

A Changing Melody 2005

Tips and Strategies for Persons with Dementia and Family Partners in Care

(from comment cards completed at the forum)

Tips for Persons Living with Dementia

- ❖ Utilize the support services offered in your communities that can not only support you on your journey, but guide you, and educate you and your family.
- ❖ If something is not working, let it go.
- ❖ If you can not change a situation, change your attitude towards it!
- ❖ Don't sweat the small stuff. Decide what is important and put your energy into those priorities.
- ❖ Let go of anger and turn efforts into having a positive future. Resolve "to make the best of what you've got!"
- ❖ Keep a sense of humour. Laughter can help relieve stress.
- ❖ Live in the moment.
- ❖ Don't be in a hurry.
- ❖ Do not be afraid of your emotions. Allow yourself to be sad and to cry.
- ❖ Get as many hugs as possible.
- ❖ Try using word associations and imagery to remember things.
- ❖ Use calendars as a memory aid.
- ❖ Learn a new skill or take up a new hobby, for example, learning a new card game.
- ❖ Keep things simple. Do one activity at a time and give up multi-tasking.
- ❖ Adopt a pet. Go for a walk with your dog and enjoy the moments.
- ❖ Be gentle with yourself. Allow yourself to 'disengage' as needed.
- ❖ Ask for help when you need it.
- ❖ Maintain your spiritual involvement through prayer, meditation and spiritual reading.

- ❖ Maintain your social connections. Do not 'hide' from the world. Talk to friends and family about the disease and educate them as to what is going on in care and caregiving. For example, plan for daily telephone calls from friends and loved ones.
- ❖ Keep active both physically and mentally. Volunteer in your community, exercise, practice yoga, maintain healthy intimate relations with your partner, and engage in activities that will stimulate your mind including reading.
- ❖ Label closets and dresser drawers with names of certain clothes, for example, T-shirts, pants, shoes, shirts, jackets, etc. Label clothing shelves and keep clothes sorted.
- ❖ Label cupboards and drawers in the kitchen with contents, for example, glassware, spice pantry etc., not only for the persons with dementia but for caregivers (personal support workers) as well.
- ❖ Place a list of important telephone numbers by each telephone, including "911 In Case of Emergency" in red at the top. Also, include other relevant information such as home address.
- ❖ Place objects such as eye glasses and keys in a designated spot where they are easily accessible, for example, near the front door.
- ❖ Dementia is a "loss" process. Those losing need time to grieve as do those caring for them. However do not dwell on loss, rather, change the focus to abilities. Draw on the strengths of those living with a dementia.
- ❖ Persons with dementia should be given choices without making demands on them.
- ❖ Routine is important for persons with dementia. Start creating a schedule/routine if you never had one. Try to eat at the same time each day for example. Routine can help to create a stable environment that can seem safe rather than erratic.
- ❖ Persons with dementia should be allowed to be as independent as possible for as long as possible. Their need for autonomy should be recognized. Keep normal activities going as long as possible.
- ❖ Limit the amount of distraction in the environment of persons with dementia, for example, mute the TV when commercials come on.
- ❖ Have annual medical reviews. Be aware of what medication you are taking.
- ❖ Have listed all medications and times written out in case caregiver has a medical emergency.
- ❖ Inform medical offices to speak directly to the family partner in care so he/she will get the message about appointments, etc.

- ❖ Persons with dementia should be encouraged to continue doing what they do well, in whatever degree they are comfortable with.
- ❖ Don't be afraid of seeking professional help, such as a psychologist when depressed. This is helpful for both the person with dementia and the caregiver.
- ❖ Educate yourself on issues related to Alzheimer Disease and other related dementias whether you are a caregiver or a family partner in care.

Tips for Partners in Care

- ❖ When a person with dementia seems bored or can not find anything to do: make lists or generate ideas together of projects that they feel they can handle that day, and stroke it off the list when it is complete.
- ❖ Encourage the building of a network beyond the caregiver to allow encouragement in self-esteem and self-worth.
- ❖ Use different methods to inform the public that the care receiver has a dementia, for example, business cards with a flower and the words “my companion is suffering from Alzheimer. Please be patient”. These can easily be handed to a retail worker or other person.
- ❖ Be respectful of the wishes of the person with dementia. Ask him/her if they want others to know about their situation.
- ❖ Be patient. When dealing with repeated questions from a person with dementia take a deep breath and count to 10.
- ❖ If you do feel impatient, make your feelings known and do not hide the fact that as a caregiver you need a break.
- ❖ Be flexible. Everyday can change what routinely was a workable daily plan only just the day before.
- ❖ Caregiver should allow more time for activities that used to take very little time, for example, leave lots of time to get ready to go out.
- ❖ Don't take things personally. As a family caregiver remind yourself that the dementia is causing the behaviours of the person with dementia. It is not their fault but that of the disease process.
- ❖ Leave a note for the person with dementia if you go out with information regarding telephone number, time of return, etc.
- ❖ Keep detailed notes about changes in the condition of persons with dementia.

