



## Thank you

**Our Network is all about improving lives by improving support for people living with young onset dementia, their partners and children. To do this we need to know what is available and where, and we need an estimate of the numbers of people affected.**

If we know that, we can help all who are working to improve lives too. That's the point of the Network.

So **a big thank you** to everyone who contacted us last month to share the details of their local services – this is the real strength of our collaborative community.

And **a big thank you** to those who worked out an accurate method of estimating the number of people living with young onset dementia at **[70,800 in the UK](#)**. We are hoping to share the local estimates soon but in the meantime check our **[October webinar recording](#)** for how to work it out for your area.

**Tessa Gutteridge**

Chair, Young Dementia Network

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## Young onset dementia webinars

### **Different models – Young Onset Dementia Service, Doncaster**

**Our next webinar will be presented by Dr John Bottomley, Associate Medical Director and Consultant Psychiatrist at Rotherham Doncaster and South Humber NHS Foundation Trust.**

It will focus on the long-established Young Onset Dementia Service in Doncaster, which offers a single point of access and a pragmatic approach and process to achieving a timely diagnosis.



**Wednesday 24th May 2023**

🕒 12.30-1.30pm

[Sign up here](#)

## Different models – Young Onset Dementia Nurse-Led Service, Northamptonshire

**Our webinar in June will be presented by Jenny Kerti alongside colleagues from the Younger Persons with Dementia Team based in Northamptonshire.**

It is a nurse-led service which provides assessments, diagnosis, and support for individuals under the age of 65 who are living with dementia. The team understands the complex needs of younger people with dementia and works to provide tailored support to each person and their family.

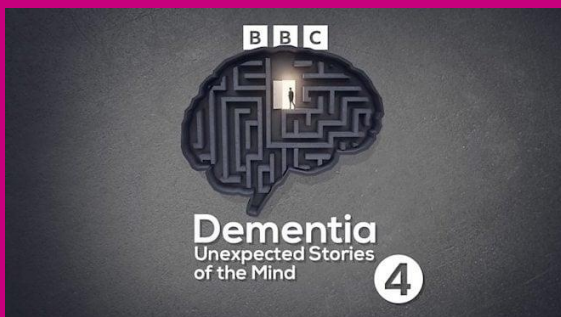
During this webinar, Jenny and the team will focus on how they set up the service, the structure of the team, their referral pathway and the experience of diagnosis that they provide.

📅 **Wednesday 21st June 2023**

🕒 12.30-1.30pm

[Sign up here](#)

## Radio 4: 'Unexpected stories of the mind'



Radio 4 recently shared a fascinating five-part series featuring neurologist Dr Jules Montague and William Miller, whose father had Alzheimer's disease. They went into the homes of people living with rare dementias and discovered that the symptoms of these dementias go far beyond memory loss.

The series featured people affected by primary progressive aphasia (PPA), posterior cortical atrophy (PCA), Lewy body dementia, frontotemporal dementia and Huntington's disease.

Young Dementia Network steering group member Nikki Zimmermann of Rare

Dementia Support, was involved in the making of the series.

[Listen here](#)

## Different symptoms of young onset dementia



**Dementia UK has created a new leaflet and film detailing the symptoms other than memory loss that may be experienced by younger people living with dementia.**

The film and leaflet contain information about symptoms affecting a person's:

- behaviour and personality
- language and communication
- movement and coordination
- social and life skills
- vision and spatial awareness

Find out more about the different symptoms of young onset dementia and watch the short film via the link below.

[Visit the website here](#)

## Young onset dementia and dementia-related news

### **Dementia UK Twitter Space – symptoms of young onset dementia**

Dementia UK's next live conversation on Twitter will take place on Wednesday 26th April 2023 at 5.30pm. Dementia specialist Admiral Nurses Vic Lyons and Jules Knight will be joined by Tracey Shorthouse, who was diagnosed with posterior cortical atrophy (PCA) in 2015 aged 45. They will be discussing the different symptoms of young onset dementia. Set a reminder to join [here](#).

