to be referred to a social worker for counselling as a caregiver

# Depression

Sadness, loneliness, and anger are all normal emotions, but if they are intense for a prolonged period of time they could be a sign of depression. Caregivers are placed under a considerable amount of stress and can sometimes develop mild or severe depression. This does not mean that caregiving causes depression or that everyone's experience of providing care is a negative one. However, caregivers do often neglect their own needs while caring for a loved one and may experience feelings of anger, isolation, exhaustion, guilt, and anxiety.

Unfortunately many people mistakenly view feelings of depression as a sign of weakness. Telling a person to "snap out of it" is not helpful and will not make the feelings go away. If you are experiencing depression, do not let these misconceptions keep you from talking about it and seeking help.

There are many symptoms that are indicative of depression. If you or someone you know is experiencing any of the following, it may be time to consider speaking to a professional:

- Sudden weight gain or loss resulting from a change in eating habits
- A withdrawal from people or activities that once brought joy
- Insomnia or, conversely, a need to sleep all of the time
- Thoughts of death or suicide, including attempted suicide
- Physical symptoms such as headaches, digestive problems, and chronic pain that do not respond to treatment
- Feelings of helplessness, apathy, and inadequacy

The first person you should speak to about depression is a mental health professional. You should also schedule a physical exam with your doctor to rule out any medical conditions, such as a viral infection, which may be causing some or all of your symptoms.

Many physicians prescribe antidepressants for depression. If medication is not the best fit for you or you are uncomfortable with the side effects develop a treatment plan with a mental health professional. Even if you do wish to take antidepressants it is strongly recommended that you seek the guidance of a therapist or counsellor as well. Find someone that you trust and feel comfortable speaking openly with. Call your health region, ask a spiritual leader, your doctor, or your employer's health insurance provider for suggestions on whom to speak with.

Other things that help battle the symptoms of depression are exercise, a balanced diet, and a supportive network of peers and professionals. Take full advantage of adult daycares, respite care, community agencies, support groups, and home care services.

# Grief

Grief is a natural reaction to loss. It is commonly associated with the death of a loved one, but grief can be caused by any change in life where something valued is lost. Anticipation of a loss can also be a source of grief. Caregivers may experience losses like the loss of financial security, loss of time for outside activities, or the relationship with their loved one as it once was. Grieving has mental, physical, emotional, spiritual, and social symptoms, however, each experience of grief is unique. Symptoms that may be experienced include:

- Crying
- Fatigue
- Pain – headaches, stomach aches, stiffness
- Appetite disturbance – eating too much or too little
- Sleep disturbance—sleeping too much or too little, having disturbing dreams
- Social disturbance – wanting to isolate yourself from socializing or not wanting to be alone
- Fluctuating emotions
- Feeling sad, angry, confused, guilty or worried
- Irritability
- Pushing yourself to do too much or not wanting to do anything
- Reckless, self-destructive activities such as drinking too much
- Memory problems, feeling distracted or pre-occupied
- Questioning your faith, the meaning of life, or suffering

There is no “right way” to grieve or deal with loss. If you are experiencing grief, try to care for yourself by eating well, getting some physical activity, and accepting your process. Time to experience and express what you are going through is important and everyone will do that in their own way and at their own pace. However, if you feel concerned about your own grieving process over time, you should seek the help of a professional.

# Alzheimer's Disease

Alzheimer's is the most common form of dementia. It is a degenerative disease of the brain that is characterized by the destruction of vital nerve cells. While Alzheimer's is most common in older adults and gradually worsens over time, it is important to know it is not a normal part of aging.

Alzheimer's primarily affects people aged 65 and over. As the population ages, the number of people living with Alzheimer's is expected to increase and include people under the age of 65. More women are affected than men and, while the reasons are not understood, it can partially be attributed to the fact that women tend to live longer than men. Common symptoms that a person has Alzheimer's include:

- Memory loss that affects day-to-day functioning
- Difficulty performing uncomplicated, familiar tasks
- Disorientation of time and place
- Changes in mood, behaviour, and personality
- Problems with abstract thinking
- Frequent misplacing of things

The above symptoms can also be indicative of other diseases. If you observe any of the symptoms it is best to consult a physician for a proper diagnosis.

Alzheimer's appears in three stages: early, middle, and late. In the early stage, people need limited assistance with simple, day-to-day tasks. As the disease progresses to the middle stage personality changes may occur and the long-term memory is affected. In the late stage of Alzheimer's people are entirely dependent on caregivers. Keep in mind that there is not always a clear progression from one stage to the next and it can happen rapidly or over time.

While the cause of Alzheimer's remains unknown, several factors increase the risk of being affected by the disease. People over the age of 65 have the highest likelihood of being diagnosed with the disease. Even though most cases of Alzheimer's show no distinct inheritance pattern genetics are also believed to play a role. People with Down syndrome, brain injuries, hypertension, diabetes, and high cholesterol are at an increased risk of developing Alzheimer's.

The only way Alzheimer's can be diagnosed accurately is through an autopsy. However, physicians use a variety of tools to help them make a generally precise diagnosis. Physicians conduct tests to assess memory, language skills, and problem solving. The individual's medical history is analyzed and samples of blood, urine, and/or spinal fluid are tested. Computed Tomography (CT) scans and Magnetic Resonance Imaging (MRI) testing is also sometimes used.

While there is no cure for Alzheimer's to date, there are medications to help slow down the progression of the disease. Caregivers will need to implement appropriate safety features in the home to decrease the risk of injury and modify their communication techniques as language skills are lost. Be informed about the disease and what local resources are out there to help both the person living with Alzheimer's and the family members.

Since the cause of Alzheimer's is unknown there are no guaranteed ways to prevent it. On the bright side, research has shown a healthy lifestyle may help prevent or delay the disease. Keep your mind

active with activities such as crosswords or card games, remain socially and physically active, eat lots of fruits, vegetables, and fish, and maintain healthy levels of blood pressure, blood sugar, and cholesterol.

## Caregiving and Employment

If you are balancing caregiving and employment, it can feel like having two full-time jobs. Communicating your role as a caregiver to your coworkers and employer can help you get the support you will need to balance your paid and unpaid work. With 35% of employed Canadians also being caregivers, coworkers can be a valuable source of support, understanding, and advice. Let your employer know that you are committed to your job and share your needs. Some workplaces can accommodate caregiving with more flexible hours or working from home. Contacting the human resource department or your union representative can help you find out about other options that may be available to you like extended health benefits or employee assistance programs. By communicating your new role to your employer as soon as possible you can find out what kind of support is available to you.

### **A Guide to Balancing Work and Caregiving Obligations:**

[http://www.chrc-ccdp.gc.ca/sites/default/files/a\\_guide\\_to\\_balancing\\_work.pdf](http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf)

# Communication

Caregiving will sometimes involve difficult conversations, stressful situations, and life changes. Good communication can help you navigate those times and get the support you and your loved one need. Communicate clearly by being concise, specific, and listening when others speak.

