

## 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 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 our website [youngdementianetwork.org](http://youngdementianetwork.org)

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

Information about young onset dementia can be located on the Dementia UK website. [dementiauk.org/young-onset-dementia](http://dementiauk.org/young-onset-dementia)

## Useful resources

### Personal checklist

For anyone who has signs and symptoms of young onset dementia  
[youngdementianetwork.org/personal-checklist](http://youngdementianetwork.org/personal-checklist)

### Diagnostic clinic leaflet

Provides sources of support and information following a diagnosis of young onset dementia  
[youngdementianetwork.org/diagnostic-clinic-leaflet](http://youngdementianetwork.org/diagnostic-clinic-leaflet)

### Young onset ID cards

ID cards designed for people living with young onset dementia and their family members to use when out and about  
[youngdementianetwork.org/young-onset-id](http://youngdementianetwork.org/young-onset-id)

## References

A Delphi study of people living with young onset dementia and their families **Receiving a diagnosis of young onset dementia: evidence-based statements to inform best practice (2020)** O'Malley M, Parkes J, Stamou V, LaFontaine J, Oyeboode J, Carter J



## Improving the experience of diagnosis

## Checklist for individuals and families

We have created this checklist to help improve the diagnostic experience for people who may have young onset dementia and their families.

## Why we created this checklist

**Better recognition of key symptoms, reducing diagnostic errors and identifying the emotional needs arising from the diagnostic process are important. Each aspect helps improve the individual and their family's personal experience, reduces delays and promotes engagement with services after diagnosis.**

This checklist details recommendations from The Angela Project, the largest study of young onset dementia carried out in the UK. The researchers asked younger people living with dementia and their families 'what mattered most' when receiving a diagnosis and asked international clinical professionals and service providers about barriers and facilitators to providing good services.

Younger people with dementia and their families said that paying attention to the clinic environment, the style of communication and the clinicians' use of language make a difference to their experience of receiving a diagnosis.

In this checklist, we set out the experience you should expect during the process of assessment and diagnosis.

## What should you expect during the diagnosis process

### Appointment times

- You and your family members should be given enough notice between the appointment letter/ notification and the appointment
- Where possible your appointments should be made at a time convenient for you
- Family members should be contacted if the healthcare professionals are unable to contact the person being assessed for young onset dementia

### Home visits

- Where appropriate you should be able to request appointments to be at home

### In person meetings

- If you prefer, you can request face to face appointments

### Considerate use of language

- The language used by the health care professionals should be compassionate, empathic, respectful, and sensitive

### Time to ask questions

- You and your family members should be given the opportunity and enough time to ask questions

### Calm approach

- The discussions should be calm and the clinicians easy to talk to

### Private discussions

- You and your family members should be given the opportunity to speak separately with the clinicians

### Private location

- Assessments should be conducted in a quiet and private room

### Explanation of assessments

- You and your family members should be provided with written information about the investigations and assessments

### Explanation of diagnosis

- If you wish, you can be given information about the diagnosis and prognosis

### Single point of contact

- You should be able to have an identified person as a single point of contact throughout the whole diagnostic process

### Medical terminology

- Medical terms and what they mean should be explained to you in a simplified manner

### Follow up letter

- You and your family members should be sent a follow up letter with information about your diagnosis and follow up advice

### What to do if you think the level of care has not met these standards

If you do not feel you have received the level of care you would expect, you should discuss this with the healthcare professional during the diagnosis process.

If you still have concerns, refer to your local Patient Advice and Liaison Service who can offer you confidential advice and support.