

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



Would you like to get involved?

This month's newsletter is all about getting involved with the Network, whether you offer feedback, fill in a survey or attend an event.

The Network was set up so people who are affected by young onset dementia, work within the field or have an interest in the condition, could have a voice to encourage improved young onset services, information and resources.

No resource or event is created without consulting the Young Dementia Network members first so please get involved.

Best wishes

Donna
National Development Manager

Let us know what you think about our new draft resources

We are working to create some new resources based on what Network members have told us they would like to use.

Personal checklist - this will be a downloadable resource and is for anyone who has concerns about young onset dementia. It is a checklist which individuals can use to record symptoms they may be experiencing and use it to aid a discussion with their GP.

Young onset dementia ID card - these cards have been designed so that people living with young onset dementia and their family members or friends can discreetly explain to someone that they may require support or help. These cards will be piloted in a few areas over the next few months before being made available nationally.

We would welcome your comments on the draft versions of the personal checklist and ID cards. You can view them both [here](#). Please email network@youngdementiauk.org with your feedback.



MacIntyre

Providing support...your way

Dementia and Learning Disability – the time for action is now

Figures now show that one in ten people with a learning disability develop young onset Alzheimer's disease between the age of 50 and 65.

MacIntyre is an award-winning charity who provide learning, support and care for more than 1,500 children, young people and adults who have a learning disability and / or autism, at more than 150 services across England and Wales.

In 2016, a Department of Health social care grant enabled them to start the MacIntyre dementia project that aimed to

- * Raise awareness about dementia and learning disabilities
- * Support individuals with learning disabilities to receive a timely diagnosis
- * Educate professionals around the subject.

The charity offers free resources every Friday on their website that are developed by people with a learning disability.

To find out more about dementia and learning disabilities, please click [here](#) to read an article written by Network member, Sarah Ormston, Health, Dementia and Wellbeing Manager, MacIntyre.

Save the date - 24 June 2019 - Research event



In November, we asked you to vote on six themes that you felt were important in terms of young onset dementia and research.

The votes are in and the top three themes are

- Employment
- Health and Social Care education
- Family interventions (including children and young people)

On the 24 June 2019, we will be holding our second research event to bring together people affected by young onset dementia and researchers. The event will be at The Diamond in Sheffield and will focus on the themes above as chosen by Network members.

If you have young onset dementia and would like to register your interest for a **free place** at the event then please get in touch via email. Places are limited. Invitations for researchers will be sent out shortly.



Young Dementia Network member Tracey Shorthouse stars in new promotional film

A new Alzheimer's Society guide around sport and physical activity has been launched along with a promotional film

which features Network member, Tracey Shorthouse, who is living with PCA. Click [here](#) to watch the film.



Project funded by DEEP to feature at Alzheimer's Society annual conference

PACE, Oxfordshire and Lifting the Cloud, Derby City are working together to develop a checklist for Dementia Advisors, to aid them in supporting people affected by young onset

dementia.

The year-long project, funded by DEEP, will involve YoungDementia UK facilitating three workshops with each group in order to develop a resource that will be available for download in November.

Both groups are hoping to meet in April to discuss their ideas face to face. The project will be shared at the Alzheimer's Society Annual Conference in May and we will be asking for Young Dementia Network member feedback in the summer, so keep a look out for it.



Decision-making guide for GPs now available in Italian

We were thrilled to discover that a Young Dementia Network member based in Italy from the Associazione Novilunio Onlus has translated our Decision-making guide for GPs into Italian and has made it available to doctors there. You can view the Italian version [here](#).

To date we have sent out over 14,000 copies of the guide which is endorsed by the Royal College of GPs. If you would like to find out more, please click [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 Measuring younger onset dementia: What

the qualitative literature reveals about the 'lived experience' for patients and caregivers, has been reviewed by [Dr Hilda Hayo](#). You can read her review [here](#).

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

'I was really excited to see the title of this review, What the qualitative literature reveals about the 'lived experience' for patients and caregivers, especially as they'd found 23 studies to report on from around the world.

'However, that was where my excitement subsided as I read on. The first statement, how 'people with symptoms of young onset dementia experience changes in cognition and functioning but are unsure about what these changes might indicate and may be reluctant to seek a medical opinion,' simply reiterated my thoughts around the numbers currently diagnosed being far less than reality.

'But what surprised me more was the short list of recommendations that followed. No mention of the value of peer support being found, or the inappropriateness of caregiver's intervention leading to disabling the person with dementia. No mention of the difference in support needed, financial, children's support etc - I realise it said, 'age appropriate,' but unless it's spelt out, people will think they know best when maybe the opposite is true.

'Nothing new came at me, which only goes to show the need and importance of more research being done into young onset dementia.'



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