

This is an email from the Young Dementia Network sharing Network related news and information.



## Young Dementia Network Newsletter - Research Special

Welcome to the Young Dementia Network Newsletter. This issue is sharing the latest news about young onset dementia focused research.

You're receiving this email because you've joined the Young Dementia Network, or because you've signed up to other mailings from YoungDementia UK. If you haven't joined the Network yet, you can do so [here](#).

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### A new project focused on young onset dementia

The ANGELA project has recently got underway and aims to

- Improve the accuracy and the process of diagnosis in young onset dementia
- Improve the support that younger people with dementia and their families receive after diagnosis.

There will be opportunities to find out more and get involved in this research, and details will be available soon on the project website [here](#). We will also keep you updated on the project via our Network newsletters.

The project is a three-year research collaboration between University College London (Lead Partner), University of Bradford, University of Northampton and the University of Surrey. External collaborators

### Hearing from children and young people who have a parent with dementia

Pat Sikes and Mel Hall at the University of Sheffield have been working with children and young people to understand their experiences of having a parent with dementia. They presented some of their findings at the Young Dementia conference in September, an overview is available [here](#). The team have published a number of papers discussing the issues young people talked to them about. You can find all of these papers on the research project site [here](#).

Respondents to our [Network Survey](#) have told us that there should be more information and support for children and young people. So we're going to create an area of our website which will bring together this type of information. If you're aware of useful

also include the Alzheimer's Society, YoungDementia UK and Dementia UK. The project is funded by the Alzheimer's Society.

tools, books or websites we can include, then please [let us know](#).



## Why I get involved in research, by Wendy Mitchell

Imagine yourselves being given a diagnosis of young onset dementia. Your life falls apart, you feel worthless and of no use to anyone any more. Services are non-existent so you feel abandoned.

That's what happened to me in July 2014 when I was diagnosed with young onset dementia.

Now, imagine, if someone then came along and asked for your opinions, asked you to be involved in gathering information. Someone who was genuinely interested in what you had to say. Someone who was willing to travel to your home just to see you. Imagine how that would make you feel.

Imagine the impact on your well-being finally hearing someone acknowledging that you still had something to give; that you still had a valuable opinion and views that mattered.

That's what happened to me when I started to be involved in research. There is no cure and no proven consistent ways to live well and care for someone with dementia, so to be involved in research is a no-brainer for me.

Please feel free to read [my blog](#) on living with dementia, or follow me on Twitter @WendyPMitchell.

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## News from Japan

Two members of the Young Dementia Network Steering Group, Dr Janet Carter and Sarah Plummer, were invited to speak at an international symposium on young onset dementia in Japan. The symposium was organised by Professor Jun Yaeda who is researching support to help people remain in work when they are diagnosed with young onset dementia or other brain injuries.

Colleagues in Japan were interested to learn about the **Young Dementia Network** and to discuss whether something similar could be set up in Japan. We'll continue to work with Professor Yaeda so we can learn about the ways people are supported to stay in work in Japan, and share that learning through the Network here in the UK.

Fellow speaker Tomofumi Tanno, Sarah Plummer and Dr Janet Carter.



## How do I find out about research?

Many of us are interested in research, but don't know how to find out more. The Young Dementia Network Steering Group has set up a research work stream to promote young onset related research and also make it accessible. The work stream is currently creating a simple guide to explain

- How you can find out about the latest research
- How you can get involved
- What learning has come out of research and what this means for you.

We'll share this guide as soon as we can.



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PO Box 315, Witney, Oxfordshire OX28 1ZN