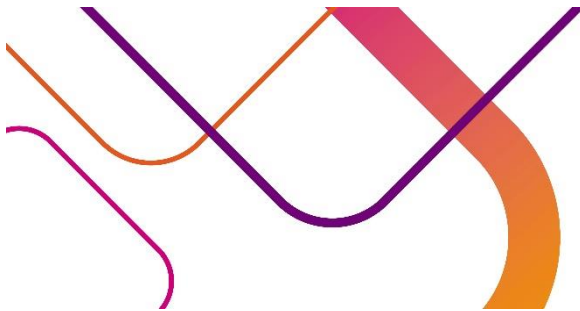


This is an email from the Young Dementia Network sharing Network and young onset dementia related news and information

Young Dementia Network News - January 2022



## Dare to hope?

**In January, it's natural to look for a glimmer of hope, something to lift the spirits, something to look forward to. Here are a couple of positive projects coming up during 2022.**

The Young Dementia Network, as a member of the One Dementia Voice collaboration, has been working on a Dementia, Disability and Hope project. We want to focus on the positive benefits that can come from all of us working together to remove the external obstacles that stop people with dementia from living as well as they possibly can. Look out for more about this in the spring issues of the News.

Then too the Young Dementia Network [steering group](#) is keen to improve the experience of diagnosis for younger people and their families. Later in the year, one of the activities highlighting this will be our new young onset dementia online event, hosted by Dementia UK. We've included an invite in this issue to email us your suggestions for the event programme.

Best wishes

Tessa Gutteridge

**Chair, Young Dementia Network**

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## **Authori-tea with Wendy Mitchell webinar**

**On Wednesday 16th February 2022, we will continue our series of young onset dementia webinars, with a very special webinar.**

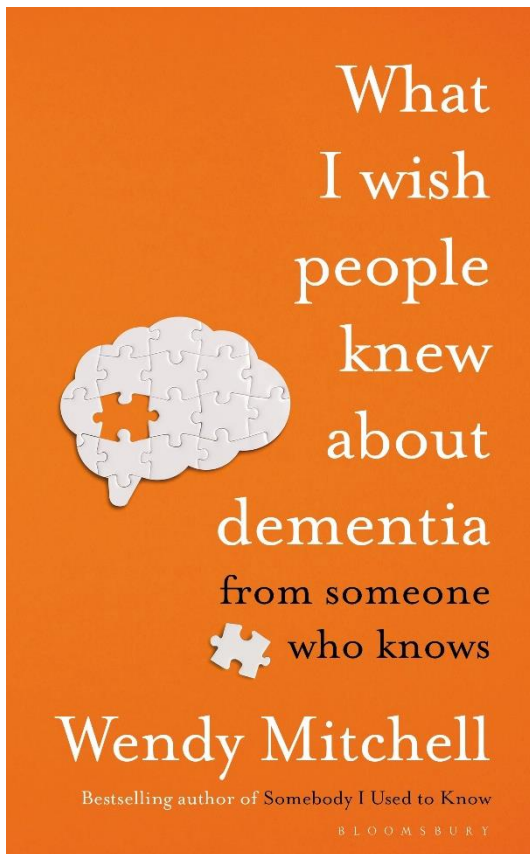
Young Dementia Network steering group member and best-selling author **Wendy Mitchell**, who is living with young onset dementia, will be joining us to talk about her new book, *What I wish people knew about dementia*, alongside Philly Hare, Director, Innovations in Dementia.

Sign up to join the webinar [here](#). Find out more about Wendy's book below.

**Watch a recording of our January webinar - Vitali-tea - keeping well after a diagnosis of young onset dementia [here](#).**

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

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## Wendy Mitchell's new book is available now!

Wendy Mitchell was diagnosed with young onset Alzheimer's disease in 2014 at the age of 58. Since her diagnosis she has become a best-selling author, blogger and leading dementia campaigner.

