

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



Young Dementia 2020 conference update

You will not be surprised to hear that we are not able to hold our biennial Young Onset Dementia conference this autumn. The event, hosted by the Journal of Dementia Care in association with YoungDementia UK, is a casualty of COVID-19.

Young Dementia Network members contributed such a rich and diverse range of wonderful suggestions for the programme. We were very much looking forward to bringing those ideas to life, with your help. Thank you so much for all your contributions. Perhaps we can set up some digital sessions - we will be in touch if we can do this.

Tessa Gutteridge, Director YoungDementia UK, Chair Young Dementia Network



A call for people with pre-existing medical conditions to join the world's largest COVID-19 study

Young Dementia Network members, Alzheimer's Research UK, have asked us to share details of a smartphone app called the COVID-19 Symptom Tracker which has been developed by King's College London. More than 3.5 million people have downloaded the app and are using it to regularly report on their health in the largest public science project of its kind anywhere in the world.

It could provide crucial information about how COVID-19 affects people with dementia but people with pre-existing health conditions such as dementia are significantly under-represented in the group of people currently using the app. Early analysis shows that the illness may start with different symptoms, such as diarrhoea and confusion, rather than the classic cough and fever. So, in order for scientists and doctors to really understand how the

virus affects the more vulnerable people in society, they need the support of the public to download the app and take part.

Anyone can join the study by downloading the simple, free COVID Symptom Tracker app and answering a few questions about their health and medications; participants then spend a minute checking in every day, whether they are feeling physically healthy or experiencing any new symptoms. For someone living with dementia, a family member or carer can download the app and report on their behalf if they need support. You can download the app [here](#).



FREE dementia book give away

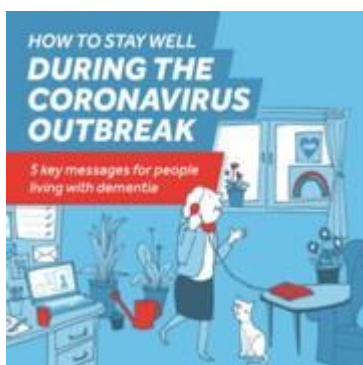
This month, we have a copy of two fantastic books to give away to Young Dementia Network members thanks to the generosity of Jessica Kingsley Publishers.

Keith Oliver (pictured) was diagnosed with young onset dementia in 2010 and has since become a leading dementia activist and speaker and is a valued Young Dementia Network steering group member. In his book, [Dear Alzheimer's](#), he tells his story in diary format and gives insight into what

day-to-day life with dementia is like and how he has continued to live a full life after diagnosis.

Dave Pulsford and Rachel Thompson's book, [Dementia - Support for Family and Friends](#), is a supportive guide to dementia care. It is ideal for anyone with a friend or relative with dementia and covers the latest developments in terms of policy, debates and approaches to care and features the voices of people with dementia.

You can put yourself forward to win either book by [emailing us](#) with your name, postal address and the title of the book you would like to win by Sunday 31 May.



A guide to staying well during the coronavirus outbreak

The IDEAL programme (Improving the experience of Dementia and Enhancing Active Life) is the largest study of living well with dementia in the UK. They have recently published a leaflet which explains five key ways for

people living with dementia and their care givers to stay well during the coronavirus outbreak.

Whilst not young onset dementia focussed, Network member Keith Oliver (see above article) advised on the content and feels it has a young onset slant. It contains information about how to stay safe and well, stay connected, keep a sense of purpose, stay active and positive. You can download a copy of the leaflet [here](#).

Network members share hints, tips and resources for life during lockdown

The current coronavirus pandemic is a worrying time for everyone and the impact of life in lockdown has brought changes to all our lives, but for people whose lives are also affected by young onset dementia, it has raised lots of additional issues and challenges.

So we have asked our Network members to share their stories of life in lockdown with us. They have told us how they have adapted, what they are doing to keep busy and have shared the worries and challenges they are facing as well as positive things too. You can read their stories on the YoungDementia UK website [here](#).

The **Alzheimer's Society** has published a guide which shares their five **top tips for individuals volunteering** their time as part of the coronavirus response to support people living with dementia. Click [here](#).

Dementia Carers Count has launched a **virtual carers centre** with lots of useful information for family members. Click [here](#).

Dementia UK has created a **coronavirus hub** on their website which shares information for families looking after someone with dementia. Click [here](#).

Innovations in Dementia has created new **resources, guidance and videos for volunteers** who are supporting people living with dementia during the coronavirus crisis including helpful tips around transport, deliveries and keeping in touch using Zoom. Click [here](#) to visit their website.

Rare Dementia Support has a section on their website dedicated to sharing **practical tips, information and resources** about coronavirus and what it means for people living with dementia. It includes specific information about caring for a person with bvFTD during times of isolation. Click [here](#).

tide host a **weekly Zoom wellbeing session for carers** as well as online support, resources and information, find out more [here](#).

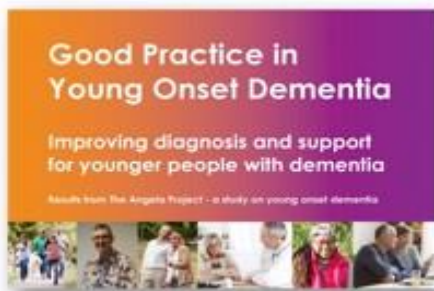
If you would like to share your story or what your group or organisation is doing to support people living with young onset dementia during the coronavirus pandemic, please [email us](#).



Have you got your young onset dementia ID card yet?

We know that many people are not able to get out and about much at the moment but in the last few months, the Young Dementia Network has sent out over 2300 ID cards to be used by people who are living with young onset dementia and their family members / supporters.

We hope that the cards will give reassurance and help people to feel more confident when leaving the house as lockdown is eased. The cards are available to download or request via our website [here](#).



The Angela Project - key recommendations on assessment for dementia

The Angela Project was a three-year long Alzheimer's Society funded research study.

Researchers consulted young people living with dementia and their families, international clinical experts and service providers in the largest study of young onset dementia ever carried out in the UK.

Their newly published [Good Practice in Young Onset Dementia guide](#) summarises their findings including the recommendation that the assessment for dementia should

- Use considerate language
- Offer home visits
- Allow time to ask questions
- Adopt a calm approach
- Improve the MRI experience
- Make quicker referrals
- Refer to specialists
- Use a multi-disciplinary team
- Explain assessments
- Offer improved access to clinics
- Issue results more quickly
- Reduce time to diagnosis.

You can download or request a copy of The Angela Project Good Practice in Young Onset Dementia guidance [here](#).

Interested in studying for a dementia Masters?

Network steering group member, Dr Janet Carter, has asked us to share information about the University College London Dementia MSc. She hopes it will be of interest to some of our Network members.

The MSc is a modular course and can be studied full-time, part-time or flexibly. There are two pathways within the MSc - mental health and neuroscience. The mental health pathway is based in the UCL Division of Psychiatry which delivers many of the core and optional modules. The MSc is highly suitable for clinicians from all disciplines working in the field of dementia. Applications for the next academic year close on the 24 July 2020.

Please click [here](#) for further details. You may also find the student perspective [videos](#) helpful if you are interested in the course.



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