It is important to be honest about the demands caregiving puts on you. It can feel as though concealing the burden of caregiving protects your loved one's sense of independence or privacy, however, it keeps others from understanding your situation and how best to help. Because every caregiving situation is unique, no one knows the challenges you and the person you care for are facing unless you share your story.

Ideally, a family pulls together to support each other when a loved one needs care, but for many reasons this is not always possible. When you have no one close to rely on or cannot get the support you need from family, turning to other caregivers can be helpful. Take advantage of local resources as much as possible. Create your own support network made up of friends, counseling services, and support groups to help with the emotional impact of caregiving. In-home support, short-term respite, hotlines, and other community resources are available to assist with daily living.

## Communicating with Loved Ones

### **Communication between Caregiver and Care Receiver**

It is best to sit down and talk about issues such as finances, living arrangements, and end of life wishes before a crisis occurs. Certain topics can be tough to bring up or discuss, however, by having these conversations early, you and your loved one will be better prepared to make difficult decisions further down the road. The person receiving care needs to take an active part in making care decisions. Even if memory problems exist, the person should be given the opportunity to express their preferences. It is not uncommon to meet resistance the first time you bring up the topic but don't let it discourage you.

When it comes to making decisions about day to day living it is important to know where your values and preferences lie. As a caregiver, sometimes your values will differ from those of the person you are caring for. If you are having trouble agreeing with what your loved one sees as being in their best interest and health or safety is at immediate risk, enlist the help of a skilled professional to mediate the conflict.

Tips for communicating with the person you care for:

- Discuss difficult matters sooner rather than later. Talking about finances, end of life planning, or topics you and your loved one disagree on are some of the tough conversations you may encounter as a caregiver. Take time to carefully think about what you want to say, but do not

wait too long to address the issue. Talking about things before the point of crisis is one of the ways you can mitigate some of the stresses of caregiving.

- Articulate your thoughts and feelings in writing before talking about an issue. Writing or journaling gives you a chance to explore and better understand your own feelings, opinions, and values. It can also help you to find the best way to bring up tough subjects.
- If the conversation becomes emotional or you feel yourself getting angry or frustrated, take a moment to breathe. It will help you calm down but also give you time to think about what you are going to say so you don't blurt something you will later regret.
- Be patient with yourself and your loved one. Remember that being cared for involves giving up independence and feeling vulnerable. It may take you and the person you care for to feel comfortable with your new roles and relationship
- Be respectful. Try not to talk about the person you care for as if they are not in the room and include them, when possible, in decisions about their care
- Use humour when appropriate
- When communicating with someone who is hearing impaired check to make sure their hearing aid is turned on and do not eat or smoke while talking. Do not shout at the person but speak slowly and clearly instead. If the person is having difficulty comprehending what you are saying, use different words instead of repeating the original sentence. Use short, simple sentences and write messages if necessary.
- When communicating with an individual with Dementia or Alzheimer's disease do not patronize the person or treat them like a child. Use orienting names as much as possible, such as "your daughter, Betty". Allow ample time for information to be interpreted and make it easy for the person to join in the conversation by asking close-ended questions that require yes or no answers. Talk to caregivers and health professionals to see what works for them. Keep your standards realistic and remember to modify your expectations as the disease progresses.

### **Working With "Difficult" Loved Ones**

When loved ones become "difficult" to care for, it is important to understand why. A common reason why people suddenly begin to act out is because they are losing their sense of autonomy, or freedom. Other reasons include the fact that Alzheimer's disease can drastically alter a person's temperament and depression can be a side effect of a long-term illness or disease.

While knowing why your loved one is being difficult is helpful, it doesn't mean you won't get frustrated from time to time. Acknowledge your feelings and know that it is okay to feel the way you do. Even though you may not be the one who is ill, your life has still been profoundly affected and adjusting will take time. Vocalize your feelings when necessary so that the person you are caring for understands where you are coming from. If that does not help and you find yourself becoming destructive, temporarily remove yourself from the situation and cool down.

Separate the person from the illness and remember the good times. Even though the person is ill, they are still your loved one and you should not take their change in behaviour personally. If they hurt you, they do not mean to. Being overwhelmed by the responsibility of caregiving is not uncommon, so do not view enlisting outside help as "running away". Taking a break when needed is healthy and can actually help strengthen the bond between caregiver and recipient.

## **Communicating with Family**

Each family has a unique history and this will play a large role in family communication. Secrets, rivalries, rules, guilt, differing values and interests are all major factors in how a family will interact with one another. Family members often play certain roles based on their position in the family unit, relationship to the person receiving care, expertise, and many other factors. Where family members live in reference to the loved one receiving care and the other demands of their lives further complicate matters.

Some people find themselves in a situation where they are caring for a loved one while also raising their own children. If this is the case for you, it may be valuable to put a bit of extra energy into communicating with your kids. Allot a specific amount of time to spend only with your children. Take the time to play a board game, go to the park, or just sit and talk with them so they know that their feelings and concerns are important too. Be alert of signs that your child is in distress, such as abnormal eating and sleeping habits, frequent nightmares, angry outbursts, or clinginess. If the behaviours persist, seek advice from a professional.

When discussing care of a loved one, families sometimes disagree on what is best and how to share the work. The needs and opinion of the care receiver should play a significant role in decisions, but the needs of the caregiver and concerns of other family members should also be addressed. An even distribution of work is rarely possible and family members should try to provide respite and support for the primary caregiver as much as they can while voicing their appreciation frequently so as to minimize hard feelings. Having clear roles and expectations can help minimize conflict.

When feasible, a family meeting can be a practical way to get everyone working together. If time constraints or geographical location makes meeting difficult, electronic technologies may be useful. Video conferencing or group chats can be a way to have everyone involved in a discussion without being in the same place. Online calendars can be shared with the family to keep everyone informed of appointments or routines and, ideally, share responsibilities. There are applications for smart phones and other electronic devices designed for caregiving that may be useful if your family is comfortable using those types of technologies.

## **Family Meetings**

It is important to include everyone who is a part of the caregiving team, which may include a friend, neighbour, or paid caregiver. An objective third party, such as a social worker or mediator, may be helpful if the discussion is not moving forward or is becoming too emotional.

It should be decided before the meeting if the care receiver is to attend. You do not want to exclude the person from having a say in their care, but if the person has dementia or another condition that hinders their ability to understand the discussion it may be appropriate to hold an initial meeting without them being present. At this first meeting, discuss issues that may be painful for the ill person to hear. At the second meeting the care receiver should be present and take an active part in the discussion.

Host the meeting at an easily accessible place for everyone involved. If some people are not able to attend in person, make use of other communication methods such as speaker phone. Create an agenda if

possible and include topics such as fears, the latest report from the doctor, financial concerns, daily caregiving needs, who should take the lead, and a list of tasks to be completed. Needs change as an illness progresses so additional meetings will be necessary.

