



Greetings dear member

Isolation is experienced by people affected by young onset dementia. Isolation is also experienced by professionals working in the field of young onset dementia. Trying to ease this is a really powerful motivator for the Network. And one way we do this is through learning events.

So, it has been hugely pleasing that our recent Network webinars have attracted hundreds of attendees. The more we learn from each other, the more we connect with each other then the more progress we can make together.

Tessa Gutteridge

Chair, Young Dementia Network

Young onset dementia webinars

Changing perceptions of diagnosis webinar

Our next webinar – Young onset dementia: changing perceptions of diagnosis – will take place at 12.30pm on Wednesday 8th February 2023.

Presented by Dr Susan Mitchell, Head of Policy at Alzheimer's Research UK alongside a panel of experts, the webinar will focus on the preferences of people living with dementia, the shifting political landscape and how advances in research and drug discovery can help the dementia diagnosis pathway evolve.



8th February 2023



12.30-1.30pm

[Sign up here](#)

Young onset dementia and general practice – identifying

symptoms before diagnosis

Our webinar in November featured Professor Marjolein de Vugt and Dr Stevie Hendriks from the Netherlands, who presented the results of a recent study on pre-diagnostic symptoms of young onset dementia.

They were joined by Diana Smith Harris, who cared for her husband with young onset dementia and Dr Sara Humphrey, who offered a General Practitioner's perspective. They shared their views on why it is important to have better awareness of the early symptoms of young onset dementia and the benefits of having a quicker diagnostic process.

[**Watch the webinar here**](#)

Are you interested in shaping the future direction of Alzheimer's Research UK's policy work?



Alzheimer's Research UK will soon be recruiting individuals affected by dementia, either personally or as a family member or friend, to a new Policy Insight and Experience Panel.

Applications from people of all ages, backgrounds and cultures are actively encouraged for this volunteer role.

If you're interested in getting involved, please email Shamma via the link below for further information.

[**Email Shamma**](#)

Young onset dementia and dementia-related news

Younger People with Dementia (Berkshire) Christmas concert

The concert is taking place on Tuesday 6th December 2022 from 7-9.30pm at the Whitty Theatre, Wokingham. Book your ticket to watch YPWD's young onset dementia choir [here](#).

Creative arts taster session, 7th December 2022 in Derby

If you are under 65 and living with dementia, or are a family member, friend or carer of someone with the condition, you are invited to take part in a fun creative arts taster session on Wednesday 7th December 2022 from 2-3.30pm. Find out more [here](#).

Our Dementia Choir Christmas concert

The choir, made famous on Vicky McClure's Our Dementia Choir programmes on BBC One, features a number of people living with young onset dementia. Their Christmas concert is taking place on Monday 12th December 2022 at 7.15pm at the Theatre Royal, Nottingham. Book tickets [here](#).

Rachel Thompson and Chris Maddocks – Lewy body dementia podcast

Chris was diagnosed with dementia six years ago at the age of 60; Rachel is an Admiral Nurse, who specialises in Lewy body dementia. In this podcast they are interviewed by Pippa Kelly and discuss the impact of Lewy body dementia. Listen [here](#).

Dementia Carers Count – Family Carers survey 2022 results

Dementia Carers Count has published the results of its first nationwide survey. 435 family carers participated, sharing their experiences of caring for someone with dementia and what they thought would make the greatest difference to daily life. Download their survey insights [here](#).

YODA, Bromley film shines a light on young onset dementia

This inspiring film features the Young Onset Dementia Activists peer support group in Bromley. It aims to raise awareness of young onset dementia, and showcases the activities the group take part in. Watch the film [here](#).

Lorenzo's House – providing hope and support in the USA

Lorenzo's House is a USA-based charity that empowers families living with young onset dementia. Founded by Diana Cose, based on her family's experience of young onset dementia, the charity's care model and activism are inspiring. Check out their website [here](#).

Young onset dementia research round-up

Involvement opportunities

Nurses who have current or previous experience working with people with young onset dementia in the UK

Stephanie Browne is a third-year doctoral student at Bangor University. She is conducting research into the experiences of nurses working with people with young onset dementia in the UK. She hopes that by learning more about these experiences, we may be able to help local services develop strategies to support nurses working in these roles, promote their wellbeing and enhance the service and care provided to people living with young onset dementia. For more information, click [here](#) or email Stephanie stb20fyg@bangor.ac.uk

The care of people living with dementia in mental health wards

If you have had experience of care on a mental health ward or support a person with dementia who has been cared for within a mental health ward, please complete this short survey to tell Dementia UK what you think are the priorities for researchers – click [here](#). For more information, please contact Emma Wolverson at emma.wolverson@dementiauk.org

Self-compassion in dementia

Jessica Baggaley is a trainee Clinical Psychologist at the University of Hull. She is conducting a research thesis on self-compassion in dementia using a one-off online questionnaire. It is open to people of all ages living with any subtype of dementia. She is very keen to gain the perspectives of people living with young onset dementia. Click [here](#) to view the advertisement poster or click [here](#) to open the questionnaire which also provides further information about the study.

Unpaid carers' attitudes towards people with early-stage dementia using social media

Dr Catherine Talbot of Bournemouth University is researching unpaid carers' attitudes towards people with dementia using social media, including the perceived benefits, logistical barriers, key concerns and experiences of supporting people with dementia to use social media. If you would like to take part, please follow this [link](#) to the online survey.

Recently published research

Pre-diagnostic symptoms of young onset dementia in the general practice up to five years before diagnosis

Stevie Hendriks, Marjolein de Vugt et al

Read the research article [here](#).

Incidence, age at diagnosis and survival with dementia across ethnic groups in England: A longitudinal study using electronic health records

Naaheed Mukadam, Louise Marston, Gemma Lewis, Rohini Mathur, Greta Rait, Gill Livingston

Read the research article [here](#).

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

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



DEEP – 10th anniversary online festival

Since 2012, the Dementia Engagement and Empowerment (DEEP) Project has grown from 17 groups to a UK wide network of over 80 groups of people with dementia.

To celebrate their 10th anniversary, they are hosting an online festival of 21 events throughout the week of 5-9th December 2022. There will be a wide range of talks, film showings, podcasts, conversations and discussions. All are free and open to all, but booking is essential.

Check out their programme of events and book your place via the link below.

[Book your place](#)



Dementia Enquirers: research legacy film

Innovations in Dementia has shared a wonderful new film about their Dementia Enquirers research project, which features a number of people who are living with young onset dementia.

The film highlights the importance of involving people living with dementia in research, their achievements and the benefits their involvement brings. If you are an academic or researcher, they hope it will change the way you approach research forever.

[Watch the film](#)

Resource showcase: Personal checklist



Our Personal checklist is a resource 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 that 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.

[**Download here**](#)

If you know of any helpful young onset dementia resources, please share them with us.

[**Email us**](#)

[**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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