



## Share your experiences - people power

**In this noisy world, I can't think of anything more powerful to change the status quo than a personal story. Well-delivered, the personal story takes us to the heart of the matter quicker than most other communications. It reminds us of our own humanity and why we do what we do in terms of vocation.**

This issue is packed with an array of useful information, including how and why, if you are affected by young onset dementia, we need you to share your experiences.

Tessa Gutteridge  
Chair, Young Dementia Network

## Young onset dementia webinars

### Improving the experience of diagnosis

#### **Mind the gap – navigating young onset dementia from pre-diagnosis onwards**

Our first webinar of 2024 will be led by Jill Quinn, CEO of [Dementia Forward](#), North Yorkshire.

Jill and her colleagues will share the learning from Dementia Forward's work with families at all stages of young onset dementia.

 **Wednesday 21st February 2024**

 **12.30-1.30pm**

[Register today](#)

**Tailored memory clinic care; using the diagnosis process as a**

## starting point for person-centred young onset dementia support

Our webinar on Tuesday 12th March 2024 will be led by Dr Janne Papma, Head of the Alzheimer Centre Erasmus Medical Centre (ACEMC) in Rotterdam.

Dr Papma, alongside panellists Dr Rumana Chowdhury, Neurology Consultant and Leeds Cognitive Neurology Service Lead, and Harro Seelaar, Neurologist and Associate Professor at ACEMC, will address support for people with young onset dementia and their family members during the diagnostic pathway at the memory clinic, and how the gap from diagnosis to post-diagnostic care and support could be bridged.

 **Tuesday 12th March 2024**

 **12-1pm**

[Register today](#)

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## Help us help others by sharing your experiences



**During 2024, the Young Dementia Network will be launching a campaign around improving the experience of diagnosis and raising awareness of young onset dementia.**

We want to show how receiving a dementia diagnosis in mid-life changes people's lives so we can create powerful messaging for our campaign.

To do this we need your help.

If you are living with young onset dementia or are a family member or friend of someone with a diagnosis, we would love you to share your experiences by answering three short questions. Find out more and take part via the link below.

[Take part here](#)

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## Gareth and Sarah's story



**Gareth and Sarah have been together for 23 years and have two sons aged 21 and 12.**

Gareth first noticed Sarah was exhibiting dementia symptoms when she was 46; she was diagnosed with frontotemporal dementia (FTD) aged 48.

In their story, Gareth reflects on the challenges of caring for a partner with young onset dementia and shares the impact it has had on their two children.

[Read their story in full here](#)

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## Young onset dementia and dementia-related news

### Marking World Lewy Body Day

Lewy Body International is holding an event to raise awareness of World Lewy Body Day on Sunday 28th January 2024 from 2-5pm at the Helix Science Centre, Newcastle upon Tyne. There will be presentations about Lewy body dementia followed by a tea party in honour of Dr Lewy, the doctor who first identified the proteins in the brain that cause this form of dementia. Find out more [here](#).

### 26th National Dementias Conference, London

The 26th National Dementias Conference is a two-day event that will be held on Thursday 8th-Friday 9th February 2024 at the Cavendish Conference Centre, London. This annual event will be chaired by Alistair Burns, Professor of Old Age Psychiatry at the University of Manchester, and John O'Brien, Professor of Old Age Psychiatry at the University of Cambridge, and will bring together leading specialists in dementia care and research. For more information, click [here](#).

### Young onset dementia information and support in Surrey

Surrey and Borders Partnership NHS Foundation Trust has a dedicated Young Onset Dementia Team offering assessment, diagnosis and early intervention. It accepts GP referrals. The team has developed a [webpage](#) where people in Surrey can access information about the service, find support and learn about practical things to consider

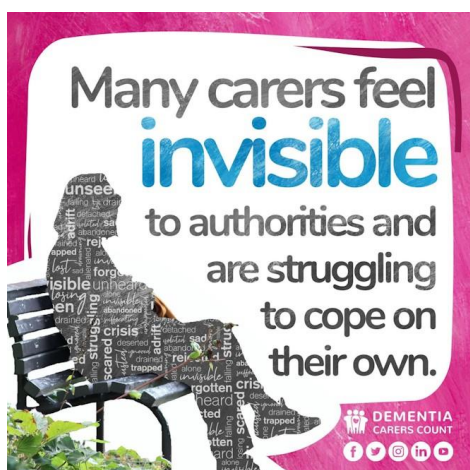
after diagnosis and advice on living well.