Some questions that may help guide a family discussion include:

- How much are we able to spend on paid care?
- What kind of help is necessary at the moment, and what will be needed in the future?
- Do we want in-home care or out-of-home care? What kind? How often?
- Does the person receiving care mind if someone of the opposite sex helps them bathe?
- What kind of role does each person have? Do they help with care? Support the caregiver?

A family meeting is successful when everyone is given a chance to speak and is respectful when others are speaking. Everyone will have their own individual fears and these fears must be acknowledged. The goal is to have the family working as a unit to ensure the proper care of a family member regardless of conflicts. Every family fights, but it is important to learn how to move past the disagreement and work in the best interest of everyone.

Acknowledge that everyone has special talents and find a creative way to utilize them. For example, Fran loves to cook so she will make meals to freeze once a week and Josh has a van that is easy to get into so he can take their father to medical appointments. Distributing a calendar with everyone's responsibilities can help people remember their tasks and also determine when someone else might need a break or extra support. Most importantly, remember that you can't resolve long-standing family issues with one meeting. The goal is not to "fix" the family, but rather to have everyone on the same team, as much as possible, in caring for someone who is ill.

At the conclusion of the meeting take the time to make sure everyone has a clear understanding of the issues discussed. Each person should know what the next steps are and what they have agreed to do. Set a time and place for the next meeting and make plans to keep in touch with those who cannot make it via phone, mail, or email. Keeping in regular contact with the other family members will help the caregivers not feel isolated and allow everyone an opportunity to voice concerns or questions as they arise.

## Communicating with Health Care Professionals

Communicating with health care professionals is sometimes challenging. Being prepared for appointments can help both you and your loved one get what you need out of your time with the physician or other healthcare professional. Before speaking to a health care professional, make a prioritized list of questions, symptoms, and concerns. Make a list of the medications or supplements your loved one takes to bring with you.

During appointments or while at the hospital, be open and honest with healthcare professionals. Repeat information given to you in your own words to make sure you understand everything. Bring a note pad, recording device or someone else along, like a family member or friend, to help keep track of all the details. If you have doubts about a recommendation, advocate for your loved one by asking for more information or a second opinion.

## **Tips for Communicating with Health Care Professionals**

- Ask why medications, tests or procedures are being given and if there are any side effects
- Discuss what to expect with your loved one's illness and/or aging
- Talk with the nurse. Many caregiving questions relate more to the practice of nursing than the practice of medicine. Nurses can help you make sense of information the doctor has given you, sort out what different medications are for, and provide practical advice about caregiving tasks
- Talk to the pharmacist about medications. Pharmacists can provide you with instructions for how to properly take or give prescriptions and information on possible side effects
- Occupational therapists and physiotherapists can give you advice on maintaining mobility and transferring, lifting, and repositioning your loved one
- Ask if there are other services, resources, or information the professional knows of that would be of use to you and your loved one

At any time, you can call the HealthLine. In Saskatchewan, HealthLine is a free, 24-hour a day, confidential telephone service that allows you to reach experienced health care professionals for health information and support. Registered nurses, registered psychiatric nurses, and social workers are available to answer questions, aid you in finding services, and help you make health-related decisions for you and your loved one.

### **HealthLine**

Phone: 811

TTY hearing impaired telephone service phone: 1-888-425-4444

Website:<http://www.saskatchewan.ca/live/health-and-healthy-living/manage-your-health-needs/healthline>

## **Special Considerations for Long Distance Caregivers**

In today's society family members often live in different locations. This has added a unique element to caregiving. If you live away from the person you are caregiving for, communication will be an integral part of how you provide care. Even though you are not in direct contact with the person, there are many things you can do.

To be successful at long distance caregiving requires excellent organizational and planning skills. You can gather information via the telephone or internet on subjects such as medications, community resources, support groups, and social programs can be done from anywhere. Familiarize yourself with resources in your loved one's community and establish a contact with the organization or person. Set up a meeting that includes professionals, family members, and your loved one so that they do not feel left out of the decision making. Even banking and paying bills can now be done online, through direct deposit, or in the mail.

Long distance communication is becoming easier all the time. You can feel connected to a person by talking to them on the telephone or by writing letters or emails to keep them informed and let them know you are thinking of them. Keep in mind that this is most useful when people are at the beginning stage of an illness and that face-to-face contact may be more beneficial later on.

To make sure that you are included in the person's care, keep in regular contact with people near your loved one such as social workers, community agencies, neighbours, or friends and relatives. You will need to rely on others to be your eyes and ears. A communication book, where each person who provides care can make notes can help to coordinate care and keep you informed. Offer support to your loved one and those involved with caregiving by communicating regularly. Provide respite for the primary caregiver when you visit and remember to find emotional support for yourself as well.

Be creative about ways to check up on your loved one to make sure that they are okay. Examples include a "telephone reassurance" service that will phone the person daily, Letter Carrier's alert, which checks to see if the person has picked up their mail, or ask a neighbour to drop by. Emergency response systems linked to the telephone can also be helpful. Take advantage of home-delivered meals, hairdressing, adult day programs, and transportation services.

# Living Arrangements

The care needs of your loved one, your relationship with them, your loved one's preferences, and the other demands of your life are some of the things that influence what living arrangements will be best for your situation. Things to consider when making your choice are your health, work situation, and available supports. If appropriate resources are available in your community, you may be able to care for your loved one at home. If not, a long-term care facility may be the best option. These factors may change over time and require living arrangements to be reconsidered as circumstances evolve. Gather information about care options early so that you are able to make an informed decision that is not guided by emotion or urgency.

Information on services and living arrangements for individuals who can no longer live independently or need assistance to do so can be found at: <http://www.saskatchewan.ca/live/health-and-healthy-living/manage-your-health-needs/care-at-home-and-outside-the-hospital>

## Staying at Home

For some, care needs can be met at home with assistance, adaptive equipment and home modifications. Home modifications are alterations made to the home that help your loved one maintain independence and remain safe. Adaptive equipment refers devices that aid in completing activities of daily living. Simple changes such as removing clutter, additional lighting, or adding a grab bar are sometimes all that are required. The assistance your loved one needs may be provided by you, a family member, friend, Home Care or a private service. In Saskatchewan, Home Care services are accessed through CPAS. Home Care services fall into one of two categories: professional services or support services.

Professional services through Home Care have no direct cost, provided you are a resident of Saskatchewan and have a valid Saskatchewan Health Card. The professional services available are:

- Nursing
- Physiotherapy
- Occupational therapy
- Social work
- Nutritional counselling
- Education and rehabilitation
- Palliative care

Support services do have a cost associated with them, which is set by Home Care. Support services include:

- Personal care
- In-home respite
- Meal preparation
- Home management
- Community volunteer services can provide Meals on Wheels and transportation needs

To gain access to Home Care services, contact CPAS as 306-655-4349

For more information on Home Care and financing, visit: <http://www.saskatchewan.ca/live/health-and-healthy-living/manage-your-health-needs/care-at-home-and-outside-the-hospital/home-care#services>

A few strategies can be employed to identify what home adaptations or adaptive devices will be helpful. Ask your loved one which activities or tasks they find difficult. Watch your loved one go through their daily routines or go through them yourself, with your loved one's limitations in mind, looking for any areas that present difficulty or danger. Complete an assessment tool, like the one in *Maintaining Seniors' Independence: A guide to home adaptations*. Enlist the help of professionals by talking with your loved one's physician and contacting CPAS.

