



February 2015

Newsletter No. 83

# 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.

### Developing 'My Brain Book'

Nada has had a case study published by the European Union initiative on 'Responsible Industry' about involving people with dementia in the development of products.

Read more on page 2.



In this newsletter:

Developing 'My Brain Book'	p2
Finding your way in York	p3
Still Alice – a film about dementia	p3

## Developing 'My Brain Book'

Nada is working with the Health Innovation Network in South London (one of the Academic Health Science Networks) to help them to include people with dementia in their work. Together with a company called IXICO, they have been running a project to develop a device to help people with dementia and their carers to collaboratively plan and control their care.

The product will be used by people with dementia, with support from trained facilitators, to store information about themselves, friends and family, interests, likes and dislikes, and how they wish to be supported. This information is used to inform their own personalised support plan which can be shared with people of their choosing to help keep in contact and coordinate care and support.

Nada has had a case study published by the European Union initiative on 'Responsible Industry'. The case study describes the ways in which people with dementia have been involved in the initial development and testing of a working prototype of My Brain Book. Engagement activities included: a parallel priority setting event, focus groups, involvement in design workshops and testing of the prototype.



The involvement of people with dementia has influenced the development of the product and also changed the way ICT researchers see people with dementia. People with dementia convinced the designers that more emphasis should be given to elements of the system which enable families and professionals to really get to know the person with dementia before any care planning process begins. The design process and timelines were also influenced by people with dementia in order to ensure that they could be involved in meaningful ways.

There are still many lessons to be learnt about the best ways for a responsible health and care industry to engage with people. This case study shows that, with the right combination of support, engagement is possible and does lead to better products.

Find out more about the Health Innovation Network - [www.hin-southlondon.org/](http://www.hin-southlondon.org/)  
Read the case study at - <http://www.responsible-industry.eu/activities/bu-casestudies-results>

## Finding your way in York

Damian and Emily have been supporting people with dementia to take part in York City Council's consultation around way finding.

York is modernising all the tourist maps around the city. The group has had a significant influence in ensuring that the maps are clear and easy to understand with places flagged and named on the map, without the need to try to follow a key.



### We need your help

The people in York were from a new group that is part of the Dementia Engagement and Empowerment Project (DEEP) network.

We are hoping for members of another DEEP group (or any group of people with dementia) from outside of York to visit and identify the best place for the new maps to help find the way from the train station to York Minster.

**Any takers?** Please contact us on [ideas@innovationsindementia.org.uk](mailto:ideas@innovationsindementia.org.uk)

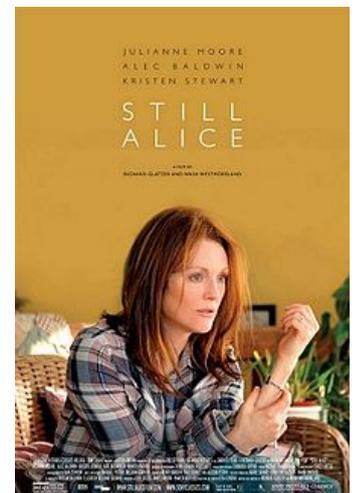
## Still Alice – a film about dementia

At the BAFTA awards Julianne Moore thanked people with dementia, including our friends Christopher and Wendy who were guests with Alzheimer's Society at the film première where they spent time chatting over coffee with her.

A big thank you to Wendy from York for sharing her adventures in reviewing the Oscar winning film 'Still Alice' and being the subject of a Channel 4 feature about the film which included a brilliant and eloquent testimony of her own life with dementia.

Wendy writes a regular blog available at <https://whichmeamitoday.wordpress.com> which is well worth a visit.

Still Alice is one of a number of books recommended on the Reading Well Books on Prescription list - <http://readingagency.org.uk/adults/news/reading-well-books-on-prescription-for-dementia-booklist.html>





## 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**

Email: [ideas@innovationsindementia.org.uk](mailto:ideas@innovationsindementia.org.uk). Telephone: 01392 420076

Innovations in Dementia CIC, PO Box 616, Exeter, EX1 9JB

Website: [www.myid.org.uk](http://www.myid.org.uk)

If you wish to receive (or stop receiving) copies of this newsletter email [newsletter@innovationsindementia.org.uk](mailto:newsletter@innovationsindementia.org.uk)

Registered as a community interest company No. 06046815