

**As an
Alzheimer's survivor,
I have no reason to hold
back or
to be ashamed of
having Alzheimer's.
I am open to sharing
what is happening
in the experience and
advocating for
a better understanding
of the disease.**

*—T. Raushi**

**SECTION 4:
LIFE AFTER DIAGNOSIS**

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* Raushi, T. Perspectives - A Newsletter for Individuals with Alzheimer's or a Related Disorder, Vol. 7, No. 4, May-July, 2002, pp. 1-3. Published by the University of California, San Diego, Shiley-Marcos Alzheimer's Disease Research Center. Contact Lisa Snyder at lsnyder@ucsd.edu for a free email subscription.

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LIFE AFTER DIAGNOSIS

IN THIS SECTION OF THE WORKBOOK, YOU WILL LEARN ABOUT:

- the kinds of changes that follow a diagnosis of an illness that causes dementia
- suggestions for dealing with these changes
- the feelings that follow a diagnosis of an illness that causes dementia
- suggestions on dealing with these feelings
- practical suggestions to help with the emotional side of living with dementia

COMING TO TERMS WITH A LIFE I DID NOT PLAN

Enduring life's inevitable changes can be challenging. Human beings have a built-in ability to adjust to change. In adjusting to change, we experience a psychological process described as "transition." It can require true courage to weather this process.

We can think of change as moving from one state (an end) through a transition phase to a new beginning.

PSYCHOLOGICAL STATE OF CHANGE



ENDING	transition	NEW BEGINING
<ul style="list-style-type: none">▪ what is left behind▪ what ceases to be▪ letting go▪ loss (grief, anger, "blues")	<p>"NEUTRAL ZONE"</p> <ul style="list-style-type: none">▪ movement from old to new▪ risky (apprehension)▪ uncertainty (tension)▪ boundaries are fuzzy	<ul style="list-style-type: none">▪ new roles/work▪ involves a shift in attitude/perspective▪ alignment▪ gain

Transition can also be called a transformation. Alzheimer's disease and related dementias have been described as life-transforming conditions. Things will not be the same. You will need to come to a decision about how to live with your new reality.

We adjust more readily to changes/transitions that are:

- our choice
- have a net gain (more gains than losses)
- final

The changes that happen with Alzheimer's disease and related dementias do not follow this pattern. There are, and will continue to be, a multitude of changes in many aspects of one's life that will require adjustment. There are, and will be, a variety of reactions to and feelings about the ongoing process of adjustment and readjustment.

Before thinking about the changes you are facing, it is important to think about who you are right now.

Thinking about your "self," list as many labels as possible in answer to the question: Who am I? For example: father, architect, partner, sister, singer, writer, peacemaker, friend.

CHANGES

Here are some ways people talk about the changes that come with Alzheimer's disease or a related dementia:

- **Changing abilities**—“Certainly I miss the abilities that I am losing; daily I am reminded of the losses.”

*T. Raushi.**
- **Sense of mastery**—“The worst feeling is that of not being able to trust myself.”

Sheila
- **Changing activities and roles**—“We do not take well to uselessness. Retirement and illness challenge us to redefine what it means to be of use and to have a purpose.”

W. Lustbader
- **Noticing shifts in key relationships**—“In the economy of illness, the supply of friends tends to shrink. Peripheral friends drop away, since such relationships are reliant on contexts in which little effort has to be exerted.”

W. Lustbader
- **Changing sense of self and place in a now “unsure” world—no longer able to maintain illusion of constancy**—“It’s a strange world I’m trapped in...On a bad day, even my solutions have problems...There is so much frustration in my daily life...some days, I could just cry”.

Norma Selbie

* Raushi, T. The Alzheimer's Survivor: Some Thoughts on Being an Alzheimer's Survivor through the Eyes of a Person Diagnosed Early with the Disease: *Perspectives - A Newsletter for Individuals with Alzheimer's or a Related Disorder*, Vol. 7, No. 4, May-July 2002, pp. 1-3. Published by the University of California, San Diego, Shiley-Marcos Alzheimer's Disease Research Center. Contact Lisa Snyder at lsnyder@ucsd.edu for a free email subscription.

What changes are you noticing in yourself?

What are you still able to do and enjoy?

