

ABOUT YOU... TALKING ABOUT THE DIAGNOSIS

If you have been diagnosed with dementia, this Help Sheet may be useful. It suggests some things to consider when talking about your diagnosis.

Anyone receiving a piece of news, whether good or bad, has to decide who to share the information with and when. In some cases, these decisions may be very straightforward. However, when the news is a diagnosis of dementia it is common for people to spend a lot more time considering who among their family and friends to tell, and when.

Coming to terms with the diagnosis

One of the steps in discussing a diagnosis is to come to terms with the information in your own mind. Many people 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 minimising your concerns.

However, when the diagnosis is dementia, 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, it is often helpful to share the diagnosis with those trusted individuals.

Making the decision to discuss the diagnosis

There are a number of questions you may be considering:

- Who do I tell?
- Do I have to tell anyone?
- How and when should I raise it?
- How will people respond to me after I tell them?

These are all difficult questions and there are no right or wrong answers. It can help to talk to someone outside the family. Your doctor, a social worker or an Alzheimer's Australia counsellor will be able to listen to your views and discuss your options with you.

Family and friends are usually happy to help if you let them know what you need.

Discussing the diagnosis

Although the news may be difficult, sometimes people feel relief just to have the problem identified. Discussing the diagnosis also means that you and your family and friends may be able to use community or medical resources for managing with dementia.

Some people with dementia feel that letting other people know about their disease improves public education and sensitivity about dementia.

"I tell everyone – it's nothing to be ashamed of. People need to know that we're just like them."

Sometimes people are concerned 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 catch it too. They don't know what to do. People don't know how to deal with it."

Some people have mixed feelings about sharing the diagnosis.

“I’ve told my friends about Alzheimer’s disease. 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 the disease has. They listen.”

What is important is to respect your own needs for privacy while also acknowledging the value of allowing selected others to know of your diagnosis. It can be very helpful to rely on a few caring or understanding people to see you through the adjustments.

You can’t always predict how others will respond to your news and while some may shy away when they hear the word dementia or Alzheimer’s, you may also make new friends as a result of sharing the diagnosis.

“If you know 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.”

Sometimes you may find that family members have shared your diagnosis without your consent. This can lead to mixed feelings – perhaps anger that you were not in charge, or maybe relief that it was done for you. 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 people want to know that they will be able to find caring and listening ears.

Based on:

Snyder, L, **Disclosing the diagnosis – who and when to tell**, In Snyder, L, Yale, R, eds., **Perspectives – A Newsletter for Individuals with Alzheimer’s Disease**, 1997: 2 (4): 1-3

FURTHER INFORMATION

Alzheimer’s Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at fightdementia.org.au



Interpreter

For language assistance phone the Translating and Interpreting Service on **131 450**