



New year, renewed determination

Continuing diagnosis struggles

The 66.7% target for all-age dementia diagnosis hasn't yet recovered from the pandemic. Imagine the impact for those seeking an answer to worrying and persistent changes in mid-life. The diagnosis rate for young onset dementia barely reaches 50%. All the benefits of diagnosis, of understanding, of being informed, are lost.

The Young Dementia Network's project, Improving the experience of young onset dementia diagnosis, concludes its first phase this month. Thanks to all who have contributed. We'll be in touch soon to report back.

To guide this and other Network activities, we are following up recommendations for new steering group members with lived experience, and who are active advocates themselves. New year, new members, new energy!

Tessa Gutteridge

Chair, Young Dementia Network

Young onset dementia webinars

Changing perceptions of diagnosis webinar

There are still places available for our next webinar – Young onset dementia: changing perceptions of diagnosis – which 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.

Imran Sherwani, a gold medal-winning hockey player for Great Britain at the 1988 Olympic games who is living with young onset Alzheimer's disease, will provide a lived experience perspective, alongside his son Zac.

 **8th February 2023**

 **12.30-1.30pm**

[Sign up here](#)

Improving the diagnosis process for people with atypical dementia symptoms

Our webinar on Wednesday 15th March 2023 will be presented by Rare Dementia Support.

 **15th March 2023**

 **12.30-1.30pm**

[Sign up here](#)

Jude's story: living with young onset dementia



Jude Thorp was diagnosed with young onset Alzheimer's disease in 2021 aged 57. Dementia UK has created a two-part film about her life since she was diagnosed.

[Part 1](#) focuses on Jude's diagnosis, and in **[part 2](#)** she talks about the support she receives from Dementia UK's **[Young Dementia Oxfordshire](#)** service.

Jude explains how she initially thought her dementia symptoms were being caused by menopause. She also shares why getting a diagnosis was important to her and why the support she's received since has "been a godsend."

Dementia UK has recently published new information pages and advice leaflets on the topics Jude touches on in the two films: **[Dementia and perimenopause and](#)**

[menopause](#), [Young onset dementia: getting a diagnosis](#) and [Young onset dementia: next steps after diagnosis](#).

Young onset dementia: the marginalised lost voices of their children



The team at the University of Northampton Dementia Research and Innovation Centre is hosting its first 2023 Dementia Digest Series lecture on 2nd February from 12.30-2pm.

The online lecture is being delivered by Dr Pat Sikes, Professor Emeritus of Qualitative Inquiry at the University of Sheffield, and Professor Sir Al Aynsley-Green, former Children's Commissioner for England.



They will be speaking about the experiences of young people and children in supporting a parent living with dementia. They will explore the impact of a young onset dementia diagnosis on the younger members of the family, and will ask the question, "What more can be done to highlight and support the unique needs of this marginalised group in our society?"

Find out more [here](#) or register for the event [here](#).

Young onset dementia and dementia-related news

DYNAMIC Project Research Assistant vacancy – Centre for Applied Dementia Studies, Bradford

Are you interested in improving social care provision for people with young onset dementia? This is an exciting opportunity for someone with a keen interest in applied dementia care research to join the world-leading [Centre for Applied Dementia Studies](#) in Bradford as the Research Assistant in the DYNAMIC project. The position will be fixed-term, four days week, from 1st April 2023 to 30th September 2025. Full details are available [here](#). The closing date is 27th January 2023. The Young Dementia Network is supporting this research.

The needs of children and young people living in the shadow of young onset dementia

In December 2022, the [Journal of Dementia Care](#) published an article by Professor Sir Al Aynsley-Green, 'It's time to take seriously the needs of children and young people living in the shadow of young onset dementia affecting parents in families.' The Journal of Dementia Care has given its kind permission for us to reproduce it. Read the article [here](#).

Salford Institute for Dementia and Ageing's Dementia Associates' Group

The Salford Institute for Dementia and Ageing is recruiting new members with lived experience of dementia to their Dementia Associates' Group. Members consult on research, speak to students by leading lectures and provide a living library for students and professors to consult. They also do fun activities such as gardening, theatre and art; however, this is a quite high-functioning group. The overarching goal is to provide people with access to a positive lived experience of dementia while advocating and educating people along the way. Many members of the group have a young onset dementia diagnosis. For more information, click [here](#) or email m.j.pocsai@salford.ac.uk

Essays by people living with young onset dementia on life after diagnosis

Alzheimer's Disease International's World Alzheimer Report 2022 focuses on life after diagnosis: navigating treatment, care and support, and includes a series of essays written by Helen Rochford Brennan, Emily Ong and Keith Oliver who are all living with young onset dementia. They each highlight the importance of disclosure, person-centred care plans and understandable language in post-diagnostic care. Download the report [here](#).

