

## Des, Ken and Wendy share their experience of the early signs of young onset dementia

“Deep down, I knew there was something wrong with me, but I just couldn’t put my finger on what exactly. People had difficulty taking my symptoms seriously. It was such a relief when the diagnosis validated so many of my experiences. At last I recognised myself.” – **Des**

“My wife was diagnosed with anxiety and depression and given early retirement from work. One of the main issues she had was remembering dates. She also lost her ability to do hobbies like baking, tapestry and singing. She was finally diagnosed with frontotemporal dementia nine years later.” – **Ken**

“A diagnosis puts an end to all the uncertainty of why you’re experiencing strange symptoms and allows you to put things in place while you can.” – **Wendy**

**This checklist has been created in collaboration with Des O’Sullivan who is living young onset Lewy body dementia.**

**This checklist has been endorsed by:**

**ALZHEIMER’S RESEARCH UK** FOR A CURE



**Rare Dementia Support**  
Advice Community Learning

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 young onset dementia can call the Admiral Nurse Dementia Helpline on **0800 888 6678**.

## Signs and symptoms of young onset dementia

### A personal checklist

This checklist is intended to help a person to be aware of the most common signs and symptoms of young onset dementia and record changes and symptoms they may be experiencing.

The information can be used to provide prompts for a conversation with a GP or health professional.

**It is not intended to be a diagnostic tool.**



# Why we created this checklist

- **Over 70,000\* people are living with young onset dementia in the UK**
- **The early signs of dementia vary from person to person but often affect more than memory, particularly in a younger person**
- **Symptoms of young onset dementia can mirror, and be confused with, those of other conditions such as depression, menopause and stress. Dementia may be overlooked in a younger person**

We have created this personal checklist to make people more aware of some of the common signs and symptoms of young onset dementia.

It should be used to record the symptoms a person experiences and help to guide a conversation with a GP or health professional.

It is not intended to be a diagnostic tool.

To find out more information about young onset dementia:

[dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

\* Prevalence of all cause young onset dementia and time lived with dementia. Carter J et al 2022

**Do you recognise any of the following signs relating to memory, communication, vision, balance, behaviour, personality and movement?**

**Tick all of the signs that apply to you.**

- Are you aged 40–65?
- Are you experiencing brain fog or not feeling as mentally ‘sharp’?
- Are your family and friends expressing concern that something is not quite right?
- Do you feel in yourself that something isn’t right?
- Do you sometimes find it difficult to find the right words?
- Is your speech more hesitant, vague or over-detailed? Do you find it difficult to ‘get to the point’ when you are speaking?
- Have you developed problems with reading, managing money, figures or other mental skills?
- Are you finding it harder to keep up with work demands than you used to?
- Have you noticed an increase in falls or clumsiness; a change in how you walk or your balance, mobility, or steadiness?
- Are you making repeated visits to your optician and finding nothing wrong?

- Do you mis-reach for objects or fail to find things that are right in front of you?
- Do you have difficulty judging depth and volume?
- Do words appear to float off the page? Do you sometimes get double or blurred vision?
- Do you have difficulty judging distances when driving?
- Have you noticed changes in your behaviour or personality?
- Do you forget conversations and future plans?
- Do you repeat yourself without realising it?
- Do you get lost in familiar places?
- Are you sometimes uncertain of the day or date?
- Do you forget names and faces?

**If you have noticed some, or all, of these symptoms over a period of time, it does not mean you have dementia, but if you have concerns then please visit your GP.**

**Take this checklist with you as a prompt to help you detail what you are experiencing. We also recommend keeping a daily diary to give further examples.**