

Younger onset dementia

This help sheet is about younger onset dementia. It emphasises the importance of seeking a diagnosis and describes some of the impacts living with younger onset dementia can have on a person, their family and carers.

- Younger onset dementia is the term used to describe any form of dementia diagnosed in someone under the age of 65.
- Dementia in younger people is much less common than dementia occurring after the age of 65.
- Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease.
- Dementia can affect thinking, memory and behaviour. Brain function is affected enough to interfere with someone's normal social or working life.
- No two people experience dementia in the same way.
- People often lead active and fulfilling lives for many years after their diagnosis.

Seeking a diagnosis is important

It is essential to speak with a doctor when symptoms first appear. If you feel comfortable, take a relative or friend with you.

Diagnosis in a younger person may take some time, because doctors must eliminate other possible causes of symptoms. A complete medical and psychological assessment may identify a treatable condition, or it may confirm the presence of dementia.

If the symptoms are caused by dementia, there is early access to support, information and any available medication.

Diagnosing dementia

Currently there is no single test to diagnose dementia. A diagnosis is made after careful clinical consultation.

The assessment might include:

- a detailed medical history
- a physical examination (to assess senses and movement)
- blood and urine tests
- a psychiatric assessment (to assess symptoms for other treatable disorders or symptoms connected with dementia)
- Neuropsychological tests (to assess retained abilities and specific problems such as comprehension, insight and judgement, memory and thinking)
- brain scans
- other tests, including X-ray and electrocardiogram.

Impacts of younger onset dementia

Younger onset dementia presents unique social, emotional, financial and support challenges, because the dementia appears at a life stage when someone is likely to be more physically and socially active.

When diagnosed the person may be:

- in full-time employment
- actively raising a family
- financially responsible for their family
- physically strong and healthy.

These factors should be considered when seeking or accessing support services.

Change in lifestyle

The sense of loss for the person with younger onset dementia and their family can be enormous.

Dementia can affect your ability to work. Unplanned loss of income can have a major impact on the family. This can be made worse by the loss of self-esteem that comes if employment ceases, and the loss of a purpose in life.

Dementia can affect a person's ability to complete daily activities and routines. This impacts independence and wellbeing.

Long-term plans may no longer be viable, such as travel, retirement or time spent with children or grandchildren.

Change in family dynamics

Partners may take on extra family roles, such as caring for the person with dementia while also raising children and managing finances. This may lead to reducing work hours or giving up work altogether. These can be significant changes.

Children are likely to have strong feelings about dementia and what impact it may have on them. They may feel angry, resentful and withdrawn. Some young people may have problems talking with their parents because they don't want to worry them or are afraid of making them sad, or of being an extra burden. They may prefer to talk to people their own age or to a counsellor.

Change in social connections

Other people's attitudes can be challenging. It can be hard for family and friends to accept that a younger person can have dementia, particularly when no obvious physical changes can be seen. It can lead to losing touch with family, friends and hobbies previous enjoyed.

Seeking support

Dementia is progressive. Symptoms often begin slowly and gradually worsen over time.

There is no known cure for dementia. There are healthcare professionals, medications and other therapies that can help with some symptoms and support you to look after your health and wellbeing.

Support is vital for people living with younger onset dementia. The help of families, friends and carers can make a positive difference to managing the condition and living well.

Additional reading and resources

- Younger onset dementia information hub
Visit: yod.dementia.org.au
- Dementia Australia library service
Visit: dementia.org.au/library
- Dementia Australia support
Visit: dementia.org.au/support
- Dementia Australia education programs
Visit: dementia.org.au/education

Further information

Dementia Australia offers support, information, education and counselling.

National Dementia Helpline: 1800 100 500

For language assistance: 131 450

Visit our website: dementia.org.au