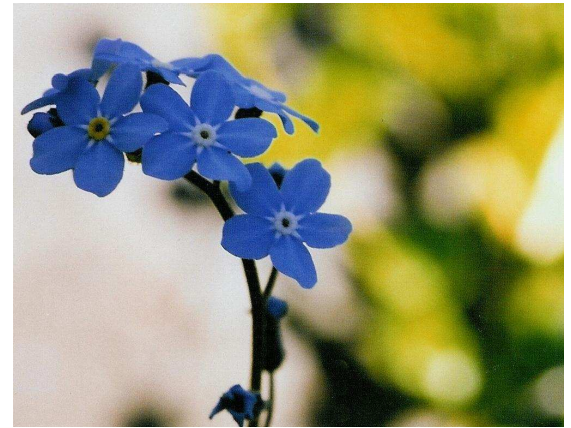


Coping with changes, loss and grief

Dealing with life's inevitable changes is always challenging. As a caregiver of a person with Alzheimer's disease or a related dementia, you, your family, and the person you are caring for are continually experiencing life-altering changes to which you must try to adapt. This issue of In Touch offers perspectives on coping with the changes and transitions that caregivers experience on their journey with dementia. Strategies for understanding, acknowledging and beginning to work through these changes will be introduced. In addition, this issue will explore ideas around coping with the difficult feelings, including grief, that often accompany change.



Dementia as a “life-transforming” disease

Alzheimer's disease and related dementias have been described as “life-transforming conditions”. Following a diagnosis, there are, and will continue to be, a multitude of changes in many aspects of life that will require ongoing adaptation. Because of the progressive nature of the disease, dementia is characterized by a series of losses. Some examples of the many changes caregivers must cope with include: noticing initial symptoms in the person with dementia, receiving a diagnosis, telling others about the disease, shifting roles within the family, removing a person's driver's license, providing increasing support for the person with dementia in day-to-day activities and the decision to move the person into a residential care facility.

We adjust more readily to transitions that are our choice, have a net gain (more gains than losses), and are final. The changes that happen with Alzheimer's disease and related dementias often are not like this. As a caregiver you will need to come to a decision about how to live with your new reality. You will also experience a variety of reactions to and feelings about the ongoing process of adjustment and readjustment. Recognizing that significant changes are unavoidable, and learning how to cope with the emotional and practical implications of these changes, is key to living well with this disease.

Although circumstances vary and each family living with dementia will face unique challenges, it is important to recognize that as a caregiver of someone with dementia, you are not alone. There are other people in your community who are dealing with similar changes. Contacting your local Alzheimer Society of B.C. resource centre is a good way to connect with others and get the support you need.

“Find a way to live with what cannot be changed – it will be the easiest for you.”
– Caregiver Support Group member

Perspectives on change

Who needs to change?

Imagine communicating with someone for 50 years or longer. Then they change. They are not the person you always knew? If not, then who are they? Who?

This person you always knew starts acting and coping with the world in new and different ways. Strange, bizarre, unsettling ways. Many of these new behaviors make you angry, they drive you crazy, you feel out of sorts. You just can't understand.

You continue to try and make sense of what is happening in the way you always have. It doesn't work.

Every day, many times a day, you are at wit's end. You don't know what to do. It's hopeless. Or is it?

You know that something needs to change. But discovering this change – the “what to do” is elusive. You rack your brain. You just can't figure out what to do.

Then finally out of the nowhere -- the dark clouds separate. You see the light. You come to a conclusion that seems to be so simple....

Something has to change and that something is YOU.

Source: *Alzheimer's Reading Room*

The only real norm is change

I've had to make many new adjustments since I've been caregiving. New schedules, new expectations, new relationships – I've found a way to work them all into my life. But just when I've settled into these new routines, along comes another change to wrench away the now familiar patterns and demand yet another round of adjustments.

I realize that the only real norm is change. Yet each new procedure or activity – once I get used to it – becomes “mine.” When I am asked to give it up, I resist, at least momentarily. It's my “security blanket.” I want to be flexible and ready to adapt to changing needs, yet it is important to be patient with my natural desire for the familiar. When it's time to give up a person or activity I've grown used to, it helps to find extra ways to comfort myself during the transition. I snuggle up with my pet, chat with an understanding friend, or buy myself flowers.

