



Challenging the 'postcode lottery'

People with young onset dementia and their families so often struggle to get the right diagnosis and good support – depending on where they live. To make a difference to this, some basic information is vital but hard to find unless we can rely on you, our members, to help.

We need to **identify dedicated young onset services and teams**, and also **identify services and teams that include young onset dementia expertise as part of all-age provision**. We are working with our host Dementia UK to contact and map these services. Then we can set up opportunities to learn from the best, improve the support on offer and identify the geographical gaps too.

For this first phase, we are focusing on **NHS services in England**.

Here's how you can help. Just [email me](#) with the name of the service or team, town or city, and a contact email and a phone number too if possible – we will do the rest! We are wanting to know about Memory Assessment Services, Community Mental Health Teams, Neurology Services – wherever young onset is diagnosed and supported.

Let's all make the postcode lottery a thing of the past.

Tessa Gutteridge
Chair, Young Dementia Network

Young onset dementia webinars

Different models - Young Onset Dementia Service, Doncaster

There is huge variability in the diagnosis experience of people with young onset dementia across the UK, ranging from access to dedicated specialist

services, all-age and older people's services or almost nothing appropriate at all.

Upcoming Young Dementia Network webinars will feature different models of service, sharing what works well and what solutions overcome barriers to a good experience.

 **Wednesday 24th May 2022**

 **12.30-1.30pm**

Our next webinar will be presented by Dr John Bottomley, Associate Medical Director and Consultant Psychiatrist at Rotherham Doncaster and South Humber NHS Foundation Trust.

It will focus on the long-established Young Onset Dementia Service, in Doncaster, which offers a single point of access and a pragmatic approach and process to achieving a timely diagnosis.

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

Improving the diagnosis process for people with atypical dementia symptoms

Our webinar in March 2023 was led by Nikki Zimmermann, Direct Support Lead at Rare Dementia Support alongside Dr Natalie Ryan, Consultant Neurologist.

It focused on why specialist interventions and assessments are needed when young people present with non-memory led dementias. Julie, who is living with posterior cortical atrophy, also shared her views.

[**Watch a recording here**](#)

Young onset dementia search words



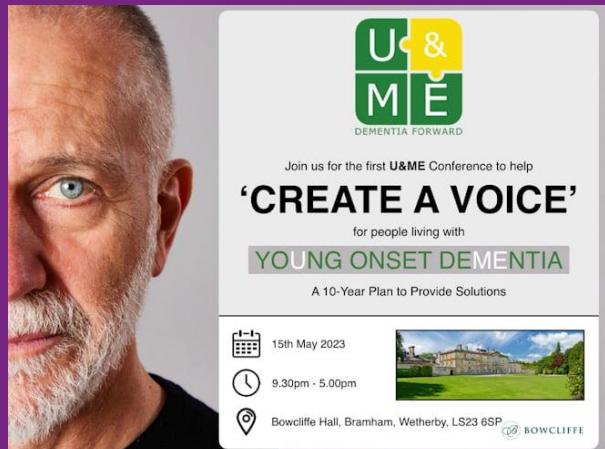
When you look for information about young onset dementia on the internet via a search engine such as Google or Bing, what search words do you use?

Do you search for 'young onset dementia', 'early onset dementia', or 'working age dementia', or do you search for a particular type of dementia, or some other term? We would love to know in order to help us to improve the searchability of our website and resources.

Please let us know what words you use to search for information our short survey via the link below.

[Take part here](#)

Dementia Forward - young onset dementia conference



Dementia Forward is hosting its first U & Me young onset dementia conference on Monday 15th May 2023 at Bowcliffe Hall, Wetherby.

The keynote speaker Professor Martin Green OBE, Chief Executive of Care England will be joined by speakers including people with lived experience of dementia.

Tickets are free-of-charge and include lunch and refreshments. Do look out for Catherine Kiely, Young Dementia Network Co-ordinator, who is attending on our behalf and will be pleased to say hello.

[Book your place here](#)

Young onset dementia and dementia-related news

'Involving under-researched communities and people living with dementia in dementia research' workshop

The Economic and Social Research Council is hosting a workshop at 1pm on Wednesday 26th April 2023. It will explore the practicalities and opportunities of involving under-researched communities and people living with dementia across all stages of dementia research. Find out more [here](#).

Posterior Cortical Atrophy (PCA) Support Group Annual Seminar

Rare Dementia Support's PCA Support Group Annual Seminar takes place at Conway Hall in London on Friday 28th April 2023. This one-day conference offers a unique opportunity to learn about PCA. Health and social care professionals and Rare Dementia Support members can attend for free. Find out more and register by clicking [here](#).

'The Nature of Forgetting' – a play about young onset dementia

Theatre Re has added an extra show to its tour of 'The Nature of Forgetting' at Nottingham Playhouse on Thursday 9th May 2023. For ticket information, please click [here](#).

Visit our stand at the Alzheimer's Society Annual Conference

The Young Dementia Network will have a stand at the Alzheimer's Society Annual Conference at the Park Plaza Hotel, London on Thursday 18th May 2023. If you are attending, we would love to meet you. The conference is hybrid, so you can attend in-person or online. For more details, please click [here](#).

