

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

Young Dementia Network News - October 2021



Changed lives, different but not the end

A groundswell is gathering momentum that a diagnosis of dementia can be the start of a changed life, a life that is worthwhile and to be valued. This message is from people living with the condition. For this to become the reality for more people, and for their families to feel this too, what 'surrounds' the person and family needs to be as enabling as possible. Diagnosis needs to be timely and accurate. Effective support needs to be in place to be drawn on as required.

We know that Covid is continuing to create serious challenges to all of this. And it feels as though we are steeling ourselves to cope with winter now, having hardly drawn breath. However this month's News is packed full of positive initiatives which accept the realities of the times but push forward with hope anyway.

Keep on keeping on!

Tessa Gutteridge
Chair, Young Dementia Network

A graphic for a webinar invitation. It features a stylized purple and gold 'W' shape on the left, a purple silhouette of a person's head in profile on the right, and a white teacup with a purple logo on the front. The text is arranged around these elements.

invites you to a webinar
Financial Securi-tea

Financial issues affecting people with young onset dementia and their families

Join us with a cuppa for the latest in our series of young onset dementia webinars

Wednesday 17th November 2021
2.30-3.30pm

youngdementianetwork.org/our-webinars

Coming up in November: Financial Securi-tea webinar

Our next tea-themed webinar – Financial Securi-tea - financial issues affecting people with young onset dementia and their families will take place on Wednesday 17th November 2021.

This webinar will be hosted by Calum Macdonald, an Advanced Associate (legal) at the Financial Conduct Authority. Calum also has personal experience of young onset dementia.

It will cover a range of topics including the financial challenges people with a diagnosis of young onset and their families can face, what your rights and options are and what banks can do to help.

You can sign up for the webinar [here](#).

Watch a recording of our October webinar - Individuali-tea - tailoring care and support for individuals affected by young onset dementia by clicking [here](#). You can catch up with all our past webinars on our [website](#).



Diana and Eugene's story

Diana is a member of the Young Dementia Network steering group and a dementia activist in the Leeds area.

As part of Black History Month, she has shared her experiences of caring for her late husband Eugene who had young onset dementia.

She explains the impact that cultural factors had on getting Eugene's dementia diagnosis. Read their story [here](#).

Young onset dementia research round up

Involvement opportunity

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:

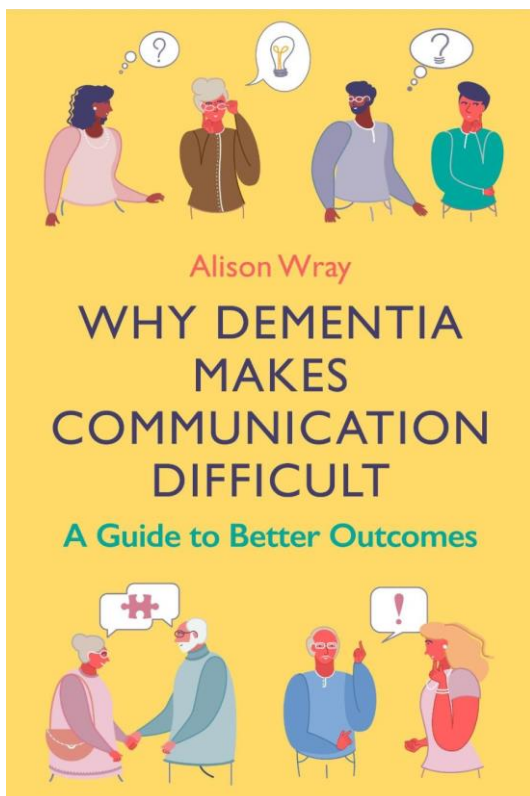
- living with young onset dementia and under the age of 65
- an informal caregiver or healthcare worker of a person living with young onset dementia and above the age of 18

The study involves online surveys which will include questions about how the pandemic has impacted various aspects of your life such as your ability to access care services, your social life, work life, relationships, mental health etc. You can take part in the survey via this [link](#) or contact Zeenia Ellikka at z.ellikka@student.reading.ac.uk or Professor Arlene Astell at a.astell@reading.ac.uk

Recently published research

“Thrown into the deep end”: Mapping the experiences of young people living in a family affected by a neurological condition

Patricia Masterson-Algar and Sion Williams. Read [here](#).



