

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

May 2021



Dementia Action Week - this week, every week

This month's News is action-packed. From supporting the campaign to cure the care system, highlighting the benefits of working, activity and nature, to getting involved in research opportunities and sharing your experience of Continuing Health Care funding - the Network and its members is all about taking action to improve the lives of people affected by young onset dementia.

Tessa Gutteridge
Chair, Young Dementia Network



Introducing Catherine Kiely...

The Young Dementia Network has recently recruited a new member of staff. We are delighted to welcome Catherine Kiely as the Young Dementia Network Coordinator.

Catherine will be coordinating the activities of the Network, working closely with the steering group and members to help achieve the aims and objectives.

Prior to taking on this role, Catherine worked for YoungDementia UK for a number of years, looking after their database.

She has personal experience of dementia as her dad was diagnosed with frontotemporal dementia in his 60s. She is looking forward to the new challenge and helping to improve the lives of people living with young onset dementia.



Activities and the impact on people living with young onset dementia webinar - Wednesday 16th June 2021

Join us with a cuppa on Wednesday 16th June 2021, 2.30-3.30pm for a webinar, **Activi-tea – activities and the impact on people living with young onset dementia.**

This interactive webinar will see Mark Hainy, Director and Karen Ive, Service Manager of YPWD Berkshire explore the impact of regular activity, be it physical or cognitive, by talking to people with young onset dementia who participate in it.

Family members will join the discussion to give their thoughts on what they see as a result of regular activity, whilst Dr Jacqui Hussey, a Consultant Psychiatrist will provide a clinical viewpoint.

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



Webinar catch up - stress and distress in dementia

in dementia.

On Wednesday 19th May 2021, we continued our series of young onset dementia webinars with Intensi-tea – stress and distress

This webinar focused on why a person living with young onset dementia may experience increased feelings of stress and distress, and how you might help them manage these feelings. Lissy and Sue from Dementia Carers Count facilitated this fascinating webinar and were joined by Sarah and Jill who each support husband's living with young onset dementia.

It was an enlightening webinar, full of interesting information, helpful tips and suggestions. Jill said, "Glean as much information as you possibly can. As carers we beat ourselves up, but the more you understand, the better you can cope with it and help them."

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

Work after a diagnosis of dementia

by Martin Robertson

New peer to peer resource: Work after a diagnosis of dementia

A new resource has been launched to provide information and support for people living with dementia who are thinking about or have given up work due to their diagnosis. Written by

Martin Robertson, who has young onset dementia, it is full of useful information about reasonable adjustments, benefits and more.

Martin says, "I hope that this booklet encourages people to look beyond the boundaries, and perceived shame, of receiving a dementia diagnosis. Most importantly, my wish is that people can find fulfilment in a life with dementia and be able to find some sort of activity that they can enjoy: many studies have shown that using the brain is helpful for one's general physical health, and this does not stop being the case if one has dementia. Focus on what you can do and keep striving."

Download Martin's booklet [here](#).

Young onset dementia research round up

Involvement opportunities

Volunteering in young onset dementia research project

Rose Vincent is a PhD candidate at the University of Edinburgh and funded by Alzheimer's Society. She is currently looking for a small, diverse group of people living with young onset dementia to join a research project on volunteering in young onset dementia, which is guided by the principles of co-production. The work will be done online, using Zoom and co-researcher's will be paid for their time in vouchers at the rate of £20 per hour. It is expected the work will involve 20 hours of time spread over six-eight months. For more info, please contact Rose on r.e.vincent@sms.ed.ac.uk or via Twitter [@roseevincent](https://twitter.com/roseevincent)

Research project - accessing dementia treatment and support services in Oxfordshire / Warwickshire

As part of a Warwick University research project, researchers want to talk to people about their experiences, and what problems they have faced, accessing dementia treatment and support services and share ideas that could help. If you live in either Oxfordshire or Warwickshire, and are interested in sharing your story and experiences, please email the lead researcher, [Dr Rene Wiedner](mailto:Dr.Rene.Wiedner) or call 07387 238359.

Forget-Me-Not research group - Swindon / Bristol

The Forget-Me-Not research group was founded by three researchers living with dementia, Roy James, Harry Davis and Sandy Read. Dr Joseph Webb and Dr Jemima Dooley (University of Bristol) support and collaborate with them in their research. They meet once a week, currently via Zoom. New members are welcome. Find out more [here](#) or email forgetmenot.research.group@gmail.com.

Recently published research

Research paper - post-diagnostic services

Helpful post-diagnostic services for young onset dementia: Findings and recommendations from The Angela Project (May 2021) Read the paper in full [here](#).

