

Alzheimer's disease and other dementias:

working in partnership with psychiatrists and carers

Introduction

This leaflet is aimed at:

- the carers of people with Alzheimer's disease and other dementias who provide continuing help and support, without payment, to a relative, partner or friend;
- the psychiatrists and members of the mental health team involved in the care and treatment of the person with the disorder.

It suggests ways of improving communication and partnerships when the person has first been diagnosed with Alzheimer's disease or another dementia.

For the carer

About Alzheimer's disease and other dementias

Dementia is a term used to describe brain disorders that have in common loss of brain function. This is usually progressive and eventually severe. There are over 100 different types of dementia. The most common are Alzheimer's disease, vascular dementia and Lewy body dementia.

Dementia is not a normal part of ageing, although it is more common in the elderly.

About 20% of people over the age of 80 develop dementia.

Early changes in the person's behaviour

As a carer you may notice:

- forgetfulness which affects daily living
- problems with common everyday tasks
- problems naming common objects
- getting lost easily, even in familiar places

- changes in mood, behaviour or personality
- loss of interest in hobbies
- loss of interest in hygiene and personal appearance
- anxiety about loss of memory.

Making a diagnosis of dementia

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.

As the carer, you may feel:

- worried that you are losing the person you knew
- scared about admitting that there is a problem
- exhausted by caring and ensuring that the person is safe
- impatient with the person's changed behaviour
- ashamed about complaining or seeking help for fear of betrayal of the person
- worried about the future and possible loss of income and earnings
- worried about the long-term financial responsibilities of caring for someone with a chronic illness.

Tips for carers

In partnership with your doctor and members of the mental health team

Good communication between a doctor, members of the mental health team, a person with dementia and their carer is important, but takes time and effort. Forming a positive, long-term relationship with all the staff and doctors involved in the care of the patient 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. Regular well prepared visits to the doctor will help get the best care for both of you.

The general practitioner does the initial tests before referring the person to a specialist. The specialists that you are likely to come across are:

- Neurologists
- Geriatricians
- General Adult Psychiatrists
- Old Age Psychiatrists
- Nurses or other members of the mental health team.

Questions to ask the doctor

- What does the diagnosis mean?
- Can you explain it in a way that I will understand?
- Are there any treatments?
- Are there other things we can do to help ourselves?
- 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?
- Which health service worker is my main contact for guidance and advice?

Remember to arrange your next visit before you leave.

The following advice may help you prepare for follow-up visits to the doctor

Before your visit:

- Keep track of changes in behaviour and medication in a notebook, along with any concerns or questions since you saw the doctor.

- Look at all the information you have collected since your last visit and write down your top three concerns. This will make sure that you remember to talk about the things that matter. Your concerns may include questions about:

- Changes in symptoms
- Side-effects of medicines
- General health of the patient
- Your own health
- Help needed.§

During your visit:

- If you do not understand something, ask questions. Don't be afraid to speak up.
- Take notes during the visit. At the end, look over your notes and tell your doctor what you understood. This gives your doctor a chance to correct any information or repeat something that was missed.

Further tips for carers when dealing with doctors

Doctors can be reluctant to discuss a person's diagnosis with the carer, as there is a duty of confidentiality between a doctor and the patient. If the person is too ill to understand what is happening, doctors will usually involve the carer in discussions and decisions.

If the doctor is unwilling to involve you as a carer, there are a number of things you can do:

- Ask the person you are caring for if you can stay with them during the visit. If the person agrees, the doctor is less likely to refuse.
- Talk with other carers as they may have some helpful suggestions.
- Try to talk to other members of the mental health team, such as nurses.
- Ring the Alzheimer's Society helpline on 0845 3000 336 or contact other organisations which have helped you before.

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Don't forget to look after yourself as well.

- Share your worries with friends or members of the family.
- Don't bottle your feelings up – there is nothing wrong with a good cry.
- Try to keep in touch with friends – ask them to pop in to see you.
- Go and see your own doctor if you cannot sleep, are exhausted, anxious or depressed.
- Make sure that you find time for yourself and do some simple exercise.

For the professional

As a professional working with people with dementia and their carers, we hope that the following is a helpful guide to good practice.

When doing an assessment, do you?

- Try to see the person with dementia and the carer separately, as well as seeing them together
- Try to see them at home first

Do you allow yourself enough time to?

- Listen, ask, listen
- Obtain a life history
- Leave time for questions and discussion
- Explain how you arrived at the diagnosis
- Talk about the prognosis

In the management of the illness, do you?

- Discuss possible treatments
- Talk about the possible side-effects of drugs
- Spend time asking about the carer's health – physical and emotional
- Discuss how to meet the care needs of both the person with dementia and the carer

Points to remember:

- Everyone needs some respite.
- Make it clear that you will be happy to talk to other members of the family.

- Refer everyone you see to the Alzheimer's Society or other carers support organisations.
- Make it clear that you are always available.
- Give a telephone number where you can be reached for further questions.
- Make sure that there is a named professional person whom the family can contact at any time.
- When you write your letter to the GP, send copies to the carer.
- Try to talk to the GP on the telephone as well as writing.

Further help

Alzheimer's Society

Gordon House, 10 Greencoat Place,
London SW1P 1PH. Tel: 0207 306 0606;
Fax: 0207 306 0808;
www.alzheimers.org.uk

The Society is dedicated to supporting people with dementia and their families and provides:

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

The Dementia Relief Trust

6 Camden High Street, London NW1 0JH
Tel: 0207 874 7210; Fax: 0207 874 7219.

The Trust supports people with dementia and their carers, both in the community and in residential settings, by providing one-to-one support, advice and counselling.

The Princess Royal Trust for Carers

Further information for carers is also available from The Princess Royal Trust for Carers.
142 Minories, London EC3N 1LB.
Tel: 0207 7480 7788; www.carers.org

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This leaflet has been produced as part of a year-long joint campaign between the Royal College of Psychiatrists and The Princess Royal Trust for Carers (2004). One of the aims of the campaign is to show that if all those involved in the care of people with mental health problems or learning disabilities can work together, a trusting partnership can develop between carers, patients and professionals which will be of benefit to all.

The Partners in Care campaign has produced a checklist for carers of people with mental health problems designed to help them get the information they need.

For copies of this leaflet and details of other materials produced by the Partners in Care campaign, contact the External Affairs Department, The Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG.
Tel: 020 7235 2351 exts.131 or 127;
or e-mail: awedderburn@rcpsych.ac.uk or dhart@rcpsych.ac.uk

Further information about the campaign can be downloaded from www.partnersincare.co.uk



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Working together to make a real difference