



Cheers to collaboration

Our Young Dementia Network members believe that by working together we can and will make a difference to the lives of people affected by young onset dementia. Sharing what works and what doesn't plus learning from personal and professional expertise accelerates the positive progress we can make.

So we were delighted to accept an invitation from the renowned [Young Onset Dementia Knowledge Centre](#) in the Netherlands to collaborate. March 2024 sees our first [joint webinar](#) and builds on our theme of improving the diagnosis experience. For all of you who requested topics, thank you. We have a long list so look out for more dates!

Whether you are newly involved with young onset dementia or have a long-term interest, the Netherlands Centre has a wealth of research and publications for you.

Tessa Gutteridge
Chair, Young Dementia Network

PS Our next Network News is in January 2024. Is it too early to wish you 'Season's greetings'? I expect it is so I will send my best wishes to you instead.

Young onset dementia webinars

Improving the experience of diagnosis

Mind the gap – navigating young onset dementia from pre-diagnosis onwards

Our first webinar of 2024 will be led by Jill Quinn, CEO of Dementia Forward, North Yorkshire. Jill and her colleagues will share the learning from Dementia Forward's work with families at all stages of young onset dementia from before diagnosis and beyond.

 **Wednesday 21st February 2024**

 **12.30-1.30pm**

[Register today](#)

Tailored memory clinic care; using the diagnosis process as a starting point for person-centred young onset dementia support

Our webinar in March 2024 will be led by Dr Janne Papma, Associate Professor and Head of the Alzheimer Centre Erasmus Medical Centre in Rotterdam. She will address support for people with young onset dementia and their family members during the diagnostic pathway at the memory clinic, and how the gap from diagnosis to post-diagnostic care and support could be bridged.

 **Tuesday 12th March 2024**

 **12-1pm**

[Register today](#)

Our **November 2023 webinar** featured the North Thames Genomic Medicine Service Alliance project to embed genomic testing in memory clinics and national initiatives to promote equitable access to genomic investigations for younger people undergoing dementia assessment.

It also included an interview with Jessica Harrison whose father has an inherited form of Alzheimer's disease and has herself undergone genetic testing.

[Watch here](#)

Join Dementia UK's Fix the funding campaign

Dementia UK is campaigning to improve the NHS continuing healthcare process in England so that more people with young onset dementia, and other forms of dementia, can access vital funding to pay for their care.

NHS continuing healthcare funding can be a lifeline for many people with long-term and complex health needs in England because it covers costs like home carers or care home fees. But many people with dementia, particularly those who are younger, are missing out on vital care funding because the assessment process is failing to meet their needs.

Dementia UK's 'Fix the funding' campaign is calling on the Government to urgently review the NHS continuing healthcare process to make care fairer for people with dementia.

[Find out more here](#)

Rachel's continuing healthcare story



Rachel's late dad was 54 when he was diagnosed with young onset vascular dementia following a stroke.

As his needs progressed, Rachel applied for NHS continuing healthcare funding so that he could be moved into a specialist dementia care home.

Although they received the funding, Rachel found the process long, scary and impersonal. She said: "The assessment was really overwhelming. I was scared that if I said something wrong, we wouldn't get the funding. The process needs to consider the unique needs of people living with dementia, particularly those who are younger."

[Read Rachel's story here](#)

Young onset dementia and dementia-related news

Online event to mark the end of the IDEAL dementia research programme

The IDEAL dementia research programme concludes at the end of the year after a decade of research. 'Evidence and resources from 10 years of the IDEAL programme' is a free online event taking place from 10am-12pm on Wednesday 6th December 2023 to discuss the evidence which has come out of the study and to launch free resources. All are welcome. Click [here](#) to book via Eventbrite.

Younger People with Dementia Christmas Carol Concert

The Younger People with Dementia Christmas Carol Concert takes place from 7pm-9.30pm on Tuesday 12th December 2023 at the Whitty Theatre, Wokingham. The Younger People with Dementia Choirs will perform. Tickets cost £10 per person, with a Christmas drink and mince pie included. Book your ticket [here](#).

New IDEAL resource for people with mild-to-moderate dementia

'My Life Questionnaire' is a scientifically validated and fully co-produced measure of living well for people with mild-to-moderate dementia. This easy-to-use questionnaire can help to identify areas where changes could be made to improve quality of life. Click [here](#) to view.

Dementia Carers Count — young onset dementia carer clinic

Dementia Carers Count held a Facebook Live carer clinic event focusing on young onset dementia led by Sue Hinds, Head of Service with Dr Raja Badrakalimuthu, consultant old age psychiatrist, and Chris Maddocks, who was diagnosed with young onset dementia in 2016 and has also cared for a friend with dementia. Watch a recording of the clinic [here](#).

Greengross A4D Global Arts for Brain Health Changemakers — Young Onset Conversation

The Greengross A4D Global Arts for Brain Health Changemakers — Young Onset Conversation took place online on Thursday 26th October 2023 and featured several high-profile people who are living with young onset dementia. You can watch a recording of the event [here](#). Their next webinar takes place on Thursday 18th January 2024 from 4-5.30pm; chaired by Professor Sebastian Crutch of University College London, it will focus on rare dementias. Click [here](#) for more information.

