



## Disclosing a diagnosis of dementia to friends and family

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Deciding if and when to let friends and family know that you have been diagnosed with dementia can be a difficult decision. When diagnosed with a chronic illness many people fear that others will treat them differently, which can lead to social phobia. However, the most important thing you can do after being diagnosed is to keep on living life to its fullest and change as few things as possible. It is also important to know what to expect and what the future may hold, and, take a realistic approach to emphasizing your abilities while finding support for your disabilities. Here are some important steps to take when deciding to disclose your diagnosis to others:

#### Step 1: Know yourself

It is important to know what your diagnosis means, and what it doesn't mean. You want to be prepared to answer questions asked by family and friends. Therefore, you must educate yourself first. Ask questions of your doctor that you think other people might want to know, such as "How long have I had this problem", or, "What changes do I need to make in my life for safety or life planning", and, "Should I expect to get worse over time? If so, what changes should I expect and over what period of time?" Knowing the answers to these types of questions will better equip you to let friends and family know how they can help support you.

#### Step 2: Know your resources

The Alzheimer's Association is an excellent resource for you to begin to learn more about your disease. Examples of material available include pamphlets such as "Basics of Alzheimer's Disease", "Stages of Alzheimer's", "Treatments for AD", and "Take Care of yourself", "Early-Stage Alzheimer's: If You Have AD, What You Should Know, What You Should Do", and practical guides such as "Money Matters: helping the person with dementia settle financial issues", and many more. You can also print these pamphlets yourself from [www.alz.org](http://www.alz.org) under their publication section.

#### Step Three: Where, When and Who

Only disclose when you are ready and you feel disclosure will be beneficial to you and be able to provide support. Use a strict need to know rule if you find yourself asking the question "Should I tell them". After that, chose a setting and time when you will be able to meet personally and address questions and concerns. Come prepared with information pamphlets, giving you the ability to say, "I brought you some information that I thought might help answer some questions," and by letting them know how they can support you now and in the future.

In summary, take a planned and thoughtful approach to disclosing your diagnosis to friends and family. Consider who will provide you with support and who will cause you distress. By doing this, the fear of disclosure can be replaced with the security of knowing that your friends and family will be there for you when you need them.

## Support information resources

Banner Alzheimer's Institute  
[www.banneralz.org](http://www.banneralz.org)  
(602) 239-6900

Alzheimer's Association  
(National)  
[www.Alz.org](http://www.Alz.org)  
(800) 272-3900

Alzheimer's Association Desert  
Southwest Chapter (Local)  
[www.Alz.org/dsw](http://www.Alz.org/dsw)  
(602) 528-0545

Alzheimer's Disease Education  
and Referral Center  
[www.alzheimers.nia.nih.gov](http://www.alzheimers.nia.nih.gov)  
(800) 438-4380

Lewy Body Dementia Association  
[www.lbda.org](http://www.lbda.org)  
(800) LEWYSOS

Association of Frontotemporal  
Dementias  
[www.ftd-picks.org](http://www.ftd-picks.org)  
(866) 507-7222



## “Ask the Expert”

By Adam Fleisher, MD, MAS  
Associate Director of Brain Imaging

Dear Dr. Fleisher

I am 61-years-old and was recently diagnosed with Alzheimer’s disease. I am still working and enjoy what I do. I am afraid to tell my boss about my diagnosis for fear that I may be fired. At this point I am able to keep up with my responsibilities. What do you suggest I do?

Signed:  
Worried and Working

Dear Worried and Working

Many people with early mild dementia encounter this dilemma; “Who do I need to tell, and how will it affect those relationships”? Having a chronic disease is very personal, and disclosure in the work place is a difficult decision. The most important thing to remember is that you need to learn to live *with* your illness. That includes continuing to do the things you enjoy and have meaning in your life as long as possible, without excuses or using your diagnosis as a crutch.

The general rule I use is the “need to know” rule: If someone else knowing your diagnosis won’t contribute to supporting your quality of life and it is not causing anyone potential harm by not knowing, they don’t need to know. If your memory and thinking problems are not likely to endanger yourself or your co-workers, you are not obli-

gated to disclose your diagnosis to your boss. With that in mind, there are things you can do to maintain your ability to perform your responsibilities if you are insightful and realistic about your limitations. It may be important for you to begin relying on written “to do” lists, “instruction sheets,” or calendars to maintain the level of performance at work that is expected of you. You need to remain flexible, acknowledge your limitations and allow yourself to modify the way you do things to accommodate and compensate for your memory and thinking problems. Be honest with yourself and recognize when you are no longer able to perform your responsibilities at the level that is expected of you. This may be difficult, and disclosing your diagnosis to a co-worker or friend to help you assess this may be necessary. When you believe your work duties are suffering, you need a reduction in work-load, or more time to complete your responsibilities, then it is time to confront your boss. In most cases, accommodations can be made to enable you to continue your work as long as possible. By following these simple guidelines for work and personal relationships, you can learn to live *with* your illness, rather than allowing your fears of what may come interfere with your happiness today.

## Our Mission

*To end Alzheimer’s disease without losing a generation, to set a new standard of care for patients and their families and to forge a model of collaboration in biomedical research.*

## What’s New in the Library

**Alzheimer’s Action Plan: The Expert’s Guide to the Best Diagnosis and Treatment for Memory Problems** (Doraiswamy et al, 2008 ). This book was written to help individuals and families know what steps to take if they suspect Alzheimer’s disease and how to intervene early to maintain the highest quality of life. It also has answers to 40 commonly asked questions about living with Alzheimer’s disease and more.

**Speaking Our Minds: Personal Reflections from Individuals with Alzheimer’s** (Synder, 2000), tells the stories of seven people diagnosed with Alzheimer’s disease. This book provides help to both individuals diagnosed with dementia as well as family and friends to better understand the unique aspects of living with this chronic disease.

### Check it out:

Dementia Advocacy and Support Network International (DASNI) an international group of people with dementia via an Internet-based support network established to: promote respect and dignity for persons with dementia; provide a forum for the exchange of information, encourage support mechanisms such as local groups, counseling groups and Internet linkages, and ; assist people to connect with their local Alzheimer’s Association. Twice-daily Internet chats in a chat room help ease the isolation of dementia and educates participants about living with their diseases. [www.dasninternational.org](http://www.dasninternational.org)

## Beacon Bits

**Upcoming educational opportunities for caregivers:**

**COMPASS for Care Partners** will be held:

- May 5, 1 p.m.-2:30 p.m. Pyle Adult Center, Tempe
- May 14, 10 a.m.-11:30 a.m. BAI 3<sup>rd</sup> floor Conference room
- May 20, 7 p.m.-8:30 p.m. Pyle Adult Center, Tempe

**2009 Arizona Alzheimer’s Consortium Annual Conference** is a free conference on May 29, at Renaissance Glendale Hotel & Spa to learn about the progress in research. Go to [www.azalz.org](http://www.azalz.org) and reference Banner Alzheimer’s Institute or call (480) 440-7177.

### Support groups:

Circle of Friends, May 14, 12:30 p.m.-2 p.m. BAI Library  
NEW Frontotemporal Dementia Support Group, May 11 from 12:30 p.m.-2 p.m. BAI Library  
BAI Explorers – Enjoy a privately guided tour of the **Hall of Flames**, Museum of the History of Fire-fighting, on May 27 (Wednesday) from 10 a.m.-noon. \$3 per person, registration is required and limited.