

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



Young Dementia Network

Action needed to support people with young onset dementia

The concerted action of individuals and organisations has never been more needed than now. People living with dementia and their carers have been drastically affected by Covid-19. The impact on people with young onset is poorly evidenced but personal accounts talk of faster deterioration of health and well-being, families with children and adolescents struggling with disrupted work, reduced finances and loss of support.

If there was a time to draw together, that time is now. YoungDementia UK and Dementia UK's merger in November is timely. A key aim now is to increase the strength of the Young Dementia Network through investment and to harness the shared expertise, capacity and resources of the two charities.

Young onset dementia services were already inadequate, Covid-19 has reduced them further. Let us, through the Young Dementia Network, do our best to change this for the better and offer those with young onset a more optimistic future.

Tessa Gutteridge
Chair Young Dementia Network
Programme Director for Young Onset Dementia, Dementia UK



Young onset dementia webinars



An opportunity to connect, support and inform each other

Catch up on our October and November webinars

The Young Dementia Network webinars aim to bring together Network members, people living with young onset dementia, family members, professionals working in the field and all those interested in young onset dementia to create an opportunity to connect, support and inform each other.

If you weren't able to join us for our webinars in October and November, we are delighted to be able to share links so you can watch them online. Watch our October webinar, Adaptabili-tea - Adapting to life after a diagnosis [here](#) and Sensitivi-tea - What matters most during diagnosis [here](#).

Diagnosis, what matters most - involvement opportunity

As a follow up to the Sensitivi-tea - What matters most during diagnosis webinar, Dr Mary O'Malley plans to run an online consultation / focus group session. If you would be interested in getting involved, please email Dr Mary O'Malley - Mary.O'Malley@uwl.ac.uk



Our monthly FREE young onset dementia related webinars continue

Join us with a cuppa on **Wednesday 16 December, 2.30-3.30pm** for Festivi-tea - Hints and Tips for the festive season.

The webinar will be led by Clare Mason, Dementia Care Trainer and PPI lead at the University of Bradford, with Michael Andrews, Anne Marie Norris, Julie Hayden and Kit and Julie Swann who are members of Pathways, a young onset dementia group from Bradford. They will share their experience on what helps reduce stress and increase enjoyment. Places are limited. Sign up to the Zoom webinar [here](#).

This will be followed by Research Priori-teas - Why should I get involved? on Wednesday 20 January, 2.30-3.30pm. The webinar will be led by Professor Jacqueline Parkes, Professor of Applied Mental Health, University of Northampton; Dr Mary O'Malley, Lecturer in Ageing and Dementia, University of West London and Wendy Mitchell, who is living with young onset dementia and is a best-selling author and blogger. During this interactive session they will discuss the research priorities that matter to you and why you should get involved. Sign up to the Zoom webinar [here](#).

Join the DEFIN-YD Project virtual event in January 2021

On Thursday 28 January 2021, the DEFIN-YD Project will host a virtual event focused on engaging people living with young onset dementia in research. The event will include talks by researchers in the field, people affected by young onset dementia who have been involved in research studies and highlight how you can take part in research.

If you would like to attend this event, please express your interest by visiting their Eventbrite page and register [here](#). If you have any questions, please contact Anna Crawford by email at Anna.Crawford2@uwl.ac.uk



Young Dementia Network resources survey - can you help us?

We have created a short online [survey](#) to get feedback about the [resources](#) such as

ID cards or leaflets created by the Young Dementia Network. If you have downloaded or requested our resources, we would be extremely grateful if you could take part in the survey.

Your responses will help provide us with evidence about the need for, and value of, these resources. This helps us to access funding which enables us to keep them available free of charge and to create additional young onset specific materials.

The survey takes under 10 minutes to complete - click [here](#). Thank you so much in advance. Ideas for new young onset specific resources are always welcome, please do [email us](#) if you have any suggestions.



The Angela Project - key needs young onset short films launched

As part of The Angela Project, a three-year long young onset dementia research study, the team asked people living with young onset dementia and family members to tell them about services they had

found helpful. They received over 850 examples and analysed these to see what needs these services met; this led to a set of eight needs that seem to be central to receiving quality support.

These have been translated into three new short films which detail what people living with young onset dementia and family members need, separately and jointly. You can watch the films [here](#).



Online support for young adults aged 18-35

A new online support network has been set up for young adults 18 - 35, who support / care for a parent with young onset dementia. It aims to connect young adults in similar situations to provide support and learn from each other.

Lara, who has set up the network says, 'As a young carer myself - I'm now 30 years old, an only child and have been supporting my father with young onset PCA + Atypical Alzheimer's for the last three years - I came to realise the real need for this, following chance meetings with others in a similar situation. These vital connections have been a game changer for me in the last year and I want to create a space for others to have the same thing.'

Lara has set up a Too Young For Dementia [Instagram](#) and private [Facebook group](#). You can read her blog [here](#).

Young Dementia Network survey 2020 - key findings

We recently asked you, our members, to give us feedback about the Young Dementia Network and had over 140 responses. A very big thank you to

One Dementia Voice - collaborative campaigning for change

You may have seen the first campaign by One Dementia Voice to enable families of people with dementia in care homes to

everyone who took the time to complete the survey.

We received some fantastic feedback. Your responses told us **96%** of members found the Young Dementia Network useful for receiving information about young onset dementia; **80%** said being a member helps them feel better informed and **93%** of respondents said they read all, or part of Young Dementia Network News. We'll share more results in future newsletters.

safely be with them during Covid-19. This means having access to testing and PPE in the same way that key workers do. **There is a very fundamental human right to a family life that is at stake here.**

One Dementia Voice is a collaboration of key national groups and charities, and the Young Dementia Network is honoured to be offering up a young onset dementia perspective. We will keep in touch with all Network members on this as the collaboration develops.



Online peer support group for LGBTQ+ people living with dementia

Speak out with dementia is a new online group for people who are living with a diagnosis of dementia, and who identify as LGBTQ+ (lesbian, gay, bisexual, trans, queer). The group will give members the chance to express themselves and support each other in a safe environment where their experiences, their identity and their relationships will be affirmed. Meetings will be held on Zoom.

The group is supported by [AD Advocacy](#) with funding from The National Lottery Community Fund Grant. The group will be affiliated to the DEEP (Dementia Engagement and Empowerment Project) network and meets every week on Tuesdays from 5.00–6.00pm. If you would like to join, or want to know more about the group, contact Lucy Whitman or Aimee Day at Speakoutwithdementia@gmail.com



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The Young Dementia Network is a YoungDementia UK initiative.

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