Lorenzo's House's virtual youth summit

US-based charity Lorenzo's House is hosting a virtual Young Summit on Saturday 17th June 2023, specifically for people aged eight to 30 who have a parent with young onset dementia. Find out more [here](#).

Talking Sense – free online course

The Talking Sense free online course explores the effects of ageing and dementia on the senses. Informed by Agnes Houston's research and book, 'Talking Sense: Living with sensory changes and dementia', the course covers changes to vision, hearing, balance, touch, taste and smell. The course is designed for people living with dementia, care partners and support workers. You can access the course [here](#).

Young Carers Alliance

The Young Carers Alliance is a growing network of over 100 organisations and 200 individuals committed to improving the support available for young carers, young adult carers and their families. Visit its website [here](#).

Young onset dementia research round-up

Invovlement opportunities

Experiences from people in the early stages of young onset dementia on using / not using technology for financial services

Have you used technology to manage your personal finances, check your balance, make transfers or bill payments, change your PIN or make financial decisions? Or have you thought about using your mobile phone, tablet, computer, internet banking or a mobile banking app for financial services but decided against using it? Has the Covid-19 pandemic changed the way you access your bank accounts? Have you experienced more difficulty in accessing your local bank branch?

Whatever your views or experiences, researchers from the University of Huddersfield would like to hear from you. To find out more information contact Yusra Shaikh at yusra.shaikh@hud.ac.uk

People living with dementia and hearing conditions invited to shape future research

People living with dementia and hearing conditions, their families, and their clinicians are being encouraged to make their views known through a new national research prioritisation programme that could drive future research. It will entail reviews of published evidence as well as surveys and a workshop with people affected by dementia and hearing conditions and clinicians. To find out more, email sian.calvert@nottingham.ac.uk or follow the latest updates on Twitter at [@DementiaHearPSP](#), [@NottmBRC](#) and [@hearingnihr](#).

Recently published research

The digitalisation of finance management skills in dementia since the Covid-19 pandemic: A qualitative study

Clarissa Giebel et al

Read the research paper [here](#).

Research paper showcase

Title: Lessons learnt from delivering the public and patient involvement (PPI) forums within a younger onset dementia project

Authors: Jacqueline Parkes, Mary O'Malley, Janet Carter et al

Summary: Including the 'voices' of people living with dementia in a meaningful way is pivotal in shaping dementia health and social care research. Published in 2022, this paper explores how the perspectives of those with a younger onset dementia can be included in a UK national research study in an active and meaningful way.

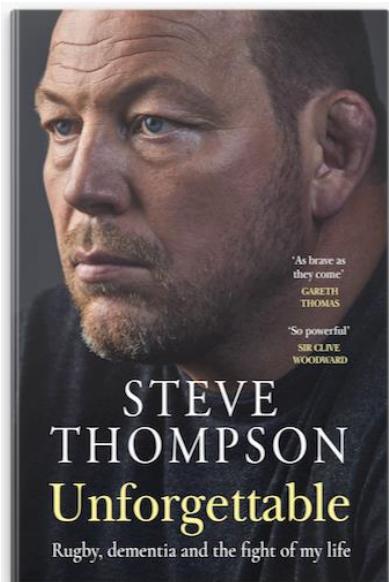
By establishing two Project PPI Forums, The Angela Project (2016-19) Team was able to ensure that the knowledge and expertise of people with young onset dementia were integral to all decisions taken in respect of overall project design, implementation, and dissemination processes. The paper describes how the two groups were formed; the format of the meetings; and the key points learnt by the team from involving people with dementia in all aspects of developing and delivering The Angela Project.

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

July 2022, Sage Journals

For other current dementia research opportunities visit the Young Dementia Network website [here](#) or visit [Join dementia research](#).

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



Book giveaway – 'Unforgettable'

Steve Thompson MBE is a former Rugby Union player and 2003 Rugby World Cup winner. Once England's most capped hooker, Steve was diagnosed with young onset dementia in his early 40s as a result of multiple concussions. He now campaigns to improve the game and safeguard those who play it.

Steve has very kindly given us two copies of his autobiography '[Unforgettable](#)', to give away. To be included in the draw, please [email us](#) by Friday 31st March 2023 with your name and postal address.

Book giveaway winner – 'One tear at a time'

We are delighted to announce that the winner of our February 2023 book giveaway was Trevor Chapman. He has won a copy of Natalie Baxter's book, '[One tear at a time](#)'.

Resource showcase: Diagnosis experience checklists



Our diagnosis experience checklists have been created using the recommendations from The Angela Project, the largest study of young onset dementia carried out in the UK. They are designed to help improve the experience of diagnosis.

The diagnosis experience checklist for individuals and families is for use by people who may have young onset dementia and their family members.

It sets out the experience a person should expect during the process of assessment and diagnosis and what to do if the level of care does not meet these expectations.

The other checklist is for healthcare professionals who are involved in the process of assessing and diagnosing dementia to help them to better understand the needs of younger people going through this process.

[**Download our checklists 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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