

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



Young Dementia Network News - April 2022

The benefits of sharing

A great strength of the Young Dementia Network is our members' passion for sharing expertise and experience to improve the lives of people affected by young onset dementia, now and in years to come.

One of the ways in which we do this is by sharing knowledge with others. In this issue of Young Dementia Network News, we are highlighting how the Alzheimer Society of Canada has adapted our [resources](#) to improve its support for people in Canada who are living with young onset dementia.

We are also delighted that Alzheimer's Disease International has adapted our [ID cards](#), and other organisations have translated our resources into Hebrew and Italian.

Let's all continue to look out for opportunities to learn from each other and share what we do as widely as we can.

Thank you for your support.

Tessa Gutteridge
Chair, Young Dementia Network



Connectivi-tea webinar

On Wednesday 18th May 2022, we will continue our series of young onset dementia webinars with Connectivi-tea. This webinar will focus on the use of technology and social media by people affected by young onset dementia.

We will be joined by two panellists: Dr Catherine Talbot, a cyberpsychologist at Bournemouth University who specialises in social media and its intersection with health and wellbeing; and Michael Andrews, who lives with posterior cortical atrophy.

They will explore how the use of technology and social media by people with young onset dementia has become increasingly important for maintaining their independence and connection with others.

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

Watch a recording of our April webinar, Employabili-tea [here](#).

Catch up with past webinars on our [website](#).

New Canadian young onset dementia resources

Alzheimer Society of Canada has adapted the Young Dementia Network's [personal checklist](#) into [English](#) and [French](#) versions for use by people in Canada. It has also translated our [ID cards](#) in both [English](#) and [French](#).

Alongside this, it has recently launched a [young onset dementia hub](#) which includes articles aimed at people living with young onset dementia, along with three videos featuring people with lived experience.

It will be expanding its hub in the next few months, adding more articles providing information for family carers, teenagers, young adults and healthcare providers.

Young onset dementia and dementia related news

Co-created with the Young Dementia Network, Alzheimer's Research UK has published a new booklet *Young onset dementia*. It shares information about different types of dementia, diagnosis and where to go for support. You can read it [here](#).

[Another Presence](#) is a short film about dementia, hallucinations and altered perceptions. It explores the unique and often intriguing experiences of people with Lewy body dementia: the third most common type of dementia in the UK. Told through the testimonies of people living with the diagnosis, the film explores the surreal and lesser-known effects of the condition. You can watch Another Presence online at anotherpresencefilm.com

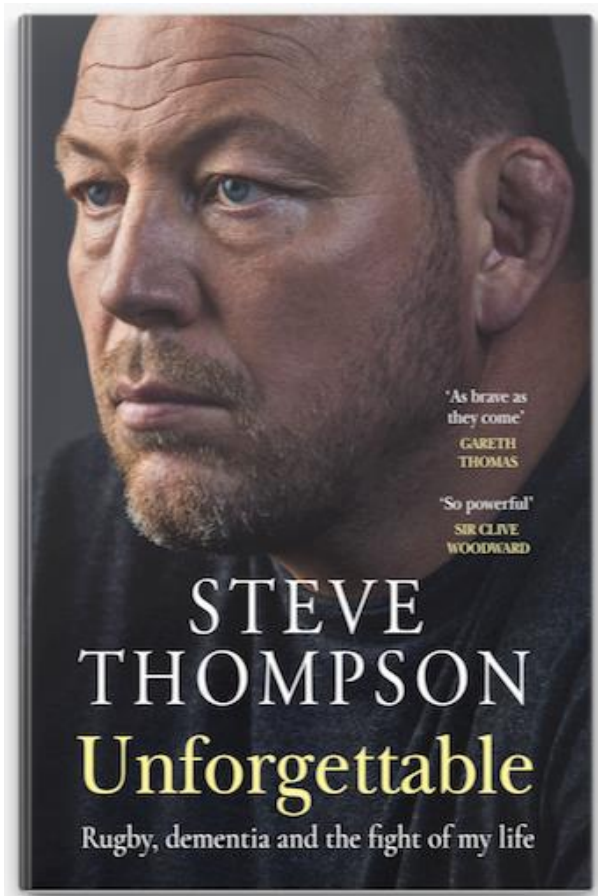
On Tuesday 10th May 2022, Sunday Times bestselling author and Young Dementia Network steering group member Wendy Mitchell and playwright Rosa Peterson will be in conversation at Leeds Playhouse. Wendy and Rosa, who are both diagnosed with dementia, will read from their recent works and discuss what it means to write with dementia. Find out [more](#).

Maggie May, a play about an ordinary Leeds family in their 60s balancing the challenges of daily life whilst living with dementia, runs at the Courtyard Theatre, Leeds, from 7th-21st May 2022. The play is a heartfelt story of hope by award-winning playwright Frances Poet. All performances are dementia friendly. Click [here](#) for more information.

Dementia Adventure offers supported holidays for people living with dementia and their family and friends, including people affected by young onset dementia. Find out more about their small group holidays [here](#).

Music for Dementia has published its [Power of Music report](#) into how music can help to transform communities and improve health and wellbeing.

