

Myth busting

Today is World Alzheimer's Day, an awareness raising day that has been observed for nearly 30 years to educate people around the globe about the causes, symptoms and emerging treatments for Alzheimer's disease.

Improving our understanding of Alzheimer's and other dementias is slowly reducing the stigma and fear. Individuals are increasingly prepared to be open about their own diagnosis. People with young onset dementia are particularly influential in demonstrating positive ways to adapt to life with dementia. This simultaneously challenges negative mindsets and that dementia is the preserve of old age.

Around a third of the estimated 70,800 people living with young onset dementia in the UK have Alzheimer's disease. In fact, the first person diagnosed with Alzheimer's disease in the 1900s was just 51 years old.

This month, our Young Dementia Network steering group shared the efforts being made to ensure that there is more education about young onset dementia and its different impact - at every level - for those with Alzheimer's disease and other types too. Myth busting must mean change for the better.

Tessa Gutteridge
Chair, Young Dementia Network

Young onset dementia webinars

Increasing awareness and opportunities for genetic testing

Service improvement project to support the person with young onset dementia and their family

The diagnostic process for younger people with dementia should include access to genetic testing if required, however this is often not routinely available.

 **Wednesday 18th October 2023**

 **12.30-1.30pm**

[**Register today**](#)

The Wokingham Memory Clinic and Oxford Centre for Genomic Medicine have developed a multidisciplinary approach to ensure genetic testing can be considered for younger people with dementia and their families.

Dr Jacqui Hussey, Consultant Old Age Psychiatrist and Lead Consultant for the Memory Clinic in Wokingham, will lead the webinar and alongside expert panelists who will describe this shared pathway, the unique role the dementia specialist Admiral Nurse plays and the positive outcomes for the service.

Memory clinics and the NHS England Genomic Medicine Service

England's NHS Genomic Medicine Service (GMS) is working with different medical specialities to integrate genomic testing into routine care. We will consider how this applies to the investigation of young onset dementia in memory clinics.

 **Wednesday 15th November 2023**

 **12.30-1.30pm**

[**Register today**](#)

Dr Nick Bass, Honorary Consultant Psychiatrist, UCL Division of Psychiatry and Tower Hamlets Memory Clinic, will lead the webinar and alongside Jana Mikova, Clinical Nurse Specialist in Genomic Medicine, explain the North Thames Genomic Medicine Service Alliance transformation project to embed genomic investigation in mental health service-provided memory clinics.

They will go on to discuss implications and initiatives at the national level to promote easy and equitable access to genomic investigations for younger people undergoing dementia assessment.

International young onset dementia webinars – an opportunity to influence what is featured

The Young Dementia Network and the Young Onset Dementia Knowledge Centre, Netherlands, are planning a series of young onset dementia webinars in 2024.

We want the webinars to be useful and accessible to a wide audience and would love to hear which topics you would most like them to cover. Click [here](#) to complete a short survey containing a list of topic ideas; it takes less than a minute to complete.

Member showcase: Hilda Hayo, Chief Admiral Nurse and CEO, Dementia UK



Hilda Hayo recently celebrated her 10th anniversary as Chief Admiral Nurse and CEO of Dementia UK. She is also a founding member of the Young Dementia Network steering group.

To mark this milestone, we put a series of questions to Hilda including whether she feels awareness of young onset dementia has grown in the last 10 years, what improvements there have been around diagnosis and support, why she joined the Network and what changes she'd like to see in the future.

[Read Hilda's Q&A here](#)

Young onset dementia and dementia-related news

Tipping point: The Future of Dementia Care

Alzheimer's Research UK has published a report that sets out a series of calls for party leaders ahead of the next general election. They believe these recommendations are vital to tackle the increasing pressure that dementia places on society, the NHS, and the economy. Read the report [here](#).

World Frontotemporal (FTD) Awareness Week

World FTD Awareness Week runs from Monday 25th September to Sunday 1st October 2023. If you want to learn more about FTD, Dementia UK has leaflets about [Understanding frontotemporal dementia](#) and [Understanding genetic forms of dementia](#), and [Rare Dementia Support's website](#) provides information and support around FTD.