## Resources for Home Adaptations and Assistive Devices

### **Maintaining Seniors' Independence: A guide to home adaptations by CMHC**

<http://www.cmhc-schl.gc.ca/odpub/pdf/61042.pdf?fr=1421179776520>

- Guide identifies the types of difficulties that seniors can experience and describes types of adaptations that can help overcome these difficulties.
- Has a comprehensive assessment tool for evaluating what home adaptations may be needed

For more information contact Canadian Mortgage and Housing Corporation (CMHC)

Website: <http://www.cmhc-schl.gc.ca>

Phone: 306-975-4900

### **The Saskatchewan Home Repair Program**

Phone: 1-800-667-7567

Website: [www.saskatchewan.ca](http://www.saskatchewan.ca)

- Adaptation for Independence Program provides financial assistance to low-income homeowners or rental property owners to make a home more accessible for a person with a housing related disability.

Application information available at:

<http://www.saskatchewan.ca/live/housing-municipal-planning-and-public-works/home-repairs-and-renovations/adapt-a-home-for-a-person-with-a-disability#how-to-apply>

### **Go for it! A guide to choosing and using assistive devices**

[http://publications.gc.ca/collections/collection\\_2012/aspc-phac/HP25-4-2007-eng.pdf](http://publications.gc.ca/collections/collection_2012/aspc-phac/HP25-4-2007-eng.pdf)

### **The Safe Living Guide: A guide to home safety for seniors**

[http://publications.gc.ca/collections/collection\\_2012/aspc-phac/HP25-7-2011-eng.pdf](http://publications.gc.ca/collections/collection_2012/aspc-phac/HP25-7-2011-eng.pdf)

### **Tools for Living Well by the Canadian Association of Occupational Therapists**

<http://www.caot.ca/pdfs/ToolsforLivingWell.pdf>

- information about preventing falls, bath seats, hip protectors, canes, bath mats, home safety, and funding information.

## **Saskatchewan Abilities Council Saskatoon Special Needs Equipment Depot**

2310 Louise Avenue

Saskatoon, SK S7J 2C7

Phone: 306-664-6646 Fax: 306-955-2162

Email: [sne.saskatoon@abilitiescouncil.sk.ca](mailto:sne.saskatoon@abilitiescouncil.sk.ca)

The Special Needs Equipment program provides the following services:

- Equipment Loan Program, funded by Saskatchewan Health
  - Available for Saskatchewan residents with a valid Saskatchewan Health Services card
  - Equipment must be requisitioned by an authorized healthcare professional.
  - A variety of mobility (wheelchairs, walkers etc.) and environmental equipment (hospital beds, commodes etc.) are available for loan.
- Repair and Maintenance
- Retail Sales

## **Saskatchewan Aids to Independent Living (SAIL) Program**

<http://www.saskatchewan.ca/live/health-and-healthy-living/manage-your-health-needs/support-programs-and-services/sail#eligibility>

- Requires a referral from a health care professional
- This service cannot be accessed directly by individuals, but caregivers should be aware of it

## **Moving in with You**

If your loved one does not already live with you, moving in may be an option. If your loved one moves in with you, you will be able to keep an eye on what is happening, have some control over the environment, and may save money. Your home may require adaptations or modifications to make it accessible and safe for your loved one.

When deciding if this is the best decision for both you and your loved one, consider the following questions:

- Does my loved one want to move?
- What is your relationship with the person? If it is tenuous, moving in with them is probably not the best option, as this may add unneeded stress to the situation
- Are all members of your family comfortable with a new addition to the household?
- Is your house safe and appropriate for your loved one? If not, are you willing and able to make the necessary adjustments, such as grab bars and an entrance ramp?
- Will your loved one feel included and have opportunities to socialize?
- Does your loved one have important community and social support that they will lose if they move? A disadvantage of moving may be that the person may feel sad leaving their old friends and community

- Are there respite supports, either formal (i.e. home care) or informal (friends, family), accessible to you?
- Are you prepared financially, physically, and emotionally to care for your loved one?
- Can you care for your loved one while holding down a job or will you or another family member have to give up your job?
- How long are you willing to care for the person- a limited amount of time or as long as necessary?

If you decide that the best option for your loved one is to have them move in with you, be prepared for many lifestyle changes. This does not always mean that you will be the one making concessions; there will have to be give and take in order to ensure a smooth adjustment. For example, if your loved one smokes but you do not want them to smoke in your home, ask them if they would be willing to go outside in the summer or in the garage during winter. Get the person's input on what foods they like to eat, television shows they enjoy watching, and what time they usually go to bed. Accommodate the person into your family's daily life and allow them time to do the same.

You as a caregiver will have an addition to your household, which has an enormous impact on the entire family. Adding another person to the household means a shift in family roles, particularly if you are caring for a parent. You may find it difficult to be the primary decision maker and the person with authority if your parent was once authoritarian. This is a difficult transition for both parties, as your parent may take a while to adjust to their limited control and independence. Be there for them and remember that you are both adapting to new roles.

Determine as soon as possible if you will need to make adjustments to your work schedule, who you can count on for respite services, and when you can make time for your friends, spouse and/or children. Remember that you will need to arrange medical appointments for your loved one and most likely provide transportation as well. If the person has a tendency to become restless and wander you may need to use your breaks at work to come home and check on them.

Make a schedule that suits everyone and will help you remember everything. If your loved one likes to take a nap in the late afternoon don't schedule anything and instead use that time to do something for yourself, like taking a walk or reading a book. Allot a certain amount of time for yourself and put it on the schedule so that everyone knows when you require respite care. Even though other things may come up, try to stick to the schedule. You deserve a break.

## Other Living Arrangements

The decision to move a loved one from home into a different living situation is a difficult one. Although the person may not wish to move and the caregiver may have feelings of guilt, sometimes moving is the best option when it comes to providing quality care.

Several things can trigger a discussion about moving. Medical or personal care requirements may change or become greater. Problematic behavioural issues may include insomnia, frequent wandering, aggressive behaviour, or memory loss that affects day-to-day functioning. When needs increase in number and intensity it is not uncommon for caregivers to feel overwhelmed and re-evaluate who is best able to care for their loved one.

## **Level of Care**

When determining what type of facility is best for your loved one you must consider the level of care that is required. Does the person need 24-hour supervision or assistance with daily living? What activities can the person perform on their own? Are proper resources available in the community or will you have to travel elsewhere?

When deciding on the level of care you must also evaluate yourself. Are you comfortable providing personal or basic medical care? Do you have the abilities, time, money, and resources to properly care for the person? The greatest thing you can do for your loved one is provide them with the best care, even if that means that you are no longer the primary caregiver. For more information contact Saskatchewan Health at 306-787-1715 in Regina or 306-933-5843 in Saskatoon.