Her second book, What I wish people knew about dementia, combines anecdotes, research and Wendy own wit and wisdom to tell readers exactly what she wishes they knew about dementia.

It is available to purchase from [Amazon](#), [Foyles](#), [The Bookshop](#) and [Waterstones](#).

**Congratulations to Kristina who won a copy of [Big Bear, Little Bear and dementia](#) in our December book give away.**

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## Young onset dementia online event - your programme suggestions please

**The Network is planning a learning exchange event in autumn 2022. The theme shines a light on a Network aim - to ease the many issues arising from the young onset dementia diagnosis experience and process. Our event, intended to be the first of a series, will offer an opportunity to learn from each other and to reach out to those who are faced with this challenge and who are seeking improvements.**

So, 'dementia diagnosis' is the broad theme. There are many different elements within it - from recognition of potential symptoms by the person, family and GP, referral on from the GP, the support, communication and information for the person and for the family throughout, and the optimum assessments and tests undertaken to achieve an accurate diagnosis to name a few. Then of course, how diagnoses of young onset dementia are recorded, collected and submitted to provide accurate prevalence and incidence data.

And the importance of having accurate diagnosis of the type of dementia, so important for young onset dementia... There are so many elements.

### **Tell us what you want to be featured**

Whether you are a person living with the condition, a family member, a health or social care professional or researcher in this field, tell us about the positive solutions, good practice or service you want us to include in the programme.

Email [youngdementianetwork@dementiauk.org](mailto:youngdementianetwork@dementiauk.org) by Monday 7<sup>th</sup> February 2022 with your suggestions, including a brief summary of what you feel would be good to cover and who might be involved in telling us about it online, or at the event.

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## **Young onset dementia / dementia related news**

### **All-Party Parliamentary Group on Dementia inquiry**

**The All-Party Parliamentary Group on Dementia (APPG) is undertaking an inquiry into what people affected by dementia want and need from a social care workforce to enable them to live well and on their terms.**

They are keen to hear the voices of people affected by dementia, sector experts, charities and care organisations.

If you are living with dementia, or are a carer of someone with dementia, complete their [online survey](#) to share your story.

If you are an organisation or work in social care or academia, you can either email in your evidence using [this Word Document](#) or submit evidence online by [completing this online form](#).

The evidence submission window will be close on Monday 14th February 2022. For further information about the APPG, click [here](#).

**Pamela's husband, Rob, was diagnosed with dementia at the age of 65.** As his care needs increased, Pamela applied for **continuing healthcare** (CHC), but felt the process was stacked against them. Read Pamela's story [here](#). You can find out more about CHC, or share your experiences [here](#).

**The Work and Pensions Committee has launched a survey to hear about first-hand experiences of PIP and ESA.** The survey is open to

everyone who has had an assessment to claim Personal Independence Payment or who has had a Work Capability Assessment either to claim Employment and Support Allowance as part of a Universal Credit claim. The survey is open until mid-February 2022. Take part in the survey [here](#) or click [here](#) to find out more.

**In a recent podcast, Pippa Kelly interviewed Trevor Salomon whose wife was diagnosed with Alzheimer's disease aged 56.** At the time she was working at Sainsbury's, and they adapted her role, enabling her to continue in work for four and a half years after her diagnosis, providing her with what her family describe as a lifeline. Listen to the podcast [here](#).