From research to practice: solutions to improve dementia and ageing care

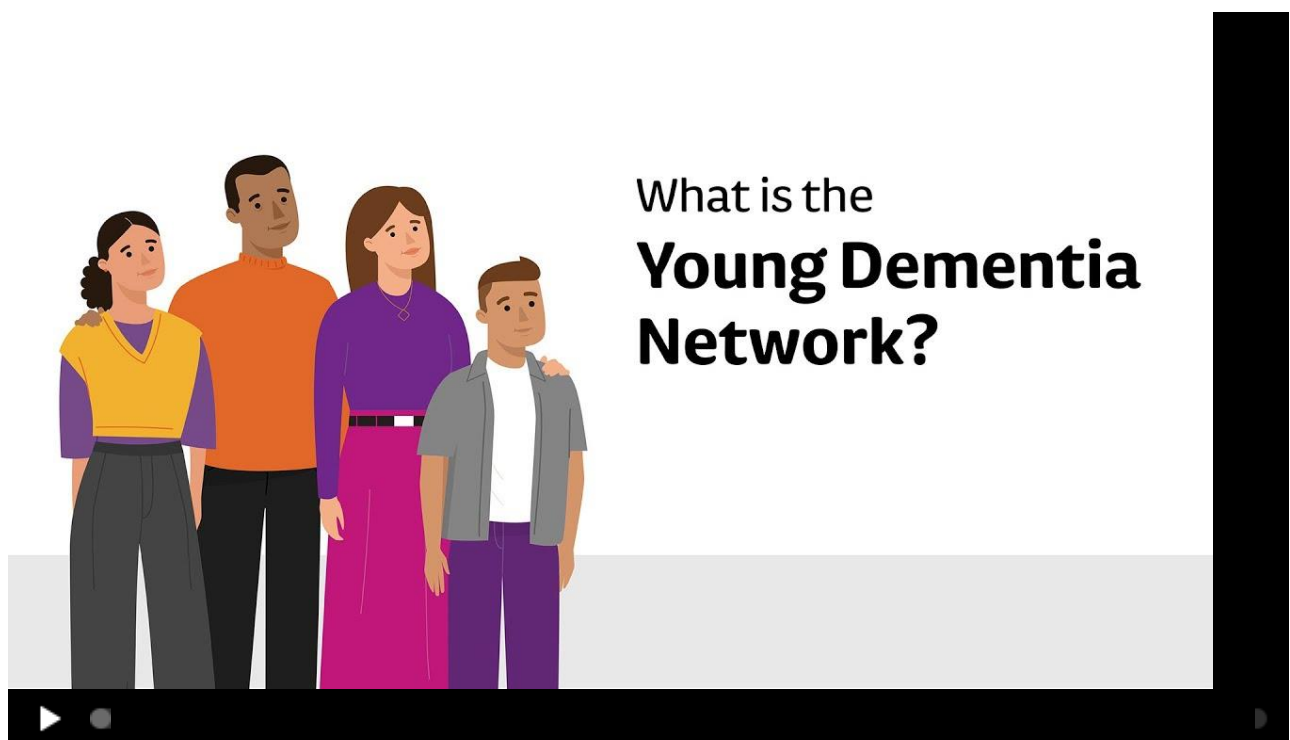
The fifth Annual Liverpool Dementia and Ageing Conference takes place on Wednesday 25th October 2023. A number of free tickets are available for people living with dementia and unpaid carers. Find out more or register [here](#).

UK Dementia Congress at Aston University, Birmingham

Tickets and programme information are now available for the UK Dementia Congress on Tuesday 7th and Wednesday 8th November 2023. The programme includes a talk by Dementia UK's Consultant Admiral Nurse for Young Onset Dementia, Jules Knight, and speakers living with young onset dementia. Click [here](#) to find out more.

Alzheimer's Research UK annual clinical conference

Alzheimer's Research UK will host its fourth annual clinical conference on Friday 10th November 2023 at the Royal College of Physicians, London and online. The primary purpose of the conference is to bring UK dementia healthcare professionals together to discuss the latest research and innovations, and future policy and research implications on clinical practice. For more information visit its [website](#).



Check out the Network's new animation

We have created a short animation to explain in brief what the Young Dementia Network is, what it does and how to join, told from the perspective of a person living with young onset dementia.