## **Choosing the Right Facility for You and Your Loved One**

Choosing a facility means making an investment in your loved one's care. Therefore, it is a good idea to shop around until you find a good fit. Try visiting the facility at various times of the day and talking with the current residents to gather their thoughts and experiences on the facility. Observe the dynamics between residents and staff, as well as the social and recreational events provided. Talk with staff and make yourself knowledgeable about the facility's grievance procedures, transfers, refund policies, discharge, and medical care.

Prepare early for the possibility of moving your loved one into residential care. If you wait until a crisis occurs you will be forced to make a decision under pressure and may not have the time to fully weigh your options. Hold a family meeting with your loved one present and determine which facility best suits their needs and preferences. Things to consider include cost, level of care provided, future needs, and location. Remember to get support for yourself as well. While it is not uncommon to have some feelings of guilt, you need to remind yourself that a residential facility may be the best choice for your loved one's health and safety, as well as your own.

### **Types of Facilities**

#### Retirement Communities

- Services depend on the type of community.
- Cost is typically high
- Most facilities accommodate a large number of residents
- Large building with private rooms and various shared living spaces.

#### Assisted Living Facilities

- Provides meals, housekeeping services, assistance with daily activities, transportation, help with medications, social activities, 24 hour supervision
- Cost varies depending on number of services required. Most facilities have a monthly rate and then charge separately for all other (extra) services
- On average there are 40 to 100 residents

- Apartment-style setting. Residents may have one bedroom or full apartments with large, shared living space
- Enriched housing information is available through the Saskatoon Health Region or can be picked up at the Saskatoon Council on Aging

#### Personal Care Homes

- Provides rooms, meals, and assistance with daily activities
- A private business
- Cost is typically higher than other facilities. These facilities are currently not subsidized
- Number of residents is relatively small
- Family-style care. Residents may share some living spaces
- Copies of the Personal Care Homes Directory are available through the Saskatoon Health Region or can be picked up at the Saskatoon Council on Aging

#### Special Care Homes

- Provide medical services, 24-hour nursing care, assistance with daily activities, recreational activities
- Cost is income based and is government subsidized
- Number of residents is dependent on location. There can be anywhere from 20 to well over 100 residents
- Hospital-like setting with round-the-clock care and professional medical services
- All residents are admitted through an assessment with CPAS with the Saskatoon Health Region

## Long Term Care

Many full-time caregivers will eventually be faced with investigating the placing of their care receiver in long-term care. This may be the result of deterioration of the care receiver's condition, where proper care might no longer be possible in the home or it may occur because caregivers can no longer carry out their duties. In the first case, it is often a health care worker that recognizes that a move is required. However, caregivers are often unwilling to admit that they can no longer function safely or that they are approaching burnout. In this case it may be family members who recognize a change is necessary.

Whatever the reason, most caregivers are initially very reluctant to give up their duties because that decision is one of the most difficult they will ever have to make. One of the arguments often heard is "I've been doing this for years, and I can still do it". It may well take the combined efforts of health-care workers and family to convince the caregiver to even consider long term care placement.

An important point to remember is that the process takes time. For subsidized long-term care, the first step is to get an assessment of the care receiver (from CPAS) to decide if a care home is required. Once approved, the waiting time for bed availability may be anywhere from a few weeks to a few months. When a bed is found, the cost will be based on provincial rates, subsidized according to ability to pay.

Caregiver duties do not end when this move takes place. Caregivers will find themselves with more free time and fewer responsibilities, but will in all likelihood still be very much involved with the care of their loved one and will continually be asked to make decisions related to their care receivers. Some caregivers adapt to this new regimen quite easily. Others, mainly because of guilt (they still believe they should have kept their loved one at home) will find some difficulty in adjusting and may create unnecessary problems at the care home. In such instances some counseling is vital and should be sought. This may be available at the care home, but many find a discussion with caregivers who have already been through this quite helpful. Family members are also a good source of comfort in these situations. This adjustment is never easy and will take some time.

# Legal and Financial Planning

Legal and financial planning considers the present and the future. Planning can help you understand your choices and ensure your future wishes are met. When making these plans, long and short term needs should be considered. Valuable things to consider are current and future living expenses, sources of income like government or benefits, assets, insurance needs, or personal preference and values. If your financial or legal situation is complicated, consider hiring a professional to help you.

Even though this type of preparation is important for everyone, these issues can still feel daunting or uncomfortable. As a caregiver, you may need to consider these issues for yourself and the person you care for. Consider how to best bring up these topics before discussing them. Using news articles and brochures or discussing your own plans can sometimes aid in starting the conversation.

## End of Life Wishes

Communicating end of life wishes can ensure that your values and choices are understood and followed. While it is not required to formally prepare documents, doing so can remove confusion or dispute and ensure your wishes respected. Creating a health care directive or legal will and appointing an enduring power of attorney can ensure you are cared for the way you wish to be if you are ever incapacitated.

End of life wishes often include funeral planning. If you would like a funeral service and if so what kind, what will be done with your remains, and financing information are some of the things you may wish to specify. Your preferences and plans can be discussed with your loved ones, written out, or included in a legal will.

Harold Empey, a Saskatoon resident, has created a binder called “Just In Case”. The binder is a resource designed to help you consider, discuss and prepare your end of life wishes. Binders are \$30 each and are available for sale at the Saskatoon Community Foundation office.

### **Just In Case Planning Binder**

Cost: \$30

Saskatoon Community Foundation

Phone: 306-665-1766

308 4th Ave North, Saskatoon.

## Health Care Directives

A living will is not the same thing as a legal will. It is a health care directive that instructs others on how you would like to be treated if you lose your capacity to make those decisions yourself. It details which procedures and medical treatments you would and would not like. The best time to make a living will or health care directive (the terms can be used interchangeably) is while you are still healthy and mentally capable. Each person's health care directive will be different and should reflect their morals, values, and wishes.

In the health care directive you can also name a proxy, or a person who will make decisions for you should you become unable to do so. In the absence of a health care directive your next nearest kin would be responsible for making decisions. If no relative is present or able your health care provider will make decisions for you by consulting with other professionals

## Power of Attorney

Power of attorney is a legal document that appoints a person or persons of your choice to act on your behalf for personal or financial decisions. This person acts as a proxy decision maker for you. A power of attorney document can be general, empowering the appointed party to act on your behalf in all personal affairs or it can be specific and limit their decision making power to certain financial affairs or property.

Enduring power of attorney (EPA) is a power of attorney document that empowers a person or persons to make decisions on your behalf if you are incapacitated. An EPA can be used to appoint a proxy to make health care decisions for you as well as financial choices. Like regular power of attorney, the decision making power you give to an individual can be general or limited to certain areas.

