

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

January 2021



## Reasons to feel positive

**At this time of year, we look for positive signs of growth in nature, in life and in our communities. Undeniably the challenges of Covid-19 continue, with a severe impact on people affected by young onset dementia. See the reports featured in this newsletter for evidence. So, is there room for hope? I think so.**

Young Dementia Network membership - we are now tipping 3,400 members – growth indeed. And all of us are keen to improve the support options for all people with young onset dementia.

To mitigate the effect of the pandemic which has diminished already inadequate young onset services, we're reviewing the Network's priorities. Let's be more sharply focussed on achieving powerful influence in these turbulent times – voicing a young onset dementia perspective where and when it counts.

With Dementia UK now hosting the Young Dementia Network, we will take a fresh look at our identity too to link us to our host. This is a great opportunity for the Network to have its own platform, communications and activities and to nurture our wonderful collaborations that bring strength to the cause.

News on more positive signs next month!

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

PS Please note - the Young Dementia Network has a new email address - [youngdementianetwork@dementiauk.org](mailto:youngdementianetwork@dementiauk.org)



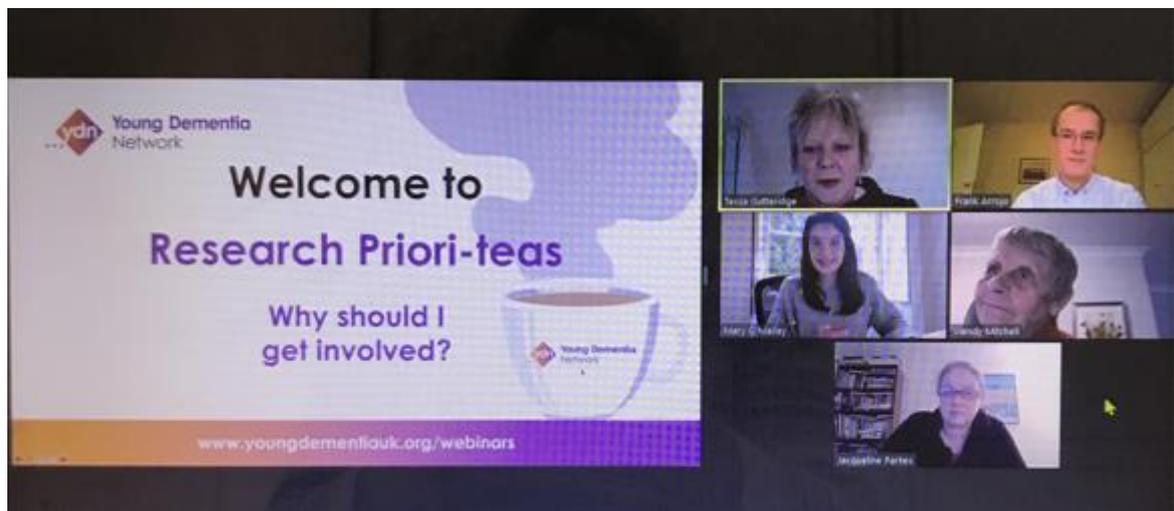
## Generosi-tea - the power of peer support webinar - 17 February

**STAND (Striving Towards A New Day) is a young onset dementia group from Fife. They are part of the UK DEEP network and Young Dementia Network.**

They will be DEEP in conversation with Rachel Niblock on Wednesday 17 February, 2.30-3.20pm, sharing the

power of the Generosi-tea that they give and receive within their group.

They will talk about difference it makes to their sense of well-being to be part of a supportive and meaningful group and a wider network. Sign up to the webinar [here](#).



## Catch up on our young onset dementia research webinar

The Young Dementia Network webinars provide a wonderful opportunity to bring together people with experience of, or an interested in, young onset dementia to share and learn from each other. If you weren't able to join us for our Research Pori-teas - Why should I get involved? webinar on 20 January, it was a fantastic interactive session.

Panellists Prof Jackie Parkes, Dr Mary O'Malley, Wendy Mitchell and Frank Arrojo shared their personal experience of a wide range of young onset research projects. Their words and the contributions of others were really inspiring.

