Younger people with dementia

**Information sheet 440**

There are more than 16,000 younger people with dementia in the UK. However, this number is likely to be an under-estimate, and the true figure may be up to three times higher. Data on the numbers of people with early onset dementia are based on referrals to services, but not all those with early onset dementia seek help in an early stage of the disease. The symptoms of dementia may be similar whatever a person's age, but younger people may have different needs, and their problems often require a different approach.

**Types of dementia in younger people**

'Younger people with dementia' is a term that includes anyone diagnosed with dementia under the age of 65. People also use the terms 'early onset dementia', 'young onset dementia', or 'working age dementia'.

Only around one-third of younger people with dementia have Alzheimer's disease. Other common forms of dementia in younger people are:

- **Vascular dementia**? Occurs when the blood vessels in the brain are deprived of oxygen. This can cause various symptoms, depending on the type of vascular damage. (See Factsheet 402, What is vascular dementia?)

- **Fronto-temporal lobar degeneration (FTLD)**? Includes three clinical presentations: a behavioural form (fronto-temporal dementia) and two language forms (semantic dementia and progressive nonfluent aphasia). The same syndromes have also been known as Pick's disease. This term describes the pathology found in a subgroup of these patients. (See Factsheet 404, What is Fronto-temporal dementia (including Pick's disease)?)

- **Dementia with Lewy bodies**? Caused by the build-up of tiny protein deposits in the brain. Symptoms tend to fluctuate, and people can develop the symptoms of Parkinson's disease and hallucinations. (See Factsheet 403, What is dementia with Lewy bodies?)

- **Alcohol-related brain impairment**? Often called Korsakoff's syndrome, this can occur in people who have regularly consumed a large amount of alcohol. It is caused by a lack of thiamine (vitamin B1) in the body, which affects the brain and other parts of the nervous system. (See Factsheet 438, What is Korsakoff's syndrome?)

- **Rarer forms of dementia**? Include prion disease (for example, Creutzfeldt-Jakob disease (CJD) - see Factsheet 427, What is Creutzfeldt-Jakob disease (CJD)?) or inherited conditions that can cause dementia (such as CADASIL). Around one-fifth of younger people with dementia have a rarer form of the condition. (See Factsheet 442, Rarer causes of dementia.)

People with other conditions, such as Parkinson's disease, multiple sclerosis, Huntington's disease or HIV and AIDS, may also develop dementia as part of their illness (see Factsheet 446, What is HIV-related cognitive impairment). People with Down's syndrome and other learning disabilities can also develop dementia at an early age. (See Factsheet 430, Learning...
disabilities and dementia.

Age as a barrier to care

Most people think of dementia as a condition affecting older people only. However, dementia can affect anyone, at any age. There is little awareness or understanding of people who develop dementia at an early age, and this can make it very difficult for younger people to access adequate support.

There are sometimes significant age-related barriers for younger people trying to get access to dementia services. Many dementia care services have a minimum age requirement of 65, and are not available to younger people. Where services are open to younger users, these may not be appropriate to their needs. Younger people often feel that they are made to ‘fit in’ to a service, rather than the service fitting their needs.

If no specialist services exist, younger people with dementia can find themselves lost between services, none of which will accept responsibility for their care.

Diagnosis

Getting an accurate diagnosis of dementia can take a very long time for younger people, often due to lack of awareness of dementia in people under 65. Medical professionals often misdiagnose younger people as being depressed, or as suffering from the effects of stress.

If a GP decides that specialist assessment is required, there can be confusion over the most appropriate consultant to refer to. Specialists in old age psychiatry are usually responsible for older people with dementia. Specialist diagnostic services, or named consultants for younger people with dementia, tend to be run by neurologists with a special interest in cognitive problems and dementia — however, these are few and far between, due to lack of resources. Someone may be seen by a neurologist, a psychiatrist or an old age psychologist.

This means that the route to diagnosis can be circuitous, and that younger people with dementia can receive very different levels of support from different doctors and professionals.

Specialist services

It is important that younger people with dementia have access to a range of specialist services, even at the time of diagnosis. A small number of areas of the UK have named consultants with responsibility for younger people with dementia. A specialist diagnostic service should help people get access to care more quickly and easily. Alzheimer's Society is campaigning for similar services across the whole of the UK.

Younger people also need specialist services following diagnosis. Even if dementia services accept younger users, the type of care they provide may not be appropriate. The needs of younger people with dementia and their friends and family are not just related to age. In many cases, people's fitness, activity and relationships matter as much as their age and diagnosis. In general, younger people with dementia are more likely to:
Younger people may have different concerns and interests to older people. A service set up for people of a different generation, where activities are planned for older people who are less physically active, is unlikely to meet the needs of younger people. Younger people with dementia require specialist services able to meet their complex needs.

The number of specialist services is growing, as more people come to understand the needs of younger people with dementia. In 1996 there were about 20 services in the UK that offered specialist support, and in 2004 there were over 120. While this figure is encouraging, progress is slow. Provision of services for younger people is variable around the country, and some regions still have few, if any, services.