Problem solving with posterior cortical atrophy (PCA)

Martina Davis is 64 years old and is living with PCA. She featured in a recent Alzheimer's Society Dementia together magazine article where she talks about how she deals with the challenges presented by this rare form of dementia. Click [here](#).

New young onset dementia café launches in Broughton

A new group for people under the age of 65 living with young onset dementia has opened at the Toll Bar Cottage Café, Broughton. The group meets on the third Thursday each month from 5.30-7.30pm and promises a relaxed atmosphere, laughter, and a simple meal in the company of people who understand your situation. For more information click [here](#) or email rosemaryandtime01@gmail.com

Rare Dementia Support group for people in Wales

Rare Dementia Support's online support group for people in Wales meets monthly, via Zoom and provides a friendly social gathering for people who are affected by rare dementias. For more information click [here](#) or email j.roberts@bangor.ac.uk

Do you attend or run a young onset dementia support group?

The Dementia UK website provides a [searchable listing](#) of young onset dementia support groups and services across the UK. If you provide, or attend, a young onset dementia group or service that could be added to the listing, please share the information with us via this [webform](#).

Young onset dementia research round-up

Involvement opportunities

Exploring post-diagnostic services available to informal caregivers of people living with young onset dementia in the aftermath of Covid-19 and how they facilitate caregiver resilience

Jessica Bird, a student at the University of Liverpool, is conducting a research project to explore the post-diagnostic services available to informal caregivers of people living with young onset dementia in the aftermath of Covid-19. Her study aims to explore the types of post-diagnostic support available, how adequate these services are and how Covid-19 has impacted them. The research will consist of recorded online interviews via Zoom, lasting 40-60 minutes. For more information, click [here](#) or email hljbird@liverpool.ac.uk

Research study for people with early-stage dementia

Cassandra Seah, a PhD student at Imperial College, is looking for people with early-stage dementia and their family members/carers to take part in a research project. The study involves doing a daily 10-minute mindfulness activity as a couple via an Alexa device, before answering a few questions. Each pair of participants will receive an £80 Marks & Spencer voucher. For more information, click [here](#) or email Cassandra Seah c.seah@imperial.ac.uk

Is owning a pet a positive or negative for people with young onset dementia?

Isla Scullion, a psychology student at the University of the West of Scotland, is carrying out a study to investigate whether owning a pet is a positive or negative for people with young onset dementia. She is looking to interview the family members or close friends of people with young onset dementia who have been diagnosed and own/have a close relationship with a pet. Participants must be willing to take part in an hour-long online interview using Microsoft Teams. For more information, contact Isla Scullion at B00374877@studentmail.uws.ac.uk

Recently published research

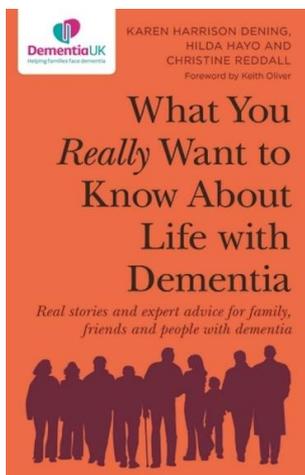
Good practice in needs-based post-diagnostic support for people with young onset dementia: findings from The Angela Project

Vasileios Stamou, Jan Oyebode, Jenny La Fontaine, Mary O'Malley, Jacqueline Parkes and Janet Carter

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](#).

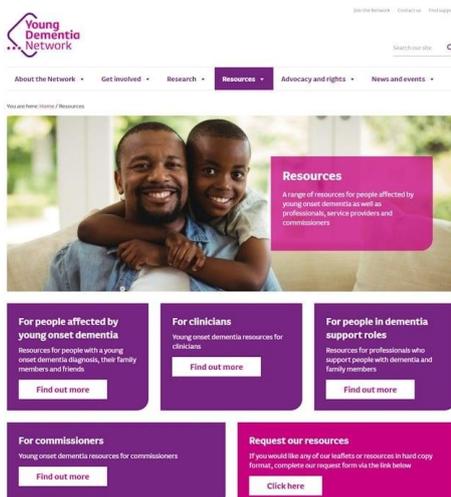


Book giveaway winner

We are delighted to announce that the winner of our December 2022 book giveaway was Pamela Saxby.

She has won a copy of [What you really want to know about life with dementia: real stories and expert advice for family, friends and people with dementia](#) by Karen Harrison Dening, Hilda Hayo and Christine Reddall. The book is on sale now.

Making our Resources web section easier to navigate



We have updated the Resources section of our website to make it easier for users to find the resources that they will find most relevant.

We have split up our Resources web pages by audience so if you are a person affected by young onset dementia, a clinician, a person working in a dementia support role or a commissioner, it is now simpler to find the resources that we have created with you in mind.

[Visit the resources section](#)

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

[Email us](#)

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[Join the Network](#)

[Our resources](#)



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The Young Dementia Network is hosted by Dementia UK.

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