

IN TOUCH

newsletter for caregivers

Alzheimer Society
BRITISH COLUMBIA

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Facing Changes

Life is full of irony. We don't always look for change and yet it finds us. We are creatures of habit and yet we have to face change all the time. Caregivers face challenges that are not a result of changes happening within themselves. Instead, they are a result of changes happening to the person with dementia.

In Touch for Caregivers

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Dealing with Role Changes in Families: Caregiver change - Elder change

Family members have to take on different responsibilities when a relative is diagnosed with dementia. Sons and daughters may become caretakers for a parent with dementia. A spouse may assume a caregiving role for their husband or wife. You or others in your family may find these role changes difficult to accept. Often the roles change in some ways, but not in others, leading to some confusion about how to act. It sometimes takes a while to figure out just who will do what.

One change that often occurs is that the family member with dementia becomes the center of attention. A great deal of energy is focused on the person who is becoming impaired. Other family members, including spouses or other children, can feel neglected. They may become resentful because they feel they are not getting the attention they need. Chores must often be shifted to others, who may then feel burdened. Severe disruptions of family roles sometimes result in the withdrawal of one family member from all family activities or even divorce.

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It is good to remember that different family members respond in their own unique ways. Some people will not be helpful at all and will distance themselves from the situation because they cannot cope with the changes. However, some people who care for a family member with dementia report that their families experience a new kind of closeness, as they work together to deal with stressful situations. Some people even show strengths that they never knew they had. Here are some things that might help you cope with role changes in the family:

- Ask for help when you need it. Sit down with your family members and ask what they are willing to do to help. Give them ideas and suggestions. Don't just assume that they know what you need. They can't read your mind, and they may already be doing what they think is helpful. Assume that most people are doing the best they can under the circumstances. While this is not always the case, most often it is.
- Recognize that you are dealing with a stressful situation. Some people overlook the difficulties they are experiencing because they slowly take on more and more responsibility. Recognize all that you have taken on,

and congratulate yourself on what you have been able to do. Then see about getting any help you might need.

- Keep all family members informed of the details of the disability. This can be done in different ways. You can call and talk to people individually, or you can write a family newsletter. Copy the letter and send it to different family members so you don't have to rewrite the same information to each one.

Just remember, if you keep open the lines of communication with your family and friends, they are better able to understand what you and your family member are going through. The better they understand, the more willing they'll be to pitch in and help. Caregiving isn't easy, and it's important to make sure your aging family member does not take up all your energy. Make sure you find ways to pull together as a family and work together for everyone's benefit.





Family Decisions in Dementia Care

Adapted from article by Sara Qualls, Ph.D. , *Clinical Geopsychology News*, Fall 2002, vol. 9, no. 3

As a professional clinician, researcher, trainer, and family member of a cognitively impaired mother and father-in-law, I am increasingly impressed with how well many families manage the amazing quantity and rate of change (especially in decision-making) that runs their lives.

Dementia is a prime example of a change that disrupts family functioning because it affects biological, psychological, and social functioning, with profound consequences for the surrounding family.

Decision Making

Persons with dementia, over time, rely increasingly on the people around them to meet basic needs. With their growing dependence comes the increasing level of responsibility that is assumed by others, typically family. The sequence of changes experienced by families providing care for a person with dementia mirrors the shifts in roles over time experienced during childrearing. We understand that change is happening and are only slowly developing an awareness of how this affects caregivers.

Consider the case of an elderly widow with dementia whose three adult children all have families of their own. Since her husband's death, she has retained familiar generational boundaries around primary decisions (e.g. finances, health, housing, legal matters). Recently, however, her older daughter has grown concerned about her mother's well-being. Now what? If the daughter honours the generational boundaries, she can do no more than express concern or empathy. If the elderly mother honours those boundaries, she can do no more than ask for assistance with tasks.

Move forward in time a couple of years...everyone in the family acknowledges that mother has dementia. Who decides when a housing change is needed? Dementia demands that family structures change in order to meet the needs of members, but a manual does not exist to tell families how to renegotiate those changes.

‘Only rarely do I hear of families convening a formal meeting to investigate ...their concerns over behavior changes.’

The process of renegotiation of roles around decision-making is challenging to families, and patterns appear that reflect long-term family dynamics.

There are several processes in making a transition in the face of the changes they see in the person with dementia. Families must:

- perceive change
- label the change
- claim authority to act on their perception
- decide who should act
- choose a specific action

Only rarely do I hear of families convening a formal meeting to investigate, let alone address, their concerns over behavior change.

Another important aspect of the family’s involvement in decision-making is the frequent experience of resistance from the family member with dementia. This task is dreaded precisely because it so often generates resistance to the family member’s view: “There’s nothing wrong with my driving...I’ve never had an accident and you get speeding tickets all of the time.” “Throughout my career I’ve balanced \$40-million budgets at work and you are telling me I cannot manage my own finances?!”