FEELINGS

When facing changes, and particularly as you move through the “Neutral Zone,” you will experience a variety of feelings. This is a necessary part of coming to terms with the changes.

Feeling (definition): *A subjective response or reaction to a person or a situation.*

Feelings are real and powerful. Although you cannot see or touch them, feelings can heavily influence your behaviour, your thoughts, and even your spiritual life.

No matter how much you try to suppress your feelings, try to make them go away, or pretend they do not exist or are relatively unimportant, they will eventually surface and clamour for your attention.

One of the most important components of the healthy transformation of your life is to find and come to terms with your feelings.

Your relationships can be affected, and you may not be able to think as clearly as you used to. At times, you may even fear that you are losing yourself. However, in finding your emotions you do not lose yourself, instead, you find yourself.

Seven things to be aware of:

1. Feelings are neither good nor bad, right nor wrong; feelings are messages to be interpreted.
2. Feelings do not last forever. No matter what you are feeling, eventually that feeling will lift and another emotion will take its place.
3. Everyone has a right to their feelings.
4. When you are overcome by a strong feeling, you do not have to act on it. Feelings are not dangerous but actions can be.
5. Feelings are not facts. Feeling a certain way does not necessarily reflect an accurate picture of the real world.
6. Denying a feeling does not make it go away.
7. It is important to acknowledge your feelings—even uncomfortable ones. Excessive self-judgment will block feelings. This is not helpful.

We typically think of feelings as falling into four categories. You may experience any or all of these emotions; and there are many degrees and shadings of each one: **sadness, anger, joy, and fear.**

When a chronic illness intrudes on your life, you may experience intense emotions. Strong feelings such as sadness, discouragement, and anger are common reactions to the implications of being ill. Emotional reactions can be intensified by the dementing illness. Your emotional reactions may seem stronger than before and harder to moderate.

Some of the uncomfortable feelings and reactions that people with Alzheimer's disease and related dementias have identified as being part of their experience include:

- **frustration and anger** at the disease, sometimes at others, and even at oneself. There are four roots of anger:
 - » fear—"What is going to happen next?"
 - » frustration—"I can't believe I can't do that any more!"
 - » intrusion—"I didn't ask for this!"
 - » injustice—"This isn't fair!"
- **embarrassment and shame**—"I hate it when people see my mistakes."
- **fear**—"What will happen to me?"
- **sadness and grief**
Grief is a normal, universal response to all losses, including the loss of "what was" and the loss of "what might have been." For example, you may miss the healthy person you once were, your feelings of confidence, your independence, your privacy, job satisfaction, untroubled family relationships, feelings of energy, a sense of happiness, and enjoyable hobbies.

- **loneliness**

People with a serious illness may experience periods of intense and painful loneliness. Many people with dementia find it helpful to join a support group for people with early symptoms Dementia Support Group (see Section 7 for contact information).

- **guilt**

You may think that you are somehow failing yourself and those closest to you.

What feelings have you experienced?

TIPS FOR HANDLING FEELINGS AND REACTIONS

Here are some techniques and strategies others have found useful:

- Recognize that your losses are important, not trivial.
- Admit your feelings to yourself and to others. Acknowledging and talking about these feelings is an important step towards emotional health. Consider speaking with a neutral person, such as a counsellor.
- Moderate intense reactions in the moment:
 - » Cool down.
 - » Stop what you are doing at the time.
 - » Breathe! Take four or five slow, deep breaths.
 - » Clear your mind by using a strategy such as counting to ten. This distracts you and buys some time to allow the thinking brain to re-engage.

- Plan ahead: minimizing factors such as hunger or fatigue can help.
- Self-soothe by:
 - » engaging in physical activities such as walking, running, dancing, etc.—whatever works for you
 - » laughing—look for the lighter side of the situation
 - » using relaxation techniques such as deep breathing, listening to music, playing with a pet, writing in a journal
- Practice positive thinking. Remind yourself that feelings are not facts. When negative thoughts or unrealistic expectations intrude, switch to positive thinking.
- Say consoling things to yourself such as “I can handle this.”
- Develop the habit of positive self-talk to preserve self-esteem.* Self-esteem comes not only from the messages other people send you, but also from the messages you send to yourself via a subconscious voice in your head. Self-talk refers to that subconscious voice.
- You have the power to override negative messages (i.e. “I’m stupid!” and “I’m not good enough!”) from yourself and others with positive self-talk. Examples of positive self-talk include:
 - » “There are people who love me and will be there for me when I need them.”
 - » “I deserve to be happy.”
- First, consciously stop the negative thought. Then, replace it with a helpful or positive thought. Refer to page 39 in Section 3 on “Stop Your Negative Thoughts.”

