



## Steering towards positive change

**Amidst all the current constitutional, political, environmental and economic disruptions, the Young Dementia Network steering group met this month to keep a steady focus on improving the experience of diagnosis.**

During this febrile political season, it is encouraging that the major dementia organisations are actively pressing for improvements in support approaching the life changing diagnosis and beyond. Many are Network members so there is potential to amplify the voice and expectations of people affected by young onset dementia.

The Young Dementia Network and its steering and working groups will, with persistence and determination, push for young onset dementia to be a priority in areas that count. Knowing the grinding determination needed to live with young onset dementia, we must succeed.

**Tessa Gutteridge**

Chair, Young Dementia Network

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## An estimated 70,800 people are living with young onset dementia in the UK

**New figures show a 'hidden population' of an estimated 70,800 people in the UK who are currently living with young onset dementia — a rise of 28,800 (69%) since 2014.**

In a recent study, researchers from the Neurology and Dementia Intelligence Team, Office for Health Improvement and Disparities, analysed datasets from GP practice records in England. By using an alternative method of identifying cases, they found that the estimated number of people in England with young onset dementia (when symptom onset occurs under the age of 65), represented an estimated 7.5% of all

those living with a dementia diagnosis.

The findings were authored by Dr Janet Carter, a Young Dementia Network steering group member, and Michael Jackson from the Department of Health and Social Care and were published in the [Journal of Dementia Care](#). The Young Dementia Network and Dementia UK have used these findings to arrive at the figure of 70,800 in the UK and to highlight the need for greater awareness of young onset dementia and more age-appropriate services and care. The Young Dementia Network is now encouraging everyone to adopt these more accurate figures. Read more [here](#).

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## Young onset dementia webinars

### Why numbers matter and change is possible

**Join us on Wednesday 19th October 2022 for the first in our new series of young onset dementia webinars which will provide an opportunity to share knowledge and experience. The series theme is improving the experience of diagnosis for people affected by young onset dementia.**

Dr Janet Carter, Associate Professor in Old Age Psychiatry in the Division of Psychiatry, Faculty of Brain Sciences, University College London and Michael Jackson, Programme Lead for Neurology and Dementia Intelligence, Department of Health and Social Care, will be joined by Wendy Mitchell, living with young onset dementia, who will offer her personal view on why numbers matter, how commissioners could use the data and what needs to happen next if we are to make the most of the data to create change.



**19th October 2022**



**12.30-1.45pm**

[Sign up here](#)

### Young onset dementia and general practice – identifying symptoms before diagnosis

**Our webinar on Wednesday 16th November 2022 will focus on the first symptoms of young onset dementia and how to increase their recognition by GPs and better identify people with young onset dementia at an earlier stage.**

Professor Marjolein de Vugt and Dr Stevie Hendriks from the Netherlands, will present the results of a recent study on pre-diagnostic symptoms of young onset dementia.



**16th November 2022**

🕒 12.30-1.30pm

[Sign up here](#)

You can catch up with recordings of our tea-themed webinar series from October 2020-June 2022 on our website [here](#).

## Member showcase: Young Onset Dementia Activists Group, Bromley



**The Young Onset Dementia Activists Group (YODA) in Bromley was set up in May 2021 by Bromley Dementia Services Manager Saira Addison, a Young Dementia Network member.**

Since its launch, the YODA group has gone from strength to strength and now supports around 20 people who are living with young onset dementia in Bromley, Lewisham and Greenwich, as well as their family members and friends.

YODA offers a varied and exciting programme of activities and events as well as vital

peer support and social interaction. Raising awareness of issues around young onset dementia is another important part of the group's purpose.

[Read more here](#)

## Young onset dementia and dementia related news

### **New young onset dementia social group launches in Hythe, Kent**

Hythe and Lyminge Age UK has launched a young onset dementia social club. The group meets monthly on Tuesdays at The Chambers. For more information, click [here](#).

**Dementia carers charity tide is hosting a Setting up a peer support group session on Tuesday 4th October 2022, 10.30am-12pm.** The session will share examples from carers who run their own peer support groups and will include information about how to get started, format, structure, benefits, challenges and top tips. Book your place [here](#).

