



Drop by drop – glass half-full?

Pursuing, as the Network is, improvements in the diagnosis experience for individuals and their families affected by young onset dementia, recent developments are welcome.

National reporting of dementia sub-types has begun, routine publication of dementia diagnoses for under 65s is expected soon and high-profile individuals are publicly sharing their young onset experiences.

In this issue, you can get involved in the Alzheimer's Society Innovation Team's initiative to expedite diagnosis by getting more value from early health appointments. And we have included links for you to catch up on recent webinars which are packed with a great blend of professional and personal expertise on diagnosis. Our next series of webinars starts in the autumn.

So, drop by drop, progress is being made. Is the glass half-full? This depends on your perspective and personality. Some people with dementia may look deep into that glass and see the bottom of it all too clearly. Others will choose hope. Either way, there is a lot for us to do to improve life with young onset dementia and we must keep making progress – no question there.

Tessa Gutteridge

Chair, Young Dementia Network

Phillip's story



Phillip is living with young onset dementia. His passion for cricket began when he attended his first match with his dad at the age of six.

He says watching cricket helps him to stay mentally active and maintain connections with his family and friends.

[Read Phillip's story](#)

Jane's story



Jane's husband Ash was diagnosed with young onset dementia five years ago, aged 58.

Caring for him at home became increasingly exhausting and challenging so she made the difficult decision to move him into a care home.

[Read Jane's story](#)

Young onset dementia and dementia-related news

Rare Space – a celebration of creativity by people living with rare dementias

Rare Space is an exciting new venture from Rare Dementia Support (RDS). It brings together and celebrates the creative and cultural life of RDS members and combines individual stories, group projects, creative research and activity suggestions. Visit the Rare Space website [here](#).

Talking about the three 'D' words: Death, dying, and young onset dementia

A webinar from the Australian Young Onset Dementia Special Interest Group, taking place on Wednesday 16th August 2023. For further information click [here](#).

Primary progressive aphasia: supporting people with language-led dementias to have better conversations

On Wednesday 6th September 2023 from 1-2pm, the Liverpool Dementia and Ageing Research Forum is hosting a webinar featuring [Dr Anna Volkmer](#) of University College London (UCL) who will talk about her work supporting people with language-led dementias. Sign up [here](#).

Dementia Carers Count – Family Carers Survey 2023

Dementia Carers Count want to ensure that family carers who support people living with dementia get the health and social care services they need. Their Family Carers Survey 2023 gives participants the opportunity to share their experiences and help to shape services. The survey closing date is Friday 15th September 2023. Take part [here](#).

Alzheimer Scotland Annual Conference 2023

The Alzheimer Scotland annual conference is taking place on Friday 15th September 2023 at the Edinburgh International Conference Centre. Free tickets are available for people living with dementia, their partners and family carers. Find out more [here](#).

Fundamentals of dementia care online workshop

The Dementias Online Workshop on Thursday 28th September 2023 will provide an opportunity to develop clinical practice and hear about emerging treatments and pressing topics in the world of dementia care. The event organisers are offering a 20% discount for Young Dementia Network members: use the code YDN20 when registering on their [website](#).

'From research to practice: Solutions to improve dementia and ageing care'

The fifth Annual Liverpool Dementia and Ageing conference takes place on Wednesday 25th October 2023. A number of free tickets are available for people living with dementia and unpaid carers. Find out more or register [here](#).

Member showcase: Martin Robertson – Scottish Dementia Strategy



Martin Robertson was diagnosed with young onset dementia aged 58. He is a Network member and passionate dementia activist.

As a member of the Scottish Government's Dementia Unit Lived Experience Panel, Martin fed his thoughts and ideas on topics such as post-diagnostic support, mental health and dementia wards into the fourth Scottish Dementia Strategy which was published in May 2023.

[Read more here](#)

Young onset dementia research round-up

Involvement opportunity for clinicians and people affected by young onset dementia

Alzheimer's Society: improving access to a timely and accurate diagnosis

The Research Innovation Team at Alzheimer's Society is exploring how they can improve access to a timely and accurate diagnosis, particularly for younger people. They are looking to develop a solution that enables clinicians and their patients to access more valuable health data in their appointments.

