



Naming it

Getting to grips with a diagnosis of young onset dementia is, without doubt, difficult. Experiencing unexplained symptoms affecting everyday life is so much harder. Younger people with dementia and their families have a particularly tough time before their condition is 'named'.

One of the Network's key aims is to improve the experience of diagnosis for younger people and their families. Our campaign to achieve this is being planned. So we welcome the Alzheimer's Society's recent Dementia Action Week focus on diagnosis and are keen to collaborate and support the actions that follow.

An accurate and timely diagnosis can open up the opportunity to be informed, supported and adapt to a changed life. Huge efforts are needed to ensure the range of help is there for everyone. It is not yet, but the start is to 'name it'.

Tessa Gutteridge
Chair, Young Dementia Network

Communi-tea webinar - the importance of support and connection for family carers

22nd June 2022

2.30-3.30pm



On Wednesday 22nd June 2022, we will continue our series of young onset dementia webinars with Communi-tea – the importance of support and connection for family carers of people with young onset dementia.

The webinar will be led by tide (together in dementia everyday) and will focus on the support that is available for family

members and carers and how connection to others affected by young onset dementia helps them to feel less alone.

Sarah Merriman, Head of Delivery, tide, will be our lead panellist. She will be joined by members of tide's young onset dementia carers focus group who will share their experiences and talk about how being part of the group has helped them.

[Sign up here](#)

Watch a recording of our May webinar, Connectivi-tea [here](#).

Catch up with past webinars on our [website](#).



Member showcase: Dementia Forward

The Young Dementia Network now has over 4500 members and this month we'd like to shine a light on one of our member organisations.

Dementia Forward, based in North Yorkshire, supports over 300 people living with young onset dementia. Its progressive approach combines Dementia Care Coordinators, Dementia Support Advisors, a helpline, activity and peer support



Learn more about young onset dementia

The Dementia UK Summer School returns for a second time this July. It provides a free opportunity for health and social care professionals to improve their practice and knowledge of dementia care.

The three-day virtual online programme features a session on Lewy body dementia on Wednesday 6th July 2022, 2-4pm, as well as a focus on young onset dementia on

groups, volunteering and befriending opportunities.

[Find out more](#)

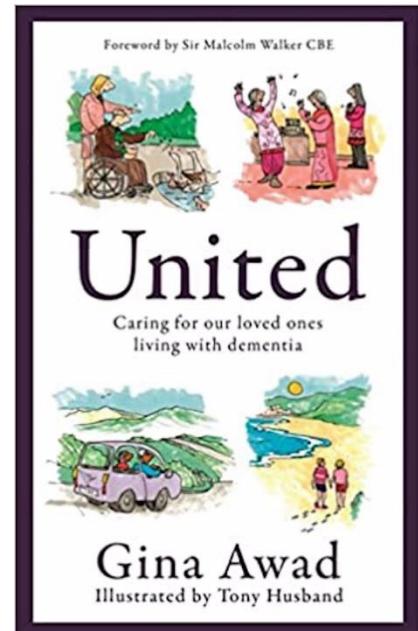
Thursday 7th July 2022, 10.30am-12pm.

[Book your place](#)

Book giveaway: United by Gina Awad

Written by Gina Awad and beautifully illustrated by Tony Husband, United is a moving new book that captures the real life tales of people living with dementia, including two stories of people with young onset, as told by their family members.

Launching on 2nd June 2022, the book can be pre-ordered [here](#). We have a free copy to give away. If you would like to be entered into the book giveaway, please [email us](#) with your full name and postal address by Tuesday 31st May 2022. The winner will be drawn at random.



Young onset dementia and dementia related news

Rare Dementia Support and The National Brain Appeal have launched a book of poems called There is so much I could say. Created by people living with rarer forms of dementia and their carers, the book is available for sale [here](#).

The MindCare Young Onset Dementia Activists group (YODA) in Bromley has launched a short film offering practical advice on tackling loneliness for anyone affected by young onset dementia. It also shares their group members' views of the YODA group and service. Watch the film [here](#).

Living well with dementia in Greater Manchester is an event taking place on Monday 6th June 2022. The event will be led entirely by people with lived experience and will reflect on the adverse impact of the Covid-19 pandemic on people affected by dementia and refocus on recovery looking forward. Find out more [here](#).

Young onset dementia research round-up

Involvement opportunities

Alzheimer's Disease International would like to hear your experience of post-diagnosis for the World Alzheimer's Report 2022. Their survey is open until 6th June 2022 to people living with young onset dementia, family members and carers and clinicians and healthcare professionals. Find out more or take part [here](#).

Recently published research

The use of digital technologies by people with mild-to-moderate dementia during the COVID-19 pandemic: A positive technology perspective

Catherine Talbot, Pam Briggs. Read [here](#).

Age of symptom onset and longitudinal course of sporadic Alzheimer's disease, frontotemporal dementia, and vascular dementia: A systematic review and meta-analysis

Sally Day, Stefanie Roberts, Nathalie H Launder, Anita M Y Goh, Brian Draper, Alex Bahar-Fuchs, Samantha M Loi, Kate Laver, Adrienne Withall and Monica Cations. Read [here](#).

For current dementia research opportunities, click [here](#), or visit the [Join Dementia Research](#) website.

To view a collection of research focusing on the most pertinent subjects relating to young onset dementia, click [here](#).

Resource showcase: Diagnostic experience checklists



Our new checklists have been created using the recommendations from The Angela Project, the largest study of young onset dementia carried out in the UK. They are designed to help improve the experience of diagnosis.

The diagnosis experience checklist for individuals and families is for use by people who may have young onset dementia and their family members.

It sets out the experience a person should expect during the process of assessment and diagnosis and what to do if the level of care does not meet these expectations.

The other checklist is for healthcare professionals who are involved in the process of assessing and diagnosing dementia to help them to better understand the needs of younger people going through this process.

[Download our checklists here](#)

[Visit our website](#)

[Join the Network](#)

[Our resources](#)



Contact us

Young Dementia Network
7th Floor
One Aldgate
London EC3N 1RE

email: youngdementianetwork@dementiauk.org

The Young Dementia Network is hosted by Dementia UK.

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