### **YouTube playlist of young onset dementia-related films**

Dementia UK has created a playlist on its YouTube channel of young onset dementia-related films. To view the playlist, click [here](#) and select the 'playlist' tab.

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## **Dementia Carers Count – 'Invisible' report**



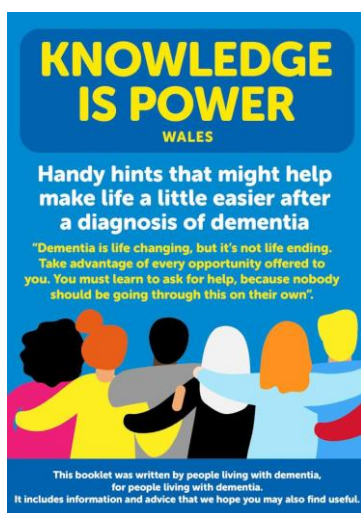
**Dementia Carers Count has launched a report, 'Invisible', which shares findings from its 2023 annual survey.**

Over 1,300 dementia carers took part in the survey sharing their experiences of caring for someone living with dementia. They spoke about their desperate need for emotional and practical support to help them cope with the complexities of caring, and said they felt unseen, unheard and unsupported.

[Read the 'Invisible' report here](#)

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## **Booklet giveaway: 'Knowledge is power'**



**The 'Knowledge is power' booklet contains handy hints that might help make life a little easier after a diagnosis of dementia.**

It was created in a collaboration between four groups in the DEEP network, by people living with dementia, for people for dementia.

You can download the booklet [here](#) or we have five copies to give away. To be included in the draw, please email us by Friday 8th February 2023 with your name and postal address.

[Enter here](#)

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## Young onset dementia research

### Involvement opportunities

#### **Are you interested in helping to improve social care for people with young onset dementia?**

The DYNAMIC study is seeking to better understand current social care planning and provision for people with young onset dementia. Researchers from the University of Bradford are looking for people who have a role in, or an awareness of, adult social care planning, provision, management or commissioning in England to complete an online survey. The survey takes no more than 10 minutes to complete; you can access it [here](#).

#### **Research study about the psychological impact on children experiencing parental young onset dementia**

Researchers at the University of Liverpool are looking for people with a young onset dementia diagnosis, or their partners and children, for a research study about the psychological impact on children experiencing parental young onset dementia. Click [here](#) to open a flyer with more information about the study. To take part or find out more email [icarlin@liverpool.ac.uk](mailto:icarlin@liverpool.ac.uk).

### Published research

#### **'Misdiagnosed and misunderstood': insights into rarer forms of dementia through a stepwise approach to co-constructed research poetry**

Paul M Camic et al

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

#### **Risk factors for young onset dementia in the UK Biobank: a prospective population-based study**

Stevie Hendriks, Janice M Ranson, Kirsten Peetoom et al

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

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## Resource showcase: Guidance for dementia support roles

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**This guidance is primarily for dementia advisors, support workers and key workers who may not usually support people living with dementia under the age of 65 years old.**

It is intended to:

- guide discussion with the person with dementia and their families
- be used flexibly to adapt to individual needs and circumstances
- be a prompt to aid the support that workers offer

[\*\*Find out more here\*\*](#)

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[\*\*Visit our website\*\*](#)

[\*\*Join the Network\*\*](#)

[\*\*Our resources\*\*](#)

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## Contact us

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The Young Dementia Network is hosted by Dementia UK.

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