

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

## Young Dementia Network News - September 2021



### Trying to get into the light

"Trying to get into the light" - a quote from the film Untold - Keith (link below) which in many ways is a welcome thread in this month's News. Whilst we are still enduring uncertainty and disruption in the world around us, it is uplifting to read about projects inspiring hope, encouraging the setting of life goals, and the development of new information and services for people with young onset dementia and families.

Reassuring too to be able to put in place what we can for the future - check out a recording of our latest Network webinar for legal planning advice.

We are struck both by the lively level of activity, especially on hybrid digital and face to face support, but also by how unclear national dementia plans seem to be. Our Network's collaborative community looks forward to learning more about these and offering a young onset perspective.

Tessa Gutteridge  
**Chair, Young Dementia Network**



### Young onset dementia information resources survey

We are all aware that there is a lack of information created specifically for people living with young onset dementia and their families.

The Network's host and long-term member Dementia UK is planning to improve the availability of young onset specific information and would like your help.

They would like anyone who has a diagnosis of young onset dementia or is experiencing symptoms, family members and friends to complete a short survey to help them understand what information you would like, what has been helpful and how you prefer to access/receive information.

Find out more or complete the survey [here](#). The survey closes on Thursday 14th October 2021.



## Coming up in October: Individuali-tea webinar

**Our next tea-themed webinar – Individuali-tea - tailoring care and support for individuals affected by young onset dementia will take place on Wednesday 20th October 2021.**

This webinar will present the idea of creating a toolkit for planning post-diagnostic support. Professor Jan Oyebode from the University of Bradford will be joined by Keith Oliver who has a diagnosis of young onset dementia and Reinhard Guss, a clinical psychologist.

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



## Planning for the future: webinar catch up

**In September we continued our series of young onset dementia webinars with Securi-tea – planning for the future.**

This webinar was hosted by Jacqueline Almond, a partner at IBB Law who specialises in Wills and lasting power of attorney.

Jacqueline provided financial and legal information and advice and answered questions on planning for the future.

Watch a recording of the webinar [here](#).

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

## Young onset dementia research round up

### Involvement opportunities

## **Have you or your partner received a diagnosis of young onset dementia?**

Louise Sheppard, a Trainee Clinical Psychologist at the University of Liverpool, would love to talk to you about what life was like before and after the diagnosis. She is looking to speak with couples who have been together for at least three years, where one person in the couple has young onset dementia, for up to 60 minutes in an online interview. For more information, click [here](#), or email Louise: [L.Sheppard2@liverpool.ac.uk](mailto:L.Sheppard2@liverpool.ac.uk)

## **Are you a young person with caring responsibilities for someone with dementia?**

Researchers at Bangor University are looking for participants aged 11-17 to take part in a study that aims to improve the support available to young carers. There are many secondary school children who help care for somebody with dementia (often a parent or grandparent) and there is very little support available to them. Email Patricia Masterson Algar for more information [p.m.algar@bangor.ac.uk](mailto:p.m.algar@bangor.ac.uk) or click [here](#).

## **Online peer support for people with young onset dementia**

Esther Gerritzen, a PhD student from the University of Nottingham, is interested to find out more about how people experience online peer support, and for those who don't use it, she would like to learn more about why that is. She is looking for participants with a young onset dementia diagnosis. You do not need to have any experience with online peer support in order to take part. Contact Esther on [Esther.Gerritzen@nottingham.ac.uk](mailto:Esther.Gerritzen@nottingham.ac.uk) or click [here](#) to take part in the survey.

## **Recently published research**

### **Current UK clinical practice in diagnosing dementia in younger adults: compliance with quality indicators in electronic health records from mental health trusts**

Mary O'Malley, Jacqueline Parkes, Vasileios Stamou, Jenny LaFontaine, Jan Oyebode, Jackie Campbell and Janet Carter. Click [here](#).

### **"A piece of paper is not the same as having someone to talk to": accessing post-diagnostic dementia care before and since COVID-19 and associated inequalities**

Clarissa Giebel, et al. Click [here](#).

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## **Young onset dementia / dementia related news**

**Dementia & Us, a new two-part documentary series that followed four people with dementia and their families over a two-year period is being screened on BBC2 on Tuesday 5th October and Saturday 9th October 2021.** Two of the people featured have young onset dementia - one

has familial Alzheimer's disease, the other has PCA. Click [here](#).

**Age Exchange is launching Cafe Create, a new group for people aged under 65 and their family members in the Lambeth area.** Starting on Tuesday 5th October 2021, 12-2pm, for more information, click [here](#) or email [hello@age-exchange.org.uk](mailto:hello@age-exchange.org.uk)

**Rare Dementia Support has recently launched a Suffolk based Rare Dementia Group.** They now run over 30 regional groups. Find out more [here](#).