I make sure my sense of security is well tended to during times of transition.

Source: Samples, P. (1999). *Daily Comforts for Caregivers*. Fairview Press, Minneapolis, MN.

“When we are no longer able to change a situation, we are challenged to change ourselves.”

- Victor Frankl

Changes in families

One of the many areas of life that dementia can cause significant changes to is the relationships among family members. Although only one individual may have received a diagnosis of dementia, it is likely that the whole family will be deeply changed by it. For example, if the person with dementia is your parent, you will face a role reversal in caring for them. If you have siblings, you will all have to work together to share responsibilities and make important health care decisions for your parent. If you are caring for your spouse, you will become responsible for someone who has previously been a partner. In addition, children and teens can be confused and upset by the changes they are seeing in a parent or grandparent with dementia.



The changes and challenges that dementia brings can often ignite or magnify family conflicts, especially when people cope differently when it comes to caregiving responsibilities. Family members may deny what is happening or resent family members who live far away or are not helping enough. There may also be disagreement about financial and care decisions. Here are some suggestions on how to work together:

- **Have a family meeting.** Talking about caregiving roles and responsibilities, problems and feelings can help ease tensions. You may want help from a professional counsellor or moderator to facilitate the meeting and keep things on track.
- **Recognize differences.** Some family members may be hands-on caregivers, responding immediately to issues and organizing resources. Others may be more comfortable with being told to complete specific tasks, such as mowing the lawn or paying the bills.
- **Learn together.** Register for an Alzheimer Society dementia education workshop and attend with other members of your family. Contact your local Alzheimer Society of B.C. resource centre and ask about upcoming learning opportunities.
- **Continue to communicate.** Periodic family meetings or conference calls keep family members up-to-date and involved. Discuss how things are working, reassess the needs of both the person with dementia and the primary caregiver, and decide if any changes in responsibilities are needed.

How I've changed

I've changed since I've become a caregiver. I'm not sure exactly how, but I know I'm not the same. In fact, I'll never be the same person I was before. That's partly a good thing. I've learned a lot. I'm stronger in certain ways. A few of my opinions have changed. I've gotten tougher in some ways, softer in others. These changes haven't come easy. I've had to give up some things along the way that mattered to me. I can't do everything I used to. It might be worthwhile to make a list of all the changes I see in myself. That way I can celebrate the gains and mourn the losses. I can mark the milestones and know where I'm starting from today. I'll know myself better.

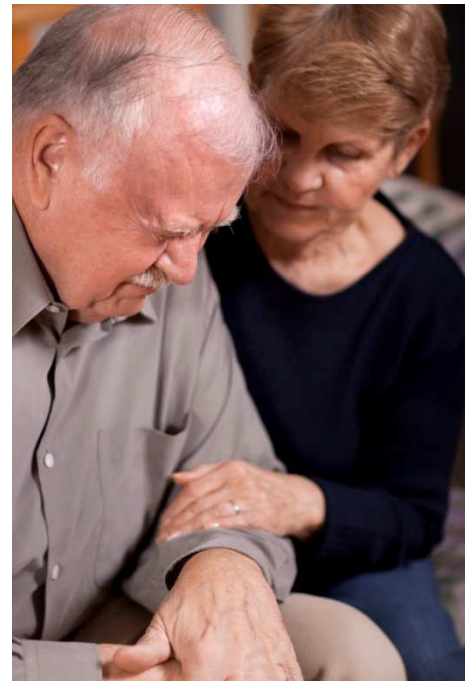
Source: Samples, P. (1999). *Daily Comforts for Caregivers*. Fairview Press, Minneapolis, MN.

Understanding feelings

One of the most important strategies for coping with transitions in your life is to understand and come to terms with your feelings. As a caregiver, your relationships can be affected, you may not be able to think as clearly as you used to, and at times you may even fear that you are losing yourself. However, in recognizing and acknowledging your emotions you do not lose yourself; instead, you are given the opportunity to find yourself.

