



Dear Member

Do you feel the need to look for a glimmer of light amidst the autumn mist and mayhem? I do.

'Diagnosed then dumped' was a stark and dark comment at a recent young onset dementia event which powerfully highlights the need for positive action from all of us.

So, if you are looking for something uplifting, this issue of the Network News is full of opportunities to get involved in research and campaigns, become better informed on vital issues and connect with others who are keen to improve young onset dementia services.

Tessa Gutteridge

Chair, Young Dementia Network

Young onset dementia webinars

Young onset dementia and general practice – identifying symptoms before diagnosis

Our webinar on Wednesday 16th November 2022 will focus on the first symptoms of young onset dementia and how to increase their recognition by GPs and better identify people with young onset dementia at an earlier stage.

This webinar will be presented by Professor Marjolein de Vugt and Dr Stevie Hendriks who are both members of the Young Onset Dementia Knowledge Center, a network of organisations committed to excellent care and support of younger people with dementia in the Netherlands. They will present the results of a recent study on pre-

diagnostic symptoms of young onset dementia. A family member of a person living with young onset dementia will also share their views.



16th November 2022



12.30-1.30pm

[**Sign up here**](#)

Why numbers matter and change is possible

Our webinar in October featured Dr Janet Carter, Associate Professor in Old Age Psychiatry and Michael Jackson, Programme Lead for Neurology and Dementia Intelligence, Department of Health and Social Care.

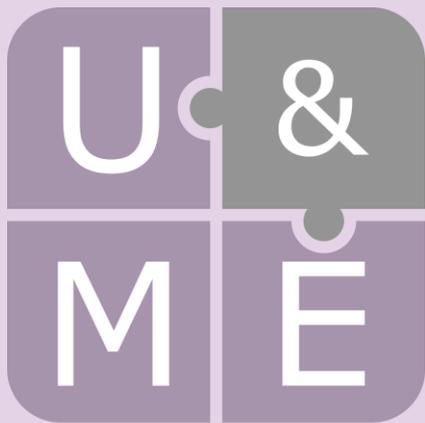
They were joined by best-selling author and blogger Wendy Mitchell who is living with young onset dementia, Sheila Fletcher, Commissioning Manager, Mental Health and Vulnerable Adults at Humber and North Yorkshire Health and Care Partnership and Helena Hounslow, Mental Health Programme Manager at NHS Lancashire and South Cumbria Integrated Care Board.

They shared their views on why the number of people living with young onset dementia matters, how commissioners could use the data and what needs to happen next if we are to make the most of the data to create change.

[**Watch the webinar here**](#)

You can catch up with recordings of our tea-themed webinar series from October 2020-June 2022 on our website [here](#).

Dementia Forward is launching a young onset dementia national awareness day



DEMENTIA FORWARD

On 24th October 2022, Network member Dementia Forward is launching a Young Onset Dementia Awareness Day to raise awareness of the condition, tackle stigma and champion change.

They plan to make it an annual awareness raising day to be held on 24th October each year. They are asking us all to use #YODA to join the conversation on social media and raise awareness on the day. Find out more about their plans [here](#).

As part of their awareness raising activities, this year they are inviting people to join them to 'create a voice for young onset dementia' by taking part in their [U & Me campaign](#). The campaign launches on 31st October 2022, and whether you are living with young onset dementia, a professional working in the field or a supporter, your voice matters and they want you to be part of it.

[Find out more here](#)

Young onset dementia and dementia-related news

An evening with Wendy Mitchell, 25th October 2022

Wendy Mitchell was diagnosed with young onset Alzheimer's disease in 2014, aged 58. Since her diagnosis she has become a leading dementia activist, blogger and best-selling author. On Tuesday 25th October 2022 at 6.30pm,

she will be speaking at an event in Salisbury, Wiltshire. Tickets are £10. For more information, click [here](#).

UK Dementia Congress, 8-9th November 2022, Aston University, Birmingham

This two-day conference features a number of speakers with lived experience of young onset dementia as well as sessions on topics relating to the condition. Check out the conference programme [here](#) or visit the website [here](#).

