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### **In Touch for Caregivers** electronic version

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## Caregiving from a Distance

Many caregivers are presented with the challenge of supporting a loved one with dementia from a distance. Whether you live across the province or across the country, long-distance caregiving often involves specific concerns that are different from those of families who are able to see each other more frequently. This issue of *In Touch* provides some practical suggestions for long-distance caregivers, including how to make your time together valuable, as well as how to effectively use local services when you are away. You will also read inspiring stories and practical tips from other long-distance caregivers.

## Good Mourning Flowers

My beloved father, Bernard Fleischer, died in January 2008, in his final stages of Alzheimer's disease. While he was living with Alzheimer's, my family and I made the journey along side him.

There were many losses throughout those years. As one of six siblings, I was the only one to leave our hometown of New York. My husband and I left shortly after we were married and headed for a new life on the West Coast. I never thought or even imagined what it would be like to have aging parents. Years later, the emergency calls would come from one of my brothers or sisters.

I made many trips back and forth. I would rush to catch the first plane to New York, feeling colorless and full of anxiety not knowing what to expect when I arrived or how long I would be there. I found myself in a heart-wrenching situation filled with the fear of the unknown, fear of death, and fear of loss.

During one stage of my father's disease, he was having nighttime rages



*Visual artist Melenie Fleischer displayed her paintings at the Sidney and Gertrude Zack Gallery at the Jewish Community Centre.*

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# Caregiving from a Distance

*(Good Mourning Flowers continued from page 1)*

(sundowning) and his neurologist prescribed a drug to sedate him. Not being a health expert or the family proxy, I felt helpless. As I left Dad's home the next day to return to Vancouver, he was drooling and unaware of his surroundings. No hugs, no kiss goodbye and I missed those words, "I love you." It broke my heart. My gut reaction was that there must be a better way to cope with the present condition.

The first thing that I did upon my return was go to the Alzheimer Society of B.C. for information. As well as being given informational pamphlets to take home and pass onto my family, I received validation and compassion. The Support and Education Coordinator was open-hearted and her first hand knowledge was invaluable. She gave me her office number in case I needed to speak with her again, and I did, many times. This was a turning point for me. I then became a proactive long-distance caregiver.

Some months later, after coming back from New York, I felt lonely, isolated, and unable to physically help my Dad or my family. I was far away. One evening, I met an elderly couple as I walked my dog. They shared their story and I learned that the husband had Alzheimer's and the wife was attending a local support group. They gave me the gift of connection. I joined her group and realized that no one should have to go through the Alzheimer's journey alone. I began to accept and embrace my father's journey through Alzheimer's disease.

Each time my father rallied, I realized it was my opportunity for another loving "good-bye." My father showed me the way. He guided me. I learned from him. He would touch his heart and say, "my heart." He was grieving his losses too. He would say, "Mein kop nish git" in Yiddish (his first language), or "My head's not good."

My last emergency visit with my dad lasted a month until his death. Upon my return home, I felt terrible grief knowing that I would never see him again. Comforting gifts of flowers from caring friends arrived at our door. Being an artist, I was inspired to paint them. They were my mourning flowers.

Some of my paintings were created in direct response to my grieving process, but all were part of a common



*Guests experienced an evening of sharing stories, music, and education through art.*

theme about the "dance of life". They reflect some of the emotions that I went through as I dealt with the feelings of loss, the joy of remembrances, love between family and friends and the nurturing of self.

While painting the vibrant color bouquets of flowers, I cried and smiled at the same time. I was experiencing peace and comfort after difficult times. That insight made me laugh! They were my "Good Mourning Flowers." These words became the title of my art exhibition, which took place at the Sidney and Gertrude Zack Gallery at the Jewish Community Centre in Vancouver.

On March 5, 2009, I devoted an evening to the Alzheimer's Society of B.C. as a way of expressing my appreciation for their unending support through education, knowledge, and compassion. In collaboration with the gallery director and the Alzheimer Society's event facilitators, we called the evening, "The Unexpected Gift of Alzheimer's." During the evening, guests were able to share stories, meditate through live music, and experience metaphor by observing visual art. It turned out to be an evening of inspiration where the arts, humanities, and poignant storytelling could intermingle.