**My Life, My Goals is a new self-help guide designed by people living with dementia and researchers from the University of Exeter.** Find out more or download your free copy [here](#).

**Moving Forward is a new guide for families and relatives involved in or supporting someone to move into a care home.** Created by carers group tide, click [here](#) to download a copy.

**The IDEAL Programme want to hear ideas from 11-18-year olds for what should feature on a new website to offer people with dementia hope, inspiration and ideas about how to live life as they choose.** The first prize is £100, deadline Friday 12th November 2021. Find out more [here](#).

**The Alzheimer's Show - a four-day programme of online presentations on 28-29th September 2021 and 12th-13th October 2021.** The event will bring together leading experts and cover all stages of living with dementia from diagnosis to end of life care. Click [here](#) for programme and ticket information.

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## **Theatre, dance, singing, film and golfing opportunities!**

**Manchester Camerata has released a powerful short film: Untold – Keith. It tells the story of Keith who is living with young onset dementia.**

It is a deeply personal account of how dementia affects his everyday life and that of his wife Joan. With an all-star cast, the film shows how it feels to live with dementia as well as the transformative ways in which music can help. Watch Untold - Keith [here](#).

**Beatrice Allegranti's Moving Kinship** is a psychosocial dance theatre project funded by Surrey Arts and Arts Council England. They are looking to reach people in Surrey living with young onset dementia to participate with a view to creating a supportive and sustainable network that will continue beyond the life of the project. They are running six hubs in Surrey on 24th September and 8th October 2021 at Camberley Theatre, 6th and 20th November 2021 at Riverhouse Barn Arts Centre and 26th November and 3rd December 2021 at Guildford Library. These events are subsidised by Surrey

Arts and Arts Council England and are free of charge. Please contact Rachel Crookes on 07927 327771 or click [here](#) for more information.

**The Southwark Playhouse is running a weekly drama workshop for adults with a diagnosis of young onset dementia and their family members / carers.** They are currently recruiting participants for the project which will run every Friday morning at 10-11.30am until Friday 14<sup>th</sup> December 2021. For further information click [here](#) or contact David Workman on 07732 249159 or email [david.workman@southwarkplayhouse.co.uk](mailto:david.workman@southwarkplayhouse.co.uk)

**Dementia-friendly performance of Carmen on Tuesday 26th October 2021 at 1.30pm at Leeds Grand Theatre.** Bright lighting and loud noises will be reduced, quiet spaces outside the auditorium will be available and there will be a relaxed attitude to people leaving and returning if people need a break. For information, click [here](#).

**Lichfield Garrick is presenting a dementia-friendly screening of the new James Bond film 'No Time To Die' on Wednesday 27th October 2021 at 2pm.** They would love younger people living with dementia to attend. For more information, click [here](#).

**Turtle Song is a singing and song-writing project for people living with dementia and companions.** It's a unique musical and creative experience, led by professional musicians, workshop leaders and music students. They will be running a project at **Chetham's School of Music in Manchester** on Thursday afternoons from 2.15pm-4.00pm, starting on Thursday 7th October 2021, with a final sharing performance on 9th December 2021 for family and friends. If you are interested in taking part, please complete this [form](#), email Ellen McGahey [ellen@turtlekeyarts.org.uk](mailto:ellen@turtlekeyarts.org.uk) or call 020 8964 5060.

**Dementia-friendly golf project at Mearns Castle Golf Academy, Glasgow supporting people with dementia to play golf.** Welcoming existing golfers and newcomers, they are keen to help people to stay connected, active and purposefully engaged in a supported environment. They offer a Thursday afternoon group from 3-5pm and 1:1 or bespoke supported sessions. There is a nine-hole course, driving range, short game area and a four-seater buggy to get around. Click [here](#) for more information.

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## Thanks for your help with Dementia UK's digital survey

**Earlier this year, Dementia UK carried out a survey to explore whether digital health information, care or support solutions are acceptable to people living with dementia and their family members.**

It was an all-age survey; 13 people living with young onset dementia and 34 family carers of people with younger people with dementia took part. An

overwhelming majority reported that they use digital technology every day, mostly using a mobile phone /smart phone.

Over 70% said that accessing digital information or resources specifically about young onset dementia was of particular interest but for some, lack of confidence and knowledge was a barrier; a few also said that they were limited by a physical, hearing or sight disability.

Dementia UK would like to say a big thank you to everyone who took part. Your replies will help Dementia UK understand how best to develop digital support services for people living with dementia, including people with young onset dementia and their families.



## Resource showcase – young onset dementia group guidance

**Peer support groups are a lifeline for many people affected by young onset dementia but provision is lacking in parts of the UK.**

So we have put together some guidance which shares suggestions and ideas to help people who are considering setting up a group specifically for younger people, either face to face or online. Find out more [here](#).

You can download or request other Young Dementia Network resources [here](#).



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