It may be helpful for you to consider the following information on the dynamics of feelings:

- Feelings are neither good nor bad, right nor wrong; feelings just are, they exist. You need not, and should not, judge yourself negatively just because you have or don't have a particular feeling. Some feelings are more comfortable than others.
- Feelings do not last forever. No matter what you are feeling, eventually that feeling will lift and another emotion will take its place.
- Everyone has a right to their feelings.
- When you are overcome by a strong feeling, you do not have to act on it. Feelings are not dangerous but actions can be.
- Feelings are not facts. Feeling a certain way does not necessarily reflect an accurate picture of the real world.
- Denying a feeling does not make it go away. Not talking about a feeling also does not make it go away.
- It is important to acknowledge your feelings—even uncomfortable ones. Excessive self-judgment will block feelings and this is not helpful.



“Remember that an emotion is just an emotion – neither good nor bad, right nor wrong. Emotions are not rational, but they are very real responses. Emotions or feelings can be uncomfortable but they can't hurt you. To begin, take things a little at a time and deal with each emotion as it comes. Let yourself be in the experience, be curious about it, attend to what it is like in detail, and allow the feeling to move through you and out of you. With practice, you can choose where, when, and for how long to feel your emotions. They become something you journey with rather than something you avoid.”

Source: *Transitions in Dying and Bereavement*, Victoria Hospice Society, 2003.

The ups and downs of grieving

Grief has been identified as the “constant yet hidden companion” of Alzheimer’s disease and other related dementias (Kenneth J. Doka). Caregivers often experience a continuous and profound sense of loss and subsequent grief as they continue to experience the changes associated with the progression of the disease. You may be grieving the losses that are occurring in your own life as well as in the life of the person with dementia.

Grieving is an up and down process. In the earlier stages of the person's dementia, you may swing between despair and wild optimism that a cure will soon be found. You may even deny that anything is wrong with the person and try to suppress your feelings. Later, if you have accepted the situation, you may find that there are periods when you can cope well and make the best of things. At other times, you may feel overwhelmed by sadness or anger, or you may simply feel numb.

Feelings like these are a normal part of grieving; but if you experience them, it is important to realize that you may be under a great deal of stress and you may need to seek emotional support for yourself.

Tips for coping with grief:

- **Feel the pain.** Allow yourself to really feel what you are feeling, no matter what that is. Denying your feelings only intensifies and prolongs the pain.
- **Cry.** Tears can be therapeutic. Let them cleanse and relieve the pain inside. Relieve tension through shouting or punching a cushion. However, make sure that the person with dementia is safe and out of earshot or you may distress them.
- **Talk.** Share the pain. It is important to talk about your feelings even at the most difficult times. Sharing grief will help diminish it. It can be helpful to talk to a person outside the family, such as a counsellor or trusted friend. Joining an Alzheimer Society support group gives you the opportunity to talk with others who are on a similar journey.
- **Keep a journal.** A journal is a private place where anything can be written including unfulfilled wishes, guilt, anger and any other thoughts and feelings. A journal is a place where you can explore your frustrations and express your thoughts and ideas without interruption.
- **Consider your own needs.** If you spend a lot of time with the person with dementia, taking regular breaks can keep you in touch with the outside world and raise your morale. Just relaxing with a cup of tea or having a good chat on the phone will help you recharge your batteries and cope with your emotions.



- **Find comfort.** Different people have different ways of finding comfort. For many there is comfort in rituals, such as prayer, meditation or other activities.
- **Hold off.** Tread carefully before making decisions. Thoroughly explore all options before making major steps. You may be unable to make important decisions at times.
- **Be kind to yourself.** Be patient with your feelings. Find a balance between the happy and sad person, the angry and peaceful, and the guilty and glad self. Have patience with yourself.
- **Learn to laugh again.** Rediscover your sense of humour. Watch a funny movie, read the comics, or spend time with a friend who makes you laugh. Finding joy in life can be one way of honouring the happy times that used to be shared.

