

# A Guide for the **CAREGIVER**

Information and Resources for  
Caregivers of Older Adults



## ACKNOWLEDGEMENTS

The Seniors and Healthy Aging Secretariat developed this booklet in consultation with community organizations and caregivers. Some of its content is based on the book, *Keys to Eldercare in Manitoba* by Jan Cooper (St. Boniface Hospital Auxillary, 1990).

For copies of the guide or to offer ideas for future editions, please contact the **Seniors and Healthy Aging Secretariat** at 204-945-6565 in Winnipeg, toll-free 1-800-665-6565 in Manitoba; email [seniors@gov.mb.ca](mailto:seniors@gov.mb.ca) or visit [www.gov.mb.ca/shas](http://www.gov.mb.ca/shas).

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# INTRODUCTION

Caregivers have and will continue to play an important and valuable role in our lives, communities and province. This guide has been created to provide caregivers of older adults with information on the rewards, challenges and resources available that may support them.

Manitoba's population of older adults is growing. It is expected to increase by 43 percent over the next 20 years. Of the older adults currently living in Manitoba, 93 percent of them live in the community. Many of these individuals have chosen to age in place and remain in their homes and/or communities for as long as possible. For many, informal caregivers play a key role in helping older adults achieve this goal. In fact, within our long-term care system, informal caregivers are an essential support.

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# THE CAREGIVING EXPERIENCE

Anyone can find themselves in the caregiving role. A caregiver is a person who is providing informal and unpaid personal care, support and/or help to another person because that other person lives with challenges due to a disability, an illness, an injury and/or aging.

One might be caring for someone under the same roof or miles away. This may be a new experience for you or perhaps, you have been providing care for several years. Whether you are caring for an aging partner, friend or parent, seeing yourself in the caregiving role can be key to coping and accessing support services.

It is important to establish a relationship that is comfortable for the person you are caring for - and yourself. Focus on what the person can do today - respect his/her desire to remain independent.

Learning how to accept help is key to self-care for everyone. Accepting help from others is hard, especially for someone who has not needed help before. Sometimes, people receiving care want to keep or regain control so much that they show challenging behaviours. These can include refusing help, belittling the caregiver's efforts, making constant demands or taking out their frustrations on those trying to help.

While the behaviour can be upsetting, it might be easier to understand if you look at what is happening from the older person's perspective. The older person may be frustrated and trying to cope with the new situation. Help the older individual be as independent as possible.

## THE CAREGIVING EXPERIENCE (CONTINUED)

An honest conversation can help relieve tension, solve problems and express feelings. Listen to the older person. If possible, come up with a new plan/approach together. If communicating is hard, try:

- Making sure the area is quiet.
- Speaking calmly.
- Using simple terms.
- Using gentle touch for assurance.
- Suggesting several choices instead of asking open-ended questions.
- Allowing the person time to respond.
- Avoiding arguments.

Many disease-specific organizations have helpful advice about how to approach difficult behaviours (ex: refer to resource section on page 39). It can also be helpful to join a caregiver support group so you can talk to other caregivers who have been through similar experiences.

Challenging behaviours can also be signs of age-related disease, such as dementia. In this case, it is important to learn about the disease and stay informed about common behavioural symptoms. The more you understand about the medical condition, the more confident you will be in providing care.

### **See the caregiving role as a change rather than a role reversal.**

There is a myth that children and parents reverse roles when the adult child must tend to the needs of an aging parent. This is not true. Caregivers who recognize that their parents or partners are **not** children are better prepared to care for an increasingly dependent person. Avoid treating older people as children - either through actions or tone of voice - to help them keep a sense of dignity. Ensuring dignity and privacy will encourage their independence.

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## THE EMOTIONAL JOURNEY OF CAREGIVING

The caregiving journey can be emotional for the caregiver and the older person receiving care. There are many rewards and joys of caregiving, such as:

- Having a new relationship with person receiving care;
- Giving back to someone who cared for you;
- Enjoying a sense of accomplishment and satisfaction from doing a job well;
- Developing new skills, knowledge (ex: advocacy abilities);
- Increasing compassion and personal growth;
- Making friends through support groups;
- Building greater self esteem;
- Creating memories;
- Experiencing less grief for what used to be; and
- Finding joy in the present.

Along with the positive, life-affirming feelings, it is common to have upsetting thoughts and emotions that challenge your effectiveness as a caregiver. Recognizing that you are not alone in experiencing these powerful emotions can be helpful.

### **Feeling guilty can be normal, but do not let it get the best of you.**

Almost every caregiver occasionally experiences feelings of guilt, including guilt over not doing enough or choices made. Do not let guilt overwhelm you. This includes not feeling guilty when you take time for **yourself**. Proper self-care will help you cope with the stresses of being a caregiver. Getting help can reduce feelings of guilt, so make the most of your support network.

### **Feeling angry and frustrated is natural.**

Feelings of anger and frustration are common among caregivers. You may be angry about the way your relationship with the older person is changing, or your new role as a caregiver. Many caregivers feel frustrated at their inability to meet all the needs of the older individual or to balance their caring roles and their own personal lives.

