

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

March 2021



Spring has sprung

This weekend, before you head out for the daily walk or to admire the blooming blossom (!), if you or your family are affected by young onset dementia please do spare a few minutes to complete the Dementia UK survey below.

Dementia UK are the Young Dementia Network's new hosts and are very keen to expand their services to you, both in person and digital. This survey focusses on digital and gaining a thorough understanding of your experience is so valuable. Deadline Sunday 21 March 2021.

Talking of digital, we'll be linking you to the Network's new website very soon. You will notice a fresh look too, a few changes ... but what hasn't changed is our collective aim to influence support improvements for all people affected by young onset dementia.

Tessa Gutteridge
Chair, Young Dementia Network

Please note - the Young Dementia Network has a new email address youngdementianetwork@dementiauk.org



Your urgent help is requested - Dementia UK survey

Access to dementia care and support has changed for many people since the start of the coronavirus pandemic (Covid-19), with more services delivered digitally eg support groups and online health appointments.

Hosts of the Young Dementia Network, Dementia UK, want to hear about your experiences of accessing dementia information, care or support services digitally since the start of the pandemic.

Whilst digital support can never replace face to face, given how patchy young onset dementia support services are across the country, we believe there is great potential in enabling greater access to remote support, information and advice 24/7 via digital channels.

We believe this would be hugely beneficial for many people living with young onset dementia and their family members. By taking part in the survey, your views will help Dementia UK to develop and improve their digital services to best meet your needs.

Please take a moment to fill out their survey [here](#). The survey closes on Sunday 21 March 2021.



Rari-tea - rarer types of dementia webinar - Wednesday 21 April

Join us with a cuppa on Wednesday 21 April, 2.30-3.30pm for the latest in our series of young onset dementia webinars, Rari-tea - explaining rarer types of dementia experienced by younger people.

This webinar will focus on rare types of dementia which predominantly affect younger people. Nikki Zimmermann, Direct Support Lead, Rare Dementia Support will be joined by Martina, Jane and Chris and Paul and Pippa. They will discuss the unusual sets of symptoms and share their personal experiences on how rare dementias have impacted on their daily life and strategies of resilience.

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



The importance of supporting families affected by young onset

The Young Dementia Network webinars provide a wonderful opportunity to bring together people with experience of, or an interest in, young onset dementia to share and learn from each other.

Our Continui-tea and Stabili-tea - the importance of supporting families affected by young onset dementia webinar on 17 March, was a thought-provoking webinar. Family member Hannah talked at length about her children who were just five and six years old when her husband was diagnosed and the impact dementia has had on their family life.

Jules Knight and Lizzie Harrison spoke about the invaluable service that Admiral Nurses provide families like Hannah's in the community and other settings, and via their Helpline. You can watch a recording of this fascinating webinar via this [link](#).

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



Being honest about young onset dementia by Jane Robinson

Jane's husband was diagnosed with young onset dementia three years ago at the age of 58. She says her first instinct was to 'run and hide' and she only told a few of her closest friends about his diagnosis.

But in the years that followed, Jane has come to realise that being open and honest about Ash's dementia makes things easier for both of them.

Jane says that by raising awareness and making others feel more comfortable, we can make all the difference not only to us but to others in the future. Read Jane's piece in full [here](#).

Research opportunity for younger people with a diagnosis

The DEFIN-YD project is looking for younger people with dementia (people diagnosed 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 the condition and influence research based on your own experiences. You will be paid a small contribution, using gift cards, for your time and commitment to the project.

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 we welcome family supporters to join too if you wish.

Please contact Research Assistant [Anna Crawford](#) if you would like to get involved. For general enquiries about the project, please get in touch with the Project Lead [Dr Mary O'Malley](#) or click [here](#) for more information.

To find other dementia research opportunities, please visit [Join Dementia Research](#).



Pippa Kelly podcast featuring Peter Berry, living with young onset

Journalist Pippa Kelly has recently



Journey with music through dementia

A colourful and inspiring new guide is available from Music for Dementia to help people understand how to use and

launched her fourth series of dementia themed podcasts with an interview with Peter Berry who was diagnosed with dementia aged 50.

Peter was interviewed alongside his great friend and cycling buddy, Deb Bunt. In the interview Peter says, 'I live every day; I enjoy every day even if I might forget it moments later. They say you only live once, but that's rubbish: you only die once. You live every day. And that's what I fully intend to do.'

Listen to the podcast [here](#).

experience music at every phase of a person's dementia journey.

The Musical Dementia Care Pathway explains visually why, how, who with, where, and when people might access music to help enhance quality of life through music.

It was produced in collaboration with people with lived experience, family members and representatives from dementia and care organisations.

Find out more [here](#).

New additions to our young onset groups and blogs listings

Young onset group in north and north east Lincolnshire

The Alzheimer's Society run a focus group for younger people living with dementia across north and north east Lincolnshire. The group is held every fourth Tuesday of the month, 2pm-3pm. Each month, they discuss a different topic and gather people's experiences and feedback in order to inform local and national services and influence positive change. The group is held via Zoom. If you are interested in joining, contact 01472 359247 or send them an [email](#). Or check out their poster [here](#).

Frozen chips in the salad drawer

Chris is 53 years of age and was diagnosed with young onset Alzheimer's disease in February 2020. Following his diagnosis, he started to write a blog for his friends and family but would now love it to have a wider audience. A skilled writer, we recommend you read the oldest (first) entry first as that is the beginning of his story. Read Chris's blog [here](#).

If you are looking for young onset dementia services and groups across the UK, check out our regional listing [here](#).

Or to find young onset related blogs like Chris's, click [here](#).

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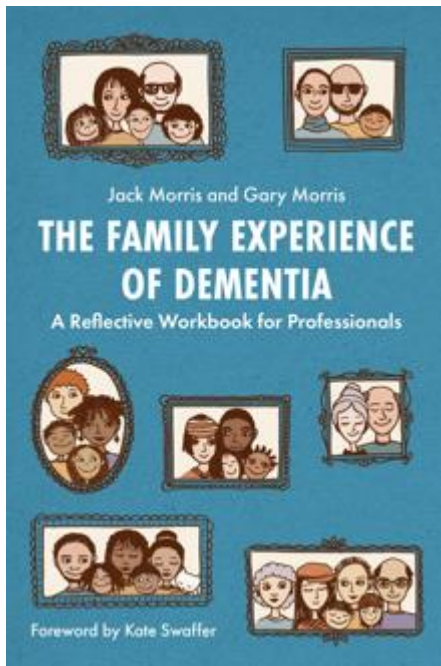
Caring and dementia: Support, advice and education - two-day online event

The Alzheimer's Show, in partnership with Dementia UK, will be delivering two days of live practical online presentations about caring and dementia on 30 and 31 March 2021.

Presentations from dementia experts will cover a wide range of topics, including sessions on rare and young onset dementias that will provide you with a better understanding of dementia

to help you support those you care for and make a positive difference, whether you are a family carer, healthcare professional or member of the public.

Find out more [here](#).



The Family Experience of Dementia - book giveaway winner!

In the February issue of Young Dementia Network News, we offered the chance to win a copy of [The Family Experience of Dementia](#), a book that provides practitioners with strategies to support the whole family and understand their dementia journey both pre- and post-diagnosis.

We are delighted to announce that the winner of the book is Helen from Leicester.

Jessica Kingsley Publishers is very kindly offering a 25% discount to Young Dementia Network members on all dementia titles ordered via their [website](#). Insert the discount code DEMENTIA25 at checkout.

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](#)



The Young Dementia Network is hosted by Dementia UK

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