

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

April 2021



New beginnings

By happy coincidence, we are experiencing a fresh start with life opening up for us again at the same time as introducing the new look Young Dementia Network through the launch of our first dedicated [website](#) and social media.

The Network, now hosted by Dementia UK, also has more support too in the shape of our Network Co-ordinator, Catherine. Next month Catherine will let you know how she will work with members, and why.

So new look, new ways to connect with you, new investment but be reassured, the whole point is to ensure the Network is as strong as possible to bring about the changes for people with young onset dementia that are so needed - our purpose is the same as ever.

Tessa Gutteridge
Chair, Young Dementia Network

Please note our new email address youngdementianetwork@dementiauk.org



The Network has a new look and a new website

The Young Dementia Network has recently undergone a bit of a visual transformation. We are delighted to be able to share with you our new logo and refreshed brand style.

Even more excitingly, we are today launching our new, dedicated website - www.youngdementianetwork.org - which brings together information about the [Network](#) and its membership / steering group, as well as young onset dementia [research](#), [resources](#) and [news and events](#).

We have also rebranded the YoungDementia UK social media channels as Young Dementia Network to provide an enhanced platform from which the Network can share young onset dementia-related news and information. You can now follow us on [Facebook](#), [Twitter](#) and [YouTube](#).

If you have anything you would like us to share on our website or social media channels, please do [get in touch](#).



Intensi-tea - stress and distress in dementia webinar - Wednesday 19 May 2021

Join us with a cuppa on Wednesday 19th May 2021, 2.30-3.30pm for a young onset dementia webinar, Intensi-tea – stress and distress in dementia.

This session, facilitated by Dementia Carers Count, will help you understand why a person living with young onset dementia may experience increased feelings of stress and distress, and how you might help them manage these feelings.

Lissy Edwards, Speech and Language Therapist / Dementia Carers Services Practitioner and Sue Hinds, Head of Services of Dementia Carers Count will be joined by family carers of younger people with dementia who will share their experiences, especially focusing on how they maintain their own health and well-being.

Sign up to the webinar [here](#).



Webinar catch up - rarer types of dementia

On Wednesday 21st April 2021, we continued our series of young onset dementia webinars with Rari-tea – explaining rarer types of dementia experienced by younger people.

This webinar focused on rare types of dementia which predominantly affect younger people and looked at the unusual sets of symptoms.

Nikki Zimmermann, Direct Support Lead, Rare Dementia Support was joined by Martina, Geraint, Jacqui, Paul and Pippa who shared their personal experiences on how rare dementias have impacted on their daily lives and their strategies of resilience. They were full of fascinating insights and inspired all who attended.

You can view a recording of the webinar [here](#).

You can catch up with all our past webinars on our [website](#).



In search of a good death: What would a good death in dementia look like?

The University of Kent and Dementia UK are undertaking a small study to explore what people with dementia see as constitutes a good death in light of a diagnosis of dementia.

People with other life-limiting conditions (eg cancer) have been asked to share their opinions on what good death and dying means to them. Understanding the perceptions of the person with a diagnosis of such diseases can better inform healthcare policy and so practice.

To date, a good death in dementia is largely defined from a clinical perspective and often focuses on symptoms. They believe it is very important to bring the voice of people living with dementia to these discussions of death and dying, and drive user-led policy development.

If you would like to know more you can download the study information sheet [here](#), or contact one of the researchers: [Dr Rasa Mikelyte](#) of the University of Kent - tel: 01227 823666 OR [Dr Karen Harrison Dening](#) of Dementia UK – tel: 07585 508 088.



The poster for 'Young Onset Dementia Research' features the logos of the University of West London and IAM (International Association of Geriatric Psychiatry). The text on the poster reads: 'We are looking for younger people with dementia (people diagnosed with dementia before the age of 65) to join a project about research. If you live in England, and have a diagnosis of young onset dementia, we would like to hear from you. You will meet other people living with young onset dementia, and influence research based on your own experiences. You will need to come to four two-hour Zoom meetings between May and November 2021. If you are interested, please contact Anna Crawford at anna.crawford@uwl.ac.uk'. Logos for partners like West London, NHS, and others are also visible.

Research opportunity for younger people with a diagnosis

The DEFIN-YD project is looking for younger people with dementia (people diagnosed with dementia before the age of 65) to join a project about research. They are looking for people who live in England, who have a diagnosis of young onset dementia, and who are interested in shaping current and future research.

The group will enable you to meet other people living with young onset dementia and influence research based on your own experiences. You will need to come to four two-hour Zoom meetings between May 2021 and November 2021. At the Zoom meetings, you will discuss young onset dementia research and there will be regular breaks throughout. There will be someone to guide the meetings, and they welcome family supporters to join too if you wish.

Please complete this [expression of interest form](#) by Wednesday 5th May 2021 if you would like to join or receive more information.

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



Young Dementia Network members interviewed on Woman's Hour

Earlier this month, Young Dementia Network steering group members Dr Wendy Mitchell and Prof Jan Oyebode were interviewed alongside author Anna Wharton about dementia on Radio 4's Woman's Hour programme.

They discussed whether fiction could be the answer to showing a more rounded and factual portrayal of life with dementia.

Wendy is a best-selling author and was diagnosed with young onset dementia at the age of 58. She said on the programme, 'There is life still to be lived and there is so much more we can still do. Even though clinical experts can't do anything, we can still do so much.'

Listen to the podcast of the programme [here](#). The dementia feature starts around 15 minutes in.



Online learning sessions aimed at family members and friends

Young Dementia Network members, Dementia Carers Count, has created a range of online services so that they can continue to support family members and friends

caring for someone with dementia, regardless of public health restrictions.

Their online webinars are designed and delivered by expert professionals and cover a wide range of topics. Each session runs for between 1 and 1.5 hours, and groups are kept small to allow you the opportunity to connect with others, ask questions, and relate the information to your own circumstances.

They keep these sessions very informal and encourage you to bring a cup of tea and relax. You can see their full range of topics and book your free place in the Live Online Learning section of their [website](#).

If you have received this email direct to your own email address, you are already registered as a Young Dementia Network member. If someone has forwarded this newsletter to you, please sign up to join the Network [here](#).

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

**Join the
Network**



The Young Dementia Network is hosted by Dementia UK

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