You can watch the animated film via [this link](#) – we hope you like it. Please feel free to

share the animation with others.

Young onset dementia group information

Halifax young onset dementia group

This group is open to people with a diagnosis and their family members. The group meets on the first Friday of the month from 10.30am-12.30pm at Brewers Fayre Water Mill, Halifax, HX3 0QT. Email Julie at juliehayden@rocketmail.com or click [here](#) for more information.

Young onset dementia support group, Chesterfield

The group meets every other Monday from 10am-12.30pm at the Sorbo Lounge, Chesterfield, S40 1TW. It offers support and signposting to people living with dementia and those who care for them. Contact jansugar@live.com or click [here](#) for more information.

Young onset dementia peer support group, Basingstoke

Andover Mind has launched a group which meets on the third Friday of each month from 10.30am-12pm at Dashwood Manor Care Home Cafe, Bradley Way, Basingstoke, RY3 7GF. The group provides support and information for people with young onset dementia and their family members. Find out more [here](#).

Did you know that the Dementia UK website has a unique database of young onset dementia groups and services? Check it out [here](#). Please let Dementia UK know via the links on the webpage if a group you attend or run is not listed or if its details need to be updated.

Young onset dementia research round-up

Involvement opportunities

The lived experiences of former athletes living with young onset dementia

Loughborough University student Kieran McGee would like to speak to people living with young onset dementia who are former athletes or have a history of playing sport. Find out more [here](#).

How do you use technology to manage your young onset dementia?

University Hospital, Southampton is carrying out research to better understand how people with young onset dementia use digital health technology such as video consultations and mobile health apps or search the internet for health information or

support. Further information and a link to the survey can be found [here](#).

Understanding family carers' experiences of providing personal care for someone living with dementia

Are you a current or previous family carer of a person with dementia with direct experience of providing them with personal care? If so, researchers from the University of Worcester would like to hear from you. Find out more [here](#), or complete their survey [here](#).

Dementia and hearing loss

Clare Burgon, a research assistant at the University of Nottingham, is looking for participants from black, Asian, other minority ethnic or LGBT+ communities to take part in a study to help make sure dementia and hearing loss research includes people from under-served groups. Find out more [here](#).

An exploration of the journey of living with dementia in males and females in light of gender identity

Rachel Fletcher, a doctoral student at the University of Wolverhampton, is interested to learn what it is like to live as a man or woman with dementia, and how it affects your identity. She is looking for people in the West Midlands to share their experiences. Find out more by emailing r.fletcher4@wiv.ac.uk or click [here](#).

Non-binary individuals living with dementia research project

Non-binary individuals with dementia are being sought to take part in a research project aimed at understanding the unique experiences and challenges faced by this population. Find out more in this [advert](#).

Published research

"I felt like I had been put on the shelf and forgotten about" – lasting lessons about the impact of Covid-19 on people affected by rarer dementias

[Emma Harding](#), [Sam Rossi-Harries](#), [Esther Vera Gerritzen](#), [Nikki Zimmerman](#), [Zoe Hoare](#), [Danielle Proctor](#), [Emilie Brotherhood](#), [Sebastian Crutch](#) and [Aida Suárez-González](#)

Read the paper [here](#).

Exploring how family carers of a person with dementia manage pre-death grief: a mixed methods study

[Kirsten J Moore](#), [Sophie Crawley](#), [Emily Fisher](#), [Claudia Cooper](#), [Victoria Vickerstaff](#), [Elizabeth L Sampson](#)

Read the paper [here](#).

Evaluating 'living well' with mild-to-moderate dementia: co-production and validation of the IDEAL 'My Life Questionnaire'

[Linda Clare](#), [Claire Pentecost](#), [Christina Victor](#)

Read the paper [here](#).

Resource showcase: GP surgery leaflet



The Young Dementia Network's GP surgery leaflet is intended to inform people who may have concerns about young onset dementia about the organisations who may be able to offer them support and information.

We hope this leaflet, suitable for use in GP surgeries and other clinical settings, will help to raise awareness of young onset dementia and enable people to access the key sources of young onset dementia support nationally.

[Find out more here](#)

[Visit our website](#)

[Join the Network](#)

[Our resources](#)



Contact us

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The Young Dementia Network is hosted by Dementia UK.

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