

## What patients and their family 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 dementia and social care. We are working together to improve services for all people affected by young onset dementia.

The Young Dementia Network is guided by a collaborative group and managed by YoungDementia UK.

To find out more about the people and organisations involved, and to join, visit

[www.youngdementiauk.org/young-dementia-network](http://www.youngdementiauk.org/young-dementia-network)

Pilot version 04/2017

## Diagnosing dementia in younger people

A decision-making tool for GPs

This pilot diagnostic aid is designed to support GPs in understanding young onset and rarer forms of dementia.

It is also a tool to identify 'red flags' which suggest referral to specialist diagnostic services may be required.



# Why we created this guide

- Between 42,000 and 65,000 people are living with young onset dementia in the UK.
- In 2016 it took twice as long for younger people to be diagnosed as it did older people, delaying access to treatment and support.
- Many 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.

We welcome your feedback on using this tool.

Please complete our survey online at [www.youngdementiauk.org/gp-decision-making-tool](http://www.youngdementiauk.org/gp-decision-making-tool)

## Is this your patient?

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

Are family and friends expressing concern but the patient doesn't recognise these concerns?

Are they aged 40–65? People under 40 can have dementia but this is less common. See website below for further guidance.

As their GP, you feel that something isn't right and further investigation is required?

## Have 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 skills, struggling at work, more isolated.

### Movement disorder

Clumsiness, changes in gait, falls (particularly backwards), 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, obsessive behaviour.

### 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?  
See website below for further guidance.

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

Consider using a brief cognitive instrument (refer to NICE Dementia Guidance) 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, 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 PQ9.

## Refer to young onset dementia specialist in local diagnostic service

For more information, for you and your patient, please visit [www.youngdementiauk.org/gp-decision-making-tool](http://www.youngdementiauk.org/gp-decision-making-tool)