New young onset dementia services launch in Haverfordwest, Pembrokeshire

A day service for people living with young onset dementia has launched in Haverfordwest, Pembrokeshire. It runs on Wednesdays from 10am-3pm and offers opportunities for people with a diagnosis, or who are awaiting a dementia diagnosis, to engage in age-appropriate activities. There is also a peer support group for carers called 'Together,' where family members and friends can meet others and access advice and information. For more information email pembsyoungonsetdementia@outlook.com

'The Nature of Forgetting' – a play that asks what is left when memory is gone

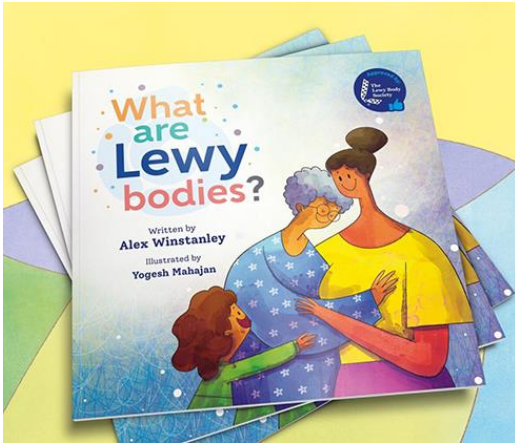
'The Nature of Forgetting' is a thought-provoking and moving play about Tom, who is living with young onset dementia. It begins as he is preparing for his 55th birthday party and past memories come flooding back. The play will tour the UK from Wednesday 31st January to Wednesday 6th March 2024 visiting The Crucible, Sheffield; The Lighthouse, Poole; The Playhouse, Norwich; The Arts Centre, Aberystwyth; The Royal Welsh College of Music and Drama, Cardiff; and The Storyhouse, Chester. For tickets and information click [here](#).

'Everywhere' – a play about a boy whose mum has young onset dementia

'Everywhere' is a play by Nicky Bellinger that tells the story of a boy whose mum is diagnosed with young onset Alzheimer's disease just before his 13th birthday, and how he and his parents cope with this life-changing news. Written for young people to perform, it also serves as a resource for all ages to support a greater understanding of the condition. Created in collaboration between Nicky, Derby Theatre attendees, Universal Services for Carers in Derby Carers Café and members of Derby Theatre's Youth Theatre, you can

download the script [here](#).

The Lewy Body Society's new website and resources



The Lewy Body Society has launched a new [website](#) and [podcast](#) to help to communicate more clearly about the condition with people living with dementia, families and carers, researchers and health and care professionals. The website also features [case studies](#) and a dedicated section for [carers](#).

You can also purchase a book for children aged five to 11 that explains Lewy body dementia in a fun and accessible way. '[What are Lewy bodies?](#)' by Alex

Winstanley is available through the Lewy Body Society's website.

[Visit the website here](#)

Shining a light on how dementia impacts children



In 2024, Dementia UK will be launching its largest ever awareness campaign, and as part of this wants to shine a light on how dementia impacts children.

The charity is inviting children to share their experiences of dementia in drawings, paintings and pictures which express how dementia affects them. Dementia UK will exhibit these pictures in a public space and share them on its social media channels.

[Enter or find out more here](#)

Young onset dementia research

Involvement opportunities

Dementia at Younger Ages-Mapping Ideal Care (DYNAMIC)

The DYNAMIC research study focuses on social care provision for people with young onset dementia and how it may be improved. They are currently looking for people in England who are living with young onset dementia, their family members or friends to interview for the study. Register your interest via [this form](#) or click [here](#) for more information.

Are you a healthcare professional with experience of posterior cortical atrophy, primary progressive aphasia or behavioural-variant frontotemporal dementia

The Rare Dementia Support Impact Study aims to produce tailored online interventions for individuals living with rarer dementias. They are currently recruiting healthcare professionals who are familiar with the lived experience of people affected by PCA, PPA or bvFTD to complete a short online survey. Click [here](#) to take part.

Does the way a person experiences hope change with age following a dementia diagnosis?

Abby Morris, a trainee clinical psychologist at the University of Hull, is looking for people living with dementia to complete four short online questionnaires about hope, mood, optimism and wellbeing. You can find out more about the study and sign up to take part [here](#).

Published research

Prevalence, timing, and network localisation of emergent visual creativity in frontotemporal dementia

Adit Friedberg, Lorenzo Pasquini, Ryan Diggs et al

Read the paper in full [here](#).

Ethnic disparities in the uptake of anti-dementia medication in young and late-onset dementia

Clarissa Giebel, Monica Cations, Brian Draper, Aravind Komuravelli

Read the paper in full [here](#).

Situating support for people living with rarer forms of dementia

Mary Pat Sullivan, Paul M Camic, Emma Harding, Joshua Stott, Gill Windle, Emilie V Brotherhood, Adetola Grillo and Sebastian J Crutch

Read the paper in full [here](#).

Resource showcase: Personal checklist



Our Personal checklist is a resource that is for anyone who has concerns about signs and symptoms of young onset dementia.

It is not a diagnostic tool but is intended to be used as a checklist which individuals can use to record symptoms they, or a family member or friend, may be experiencing and then, if necessary, use it to aid a discussion with their GP.

The Personal checklist is endorsed by Alzheimer's Research UK, Dementia UK and Rare Dementia Support.

[**Find out more here**](#)

[**Visit our website**](#)

[**Join the Network**](#)

[**Our resources**](#)



Contact us

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The Young Dementia Network is hosted by Dementia UK.

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