Some feel angry about the physical/mental changes the older person is experiencing. It is normal to feel upset about these changes, but keep in mind that we all experience physical changes as we age. Some people experience mental changes. Some changes are reversible, others are not. Regular medical checkups improve the success rate for reversible changes.

Taking out your frustration on others only adds to your feelings of guilt and loss of control. It also creates tension between you and others. If you find yourself snapping at the person you are caring for, then stop and take a break. Do something positive for yourself to relieve the tension. You can ask for help from your support network or from a trained professional (ex: refer to Resource Section starting on page 31).

### **Feelings of depression can be normal; help is available.**

The losses suffered by the aging person, family and caregivers themselves can often lead to depression. It is important to take regular breaks and pursue interests you enjoy outside of the caregiving role. Build a support network and take advantage of community or professional counselling services. All will help you manage your caregiving responsibilities. If you are sad or depressed, talk to someone you trust (ex: friend, family member, clergy) about how you are feeling.



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# TIPS FOR CAREGIVERS

The caregiving journey can be a very rewarding and challenging experience. Caregivers are often juggling several responsibilities, such as caring for an older person, raising a family, working full-time, volunteering and personal interests. The following are practical tips that may be helpful along this journey:

- Learn about the condition of the older person, the physical and behavioural changes of normal aging and changes that may occur over time due to the illness (ex: Normal aging does not cause dementia.) Get information from organizations and professionals will help you make informed decisions in caregiving. It will also help you assess any changes you may notice in the older person.
- Get resources (ex: books, magazines, DVDs) from your local library on helpful topics such as stress management and self-care.
- Consider getting equipment designed to help people with disabilities (ex: bathtub aids, walkers). Many items can be borrowed or rented. Stick to a routine when caring for an older person to promote a sense of security.
- It is important to plan for the future. Consider your finances, your support networks and the resources available in your community.
- Be realistic. Ask family, friends, health care providers or professionals for help whenever you need it.

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## YOU DON'T HAVE TO BE ALL THINGS TO ALL PEOPLE.

Strive for balance, not perfection, in life. Caring for another is an emotional experience for everyone. It can be difficult to find solutions that make everyone happy. The following suggestions can help you cope more effectively with the caregiving challenges:

- Accept that there are some things you cannot change, so focus on the things you **can** do.
- Keep a record of the older person's major behaviour changes and your responses to them.
- Help the older person cope with his or her own feelings.
- Use various communication methods, such as touching, hugging, humming and singing. Things like serving a favourite food or taking walks together can help strengthen your relationship with the older person in your care.
- Use humour when handling difficult situations.
- Take time to reflect on success and don't dwell on what you see as failure. Make a point of noting the positives each day.

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## GETTING THE FAMILY INVOLVED

Keep in mind that every family is unique. Designing a support plan in advance, with input from all family members, has many advantages.

If something happens, each family member has the satisfaction of knowing a system is in place that outlines what needs to be done and who will do it. You may find family relationships strengthen when you work together to find creative ways to solve problems.

Finding ways to share caregiving responsibilities helps to keep the situation - and ourselves - in balance.

Here are some tips for planning with your family:

- If your older family member is mentally alert, determine his or her wishes about the need for help and plans for the future. Discuss what type of care will be needed and where this care will be given.
- Consider the larger network you already have, such as friends, neighbours and relatives.
- Listen to each other and agree on plans for your older family member.
- Ensure that your plans are workable.
- If you reach a deadlock, do not give up. To get back on track, focus on the wishes of the older person.
- Try to establish a clear back-up plan for times when you are not available.
- Make sure friends and support group members fully understand your challenges so they can be as helpful as possible.
- Do not demand too many changes from family members. Accept the help they offer and realize that they may want to do it their way.
- Everyone should accept a compromise once all options are explored.
- Ask questions, get information about resources, supports and options.

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## DEALING WITH STRESS

### SELF CARE

To care for others, first be a friend to yourself. It is critical to take care of yourself. To avoid caregiving stress, you need to find ways to manage your own stress. The following are some suggestions you may wish to consider:

- Take care of your health. Make sure you get enough rest, good nutrition and regular exercise.
- Trust and accept your own abilities and talents.
- Practice gentleness with yourself and others.
- Be proactive, not reactive. Do what you think is right.
- Remember that anger and resentment are often symptoms of exhaustion.
- Think of resting as recharging, not as being lazy. Let go of petty grievances and grudges.
- Pursue hobbies and interests you enjoy.
- Recognize and respect your limits as a caregiver. When you reach your limits, ask family, friends, health care professionals or the community for help. Do not be afraid to share your feelings with others, especially professionals, as they can help you cope.

### PREVENTING BURNOUT

Continuous feelings of rage, alienation and fear are **not** normal. Caring for another person, especially over a long period of time, can be physically and emotionally draining. You may find yourself being forced to continually do routine tasks, while wishing you were someplace else. If this sounds familiar, you may be reaching the burnout stage.