More information on power of attorney including how to appoint one, who can be appointed, and how to terminate one can be found at: <http://www.saskatchewan.ca/live/justice-law-and-civil-rights/power-of-attorney-guardianship-and-trusts/power-of-attorney>

## Adult Guardianship

Sometimes people become unable to make informed decisions about their life due to a debilitating illness or because of an injury. *The Adult Guardianship and Co-decision-making Act* allows for a concerned person with interest in the personal and financial well-being of the adult to become a legal adult guardian. They will be able to make decisions regarding the daily life of the adult and their property.

Occasionally the court will also order a co-decision-maker or, if the situation is serious enough, give the guardian the power to make all decisions for the adult. A minimum of two written opinions stating that the adult is incapable of making decisions for themselves is required before a court will grant the power to someone else. Contact the Public Guardian and Trustee office if you wish to receive an application for adult guardianship. In cases where no family or friends wish to take on the responsibility the Public Guardian and Trustee will become the guardian or co-decision-maker.

For more information about adult guardianship, legal responsibilities of an adult guardian, and the application process visit: [www.saskatchewan.ca/live/justice-law-and-civil-rights/power-of-attorney-guardianship-and-trusts/guardianship-of-dependent-adults](http://www.saskatchewan.ca/live/justice-law-and-civil-rights/power-of-attorney-guardianship-and-trusts/guardianship-of-dependent-adults) or contact the Public Guardian and Trustee of Saskatchewan in Regina at 306-787-5424

## Legal Wills

A will is a legal document that details how you wish your estate to be handled after your death. Without a will property may not go to the family member you intended to inherit it and can also create turmoil for the family members left to determine your wishes on their own. Having a will allows you to name an executor.

A will is usually drawn up by a lawyer who will ensure that the document meets legal standards and clearly states your intentions. A will is not considered valid if created under force or influence of another individual. When making your will you must appoint an Executor who will be responsible for settling your estate and arranging your funeral and burial. You can choose a family member, spouse, or close friend to do this even if they are your main beneficiary. It is a good idea to speak with the person first before naming them your Executor.

Remember that you can cancel your will at any time by physically destroying it, creating a new one, or by writing an informal document stating that you are changing your will and the former one is void.

## Registered Retirement Savings Plans (RRSPs)

Individuals are allowed to make contributions to their RRSP until they are 71 years of age. After that the person chooses whether to cash in all of their RRSPs and pay income tax on the funds you receive, or use the money to purchase an annuity or a registered retirement income fund (RRIF). People choose an annuity or RRIF because it allows them to spread the money out for a number of years without having to be taxed on the full amount in one year.

## Paying For Long-Term Care

Individuals living or who have a loved one living in a long-term care home are responsible for a portion of the cost of living. The province usually determines the monthly fees and adjusts the amount quarterly to reflect changes to Old Age Security (OAS), Guaranteed Income Supplement (GIS), and Seniors Income Plan (SIP). The amount the individual is required to pay is dependent on their annual income. Income is taken into account but personal assets, such as land and property, are not. If only one spouse is in a long-term care home the couple has the option to base the fee on half of their combined income or on the income of the spouse who is receiving care. Contact Service Canada at 1-800-227-9914 for more information.

<http://www.saskatchewan.ca/live/personal-and-family-support/assistance-for-seniors>

## **Personal Care Home Benefits**

<http://publications.gov.sk.ca/documents/17/76764-Personal-Care-Home-Benefit-Application-Guide.pdf>

<http://www.saskatchewan.ca/live/personal-and-family-support/assistance-for-seniors/seniors-living-in-personal-care-homes>

## **Financial Fraud**

In today's world it is sometimes difficult to determine what is legitimate and what is not. Here are some helpful hints on how to hang onto your money and get the best bang for your buck:

- Take the time to shop around and compare prices.
- Be wary of claims that seem too good to be true- they probably are. Never give out any personal information until you have researched the company and know them to be legitimate.
- Never pay money in order to claim a prize.
- Try not to pay cash to telemarketers or door-to-door solicitors, particularly if they pressure you to pay right away.
- Never call a "1-900" phone number. You will have large charges on your next phone bill
- Before donating to a charity make sure that it truly exists by asking for an official income tax receipt.
- Check your monthly credit card statements for any suspicious purchases.
- Only use secure links to make online transactions. The link address should say "HTTPS" at the beginning as opposed to "HTTP" if it is secure. Having a secure link does not ensure the website itself is not fraudulent, but does protect your information from being stolen by a third party.

If you think that you have experienced consumer fraud contact the Consumer Protection Branch of Saskatchewan Justice right away.

### **Additional Resources**

Seniors Guidebook to Safety and Security by the RCMP

[http://publications.gc.ca/collections/collection\\_2012/grc-rcmp/PS64-55-2011-eng.pdf](http://publications.gc.ca/collections/collection_2012/grc-rcmp/PS64-55-2011-eng.pdf)

## Dealing with Financial Problems

The simplistic answer here is to prepare a detailed budget and then stick to it. The problem most caregivers encounter, however, is that unexpected (and therefore unbudgeted) expenses often arise and must be dealt with. This may include medicine, supplies or other items.

In discussion with a number of caregivers, two significant factors came out. First, many were not aware of existing programs within the Health Care System that may provide financial assistance. For example SAIL (Saskatchewan Aids to Independent Living) will loan wheel chairs and other equipment. Second, there are a number of tax benefits available that can provide some relief. Not only are many of these not well known, they are difficult to find unless one is familiar with benefits available through Canada Revenue Agency. Many people have discovered that engaging a competent accountant at income tax time will provide a significant tax reduction. Because of this, it is important that caregivers save all receipts for expenditures related to caregiving duties.

Information about financial support programs offered by the Province of Saskatchewan can be found at:

<http://www.saskatchewan.ca/residents/family-and-social-support/financial-help>

## Driving

In Saskatchewan, SGI does not automatically evaluate someone's driving once they reach a certain age, but they do perform an assessment if there has been a significant change in health status that could affect driving. If it is deemed necessary for the safety of the public, restrictions may be placed on a driver's license, such as not being able to drive at night, or having the license cancelled.

You may also write a letter to the Medical Officer if you believe that your loved one is not competent to drive. This will trigger a driving test. If your loved one is designated incompetent to manage his or her decisions, he or she should not have a drivers' license.

