

An Introduction to Young Onset Dementia



A meeting of the [Posterior Cortical Atrophy](#) support group.

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What is young onset dementia?

People with symptom onset **before the age of 65** are described as having young onset dementia. There are more than **64,000 people with young onset dementia** in the UK [1]. Younger people with dementia are much **less likely to have memory problems**. Instead, problems with **language, vision and behaviour or personality change** may be the first symptoms.

Causes of young onset dementia

People with young onset dementia are more likely to be diagnosed with **rarer forms of dementia**, for example, behavioural variant frontotemporal dementia, primary progressive aphasia or posterior cortical atrophy [PCA]. They are also **more likely to suffer from a genetically inherited form** of the disease.

[1] <http://www.alzheimersresearchuk.org/dementia-statistics/>

Key issues

People who are diagnosed with young onset dementia are typically **in paid employment**, have young or teenage **children living at home**, are **physically fit and healthy**, and have significant financial and other commitments, such as mortgages or caring for an older relative.

Of particular concern is the **lack of age-specific and disease-relevant provision** of care for people with young onset dementia. Whilst pockets of excellent practice do exist, there is a general acceptance that **needs are not routinely met by existing services**. With the incidence of dementia set to rise across all ages it is vital that the needs of younger people with dementia are recognised and addressed. This can be through **greater awareness** leading to more **timely diagnosis**, and providing **information and support** that is relevant to their circumstances.



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MYRTLE ELLIS FUND
supporting rare dementia



Frontotemporal Dementia Support Group
(formerly Pick's Disease Support Group)

FTD SUPPORT GROUP
FTDSG

Key Terminology

Dementia is a general term, meaning **progressive impairment in two or more aspects of thinking** (e.g. memory, behavior, decision making) that **affects everyday life**.

Different forms of dementia are named according to what is seen under the microscope (e.g. [Alzheimer's disease](#), [vascular dementia](#)), **the part of the brain affected** (e.g. [Posterior Cortical Atrophy](#), [Frontotemporal Dementia](#)) or **the aspect of cognition affected** (e.g. [primary progressive aphasia](#)).

Support groups for young onset dementia

People with young onset dementia often have very different symptoms; and therefore require [specialist support groups](#). For example, some patient groups may need advice and support for dealing with a difficulty in spoken language, whilst others may require support in dealing with impulsive or rash behaviour. Importantly, these groups allow patients and carers to **connect with others in similar situations**; exchanging experiences and **building essential social support**.

We have a number of [support groups](#) for people with different types of young onset dementia. The first four are funded by the Myrtle Ellis Fund, the fifth by the Frontotemporal Dementia Support Group. Click on each logo on the right for a link to each support group's website. These groups hold meetings in London and more recently regional support groups have been started.



Magnetic resonance imaging can be used to scan the brain, giving information about structure and function, and how these can be affected at the earliest stages of dementia.

Research into young onset dementia

At the Dementia Research Centre (part of the UCL Institute of Neurology) we carry out [research into these various forms of young onset dementia](#). This research allows us to better understand the diseases and therefore give better information to patients and their carers, and improve diagnosis.

Our research involves asking participants to do tests of thinking skills such as memory and language, have brain scans, and undergo detailed neurological assessments. We also test new markers of disease including cerebrospinal fluid examination and brain scans that can show amyloid (one of the proteins deposited in Alzheimer's pathology) in the brain.

Genetically inherited forms of dementia allow the very earliest changes to be observed. New therapeutic trials (e.g. [DIAN-TU](#)) aim to assess whether treatments can be given before the first symptoms develop, with the aim of preventing or delaying onset of symptoms. Research is being encouraged by initiatives such as ['Join dementia research'](#) which matches up people who would like to take part in research with suitable studies and scientists.

Links for further information

UCL support groups

Alzheimer's Society

Alzheimer's Research UK

Queen Square Dementia Biomedical Research Unit

Join Dementia Research

www.ucl.ac.uk/drc/support-groups

www.alzheimers.org.uk/

www.alzheimersresearchuk.org/

www.ucl.ac.uk/bru

www.joindementiaresearch.nihr.ac.uk/