

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

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

Useful resources

Supporting implementation of the NICE guideline for people with young onset dementia

Designed to support implementation of the NICE dementia guideline, this resource sets out the tailored approach needed at key stages of diagnosis and support.

youngdementianetwork.org/resources/nice-guideline

Young onset dementia pathway

Diagnosis and support for people with young onset and their families

youngdementianetwork.org/resources/young-onset-pathway

Diagnostic clinic leaflet

Provides sources of support and information following a diagnosis of young onset dementia

youngdementianetwork.org/resources/diagnostic-clinic-leaflet

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 healthcare professionals

We have created this checklist to encourage an open collaborative approach with individuals who may have young onset dementia and their families to improve their experience of diagnosis.

Why we created this checklist

Better recognition of key symptoms, reducing diagnostic errors and identifying the emotional needs arising during the diagnostic process are important in helping improve the individual's and their family's experience, reducing delays and promoting engagement with services after diagnosis.

Younger people with dementia and their families say that paying attention to the clinic environment, the style of communication and the clinicians' use of language makes a difference to their personal experience. Working in partnership with openness in discussion and a willingness to review helps support autonomy and a positive outlook.

This checklist details recommendations from The Angela Project, a three-year research study. 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 in the largest study of young onset dementia carried out in the UK.

Assessment and diagnosis process

Appointment times

- Ensure there is enough notice between the appointment letter/notification and the appointment
- Where possible make the appointment at a time convenient for working adults
- If unable to get in touch with the person being assessed for young onset dementia, contact family members

Home visits

- Individuals should be seen at home for assessments and support where appropriate and possible

In person meetings

- If preferred by the person with young onset and their family, consider face to face appointments where possible

Considerate use of language

- Use compassionate, empathic, respectful and sensitive language when providing information about a diagnosis

Time to ask questions

- Give the person with young onset dementia and their family enough opportunities to ask questions

Calm approach

- Be calm, approachable and easy to talk to

Private discussions

- Offer opportunities for the person with young onset dementia and their family members/supporters to speak separately about any issues they wish to discuss

Private location

- Assessments should be conducted in a quiet and private room

Explanation of assessments

- Provide written information about investigations

Avoid repetition

- Avoid the same questions being asked repeatedly

Single point of contacts

- Try to have an identified professional as a single point of contact throughout the whole diagnostic process

Diagnosis

Use lay terms

- Explain medical terms and what they mean in a simplified manner

Explanation of diagnosis

- Provide information about their diagnosis and prognosis if requested

Reaction to diagnosis

- Receiving a diagnosis is a lot to take in for the person with young onset dementia and their family. Ensure there is a point of contact provided for follow up questions

Follow up letter

- Provide the person with young onset dementia and their family members/supporters with a letter detailing the diagnosis and follow up advice