



October 2014

Newsletter No. 79

# Brain Waves



A monthly newsletter from Innovations in Dementia CIC

The aim of these newsletters is to keep people with dementia and their allies informed about the work of Innovations in Dementia Community Interest Company.

## Dementia words matter

The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves. Read more on page 3.



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## Getting along<sup>®</sup> in York

Innovations in Dementia has been awarded a Big Lottery Fund grant which will fund a pilot of the UK's first Getting Along<sup>®</sup> programme in York.

The Getting Along<sup>®</sup> programme supports couples where one person has been diagnosed with dementia. The Getting Along<sup>®</sup> project will work with couples TOGETHER, and will help them to think about the unattended antagonisms that frequently occur within relationships where one partner has a dementia.

Changes in relationships can often result in the person with dementia losing a voice within their own home, gaps between respite and crises shortening and an avoidable early and permanent separation.

The project will be led by one of our York-based associates, Damian Murphy. He says:

“I have lost count of the number of times I have gone in to people's houses and found them questioning the validity of decades of marriage because neither understood the impact of the dementia upon the relationship.”

The aims of the Getting Along<sup>®</sup> programme are:

- To gain a more balanced picture of both sides of the caregiving relationship.
- To help couples spot potential antagonisms within the relationships and attend to them.
- To highlight an area of support that is needed yet hitherto not provided.
- To create what could then be a self-sustaining user group for couples.

The primary focus of the project will be to enable couples to broach subjects they had not been able to discuss and to facilitate conversation on an equal footing for both participants.

Damian plans to work with a small number of couples soon after diagnosis in York. If you know anyone who might benefit from being part of this project, or would like to know more please get in touch.

## Dementia words matter

Dementia is discussed more regularly now in the media – both on television and in newspapers and magazines. The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves.

The Dementia Engagement and Empowerment Project (DEEP) got together 20 people with dementia for a day in Liverpool to discuss the words that are used about dementia.

People with dementia prefer words and descriptions that are accurate, balanced and respectful.

The result of the discussion was the publication of a new DEEP guide on the language used to describe dementia. The guide is intended for use by journalists, organisations and communications departments.

The guide lists:

- Words that make people physically flinch when they hear or read them.
- Words that send out the message that a life with dementia is not worth living, or that people with dementia are helpless and have nothing to contribute.
- Words that are negatively attached to the person rather than the condition of dementia.
- Words that create stereotypes.

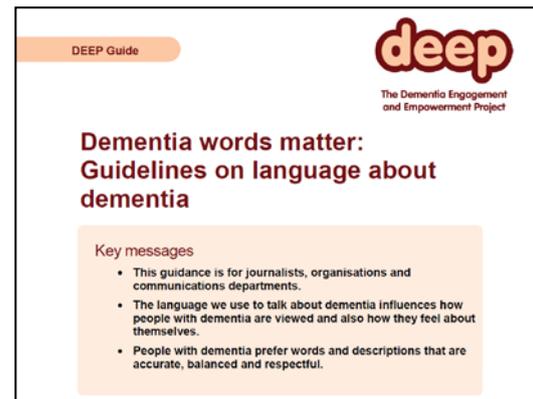
Top of the list is 'dementia sufferer'.

The guide also goes on to give alternative words, and to discuss the context of words and descriptions of dementia and the use of accompanying images.

## Please help us to distribute the guide widely

We hope that all organisations and press offices will have access to this guide. Please download the guide from the DEEP website - <http://dementiavoices.org.uk/resources/deep-guides/>

As always, DEEP guides are under continual review. If anyone has any comments, please get in touch. [rachael@innovationsindementia.org.uk](mailto:rachael@innovationsindementia.org.uk)



## Christopher and Veronica work with Grayson Perry

Long-standing Innovations in Dementia ThinkTank member, Christopher and his wife Veronica have been working with the Turner Prize-winning artist Grayson Perry as part of his new Channel 4 series "Who Are You".

Find out more from the Channel 4 website

Go to: <http://www.channel4.com/programmes/grayson-perry-who-are-you>



## Innovations in Dementia

Innovations in Dementia is run by three directors – Rachael, Steve and Nada. We are a Community Interest Company. This means that any profit we make is put back into the organisation.

We do not offer services for people with dementia. Instead we work with other organisations to make sure that people with dementia can continue to take part in their communities and have active lives.

Please share your ideas, experiences and positive stories with us.

### Contact us

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