

From policy to personal

We have made sure that young onset dementia is part of the Government's 'Major conditions strategy: call for evidence'. We must hope that dementia features strongly, and that young onset dementia features explicitly. It feels hard to penetrate the opaque systems and decision-making processes for dementia.

So if you, like me, are looking for something enlightening, something real — check out the "I didn't sign up for this" podcast (see below) with Jo and Emma who have personal experience of young onset dementia. I started with their conversation with GP Dr Katherine Hickman as that's the first point of call for our work to improve diagnosis experience. An excellent listen, grounded in the reality of life with young onset dementia.

Meanwhile — a blend of realism, optimism and determination keeps us working together to achieve improvements. And listening to those with personal experience is a vital part of that blend.

Tessa Gutteridge

Chair, Young Dementia Network

Young onset dementia webinars

We have come to the end of our series of six webinars focusing on improving the experience of diagnosis for younger people with suspected dementia and their families.

We will begin a new series of webinars in October 2023. In the meantime you can catch up on recordings of all our webinars on our [website](#) or on [YouTube](#).

Webinar catch-up — young onset dementia nurse-led service, Northamptonshire

Our June webinar was presented by Jenny Kerti, Community Psychiatric Nurse Manager, alongside colleagues from the Younger Persons with Dementia Team in Northamptonshire.

They shared how their unique nurse-led model offers the continuity of support needed and valued by younger people going through the dementia diagnosis experience from GP referral onwards. The webinar also featured a short film where people affected by young onset dementia shared their thoughts and experiences.

[Watch here](#)

"I didn't sign up for this" podcast



Jo Beardsworth and Emma Jardine, whose husbands both have young onset dementia, describe themselves as 'dementia wives'.

They have joined together to create a podcast called "I didn't sign up for this" to provide a platform where they can discuss and raise awareness of young onset dementia and the challenges they face, and help others to not feel alone.

Their podcasts are a mixture of real-life conversations, thoughts and expert input, designed to help others to navigate the unique challenges that come with a dementia diagnosis before old age. Listen to the "I didn't sign up for this" podcast [here](#).

Young onset dementia and dementia-related news

New advice leaflet: supporting children when a parent has young onset dementia

Dementia UK has published a new advice leaflet offering information and tips around supporting children and adolescents when a parent has young onset dementia. Read the

leaflet [here](#).

Creative course for people with young onset dementia launches in Cornwall

A six-week long creative course is launching on Friday 23rd June 2023 for people living with young onset dementia at the Fish Factory Art Space in Penryn, Cornwall. View a poster about the course [here](#), or visit the Fish Factory website [here](#).

Engaging people living with young onset dementia in research: reflections and insights gained from the DEFIN-YD patient and public involvement project

The University of Northampton's Dementia Research and Innovation Centre hosts its summer 2023 'Dementia Digest series' lecture from 12.30-2pm on Tuesday 4th July 2023. The online knowledge exchange event will be led by keynote speakers, with opportunities for the participants to exchange ideas and views in discussion and debate. Find out more [here](#) or register to attend [here](#).

Free online event for health and social care staff

Dementia UK is hosting its free online annual Summer School between Tuesday 4th and Friday 7th July 2023 which aims to improve practice in and knowledge of dementia care. All health and social care staff are invited to attend. The programme includes a session on 'The importance of maintaining social contact' where young onset dementia support groups will be discussed. View the programme and sign up [here](#).

Accredited dementia distance learning courses

The University of Worcester offers three ways in which you can enhance your ability to influence positive change in dementia via its accredited dementia distance learning courses. For more information click [here](#).

Alzheimer's Society 'Barriers to diagnosis' report

In May 2023, the Alzheimer's Society published a report examining the barriers to getting a timely and accurate diagnosis identified by people living with dementia, researchers and clinicians, and recommendations to overcome them. Read the report [here](#).

Member showcase: Emily Ong



Network member Emily Ong lives in Singapore. She is a passionate dementia advocate and is living with young onset dementia.

Peer support for people with dementia is a relatively new concept in Asia and Emily believes the focus is usually on keeping the people with dementia occupied and engaged via activities rather than providing them with a space to empower and support each other.

To offer people with dementia something different, Emily established the online La Kopi peer support group. She shares how and why she set up the group [here](#).

Young onset dementia research round-up

Opportunity for researchers

Professor Dr Paul Camic and Professor Dr Mary Pat Sullivan are inviting contributions from researchers of manuscripts for publication in the International Journal of Environmental Research and Public Health.

They are editing a special issue which will focus on 'Innovations in care and support for people living with young onset or rarer forms of dementia'. Manuscript proposals should be submitted by Sunday 1st October 2023. For more information, click [here](#).

Recently published research

The legalities of managing finances and paying for future care in dementia: a UK-based qualitative study

Clarissa Giebel, Kath Halpin, Lena O'Connell and Joan Carton
Read the paper [here](#).

A three-UK-nation survey on dementia and the cost of living crisis: contributions of gender and ethnicity on struggling to pay for social care

Clarissa Giebel and Bronte Heath
Read the paper [here](#).

"I'd be lost without my smartphone": a qualitative analysis of the use of

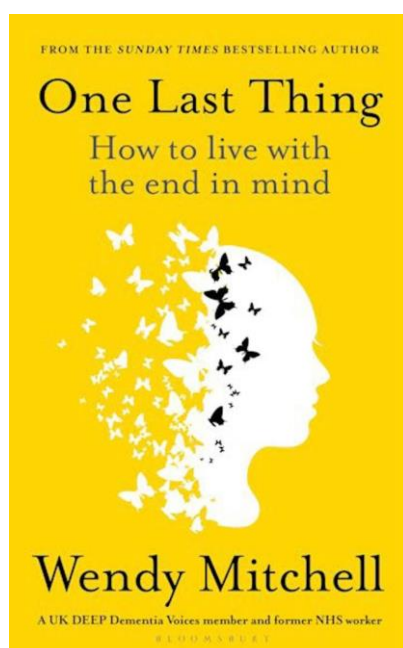
smartphones and tablets by people living with dementia, mild cognitive impairment, and their caregivers

Samantha A Wilson

Read the paper [here](#).

For other current dementia research opportunities visit the Young Dementia Network website [here](#) or visit [Join dementia research](#).

To view a collection of research relating to young onset dementia, click [here](#).



Book giveaway - 'One last thing' by Wendy Mitchell

Bloomsbury Publishing has kindly given us three copies of Wendy Mitchell's latest book, '[One last thing](#),' to give away.

The book, which went on sale yesterday, explores all angles of death: how we can prepare for it, how we talk about it and how we can be empowered to make our own choices.

To be included in the draw, please [email us](#) by Friday 14th July 2023 with your name and postal address.

Resource showcase: Young onset dementia group guidance



Age-appropriate dementia support is lacking in many parts of the UK so we are very keen to encourage people to start up groups that will cater specifically for people aged under 65.

Based on our experience, we have put together guidance which shares suggestions and ideas to help others who are considering starting up groups, either face to face or online.

[**Find out more 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



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