

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

June 2021



## Loneliness and young onset dementia

This week is **Loneliness Awareness Week**. Many people affected by young onset dementia know no one in a similar situation and coupled with a lack of support, it can lead to them feeling very isolated.

**Jane's story** shares the feelings she experienced after her husband was diagnosed with young onset dementia. It is a story we know many will identify with.

The Young Dementia Network wants to reduce the isolation and loneliness people affected by young onset dementia feel. This newsletter shares some ways you can connect with others, make a positive difference by getting involved in research and be uplifted by the words of younger people living with dementia.

**Tessa Gutteridge**  
Chair, Young Dementia Network

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## Rare Dementia Support

Advice Community Learning

### New online young onset Alzheimer's disease support group

In March 2021, Rare Dementia Support launched a new online support group for people affected by young onset Alzheimer's disease.

Their next meeting is taking place on Friday 25th June 2021, 2.30-4.00pm. The theme of the meeting will be young onset Alzheimer's disease and work. They will consider the difficulties that an Alzheimer's diagnosis brings to people who are of working age, the implications for people who choose to continue to work and also the difficulties of giving up work, sometimes at short notice.

Rare Dementia Support kindly ask anyone interested in joining the group to **sign up** as a member so they can keep you updated with invitations and newsletters. A recording of the meeting will be available on the **Rare Dementia Support YouTube channel** after the meeting takes place.

For more information about the group, please email

[contact@raredementiasupport.org](mailto:contact@raredementiasupport.org)



## Adapting to the easing of Covid restrictions webinar - Wednesday 21st July 2021

Join us with a cuppa on Wednesday 21st July 2021, 2.30-3.30pm for our next young onset dementia webinar, Normali-tea – adapting to the easing

of Covid restrictions.

This webinar will be a discussion between members of the PACE (Positive Activists Consultants and Educators) group, part of Young Dementia Oxfordshire, who are all younger people who live with a dementia diagnosis.

The group will tackle issues such as the loss of confidence and the anxiety people living with young onset dementia face as Covid restrictions are eased.

They will offer their thoughts and suggestions on how to return to being active, involved and part of the community, and how people can gradually rebuild their lives.

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



young onset dementia.

## Webinar catch up: Activities and the impact on people living with young onset dementia

On Wednesday 16th June 2021, we continued our series of young onset dementia webinars with Activi-tea – activities and the impact on people living with

Led by Mark Hainy and Karen Ive of YPWD Berkshire alongside people with young onset dementia, their family members and Dr Jacqui Hussey the webinar gave a fascinating insight into the benefits of engaging in meaningful physical and creative activities.

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



Make breakthroughs possible

## New policy reports - improving dementia diagnosis and clinical trials

**Dr Susan Mitchell, Young Dementia Network steering group member and Head of Policy – Prevention, Early Detection and Diagnostics at Alzheimer's Research UK has asked us to share their new policy reports on improving dementia diagnosis and clinical trials.**

**The Right to Know: Accurate and Earlier Diagnosis of Dementia** outlines a stepwise approach to progressively build dementia diagnostics capability in the UK and prepare the health system for the changes that may come.

**Are we ready to deliver disease modifying treatments** is a joint report with the Royal College of Psychiatrists. The report lays out key recommendations that need to be addressed now to prepare services for new life changing treatments and to improve services' ability to meet national guidelines and provide appropriate diagnostics to those currently living with dementia.

**Translating Science into Breakthroughs: the future of late-stage clinical trials in the UK**, published in May 2021 to mark International Clinical Trials Day, sets out how the UK can become a global leader in clinical research, with a focus on overcoming barriers to participation for late-stage dementia trials.



### 'Moments' - a song inspired by the words of Wendy Mitchell

**Smitten Fox Productions are a song writing duo from Leeds. They have written a musical called 'Once Lost' about living with dementia which they hoped to stage at this year's Edinburgh Fringe Festival.**

Sadly, this has not been possible due to Covid, so instead they have released a beautiful song titled 'Moments' that was written for the musical. 'Moments'

addresses the reality of living with dementia and presents the idea of embracing each moment. Wendy Mitchell, a Young Dementia Network steering group member who lives with young onset dementia, directly inspired the song.