### **Primary progressive aphasia annual seminar**

Rare Dementia Support will be hosting the primary progressive aphasia annual seminar on Tuesday 25th October 2022, from 10am-2pm at Mary Ward House Conference Centre, London. Register or find out more [here](#).

### **Supporting people living with a rare dementia - free event**

If you are interested in learning more about rare dementias, there is a free event taking place on Friday 28th October 2022, from 10am-1pm at the Reichel Hall in Bangor. There will be short presentations from people affected by rare dementias, experts and researchers. Lunch will be provided. Find out [more](#).

### **Young onset Alzheimer's disease annual seminar**

Rare Dementia Support will be hosting the young onset Alzheimer's disease annual seminar on Monday 31st October 2022, from 10am-2pm at a location to be confirmed. Click [here](#) for more information.

**The University of Bradford's Centre for Applied Dementia Studies is running a 'But you're too young to have dementia' session as part of their [50 shades of dementia](#) course programme.**

Professor Jan Oyeboode will lead the young onset dementia sessions and provide an understanding of the unique needs of people diagnosed with dementia under 65 years old and explore the different types of dementia which are more common amongst younger people. The sessions take place on Monday 14th November and Monday 21st

November 2022 from 9.30am-1.30pm. Bookings are welcome from people living with dementia, their supporters, health and social care staff and anyone with an interest in improving dementia services. Book your place [here](#).

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## Young onset dementia research round-up

### Involvement opportunities

#### **Have you been recently diagnosed with dementia?**

DETERMIND is a joint research study being carried out by King's College London and South London and Maudsley NHS Foundation Trust. It aims to investigate inequalities in care and outcomes for people with dementia, their families, and carers. They would like to speak to people who have been recently diagnosed with dementia to hear their experiences. Email [determind@kcl.ac.uk](mailto:determind@kcl.ac.uk) or click [here](#) to find out more.

#### **Do you support someone who has dementia?**

The CareCoach programme is leading a research study in the UK to develop online support tools for people involved in the care of people living with dementia. The team is looking for volunteers to feature in videos about caring which will form part of an online programme to support carers in the UK. They will provide support and can offer an allowance of £75 for each half day of filming. For more information or an informal discussion please contact: Fiona Scheibl, Senior Researcher at University of East Anglia on 07599 926354 or email the study team at: [CareCoach@uea.ac.uk](mailto:CareCoach@uea.ac.uk)

#### **Are you a family member or friend of someone who was living in a care home during the Covid-19 pandemic?**

Researchers at the London School of Economics are researching how care homes in England developed and implemented their visiting policies during the Covid-19 pandemic, and the factors that helped to shape them. They would like to speak to family members or friends of care home residents to understand how care homes can improve how visiting policies are developed during public health emergencies such as the Covid-19 pandemic. To discuss taking part, please email [e.stubbs@lse.ac.uk](mailto:e.stubbs@lse.ac.uk) or click [here](#) for more information.

### Recently published research

#### **Peer support for people living with rare or young onset dementia: An integrative review**

Mary Pat Sullivan and Veronika Williams, on behalf of the Rare Dementia Support Research Team. [Read the full research article here >](#)

### **Everyday experiences of people living with mild cognitive impairment or dementia: A scoping review**

Jacoba Huizenga et al. [Read the full research article here >](#)

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

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

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## **Young onset dementia: next steps after diagnosis leaflet**

**A diagnosis of dementia aged under 65 may leave a person feeling anxious and uncertain about the future and how to plan for it.**

Network host Dementia UK has created a new leaflet that shares information about what to do next and the key things to address to help make life more manageable. It covers issues such as financial matters (eg lasting power of attorney, Wills, benefits), employment, driving and helpful tips for daily life.

[Download here](#)

## **Do you have personal experience of dementia and menopause?**

**World Menopause Month takes place in October and Dementia UK is keen to share the stories of women who are experiencing both menopause and young onset dementia and family members who are caring for a person in that situation.**

If you are interested in sharing your story, please contact Flora Harding via the button below.

[Send an email to Flora](#)

If you know of any helpful young onset dementia resources, please share them with us.

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