### **The Older and Wiser Driver**

- A guide written by SGI on driver safety for seniors

[https://www.sgi.sk.ca/pdf/older\\_wiser.pdf](https://www.sgi.sk.ca/pdf/older_wiser.pdf)

### **Parking Program for People with Disabilities**

- Parking passes are available for parking in spots designated for those with mobility issues

Phone: 306-374-4448

Website: [http://www.abilitiescouncil.sk.ca/html/parking\\_program\\_people\\_disabilities/index.cfm](http://www.abilitiescouncil.sk.ca/html/parking_program_people_disabilities/index.cfm)

Email: [parkingprogram@abilitiescouncil.sk.ca](mailto:parkingprogram@abilitiescouncil.sk.ca)

## Alternatives to Driving

### **Saskatoon Transit**

- Bus service within Saskatoon

Phone: 306-975-3100

Website: <https://transit.saskatoon.ca/>

Fee: \$3.00 for a single ride, Monthly and Annual passes available at a reduced rate

For information on fares and passes visit: <https://transit.saskatoon.ca/fares-passes>

### **Access Transit**

- Service available through Saskatoon Transit for disabled individuals

Phone: 306-975-3555

Website: <https://transit.saskatoon.ca/rider-guide/accessibility/access-transit>

Information video: <https://www.youtube.com/watch?v=34S3zQDwyeA>

Fee: \$50.00 for 20 fares, reduced fares available for individuals with low-income or those on social assistance

# End of Life Care

## Compassionate Care Benefit

As part of employment insurance the Government of Canada offers compassionate care benefits to those who must be away from work temporarily to care for or support a loved one who is gravely ill and has a significant risk of death. Coverage is for a maximum of 26 weeks for those who are eligible. To find out about eligibility, how much you may be able to receive, and how to apply visit: <http://www.esdc.gc.ca/en/ei/compassionate/index.page?>

## Palliative Care

Palliative care is a specific form of health care for individuals living with a critical or terminal illness. People receiving this form of care include those with cancer, Alzheimer's disease, AIDS, multiple sclerosis, and those with advanced heart, respiratory and kidney disease. The goal of palliative care is to provide the best quality of life for the person by meeting the physical, psychological, social, cultural, emotional, and spiritual needs of the ill person and their family.

### What is involved in Palliative Care

- **Pain management.** People with a terminal illness who are experiencing pain may be given medication to comfort them or manage the pain by using massage therapy and relaxation techniques.
- **Symptom management.** Every person will experience different symptoms. These may include nausea, a loss of appetite, laborious breathing, weakness, or bowel and bladder problems.
- **Social, psychological, emotional, and spiritual support.** Palliative care uses a holistic approach that takes into account the well-being of the whole individual. Bereavement support is also a facet of palliative care that helps the family grieve the loss of a loved one.
- **Caregiver support.** Palliative care recognizes the impact terminal illness has on caregivers and offers ways to help the family cope. These include home support services, respite for the caregiver, advice and assistance, and instructions on how to perform basic medical care such as administering medications.

### Who Provides Palliative Care?

The needs of the person who is ill and his or her family determine who will make up the palliative care team. The team can include a physician, social workers, spiritual counsellors, nutritionists, home support workers, and physiotherapists, among others. Volunteers may also offer support by providing services such as companionship, respite for the caregiver, and transportation.

## **Where Do People Receive Palliative Care?**

People can receive palliative care in a variety of locations. Home care allows people to remain in their home by offering professional nursing care and support services in the individual's own home. Volunteer services, day programs, pain and symptom management teams, and 24-hour emergency response teams also help a person remain in the comfort of their own home.

Some people do not have the choice to remain in their own home. However, they do still have options. Palliative care services may be accessed in long-term care facilities or in residential hospices, but it is important to note that these hospices are few and far between in Canada. Many people receive palliative care in hospitals that have specialized units dedicated to the comfort and care of those in an advanced stage of a terminal illness.

## **Who Pays for Palliative Care?**

Palliative care is paid for in different ways across Canada. Often it is dependent on whether the care is being provided at home or in the hospital.

- At home the costs may be covered by the provincial health plan as a part of home care. It is important to note that these plans do not always include the cost of drugs and equipment and may only pay for a certain number of hours of professional services. Other ways to pay for palliative care are to use private insurance or personal savings. Assistance may be provided by social agencies, service clubs, local cancer societies, or by hosting fundraisers.
- In the hospital the costs are typically covered by provincial health plans. The costs of drugs, medical supplies, and equipment are usually paid for as well.
- In long-term care facilities costs vary according to the facility. Residents are usually required to cover some of the costs.

## **Where Can I Find Out About Palliative Care Services Available in My Community?**

A good place to start is by talking to your family doctor. Home care nurses, hospital social workers, spiritual counsellors, and palliative care associations will also be able to help. The public library may also have material on community resources.

## **When a Terminal Illness Is Diagnosed**

When a loved one is diagnosed with a terminal illness it takes a while to come to terms with what is happening. Caregivers might find that their priorities have changed, life and death have a new meaning, hopes and dreams for the future are gone, or that their life has no purpose. Feelings of blame, guilt, and anger are common, as well as an anxiety surrounding death and suffering. You may struggle with current and future losses, such as family roles, financial changes, plans for the future, sexual desires, and a loss of control. You may question why something like this has happened to you and maybe even deny it altogether because the pain is too much to bear. This wide range of emotions and thoughts may go on for months, weeks, or days and can change from hour to hour. There is no "cure" for anticipatory grief, but there are some things that can help you make the most of the time you have with your loved one.

- Respect the privacy of your loved one and allow them as much control as possible when making decisions about care and activities.
- Take care not to give advice when it is not needed or wanted.
- Share your hopes, thoughts, and feelings with your loved one and encourage them to do the same.
- Think back on your life together, both the good times and the not so good.
- Make the most of your time together. Listen to music, watch television, play cards, or sit together and talk.
- Deal with any unresolved conflicts, either on your own or with a third party to help you come to an understanding.
- Help the person put their affairs in order. Make sure that the will is up to date, advanced care directives are filled out, and the estate is in order.
- Accept that you have limits and cannot solve all problems or provide all of the care. Be willing to accept help from people who want to be involved.
- Talk about your feelings and concerns with someone you trust.

### **How to Take Care of Yourself**

It is easy to get so absorbed in caring for a loved one that you begin to neglect yourself. Time management and staying active will help you keep on track. Prepare nutritious meals in double portions so that you have a second meal in the freezer. Stock your kitchen with healthy snacks such as fruit, cheese, and whole grain crackers for times when you are busy but don't have time to cook. Set aside a time to exercise regularly and keep all dental and medical appointments. If you have a paid job, consider taking a leave of absence so that you do not burn out. Most importantly, do not feel bad about receiving outside help.

### **Coping Skills**

While it is normal to feel anger and frustration, how you manage those feelings is important. Sometimes providing palliative care for a loved one intensifies the love and sometimes there is a feeling of increased inner strength and resolve. Everyone experiences feelings of sadness, anger, fear, and anxiety. There is no "right" way to feel during this time and you may feel a combination of emotions.

Remember that others are also feeling the stress of the situation so try to be open-minded and see things from their point of view. Take a large problem and break it into small, manageable pieces that you can work on one at a time. Find healthy ways to blow off steam, such as vigorous exercise, pounding into a pillow, or sitting alone in a car screaming. Don't let feelings of resentment fester- talk to a friend, family member, spiritual leader, or professional to work through it. Crying, writing in a journal, practicing breathing techniques, and complimenting yourself on a job well done are all good coping mechanisms. Don't feel guilty for laughing; it is a great way to release tension.

## **Informal and Formal Support**

Support networks exist to help caregivers when they need a break. No one is able to do everything themselves and there is no shame in asking for help when you need it.