### **Supporting people with a learning disability and dementia**

An interactive webinar is taking place on Tuesday 20th June 2023 from 2-3pm. It will feature Rosie Joustra, who is living with a learning disability and dementia, Nicola Payne, MacIntyre's Best Practice Manager – Health and Families, and Beth Britton, Freelance Consultant and former carer. They will share good practice examples and

resources to support people who are living with a learning disability and dementia. For more information or to book a place, click [here](#).

### **Free virtual courses – mild cognitive impairment and Lewy body dementia**

The Neurology Academy is running a free virtual course that focuses on mild cognitive impairment. The course consists of eight modules and features expert speakers. Find out more [here](#). It is also running 'Lewy Body Bitesize', a free online course made up of short talks from experts to help participants to appropriately support people living with Lewy body dementia. For more details, click [here](#).

### **Care City report – 'Living with dementia in London'**

Care City, an innovation centre for healthy ageing and regeneration based in Barking, has published a report titled 'Living with dementia in London'. The report for the [London Dementia Clinical Network](#) identifies several areas for improvement in services for people with dementia and their carers living in London. To access the report, click [here](#).

### **Call for presentations – UK Dementia Congress 2023**

The Journal of Dementia Care has announced that the 17th UK Dementia Congress will be held at Aston University, Birmingham on 7th and 8th November 2023. The conference is the largest annual multi-disciplinary dementia care-focused event and exhibition in the UK. The call for presentations is open; the deadline for submitting proposals is midnight on 4th June 2023. Find out more [here](#).

### **Care home for younger people living with dementia opens in York**

Wellburn Care Homes, a family-run care home provider with 14 homes located across the northeast, has refurbished one of its care homes in York: St Catherine's in Shipton-by-Beningbrough. It is now made up of two separate homes and includes The Manor which caters for under 65-year-olds who have young onset dementia. For more information, click [here](#).

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## **Young onset dementia research round-up**

### **Recently published research**

#### **Updating services for people with younger onset dementia and their caregivers**

Researchers from the Jockey Club Centre for Positive Ageing, Hong Kong  
Read the paper [here](#).

#### **"The oxygen of shared experience": exploring social support processes**

**within peer support groups for carers of people with non-memory-led and inherited dementias**

Emma Harding et al

Read the 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](#).

## A new way to follow the Young Dementia Network



**We have launched a profile page for the Young Dementia Network on LinkedIn to help us connect with a wider audience of people active in the field of young onset dementia.**

If you are a member of LinkedIn, please follow the Network page and invite any relevant contacts of yours to follow us too.

Just click the 'Invite connections' button, select the contacts who you think the Network will interest, click 'Invite' and they will be sent a link inviting them to follow the page. Thank you!

[Visit LinkedIn here](#)

## Member showcase: Martin Robertson



**Martin Robertson was diagnosed with dementia in 2016, at the age of 58. Since his diagnosis he has become a passionate advocate for people living with young onset dementia.**

A Young Dementia Network member, he is involved in many groups and committees including the co-production of Scotland's dementia strategy. He has recently got involved in a project to help rebuild Ukraine in a dementia-inclusive way.

[Read more here](#)

## Book giveaway winner – 'Unforgettable'

We are delighted to announce that the winners of our March 2023 book giveaway were Rob Simpson and Naomi Warburton. They have each won a copy of Steve Thompson MBE's autobiography, '[Unforgettable](#)'.

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## Resource showcase: Young onset dementia ID cards



In 2019, the Young Dementia Network ran a pilot project to trial young onset dementia ID cards which we designed in collaboration with our members.

Following the trial, we were delighted to be able to make the cards available to all and since 2019 we have sent out thousands of cards to our members and beyond.

If you would like a card for yourself, your group or service members, please visit our website via the link below where you can download and print out the cards or request paper copies.

[Visit our website here](#)

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