Here are some ways to cope with potential burnout:

- Learn to recognize the signs of stress.
- Find someone you can talk to about your feelings.
- Set realistic goals and determine your priorities.
- Balance work, family and time for yourself. It is critical to make time for you, even if it is just an hour or two per day.
- Consider joining a support group that can help you manage stress, find resources and reduce feelings of isolation.
- Talk to a professional (ex: social worker, psychologist, nurse) who is trained in counselling.
- Look for support through your workplace's employee assistance program.
- Take advantage of respite care, which provides temporary caregiving, while you take a break.
- Check out the Resources Section on page 31 of this guide for information on support programs.

## **COPING WITH GRIEF**

When you lose someone you are caring for, it can be an extremely difficult, emotional time. These emotions can be very intense and can come in waves for the grieving person. Each person grieves in his or her own way, but none of us should feel we have to suffer alone.

Palliative care organizations offer bereavement supports, so explore your options. These can include support through one-on-one phone calls, bereavement groups or grief seminars about working through loss.

To get more information about bereavement support, contact Hospice and Palliative Care Manitoba, or your local regional health authority (pages 39 and 42 in the Resources Section of this guide).

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# EMPLOYMENT AND CAREGIVING

Balancing work and caregiving responsibilities is a challenge. Canada's workforce has undergone dramatic changes in the past 40 years. As a result, more workers find themselves also caring for aging relatives. A large percentage of these employees are facing high stress levels associated with trying to juggle work and family.

The good news is that employers are becoming increasingly aware of this trend. They realize the struggle to balance work and family commitments affects employee productivity and, in turn, the health of the organization.

In response, workplaces are promoting more family-friendly organizational policies, such as flexible work arrangements, family leave, employee assistance programs and educational opportunities.

If you are having trouble balancing work and caregiving responsibilities, check with your employer to see what help is available to you.

## **COMPASSIONATE CARE BENEFITS**

If you are eligible for Employment Insurance and you wish to care for a sick or dying family member, you may be eligible for Compassionate Care Benefits. This program provides temporary financial compensation and job security for a certain period of time. For more information or to receive your application package, contact:

### **Service Canada**

Toll free: 1-800-277-9914 (English)

1-800-277-9915 (French)

1-800-255-4786 (TTY)

Website: [www.servicecanada.gc.ca](http://www.servicecanada.gc.ca)

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## SAFETY ISSUES

Providing long-term care for somebody can be a challenging, stressful role. Sometimes stress leads us to say and do things that we would not in different circumstances. It is important to ask for help if you are feeling pressure and are afraid you might say or do something that is harmful to the person in your care.

There are also situations where the person receiving care may be experiencing physical or cognitive changes that cause them to be physically or verbally aggressive. It is important to make sure that both of you are always safe.

The Seniors Abuse Support Line is a confidential, 24-hour service, providing older adults, family members, professionals and others with counselling, information, referral and follow-up.

You can reach the **Seniors Abuse Support Line** at 1-888-896-7183.

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## PROTECTION FOR PERSONS IN CARE

**The Protection for Persons in Care Act** (the Act) is an extra safeguard built into Manitoba's health care system. This law helps protect people from abuse while receiving care in personal care homes, hospitals or any other designated health facility.

The Act requires that a service provider or other person who reasonably believes that a patient is, or is likely to be, abused must promptly report the information to The Protection for Persons in Care Office (PPCO).

If you are concerned about the safety of someone living in a personal care home or hospital, contact:

**The Protection for Persons in Care Office**

Phone: 204-788-6366

Toll free: 1-866-440-6366

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## BUILDING A SUPPORT NETWORK

“My time for keeping up with social contacts is limited. Friends and neighbours have asked that I let them know if there is anything they can do. How can they be included without my imposing on them?”

Caregivers need to know when and where to get help. Here are some tips about asking for help:

- Keep a list of specific tasks or requests.
- Ask your friends how they would like to help.
- Express your appreciation for help given.
- Ask close friends their opinions about how the situation is going and be prepared to hear the truth.
- The company of good friends can be a tremendous morale booster.

We are often easier on others, than we are on ourselves. Remember, no one is perfect. When you look back on any mistakes you have made, recognize that you did not know then what you know now.

### **SUPPORT GROUPS CAN HELP**

Do some research to find a support group that meets your scheduling and personal needs.

Joining a support group may give you an opportunity to:

- Share experiences about coping with caregiving responsibilities.
- Exchange helpful information (ex: normal aging vs. age-related illness).
- Share thoughts and ideas without fear of judgement.
- Overcome feelings of isolation and helplessness.



- Exchange practical ideas and explore new ways to solve problems.
- Share experiences about dealing with the medical community and other professionals.
- Cultivate gentleness and humour in relationships with others.

There are a variety of support groups available, some general and some illness-specific (ex: caregivers for Parkinson's patients). See the Resources Section of this guide starting on page 31.

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## SEEKING COUNSELLING AND SUPPORT SERVICES

For more information about support groups or professional counselling, check the **Manitoba Seniors' Guide**, or call your regional health authority or refer to CONTACT Community Information, listed in the Resources Section of this guide starting on page 31.

Many Seniors Community Resource Councils also offer support groups for caregivers (see the Resources Section on page 39).

Ask for referrals to self-help or support groups, counselling, or centres for seniors, family life or family life education.

## CAREGIVING FROM A DISTANCE

Today, technology allows caregivers to help care for seniors at a distance. Even if you are caring for someone in a different area, the stress can be just as real. Although providing direct personal care may not be possible from another city, many caregivers are in contact with services for their loved ones via phone or Internet.