"But you're too young to have dementia"

Professor Jan Oyebode will lead two young onset dementia sessions as part of the University of Bradford's '50 shades of dementia' course. They take place on Monday 14th November and Monday 21st November 2022 from 9.30am-1.30pm. Book your place [here](#).

Theatre Re's The Nature of Forgetting

The Nature of Forgetting is a play which portrays Tom, a 55-year-old father who is living with young onset dementia. The play goes on tour in 2023 with dates at Shoreditch Town Hall, London from 18th-22nd January; The Lowry, Salford from 30th-31st January; Edge Hill University, Ormskirk from 2-3rd February; Northern Stage, Newcastle from 17th-18th February and The Lighthouse, Poole from 6-7th June. Book your place [here](#).

Creative arts taster session, 7th December 2022 in Derby

If you are under 65 and living with dementia, or are a family member, friend or carer of someone with the condition, you are invited to take part in a fun creative arts taster session on Wednesday 7th December from 2-3.30pm. Find out more [here](#).

Young onset dementia coverage on the BBC

Two recent television programmes on the BBC have provided a showcase for people living with young onset dementia to share their stories and raise awareness of the condition. [Our Dementia Choir with Vicky McClure](#) and [Rugby, Dementia and Me](#) featuring Steve Thompson MBE are available to watch on iPlayer.

Young onset dementia research round-up

Involvement opportunities

Experiences of using public transport

This research project is being led by eight people who are living with dementia, with support from Innovations in Dementia and funding from Motability. They want to find out about the impact of public transport on people's mental health. If you are living with dementia and use public transport (sometimes or often) they would love you to get involved. Find out more about the project [here](#) or fill out their online survey [here](#).

Are you 11-17 years old and providing care for someone living with dementia?

iSupport for YC is a research study funded by the National Institute for Health Research that aims to improve the support currently available to young carers of people living with dementia. They are looking for people aged 11-17 to user-test and give feedback on iSupport for YC – an internet-based package designed to support young carers of people living with dementia. Participants will receive a £20 Love2Shop voucher for taking part. Watch the advert video [here](#) or email Patricia Masterson Algar at p.m.algar@bangor.ac.uk for more information.

Recently published research

Keeping the conversation going: how progressivity is prioritised in co-remembering talk between couples impacted by dementia

Felicity Slocombe, Elizabeth Peel, Alison Pilnick, Saul Albert

Read the research article in full [here](#).

Suicide risk in the first three months following a dementia diagnosis for patients aged under 65 is nearly seven times higher than in patients without dementia

Danah Alothman, Timothy Card, Sarah Lewis, et al

Read the research article in full [here](#).

Non-affective psychotic disorders could increase risk of dementia in

younger patients

Sara El Miniawi, Vasiliki Orgeta, Jean Stafford

Read the article in full [here](#).

For current dementia research opportunities, click [here](#), or visit the [Join dementia research](#) website.

To view a collection of research relating to young onset dementia, click [here](#).

Healthwatch Bucks –young onset dementia survey

Healthwatch Bucks is looking for people who live in the county to share their experiences of care for young onset dementia in Buckinghamshire.

If you have a young onset dementia diagnosis yourself, or care for someone who has, you are invited to take part in a survey. The responses will feed into a set of recommendations that they hope will improve care for people in the county in the future.

[Take part](#)

Profile: Jules Knight, Consultant Admiral Nurse for Young Onset Dementia

Jules Knight is a dementia specialist Admiral Nurse at Dementia UK specialising in young onset dementia. Her role involves raising awareness of the condition, supporting other professionals working with families living with the diagnosis, and developing new information resources.

She also provides emotional support and practical advice to families affected by young onset dementia by telephone and online following referrals from

the [Admiral Nurse Dementia Helpline](#) and [virtual clinics](#) team.

[Find out more](#)

Resource showcase: Young onset dementia groups guidance



Age-appropriate support is lacking in many parts of the country. The Young Dementia Network is keen to encourage people to set up groups for the under-65 age group.

We have worked with a young onset dementia groups coordinator from Oxfordshire to create a guidance document to help people set up and run a successful young onset dementia group.

[Download here](#)

If you know of any helpful young onset dementia resources, please share them with us.

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[Join the Network](#)

[Our resources](#)