The first step in forming an informal support network is to identify who would be willing to help and who has already offered to. Make a list of things to be done, such as shopping, making meals, and housework, which are easy for family and friends to do while you rest. Formal support networks are more structured than informal and sometimes come with a cost. Formal supports include family doctors, a home care team, social workers, pharmacists, community agencies, and volunteers.

## **Spending Your Last Days at Home**

The decision of where to spend your final days can be a difficult one to make. Helping someone remain at home is hard work but can be tremendously rewarding. Start talking to your loved one about the arrangements and your concerns and feelings early on. Make sure to speak to a doctor and home care staff to ensure that dying at home is a practical option. Prepare yourself for what might be expected in your loved one's last few days and learn how you can comfort them. Give pain medication if needed, play music or read to them, turn the person every two hours or adjust their pillows, moisten the person's lips, and be aware of background noise that may be upsetting. Moderate the number of visitors and request that they call in advance in case the person is too tired or not in the mood to see anyone. Keep in contact with a spiritual leader if your loved one has one.

Keep a list of phone numbers for home care workers and doctors nearby. Information regarding care and important phone numbers should all be kept in the same place. Decide who the person wants to have with them at the time of death and any other wishes they might have. Call for help if the person is uncomfortable, having difficulty breathing, has fallen, refuses to take medications, or has problems passing urine or with bowel movements.

## **Spending Your Last Days in a Hospice or Hospital**

Sometimes it is necessary for a loved one to spend their last few days in a hospice or hospital. As a caregiver your primary job is to ensure the comfort of your loved one. Take special objects with you to the hospital, such as pictures, a quilt, and clothes to help make the room feel familiar and more like home. These last few days may be difficult on a variety of levels so it is important to also take time for yourself.

## **What to Expect in the Last Days of Life**

As death nears, a person goes through changes to help them transition. Someone who is dying may feel a separation from the world and believe that nobody truly understands what they are going through. Things such as life history, regrets, and unfinished business become increasingly important. Touch and silence often become more meaningful than words.

Illness can also affect a person's mental awareness. Your loved one may become restless or agitated and have difficulty following simple directions. They may be drowsy, have trouble communicating, and

may not recognize familiar people or objects. Even though it may feel like there is not much for you to do, here are some things that you can do to help the person transition:

- Sit quietly next to the person so they can feel your presence. Gently touch them or speak softly to remind them you are there.
- Limit distractions by turning off the television or radio and closing the door.
- The person may be confused as to what time period it is or who you are but do not disagree. Sometimes agreeing will allow the confusion to pass without upsetting the person.
- Soft music can be relaxing.
- After consulting a doctor, offer drinks or small portions of your loved one's favourite foods that are easy to eat

### **Signs That the End Is Near**

Knowing what changes to expect as the end draws nearer can help relieve some common fears and anxieties. Breathing often becomes shallow, quicker, or slower, and there may be brief intervals where there is no breathing at all. The person may have difficulty swallowing, have an irregular heartbeat, and a decreased level of consciousness. Check the person's skin for coldness and purple discoloration, particularly on the arms and legs. The individual may also have dark urine or no urine at all and will refuse drinks.

### **What You Can Do To Provide Comfort**

Whether your loved one has a high level of awareness or relatively little, your presence will be a tremendous comfort. Reassure the person that you are near and reinforce this by gently touching them. Keep the person warm and moisten their lips with water or a lubricant. If they are having difficulty breathing elevate the upper body with pillows. Even if you think the person cannot hear you, continue to speak calmly and soothingly.

At the time of death you will note a few key things. Firstly, there will be no pulse or breathing and the jaw will relax, the mouth opening slightly. If the person's eyes are open they will be fixed in one direction. You may feel the urge to do something right away but there is no rush; take time to say goodbye to the person.

### **What Next?**

When a loved one passes on there are many practical things that must get done. The following list may help you gather your thoughts during this difficult time.

- Contact family and friends to inform them of the death
- If flowers and a printed program are needed for the funeral, assign someone with the task of arranging this.
- Compose an obituary for the newspaper. This can be a very difficult process so enlist help as needed and have someone read over the final draft before submitting it.

- Choose a location for your memorial service. It could be in a chapel, community hall, or your own home.
- You may have spoken to your loved one about their wishes in regards to cremation or burial. If not, decide which option you prefer and notify the funeral home.

## **Grieving**

Following the death of a loved one comes a period of grief. Grieving, while stressful and unpredictable, is perfectly normal. Feelings that accompany grief include guilt, sadness, failure, and anger. You might be angry at your loved one who passed away or at other people who are not directly related to the death. Do not try to suppress your feelings of anger.

Grief will affect you physically, mentally, emotionally, spiritually, and socially. While the pain of loss never goes away, it will lessen over time. Allow yourself the space and time to grieve and remember that there is no “right” way to do so. Spending some time alone to gather your feelings and thoughts is good, but take care not to isolate yourself. Keep physically active, eat healthy, and continue to do the things you love. If a year passes and you still have unresolved anger, are afraid of getting close to people, or are unable to stop feeling guilty, consult a professional.

## **Life after Caregiving**

The final crisis in a caregiver’s experience will occur with the death of the loved one. Caregivers who have devoted a significant part of their lives to caregiving duties will suddenly be left in a state of total emptiness, not knowing how to cope with a totally new and different lifestyle. Feelings of guilt are common (“Maybe I could have done a better job”) and deep depression often follows. Again, in these situations counseling is vital and must be sought.

Members of the clergy are always helpful and if the care receiver had been in long term care, people trained to provide such counseling are usually available in the care home. Hopefully, the caregiver will ultimately be able to adjust to a new way of living. Some have found much comfort in taking up volunteer jobs in care homes or in making their experiences available to other caregivers.

# Conclusion

Caregiving can be a rewarding and enriching experience when caregivers receive the appropriate level of support. It is important for the caregiver to care for themselves to avoid burnout, depression, and illness. Caregivers are encouraged to reach out to *Caregiver Information and Support* to learn about resources available in the community, attend events where they can meet other caregivers, and talk to someone about some of the frustrations they may be experiencing.

A suitable conclusion to this guide is taken from a Multiple Sclerosis publication, “Real Living with Multiple Sclerosis”, Vol.7, No. 3, entitled “The Challenges of Caregiving”, as it summarizes many of the items discussed above:

- Choose to take charge of your life, and don't let your loved one's illness always take center stage.
- Remember to be good to yourself. You have a very hard job, and deserve some quality time to yourself.
- Watch out for signs of depression and don't delay in getting professional help when needed.
- Accept any offer for help.
- Educate yourself about your loved one's condition. Information is empowering.
- Trust your instincts; most of the time they will lead you in the right direction.
- Stand up for your rights as a caregiver.
- Seek support from other caregivers. It helps to know you are not alone. Don't be afraid of the bad days; good ones are sure to follow.

**Please call 306-652-4411 to speak to a staff member at the Saskatoon Council on Aging's *Caregiver Information and Support Program*.**

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