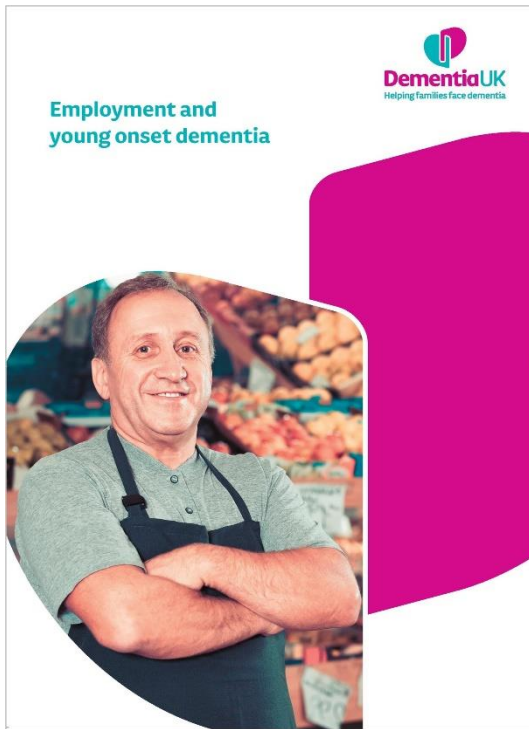
**Congratulations to Charlie Draper**, who has been appointed to the position of Director, Clinical and Operational Services, at young onset dementia charity [YPWD \(Berkshire\) CIO](#).

**The Journal of Dementia Care (JDC) has been re-launched as a Charitable Community Benefit Society, Dementia Publishing.** Led by founder and editor-in-chief Dr Richard Hawkins, managing editor Sue Benson and editor Mark Ivory, the journal is published bi-monthly and available digitally to subscribers. A free newsletter is also published, and the website is updated weekly with news and information relevant to people working in dementia care in all settings. Visit their website [here](#).

**The Many Faces of Dementia is an online course which focuses on four rarer types of dementia**, that can be more common in younger people - familial Alzheimer's disease, behavioural variant frontotemporal dementia, dementia with Lewy bodies and posterior cortical atrophy. Find out more [here](#).

**Alzheimer's Research UK** is holding a **conference for early career dementia researchers** on Monday 28th February 2022 and is running a **two-day research conference** on 1st-2nd March 2022. Find out more [here](#).

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## Employment and young onset dementia leaflet

**Dementia UK has updated their Employment and young onset dementia leaflet.**

The leaflet explains the employment rights of people with young onset dementia, has suggestions for adjustments in the workplace, information around working whilst supporting a person with dementia, alternative occupations and meaningful activities and information about self-employment.

You can view the leaflet and download or request a copy via their [website](#).

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## Young onset dementia research round up

### Involvement opportunity

**Have you or someone you care for with dementia been treated in a mental health hospital?**

Researchers from Dementia UK and the University of Hull want to improve inpatient mental health care for people with dementia. If you are a person with dementia with experience of inpatient mental health care or have cared for someone with dementia who has been treated in a mental health (psychiatric) hospital they would like to hear from you. Contact Emma Wolverson on [e.wolverson@hull.ac.uk](mailto:e.wolverson@hull.ac.uk), call 01482 464170 or click [here](#) for more information.

### Recently published research

**“Nobody seems to know where to even turn to.” Barriers in accessing and utilising dementia care services in England and The Netherlands**

Clarissa Giebel, Sarah Robertson, Audrey Beaulen, Sandra Zwakhalen, Dawn Allen, Hilde Verbeek. Click [here](#).

## **A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers**

Clarissa Giebel et al. Click [here](#).

## **The severity of neuropsychiatric symptoms is higher in early-onset than late-onset Alzheimer's disease**

Neus Falgàs et al. Click [here](#).

## **Amateur boxing and dementia: Cognitive impairment within the 35-year Caerphilly cohort study**

John Gallacher PhD et al. Click [here](#) or read a news article about the study [here](#).

## **A systematic review of smartphone and tablet use by older adults with and without cognitive impairment**

Samantha Wilson et al. 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](#).

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## **Resource showcase: Key needs videos**

**As part of The Angela Project, the largest UK study of young onset dementia, the team asked people living with young onset dementia and family supporters to tell them about services they found helpful.**



They received over 850 examples and analysed them to see what needs 'helpful services' met; this led to a set of eight needs that seem to be central to

areas of support.

Watch the Key needs videos featuring people living with young onset dementia and family members [here](#). Check out other Young Dementia Network resources [here](#).



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