It is fairly common for people facing dementia to experience depression, but this should not be regarded as inevitable. Depression is treatable – it is important to speak to your doctor if you are concerned about depression.

Sources: *Alzheimer's Society of UK; Alzheimer's Australia; "Living with Grief – Alzheimer's disease", Hospice Foundation of America (2004)*

Some things never change

Despite the impact of dementia on a person's memories, caregivers often speak about a core of self that continues to exist. Here is a story of how one caregiver was able to connect with his wife by discovering that there are some things dementia cannot change.



I stood looking at the candy counter in the grocery store. There were so many choices from which to choose! Could I remember what treat she might choose for herself if she were here? She wouldn't be able to ask because her speech is now badly confused. Alzheimer's disease has taken control of her cognitive abilities. Then I remembered her taste for chocolate maple buds! I returned home with excitement.

I divided my purchase into small containers. I planned to take one each time I went to the hospital. I took an attractive candy dish for her small lamp table as well.

She met me at the hospital door. I carried my parcel to her room and let some of the chocolates fall into the candy dish. I watched her sad face light up with expression... "Mmm, chocolate maple buds!" I did not hear the words, but I saw them! Quickly the memory returned from past years. How long it stayed I cannot tell.

Each time I go now I carry buds...maple buds. Did you ever take chocolates to your sweetheart when you were courting? Now as a caregiver, why not do it again?

Source: *Reflections on Caregiving- A Sharing of Experiences*, Alzheimer Society of B.C.

Transitioning to long-term care

One of the biggest changes caregivers may face is the transition of the person with dementia into a long-term residential care facility. Not only do your daily activities suddenly change, but it can be an especially emotional time with mixed feelings such as relief, guilt and grief.

Many people believe that full time residential care will remove them from the caregiving role. The fact is you are still caring. Allowing others to take responsibility for practical tasks does not lessen your role as a caregiver. You are the 'expert' when it comes to caring for the person with dementia.

Your role now is to work with the staff to inform, advise, recommend, make decisions and encourage the best possible quality of care for the person with dementia. You can also continue to contribute to their physical care to the extent that you want.

The care facility should involve you in the person's care by:

- asking you for information about their family background, past employment, activities and hobbies, likes and dislikes, language, religion, culture, etc.
- encouraging you to make the person's room as home-like as possible.
- working with you to develop a care plan which sets out his or her care needs and the goals, strategies and actions to ensure those needs are being met.
- reviewing the care plan with you regularly.
- consulting you about personal routines such as when the person with dementia likes to get up and go to bed, bathing times, what they wear, what they eat and when they have their meals, and so on. These preferences should be accommodated as much as possible within the care facility's routines.
- informing you about how the person is doing, not just when they are ill or experiencing declines in abilities, but about good things such as achievements, outings they have been on, how they relate to other residents and staff, and so on.



If the facility does not actively promote involvement from family members, try speaking to the manager or person in charge about how you wish to be involved and ways they can help you to do this.

Adapted from: "Letting go without giving up" - Alzheimer Scotland (June 2005)

Notes and Events

In Touch is published by:

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Our Vision

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

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 cures.

DEMENTIA HELPLINE

Alzheimer Society
BRITISH COLUMBIA

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.

Free Telephone Workshops



Thursday, March 24th, 7:00pm
Understanding Dementia

One of the best ways family caregivers can prepare for the journey with dementia is by learning about the disease and what to expect throughout the progression. This tele-workshop provides information on the kinds of symptoms that are likely to arise and explores a variety of different approaches for meeting the challenges associated with the disease.

To see a list of upcoming workshops or to register, go to www.alzheimerbc.org and click on **We Can Help**.

You can also register toll-free at 1-866-396-2433 (Mon-Fri, 6am to 2pm P.S.T.)

Coping with Transitions in Dementia Caregiving: Dimensions of Grief and Loss

This six-session series explores the loss and grief issues of the caregiving experience in order to identify tools and strategies for weathering the myriad of these transition losses.

We are currently seeking participants for telephone and web-based versions of this series. If you are interested in registering, please phone 604-742-4907 (toll-free 1-800-667-3742) or email:

infocoordinator@alzheimerbc.org