

## Have your say about young onset dementia

**Dementia, along with cancers, cardiovascular disease, respiratory diseases, mental ill-health and musculoskeletal disorders, is part of the Government's new five-year plan to prevent, diagnose, treat and manage these conditions. It presents an opportunity for every Young Dementia Network member to have a say and ensure that young onset dementia features strongly in terms of what is prioritised.**

So, if you feel that getting more people diagnosed quicker, improving treatment and care, delaying the progression of dementia or one of the other suggested areas should be prioritised, do share your views and take part in the consultation; it closes on **Friday 27th June 2023**. You can read the 'Major conditions strategy: call for evidence' and find out how to respond to it [here](#). An interim report is expected in the summer.

Scotland and Wales are further ahead with their strategies for dementia and we hope to report how young onset dementia features in each soon.

**Tessa Gutteridge**

Chair, Young Dementia Network

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## Young onset dementia webinars

### **Different models – young onset dementia nurse-led service, Northamptonshire**

**Our webinar in June will be presented by Jenny Kerti, Community Psychiatric Nurse Manager, with Community Psychiatric Nurses Emma Green and Nina Picton, and Occupational Therapist Frances Hooper, from the Younger Persons with Dementia Team in Northamptonshire.**

They will share how this unique model offers the continuity of support needed and valued by people going through the diagnosis experience from GP referral onwards.

How is this service sustained? What are the essentials that make the service work for the families, the professionals and the local health and care system? What are the challenges and how are they overcome?

Jenny and her team will offer their expertise on all these topics, feature a person who has personal experience of the service and answer your questions live on the webinar.

 **Wednesday 21st June 2023**

 **12.30-1.30pm**

[Sign up here](#)

## Webinar catch up – Young Onset Dementia Service, Doncaster

Our webinar in May was presented by Dr John Bottomley and focused on the long-established Young Onset Dementia Service in Doncaster. It featured an interview with Michael Booth, who is living with young onset dementia.

[Watch here](#)

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## Memory clinics and genomic medicine



**Dr Nick Bass, Clinical Associate Professor at University College London, and Jana Mikova, Senior Nurse Practitioner, Tower Hamlets Diagnostic Memory Clinic, are leading a major transformation project to ensure that people, including those with young onset dementia, have**

**access to genetic investigation services.**

They are looking to hear from people who have been through the genetic testing process and their families in order to develop a more user-centred pathway. Find out more about their work and the project [here](#).

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## Young onset dementia and dementia-related news

### **Dementia UK – new young onset dementia leaflet**

Dementia UK has published a new leaflet offering advice and information around choosing a care home for a younger person who is living with dementia. Read the leaflet [here](#).

### **Peer support group for rare dementia carers**

Carers charity tide is running an online group that enables people who care for someone with a rare form of dementia to connect with others. The group meets on the third Wednesday of the month from 2.30-3.30pm. Find out more [here](#).

### **What does good research co-production with people with dementia look like?**

The 'Dementia Enquirers gold standards for co-research' publication sets out principles and best practice around co-research and co-production with people with dementia. Read or download a copy [here](#).

### **Intercultural dementia care – a guide for health and care workers**

NHS England has worked with Alzheimer Europe on a new guide to support people who provide health and care to those living with dementia from an ethnic minority background  
. Read the guide [here](#).

### **'Understanding dementia better' online training course**

Dementia Adventure is offering a free online training course for family members and friends who support someone with dementia. Various dates are available to book in June and July 2023. Find out more [here](#).

### **Making a difference in dementia care event**

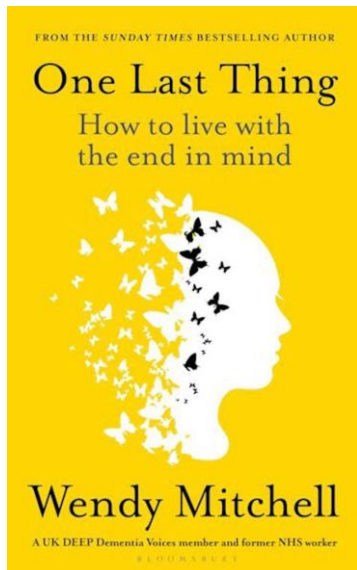
Join the NHS Lived Experience Team for an online event on Wednesday 31st May 2023 from 1-2.30pm and hear from a person living with dementia and a family member, in addition to people working within the sector who help shape and influence how services are designed and delivered in dementia care. Find out more [here](#).

