What is younger onset dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease.

Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person’s normal social or working life. The hallmark of dementia is the inability to carry out everyday activities as a consequence of diminished cognitive ability.

Younger onset dementia is a term used to describe the onset of symptoms of dementia before the age of 65. There are many causes of younger onset dementia, with the most common causes being Alzheimer's disease, stroke and frontotemporal dementia. Based on research evidence, there are more than 25,000 people in Australia who have younger onset dementia.

“Ａ Key Worker is invaluable. I could never have got so much help without her.”

Ashton – living with younger onset dementia

For further information and enquiries please contact:

National Dementia Helpline
1800 100 500
For language assistance call 131 450
dementia.org.au

Younger Onset Dementia
Key Worker Program

Dementia Australia is the charity for people living with dementia, their families and carers. As the peak body it provides information, support services, education and advocacy.

Dementia Australia is a registered NDIS provider.

The Younger Onset Dementia Key Worker Program is funded by the Australian Government and the National Disability Insurance Scheme (NDIS).

The National Dementia Helpline is funded by the Australian Government

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About the program

Dementia Australia launched the national Younger Onset Dementia Key Worker Program in 2013 to provide individualised support and services to improve the quality of life for people with younger onset dementia, their families and carers. This program is being funded by the Australian Government.

What is a Key Worker?

A Younger Onset Dementia Key Worker is the primary point of contact for a person with younger onset dementia, their carers and families to provide individualised information, support, counselling, advice, service planning and accessing the National Disability Insurance Scheme (NDIS).

The Key Worker assists people with younger onset dementia to locate and link into the service and support options appropriate for their individual needs. The principle underpinning the key worker model of service delivery is consumer directed care, which means individual control and choice over the type of services a person can receive.

In addition, the Key Worker will work with mainstream health and service providers to improve coordination of supports across agencies and ensure that the needs of people with younger onset dementia are being met in the local community.

Some examples of what Key Workers might do include:

- Working with a person with younger onset dementia and/or their family or carer to set goals and create care plans based on their individual needs.
- Assisting people to navigate and understand the available services through the NDIS.
- Assisting organisations to understand dementia and modify their services to meet the needs of people with younger onset dementia and their families.

How can a Key Worker support you?

Methods of support by a Key Worker may include meeting face-to-face, contact via telephone, email or via video, such as Skype®.

Who is eligible for the Younger Onset Dementia Key Worker Program?

People with a diagnosis of younger onset dementia, their partners, primary carers, family members, and service providers are eligible to access the Younger Onset Dementia Key Worker Program.

To be eligible for the program, a person must be under the age of 65 when they first make contact with the service or enter the program. This applies to a person who has been diagnosed with younger onset dementia (all forms of), or may include a person with symptoms of dementia that have not yet been diagnosed, depending on a needs and capacity assessment.

How do I access a Key Worker?

The best way to access the Younger Onset Dementia Key Worker Program is to call the National Dementia Helpline on 1800 100 500. Alternatively, talk to your GP, specialist or other health or community service professional about being referred to Dementia Australia.