

Working with doctors

2.9

CARING FOR SOMEONE WITH DEMENTIA

If someone you are caring for has dementia, over time you will meet many doctors, both general practitioners and medical specialists. This Help Sheet discusses effective ways of working together with doctors to obtain the information and support that you need.

A person diagnosed with dementia will have contact with a number of health professionals, usually over a long period of time. This will most likely include the family doctor, medical specialists, therapists, community nurses and social workers. The degenerative nature of dementia means that families and carers will also have a lot of contact with these health professionals. As the disease progresses these contacts will almost certainly increase. Usually it is the family doctor who provides on-going health care, sometimes for both the person with dementia and the family and carers. This means that the relationship between the doctor, the person with dementia, family and carers is critical.

Where to begin

A useful way to think about working with doctors is to regard the doctors, family members and carers as part of a team, which aims to provide the best possible care for the person with dementia.

Every person brings specific knowledge and skills to the team. Family and carers are usually in the best position to bring detailed information about the needs of the person with dementia and to monitor their well being.

Remember

Doctors cannot talk about their patients without their consent. If the person with dementia tells the doctor that no information is to be given to relatives, the doctor must abide by this. However, information can be provided to the doctor, with the doctor deciding on how that information will be used in treating their patient.

However, most people with dementia want to talk about their condition with someone close to them. This is generally done by talking to the doctor together.

A good doctor for a person with dementia, their family and carers:

- Is a ready source of advice and support
- Listens to you and your opinions
- Explains things in words that you can understand
- Takes time to answer your questions
- Makes you feel comfortable
- Provides the opportunity for you to give information discreetly
- Is respectful of the person with dementia, as well as their family and carers

What to try

Communicating with the doctor

Communication is a two way process. You need to let the doctor know what it is you want from them. If you don't understand what is being said, ask to have it explained in a different way.

Relatives can always talk to the doctor about their concerns and sometimes find it useful to ring or send written information to the doctor before an appointment to fill them in on details they don't feel able to discuss when the person with dementia is present.

You should be able to talk freely to any doctor. Remember that all discussions are confidential.

Getting the information you need

Some people find it helpful to make a list of questions to ask so that they don't forget anything. Others keep a diary of the person's behaviour and use it to explain aspects that are causing concern. Ask the health professional to write down what has been said so that you can look at it later and remind yourself, or take notes yourself.

Contact the National Dementia Helpline on **1800 100 500**

Visit Alzheimer's Australia at **www.alzheimers.org.au**

Keeping track

Many people find that it is helpful to keep a folder or notes about their conversations with doctors and who they spoke to and when. Sometimes it can feel as if you have spoken to so many people that you can't remember the details of what was discussed with whom.

Making time

Make appointments at suitable times of the day. If the early morning or late afternoon is difficult for the person with dementia, avoid these times for appointments. Ask for a longer appointment if you feel you need it. If there are long waiting times when arriving for an appointment and this is difficult, ask if something can be done to reduce the waiting time.

Speak up for yourself

Sometimes it isn't easy to get the information you need. Be prepared to look around until you find a doctor who meets your needs and the needs of the person with dementia. Talking to other families and carers about their experiences may help.

Referrals

Most doctors refer to a range of specialists they use regularly and have close contact with. You can however ask for a referral to the specialist of your choice.

Special needs

There are many doctors and practice staff who speak languages other than English, and understand the needs of different cultures. Contact the Australian Medical Association (AMA) in your State or Territory for information about doctors and specialists who may be able to help.

Remember

If the service provided by a doctor is not meeting the needs of the person with dementia and family and carers, sometimes the best thing is to change doctors.



Further Information

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**.

For further information and to view other Help Sheets visit our website at **www.alzheimers.org.au**