There is pain and there are challenges on this difficult journey; there are also gifts of learning and love. We are connected with our hearts; we keep our loved ones alive in our hearts and acknowledge their lives with our memories and love. This is sacred. Love without reservation. As I was living with and loving my father I discovered that this guiding core, which is always there, is the gift which I received while living alongside Alzheimer's disease. ✦

## Local and Long-Distance Caregiving – Are They Different ?

This is the personal experience of Morag, only child of Pauline who has dementia and lives in Scotland. Morag attends an Alzheimer Society of B.C. support group for caregivers.



Caring for a family member with dementia is fraught with emotional and physical challenges. As one navigates the “dementia road” both caregiver and family member are challenged by a range of ever changing and evolving issues. Caregiving is a task which sometimes feels completely overwhelming. Whether in the same city or at the other side of the world, caregivers have to continually adapt and find innovative solutions to changing circumstances, at the same time coping with their own emotional needs and other commitments.

Are there differences with caregiving at a distance? As a long distance caregiver I see three main differences between my task and that of local caregivers.

### **Cost:**

The cost of caregiving at a distance can be considerable. For the first year I was able to stay with my mother and we used local buses to get around, but over the eight years since her diagnosis my mother has become increasingly confused and agitated about disruptions to her normal routine. Now I have to add accommodation and car rental to the cost of flights to Scotland, but this independence permits me to include breaks to re-charge my batteries and have some necessary down time.

### **Information:**

Having to rely on others to keep me up-to-date is frustrating. I know that relatives want to spare me the worry, but lack of accurate information about changes as they occur increases my anxiety level.

My solution is to go to Scotland two or three times a year for periods of four to eight weeks. In Scotland the policy is for the elderly to remain in their own homes, with support, for as long as possible. My mother

still lives at home alone, so longer visits are needed periodically to supervise house maintenance. Changes to her care arrangements are needed at every visit and even with only four or five months between visits, there are always some things that have fallen through the cracks and need to be re-implemented.

### **Intensity:**

For me, the major difference with long distance caregiving is the need to assess, investigate and then implement changes to care arrangements over a short visit. With only four weeks to achieve this, I have to plan ahead, set up appointments in advance and ignore jet-lag.

My mother has care workers in the home three times a day with a short report written at every visit. My first task is to read the reports and talk to as many of the care workers as possible. I also take her for eye tests and to the chiropodist, and I meet with her doctor, the social worker, the dementia care nurse, the pharmacist who makes up the weekly blister pack of medications, the day programme staff, the gardener, the home-help, and the neighbours. I also review the finances. Then there are the regular maintenance issues of defrosting the freezer, washing drapes, buying new clothes, stocking the kitchen cupboards and freezer - in general all the things that are not done by care workers. Everything has to be completed in those few weeks.

Yes, it is a frantic time but I do try to schedule days off. It is certainly possible to give care at a distance with a team you can rely on. I am very lucky to have an excellent team of care workers in Scotland and to be able to juggle both my life in Canada and the care of my mother in Scotland. ♦

# Tips for long distance caregivers

## Making Effective Visits

When caring from a distance, you may not be able to visit in person frequently. Therefore, you need to make the most of your visits. Being prepared prior to your visit will help you use your limited time effectively. Here is a general list of things to consider:

### Learn about the disease

Make an effort to understand some of the issues of the disease and the care that is needed. Being aware of some of the challenges can help you to become better prepared. You may also want to educate yourself on legal, financial, and medical matters involving the person with dementia.

### Familiarize yourself with available resources

Building a list of support contacts and resources is helpful in organizing care from a distance. Prior to your visit, prepare a list of people you would like to contact including the person's doctor, neighbour(s), and friends. Find out what organizations and services are available, such as support groups, adult day centres, or geriatric care managers. Contact your local Alzheimer Resource Centre to find out how to contact the Alzheimer organization in the area where the person with dementia lives.

### Plan ahead of the Visit

Planning ahead is essential for effective visiting. Some points to consider prior to your visit:

- Schedule an appointment with the person's doctor prior to your visit. Prepare a list of questions to ask (you may want to e-mail these questions to the doctor in advance). Go over the person's medical history and list of medications. If you decide to make a separate appointment to speak with the doctor, make sure that the person with dementia is ok with it. Get a care book to keep notes on appointments and observations.
- Make a checklist of things that you would like to evaluate.
- Find out what your family member would like to do while you are visiting (for example, going to the park, looking over some photographs, visiting other relatives).

### Assess the situation

Once you arrive, try to identify problems, needs, and potential risks. This may be especially important if the person with dementia is living alone. Make note of indications that changes in care might be necessary.