Perceiving and Labeling the Change

A typical referral is from a daughter who describes her mother as “different”, “depressed”, and “she just sits a lot.” When asked about memory, the daughter denies problems, noting that her mother just forgets things like most older people do. When asked who handles her finances the daughter is emphatic that the family had to take that over a while ago because her mother just quit taking care of things after their father died three years previously. Here is a family that has a vague sense of a problem, but has not labeled it as such, and thus has not sought help from formal providers.

In dementia, the first decision is detection of the disease. Following that, the process of deterioration dictates which decisions must be made. For example, in the early stages when memory and performance deficits are subtle and often hidden, individuals and families make decisions about work responsibilities. Later, when the cognitive impairment is greater, someone typically makes decisions about independence in driving and financial management.

Families play important roles at all stages, but are in a unique position regarding decisions about early detection. They are most likely to detect the very early warning signs, long before a professional would have an opportunity to perform an assessment. They are key in labelling the change that is happening.

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Family and Dementia Care

Families provide information, monitor well-being, and provide a safety net for crises. They detect problems and seek help. Families are intimately linked to the person with dementia.

- Professionals need to engage the family in planning for health behavior changes and anticipate the influence of families in care situations
- Professionals need to expect resistance from the person with dementia when changes are introduced, and help the family at these times. Professionals need to recognize the patterns of family anxiety.



Coping with Change

Both big and small changes are inevitable, you need to be able to adjust. Try these guidelines for coping with change.



- **Expect a reaction to the change**

Realize that it's normal to feel sad or angry. Let yourself grieve. Don't try to downplay your emotions. Avoid saying, "I don't know why this is affecting me this way."

- **Find support**

Seek out friends and family who can reassure you. You don't have to brave change alone. It often takes more courage to ask for help.

- **Keep as many familiar routines as possible**

Hanging on to some of your normal daily activities can help provide a sense of stability when the world around you seems chaotic.

- **"Reframe" your thinking**

The faster you're able to change your outlook about your situation, the easier it will be for you to adjust. Try to stay positive. Rather than viewing change as a threat, try to approach it with excitement and anticipation.

Understanding the process of change

- **The ending**—This stage involves either voluntarily or involuntarily ending an attachment to an old way of doing things, or a familiar person, place, or job (for example, diagnosis of dementia or a spouse losing a driver's license).

- **The transition**—In this stage, people start to let go and move on. This stage can be easier if you know what to expect in the future (for example, joining a support group or asking a friend to drive you to your appointments).

- **The beginning**—In time, people take ownership of change. Once you've moved along in the transition, you'll begin to return to a sense of normalcy.

- **Cultivate a positive view of yourself**

Recall occasions when you successfully handled hardships in the past, and use those skills to meet your new challenge. Trust in your ability to solve problems and make the right decisions.

- **Take it one step at a time**

If you feel overwhelmed, try not to concentrate so much on the big picture. Think about how far you've progressed instead. Then break the transition period into manageable chunks—maybe even hours.

- **Keep your imagination in check**

Don't let "what if" thoughts get the best of you.

- **Stay healthy**

Coping with change or grief can be emotionally and physically exhausting. Make sure you take good care of yourself. Take breaks when you feel you need them, eat properly, and exercise.

- **Find the positive in the situation**

Everyone has something good in his/her life. This may seem impossible to keep in mind, especially if you're coping with the death of a loved one, serious illness, or job loss. But remember that change makes us wiser and stronger.

- **Remember that your struggle to deal with the change will end**

In due time, your new circumstances will become familiar to you. Make a memorial to the change or loss if it will help you in your transition. For example, you could plant a tree or flower, or you could create a scrapbook.

Trying to find balance and cope with change is a learned skill. You may find it difficult to adjust, but trust in life's renewable and sustainable potential.

**You can't
force your
acceptance
of change,
but we
have ideas
to help**

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.

In Touch

Publication Schedule

June 2008	Married to a Person With Dementia
September 2008	Maintaining the Spirit
December 2008	Research Update

The Alzheimer Society of B.C. Programs and Services

Check www.alzheimerbc.org to find out more about our programs and services.

- ▶ Education programs:
 - ▶ The Dementia Series
 - ▶ Telephone Seminars
- ▶ 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
- ▶ Safely Home/B.C. Photo Registry

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300-828 West 8th Avenue
Vancouver, BC V5Z 1E2
tel: 604-681-6530
fax: 604-669-6907
toll-free: 1-800-667-3742
dementia helpline: 1-800-936-6033
email: info@alzheimerbc.org