

DIAGNOSIS: INFORMING THE PERSON WITH DEMENTIA

This Help Sheet discusses the issue of talking to the person with dementia about their diagnosis. It suggests approaches that families may take and provides some practical ways to talk about the diagnosis with the person with dementia.

Whether or not to tell a person with dementia about their diagnosis is likely to be a difficult and emotional issue for all concerned.

Improved diagnostic techniques mean that increasingly dementia is being diagnosed at an early stage of the illness. This means that people with dementia are more likely to be able to understand the implications of the disease than has been the case in the past.

Preparing for the diagnosis

Wherever possible, the person undergoing the assessment for dementia should be allowed to decide if they want to know if the diagnosis is confirmed. In general, if a person is aware that they are going for a diagnosis they will be able to make that choice.

Some doctors will always tell their patient the outcome of the diagnosis, so it is important to discuss this issue prior to proceeding with the diagnosis.

If the person is not in a position to understand the implications of receiving a diagnosis of dementia, you need to make some judgements, based on your understanding of what the person's wishes would be. What would their choices have been if they were able to understand the implications? Have they ever given an indication in the past as to what they would have wanted in this situation?

This is an important and difficult decision to be making on behalf of another person. Talking to family and friends, as well as to the doctor or specialist beforehand may help.

To tell or not to tell?

There are many reasons for telling a person with dementia about their condition:

- It is now widely accepted that people have a right to know any medical information about themselves, if this is not to their detriment
- Many people are already aware that something is wrong. The diagnosis of dementia can come as a relief, as they now know what is causing their problems
- Knowing the diagnosis can help a person understand their situation, and make important plans for the future, particularly about legal and financial matters
- Knowing about the disease allows for an honest and open discussion of the experience of dementia between family and friends
- Access to information, support and new treatments can be accessed when the person knows about their condition

However, there are a number of reasons sometimes given for not sharing the diagnosis with a person with dementia:

- The very nature of the dementia changes the ability to understand and remember information. It can also affect people's abilities to deal with emotional issues. The person may not understand the diagnosis, or may not remember it
- It may be felt that the person will become very distressed by the discussion. Families naturally feel very protective of their relative and wish to spare them the trauma

Remember

It is generally recommended that a person with dementia be told of their diagnosis. However, a person has a right not to know their diagnosis if that is their clear and informed preference.

How to share the diagnosis

Sharing the initial news of the diagnosis may come from any one of a number of people. The doctor or specialist, assessment team or members of the family may talk to the person about the diagnosis either individually or as a group. You might like to consider having someone present at the time of telling to provide extra support.

Planning ahead about the best way to share the diagnosis will make it easier. As individual responses will be different, careful consideration must be given to every individual situation. However, there are some considerations that will be generally helpful when talking with a person about their diagnosis:

- Ensure that the setting is quiet and without competing noise and distractions
- Speak slowly, clearly and directly to the person
- Give one message at a time
- Allow time for the person to absorb the information and to form questions. Information may need to be added later
- Written information about dementia can be helpful to take away and provides a helpful reference. Alzheimer's Australia has information written specifically for people with dementia. In some instances this information is also available in video or audio format. Contact the National Dementia Helpline on **1800 100 500**
- Ensure that someone is available to support the person after being told about the diagnosis

What information to share

As a general guideline a number of things will need to be explained. These will include:

- An explanation as to why the symptoms are occurring
- A discussion of the particular form of dementia, in terms that are appropriate to the person's level of understanding
- Any possible treatment for symptoms
- The specialised services and support programs that are available for people with dementia

Informing a person that they have dementia is a serious matter, which needs to be handled with great sensitivity, calmness and dignity. It can be a very stressful time for everyone.

Based on:

The right to know? Sharing the diagnosis of dementia, by K Fearnley and D Weeks, and *Communicating the diagnosis*, Alzheimer's Society, Canada

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**