

# Getting help with caring

for someone with dementia

"It's great to be able to talk to people in the same situation as you and share the load. I can't imagine doing this alone"

Nancy, wife and carer

#### What is dementia?

Dementia is a progressive condition that affects the brain in a variety of ways. There are many kinds of dementia but the most common is Alzheimer's disease. Other kinds of dementia include vascular dementia, Lewy body dementia, frontotemporal dementias (including Pick's disease) and alcohol-related dementias. It is possible to have more than one type of dementia; for example Alzheimer's disease and vascular dementia. What all these diseases have in common is that they damage and kill brain cells, so that the brain cannot work as well as it should.

> Dementia is an umberella term for over 100 different disease symptoms

Alzheimer's disease Vascular dementia Lewy body dementia Korsakoff's syndrome Rarer dementias Progressive non fluent aphasia (PNFA) (ADASIL Parkinson's dementia Posterior cortical atrophy (P(A)

It's possible to have more than one at the same time

In Scotland, it is estimated that around **90,000 people have dementia.** It is most common in older people but can affect people in their 40s or 50s or even younger.

# Getting help with caring for someone with dementia

Caring for someone with dementia can be a demanding task. Dementia is a progressive disease, so over time it is likely that the person will need more and more care.

### Don't try to manage alone

Don't take on all of the responsibility by yourself. You may feel like you can manage alone, but doing too much for another person can damage your own health.

#### Sharing the caring

Family, friends and neighbours can help. You can help them to learn about dementia by arranging for them to be sent some leaflets so that they can help you in your caring role. Just as important is the help you can get from services and benefits provided by the social work department, the Health and Social Care Partnership the Department for Work and Pensions and voluntary organisations. Don't think twice about asking them for help. You have a right to receive help.



#### **Health services**

The doctor (GP) is the first person to contact if you have any concerns. Tell the doctor about any changes in the person's condition, and ask to be referred to a dementia specialist if you're worried. If the doctor asks how you are, don't say 'fine' if you are exhausted or upset. Be honest and explain exactly how you are feeling.

The GP or specialist will advise on whether drug treatments available for Alzheimer's disease might be suitable for the person you care for. At present the treatments will only help some people, and they are not a cure, but research is continuing. You can also ask the GP about these other health services:

- In the first year after diagnosis, you should receive Post Diagnostic Support (PDS) from a named Dementia Link Worker. Your GP or psychiatrist will discuss this with you.
- If you are allocated a community mental health or community psychiatric nurse, they can give practical help and advice on mental health.
- District or community nurses provide some nursing care at home, such as help with continence problems.
- Health visitors advise on general health.
- Allied Health Professionals can help with a wide variety of issues, including falls and difficulties with eating/swallowing.
- Day hospitals provide medical assessment, rehabilitation and occupational therapy.
- Respite care may sometimes be available in hospital for people with advanced dementia.

## Social services

The person with dementia has a right to a community care assessment from the local social work department to work out what his or her needs are and what services would help. Carers also have the right to an assessment of their own needs.

There is no charge for an assessment, but there may be charges for services, depending on the person's income. You can make a referral to the social work department yourself or ask a health professional to do it for you.

Free personal and nursing care is available for everyone in Scotland aged 65 and over who needs it; whether at home, in hospital or in a care home. Free nursing care is available for people of any age.

If you don't agree with the care assessment or are not happy with any of the services being offered, you should speak to the person who has been co-ordinating the assessment and negotiate any changes you may need. If you are still not satisfied, you can make a formal complaint.

Other services that are available for people with dementia include:

- home care services to assist with personal care
- home support services can offer short carer respite by spending time with the person who is living with dementia
- occupational therapists can suggest ways to improve safety, maintain independence and encourage wellbeing.
- Day centres provide activities suitable for people with dementia, and a chance to socialise. In some areas there may also be care available in the evenings and at weekends.
- respite care in a care home may be available to give the family a break.

Other services may be available, such as laundry services and meals on wheels.

There can be a waiting list to be allocated a social worker, depending on the urgency of your needs.

#### Money and legal matters

People with dementia gradually become less able to manage their own affairs. There are a range of benefits that may help you and the person with dementia. You can contact your local Citizens Advice Bureau or the Dementia Helpline on 0808 808 3000 for information, or you can ask your local welfare rights service.



#### Where can I find out more?

Alzheimer Scotland is Scotland's national dementia charity. Our aim is to make sure nobody faces dementia alone. We provide support and information to people with dementia, their carers and families, we campaign for the rights of people with dementia and fund vital dementia research.



Our 24 hour Freephone Dementia Helpline provides information and emotional support to people with dementia, carers, families, friends and professionals.

Our Helpline can give you information about the services we offer in your area and signpost you to other sources of support. You can also find information on our website at **www.alzscot.org** 

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