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## WORKING WITH COMMUNITY RESOURCES

Community resources can be very helpful to caregivers. Services that may be needed include:

- Meal services;
- Housekeeping;
- Private health care;
- Safety services;
- Personal emergency response systems;
- Transportation services;
- Medication information; and
- Respite.

Be realistic about your strengths and needs.

- Think about the kind of help you need before calling community resources.
- Be realistic about the contributions of family and friends.
- Do not assume you do **not** qualify for help - ask first.

Many communities have established Seniors Resource Councils (CRC) to help seniors live independently in their homes/communities as long as possible. Services provided by Seniors Resource Councils vary by area, but can include:

- Information and referral;
- Transportation;
- Emergency response information kits (E.R.I.K.);
- Advocacy;
- Shopping/errands;
- Local housing listings;

- Health and wellness activities;
- Assistance filling out forms;
- Temporary lending of mobility devices; and
- Income tax preparation.

To locate a Seniors Community Resource Council in your community, reference the Manitoba Seniors' Guide or call 204-945-6565, toll free 1-800-665-6565.

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## LEGAL INFORMATION

Legal issues are an important, but sometimes stressful, part of caregiving. The following is a brief overview of legal information and issues important to caregivers. To receive a copy of the **Legal Information Guide for Seniors**, contact the Seniors Information line (refer to page 31).

### **POWER OF ATTORNEY**

If the person in your care is competent, discuss the option of granting a Power of Attorney (POA) to a trusted individual. There are many types of Power of Attorneys, all options should be discussed with a lawyer. Also review wills and health care directives to ensure they are current and reflect the wishes of the person receiving care.

### **HEALTH CARE DIRECTIVE**

- As a Manitoban, you have the right to accept or refuse medical treatment at any time. **The Health Care Directives Act** allows you to make your own decisions about the amount and type of health care and treatment you want to receive, should you become unable to communicate.
- The Act also allows you to name another person to make medical decisions for you, if you should become unable to make them yourself. This is done by completing a Health Care Directive.
- A Health Care Directive should be a record of the person's current wishes and instructions.
- Talk to your doctor before completing the directive to ensure your instructions are clear and easily understood. Your choices should then be typed or clearly printed.

The health care directive form is available online at:  
**[www.gov.mb.ca/health/documents/hcd.pdf](http://www.gov.mb.ca/health/documents/hcd.pdf)**

## **PATIENT ADVOCATE FORM**

The Patient Advocate Form is a tool from the Manitoba Institute for Patient Safety, created to help people select someone who can speak and act on their behalf.

The tool provides information on patient advocates and why you should choose one. The patient advocate form has tips on selecting an advocate, the differences between patient advocates and health care proxies and frequently asked questions and answers. The form includes a checklist of tasks that you may want an advocate to handle.

For more information about the Patient Advocate Form and Manitoba Institute for Patient Safety, see page 35 in the Resources Section of this guide.

If you have concerns about the competency of the person you are caring for, consult his or her doctor, and then a lawyer to learn more about your legal options.

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## WORKING WITH HOME CARE SERVICES

Manitoba has a provincial Home Care program to help older adults live in their homes for as long as safely possible. The Home Care program may include respite relief, home support, adult day care and medical and personal care services. When using these services, it is important to develop a working relationship with your case co-ordinator.

To be eligible for the Manitoba Home Care program, a person must:

- Be a Manitoba resident, registered with Manitoba Health;
- Need health services or help with daily living;
- Need support to live independently; and
- Need more help than what is available from existing supports and community resources.

Day hospitals offer assessment and geriatric rehabilitation. They require a referral from a family doctor. If the older person in your care is attending a day hospital, consider its staff to be an extension of the care team.

Adult Day programs offer more long-term socialization and require a referral from a home care case co-ordinator.

Manitobans may be eligible to pay for personal attendant services or to be paid for home care services they provide to family members through the Self and Family Managed Home Care program.

Program eligibility for the Self and Family Managed Home Care Program is determined by the regional health authority before the family member can be paid for non-professional services that the Home Care program would otherwise provide. Self and family managed programs are options for people who have been receiving provincial Home Care services for at least a year.

For more information on the **Home Care Program**, visit [www.gov.mb.ca/health/homecare/nonprof.html](http://www.gov.mb.ca/health/homecare/nonprof.html) or contact your local regional health authority office (refer to page 42).

**A Guide to Home Care** is available online at:  
[www.gov.mb.ca/health/homecare/guide.html](http://www.gov.mb.ca/health/homecare/guide.html)

**Winnipeg Regional Health Authority Home Care Central Intake**, phone: 204-788-8330.

If you have concerns about your current home care service, contact the **Manitoba Health Appeal Board** at:

Phone: 204-945-5408

Toll free: 1-800-744-3257

Email: [appeals@gov.mb.ca](mailto:appeals@gov.mb.ca)

Website: [www.gov.mb.ca/health/appealboard](http://www.gov.mb.ca/health/appealboard)

For private care options, consult the Yellow Pages of your Manitoba phone book under Home Health Services, Homemakers and/or Nurses.

