

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



Twelve months of incredible work

So, we are nearly at the end of 2019 and it has been a year of growth, development and an increase in awareness for the Young Dementia Network.

Although we did not quite reach our goal of having 3000 members, we certainly made an impact nationally and internationally with the work we have undertaken.

From speaking at national conferences to creating resources that have been translated for use in other countries, we feel we have ended the year on a high. The Young Dementia Network has been active in an increasing number of areas to effect positive change and has collaborated with the national organisations in our steering group and many others towards the aim of changing policy for the better for people affected by young onset dementia.

The thing that I am personally most proud of is that every project, presentation, idea, event or piece of research we have worked on, has always included people with young onset dementia.

Our aim for 2020 is to reach even more people and to continue collaborating to improve resources, policy and services for people affected by the condition.

Is it too early to wish you all a merry Christmas and all the best for 2020? Well this is my last newsletter of this decade so I will do. And thank you for all your support, feedback and help to grow the Network this year.

Have a wonderful festive season when it arrives, and I will be back with another newsletter in the new year.

Donna
National Development Manager

What needs to be thought about straight away	What needs to be thought about in the short-term	What needs to be considered for day to day living	What can and can't be considered or offered when the need arises
Practical - Support for people who have not been advised in detail of their symptoms but need for diagnosis	Practical - Family issues - signpost and support to relevant organisations	Practical - How to live with dementia for the person who is diagnosed - the living arrangements for yourself	Practical - How to live with dementia - the person who is diagnosed - the living arrangements for yourself
Practical - What to do if you have to look after someone with dementia in the home	Practical - Support for people who have to look after someone with dementia in the home	Practical - How to live with dementia for the person who is diagnosed - the living arrangements for yourself	Practical - How to live with dementia - the person who is diagnosed - the living arrangements for yourself
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The launch of our Young Onset Dementia Guidance - see it first and let us know what you think

Over the last 12 months we have been working with DEEP groups in Oxfordshire and Derby as well as Young Dementia Network members to create

guidance for dementia advisors, support workers and healthcare professionals to assist them when they are supporting a younger person with dementia.

The aim is to offer support for these roles by way of prompts and suggestions on age-appropriate topics and themes for discussion and resources that are available.

You can download the guidance [here](#) and also access other resources that we feel may be helpful.

If you would like to give us feedback on this guidance document, please feel free to complete this [survey](#).



UK Dementia Congress 2019 - the power of collaboration

We were offered a presentation slot at the UK Dementia Congress conference in November where we planned to talk about the young onset dementia guidance, as featured in this newsletter.

It seemed the perfect topic as we were launching it the same week. It was also poignant because not only did Network members offer comments to develop the resource, but the idea, content and design was initiated by two DEEP groups. It would have been nice to share with the audience details of the collaboration that went into the project but unfortunately due to sickness on the day, we were not able to take up this speaking opportunity.

For the past two years we have had a Young Dementia Network stand at Congress but this year, that was not possible. However [Hilda Hayo](#) (Chief Admiral Nurse and CEO of Dementia UK) who is a member of our steering group very kindly offered to give us a space for Young Dementia Network leaflets on their stand.

We are sorry not to have been able to present and meet with others in Doncaster at Congress, but we hope we will be back next year.



Wellcome Trust award funding to new research project

A new young onset dementia public engagement project called the **DEFIN-YD (Dementia Experts For Involvement Network for Younger people with Dementia) Project**, funded by the Wellcome Trust, will be starting in January 2020.

Led by Dr Mary O'Malley and, Network member, Professor **Jacqueline Parkes** from the University of Northampton, the DEFIN-YD Project aims to share knowledge about young dementia research and to create a younger people with dementia and their families' public and patient involvement (PPI) network in the North (Bradford), Midlands (Northampton) and South (London) of England.

The aim is to develop ideas for future research in this area and provide a reference group to support researchers developing projects in this field. If you would like any more information on the project, please get in touch with Mary O'Malley by email on Mary.O'Malley@northampton.ac.uk



Alzheimer's Research UK and Dementia UK endorse our Personal Checklist

We launched our Personal Checklist in August 2019. It aims to make people more aware of some of the common signs and symptoms of young onset dementia and support conversations with GPs when people have concerns.

The checklist was designed with input from the Young Dementia Network steering group and we are delighted that Alzheimer's Research UK and Dementia UK have given it their endorsement.

You can download a copy for free [here](#).



ID Cards - pilot scheme

You may have seen on social media that we are running a trial of our young onset dementia ID Cards.

We'd like to say thank you to Network members Shelley Sheppard and Wendy Mitchell for sharing them on Twitter, which led to over 60 retweets!

We have just under 20 areas across the UK piloting the cards for us and one location in the USA. We will be collating feedback between 20 November and 4 December and hope to be able to roll them out nationally in 2020.

If you've been trialling the ID cards for us, please send us your feedback [here](#).



YoungDementia UK's Annual Review 2019 is available now!

YoungDementia UK's annual review has recently been published which showcases many of the Network's recent activities and achievements and shares the charity's strategic plans for the coming three years.

You can download a copy of their annual review [here](#).

The Young Dementia Network is a YoungDementia UK initiative.

Young onset research paper review

In each issue of the Young Dementia Network News, we share a review of a young onset related research article.

This article titled 'What is the impact of dementia on occupational competence, occupational participation and occupational identity for people who experience onset of dementia symptoms while in paid employment?' has been reviewed by Nicola McGarvey.

Nicola is an active Young Dementia Network member and researcher who has volunteered to write this overview for our members this month. If you would like to have the opportunity to write a review then please contact network@youngdementiauk.org

You can read Nicola's review [here](#).

[Wendy Mitchell](#) who is living with young onset dementia, said about the piece -

'Being in employment at the time of a diagnosis of dementia gives people a double whammy of stress, financial, emotional and personal. As these findings quite rightly highlighted, 'work' often gives stability and normality to life after a diagnosis, but this stability can only exist if support is available from employers. Certainly, that initial feeling of loss and worthlessness could be avoided if adaptations and conversations took place in the work place. But as this piece said, many often left work through lack of support.

'What surprised me in the recommendations was the omission of the importance of the right workplace 'culture'. Approaching management can be difficult if the culture of support isn't visible, however the focus on Rights was reassuring. 'Retiring' at a young age due to

dementia needs so much input from those around, including employers, so that those affected don't feel as though they're being thrown onto the proverbial scrap heap.

'As someone who felt totally unsupported at work to continue to work, these findings don't surprise me, and it's sad to see that attitudes haven't changed in the five years since I was diagnosed.'



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