



## Improving the experience of diagnosis

**Let's take every chance we can to voice the challenges people with suspected young onset dementia have in getting a diagnosis.**

The current All-Party Parliamentary Group on Dementia diagnosis inquiry focuses on the inequitable variations in dementia diagnosis, particularly those caused by rurality and deprivation. This is detrimental to people with young onset dementia too.

So, I am calling professional Young Dementia Network members to [email us](#) by Monday 20th February 2023 and I will let you know how you can contribute to the Network's response to the inquiry.

And if you have personal experience, do check out the dementia diagnosis feature in this issue. Apologies to all for the short notice.

**Tessa Gutteridge**

Chair, Young Dementia Network

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## Young onset dementia webinars

### Improving the diagnosis process for people with atypical dementia symptoms

**Our webinar in March 2023 will be led by Nikki Zimmerman, Direct Support Lead, Rare Dementia Support alongside Dr Natalie Ryan, Consultant Neurologist.**

The webinar will focus on why specialist interventions and assessments are needed when young people present with non-memory led dementias. We will discuss the importance of expert knowledge and access to further investigations within a clinical setting. Plus, how accessing information and guidance at an early stage can support families throughout the whole process.

A Rare Dementia Support member living with posterior cortical atrophy will provide their views on why specialist knowledge and investigations are important when assessing and diagnosing a person with atypical symptoms.



**Wednesday 15th  
March 2023**



**12.30-1.30pm**

[Sign up here](#)

## Changing perceptions of diagnosis webinar



**Our webinar in February – Young onset dementia: changing perceptions of diagnosis – was presented by Dr Susan Mitchell, Head of Policy at Alzheimer’s Research UK, alongside a panel of experts.**

You can watch a recording of the webinar via the link below.

[Watch here](#)

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## Do you have direct experience of getting a dementia diagnosis?

The latest data from NHS England shows the stark variation in dementia diagnosis rates across England. The [All-Party Parliamentary Group \(APPG\) on Dementia](#), a cross-party group of MPs and peers interested in dementia, has launched an urgent inquiry to understand the reasons behind the regional inequalities in diagnosis rates.

They want to hear first-hand experiences from across the country and are inviting people who have a diagnosis themselves, or people who have cared for a family member with dementia, to share their experience.

You can take part in the inquiry [here](#). The survey closes on Friday 24th February 2023.

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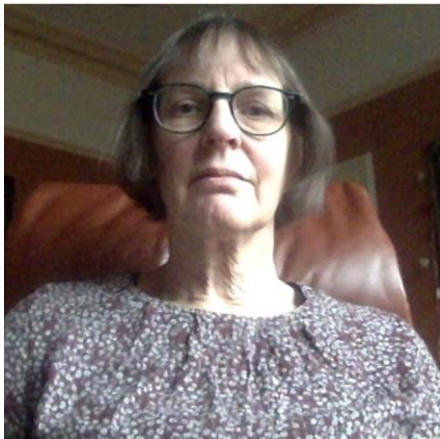
## Young onset dementia: Reconsidered



**You are invited to help inform the content of an upcoming book *Young onset dementia: Reconsidered*.**

The book is being edited by George Rook, who is living with young onset dementia, and Professor Jan Oyeboode from the University of Bradford. It will have three sections focusing on key themes that are important to people living with young onset dementia:

- maintaining control over your life
- retaining a sense of identity
- feeling connected with others



The editors are holding three online sessions during March 2023 to discuss each theme with a group of no more than 12 people with dementia. Professionals or others who want to attend can join but will be asked to observe with their cameras and microphones off. You can sign up to join the Zoom discussions or find out more [here](#).

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## Young onset dementia and dementia-related news

### **Dementia and menopause feature on Woman's Hour**

Dementia and menopause featured recently on BBC Radio 4's Woman's Hour where Anita Rani discussed the subject with Dementia UK's Consultant Admiral Nurse for Young Onset Dementia, Jules Knight. Listen [here](#).

### **Dementia and money feature on Radio 4's Money Box**

Clinical Lead Admiral Nurse Vic Lyons was part of a feature on dementia and money and gave lots of useful advice that was relevant for younger people. You can listen [here](#).

### **Wendy Mitchell's second book is out now in paperback format**

Best-selling author and blogger Wendy Mitchell's second book '[What I wish people knew about dementia](#)', is now available in paperback format.

Wendy was diagnosed with dementia aged 58 and is a Young Dementia Network steering group member. Her third and final book 'One last thing...' will be published in June 2023 and will be available to pre-order soon.

### **The Frontotemporal Dementia Support Group Annual Seminar**

The Frontotemporal Dementia (FTD) Support Group's Annual Seminar takes place on Thursday 2nd March 2023 from 11am-4pm at Conway Hall in London. It is an in-person event and will not be recorded. Attendance is by registration only. The event is free for Rare Dementia Support members who are living with, or care for someone, with dementia. You can become a member [here](#). There is a charge of £75 for health professionals. Register to attend the seminar [here](#).