Some questions to ask yourself:

- Is their home safe? (Check to see fridge for rotting foods; make sure that they do not have burns or bruises, etc.)
- How is the person's appearance and hygiene?
- Are their finances in order? Are there any unpaid bills?
- Are there any noticeable changes that stand out? (Are they eating regularly? Are they keeping appointments? Have they lost interest in their hobbies?)
- Are people regularly visiting the person with dementia?
- How are they feeling? (How is their overall mood?)

### Spend time with the person with dementia

Make time to connect with the person with dementia. This is an important part of your visit. Spend time doing activities that the person with dementia enjoys. Try to go along with the person with dementia's routine.

### Connect with the primary caregiver

If there is a primary caregiver, talk with them. Learning to know when you are needed is just as important as actively helping out. Keep in mind the following points:

- Avoid "taking over." Rather, offer assistance when asked or if it's suitable (sudden changes can be disruptive for both the caregiver and the person with dementia).
- Make observations but be mindful of how you share them. Talk about your concerns without sounding critical.
- If possible, give the primary caregiver some respite (for example, help with housekeeping, preparing meals, or transportation)
- Lend a supportive ear to the primary caregiver

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### Identify options and coordinate roles and responsibilities

Identify the tasks you can take on. It could be financial support or occasional respite for the primary caregiver. Consider having a family conference to make decisions together and to determine who will take on each role. Points you may want to discuss:

- Making schedules for respite to give the primary caregiver a break
- Discussing financial and legal affairs and future planning
- Talking about ways to support each other and share responsibilities
- Deciding who checks regularly on the person
- Determining what services are needed and who will be in charge of organizing it

### Communicate regularly

Try to communicate regularly with the people involved in the care of your family member. This might be as simple as lending a supportive ear to the primary caregiver.

### Don't feel guilty

Try not to feel guilty because you are far away or feel that you are not doing enough. Distance doesn't mean that you are immune to feeling overwhelmed — you may not feel physically exhausted, but you might feel emotionally drained. Remind yourself that you are doing the best you can in the given circumstance.

As a long distance caregiver, part of your role is to support the person and their primary caregiver in whatever way that you can. Know that you are not alone as there are many others in a similar situation. Consider joining a support group where you will be able to share your experiences with others. Contact your local Alzheimer Resource Centre to find out more about support groups in your area.

## Checklist of Things to Evaluate

Here is a general list of issues and activities to help you evaluate the needs of the person with dementia. You can then search for available services and resources to address these needs.

### Health Issues

- new health problems
- unsanitary living conditions
- excess use of alcohol/medications
- does not keep medical appointments
- poor hygiene
- fainting
- incontinence

### Eating Habits

- no appetite
- weight loss/rapid weight gain
- irregular
- unhealthy

### Emotional

- signs of depression
- hallucinations
- fearful
- sad/cries a lot

### Safety

- leaves appliances on
- leaves doors unlocked
- falls or difficulty transferring from a chair
- electrical hazards in the house
- wanders
- has burns or bruises

### Mental Functioning

- inappropriate behaviour
- disoriented with time and location
- poor judgement
- confusion

### Financial

- mismanage finances
- vulnerable to scams
- makes big purchases

### Social Issues

- loss of social skills
- loss of interest in hobbies
- isolation

### Activities of Daily Living difficulty with:

- accessing transportation
- cleaning the house / laundry
- shopping
- cooking meals

**Tips for long distance caregivers**

**Using local services and resources to address needs**

One way of avoiding crisis in the future is to start planning now. After evaluating the needs of the person with dementia, you can begin to gather information to address these needs. Keep in mind the wishes of your family members as much as possible as they may refuse some of the services that you offer them.

Organize a directory of local resource with all the contact information. Also make sure that the key contacts have your information as well. Develop a relationship with contacts and agencies that may not be in your area but are available to the person with dementia.

Some useful resources to help you find services in the community of the person you care for are:

- The Alzheimer Society of B.C.
- the Internet, to help you find listings of national and local programs
- the local phone book
- libraries
- neighbours, friends and family members who live in the same city as the person with dementia

Below are some examples of local services that might benefit both you and the person with dementia.

