

Guide To Caregivers

Caregiver Information Centre



**Prepared by Dick Strayer
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Acknowledgements

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This guide is made up partly of my own experiences as a full-time caregiver, but also includes the experiences of many full and part time caregivers I have interviewed in the past two or three years. I am grateful to all who, knowingly or unknowingly, provided valuable input.

In addition, some people may recognize ideas from many caregiver publications I have reviewed. Any direct quotations were made with approval and properly credited.

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Introduction

A family caregiver (sometimes called an informal caregiver) is one who cares for and gives unpaid support to a family member, friend or neighbour who is frail, ill or disabled and who lives at home or in a care facility. This is the definition that has been approved by most jurisdictions in Canada. As is evident, it includes caregivers in many different situations, from occasional assistance given to a friend to a full time (often referred to as a “24/7”) caregiver. When examining the needs and wants of caregivers, it must be remembered there are many different types of caregiving. 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 as an aid to caregivers, and it is hoped that it will provide some much needed assistance. It is targeted mainly to caregivers residing in the Saskatoon Health Region where the agencies providing services operate and are listed later in the guide. In attempting to help caregivers deal with their many problems and concerns, it will be helpful to first outline the *caregiving burdens* that many have encountered, as recounted by a number of caregivers. The lists are long, but in general fall into two groups – emotional and financial problems and concerns.

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”.

Preparing to Care

While careful preparation for a new job should always be a priority, it is often not possible when one is thrust into a caregiving role with little or no warning. Ready or not, the job is there, with no freedom to choose whether or not to proceed.

To provide some assistance in making the adjustment, here is a list of personal skills that a caregiver either should have or needs to acquire in order to succeed in carrying out the duties. (These were prepared by two social workers in Toronto, Dr. Chaya Mannes-Milevsky and Angela Xavier, and are taken, with permission, from the February 2003 edition of “50 Plus” magazine).

Essential Personal Skills for Caregivers:

Stamina and endurance – Caregivers must be prepared to work long and irregular hours and are often expected to be available 24 hours a day, seven days a week, providing not only care, but also companionship.

A fast learner – One must be prepared to assume specific nursing duties, assist with daily activities and other duties including mastering the use of some medical equipment and treatment. Unfortunately, caregivers are often forced to learn much of this on their own.

A stress-resistant personality – Poorly handled stress on the caregiver’s part can cause depression, health problems and, as noted previously, eventual burnout.

A self-motivator – Caregiving can be a thankless job. Patience and a strong will are needed to get through many dark moments.

A capable organizer – A caregiver cannot afford to be disorganized. The responsibilities are so numerous that a daily, prioritized plan is essential.

A positive outlook – Continually seeking out the positives in one's caregiving duties can make it a highly rewarding experience, as opposed to one of drudgery.

Challenges of Caregiving

Dealing with Emotional Problems

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. This is one of the reasons this guide is being written. 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.

As will be noted later, **the caregiver must look after him or herself** to carry out the required duties. This necessity requires minimizing stress and related problems. Stress is a normal reaction. Understanding its effects will help to 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.

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. Obviously, changes may be required to meet specific situations, but it nevertheless provides some stability to their day. An essential element both in preventing stress and relieving it, is a time-out occasionally, 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. 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.

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.

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 Customs and 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.

Looking After Oneself

To be a successful caregiver requires a total devotion to the care receiver. However, in so doing caregivers must never forget that their own health must be maintained. When faced with constant stress, worry, and often lack of sleep, this may become extremely difficult.

In some cases caregivers themselves may already have health problems such as diabetes, heart problems, high blood pressure, etc., which only

make their situation more tenuous. Maintaining a proper diet, taking prescribed medications and getting sufficient sleep are all extremely important, as are getting fresh air and exercise. These precautions will certainly aid in maintaining a healthy body and proper mental attitude. Anything that can be done to reduce stress and anxiety will ultimately improve one's physical condition. Caregivers are only as effective as their own health permits, so these precautions cannot be over-emphasized.

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.

Caregiver Assistance Available in Saskatoon Health Region

It is simply not possible to list all the agencies in the region that can provide benefits, so this list contains only a sample of what is available:

Home Care, Saskatoon Health Region

201-310 Idylwyld Dr N, Saskatoon S7L 0Z2

Phone: 655-4300 **Fax:** 655-4400

- Eligibility through **Client/Patient Access Service (CPAS)**, 655-4346.
- Nursing services, personal care, respite, volunteer services 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.

Saskatoon Caregiver Information Centre

301-506 25th Street East, Saskatoon S7K 4A7

Phone: 652-4411 **Fax:** 652-7525

Website: www.sasktelwebsite.net/caregive

Email: 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.

301 506 25th Street East, Saskatoon S7K 4A7

Phone: 652-2255 **Fax:** 652-7525

Website: www.scoa.ca **Email:** admin@scoa.ca

- Resource centre, educational programs, computer lessons, blood pressure clinic, 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

Saskatchewan Aids to Independent Living (SAIL)

2nd Floor, 3475 Albert Street, Regina S4S 6X6

Phone: 306-787-7121 **Fax:** 306-787-8679

- This service cannot be accessed directly by individuals, but caregivers should be aware of it.
- It is a division of Saskatchewan Health, and, upon proper documentation from a doctor or occupational therapist, SAIL will loan a wide variety of health care equipment such as walkers, wheelchairs, etc., for the use of care receivers.

Services for Seniors

103-115-19th Street East, Saskatoon S7K 7Y8

Phone: 668-2762 **Fax:** 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 \$13/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.

Other Services

Other services available in the Saskatoon Health Region include a wide variety of things such as adult day programs, professional nursing services, suppliers of health care products, counseling services, support groups, and many others. For a complete list, consult the **Directory of Services for Older Adults** referred to above, available from the Saskatoon Council on Aging or the Saskatoon Health Region offices. Directories can be downloaded from Council's website at www.scoa.ca or call Council at 652-2255 for a copy.

Time For 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.

Obviously, 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 regime 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.

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

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



Beverley Ann Peterson 1941-2001

This guide is dedicated to our memory of Bev Peterson, RN,BSN. Bev's passion for the information and support needs of family caregivers was the energy behind the inception of the Informal Caregiver Information and Help Centre Project. Her strong leadership as co-chair of the project's steering committee was exemplified through her attention to detail, consideration of others and her effervescent personality. Bev contributed many hours and considerable insight from her own practice and personal experience with caregiving. The work of the project resulted in the Saskatoon Caregiver Information Centre; a one of kind service in Saskatchewan. Bev was married to Lorence. Together they raised two sons. Bev's pride and joy were her grandchildren, those she knew and those she anticipated.