### **A chance to hear the stories of people affected by young onset dementia**

[The Alzheimer's Dementia & Care Show](#) takes place in London on Friday 3rd and Saturday 4th March 2023. The two-day event will feature talks by Keith Oliver who has lived with young onset dementia for over 10 years and Hannah Riches who will discuss juggling caring for a partner with young onset dementia and being a mother. In addition, Admiral Nurse Rachel Thompson will give a talk about Lewy body dementia and Consultant Admiral Nurse for Young Onset Dementia Jules Knight will offer a young onset dementia clinic.

### **Young onset dementia get-together, Bristol**

The Bristol Dementia Action Alliance is hosting a young onset dementia get-together on Monday 13th March 2023 at 2pm. It will provide an opportunity for people living with young onset dementia to meet others and discuss possible future activities. Find out more by emailing [office@bdaa.org.uk](mailto:office@bdaa.org.uk) or clicking [here](#).

### **Understanding Huntington's disease online course**

If you would like to learn more about Huntington's disease, this three-day online course taking place in April 2023 may be of interest. It will provide an opportunity to learn from leading Huntington's experts and virtually meet with fellow professionals working with people affected by the condition. Find out more [here](#).

### **Dementia and traumatic brain injury – free online courses**

Understanding Dementia is a Massive Open Online Course (MOOC) offering university-quality education about the diseases that cause dementia, how the condition affects the person, and how we can provide the best quality care.

Created by the University of Tasmania's Wicking Dementia Research and Education Centre, the free course provides an opportunity to engage with the perspectives of a global community, without requiring exams or assignments. They are also running free online courses on Preventing dementia and Understanding traumatic brain injury. For more information, click [here](#).

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## Young onset dementia research round-up

### Involvement opportunities

#### **The benefits and challenges of social media for people with early-stage dementia: The perspectives of support service providers**

Dr Catherine Talbot, Senior Lecturer in Psychology at Bournemouth University, is conducting a research study exploring support service providers' attitudes towards people with early-stage dementia using social media. Her online survey takes approximately 10 minutes to complete. Participants will have the opportunity to enter a prize draw to win shopping vouchers. Click [here](#) to find out more or to take part in the survey.

#### **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, mobile health apps, or the internet to search for health information or support. They are looking for adults with young onset dementia to complete a one-off survey to share their thoughts. Information on the research and a link to the survey can be found [here](#) or email Dr Sarah Fearn at [S.Fearn@soton.ac.uk](mailto:S.Fearn@soton.ac.uk).

### Recently published research

#### **Three or more concussions linked with worse brain function in later life**

Dr Vanessa Raymont et al

Read an article about the research [here](#), or the full research paper [here](#).

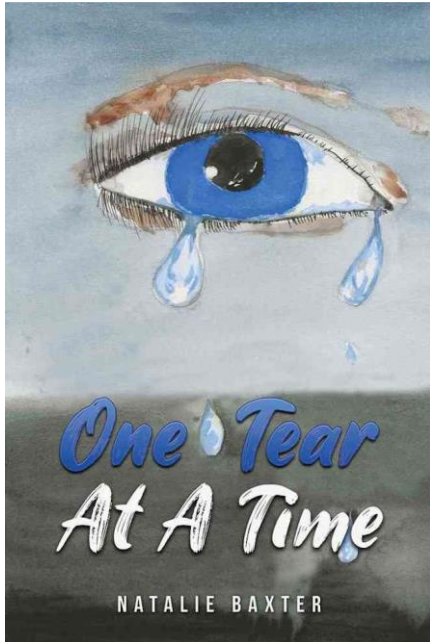
#### **"I found it the only place that spoke the same language:" a thematic analysis of messages posted to an online peer support discussion forum for people living with dementia**

Catherine V Talbot, Neil S Coulson

Read the research paper [here](#).

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 – One tear at a time

[One tear at a time](#) is a real-life account of author Natalie Baxter's mother Sue's Alzheimer's disease diagnosis at 54 years of age. In the book, she recounts the challenges that followed to increase understanding and awareness of young onset dementia and to help others.

Natalie has very kindly given us a copy of the book to give away. To be included in the draw, please [email us](#) by Sunday 5th March 2023 with your name and postal address.

## Research paper showcase

### Provisional consensus on the nomenclature and operational definition of dementia at a young age

**Authors:** van de Veen et al, the PRECODE study group

**Aim:** to consult with international experts in the field in order to reach agreement about the best terminology and definition of dementia in young people and the possible causes

#### Key findings:

- Young-onset dementia was the term preferred to describe dementia in young people, It is defined as 'onset of symptoms of dementia before the age of 65 years'
- Using the age of symptom onset rather than date of diagnosis is important because of the existing prolonged time to diagnosis
- A large mix of disorders and diseases might cause dementia at a young age was confirmed

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The strengths of the paper include the global participation of experts spread over four continents to capture a range of views. Experts came from a number of specialisms, including non-medical experts. However, the consensus study was completed online so the opportunity for face-to-face discussion may have provided greater consensus on some controversial areas

**Implications for young people and families living with dementia:** this new clear term to describe dementia in young people means that researchers and clinicians have a common language and can now compare and conduct future research based on a shared understanding.

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

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### Contact us

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