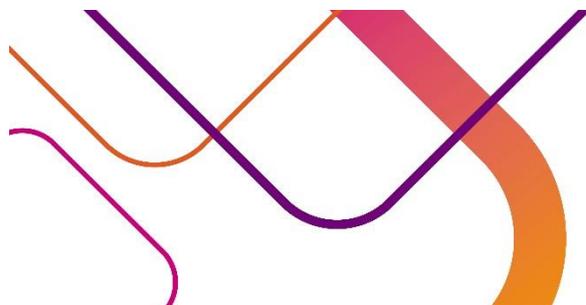


This is an email from the Young Dementia Network sharing Network and young onset dementia related news and information

Young Dementia Network News - February 2022

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Hidden challenges, Hidden gems?

Do you think that the challenges of experiencing dementia in mid-life, say 30s to 60s, are understood by your neighbour, by your local community, by the health and social care workers that you know? Or are those challenges hidden? And are the solutions hidden too?

The Young Dementia Network is keen to uncover the issues and spread the word on ways to ease them. So this autumn, we are setting up an online event to focus on a specific and enduring challenge for the person and their family - the experience of diagnosis. I am talking about the 'before, during and shortly after'. What we want to do is bring to light the hidden gems of good service and excellent practice and share them far and wide.

Whatever your connection with young onset dementia, whether you are living with the condition or working in the field, we need your ideas for the event programme. For more information read the 'Young onset dementia online event' section [here](#).

Email programme ideas to youngdementianetwork@dementiauk.org

Tessa Gutteridge

Chair, Young Dementia Network



invites you to a webinar
Dementia, Disabili-tea and Hope

The importance of human – and disability rights – to people with young onset dementia

Join us with a cuppa for the latest in our series of young onset dementia webinars

Wednesday 16th March 2022
2.30-3.30pm

youngdementianetwork.org/four-webinars



Dementia, Disability and Hope webinar

On Wednesday 16th March 2022, we will continue our series of young onset dementia webinars with Dementia, Disabili-tea and Hope.

Philly Hare, co-Director of Innovations in Dementia, will be in conversation with three people living with young onset dementia – Nigel Hullah, George Rook and Dreane Williams.

During the webinar they will discuss the importance of human – and disability rights – to people with young onset dementia and explain how legal rights and the promotion of ‘reasonable adjustments’ can be made to make life easier and more accessible for them.

They will address common questions about this approach and offer practical tips relevant to each and every one of us, whatever our role.

Sign up to join the webinar [here](#).

Watch a recording of our February webinar - Authori-tea with Wendy Mitchell [here](#).

Catch up with past webinars on our [website](#).



Supporting a friend with young onset

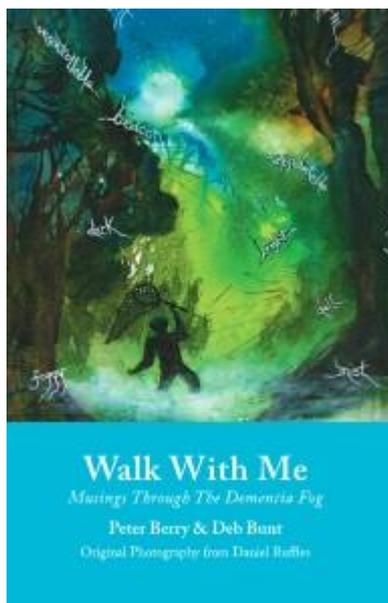
Deb Bunt met Peter Berry, who is living with young onset dementia, by chance one day in a cycle shop in Suffolk. A cycling partnership soon became established based on their joint love of the sport.

Deb admits that Peter remembers little about her life, but they have formed a close friendship based on mutual trust, reciprocal support and a shared interest

in cycling. Deb shares the story of their friendship and some of the strategies she and Peter have put in place to make their cycle rides as trouble-free as possible.

Read Deb's story [here](#).

Young onset dementia / dementia related news



Walk with me is a compilation of the thoughts and poetry of Network member Peter Berry, who was diagnosed with young onset dementia aged 50.

Peter's dementia impacts his short-term memory severely and this means that as soon as words leave his mouth, they are gone. Peter's friend, [Deb](#), has spent the last two years jotting his words down and has captured them in this book.

Walk with me is available to purchase via [Amazon](#).

Congratulations to the UK DEEP network who are celebrating their 10th anniversary this year. To mark the occasion, they are inviting dementia groups to be part of a DEEP festival which will run from March until the end of November 2022. Find out more [here](#).

tide has launched a new campaign - Front of Mind - which puts family carers' needs at the heart of dementia care. They are calling for greater awareness and understanding of dementia, for people living with the condition and their carers to be more involved in policy decisions that affect them and for clinical pathways to be clear and supportive through-out a diagnosis and beyond. Find out more [here](#).

Exciting news from [Rare Dementia Support](#) - they have announced the launch of Rare Dementia Support Canada who will contribute their research and support efforts to the rare dementia space.

The Young Dementia Network is carrying out an update on Dementia UK's behalf of the information held in their [young onset dementia groups and services listing](#). If your young onset dementia group or service is listed, please review the information and let us know if anything has changed via [email](#). Or if you run a young onset dementia specific group or service that isn't currently listed, please tell us about it via this [webform](#).

Young onset dementia research round up

Involvement opportunities

The Alzheimer's Society is inviting people to take part in a survey focusing on people's experiences of support after diagnosis. The results will form part of their evidence base contributing to a national report on post-diagnostic support. They are very keen to explore the differences of support needs amongst younger people with dementia. You can complete their survey [here](#).

Study examining exploring how people with dementia and their family carers decide to talk, or not talk, to others about the diagnosis

Gianna Kohl, a PhD student at University College London, is exploring how people with dementia and their family members decide to talk, or not talk, to others about the diagnosis and what their experiences with this are. If willing to take part, interviews will last up to one hour and you will receive a gift card for your time. Alternatively, you can take part in the online survey [here](#). For more information contact Gianna at G.Kohl@ucl.ac.uk or click [here](#).

Recently published research

Reimagining post-diagnostic care and support in young onset dementia

Christian Bakker MSc, PhD, Marjon Verboom MA, Raymond Koopmans MD, PhD. Click [here](#).

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

To view a collection of research focusing on the most prominent subjects relating to young onset dementia click [here](#).

Resource showcase: Supporting implementation of the NICE guideline for young onset dementia



The NICE dementia guidelines make no mention of young onset dementia, so the Young Dementia Network has produced a resource that sets out the tailored approach needed at key stages of diagnosis and support.

The resource, aimed at commissioners and frontline health and care professionals, provides guidance on how to address the challenges and meet the unique needs of people of working age living with dementia, which are not being met by an age-generic approach.

The resource is available to download via our website [here](#).



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