

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



Celebrating the Young Dementia Network's 2nd anniversary!

September 2018 marks the 2nd anniversary of the Young Dementia Network, so we want to take this opportunity to thank you for your support, encouragement and ideas of how to improve the lives of people affected by young onset dementia.

We hoped the Network would grow by 1000 members each year and currently our membership is 1937 so please tell your friends, family, colleagues about us and ask them to [join](#) so we can reach our next target of 2000 members by the end of September.

There are plenty of things to get excited about and involved in during the Network's 3rd year

* A GP surgery waiting room pilot which aims to increase the general public's understanding and awareness of young onset dementia. Surgeries in Oxfordshire, Kent and Derbyshire will be displaying posters and leaflets about young onset dementia.

* A potential collaboration with some groups of people with young onset dementia across the country to develop a checklist for dementia advisors. It will aim to highlight the topics and information, identified by those with personal experience as important to consider, when talking to people affected by young onset dementia. It will also aim to encourage appropriate support and offer a structure for advisors who may not be used to supporting younger people with the condition.

* A young onset dementia keyworker role for memory clinics - a description of what the role would need to consist of and the benefits of having such a post to support younger people.

I look forward to a productive third year for the Network and to working with many more individuals and organisations to bring about change that benefits people affected by young onset dementia.

Best wishes

Donna
National Development Manager

Feedback from our recent survey

181 of you took part in our recent survey and we have been looking at your feedback to see what we are doing right, what we could do better and what there is still to do.

The breakdown of people involved in the survey were

I have been diagnosed with young onset dementia - 23 responses

I am a family member/friend of someone with a young onset dementia diagnosis - 71 responses

I work with people with a diagnosis of young onset dementia - 67 responses

I am interested in young onset dementia - 20 responses

* 93% of members said they were likely / very likely to recommend the Network to others.



Leaflet for diagnostic and memory clinics

The Network has created a leaflet for individuals who are newly diagnosed with young onset dementia so they know what organisations could offer them support / information if required.

So far, we have sent out 1400 leaflets to nearly 40 areas of the UK. The leaflet was rated Good or Excellent by 86% of Network members who took part in our recent survey. The online link to the leaflet is [here](#).

If you would like free copies of the leaflet, then please contact network@youngdementiauk.org

Calling all carers, or former carers, to join the UK- wide advisory group delivered by tide

Tide (Together in dementia everyday) is committed to working in equal partnership with carers of people with dementia who share their values and commitment.



They are now looking to recruit carers of people with young onset dementia to join their UK wide advisory group. As a member of their advisory group you will be fundamental in determining how tide can achieve its mission and aims.

The advisory group will inform and add credibility to the work of tide across the UK. Advisory group members will work with the tide staff team in each country and lead activities in their areas. You can find out more details of the role, what you can expect from tide and how to apply on the tide website [here](#). **Deadline 14 September 2018.**



Dementia 2020 Engagement Panel: they want to hear from you!

The Dementia 2020 Engagement Panel: a consultation commissioned by the Department of Health and Social Care

Opinion Research Services (ORS) has opened the second phase of the Dementia 2020 Engagement project.

The Department of Health and Social Care want a better understanding of the experiences and needs of people living with dementia and have commissioned ORS to help. The overall project is spread across two years and aims to collect data on many different aspects of experiences of dementia in England.

The current phase is a questionnaire on day-to-day life with dementia and can be answered either by those with a diagnosis or by their main supporters.

The information gathered will be discussed with key partners such as NHS England and the Alzheimer's Society and used to shape policy in order to better deliver the commitments of the Dementia 2020 Implementation Plan.

To participate please click [here](#) or call 0800 311 2126.

Seeking volunteers to help people with young onset dementia in Nottingham

The Alzheimer's Society's Side by Side project does not currently have enough volunteers to support people of a similar age with young onset dementia in Nottingham so they are looking for volunteers.

They match volunteers with a person with dementia so they can help them keep on doing the things they love – and try new things too. Side by Side volunteers bring joy into people's lives by empowering them to continue playing an active part in their community.

For more information please contact Sue Button, Side by Side Co-ordinator on 0115 934 3800 or email sidebysidenotts@alzheimers.org.uk



Update from the London Assembly

The Mayor of London has now responded to the recommendations made by the London Assembly and would like to use his influence to make London the first Dementia Friendly City.

Earlier in the year, Network members took part in telephone interviews and questionnaires to express their opinion on how young onset dementia affects their lives when in London. Some of the topics that were covered were employment, travel and education.

From these interviews, the London Assembly devised recommendations that included

- * Raising awareness of how dementia affects younger people and access to the right information at the right time.
- * Making transport in London more accessible for younger people with dementia.
- * Supporting people with dementia to stay in employment.

You can read the Mayor's response in full [here](#).

Young onset research paper review

In each issue of Young Dementia Network News, we share a review of a young onset related research article. This article titled 'The experience and needs of children living with a parent with young onset dementia: results from the NeedYD study' has been reviewed by [Dr Janet Carter](#). You can read her review [here](#).

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

'The paper shows how little support is currently given to this vulnerable group of young children when a parent is diagnosed with dementia. The importance of talking to the whole family and teaching them the value of talking to one another becomes even more relevant.

'To allow young children to be left to flounder the internet for answers is so sad. They should have access to appropriate support just like everyone else. If the family is to survive the diagnosis, the family unit must be supported as a whole.

'What this research clearly highlights is the need for more understanding on the impact a diagnosis has on the whole family and the need for more all round support where the needs of every member of the family are considered, regardless of age.'

You can find the original research article by Millenaar JK, van Vliet D, Bakker C, Vernooij-Dassen MJ, Koopmans RT, Verhey FR de Vugt ME [here](#).

*Young*DementiaUK



You've been sent this email because you joined the Young Dementia Network, or because you receive other emails from YoungDementia UK. You can unsubscribe from any of our mailings by completing [this form](#).

[Privacy Policy](#) | [Unsubscribe](#)

[YoungDementia UK](#)

PO Box 315, Witney, Oxfordshire OX28 1ZN