Working with doctors

This help sheet discusses effective ways of working with the doctors and medical specialists involved in the care of a person living with dementia.

A person living with dementia is likely to receive care from a range of medical and health professionals. These may include:

- their doctor
- medical specialists
- allied health professionals (healthcare professionals who help someone maintain quality of life, independence, self-care and mobility)
- community nurses
- social workers.

When someone is diagnosed with dementia, the way they approach living with dementia can vary. Be guided by their wishes.

Some people seek to remain independent for as long as possible. Others may ask for your support to help them manage their symptoms and attend medical appointments.

Some people may be unaware of the support they need, due to changes to memory and thinking caused by dementia.

As a family member or friend, you may find yourself working with healthcare professionals to meet the person’s physical, psychological and social needs.

Where to begin

A useful way to think about working with medical professionals is to regard yourself, the family doctor and members of your family as a team that is aiming to provide the best possible care for the person living with dementia.
Family members and carers can often give doctors detailed information about the needs of the person with dementia, and monitor the person’s wellbeing.

Every person brings specific knowledge and skills to the team, including the person living with dementia.

**Doctor-patient confidentiality**

Doctors cannot talk about patients without their consent. If the person living with dementia tells the doctor that no information is to be given to family or carers, the doctor must abide by this.

However, you can provide information to the person’s doctor, with the doctor deciding on how that information will be used.

Most people living with dementia want to talk about their condition with someone close to them.

**A good doctor:**

- is a ready source of advice and support
- listens to each of you and your opinions
- explains things in words you can understand
- gives you time to speak
- takes time to answer your questions
- helps all of you feel comfortable
- respects all the members of the family
- refers you to medical specialists and health professionals, to build a healthcare team
- can discuss the importance of making plans for future medical care and how to appoint someone to make medical decisions when the person living with dementia is no longer able to.
Making the most of an appointment

If you are attending an appointment, ensure you put the person living with dementia first. Let them talk about their needs and wants.

Attending the person’s appointments means:

• You can listen and take notes when the person living with dementia can’t.

• If you or the person with dementia don’t understand what is being said, you can ask the doctor to explain it in a different way.

The doctor may also ask you about the person’s general health and wellbeing and any changes you have noticed.

Sharing information or concerns

Sometimes sharing information with the doctor about changes in memory, thinking and behaviour in front of a person living with dementia can cause distress and damage relationships.

It is often best done in a separate appointment, or with discretion. Speak to the clinic about the best way to provide information to the person’s doctor.

Tips for your visit

• Involve the person living with dementia as much as possible.

• Book the appointment at a time of day that best suits the person living with dementia.

• Book a long appointment so there is time to discuss things in detail.

• Consider calling ahead to check if the appointment is running on time.

• Prepare a list of the medications, vitamins and supplements the person is taking.

• Keep a record of any changes you have noticed to discuss at the appointment.

• Write a list of questions to ask the doctor with the person living with dementia.

• You can ask for relevant information to take home and review later, such as information about medical conditions, treatments, medications, services and supports.
**Keeping track of health information**

You may be speaking to many people, so it can be helpful to keep a folder or notebook about conversations with doctors and others. You can record who you spoke to and when, and the details of what was discussed.

**Working with the right doctor**

Sometimes it isn’t easy to get the information and support you need. 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.

Be prepared to look around until you find a doctor who meets the needs of the person living with dementia and your needs as well. Talking to other people about their experiences with doctors can help.

**Referrals**

At any time, you or the person living with dementia can ask to see a specialist or ask to be referred back to a specialist.

Most doctors make referrals to specialists they use regularly. If you prefer, you can ask for a referral to the specialist of your choice.

**Language and other cultural needs**

If you feel the person living with dementia would prefer information in another language, there are many doctors and their staff who speak different languages and understand different cultures. Your doctor may be able to assist with a referral.
Additional reading and resources

- Dementia Australia support
  Visit: dementia.org.au/support

- Dementia Australia library service
  Visit: dementia.org.au/library

- Dementia Australia education
  Visit: dementia.org.au/education

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500
For language assistance: 131 450
Visit our website: dementia.org.au