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## HOUSING

Many housing options, each offering various levels of care and support, are available to older Manitobans and their caregivers. Options include:

- Condominiums;
- Co-operative housing;
- Independent Living with Tenant Services (Assisted Living);
- Life lease rental housing;
- Private non-profit Housing;
- Residential care;
- Subsidized rental housing;
- Supportive housing;
- Supports to Seniors in Group Living (SSGL); and
- Personal care homes (PCH).

If care within the home is no longer a viable option, it may be time to consider other options, such as a personal care home or supportive housing.

- Application for placement in a PCH or supportive housing must be made through your Home Care case co-ordinator. A panel of professionals reviews the application package, which must include a form from the applicant's doctor, and lets the applicant and designated others know what is decided.
- Residents of a PCH pay a daily residential charge, based on their previous tax assessment from the Canada Revenue Agency.

Expect mixed emotions. Caregivers may feel both relief and sadness about the shift in care responsibility that results from the older person moving into a PCH.



Consider planning for the future even if additional supports are not required right now. Often, there will be a long waiting list for some places. Check the **Manitoba Seniors' Guide** for a detailed description of housing options. Discuss these options with your Home Care case co-ordinator. Whenever possible, involve the older person in any discussions and decisions about different housing options.

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## HOSPITALIZATION

When a person is hospitalized, it is often a stressful time for everyone involved. Here are some tips for getting through the experience with minimal distress:

- Ask for the name of the head nurse, or primary care nurse, in case you want to discuss a problem, get information or a referral.
- The hospital social worker can provide counselling and support and may also be involved in the discharge planning.
- Rehabilitation services require doctor referrals. Find out what rehabilitation therapy is required and how you can help the patient.
- There may be a meeting of all the professionals involved with the case to plan future care. If you wish to be involved in this meeting, notify the social worker as soon as possible.
- Before the patient returns home, connect with the home care case co-ordinator and the patient's doctor to further discuss what type of new care the older person may require.

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## HOSPICE AND PALLIATIVE CARE

### **PALLIATIVE CARE PROGRAMS**

End of life, or palliative, care is health care for people (of any age) and their families who are living with a life-limiting illness, usually at an advanced stage. The goal of palliative care programs is to manage physical symptoms and provide social, emotional and spiritual support for patients and their families throughout the course of the illness. It includes bereavement support. All Manitoba regional health authorities offer palliative care.

For more information about palliative care programs in your community, contact the Regional Health Authority Office nearest you (see page 42 in the Resources Section).

### **PALLIATIVE CARE DRUG ACCESS PROGRAM**

Manitoba Health offers this program to help people at the end stages of their illnesses, when the focus of care is on comfort, not cure. By covering the cost of eligible drugs for patients' use, a major financial burden is removed for the patients and their families.

For more information about applying for this program, contact your doctor or palliative care co-ordinator in your local regional health authority listed on page 42 or visit

**[www.gov.mb.ca/health/pcdap/index.html](http://www.gov.mb.ca/health/pcdap/index.html)**

## **HOSPICE AND PALLIATIVE CARE MANITOBA (HPCM)**

HPCM provides free, confidential, community-based support, education and companion services to adults with life-limiting illnesses, their caregivers and those who are bereaved. Programs and services include:

- The Volunteer Companion Program to give patient support and help with practical matters (ex: shopping, banking, excursions, etc.) through one-to-one matches with volunteers.
- The Sunflower Day Support Club that offers group activities, support, and information in a community-based setting for adults with life-limiting illnesses and their caregivers.
- Bereavement support services, including one-to-one telephone bereavement support, grief seminars and support groups.
- Information and education on a wide range of topics related to life-limiting illnesses, palliative care and bereavement, including the Compassionate Care course for association volunteers and community caregivers.

For HPCM contact information, see page 39 in the Resources Section.

## HOSPICE AND PALLIATIVE CARE (CONTINUED)

### **CANADIAN VIRTUAL HOSPICE**

The Canadian Virtual Hospice provides online support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators, including:

- Online access to palliative care specialists by forwarding questions to a clinical team with expertise in palliative care;
- Articles about managing symptoms, accessing financial benefits and other topics to help navigate the health care system and communicate with local health care providers;
- Tools for professionals to better care for and communicate with patients and families; and
- Latest research findings.

For contact information, see page 39 of the Resources Section.

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## FREQUENTLY ASKED QUESTIONS

### **How do I know when my family member can no longer live safely at home?**

The person you are caring for may resist change. It helps to respect and recognize that these changes may be tough for the patient. Start slowly and involve him/her in any discussions and decisions. Listen, without judging, and reassure him/her that any new services will make them safer.

### **What is respite care?**

Respite care refers to the services provided to caregivers so they can take a break from caregiving responsibilities. Respite care can be offered through formal organizations or through the patient's short-term placement in a personal care home while the caregiver takes a break.

Respite care should be used regularly, so you can become more familiar with the respite staff and confident in the care provided. Then, you can relax and enjoy your break, knowing you can trust the respite worker to provide good care while you are away.

