

DISCLOSING THE DIAGNOSIS

Any time we receive a piece of news, whether heartening or discouraging, we go through a process of deciding with whom and when we will share the information. In the case of good news or relatively impersonal information, these considerations may be minimal. But when the news is a diagnosis of Alzheimer's disease, it is not uncommon to hear individuals weigh their disclosure with a great deal more consideration. A number of questions arise such as: ***"Who do I want to tell?" "Do I tell anyone?" "At what point should I bring this up?" "How will people respond?"***

One of the steps in disclosing a diagnosis is to come to terms with the information in your own mind. Many individuals may doubt the diagnosis or just need a period of time for the news to settle in. Family and friends may also go through periods of denial by ignoring your problems or invalidating your concerns.

However, when the diagnosis is Alzheimer's disease, it is likely that there are a few close family members or friends who have acknowledged that something is happening. While there are no set rules in this process, it is often helpful to share the diagnosis with these trusted individuals. Although the news may be difficult, sometimes everyone feels a bit of relief just to have the problem defined. Disclosing the diagnosis also means that you, your family and your friends may be able to better utilize community or medical resources directed towards the better understanding and treatment of AD.

Some diagnosed individuals see their disclosure in terms of heightened public education and sensitivity training. Diagnosed at 52, Grace feels it is important for the public to be aware of the many faces and dimensions of AD: ***"I tell everybody! It's nothing to be ashamed of. People need to know that we're just like them. The other day, I was in Nordstrom's and I was in line to buy my dress. The cashier was making mistakes and joking, 'Oh no, I must have Alzheimer's!' When I got up to the register, I looked at her and I said, 'I do have Alzheimer's'. I think she was pretty embarrassed that she had joked about it."***

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Public awareness of Alzheimer's disease is invaluablely enhanced by individuals willing to be open about their diagnosis. However, while some people struggle very little with the notion of disguising their condition, others may try to conceal the information longer in order to maintain their own self-concept: ***"I don't care who knows or doesn't know. I don't try to hide it. You make a mistake or something and you try to hide it. I think it's natural. You don't want to appear to be less than you want to be. You want to appear as strong as you could be."***

Sometimes accepting the existence of changes or mistakes in ourselves is one of the most challenging tasks we can face. It can make the process less stressful when we can rely on a few caring or understanding people to see us through the adjustments. Sharing the diagnosis may begin that process: ***"If you know that you are talking with someone who knows something about the disease, who is familiar with it, it's a very different thing. There is a safety net and understanding when you talk with people who understand your condition."***

However, people with AD often express concern about how they will be treated if others know of their diagnosis: ***"Everyone acts like they don't want to get near me because they might get it or catch it too. They don't know what to do. People don't know how to deal with it."***

Many people may be familiar with this woman's experience. Ignorance and uncertainty often breed fear and avoidance. However, sometimes the opposite can be true. One man laughed as he discussed the response of others on board a small cruise ship when he and his wife disclosed his diagnosis: ***"They wouldn't let me out of their sight! I couldn't even go to the bathroom alone without someone trailing after me!"***

Indeed, as public recognition of this disease continues to grow more prominent, many people have a story to relay of a kind stranger offering assistance once the diagnosis of Alzheimer's disease was disclosed. This can be particularly valuable in the circumstances where you are lost or in danger, such as from a car accident or a fall while on a walk.

What is important is to respect your own needs for privacy while also acknowledging the value of allowing selected others to know of your condition. Sometimes you may find that your spouse or family member has shared your diagnosis without your consent. This can lead to mixed feelings—perhaps anger

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that you were not in charge, or maybe relief that it was done for you. Remember that your family will also need their own support in this process and sometimes need to share the diagnosis so that they can receive assistance. In any time of change, most of us want to know that we will be able to find a few caring and listening ears.

Diagnosed at age 70, this woman's words could be equally true for the person with AD or their family member: ***"I've told my friends about AD. They are very quiet. They don't know what to say. I don't know what to say. I think they understand because I'm telling them why it is so hard and the impact that the disease has. They listen. I don't expect them to respond any more than I could have responded two years ago before this happened to me. I don't expect more than to really have an opportunity to say what is going on and to express how I feel about it"***.

You can't always predict how others will respond to your news and sometimes we all just take our chances. While it may be true that some people will shy away when they hear the word "Alzheimer's", it may also be true that new friends may be made as a result of sharing the diagnosis. Who knows? You may just be talking with someone who has just been diagnosed too!

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