

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

—J. W. Anthony*

2

* 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.

2

HEARING THE DIAGNOSIS

IN THIS SECTION 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 five common reactions to hearing bad news. These reactions can be thought of as phases which can be experienced and re-experienced in any order. You might only experience one or some of these phases. 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. Anger and Frustration

You may feel angry that this is happening to you and ask “Why me?”. 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.

4. Despondency and Sadness

Many people 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. In fact, 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.

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 you live with these intense reactions and emotions depends on your 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.

How to Tell Someone

Once you have decided who you are going to tell, the following points can make the actual telling a little easier for you.

- Plan for the conversation by deciding what information you are comfortable sharing before you talk to the person.
“I have some news that might be difficult to hear...”
- Offer to talk now or later
- Share only the information you want to share, for example you can say...
“I don’t want to get into details, but wanted you to know...”
- Remember, others have the right to react in whatever way they need or want to react
- Be honest

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. So you might consider telling Gail and Emily about your diagnosis first.

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

		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					

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 N.S., your doctor or nurse or during your next Shaping the Journey session.

Consider:

- contacting the Alzheimer Society of Nova Scotia to join a support group or access education programs (see Section 7)
- visiting a website where people with dementia chat (see Section 7)