

## 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 an online community for everyone living with, working with or interested in young onset dementia.

It campaigns to bring about improvements for people living with young onset dementia now and in the future.

To find out more about the Network and to join, visit [youngdementianetwork.org](https://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 70,000<sup>1</sup> people are living with young onset dementia in the UK
- It takes on average 4.4 years for younger people to be diagnosed<sup>2</sup>, 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](http://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 NeedYD Study, 2010, C Bakker et al
- 3 Alzheimer's Society website

### Is this your patient?

Not feeling cognitively as 'sharp' as in the past?

Are family and friends expressing concern?

Are they aged 40–65? People under 40 can have dementia but this is less common and is more likely to have a familial link.

As their GP, your gut reaction is something isn't right and needs further investigation.

### Has the patient, family, colleagues or friends identified a progressive decline in any of these areas?

#### Language and communication

Word-finding difficulty, effortful hesitant speech, vague or over-detailed speech, not getting to the point.

#### Neuropsychiatric presentations

Later than usual onset of first episode psychosis (abnormal beliefs or perceptions).

#### Social and skills

Reduction in literacy, numeracy or other skills, struggling at work, more isolated, general decline in ability levels.

#### Movement disorder

Clumsiness, changes in gait, balance or mobility, falls, fixed eye movements, involuntary movement, signs of Parkinson's disease.

#### Visual and spatial

Repeated visits to opticians and finding nothing wrong, mis-reaching for objects in clear view, difficulty perceiving depth and volume, words appear to float off the page, misperceive the obvious, problems judging distances when driving.

#### Behavioural and personality changes

Changes in personality, reduced empathy, reduced emotional engagement, irrational and out of character decision-making, lack of insight, aggression, apathy, obsessive behaviour, decline in personal care.

#### Memory and disorientation

Forgetting conversations and future plans, repetitiveness, getting lost in familiar places, less sure of the day or date, forgetting names and faces.

### Take a detailed history

Consider asking the family member what their overall experience of living with the patient is like. This type of open question will prompt discussion which could uncover relevant symptoms. The patient or family may want to consider keeping a diary to take to future appointments.

Does your patient have a learning disability? People with learning disabilities are at increased risk of developing dementia. A third of people living with Down's syndrome will develop dementia in their 50s<sup>3</sup> Refer on to learning disability services.

Is there a family history of young onset or atypical dementia?

Consider using a brief cognitive assessment tool but bear in mind that passing these tests should not exclude the patient from being referred for memory assessment. The results should be used to supplement the detailed history only.

Exclude reversible causes – carry out medication review, physical examination, blood dementia screen, consider alcohol misuse or sleep disorder. For more information refer to NICE Dementia Guidance.

Exclude or treat depression or anxiety – you may consider using PHQ-9 for depression or GAD-7 for anxiety.

**Refer to young onset dementia specialist in local diagnostic service or memory assessment clinic**