When asked why people should get involved in dementia research, attendee Peter said, 'Quite simply, it's my duty. I want others travelling on the same road as me in later years to have an easier and longer ride.'

You can a recording of this fascinating webinar via this [link](#). You can catch up with all our past webinars on our [website](#).



**'We were given the diagnosis, told someone would be in touch in 12 months' time and then sent home'**

**Together in dementia everyday (tide) is a UK-wide charity that brings together carers of people living with dementia to share their stories.**

Keen to raise awareness of young onset dementia and the issues faced by family members, they shared a survey with their members focussing on the condition.

Their findings identified some key issues faced when caring for a person with young onset and what respondents felt would have helped them at point of diagnosis and during their time

as a carer. tide has highlighted four main areas - the need for support, the impact on relationships, the financial implications and loss.

Find out more about tide's survey [here](#) or download their report in full [here](#).

### Young onset carers group

tide offer a number of online groups to help keep family carers connected. Their Young Onset Carers Group meets virtually on the first Tuesday of every month at 10am and provides a safe space for carers to share their experiences. The group is free to attend for tide members. Find out more [here](#).



## Has your family member moved from a psychiatric ward to a care home?

**Francisca (Fran) Mada is a Professional Doctorate Student in Advanced Healthcare Practice student at Cardiff University and is also an Admiral**

**Nurse. She is carrying out a study as part of her doctoral degree to explore how we can improve the care and support of families of people with young onset dementia who have transitioned from a psychiatric ward to a care home.**

She would like to learn about your experiences from the time the decision was made to make the move to a care home and the move itself. It is hoped your experiences will help professionals to better understand what this is like and to identify where, and how, services might be improved.

If you are interested in taking part, or in finding out more, please email [MadaF@cardiff.ac.uk](mailto:MadaF@cardiff.ac.uk)

## Rare Dementia Support

Advice Community Learning

## Exploring the impact of lockdown on people living with young onset dementia

**Rare Dementia Support has published a report that explores the impact that lockdown has had on people living with young onset dementia during the first wave of the coronavirus pandemic.**

Researchers found that that people living with young onset dementia reported a reduction in the support they received, a worsening of dementia symptoms and more difficulty connecting with people socially.

People caring for people with the condition reported difficulties in both providing care and receiving support, as well as a decline in their own mental health and well-being.

Read more [here](#).



## Anna and the Beast by Christine Reddall

Christine Reddall experienced the heart-break of watching her 42 year old daughter Anna die from behavioural-variant frontotemporal dementia (BvFTD) in October 2017.

Last year she made the decision to write a book to make others aware of this little-known form of dementia. Her book titled Anna and the Beast has just been published.

Christine says, 'It was really hard to write, but I comfort myself by knowing that if I could have read a book like this when Anna was ill, it would have explained so much about what was happening her. I know Anna would approve of my writing it, and if it helps even just one family, every word will have been worth it.'

Whilst the main focus of the book is Anna, Christine has included helpful information such as links to the Young Dementia Network's [Personal Checklist](#) and [Decision-making guide for GPs](#).

Read more about Christine's book [here](#), or purchase a paperback or Kindle copy via Amazon [here](#).



## Young onset dementia research event - 28 January

On Thursday 28 January 2021, the DEFIN-YD Project will host a free virtual event focussed 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](mailto:Anna.Crawford2@uwl.ac.uk)



## Young Dementia Network resources survey findings

A big thank you to everyone who took the time to complete our recent Young Dementia Network resources survey. It provided us with lots of useful

information about how people access our resources, who they obtained them for and whether they have shared them with others.

We were thrilled to discover that 100% of respondents found the Network resources informative. 69% had heard about the resources via the website, and 1/4 had recommended them to a family member, friend or colleague.

Feedback on the [Personal Checklist](#) symptom checker included, 'Validates concerns and persuades people to seek professional help' and 'I wish I had this two years ago, very handy.'

You can view and download the Young Dementia Network resources [here](#).

---



**You have been sent this email because you joined the Young Dementia Network.  
You can leave the Network or unsubscribe from any of our mailings  
by completing [this form](#)**

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

**Dementia UK One Aldgate London EC3N 1RE Charity No 1085595**