### **Carers Week – 5th to 11th June 2023**

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make to families and communities throughout the UK. This year's theme is 'Recognising and supporting carers in the community'. For more information click [here](#).

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## Pre-order 'One last thing' by bestselling author and advocate Wendy Mitchell



Since Wendy Mitchell's diagnosis of young onset dementia in 2014, she has written two Sunday Times bestselling books and become a tireless dementia advocate and campaigner.

In her third and final book, Wendy explores all angles of death: how we can prepare for it, how we talk about it and how we can be empowered to make our own choices.

'One last thing' is on sale from Thursday 22nd June 2023 and is available to pre-order now.

[Pre-order here](#)

## Member showcase: Peter Middleton, Coronation Champion



Dementia campaigner Peter Middleton, who is living with young onset Alzheimer's disease, has been awarded the prestigious Coronation Champion title by the Royal Voluntary Service to honour his dementia awareness-raising work.

The awards were designed by Her Majesty The Queen to recognise and reward those who go that extra mile in their communities.

Peter says, "I love working with national and local charities to show people they can still be valuable and productive after a diagnosis of dementia."

[Find out more here](#)

# Young onset dementia research round-up

## Involvement opportunities

### Young onset dementia and feelings of gratitude

Lucy Hutchinson is a Clinical Psychology Doctorate Student at the University of Hull. Her thesis project will examine the meaning and experiences of gratitude for people living with young onset dementia. Find out more by clicking [here](#) or email Lucy at [l.y.hutchinson-2021@hull.ac.uk](mailto:l.y.hutchinson-2021@hull.ac.uk)

### Have you been diagnosed with cancer after your dementia diagnosis?

Georgie-Anne, a student from the University of Liverpool, is conducting research to explore how people with a dementia diagnosis feel when they are also diagnosed with cancer and how they manage this. For more information click [here](#) or email Georgie-Anne at [dementiaresearch@liverpool.ac.uk](mailto:dementiaresearch@liverpool.ac.uk)

### A survey to help identify priorities for people with dementia

This survey is exploring people's experiences of living with and/or caring for someone who has dementia. The responses will help to inform the development of LEND (Lived Experience Network 4 Dementia), a social and support group for people living with dementia and carers, run by thred CIC. Find out more or complete the survey [here](#).

### Learning disability and dementia – quality of life research study

Winnie Tsang, a part-time PhD researcher at the University of Kent, is looking to interview people with a diagnosis of a learning disability who are undergoing investigation for dementia. Interviews will be face-to-face and last around 45 minutes. To find out more, please email Winnie at [wt66@kent.ac.uk](mailto:wt66@kent.ac.uk)

## Research showcase

### Online counselling for family carers of people with young onset dementia: The RHAPSODY-Plus pilot study

**Authors:** Stephanie Perin et al

**Aim:** this study assessed the acceptability and feasibility of combining a web-based information and skills-building programme for family carers of people with young onset dementia (RHAPSODY), with individually tailored support sessions with a health professional (psychologist or social worker) via online videoconferencing.

onset dementia. The carers used the RHAPSODY e-learning programme for four weeks, followed by two support sessions facilitated by health professionals online. Following the programme, feedback was collected from the family carers and health professionals regarding the acceptability, feasibility, subjective benefits and barriers of the online counselling.

### **Key conclusions**

- The majority of family carers rated the support sessions with the psychologist or social worker as good to very good
- Positive feedback from family carers included being able to receive personal advice in addition to the e-learning programme
- The health professional participants thought the programme was acceptable and beneficial for family carers
- Limitations of the study are the small sample size, access and use of technology
- Combining e-learning with two support sessions offers the opportunity of overcoming geographical and service access barriers

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

March 2023, 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](#).

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## **Resource showcase: Young onset dementia diagnostic clinic leaflet**

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The Young Dementia Network's diagnostic clinic leaflet is designed to be given at the point of diagnosis to inform newly diagnosed people of the organisations who may be able to offer support and information.

It shares the key sources of dementia support nationally. We would like to encourage anyone working in memory clinics or diagnostic services to share it with people who are given a young onset dementia diagnosis so they can be immediately signposted to these vital sources of

information and support.

[Find out more here](#)

[Visit our website](#)

[Join the Network](#)

[Our resources](#)



## Contact us

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