



Numbers, individuals and why they count

Every individual affected by young onset dementia matters. Agreed? Everyone has a unique approach to living their life, drawing on their own networks. At times more is needed such as an accurate diagnosis, connection with others, specialist nursing, information and support. This is when every individual counts together.

Knowing accurate numbers of individuals living with young onset dementia has been a challenge for decades. The result – an unfair service ‘postcode lottery’. Numbers count to secure the investment in expertise, resources and systems to enable each life to be lived to the full.

Our Network steering group prompted action on this at a national level. This is now bearing fruit. Check out this [article](#) from the Journal of Dementia Care to read how more accurate numbers have been captured. This study shows an increase in people living with young onset dementia and helps our activist membership advocate for more services.

Thinking of just one special activist for now, Keith Oliver, who played a key role in highlighting this, and other vital issues. Keith has stepped down from the steering group after seven years of extraordinary insightful and valuable contribution. Thank you Keith.

Tessa Gutteridge

Chair, Young Dementia Network

Tea-time webinars - update

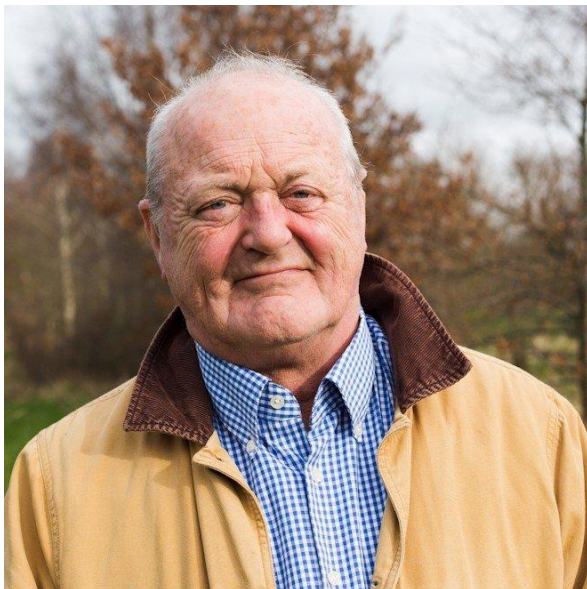
We hope you've been enjoying our tea-time young onset dementia webinars which we've been running since October 2020.

We're going to take a little break for the summer but plan to restart our webinars in October with a new theme - improving the experience of diagnosis.

We'll share more information in our upcoming newsletters but for now, you can catch up with recordings of all our past webinars on our website [here](#).



To watch a recording of our June webinar - **Communi-tea - the importance of support and connection for carers of people with young onset dementia**, click [here](#).



Member showcase: George Rook

Young Dementia Network member George Rook was diagnosed with mixed dementia in 2014 at the age of 62.

He has spent much of the last eight years meeting people who live with the condition and campaigning for better support and services.

[Read more](#)

Young onset dementia and dementia related news

MindCare YODA event

Bromley MindCare is hosting a young onset dementia event in Beckenham on Friday 1st July 2022, from 11am-3pm in Beckenham. [Find out more >](#)

Dementia UK Summer School

Dementia UK's annual Summer School is an opportunity for health and social care professionals to improve their practice and knowledge of dementia care. The free three-day virtual online programme features a session on young onset dementia on Thursday 7th July 2022, from 10.30am-12pm for which a limited number of places remain. [Sign up here >](#)

100/6000 dementia conference

Deepness Dementia's 100/6000 dementia conference will take place in Sheffield on 26th and 27th September 2022, led by and for people with dementia. If you are interested in attending, bursary places are available for people living with dementia. [Read more >](#)

Living with dementia toolkit

The University of Exeter and Innovations in Dementia have produced a Living with dementia toolkit with and for people with dementia, their families and carers. The toolkit is made up of five sections: Stay safe and well, Stay active, Stay connected, Keep a sense of purpose and Stay positive. [Visit the website here >](#)

New publication from Alzheimer Europe

Alzheimer Europe has released a new publication: Celebrating 10 years of the European Working Group of People with Dementia, 2012–2022. [Download here >](#)

Congratulations to Fiona Mitchell who won a copy of Gina Awad's book, [United](#), in our May 2022 giveaway.

Young onset dementia research round-up

Involvement opportunities

Dementia Carers Count is carrying out a survey of carers who support a family member with dementia. If you are a carer, they would value your opinions on what caring means to you, what you find difficult and what you think needs to change. Participants will be entered into a prize draw to win dementia care equipment. [Take part here >](#)

Dental care research

Dia Soilemezi, a researcher at the University of Portsmouth, is looking to talk to people living with dementia and/or their family carers, who use homecare services in England. She would like to learn about the help people receive with their mouth and tooth care. Interviews take 20 minutes and participants will receive a £20 voucher. If you are interested and can participate by the end of June, please email dia.soilemezi@port.ac.uk or [find out more >](#)

Do you have a parent diagnosed with an inheritable type of dementia?

Researchers from Hunter College, New York, the University of Sheffield and Manchester Metropolitan University are interested in understanding the impact on children who are now aged 18 or older of having a parent with an inheritable type of dementia (such as familial Alzheimer's disease or frontotemporal dementia) and their thoughts about genetic testing. This will facilitate better support for such individuals and their families. If you are interested in participating or have any questions, please email p.j.sikes@sheffield.ac.uk

Recently published research

Prevalence of all cause young onset dementia and time lived with dementia: analysis of primary care records

Dr Janet Carter and Michael Jackson

New figures estimate that 7.5% of people currently living with dementia were diagnosed under the age of 65. [Read the full article here >](#)

This article was published in the Journal of Dementia Care: subscribe [here](#).

Annual dementia reviews in general practice

The Riversiders peer support group in Shrewsbury have carried out a qualitative research project across DEEP groups in the UK to find out how many people living with dementia have had annual reviews. [Read the report 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](#).



[Download here](#)

Resource showcase - Young onset dementia: guidance for dementia support roles

We have recently updated one of our resources, co-produced by people with young onset dementia. It provides guidance primarily for dementia advisors, support workers and key workers who may not usually support people living with dementia under the age of 65 years old.

It is intended to guide discussion with the person with young onset dementia and their family and should be used flexibly to adapt to the person's individual needs and circumstances.

To view our full range of young onset dementia resources, click [here](#).

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