We'd love to hear what you think about the Young Dementia Network

Thank you to all of the Network members who have completed our survey so far. We would like to hear from as many of you as possible and there is still time to take part.

This is your opportunity to tell us what works; what may require more attention and what you would like to see from the Network in the future.

The survey takes under five minutes to complete. Results will be reported anonymously and we plan to publish them in a forthcoming issue of Young Dementia Network News.

If you would like to take part in our survey, then please click here.

The closing date is 31 May 2018.

Best wishes

Donna
National Development Manager

Network member, Peter Berry is cycling 330 miles to raise awareness of young onset dementia

Peter Berry who is 53 and from Suffolk, was diagnosed with young onset Alzheimer's disease at the age of 50. He is taking his passion for cycling to a new level in June, by leading a team to pedal 330 miles across the country in six days and raise funds for YoungDementia UK, so we can continue to increase the Network’s activities.

Peter, co-director of Dementia Help, maintains a positive outlook and creates videos online that give a unique insight into what it is like to live with dementia.

'I want people to understand Alzheimer’s and how it affects those who have the condition and their families,' says Peter. 'I know I only have a limited amount of time to do things
before my health changes. I have been cycling for many years, but this will take me out of my comfort zone, which is a little scary but also exciting.’

If you would like to sponsor Peter and his team or find out more about their cycle ride, please click here.

(Photo credit Dave Collison)

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Young Dementia 2018 Conference

Achieving improvements in Young Onset Dementia Support - positive, personal and practical initiatives

On 20 September 2018, the Journal of Dementia Care in association with YoungDementia UK will be hosting a conference focussing entirely on young onset dementia.

Taking place in Birmingham, full ticket and details of the CPD certified programme that members from the Young Dementia Network have contributed to, will be announced shortly via this link.

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Meet our members

Have you ever wondered why people join the Young Dementia Network? Then visit our new Meet our members page to find out.

If you would like to send us a quote for inclusion then please e mail network@youngdementiauk.org

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'Do I see what you see?'

We wanted to share this powerful short film from Created Out of Mind, by director Simon Ball, narrated by people living with dementia and their partners.

'Do I see what you see?' recreates the experiences of people living with Posterior Cortical Atrophy (PCA), a rare form of dementia which often affects vision, in a series of striking animations. The link to this fascinating film is here.
Service Showcase - tell us about your service

We want to be able to share information about the great services around the UK for people affected by young onset dementia.

Our Service showcase section is a place where you can tell others about the service you work for. We want to share your good practice, tips and ideas.

If you would like to see what is being delivered then please visit our Service Showcase.

Or if you work for a service and would like to share information about it with others, then please email us at network@youngdementiauk.org.

GP Decision-Making Guide

Over the past few months over 1000 copies of the Young Dementia Network’s Decision-Making Guide for GPs have been requested and copies will soon be mailed out to 12,000 GP contacts across the UK.

To view the guide please click the link here or to request a copy please e mail network@youngdementiauk.org

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 'Feeling useful and engaged in daily life: exploring the experiences of people with young onset dementia, has been reviewed by Jan Oyebode. You can read her review here.

Wendy Mitchell who is living with young onset dementia, said about the piece,

'I believe the key thing to recognise here is that the research took place in the Netherlands and all the people who took part were connected with Day Care centres. Maybe there are some day centres for people with young onset in this country, but I’m unaware of them. “Having said that, it’s always useful to read of research from other countries as it does identity the differences in service provision.

“However, I think the one valuable point this research brings out is the part played by continuing to feel useful. I found it interesting that there was no mention here of campaigning or speaking as a form of feeling useful. It was more around feeling useful by the continuation of work or normal daily activities.

‘I suppose those of us who speak out, are indeed in the minority, but it beggars the question, Is this because society believes we’re not capable, therefore immediately assuming, as in this case, that day centres are our need when diagnosed.

“People also felt safe when they were understood and accepted by other people, which was a reason why the younger people with dementia valued the company of others who also had a diagnosis.”
'This statement clears links the value placed in this country of Peer Support - a common link and one which I was glad to see included.

‘For me, it identifies a possible need to explore societies expectations on what can be achieved by someone with Young Onset Dementia when diagnosed. It also quite clearly shows the complex needs of those with Young Onset, as many variables exist, just as they do in anyone in society under the age of 65.’

You can find the original research article by Deliane van Vliet, Anke Persoon, Christian Bakker, Raymond T.C.M. Koopmans, Marjolein E. de Vugt, Annemiek Bielderman and Debby L. Gerritshehere here.

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And finally, don’t let us lose contact with you!

Thank you for being a member of the Young Dementia Network.

On 25 May data protection laws will change. We would like to mail you with other young onset dementia news.

Please take a moment to confirm the mailings you wish to receive in future via this link.