Research paper - the financial impact of a diagnosis of young onset dementia

Understanding the financial impact of a diagnosis of young onset dementia on individuals and families in the United Kingdom: Results of an online survey – Andrea Mayhofer, March 2021. Read the paper in full [here](#).

Research paper - the effect of Covid-19 on social support services and social care for dementia and older adults

Covid-19-related social support service closures and mental well-being in older adults and those affected by dementia: a UK longitudinal survey - Dr Clarissa Giebel et al, May 2021. Read the paper in full [here](#).

Innovations in Dementia and Dementia Enquirers - new website

Innovations in Dementia has launched their new website [Dementia Voices](#) which brings together all their National Lottery funded work. The [Dementia Enquirers](#) section includes the first seven reports from this research programme which were led and controlled by people with dementia.



Share your experience of the continuing healthcare (CHC) process

Dementia UK would like to find out more about your experiences of the NHS continuing healthcare (CHC) process to help inform an upcoming

campaign.

Were your experiences good or did you face challenges? How can CHC be improved?

They are looking to hold individual telephone interviews with family carers in June and July 2021. Places are limited. If you are interested in speaking to them, then please do get in touch. Email campaigns@dementiauk.org

Interviews should take no longer than an hour and you will have the option of full anonymity if you prefer.

Young onset dementia news in brief...

Peer support network for adults aged 16-24

Royal Museums Greenwich, in partnership with Dementia UK Admiral Nurses and This is Dementia, is setting up a new network for young people who support someone living with dementia. This will be a chance to share

experiences as well as to get both peer and professional support. Click [here](#) to find out more, or email learning@rmg.co.uk

Specialist nursing home for people with young onset dementia opens in Surrey

A new specialist nursing home has opened in Mytchett, Camberley for 42 residents across four specialised units; each designed to support varying complex care and neurological needs as well as provide a comfortable, safe home. Marula Lodge accepts people living with conditions including young onset dementia, Huntington's disease, Parkinson's and Korsakoff's syndrome. For more information click [here](#) or email referrals@cornerstonehc.co.uk

Bromley Mindcare - young onset dementia group pilot starts in July 2021

If you live in Bromley, Lewisham or Greenwich, there is an opportunity to take part in a young onset dementia pilot over 12 weeks starting in July 2021. Sessions will be once a week for 1.5 hours. Participants will shape the group and decide what it will be called and what activities will be included. Unfortunately, they cannot provide transport to the venue. Places are limited. If you are interested in joining, please contact Saira Addison via [email](mailto:) or tel 07764 967929.

Dynamos club: Isle of Sheppey based young onset group is looking for new members

The Dynamos club is run by Age UK Sheppey and is a group for people with young onset dementia. The club is currently closed due to the Coronavirus outbreak but is running an online session every other Thursday afternoon at 2pm. The aim of the club is to encourage participation in purposeful activity to develop and maintain active minds and bodies, provide a good social atmosphere with people with similar needs and to provide peer support. They are keen to recruit new members. Email [Sheran Mozesh](mailto:) (facilitator) to find out more.

Dementia Adventure launch 'Nature is calling' drop-in sessions for family members / friends

Dementia Adventure is offering free, informal, online drop-in sessions for unpaid supporters of people living with dementia. During the sessions they will discuss why getting outdoors is essential to the wellbeing of people with dementia, and how to overcome any barriers to getting outdoors. The sessions will give you the knowledge and practical guidance you need to connect to nature confidently. Find out more [here](#).

Dementia Action Week - Liverpool City region - young onset dementia events - 21st May 2021

As part of Dementia Action Week, Liverpool City region is running a busy programme of dementia-related events. On Friday 21st May 2021, the Alzheimer's Society will be hosting a series of young onset dementia presentations and discussions focusing on Understanding young onset dementia, Finance and legal matters, Taking part and living well and Caring for someone with young onset dementia. Find out more [here](#).



Dementia Action Week - Alzheimer's Society - Cure the care system

Right now, the broken social care system means that in the UK, nearly one million people with dementia and their families are struggling to get the support and care that they need and deserve.

Decades of underfunding and neglect have led to a care system that's difficult to access, costly, inadequate and deeply unfair. The coronavirus pandemic has exposed these problems like never before. It doesn't have to be this way.

That is why we are standing with Alzheimer's Society this Dementia Action Week. They are calling on governments to cure the care system now. To provide quality social care, that is free and easy to access, no matter where you live. Because while dementia isn't curable yet, the care system is.

Sign their petition [here](#). Watch their hard-hitting short film [here](#).

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](#).

**Join the
Network**



The Young Dementia Network is hosted by Dementia UK

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