

BBC Radio Shropshire Factsheet

Younger people with dementia

There are over 18,000 people under the age of 65 with dementia in the UK. Although the symptoms of dementia may be similar whatever a person's age, younger people may have different needs and their problems require a different approach.

Types of dementia in younger people

People use the terms 'younger people with dementia', '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**, which occurs when the blood vessels in the brain are deprived of oxygen
- **Fronto-temporal dementia**, including Pick's disease. This is caused by damage to parts of the brain that control behaviour, emotions and language
- **Dementia with Lewy bodies**, which is caused by the build-up of tiny protein deposits in the brain
- **Alcohol-related brain impairment**, which is often called **Korsakoff's syndrome** and 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 nervous system
- Rarer forms of dementia such as **prion disease** (eg CJD), or inherited conditions that can cause dementia (eg CADASIL). Around one-fifth of younger people with dementia have a rarer form of the condition.

People with other conditions, such as Parkinson's disease, multiple sclerosis or Huntington's disease, may also develop dementia as part of their illness. People with Down's syndrome and other learning disabilities can also develop dementia at an early age.

Care

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. Even if services are open to younger users, they 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, but there is no such specialty for younger people. There are very few specialist diagnostic services or named consultants for younger people with dementia. Old age psychiatrists, neurologists, and adult psychiatrists all receive referrals for younger people. This means that in one area, 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. Shropshire is lucky enough to have a named consultant with responsibility for younger people with dementia. A specialist diagnostic service should help people get access to care more quickly and easily. The Alzheimer's Society is campaigning for similar services in all areas.

Younger people also need specialist services after 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 carers 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:

- Be in work at the time of diagnosis
- Have dependent children or family
- Be more physically fit and active
- Have heavy financial commitments, such as a mortgage
- Have a rarer form of dementia.

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 and less physically active people, 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.

The Alzheimer's Society maintains a database of services that provide specialist support to younger people with dementia and their families.

For more information, go to www.alzheimers.org.uk/ypwd or contact the Alzheimer's Helpline.

For more information on services for younger people with dementia, see the Alzheimer's Society's booklet *Younger people with dementia: A guide to service development and provision*.

Support from the Alzheimer's Society

In Shropshire

Alzheimer's Society
The Roy Fletcher Centre
12 – 17 Cross Hill
SHREWSBURY
SY1 1JE

For specialist information regarding Shropshire's 'Younger People with Dementia' service please call:

Anne Johnson

For Shropshire:
Sara or Julie
Telephone: 01743 341800

Telephone: 01743 492175

For Telford and Wrekin:
Claire
Telephone: 01952 822177

Email address: moffice@salz.org.uk

In Shropshire, the Alzheimer's Society provides specialist support for younger people with dementia.

The Society can also put younger people with dementia, their families or carers in contact with others in the area. Because dementia in younger people is comparatively rare, it can be difficult to find other people who understand the situation. The Alzheimer's Society's website has a dedicated section on younger people with dementia. Go to:

www.alzheimers.org.uk/ypwd. The website also hosts an online discussion group called Talking Point, which has a dedicated group for younger people. To join the discussion, go to www.alzheimers.org.uk/talkingpoint/discuss.

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. The Society 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.

Benefits: Younger people with dementia and younger carers should ensure that they are receiving the benefits to which they are entitled. The Society's information sheet *Benefits* may be helpful.

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: the Alzheimer's Society's Living with Dementia factsheet *Will I still be able to drive?* may be helpful.

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. The Society's carer's advice sheet *Explaining to Children* and its factsheet for children, *Understanding Dementia*, may be helpful.

[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, the Alzheimer's Society supports all people with dementia, whatever their age or diagnosis.

Useful organisations

Pick's Disease Support Group
8 Brooksby Close
Oadby
Leicester LE2 5AB
Telephone 0845 458 3208
Website www.pdsg.org.uk

The Pick's Disease Support Group supports people with fronto-temporal dementia and other forms of dementia, including alcohol-related brain impairment. It provides information and advice, publishes a range of booklets, and has a network of local contacts. It also supports professionals involved in the care of people with these forms of dementia.

CJD Support Network
Gillian Turner
PO Box 346
Market Drayton
Shropshire TF9 4WN
Helpline 01630 673 993
Email: minfo@cjdsupport.net
Website: www.cjdsupport.net

The CJD Support Network supports people with prion diseases, including forms of Creutzfeldt-Jakob disease (CJD). It 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.

Alzheimer's Society's information officer for younger people with dementia

Gordon House
10 Greencoat Place
London SW1P 1PH
Telephone 020 7306 0834
Email mypwd@alzheimers.org.uk

The Alzheimer's Society website also has a dedicated section for younger people with dementia. Go to www.alzheimers.org.uk/ypwd

The following information sheets are available from the Alzheimer's Society:

- What is vascular dementia?
- What is fronto-temporal dementia (including Pick's disease)?
- What is dementia with Lewy bodies?
- What is Korsakoff's syndrome?
- What is Creutzfeldt-Jakob disease (CJD)?
- Learning disabilities and dementia
- Rarer causes of dementia.

Further reading

The Alzheimer's Society can provide a list of further reading on request.

Please contact the librarian at the Alzheimer's Society national office on 020 7306 0606 or email library@alzheimers.org.uk

Alzheimer's Society
Gordon House
10 Greencoat Place
London
SW1P 1PH

Telephone: 020 7306 0606.
Fax: 020 7306 0808.
Email: minfo@alzheimers.org.uk.
Website: www.alzheimers.org.uk/ypwd.