



A small step in the right direction

This week NHS England start publishing the number of people formally diagnosed with dementia before the age of 65 years, irrespective of their current age.

Why does that matter? People living with young onset dementia and their families need good support and information from the time symptoms develop in mid-life through to the end of their lives which may be in their late 60s or older. They continue living with the different impact of young onset dementia throughout. There is no cut off at age 65.

So it is important that all who have responsibility for making sure that people with young onset dementia can draw on support understand the real demand and accurate data helps.

That's why it matters.

Tessa Gutteridge
Chair, Young Dementia Network

Young onset dementia webinars

Increasing awareness and opportunities for genetic testing

Memory clinics and the NHS England Genomic Medicine Service



Wednesday 15th November 2023



12.30-1.30pm

Dr Nick Bass, Honorary Consultant Psychiatrist, UCL Division of Psychiatry and Tower Hamlets Memory Clinic, will lead our November webinar. He and Jana Mikova, Clinical Nurse Specialist in Genomic Medicine, will explain the

North Thames Genomic Medicine Service Alliance transformation project to embed genomic investigation in mental health service-provided memory clinics.

They will go on to discuss implications and initiatives at the national level to promote easy and equitable access to genomic investigations for younger people undergoing dementia assessment.

[Register today](#)

Watch a recording of our October webinar which featured the Wokingham Memory Clinic and Oxford Centre for Genomic Medicine's multidisciplinary approach to genetic testing for younger people with dementia and their families.

[Watch here](#)

Dementia Forward's Young Onset Dementia Awareness Day



Ten years ago, the North Yorkshire charity Dementia Forward began running an outward-bound service for younger people with dementia in the Harrogate area.

The charity now has a specialist young onset lead, two further outward-bound day services, runs social gatherings for people

across the county and provides young onset dementia education and support from pre-diagnosis to end of life.

It has established an annual Young Onset Dementia Awareness Day, taking place every year on 24th October, to highlight that young onset dementia needs to be recognised in its own right.

[Read more here](#)

Young onset dementia and dementia-related news

Everything you've always wanted to know about dementia (but were afraid to ask) 'take two' event

The Alzheimer's Authors' 'take two' event takes place at 3.30pm (UK time) on Tuesday 24th October 2023 via Zoom. The event will feature Wendy Mitchell, Peter Berry, Jennifer Bute, Michael Ellenbogen and Gerda Saunders who are all living with young onset Alzheimer's disease. Book a place or find out more [here](#).

Greengross A4D Global Arts for Brain Health Young Onset Conversation webinar

The webinar takes place on Thursday 26th October 2023 from 8.30-10am and will be chaired by Young Dementia Network steering group member Jan Oyebode. It will feature several high-profile people who are living with young onset dementia who will discuss how they use creativity to help them maintain skills and live an active life. Tessa Gutteridge will contribute to the Conversation on behalf of the Network. Reserve a place [here](#).

Launch of DEEP's Knowledge is Power England booklet

Knowledge is Power England is a booklet created by DEEP which aims to make life easier for people after a diagnosis of dementia. Full of information, resources, and support, it will be especially helpful for people who are newly diagnosed. DEEP is hosting an online event to launch the booklet on Thursday 26th October 2023 at 2pm. For more information about the booklet and event, click [here](#).

A new reminiscence book for younger people with dementia

'Working all hours' is a new reminiscence book for younger people with dementia created by Younger People with Dementia CIO. They will launch the book at an event on Friday 3rd November 2023 at The Bell Bookshop, Henley-on-Thames, RG9 2BL. You can purchase a copy or find out more about the book [here](#).