Dementia book giveaway!

Our friends at Jessica Kingsley Publishers have kindly given us a **FREE** copy of their newly published book, [Why dementia makes communication difficult](#) to give away to a lucky Young Dementia Network member.

If you would like to be entered into the book giveaway, please [email us](#) with your full name and postal address by Sunday 31st October 2021. The winner will be drawn at random.

Alternatively, you can get a 25% discount off the purchase price if you buy the book via the [JKP website](#) and use discount code **DEMCOM** at checkout, valid until 31st December 2021.

Young onset dementia / dementia related news

Wendy Mitchell was diagnosed with young onset dementia aged 58. She has written a second book, titled 'What I wish people knew about dementia from someone who knows.' Due to be published on 20th January 2022, it is available to pre-order [now](#).

Congratulations to **Bromley, Lewisham and Greenwich Mind's Young Onset Dementia Activists group** who recently raised over £4000 by taking on a 5km trek around Beckenham Place Park. The money raised will help develop and expand the service to more local people who have been diagnosed with young onset dementia. Read more [here](#) or contact the service by email Bromley@dementiahub.org.uk or call 020 3328 0366.

Dementia Alliance International has announced the retirement of its CEO, **Kate Swaffer**. Kate was diagnosed with young onset dementia aged 49, and in the years since co-founded the DAI and has become an internationally renowned dementia advocate and activist. Read more [here](#).

YoungDementia UK merged with Dementia UK in November 2020 and its website has now been taken permanently offline. A new [young onset dementia section](#) has been created on the Dementia UK website in its place, which includes a [Find support](#) page which lists young onset dementia groups and services across the UK.

Time for Dementia is a programme that is currently running across Surrey, Sussex and Devon, supported by Alzheimer's Society, that pairs families affected by dementia with undergraduate students, helping to better educate them about life with dementia and the challenges that come with it. They are looking for families affected by young onset dementia who would be willing to speak to students to help them understand what it is like to live with the condition. Click [here](#) for more information or email timefordementia@alzheimers.org.uk



Dementia & Us

Dementia & Us, a new two-part documentary series that followed four people with dementia and their families over a two-year period.

Screened on BBC2 in October 2021, the ground-breaking documentary featured two people who are living with young onset dementia - Chris has familial Alzheimer's disease and Marion has Posterior Cortical Atrophy. Both episodes are available to watch on BBC iPlayer [here](#).

Senior Consultant Admiral Nurse at Dementia UK, Victoria Lyons, shares her thoughts on the programme [here](#).

Journey to activism

We highly recommend this short film '[Journey to Activism](#)' created by STAND in Fife. They are a group of people living with young onset dementia and their families and friends.

In the film, Gerry (pictured) says, "Dementia is not the end, it's just a different chapter."

We thought the film was inspirational and applaud Gerry for sharing his story; and the whole STAND group for all they do to support each other and raise awareness of young onset dementia.

You can watch the film [here](#).

NEW RESOURCE:

Supporting implementation of the NICE guideline for people with young onset dementia



Supporting implementation of the NICE guideline for people with young onset dementia

This resource explains the unique needs of people with young onset dementia that require a tailored approach to support and care. It outlines the additional challenges younger people with dementia face throughout the dementia pathway in the absence of a tailored approach, and the consequences of this on people and their families as well as for the health and social care system.

The table provides guidance on how to address the challenges and meet the unique needs of people of working age living with dementia and provides signposting to supporting resources.

Young Dementia Network
Supporting implementation of the NICE guideline for people with young onset dementia



The Young Dementia Network has produced a resource for commissioners and frontline health and care professionals that provides guidance on how to address the challenges and meet the unique needs of people of working age living with dementia.

Young onset dementia has significant differences from late onset dementia and evidence shows that the needs of younger people with dementia are not being met by an age-generic approach – which can have a devastating impact on the individual. Designed to support implementation of the NICE dementia guideline, this resource sets out the tailored approach needed at key stages of diagnosis and support.

Available digitally, you can download a copy [here](#). You can download or request other Young Dementia Network resources [here](#).



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