

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



## Understanding the impact of COVID-19

**I am an optimist at heart and a realist in the head. With Young Dementia Network members, I have been keen to understand the very real impact that COVID-19 has had on the everyday lives of individuals affected by young onset dementia. Only by listening and understanding can any help count.**

So, this issue shares some of the challenges and enlightenments members have been experiencing. Read the stories of Keith, Nigel, Dementia Carers Count and Rare Dementia Support, all of whom are Young Dementia Network members. And check out this page on our website where we share links to a number of helpful resources, sources of practical support and advice and more personal stories, click [here](#).

Communities come together in troubled times don't they - one recent 'coming together' which has fabulous potential is One Dementia Voice. Still at an early stage, but consider what the truly collaborative effort of major national organisations dedicated to people with dementia could achieve. Our first campaign is focusing on people with dementia in care homes and enabling family members to be with them as 'equal partners in care'. The rights of these people have been swept aside as a result of the crisis. More to come on this.

**Tessa Gutteridge, Chair Young Dementia Network, Director YoungDementia UK**



**Keith's story**



**Nigel's story**

**Keith Oliver was diagnosed with young onset dementia 10 years ago at the age of 55. He is a member of the Young Dementia Network and an ambassador for the Alzheimer's Society. He is also a published author.**

Keith shares his thoughts about the impact of the COVID-19 pandemic on younger people living with dementia and his thoughts on the future. Read Keith's story [here](#).

**Nigel Hullah is the co-chair of the 3 Nations Dementia Working Group, is a regular contributor to the Dementia Diaries and is living with young onset dementia.**

He shares his views about how the COVID-19 lockdown has affected people who have a diagnosis and how things must improve in the future. Read Nigel's story [here](#).



## Dementia Carers Count's story

**Lissy Edwards tells us how Dementia Carers Count has surveyed family carers to find out the key issues and challenges being faced by people supporting a person living with dementia.**

Read Lissy's update to find out how they have responded to the pandemic and how they are planning to deliver support and courses in the future [here](#).

# Rare Dementia Support

Advice Community Learning

## Rare Dementia Support's story

**Nikki Zimmerman shares with us how Rare Dementia Support has gone completely virtual since lockdown and have increased their one to one telephone support.**

Read Nikki's update and find out how they see their support adapting in the future [here](#).

# Sheffield Hallam University

## Young onset research project into community day centres

**Chloe Rogers is a postgraduate research student, undertaking a Masters in Philosophy (MPhil) at Sheffield Hallam University. She is conducting a study to explore the experiences of attending a community day centre from the perspective of people living with young onset dementia, and what it means to them in their everyday life.**

Participants will be asked to take some photographs of things that remind them of being at the day centre, which will then be used as prompts during an interview. Interviews will be held on either Zoom or over the telephone and will last approximately 30-60 minutes.

For more information about the study, you can read the participant information sheet [here](#) or email Chloe [C.Rodgers@shu.ac.uk](mailto:C.Rodgers@shu.ac.uk)

The study has been approved by Sheffield Hallam University Research Ethics Committee (reference number: ER18653886).

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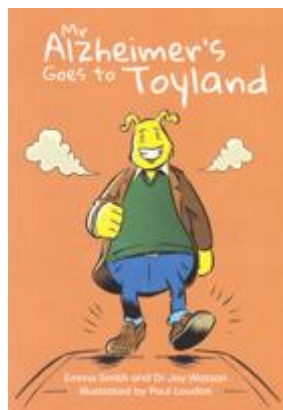
## The Angela Project publish research article on quality indicators for comprehensive assessment of dementia in young adults using a modified e-Delphi approach

Researchers from The Angela Project, the largest study of young onset dementia ever carried out in the UK, have published an article following a three-year study. The aim of the study was to develop guidance for clinicians about essential elements that can support clinical decision-making in the diagnostic workup of young onset dementia.

Their newly published article titled, International consensus on quality indicators for comprehensive assessment of dementia in young adults using a modified e-Delphi approach, can be read, [here](#).

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

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### Book give away - Mr Alzheimer's Goes To Toyland

Young Dementia Network member, Joy Watson, was diagnosed with young onset dementia on her 55th birthday. Determined to raise awareness of the



### Imprisoned by Love - C S Brahams

Imprisoned by Love is a compelling novel about deputy head teacher, Sophie Boswell. All set to tackle the new academic year at her independent school in London, her husband Michael's increasingly erratic behaviour begins to

condition, she has become a tireless campaigner and educator.

Last year, Joy launched a book, Mr Alzheimer's Goes To Toyland, in order to help children understand dementia. We have a copy to give away to a lucky Young Dementia Network News reader. Email [web@youngdementiauk.org](mailto:web@youngdementiauk.org) with your full postal address by Friday 7 August to be put in the hat to win.

take its toll on her and leads to him receiving a frontotemporal dementia diagnosis aged 49.

The novel by debut author C S Brahams, is said to provide an insight into, 'the uncomfortable realities of balancing love and duty.' You can purchase a copy of Imprisoned by Love, [here](#).



## A request from Network members, tide - together in dementia everyday

COVID-19 emergency legislation, the Coronavirus Act 2020, has been rushed through and enacted in each of the nations across the UK. Carers organisation tide is concerned what impact this is having on the day to day lives of family members of people with dementia including their access to assessment and support.

They have recently launched an anonymous [UK-wide survey](#). Responses from the survey will be collated into a formal report which will be submitted as evidence to the each of the Government's planned six-month review of the Coronavirus Act which is due in the autumn.

They would appreciate your support with disseminating this survey through your networks so that as many family carers as possible can respond across the UK. The deadline for completing the survey is 3 August 2020.



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The Young Dementia Network is a YoungDementia UK initiative.

YoungDementia UK PO Box 315 Witney OX28 1ZN Charity No 1085595