

## 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 in 2007. 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 in 2016 - 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 well with dementia.**

This checklist has been endorsed by



### Young Dementia Network

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 a collaboration, initiated 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)

## 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.**



Young Dementia Network

# Why we created this checklist

- **Over 42,000\* 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

[www.youngdementiauk.org](http://www.youngdementiauk.org)  
[network@youngdementiauk.org](mailto:network@youngdementiauk.org)

\* Dementia UK, 2nd edition 2014, Alzheimer's Society

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.

- |  |  |
|--|--|
| <input type="checkbox"/> Are you aged 40–65?   | <input type="checkbox"/> Are you making repeated visits to your optician and finding nothing wrong?            |
| <input type="checkbox"/> Are you feeling less mentally 'sharp' than in the past?   | <input type="checkbox"/> Do you mis-reach for objects or fail to find things that are right in front of you?   |
| <input type="checkbox"/> Are your family and friends expressing concern that something is not quite right?   | <input type="checkbox"/> Do you have difficulty judging depth and volume?                                      |
| <input type="checkbox"/> Do you feel in yourself that something isn't right?   | <input type="checkbox"/> Do words appear to float off the page? Do you sometimes get double or blurred vision? |
| <input type="checkbox"/> Do you sometimes find it difficult to find the right words?   | <input type="checkbox"/> Do you have difficulty judging distances when driving?                                |
| <input type="checkbox"/> Is your speech more hesitant, vague or over-detailed? Do you find it difficult to 'get to the point' when you are speaking? | <input type="checkbox"/> Have you noticed changes in your behaviour or personality?                            |
| <input type="checkbox"/> Have you developed problems with reading, managing money, figures or other mental skills?                                   | <input type="checkbox"/> Do you forget conversations and future plans?   |
| <input type="checkbox"/> Are you finding it harder to keep up with work demands than you used to?  | <input type="checkbox"/> Do you repeat yourself without realising it?  |
| <input type="checkbox"/> Do you feel an increase in clumsiness; a change in how you walk or your balance, mobility, or steadiness?                   | <input type="checkbox"/> Do you get lost in familiar places?   |
|  | <input type="checkbox"/> Are you sometimes uncertain of the day or date?                                       |
|  | <input type="checkbox"/> 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 journal to give further examples.