The Smitten Fox team wrote it after meeting her in November 2019 and when Wendy heard it she said, "Wow, that was wonderful! It just captured instantly what living in the moment is like. It captured instantly that time

takes a different perspective with dementia. It's precious and you just have to live from minute to minute."

Watch a recording of Moments [here](#) or follow Once Lost on Twitter: [@oncelostmusical](#)

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## Young onset dementia research round up

### Involvement opportunities

#### **Do you have a parent diagnosed with an inheritable type of dementia?**

Researchers from Hunter College, New York, the University of Sheffield and Manchester Metropolitan University are interested in understanding the impact on children who are now 18 years of age or older of having a parent with an inheritable type of dementia and their thoughts about genetic testing in order to better support such individuals and their families.

If you are 18 or older and have a parent with an inheritable form of dementia, they would be interested in talking to you about your experience, and about your thoughts around genetic testing. They are hoping that what you have to tell them will help support other people in your situation.

The research is being led by Caroline Gelman, Ph.D., Associate Professor of Social Work at Hunter College, New York and Pat Sikes, Ph.D., Emeritus Professor, School of Education, University of Sheffield, England. If you are interested in participating in an interview or have further questions, please contact Pat: [p.j.sikes@sheffield.ac.uk](mailto:p.j.sikes@sheffield.ac.uk)

#### **Prepared: understanding and improving support to help people with dementia and their carers prepare for advanced illness and end of life. A study funded by the Alzheimer's Society.**

Researchers from the London School of Economics and Political Science are looking to interview people living with dementia and / or family carers who have been directly involved in:

- an advance care planning discussion (or any discussion about future care with a GP or other professional)
- completing an advance statement or advance directive
- informal discussions between people with dementia and carers / family members about future care (even if there has been no discussion with professionals or ACP documentation)

Interviews would last an hour and could be conducted in person at your home or online, as you prefer. Taking part is entirely voluntary and you can change your mind at any time. All information you provide will be treated confidentially and no-one will be identified in any reports produced. The research aims to improve support for people with dementia and their families. You will receive £30 as a thank you for your participation.

For more information, contact Josie Dixon: [J.E.Dixon@lse.ac.uk](mailto:J.E.Dixon@lse.ac.uk) tel: 07989 070777 or Jackie Damant: [j.damant@lse.ac.uk](mailto:j.damant@lse.ac.uk)

### Recently published research

## **The use of Twitter by people with young onset dementia: A qualitative analysis of narratives and identity formation in the age of social media**

Catherine V Talbot, Siobhan T O'Dwyer, Linda Clare, Janet Heaton, 2021 - click [here](#)

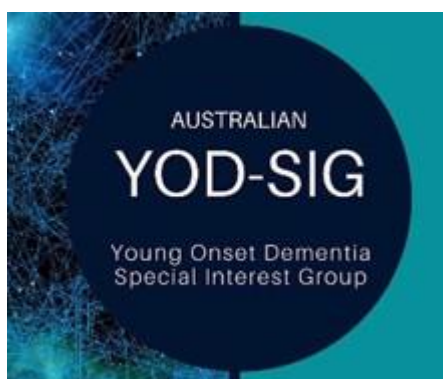
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To find other dementia research opportunities, please visit the [Current research studies](#) page on the Young Dementia Network website or the [Join Dementia Research](#) website.

To view a collection of research focusing on the most prominent subjects relating to young onset dementia visit the [Research and evidence](#) section of our website.

If you would like us to share a research study or recently published paper, please [email us](#).

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## **Australian Young Onset Dementia Special Interest Group webinars**

The Australian Young Onset Dementia Special Interest Group is hosting two free young onset dementia webinars in June and July that time zones permitting may be of interest to our members.

### **Young onset dementia: identifying the signs and diagnosis must do's**

Friday 18th June 2021, 2.30am-3.30am GMT / 12.30pm-1.30pm AEST  
Register or find out more [here](#).

### **Young onset dementia: Maximising independence with quality care**

Thursday 15th July 2021, 2.00am-3.00am GMT / 12.00pm-1.00pm AEST  
Register or find out more [here](#).

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**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](#).**

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**Join the  
Network**



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

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