They are keen to understand what information is most valuable for clinicians to have access to in appointments. They would value input from clinicians by [completing this form](#) to help inform what the solution looks like.

They are also keen to understand whether people living with and affected by dementia would be comfortable recording health data before appointments. They would value people affected by young onset dementia sharing their views by [completing this form](#) to help inform what the solution looks like.

If you would like more information about the project, including contact details, [please click here](#).

Research showcase

Young onset dementia: implications for employment and finances

Authors: Caroline Kilty, Suzanne Cahill, Tony Foley and Siobhan Fox

This article is about the impact that young onset dementia has on continued employment and finances. It was based on 22 interviews with 10 people with young onset dementia and 12 spouses and children.

Findings about employment were:

- Dementia symptoms often first became apparent at work
- Employment status, the process of getting work adjustments or retirement were all full of uncertainty
- Family members' own employment was affected – some retired; other people took on new roles to earn income

Findings about financial impact were:

- There were many barriers to accessing financial information and support
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- Dementia itself sometimes resulted in financial problems resulting from poor decision-making
 - Many people incurred extra expenses as a result of diagnosis
 - Financial problems were stressful for families
 - Data protection and patient confidentiality posed barriers that made it hard for families to resolve issues

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

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Review by Jan Oyeboode, Professor of Dementia Care, Centre for Applied Dementia Studies, University of Bradford.

Do you have an interest in young onset dementia research?

The Network's research workstream is looking to expand its membership by including additional people with a diagnosis of young onset dementia.

The group meets via Zoom four times a year. If you would like to find out more, please click [here](#) or email us: youngdementianetwork@dementiauk.org

Book giveaway winners

Congratulations to our June 2023 book giveaway winners – Tina Eperon-Stoneman, Laura Harvey and Natasha Wilson – who have won copies of Wendy Mitchell's latest book, '[One last thing](#)'.

Resource showcase: Good practice in young onset dementia



The Angela Project was a three-year research study carried out by the universities of Bradford, Northampton, Surrey and UCL.

It was the largest study of young onset dementia ever carried out in the UK and was designed to look at how diagnosis and post-diagnostic support for people living with young onset dementia can be improved.

The Angela Project team collated some of their key findings and recommendations to create a publication, [Good practice in young onset dementia – improving diagnosis and support for younger people with dementia.](#)

[Find out more here](#)

Young onset dementia webinars

Our latest series of webinars focused on improving the experience of diagnosis for younger people with dementia and their families. You can catch up with recordings of all of the webinars via the links below.

[Why numbers matter and change is possible](#) was led by Dr Janet Carter and Michael Jackson and featured Wendy Mitchell, who is living with young onset dementia. They discussed the importance of using more accurate data to better communicate the need for improved services for younger people living with dementia.

[Young onset dementia and general practice: identifying symptoms before diagnosis](#) focused on the first symptoms of young onset dementia, how to increase their recognition and better identify people with the condition earlier and was hosted by Professor Marjolein de Vugt and Dr Stevie Hendriks from the Netherlands.

[Changing perceptions of diagnosis](#) was led by Alzheimer's Research UK and focused on how people living with dementia, the shifting political landscape and advances in research and drug discovery can help the dementia diagnosis pathway evolve.

[Improving the diagnosis process for people with atypical symptoms](#) was hosted by Rare Dementia Support and focused on how we can improve the diagnosis process for people with atypical symptoms.

[Different service models: Young Onset Dementia Service, Doncaster](#) was led by Dr John Bottomley. It focused on the long-established Young Onset Dementia Service and included an interview with Michael Booth, who is living with young onset dementia.

[Young Onset Dementia Nurse-Led Service, Northampton](#) showcased the nurse-led Younger Persons with Dementia Team which provides assessments, diagnosis, and support for people under the age of 65.

[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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