### **We've been told that my husband has dementia. He's forgetful and his personality has changed. How can I cope with the changes in his behaviour that I find so irritating?**

Caring for a family member suffering from this kind of chronic confusion can be particularly heartbreaking and stressful. Knowing about the behavioural changes associated with dementia can often help caregivers cope more easily.

## FREQUENTLY ASKED QUESTIONS (CONTINUED)

These changes may include:

- Repeating questions and conversations;
- Losing and hiding things;
- Belligerence or unwillingness to co-operate;
- Pacing;
- Aimless wandering, even outside;
- Following, or staying close to others;
- Yelling, swearing, frowning or scowling;
- Starting but not completing tasks (ex: getting dressed);
- Chronic complaining; and/or
- Repeatedly retelling stories from the past.

It's important to remember that these behaviours are part of the disease. They are just as upsetting to the older individual as they may be to you. Learn all you can about dementia, what you can expect and tips to help you cope.

### **Where can I get help?**

Ask for help and keep an open mind about what services and organizations can help. Listen to the suggestions of the person in your care. There is a list of caregiver supports and services in the resource section of this guide.

### **How can I be a good caregiver and also take care of myself?**

Take time for yourself. Regular breaks allow you to cope with the stress and responsibilities of caregiving. The breaks will help you cope better with the stress of caregiving, so you can provide better care.

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# RESOURCES AND SUPPORT SERVICES

## **CAREGIVER INVENTORY OF PROGRAMS AND SERVICES**

For a list of resources and services for Manitoba caregivers, visit the Seniors and Healthy Aging Secretariat website at [www.gov.mb.ca/shas](http://www.gov.mb.ca/shas).

## **SENIORS INFORMATION LINE**

The Seniors Information Line is a bilingual information and referral phone service for seniors, family members and caregivers. Callers can access information on seniors' programs and services across Manitoba. For more information, contact (Mon. to Fri., 8:30 a.m. to 4:30 p.m.):

### **Seniors Information Line**

Phone: 204-945-6565

Toll free: 1-800-665-6565

Email: [seniors@gov.mb.ca](mailto:seniors@gov.mb.ca)

Website: [www.gov.mb.ca/shas](http://www.gov.mb.ca/shas)

## **MANITOBA SENIORS' GUIDE**

**The Manitoba Seniors' Guide** is a resource guide listing all the services and programs available for older Manitobans. To receive a copy, contact:

### **Seniors and Healthy Aging Secretariat**

#### **Healthy Living, Seniors and Consumer Affairs**

Phone: 204-945-6565

Toll free: 1-800-665-6565

Email: [seniors@gov.mb.ca](mailto:seniors@gov.mb.ca)

Website: [www.gov.mb.ca/shas](http://www.gov.mb.ca/shas)

## **HEALTH LINKS-INFO SANTÉ**

Health Links - Info Santé is a province-wide service that offers triage services, health information and referral, and nurse advice to callers 24 hours per day, 7 days per week in over 100 languages. Services include the following:

- Symptom assessment and triage;
- Referral to the most appropriate level of care;
- General health information;
- Assistance finding health resources in local communities; and
- Information on nutrition from a nutritionist.

For more information, contact:

### **Health Links-Info Santé**

Phone: 204-788-8200

Toll-free: 1-888-315-9257

## **CONTACT COMMUNITY INFORMATION**

CONTACT Community Information is a community information referral service, which refers Manitobans to social services and programs available through health, educational, cultural and recreational resources in the province of Manitoba. For more information, contact:

### **CONTACT Community Information**

Suite 410 - 5 Donald Street South

Winnipeg, MB R3L 2T4

Phone: 204-287-8827

Toll-free: 1-866-266-4636

Email: [philip.wolfart@volunteermanitoba.ca](mailto:philip.wolfart@volunteermanitoba.ca)

Website: [www.contactmb.org/index.html](http://www.contactmb.org/index.html)



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## FINANCIAL RESOURCES

### **PRIMARY CAREGIVER TAX CREDIT**

Caregivers may be eligible for Manitoba's new Primary Caregiver Tax Credit of \$1,275 (starting in 2011) per care recipient to a maximum of three.

Caregivers must meet several qualifications. The caregiver may be a spouse, other relative, neighbour or friend. They must:

- Not receive money for their help.
- Be identified as a caregiver by the person receiving care.
- Provide care to the same person for more than three consecutive months.
- Provide help with daily living tasks such as bathing, dressing, eating meals, mobility, medical care, support and supervision.
- Be the only person claiming the tax credit for the person receiving care.
- File a Manitoba income tax return.

The client must:

- Live in a private home or apartment in Manitoba.
- Be a person who needs care at a Level 2 or higher, according to the Manitoba Home Care Program guidelines.
- Be verified through the Home Care Program.
- Be assessed by either the regional health authority (RHA) or a health care professional.

## FINANCIAL RESOURCES (CONTINUED)

For more information, contact:

**Manitoba Health** at 204-788-6646 or

**Manitoba Finance** at 204-948-0352 in Winnipeg,

Toll free 1-800-782-0771

Website: [www.gov.mb.ca/finance/tao/caregiver](http://www.gov.mb.ca/finance/tao/caregiver)

### **DISABILITY TAX CREDIT**

The Disability Tax Credit is available to people who have severe, prolonged impairments in physical or mental function. A health care provider must complete a form for you, which must then be approved by the Canada Revenue Agency. The tax credit offers savings of up to \$2,000 for you, your spouse, or another supporting person. This credit is provided by both the federal and provincial governments. Manitoba also offers an additional income-related, refundable credit.

