

Section 3

Caring for the Caregiver

There are positive aspects of providing care in the home to a family member who needs it but when the care giving goes on for years, it takes a toll. In the process of providing care, the caregiver may become fatigued to the point of complete exhaustion, suffering from depression, anxiety and poor health and a feeling of hopelessness. Friends and family members of caregivers can also be on guard for signs of caregiver's burnout by asking about feelings of sadness or of being overwhelmed. If a person seems particularly low, don't be afraid to ask about thoughts of suicide. Talking to someone about such difficult feelings can help to relieve their distress. Care giving at home is a very isolating activity. It is more difficult for older men who don't have the friendships older women have. Tell the caregiver you care about them and are available to help. Caregivers need to know this.

Tips for Caregivers

1. Have a sense of humour and a good laugh.
2. Tell family and friends how they can share care-giving duties. Be honest, appreciative and clear in what you require and divide the responsibilities.
3. Take one step at a time and solve one problem at a time.
4. Be tactful, diplomatic and very patient.
5. Take care of your health - you need rest, exercise and a nutritious diet
6. Accept the impaired person as is, today.
7. Connect with other Caregivers to share experiences, but seek/obtain specific information with knowledgeable and trained professionals.
8. Accept your feelings and decisions without guilt.

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9. Take a break - use respite care when you begin to notice signs of stress - tiredness, irritability, lack of sleep, loss of appetite, depression.
10. When you take a break from care-giving, do something for yourself.
11. Make sure your family is not ignored when you are care-giving.
12. Keep a list of important phone numbers by the telephone.

Tasks of the Caregiver

1. Learn to advocate for the Care-Receiver and ask questions.
2. Accompany the Care-Receiver on appointments and assist with errands.
3. Work as a team player with the professionals.
4. Ensure respect dignity, privacy and confidentiality of the Care-Receiver.
5. Communicate with the personal care workers.
6. Make decisions that are the most suitable for the Care-Receiver and explain your reasons.
7. When a move is necessary, help the Care-Receiver deal with the emotional stress.
8. Discuss early signs of Alzheimer's disease and dementia openly - do not try to hide symptoms because of embarrassment.
9. Have a contingency plan for care if you become ill - have a list of your doctors and medical needs.

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10. Can provide assistance with regular household tasks, transportation, personal care.
11. Provide companionship.
12. Monitors challenging behaviours (wandering, aggression)

Communicating with Agencies, Organizations and Groups

1. Have your diary/notebook handy
2. Respect confidentiality of the Care-Receiver
3. Phone early in the morning, or immediately after lunch
4. Record the name, the telephone number and extension of the agency person and write down your comments/impression of the conversation
5. Have many copies of important documents
6. Be specific, polite but firm
7. Be patient; you may have to repeat your story, or be put on hold or your call may be transferred
8. Prepare to invest time in getting your questions answered
9. Read carefully any contracts and review regularly
10. Be assertive; do not apologize for asking for help

If you are going for an interview or meeting, ask what information you need to bring with you.

- Don't be afraid to ask questions
- Don't be pressured into making quick decisions because you have been told you have to decide immediately.

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Caregivers can become so frustrated that they become angry. There are some ways to control the anger.

- Take a time out
- Talk with a friend, relative or counselor
- Get away from the place of tension
- Walk around the block
- Write down feelings, in a diary or journal
- Take a deep breath
- Count to 10
- Exercise

Respite Care - When ***You*** need a rest

Respite - is a delay or cessation for a time; especially of anything distressing or trying; an interval of relief.
An interval of relief is a break or interruption in the continuity of work involved in fulfilling a responsibility.

Definition - break, time-out or relief from the caregiver responsibilities
- not a service to the Care Receiver
- should provide support to the Caregiver

Respite Care - provides short-term care or temporary care in the home to allow Caregivers of the frail, elderly or disabled, who need constant supervision, some free time from family and responsibilities. If a person requires help with personal care, he or she may be eligible for some hours from Community Care Access Centre (CCAC).

Type of Respite: - in-home care – 2 to 3 times/week for several hours
- day program – 1 to 3 times/week
- overnight and short-stay services

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List of agencies providing education & training for caregivers

Counselling services for the caregiver

Agencies providing caregiver respite

Who provides it

- 1) Baycrest Day Care Services for Seniors 416-785-2500
- 2) Circle of Care 416-635-2860
- 3) Senior Peoples' Resources in North
Toronto (SPRINT) 416-481-6411

How to apply:

Respite care is applied for through the Intake Department of the local Community Care Access Centre. A Long-Term Care Admission Form may be obtained from this Centre.

Many Retirement Homes, Homes for the Aged, Nursing Homes, and Chronic Care Hospitals provide vacation and respite care for a period of 2 to 4 weeks. Apply well in advance through a CCAC application or directly to the facility. Some respite care services require a fee. Retirement homes, which are private, can be costly. In long-term care facilities, respite costs are approximately \$29.00 per day (subsidized through the Ministry of Health and Long-term Care). The Care-Receiver is allowed to stay for up to 90 days at a long-term care facility with 30 days permitted each time. Adult Day Programs are another means of providing respite to Caregivers who are taking care of people with Alzheimer's Disease and dementias. These programs are not for all frail seniors.

Indicators of the need for respite that can alert caregivers to begin to plan for respite.

- anxiety
- fatigue
- exhaustion
- illness
- feelings of isolation, hopelessness

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- depression, feeling sorry for oneself
- sleeplessness or sleep deprivation
- health status of the care receiver
- caregiver role expectation – confused or uncertain
- extensive length of care-giving period
- intensity of care-giving
- relationship of caregiver
- overwhelmed
- emotionally numb or explosive
- unable to focus or concentrate
- resentful
- feeling inadequate (to the task)
- feeling a need for an increased use of alcohol or stimulant
- experiencing sudden weight changes

Respite could be:

- enjoyment of friends
- a trip
- a good night's sleep
- an aerobics class
- sitter/companion
- housekeeping
- adult day care
- peer support group
- facility respite
- physical modifications
- information re: resources
- transportation services
- personal emergency system
- counseling
- full-time short-term home care
- outdoor maintenance
- meal program
- spiritual support
- longer facility stay
- family counseling

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Your Notes – Section 3

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