* Adapted from: Moles, K. *The Relationship Workbook*. Plainview, N.Y.: Wellness Reproductions & Publishing, LLC., 2001

STRATEGIES FOR COPING WITH FEELINGS

Strategies for coping with feelings include:

- positive self talk
- journaling
- exercising
- engaging in enjoyable activities
- having an active social life

Positive self-talk

Be aware of your self-talk. Be mindful to not put yourself down, but to talk yourself up instead, with positive self-talk.

I AM GOING TO USE POSITIVE SELF TALK.

YES/NO

Write down some statements to repeat to yourself if you start to feel badly or feel the urge to put yourself down.

Journaling

You can use a journal to help sort your feelings and to write down positive statements about who you really are (another way of practicing positive self-talk).

I AM GOING TO USE A JOURNAL.

YES/NO

Who cares
if you
forget?
There is
no test at
the end of
the day.
Enjoy!

If you do not have a journal, write down your plan to get one and use it.

Exercising

Exercise can relieve stress. It can give you time to think positive thoughts and make you feel good about your health and your body.

I AM GOING TO EXERCISE. YES/NO

Your exercise routine does not have to be strenuous, so commit to exercising at least three times a week. Below are some examples of exercises you can do.

- » walking
- » jogging
- » swimming
- » taking a fitness class
- » other:

Engaging in enjoyable activities

Put aside some time everyday to do something enjoyable.

I AM GOING TO ENGAGE IN ENJOYABLE ACTIVITIES.

YES/NO

Select some of the activities you enjoy, or add your own ideas.

- play a musical instrument
- take a walk outside
- listen to music
- attend a support group
- other ideas:
- write in a journal
- participate in a club or group
- make crafts
- play a sport

Having an active social life

Spend time with people who allow you to feel good about yourself. Participating in healthy activities, like those listed above, will help you improve your self-esteem.

I AM GOING TO HAVE AN ACTIVE SOCIAL LIFE.

YES/NO

Stay involved with hobbies and interests.

Volunteer your time to help someone else!

List the people you will spend time with.

List some healthy social activities in which you will participate (e.g., visiting friends and family, dancing, etc.).

Join a
choir —
the mental
stimulation
is good and
it lifts your
spirits.

LOOKING AFTER THE PRACTICAL

People with dementia have provided a number of practical tips about how to cope with memory problems. Here are some of those ideas:

- Write HOT above the hot water tap in the shower or glue a red disk on the tap. Use arrows to indicate the direction to turn the tap ON.
- Carry your name, address and phone number in every sweater and coat pocket, or buy an i.d. bracelet on which to put this information.
- Put an oven mitt in the middle of the floor to remind you when the oven is on.
- Keep a day planner next to the phone to write down appointments.

ARE YOU FINDING IT HARD TO:

- **COPE WITH RECEIVING YOUR DIAGNOSIS?**
- **PROCESS YOUR FEELINGS ABOUT HAVING AN ILLNESS THAT IS CAUSING DEMENTIA?**

YES/NO

If the answer is yes to either of the above questions, consider:

- contacting the Alzheimer Society of B.C. to join a support group (see Section 7)
- contacting the Alzheimer Society of B.C. to access education programs
- **www.alzheimer.ca**
This is the official website for the Alzheimer Society of Canada. Of special interest is the section on “Creative Space”—a place where people affected by Alzheimer’s disease or a related dementia can express themselves through creative writing and artwork.
www.alzheimer.ca/english/creativespace/intro.htm
- **www.dasninternational.org**
This website is organized by the Dementia Advocacy and Support Network, a group of individuals with Alzheimer’s disease or related disorders. In the “Connecting with People” section, you will find essays and talks by persons with Alzheimer’s disease.