For more information, contact:

**Canada Revenue Agency**

Toll free: 1-800-959-8281

You can also get more information about tax credits:

**Manitoba Tax Assistance Office**

Phone: 204-948-2115

Toll free: 1-800-782-0771

Email: [tao@gov.mb.ca](mailto:tao@gov.mb.ca)

Website: [www.gov.mb.ca/finance/tao](http://www.gov.mb.ca/finance/tao)

## **COMPASSIONATE CARE BENEFITS**

If you are eligible for Employment Insurance and you wish to care for a sick or dying family member, you may be eligible for Compassionate Care Benefits. This program provides temporary financial compensation and job security for a certain period of time. For more information or applications, contact:

### **Service Canada**

Toll free: 1-800-277-9914 (English)

1-800-277-9915 (French)

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## **SAFETY PROGRAMS & SERVICES**

### **Seniors Abuse Support Line** (24 hours)

Toll free: 1-888-896-7183

### **The Protection for Persons in Care Office**

Phone: 204-788-6366

Toll free: 1-866-440-6366

### **Manitoba Institute for Patient Safety**

Toll free: 1-866-927-6477

Email: [assistant@mbips.ca](mailto:assistant@mbips.ca)

Website: [www.safetoask.ca](http://www.safetoask.ca) and [www.mbips.ca](http://www.mbips.ca)

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## SUPPORT PROGRAMS & SERVICES

### **A & O: SUPPORT SERVICES FOR OLDER ADULTS (AGE & OPPORTUNITY)**

A & O: Support Services for Older Adults is a not-for-profit social service agency that provides programs and services to older adults 55+ that support and enhance the physical, intellectual, emotional, social and spiritual lives of older persons. Specialized services are offered in the following areas:

- **Safety & Security:** Elder Abuse Prevention Services, Safe Suite, Seniors Abuse Support Line, Older Victim Services, Safety Aid: Crime & Falls Prevention for Older Manitobans and This Full House;
- **Social Inclusion:** Senior Centre Without Walls, Friendly Visiting, Paws with a Cause, Entry Program for Older Adult Immigrants and Centres/Meal Program;
- **Counselling Services:** information and referral, intake, housing and legal clinics.

#### **A & O: Support Services for Older Adults**

200 - 280 Smith Street

Winnipeg, MB R3C 1K2

Phone: 204-956-6440

Toll-free: 1-888-333-3121

Email: [info@ageopportunity.mb.ca](mailto:info@ageopportunity.mb.ca)

Website: [www.ageopportunity.mb.ca](http://www.ageopportunity.mb.ca)

## **RUPERT'S LAND CAREGIVER SERVICES**

Rupert's Land Caregiver Services offers a range of support services for family caregivers of persons 55+ such as:

- City-wide 'time-out' or short-term respite care;
- Transportation assistance in southwest Winnipeg (area codes R3L, R3M, R3N, R3P and part of R3T);
- Support groups;
- Information and help in problem-solving;
- Referral to other community services;
- Telephone support;
- Conference for Caregivers;
- Community educational presentations and workshops on caregiving and aging; and
- Publishes the newsletter **The Caregivers Page**.

For more information, contact:

### **Rupert's Land Caregiver Services**

168 Wilton Street

Winnipeg, MB R3M 3C3

Phone: 204-452-9491

Email: rlcs@mymts.net

## SUPPORT PROGRAMS & SERVICES (CONTINUED)

### **PRIME**

PRIME is a program designed to help seniors with multiple health problems in Winnipeg manage their care and maintain independence. Seniors may be eligible for PRIME if they are 65 or older and living independently in the community.

Program services include:

- Counselling;
- Personal care;
- Health and wellness education;
- Regular doctor or nurse practitioner visits;
- After hours support; and
- Exercise and therapy.

For more information, visit:

[www.wrha.mb.ca/wave/2010/10/prime-info.php](http://www.wrha.mb.ca/wave/2010/10/prime-info.php)

Phone: 204-833-1700

### **MANITOBA CAREGIVER COALITION**

The Manitoba Caregiver Coalition is a group of individuals and organizations that join with caregivers, service providers, policy makers and other stakeholders to identify and respond to the needs of caregivers in Manitoba. For more information, contact:

#### **Manitoba Caregiver Coalition**

Phone: 204-953-3720

Email: [mb.caregivercoalition@yahoo.ca](mailto:mb.caregivercoalition@yahoo.ca)

Website: [www.ccc-ccan.ca](http://www.ccc-ccan.ca)

## **SENIORS COMMUNITY RESOURCE COUNCILS (CRC)**

CRCs offer a variety of programs such as seniors congregate meal programs, transportation programs, information, referrals, etc. For the nearest CRC in your community, call the Seniors Information Line:

Phone: 204-945-6565

Toll free: 1-800-665-6565

Website: [www.gov.mb.ca/shas](http://www.gov.mb.ca/shas)