<b>Type of service</b>	<b>Example of organization or agency</b>
Meal Delivery	Meal delivery agency (for example "Meals on Wheels") Restaurant delivery service Volunteer organization
Grocery Shopping	Neighbours/family/friends Volunteer services Home support agencies Specialized taxi and assistance services
Meals at home / Cooking	Home support agencies
Personal Care at home	Home support agencies
Transportation	HandyDart / local transportation system/volunteer drive programs
Socialization	Adult Day Programs Volunteer Agencies Seniors Agencies/Clubs Social Clubs Religious Organizations Support Groups for people with Dementia Internet chatroom Neighbours/family/friends (either visits or phone calls)
Financial Assistance	Provincial and National government income programs Veterans Affairs Applicable tax credits
Legal Assistance	Non-profit legal societies Public Trustee - Representation Agreement/Power of Attorney
Protection Against Abuse	Elder abuse societies
Emergency Response	Local police Neighbours or friends (to drop by and check in on the person with dementia)

## A suggestion for long distance caregiving

from MJ Cordier

My mother has Alzheimer's disease and lives 2,000 miles away. Telephone calls are of little value as mom doesn't remember them. So I've been making "Little Notes for Mom" on a greeting card software program. I insert an old picture on the front of the card...usually a picture of my mother or one of my siblings. On the inside, I write about the picture (who is in the picture, when it was taken, what we were doing and my personal memories of that day). I have sent a new card every Monday for the past 7 months. My mother's caregiver saves all of the cards and they look at the pictures and re-read the memories over and over. It's been a win-win situation as both my mother and her caregiver enjoy the cards and it helps me feel, that in a small way, I am contributing to her quality of life.



Hi Mom,

Hope you're having a nice day today and feeling really good.

Look at this picture I found of you and Lynn. The picture is not very clear...but it is so cute. I thought I'd send it anyway. It looks like it was taken when Lynn was about one or two years old. I'm not a very good judge of age. But if the age is right, that would make it about 1948 or 1949.

I was thinking about what your life must have been like then.

You were a young mother with two little girls...because I'm just two years older than Lynn. You had an ice box instead of a refrigerator. The "ice man" used to come and deliver ice at the house. That's how the food was kept cold. I remember getting slivers of ice off the truck and we would suck on them like they were candy. We thought that was a real treat. You had a wringer washer and hung clothes outside on the clothes line to dry. I remember how good the sheets always smelled from drying outside. I hope that was a really nice time for you...because you made such a nice home for us.

You have a really good week. I'll be thinking about you everyday.



Final Notes

**The Dementia Journey**



Whether you have a formal diagnosis or are caring for someone with Alzheimer's disease or another form of dementia, it can often leave you feeling frustrated and afraid. Thanks to a partnership between the Alzheimer Society of B.C. and the BC provincial health authorities, new help is available. The Dementia Journey website has now expanded province-wide. Through the stories of real people, it supports those with dementia and loved ones as they experience their own dementia journey and links visitors to current information and to help plan the next steps of their lives. To find out more please visit [www.dementiajourney.ca](http://www.dementiajourney.ca).

**Alzheimer Society**  
BRITISH COLUMBIA

For information about our programs and services, check out [www.alzheimerbc.org](http://www.alzheimerbc.org).

- Education programs:
  - The Dementia Series
  - Tele-Workshops
- Healthy Brain
- Information Services
- Support Groups for caregivers and people in the early stages of dementia
- *Insight*—a newsletter for and by people with dementia
- Memory Bank [www.thememorybank.ca](http://www.thememorybank.ca)
- *Safely Home*/B.C. Photo Registry
- Dementia Helpline

**DEMENTIA HELPLINE**



1-800-936-6033  
(Lower Mainland 604-681-8651)

Helping people with dementia, their friends, and their family members to build the confidence to maintain quality of life when facing dementia.

**Health Link BC - Call 811**

Speak with a nurse about your symptoms, consult a pharmacist about your medication questions, or get healthy eating advice from a dietician. This service is free of charge and available 24 hours a day and 7 days a week. Simply dial 811 for health information and answers to non-emergency questions. Information is also available online at [www.healthlinkbc.ca](http://www.healthlinkbc.ca).



**Our Vision**

Our ultimate vision is to create a world without Alzheimer's disease and related dementia.

**Our Mission**

The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer's disease and related dementias, to promote public awareness and to search for the causes and the cure.

The Alzheimer Society of B.C. is committed to protecting the privacy of people whose personal information is collected and held by the Society and we adhere to all legislative requirements with respect to protecting privacy. If at any time you wish to have your name removed from this or another mailing, contact us by phone at 604-681-6530, toll free at 1-800-667-3742 or via email at [info@alzheimerbc.org](mailto:info@alzheimerbc.org).

[www.alzheimerbc.org](http://www.alzheimerbc.org)