Created by Music for Dementia and UK Music, the report was developed in consultation with representatives from charities, the government and the health and social care sectors, as well as the wider creative sector, people living with dementia and their family members.



Unforgettable **By Steve Thompson**

In 2003, England won the Rugby World Cup. Steve Thompson was in England's front row at the heart of the scrum. Today, he remembers nothing about playing in that final.

Steve, who is in his early 40s, has been diagnosed with young onset dementia and probable chronic traumatic encephalopathy. There are days when he doesn't remember the names of his wife and four children.

Unforgettable is a powerful story of hope and courage. Available now from [Waterstones](#) and other book retailers.

Congratulations to Jacqueline Green who won a copy of Hilda Hayo's book, [Young onset dementia - a guide to recognition, diagnosis and supporting individuals with dementia and their families](#), in our March 2022 giveaway.

Young onset dementia research round-up

Involvement opportunities

What are families' understanding, expectations and experiences of inpatient mental health care for people with dementia?

Researchers from the University of Hull would like to speak to the family members or friends of people with dementia who have been treated in a mental health (psychiatric) hospital in the last five years. They would like to know what you were expecting, what the care was like, and what support you received. If you are willing to be interviewed by phone or online, contact Emma Wolverson at e.wolverson@hull.ac.uk or click [here](#) for more information.

Research study focusing on the mental wellbeing of people who are caring for their partner living with dementia at home.

This University of Bristol research project will provide opportunities for family members to share their stories, experiences, and any support they find helpful via email and an online Zoom interview. For further information or any queries about the research, email Pip Collier at pc17644@bristol.ac.uk

DiSCOVERY project seeks the views of people who have attended Recovery College courses.

A new study focusing on how NHS mental health Recovery Colleges can support people with dementia is being launched by Norfolk and Suffolk NHS Foundation Trust's Research Department. The study, called DiSCOVERY, hopes to understand more about the experience of attending Recovery College courses and whether people living with dementia find designing and delivering courses helps them. For more information, email Claire Mutimer at Claire.mutimer@nsft.nhs.uk

Recently published research

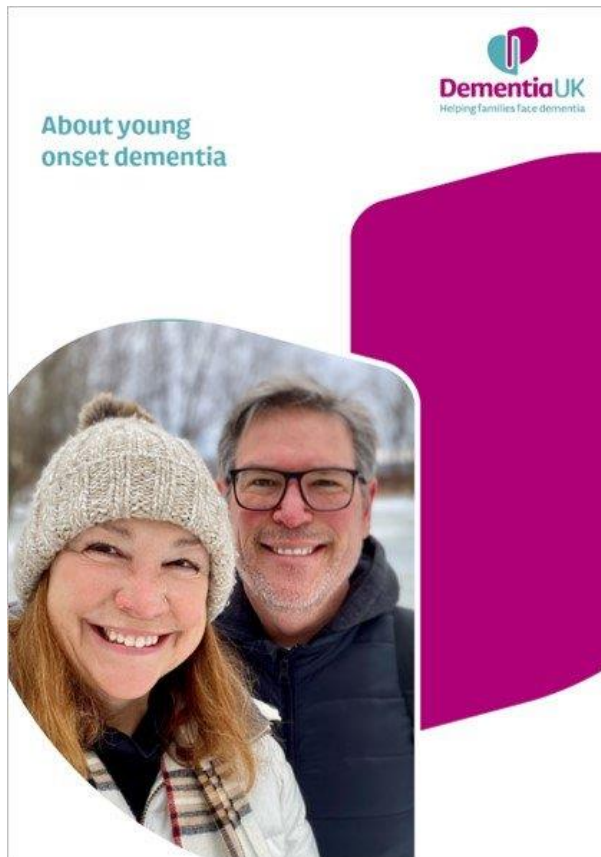
Dementia enquirers: pioneering approaches to dementia research in the UK

By Teresa Davies, Agnes Houston, Howard Gordon, Mhari McLintock, Wendy Mitchell, George Rook and Tom Shakespeare

The paper is written by six people living with young onset dementia. It explores the difficulties people with dementia have had with formal research ethics procedures, and challenges mainstream dementia research to do things differently. Click [here](#).

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

To view a collection of research focusing on the most prominent subjects relating to young onset dementia click [here](#).



New advice leaflets from Dementia UK

The Young Dementia Network's host Dementia UK has recently produced two new leaflets:

[About young onset dementia](#) and [Understanding frontotemporal dementia](#).

The leaflets share information about young onset dementia and frontotemporal dementia, including symptoms, the issues younger people may face, and sources of support.

They can be downloaded or ordered in paper format via the Dementia UK website, click [here](#).

Resource showcase: Young onset dementia pathway

Our young onset dementia pathway brings together the experience of people affected by young onset dementia and the people who work with and support them.



It shows that the impact of dementia can be very different depending on the stage of life, and that because of this, services must be tailored to meet those needs. The pathway is a set of recommendations which are designed to meet those different needs and are intended to guide policy makers, commissioners and practitioners in designing and delivering services.

Download or request a copy of the young onset dementia pathway [here](#).



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