## **HOSPICE AND PALLIATIVE CARE MANITOBA (HPCM)**

Phone: 204-889-8525

Toll-free: 1-800-539-0295

Email: [info@manitobahospice.mb.ca](mailto:info@manitobahospice.mb.ca)

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

## **CANADIAN VIRTUAL HOSPICE (ONLINE)**

Email: [info@virtualhospice.ca](mailto:info@virtualhospice.ca)

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

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## HEALTH AND CHRONIC DISEASE-RELATED ORGANIZATIONS

The following organizations are excellent sources of information about chronic diseases. Most provide a variety of services to meet the special needs of persons affected by disease and their caregivers, including help lines, support groups and more:

### **ALZHEIMER SOCIETY OF MANITOBA**

Phone: 204-943-6622

Toll free: 1-800-378-6699

Email: [alzmb@alzheimer.mb.ca](mailto:alzmb@alzheimer.mb.ca)

Website: [www.alzheimer.mb.ca](http://www.alzheimer.mb.ca)

### **STROKE RECOVERY ASSOCIATION OF MANITOBA**

Phone: 204-942-2880

Email: [info@strokerecovery.ca](mailto:info@strokerecovery.ca)

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

### **PARKINSON SOCIETY MANITOBA**

Phone: 204-786-2637

Email: [howard.koks@parkinson.ca](mailto:howard.koks@parkinson.ca)

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

### **MULTIPLE SCLEROSIS SOCIETY OF CANADA – MANITOBA DIVISION**

Phone: 204-943-9595

Toll free 1-800-268-7582

Email: [info.manitoba@mssociety.ca](mailto:info.manitoba@mssociety.ca)

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



## **ALS SOCIETY OF MANITOBA**

Phone: 204-831-1510

Toll free 1-866-718-1642

Email: HOPE@alsmb.ca

## **CANCERCARE MANITOBA**

Phone: 204-788-8080

Toll free 1-888-660-4866

Website: [www.cancercare.mb.ca](http://www.cancercare.mb.ca)

## **CANADIAN CANCER SOCIETY – MANITOBA DIVISION**

Phone: 204-774-7483

Toll free 1-888-532-6982

Email: [info@mb.cancer.ca](mailto:info@mb.cancer.ca)

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

## **HUNTINGTON DISEASE RESOURCE CENTRE**

Phone: 204-772-4617

Email: [sfunk@huntingtonsociety.ca](mailto:sfunk@huntingtonsociety.ca)

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

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## REGIONAL HEALTH AUTHORITY (RHA) CONTACT INFORMATION

**Assiniboine RHA:** 204-834-3047 (East)  
204-747-1832 (West)

**Brandon RHA:** 204-578-2340

**Burntwood RHA:** 204-778-1427

**Central RHA:** 204-428-2741

**Churchill RHA:** 204-675-8355

**Interlake RHA:** 204-467-7118 (Stonewall Area)  
204-785-7410 (Selkirk Area)  
204-642-4597 (Gimli Area)

**Nor-Man RHA:** 204-623-9661

**North Eastman RHA:** 204-753-5250

**Parkland RHA:** 204-629-3006

**South Eastman RHA:** 204-346-6250

**Winnipeg RHA:** 204-237-2400

### **MANITOBA HEALTH - INSURED BENEFITS BRANCH**

Phone: 204-786-7101

Toll free: 1-800-392-1207

Toll free 1-800-855-0511

TDD: 204-774-8618

Email: [insuredben@gov.mb.ca](mailto:insuredben@gov.mb.ca)

Website: [www.gov.mb.ca/health/mhsip/index.html](http://www.gov.mb.ca/health/mhsip/index.html)

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# THE MANITOBA CAREGIVER RECOGNITION ACT

In 2011, the Manitoba government made an important first step toward recognizing the valuable contributions of informal caregivers by developing the **Manitoba Caregiver Recognition Act**. The Act acknowledges the vital role of caregivers. It sets out principles and actions for government and non-government agencies to follow to support the health and well-being of caregivers.

The principles outlined in the Act include:

- The relationship between caregivers and the persons for whom they care should be recognized and respected.
- The valuable social and economic contributions that caregivers make to society should be recognized and supported.
- Caregivers should be acknowledged as individuals with their own needs, within and beyond the caring role.
- Caregivers should be supported to enjoy optimum health and social well-being and to participate in family, social and community life.

(Manitoba Caregiver Recognition Act continued on following page).

## THE MANITOBA CAREGIVER RECOGNITION ACT (CONTINUED)

- Caregivers should be considered important contributors with other care providers in the provision of care, support or assistance, acknowledging the unique knowledge and experience of caregivers.
- Caregivers should be treated with dignity and respect.
- Caregivers should be supported to achieve greater economic well-being and sustainability. Where appropriate, they should have opportunities to participate in employment and education.
- Support for caregivers should be timely, responsive, appropriate and accessible.

For more information on the Act, please contact the **Seniors and Healthy Aging Secretariat** at 204-945-6565 in Winnipeg; toll-free 1-800-665-6565 in Manitoba or visit [www.gov.mb.ca/shas](http://www.gov.mb.ca/shas).







(Revised March 2012)

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