

This is an email from the Young Dementia Network sharing Network and young onset dementia related news and information

July / August 2021



## New resources, prevalence updates and involvement opportunities

**This week Dementia UK, our host, launches a young onset dementia section on their [website](#). Drawing together information, personal stories, a support database and resources all with a young onset focus, it is a great new resource and will be added to over time.**

Check out the study evidencing greater global prevalence of people living with young onset dementia compared to previous studies. Health and social care commissioners and providers, please take note.

Taking tea together at our regular webinars has become such a useful way to learn from each other. Do you have a topic which you would like to feature? Let us know.

**Tessa Gutteridge**  
**Chair, Young Dementia Network**



## Dementia UK adds new young onset dementia content to website

**Following the merger with YoungDementia UK in November 2020, young onset dementia has become a more prominent part of the Dementia UK service offering.**

The charity hosts the Young Dementia Network and since the merger has created a dedicated [website](#) for the Network. The next step has been to expand the information provided by Dementia UK about young onset dementia.

This week, Dementia UK has launched a new section on its website which brings together information about young onset dementia, life with the condition and helpful resources such as films, blogs, books and other publications to help you access information more easily. It also includes a searchable database of young onset dementia groups and services across the UK. In the coming weeks, further content will be added. You can view the new young onset dementia section [here](#).

If you would like your group or service to be included, please complete this [webform](#).

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## Webinar catch up: adapting to the easing of Covid restrictions

**On Wednesday 21st July 2021, we continued our series of webinars with Normali-tea – adapting to the easing of Covid restrictions.**

This webinar was a discussion between members of the PACE group, part of Young Dementia Oxfordshire. All of the members are younger people who live with a dementia diagnosis.

The group talked openly about how the lockdowns have affected them and their hopes for returning to a greater level of normality now restrictions are easing.

Watch a recording of the webinar [here](#). You can catch up with all our past webinars on our [website](#).

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## Young onset dementia focus group - Teignbridge area

**Tracey Aldridge and Lia Tucker are Dementia Support Workers at the Alzheimer's Society. They are aware that the support services available for people with young onset dementia in the Teignbridge area of Devon are limited and want to get a focus group together to find out from people with a diagnosis who live locally what they feel they need.**

The focus group will be held at The Alice Cross Centre in Teignmouth and will last up to two hours a session with a maximum of four sessions. They hope to hold the group in September 2021. They cannot guarantee that they will be able to provide the services that people want or need but they hope to apply for funding for some identified services and to ensure that the voices of people with young onset dementia are heard.

If you live in the area and would be willing to participate in a focus group, please contact: Tracey Aldridge, tel 07935 010429 - [tracey.aldridge@alzheimers.org.uk](mailto:tracey.aldridge@alzheimers.org.uk) or Lia Tucker, tel 07709 718534 - [lia.tucker@alzheimers.org.uk](mailto:lia.tucker@alzheimers.org.uk)

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## Our resources have a fresh new look

If you have requested our Young Dementia Network resources recently, we apologise for the delay in getting them to you. This has been caused by the need to redesign and reprint them all following the recent change in the branding of the Network.

Our resources have been created for a range of audiences including people affected by the condition, people who have concerns or worries about symptoms, as well as GPs, clinicians, diagnostic services, commissioners, dementia advisors and group / service providers.

All of our resources are now available and can be downloaded or requested in paper format via our website - click [here](#).

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## Young onset dementia research round up

### Involvement opportunities

#### Online peer support for people with young onset dementia

Esther Gerritzen is a PhD student from the University of Nottingham. She is conducting research to find out more about how people experience online peer support, and for those who don't use it, she would like to learn more about why that is and what the barriers are they might experience. She is looking for participants with a young onset dementia diagnosis. Contact Esther on [Esther.Gerritzen@nottingham.ac.uk](mailto:Esther.Gerritzen@nottingham.ac.uk) or click [here](#) to find out more.

#### The association between a parental diagnosis of young onset dementia and mental health in people between 15 and 24 years of age

Amy Lord is a Master's student at the University of St Andrews. She is conducting a research study that aims to investigate whether there is an association between a parental diagnosis of young onset dementia and levels of quality of life, depression, anxiety, and stress in youth. She is interested in recruiting 15-24-year-olds who have a parent with young onset dementia, other long-lasting illnesses, and those with healthy parents. For more information click [here](#) or contact Amy Lord via email: [all9@s-andrews.ac.uk](mailto:all9@s-andrews.ac.uk)

#### The impact of the Covid-19 pandemic on people with young onset dementia, their informal carers and healthcare workers

Researchers at the University of Reading are conducting a study on the impact of the Covid-19 pandemic on people with young onset dementia, their informal carers and healthcare workers. They are looking for participants who live in the UK who are under 65 and living with young onset dementia and informal caregivers or healthcare workers of a person living with young onset dementia, aged over 18. To take part or for more information click [here](#) or contact Zeenia Ellikka at [z.ellikka@student.reading.ac.uk](mailto:z.ellikka@student.reading.ac.uk)

## Recently published research

A study by researchers from Maastricht University suggests the **global prevalence of young onset dementia** is far greater than estimates suggest. Click [here](#).

The Young Dementia Network website now hosts a collection of young onset dementia research studies related to **The Angela Project**, a three-year long research study; the largest study of young onset dementia carried out in the UK. Click [here](#).

People with **young onset dementia** are often mistaken for having **depression**. Australian research has discovered the cause: a profound loss of ability to experience pleasure related to degeneration of 'hedonic hotspots' in the brain where pleasure mechanisms are concentrated. Click [here](#).

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To find other dementia research opportunities, please visit the [Current research studies](#) page on the Young Dementia Network website or the [Join Dementia Research](#) website.

To view a collection of research focusing on the most prominent subjects relating to young onset dementia visit the [Research and evidence](#) section of our website.

If you would like us to share a research study or recently published paper, please [email us](#).



## YO Songsters - free, online music sessions

Free music and wellbeing sessions are being offered for people living with young onset dementia by Musical Walkabout, a charity that aims to harness the power of music to

**creatively engage people living with a dementia in fun, person-centred ways.**

Family members and caregivers are also welcome at their music sessions. Email [info@musicalwalkabout.com](mailto:info@musicalwalkabout.com) or visit their [website](#) for more information.

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## Supporting people with young onset dementia to be volunteers

**South Gloucestershire Dementia Friendly Communities is in the process of writing a toolkit for organisations and businesses to encourage them to support people who are living with dementia who may wish to volunteer.**

In order to create the toolkit, they would like to hear from people with young

onset dementia to know more about what they would like, what support they would appreciate and what type of volunteering role would interest them.

They would like to find out:

- What would encourage you to volunteer with an organisation?
- What adjustments would help you overcome any lack of confidence you may be feeling?
- What types of volunteering opportunities would you be interested in pursuing?
- Would travel to an organisation be an issue for you?
- If you were to volunteer, would disclosure of your diagnosis to others in the organisation be uncomfortable or would you be happy for this to happen?
- Have you been put off from volunteering in the past?

If you are interested in getting involved, please contact Winsome Winsome Barrett-Muir, Community Development Project Coordinator on 01454 868570 or email [winsomebmuir@southernbrooks.org.uk](mailto:winsomebmuir@southernbrooks.org.uk)

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**You can leave the Network or unsubscribe from our mailings by completing [this form](#).**

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**Join the  
Network**



**The Young Dementia Network is hosted by Dementia UK**

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