Talking Lines – drawings by people affected by rarer forms of dementia

Over the past four years, an interdisciplinary team of artists, social scientists, neuropsychologists, and people living with or affected by rare dementias have been working together to develop a line-drawing methodology to better understand experiences of rare dementia diagnosis and support. The drawings and words of four participants are on display alongside a film at the Drawing Room Library, New Tannery Way, London, SE1 5WS until Sunday 10th

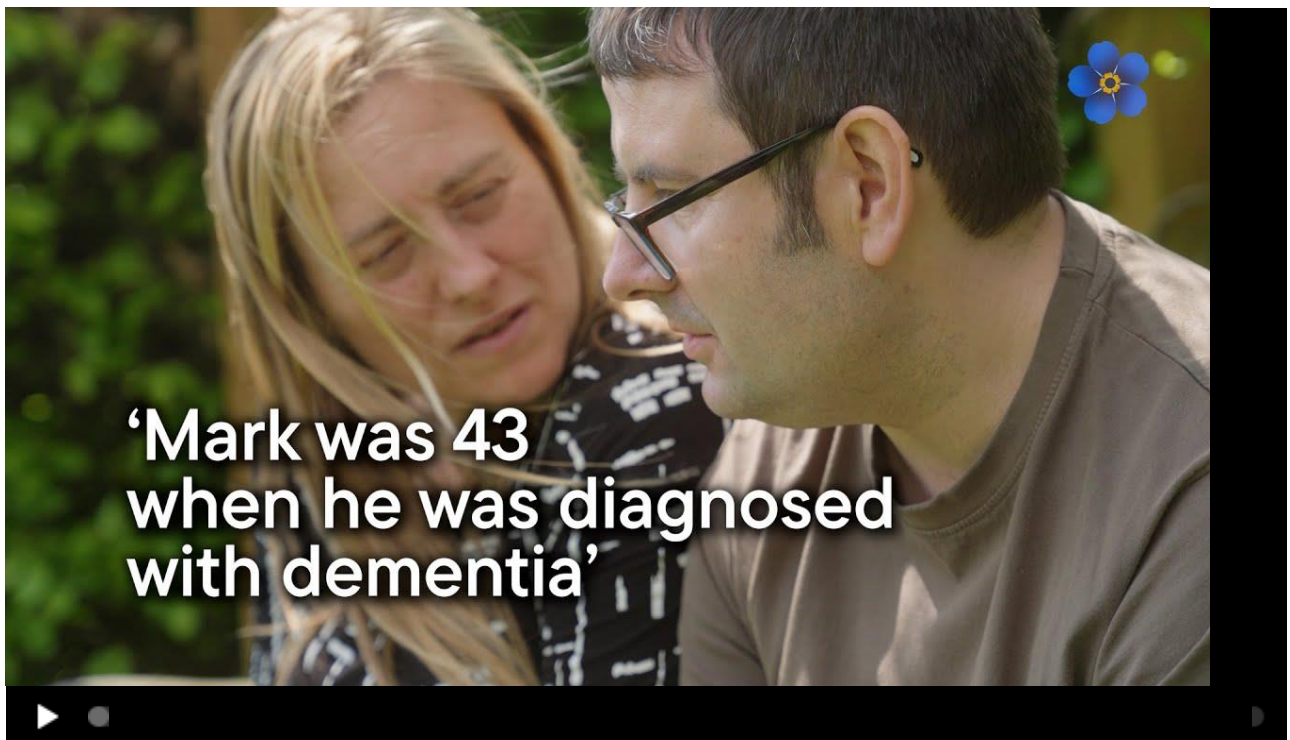
December 2023. Click [here](#) for more information.

First Scottish Dementia Arts Festival and 100/6000 Gathering 2023

The first Scottish Dementia Arts Festival and 100/6000 Gathering 2023 takes place at the Eden Court Theatre, Inverness from Monday 13th to Thursday 16th November 2023. The programme for the two events and information about how to register can be found [here](#).

Challenging assumptions around dementia

'Challenging assumptions around dementia' is a new open access book which aims to support a more person-centred, collaborative approach to dementia research. It presents co-produced dementia research between people with lived experience (many living with young onset dementia), academics and healthcare professionals. Download a copy [here](#).



Alzheimer's Society's new young onset dementia film

The Alzheimer's Society has launched a moving short film featuring Mark, who was diagnosed with frontotemporal dementia in his early forties, his wife Claire and their three-year-old son William.

In the film Claire says, "There's a huge misconception that dementia is all about memory loss and it only happens to old people."

