

What people with young onset dementia and their family members tell us about their experience of being diagnosed

“My GP was really thorough and listened to me and my wife explain our concerns. He sent me for tests to exclude a brain tumour, but eventually I was sent to my local memory clinic where I was diagnosed with Alzheimer’s disease at 55.”

“I wish our GP had asked how I found living with my husband. I would have said that I’ve lived with him for over 40 years and now the whole experience of being with him is completely different.”

“Ten years before being diagnosed I began to worry, as friends were finding it increasingly difficult to be with him. Two years before, I was noticing lack of empathy and his understanding of daily chores. If only he had been diagnosed sooner we could have accessed the support we so desperately needed.”

“My dad was a financial adviser and then he couldn’t count the change in his pocket. He was treated for depression for six months before we saw a memory specialist.”



The Young Dementia Network is a community of people living with young onset dementia, their family and friends, and professionals who work in health and social care.

We are working together to improve services for all people affected by young onset dementia.

To find out more about the Young Dementia Network and to join, visit youngdementianetwork.org

The Young Dementia Network is hosted by Dementia UK. Anyone with a question or concern about dementia can call the Admiral Nurse Dementia Helpline on **0800 888 6678**.

Diagnosing dementia in younger people

A decision-making guide for GPs

Endorsed by



Royal College of
General Practitioners

This diagnostic guide is designed to support GPs to identify the most common signs and symptoms of young onset and rarer forms of dementia.

It aims to help GPs identify ‘red flags’ which suggest referral to specialist diagnostic services may be required.



Why we created this guide

- Over 70,800¹ people are living with young onset dementia in the UK
- It takes on average 4.4 years for younger people to be diagnosed², twice as long as older people, delaying access to treatment and support
- Many younger people are misdiagnosed with depression, anxiety, stress, marital issues, menopause or personality disorder

Picking up the critical signs of these diagnoses is not always easy, and at times is based on your, or your patients' gut feeling that something is amiss. Family and friends may play an invaluable role in helping you to understand the full range of symptoms your patient might be experiencing.

To find out more information about young onset dementia:
dementiauk.org/young-onset-dementia

References

- 1 Prevalence of all cause young onset dementia and time lived with dementia. Carter J et al 2022
- 2 NeedVD Study, 2010, C Bakker et al
- 3 Alzheimer's Society website

