

**A degree of denial
is essential.
Like somebody drinking
hot coffee,
we sip the truth
of our condition
carefully and gently.**

*—J. W. Anthony**

SECTION 2: HEARING THE DIAGNOSIS

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* J.W. Anthony. "Ideas about Alzheimer's", reprinted with permission from Perspectives - A Newsletter for Individuals with Alzheimer's or a Related Disorder, Vol. 3, No. 4, May-July 1998. 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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HEARING THE DIAGNOSIS

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

- the impact of receiving a diagnosis of a life-threatening illness
- what other people have found helpful
- telling other people about the diagnosis
- getting support

Receiving a diagnosis of dementia can be overwhelmingly frightening. Every person reacts differently to an unwelcome diagnosis. **There is no right way or wrong way to react.**

We can think of the reaction to hearing bad news as having five phases. These phases can be experienced and re-experienced in any order. There are no time limits to the range of reactions and emotions that people go through when receiving catastrophic news.

1. Shock and Numbness

A diagnosis of dementia can come as a shock, even if you have been half expecting it.

2. Disbelief and Denial

“This can’t be happening to me/us!” “It isn’t as bad as the doctors say.” In the beginning, denial can be a positive force. We use denial to shield ourselves from news that is too painful to bear, as we adjust inwardly to our new reality.

3. A ‘hurricane’ or a ‘roller-coaster ride’ of uncomfortable feelings of anger and frustration; a trajectory through emotional devastation

It takes time to sort through the many reactions and emotions including frustration and anger at the situation, at the disease, at others, and even at oneself. However, some people experience a sense of relief to know there is a medical reason behind the changes they have noticed in their thoughts and actions.

4. Despondency and Sadness

Everyone will experience periods of feeling:

- helpless and powerless in the face of the implications of the diagnosis—confronting one’s limitations.
- intensely sad when considering all the losses this disease has caused and may cause as time goes on—the healthy, happy years that are past and the lost years of the future.
- worried and fearful: *“What’s going to happen next?”*

5. Acceptance

Accepting the problem rather than avoiding it, and then realizing that the situation must be adjusted to rather than actively changed. Acceptance will involve recognizing and becoming reconciled to the limits of the body.

How well do these five phases match your experience?

Understanding and acknowledging these wide-ranging reactions and emotions can help one to cope with the situation. Keep in mind that how one lives with these intense reactions and emotions depends on their personality and coping style.

There are many ways besides talking to process feelings, such as:

- writing in a journal
- painting or becoming involved in other artistic hobbies
- following your faith and other spiritual pursuits
- exercising
- reading poetry, philosophy, self-help, and other books
- listening to music
- taking time to reflect

Note how you might choose to process your feelings.

TELLING OTHERS ABOUT YOUR DIAGNOSIS

Who you tell about your diagnosis and how you tell them is an intensely personal part of any journey with an illness. There are a few things you may want to consider:

- Disclosing your diagnosis to those closest to you who may be able to give you help and support is important in facing the challenges of dementia.
- The degree of closeness or importance of the relationship with your individual colleagues, friends, and family may be a factor in deciding who to tell.
- You do not need to tell anyone unless you want to.

My Social Network Map

Write in each box the names of the people you meet in the following categories—see example below.

An example of how to complete your network map:

I meet my friend Emily every week.

I meet my sister Gail every day.

I meet Paul at the book club once a month.

I see Tony when I volunteer at the library every other week.

		Daily	Weekly or more often	Approx. every 2 weeks	Monthly or less often	Rarely
MYSELF	Family	Gail				
	Friends		Emily			
	Neighbours					
	Activities where I met people				Paul	
	Work or organizations I belong to			Tony		

In this example, Gail and Emily are much closer to **MYSELF** than Tony and Paul.

		Daily	Weekly or more often	Approx. every 2 weeks	Monthly or less often	Rarely
MYSELF	Family					
	Friends					
	Neighbours					
	Activities where I met people					
	Work or organizations I belong to					

Consider that the closer people are to the box that says **MYSELF**, the more important it may be to tell them about your diagnosis.

ARE YOU FINDING IT HARD:

- **TO UNDERSTAND AND EXPRESS YOUR FEELINGS ABOUT HAVING AN ILLNESS THAT IS CAUSING DEMENTIA?**

YES/NO

- **TO TELL YOUR FAMILY AND CIRCLE OF FRIENDS?**

YES/NO

If the answer is yes to any of the previous questions, you may want to write down what it is that you are finding hard. You can use your list to help you when talking about your situation with family and friends. This list can also serve as a reminder of the questions you might want to address when contacting the Alzheimer Society of B.C.

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
- subscribing to *Insight*—a bulletin by and for people with dementia from the Alzheimer Society of B.C.
- visiting a website where people with dementia chat, such as:

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 “Articles and Books written by DASNI People” section, you will find essays and talks by persons with dementia.