[Watch the film here](#)

Young onset dementia group information

Monthly online young onset dementia carer peer support group

Caring for someone with young onset dementia can be isolating and you may struggle to meet others in a similar situation. Carers' charity tide runs a monthly [online carer peer support group](#) to connect people who understand the unique challenges young onset dementia brings, along with other online support groups. Find out more [here](#).

Young onset dementia thematic group

The Alzheimer's Society's UK-wide Young Onset Dementia Thematic Group brings together people under the age of 65 living with a diagnosis of dementia to discuss their views and lived experience to impact meaningful change. Meetings are held monthly via Zoom. Find out more click [here](#) or email hayleigh.kicks@alzheimers.org.uk

Young onset dementia podcast recommendations

If you enjoy listening to podcasts, we have two excellent ones to recommend.



Dementia UK's Consultant Admiral Nurse for Young Onset Dementia, Jules Knight, joined Jo Beardsworth and Emma Jardine on their 'I didn't sign up for this' podcast where they present a carers' and friends' guide to living with young onset dementia.

Jules discusses dementia specialist Admiral Nurses and the unique challenges young onset dementia brings and offers her top tips. You can listen to the podcast [here](#).

'Well I know now with Pippa Kelly' is a podcast in which Pippa and her guests discuss what their dementia experiences have taught them. Her recent podcast series includes interviews with Wendy Mitchell and Keith Oliver who are both living with young onset dementia. Listen on Apple podcasts [here](#).

Young onset dementia research

Research showcase

Navigating the coronavirus pandemic two years on: experiences of people with dementia from the British IDEAL cohort

Authors: Dawson, E, Collins, R, Pentecost, C and Stapley, S.

Focus of the paper

This paper explored the experiences of people with dementia and their caregivers in England and Wales during the Covid-19 pandemic and how they changed over time.

Participants

The paper focuses on interviews involving nine participants, five of whom had young onset dementia, either before or after the start of the coronavirus vaccination programme in England and Wales.

Findings

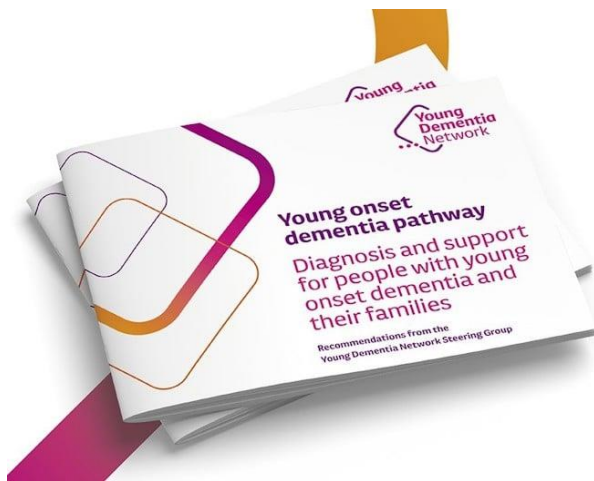
Each individual experienced the pandemic in a unique way; however, all were subject to the same changing restrictions and conditions. Initially, support groups and services were closed and access to healthcare was significantly reduced – this led to declines in health, accelerated losses in cognition and communication skills, isolation and loss of meaningful pastimes.

Although participants demonstrated resilience and a capacity to adapt, it was generally felt that the pandemic negatively affected the ability to 'live well' with dementia. It is critical to learn from the experience to ensure that people are sufficiently and appropriately supported and empowered.

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

Review by Pat Sikes, Emeritus Professor of Qualitative Inquiry, School of Education, University of Sheffield.

Resource showcase: Young onset dementia pathway



From first contact with a GP to end of life care, the 'dementia journey' can be very different for a younger person.

Our Young onset dementia pathway brings together the experience of people affected by young onset dementia and the people who work with and support them to create a set of recommendations about how they should be supported.

These recommendations will guide policy makers, commissioners and practitioners in designing and delivering services. Most importantly, we hope they will empower younger people with dementia and their families to demand the services to meet their needs.

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

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

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

[**Our resources**](#)



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The Young Dementia Network is hosted by Dementia UK.

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