**Support from Alzheimer's Society**

Because dementia in younger people is comparatively rare, it can be difficult to find other people who understand the situation. The Society can put younger people with dementia, their families or carers in contact with others in their local area, or in similar circumstances.

Many of our local services provide specialist support for younger people with dementia. If they do not, they can usually advise younger people on local services, and direct them to any specialist services that are available.

The Alzheimer's Society website has a dedicated section on younger people with dementia, at alzheimers.org.uk/ypwd. It also hosts an online discussion group called Talking Point, which has a dedicated group for younger people. To join the discussion, go to http://forum.alzheimers.org.uk/

The Society can also provide support and information for younger people with dementia and their carers in a number of areas, including:

- **Work**? Some people with dementia may want to continue working for some time after diagnosis, or they may wish to take early retirement if this is appropriate. Carers may also want to continue working, or may be concerned about giving up work to care full time. We can advise on some aspects of work and finances, but people with dementia and carers might need specialist advice. This should be available from a disability employment adviser at the local Jobcentre Plus, or from the local Citizens Advice Bureau (see 'Useful organisations').

- **Benefits**? Younger people with dementia, and younger carers, need to make sure that they are receiving the benefits to which they are entitled. Contact the Benefit Enquiry Line (see 'Useful organisations') or see Factsheet 413, Benefits.

- **Driving**? Some people with dementia are able to drive safely for some time after their diagnosis, but there will be a point when they will have to stop driving. For many people with dementia, the decision to stop driving can be difficult. See
Children
Younger people with dementia often have dependent children when they are diagnosed. It is important that children understand the condition, how it affects their parent and what changes to expect. Every child is different and will react in their own way. See Factsheet 515, Dementia and children or young people.

Support for people with non-Alzheimer's dementias

Dementia can occur as a symptom of a number of conditions, including Down's syndrome or multiple sclerosis. Many of the relevant voluntary organisations provide good information on dementia, as it affects people with these conditions. In addition, Alzheimer's Society supports all people with dementia, whatever their age or diagnosis. See Factsheet 430, Learning disabilities and dementia, or contact BILD (see 'Useful organisations').

For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/localinfo
For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

Further reading

New publication Lives interrupted (code 608) reveals the experiences of younger people with dementia and their partners through interviews.

In addition, the following booklets are available for people with dementia (Up to six booklets are free; more than six booklets £1 each).

1501. Managing your money
1502. Keeping safe in your home
1503. Who are all these health professionals?
1504. Driving and dementia
1505. What your diagnosis means for you
1506. Keeping involved and active
1507. Talking to children about your illness

All of these publications can be ordered from Xcalibre on 01753 535 751 or alzheimers@xcalibrefs.co.uk

Useful organisations

Alzheimer's Society

Devon House
58 St Katharine's Way
London E1W 1JX
T 020 7423 3500
0845 3000 336 (helpline open 8.30am-6.30pm weekdays)
E info@alzheimers.org.uk
The UK's leading care and research charity for people with dementia and those who care for them. The helpline provides information, support, guidance and referrals to other appropriate organisations.

**Benefit Enquiry Line (BEL)**

Red Rose House  
Lancaster Road  
Preston PR1 1HB  
T 0800 88 22 00 (free helpline open 8.30am-6.30pm weekdays and 9.00am-1.00pm Saturdays)  
0800 243 544 (textphone)  
E BEL-Customer-Services@dwp.gsi.gov.uk  
W direct.gov.uk/disability-money

National, free telephone advice and information service on benefits for people with disabilities, their carers and representatives. Note that advisers can send out forms and give advice but they have no access to personal records.

**British Institute of Learning Disabilities (BILD)**

Campion House  
Green Street  
Kidderminster DY10 1JL  
T 01562 723 010  
E enquiries@bild.org.uk  
W http://www.bild.org.uk/

Body that works to improve the lives of people with disabilities. Provides a range published and online information.

**Citizens Advice Bureau (CAB)**

Various locations  
W http://www.citizensadvice.org.uk/  
http://www.adviceguide.org.uk/

Your local CAB can provide information and advice in confidence or point you in the right direction. To find your nearest CAB look in the phone book, ask at your local library or look on the citizens advice website (above). Opening times vary.

**CJD Support Network**

PO Box 346
Supports people with prion diseases, including forms of Creutzfeldt-Jakob disease (CJD). Provides a range of information on the various forms of prion disease, and works with professionals to improve the level of care provided for people with these conditions.

**Pick's Disease Support Group**

Carol Jennings - Adviser  
1 Honeybourne Close  
Mount Nod  
Coventry CV5 7GU  
T 08454583208  

Supports people with fronto-temporal dementia and other forms of dementia, including alcohol-related brain impairment. Provides information and advice, publishes a range of booklets, and has a network of local contacts. Also supports professionals involved in the care of people with these forms of dementia.

**Factsheet 440**

Last updated: April 2010  
Last reviewed: October 2008

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