- ❖ Fill weekly pillboxes for the person with dementia. For example, use colour coding - green for AM, white for PM. Open the box at the right day and leave it for the person with dementia in either the AM or PM.
- ❖ Offer help and wait for the offer to be accepted - don't bulldoze in and do.
- ❖ Keep the memories you have of all the great moments close to your heart. Your loved one hasn't changed how they feel about you only how they can now express themselves.

Other Information/ Resources

- ❖ **Trillium Drug Plan** - The Trillium Drug Program helps people who have high drug costs in relation to their income living in Ontario. The program has a deductible that is based on income and family size. Once your application has been approved, the program covers the cost of thousands of quality-assured and limited-use drug products.

For more information, call the ministry **Trillium Drug Program** at 1-800-575-5386 or log on to their website [<http://www.health.gov.on.ca/english/public/pub/drugs/trillium.html>].

- ❖ **Tax credit information** – The website for the Canada Revenue Agency (CRA) provides information on non-refundable tax credits available to Canadian caregivers [<http://www.cra-adrc.gc.ca>].

There are essentially three different types of tax credits available for family partners in care:

- 1) **Medical Expense Tax** – This tax credit is available to family partners in care who have sustained significant medical expenses for themselves or their dependent to help offset the cost of specific supports such as attendant care, nursing home care, or ambulance services and medical devices such as wheelchairs, braces, or special eyeglasses.
- 2) **Disability Tax Credit** – This tax credit is available to individuals with severe and prolonged mental or physical impairment and their family partners in care if the disability clearly restricts ability to perform activities of daily living. This tax credit is to provide relief for some of the hidden and indirect costs of disability, including special or additional transportation services.
- 3) **Caregiver Tax Credit** – This is a non-refundable tax credit available to family partners in care of dependent relatives, including in-laws.

For more information about how to address financial issues, you should also contact your local Alzheimer Society Chapter or Community Care Access Centre (CCAC).

- ❖ **Compassionate Care Benefits** – Both the Canadian and the provincial governments have recently introduced legislation to allow for compassionate care leave for family members who need to be off work to care for a dying family member. Under this new legislation, an employee may take up to eight weeks of unpaid leave to care for an ill family member. The person who is receiving care *has* to be palliative, meaning that their diagnosis must indicate imminent death within 26 weeks, and therefore this is a benefit that is only available to families at the very end stages of the disease, not during the longer period of decline. To take advantage of this benefit the person does not technically have to provide the hands on care themselves, but does have to be involved in the care in some manner in order to qualify for EI reimbursement and to ensure their job will be guaranteed when they return to work.

More information on compassionate care benefits can be found at www.hrsdc.gc.ca

- ❖ **Government Representatives** – Another option for persons with dementia and family partners in care if you are facing challenges and want more attention paid to the issues related to Alzheimer Disease and related dementias is to contact your local government representative or the Minister responsible for Seniors and Long-Term Care. Visit, write or phone your public officials. Let your legislators know that your vote may be decided by their stand on those issues. Please see below for a list of your government representatives.

Government of Ontario

Ministry of Health and Long-Term Care
80 Grosvenor St, 10th Flr, Hepburn Block
Toronto ON M7A 2C4

Tel : 416-327-4300
Fax : 416-326-1571

Honourable George Smitherman, Minister of Health and Long-Term Care

Constituency Office
120 Carlton St. Suite 413
Toronto ON M5A 4K2

Tel : 416-972-7683
Fax : 416-972-7686
email : gsmitherman.mpp.co@liberal.ola.org

Honourable Jim Bradley, Minister Responsible for Seniors

Constituency Office
2 - 2 Secord Dr
St. Catharines ON L2N 1K8

Tel : 905-935-0018
Fax : 905-935-0191
email : jbradley.mpp.co@liberal.ola.org

Government of British Columbia

Ministry of Health

1515 Blanshard Street
Victoria, B.C. Canada V8W 3C8

Telephone:

Toll-free in BC: 1-800-465-4911
In Victoria or from other areas: 250 952-1742

Honourable George Abbott, Minister of Health

PO Box 9050
STN Prov Govt
Victoria BC V8W 9E2

Tel: 250 953-3547
Fax: 250 356-9587

Honourable Ida Chong, Minister Community Services and Minister Responsible for Seniors' and Women's Issues

Room 323
Parliament Buildings
PO Box 9056
STN Prov Govt
Victoria BC V8W 9E2

Tel: 250 387-2283
Fax: 250 387-4312

Ministry of Health - Health and Seniors' Information Line

Toll-free in BC: 1-800-465-4911
In Victoria or from other areas: 250 952-1742

To locate your MPP in Ontario, log on to the Elections Ontario webpage:

http://www.electionsontario.on.ca/en/Voters_en.shtml?nocache=true

To locate your MP in British Columbia, log on to the Ministry of Community Services Seniors website:

<http://www.cserv.gov.bc.ca/seniors/how-to-reach.htm>