



World Alzheimer's Day
21 September

In perfect partnership

In perfect partnership is the slogan for World Alzheimer's Day™ 2003. The campaign encourages people with dementia and their carers to take an active role in their healthcare by developing a good relationship with their doctor, nurse or specialist – the person they receive their healthcare from.

Causes or contributors to memory problems include:

- Alcohol abuse
- Delirium
- Dementia
- Depression
- Head injury
- Heart or lung disease
- High fever
- Medication
- Poor nutrition
- Thyroid problems
- Tumours

Early symptoms of dementia

- Memory loss affecting daily living
- Difficulty performing familiar tasks
- Difficulty naming common objects
- Getting lost easily, even in familiar places
- Change in mood, behaviour or personality
- Loss of interest in hobbies

Getting a diagnosis

There is no single specific test that can show whether someone has dementia. A diagnosis is made by talking to the person and a close relative or friend to get an understanding of the person's history, as well considering all other possible causes of the symptoms.

Working with your doctor to get better care

Research has shown that people who prepare for their visit to the doctor and play an active role in their treatment receive a higher quality of health care than those who do not.



Worried about your memory? Feeling forgetful or confused?

Many people, including some doctors, believe that becoming more forgetful is just a natural part of getting older. Poor memory is not normal at any age and should be investigated. Although memory and mental speed decline slightly with age, this should not interfere with everyday life. Progressive memory loss may be an early sign of dementia, or may be caused by another condition. When memory loss starts to disrupt everyday life it is time to get help.

Finding out what is wrong is the first step to getting help

If you or someone you care for is experiencing problems with memory, make an appointment to see your doctor. Explain the reason for your visit. Doctors only have a limited amount of time to spend with you. You can help by being prepared for each visit – here are some tips for your first visit:

- Take all your medications (including vitamins, aspirin, etc) to the visit.
- Take a list of past and current medical problems. Have other family members had illnesses that caused memory problems?
- Answer the doctor's questions honestly and to the best of your ability.
- Write a list of symptoms, when they began, and how frequently they occur.
- Be specific. For example, "Last Tuesday, I (my husband) got lost on the way home from the shops."
- Ask the doctor to explain any tests and how long it will take to get a diagnosis.

In perfect partnership with your doctor

Good communication between the doctor, person with dementia and carer is very important but often takes time and effort. Forming a positive, long-term relationship with the doctor is especially important for a chronic condition such as dementia. As dementia progresses, the needs of the person with dementia and their carer will also change, so regular well prepared visits to the doctor will help with getting the best care.

Self-assessment quiz

How active a role do you play in your healthcare?

Score the questions below by

never = 0, sometimes = 1, always = 2

Don't take the score too seriously – it's just a reminder of how to get better care!

How often do you:

- Make a list of symptoms and concerns before your visit to the doctor?
- Ask your doctor questions about your symptoms and concerns?
- Ask your doctor what results and side effects you can expect from medications and treatments?
- Ask your doctor what you need to do next about your illness?
- Make decisions about your care with your doctor?
- Take notes at your doctor's visit?
- Ask your doctor for written information about your medical condition?
- Leave your doctor's appointment with all your questions answered?
- Look for information about your illness on your own, outside of the doctor's office (for example by asking friends, reading books, looking on the internet)
- Bring a relative or friend with you to the doctor's office?
- How well do you know your family's medical history?
not at all = 0, a little = 1, very well = 2

TOTAL SCORE

0-9 = minimally active. Take a more active role in your healthcare by preparing for your visit to the doctor. Do not be afraid to discuss your thoughts and concerns.

10-18 = somewhat active. With a little more preparation, you will get more out of a visit to your doctor.

19 or above = very active. You seem to communicate well with your doctor and probably get the most out of your visits.

About dementia and Alzheimer's disease

- Dementia is a term used to describe various different brain disorders that have in common a loss of thinking function. The most common cause of dementia is Alzheimer's disease, followed by vascular dementia and dementia with Lewy bodies.
- Most causes of dementia are progressive – which means the symptoms will gradually get worse. How fast dementia progresses depends on the individual.
- Dementia is not a normal consequence of ageing, although age is an important risk factor. About 20% of people over the age of 80 develop dementia, which means that 80% do not.

When the diagnosis is Alzheimer's disease or dementia

Getting the most from each follow-up visit to the doctor

Before your visit Keep track of changes in your behaviour and medication (or the person you care for) in a note book, along with any concerns or questions that have arisen since you last visited your doctor.

Before your visit to the doctor, review all the information you have collected since your last visit and write down your top three concerns. Writing down this information means you do not have to worry about remembering it and guarantees that your three concerns will be talked about during your visit. Your concerns may include questions about:

- Changes in symptoms
- General health
- Carer's health
- Help needed

During your visit If you do not understand something, ask questions until you do. Don't be afraid to speak up.

Take notes during the visit. At the end, look over your notes and restate to the doctor what you understood. This gives the doctor a chance to correct any information or repeat something that was missed.

Questions to ask your doctor

- *What does the diagnosis mean?*
- *Can you explain it in a way that I will understand?*
- *Are there any treatments?*
- *What can we expect in the near future and over time?*
- *How often should I come and see you?*
- *Do you have any written material on this disease? If not, who does?*
- *Is there anything that we can change at home to make things easier or safer?*
- *Are there any organisations or community services that can help?*

Remember to schedule your next visit before you leave.

Further help

Receiving a diagnosis of dementia is the first step to planning for treatment and care. Information about dementia and services in your area is available from your Alzheimer association. Visit www.alz.co.uk for the contact details of the Alzheimer association in your country. Alzheimer associations are dedicated to supporting people with dementia and their families and provide:

- Practical and emotional help such as helplines and support groups
- Information
- Advocacy to governments
- Training for carers and professionals
- Services such as respite care

Tips for carers – dealing with doctors

Doctors can be reluctant to discuss the patient's diagnosis with their carer as technically there is a duty of confidentiality between a doctor and the patient. However, when the person who is ill is not able to understand what is happening, doctors usually recognise the need to involve the carer in discussions and decisions. If the doctor is still unwilling to involve the carer, there are a number of things you can do:

- Ask the person you are caring for if you can stay with the person when he or she sees the doctor. If the person consents, then the doctor will probably not refuse
- Talk with other carers as they may have some helpful suggestions
- Try to talk to other health professionals, such as nurses