



June 2012

Newsletter No. 51

# 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.

## Perspectives on dementia

We work with lots of different people with dementia and their allies both through ThinkTank and our projects. In this issue of Brain Waves, we look at just a few views of living with dementia.



## In this newsletter:

- |  |    |
|--|----|
| Ken writes about communication problems      | p2 |
| Ann writes about the importance of education | p3 |
| John writes about his thoughts as a gay man  | p4 |

## Ken writes about his communication problems

Some readers of Brain Waves may have heard Ken Clasper talk publically about his experience of living with dementia.

However in an article published on the Alzheimer's Disease International 'I can, I will' website, he talks about how important it is for care and nursing staff to recognise that people have communication problems.



He says:

“I have made quite a few mistakes recently by using the wrong words, and it caused some distress both to my wife and to myself when I realised what had happened. I know that words don't come out the way they used to, and whether the brain is going too fast for me, or I am going too fast for my brain, I really don't know.”

“There are times like this when I really hate this illness. It destroys your ability to control your life, and while assistive technology helps to write things on the computer, it does not help with speech or trying to get the correct words out.”

“It is times like this when I realise how easy it is for people with dementia to be misunderstood by staff in hospitals and care homes, and then be treated with a lack of respect because the staff thought they were rude. The staff don't realize that the person with dementia just made a simple mistake and used the wrong word or words--something which is taken for granted by those who have normal brains, and yet those with this illness are treated like idiots.”

### Read more

This is just part of Ken's article. You can read more and find articles by other people with dementia from across the world on the Alzheimer's Disease International website.

Go to <http://www.alz.co.uk/icanwill>



## Ann writes about the importance of education

Readers of Brain Waves will also have come across Ann Johnson. As a former nurse and nursing lecturer Ann has given lots of talks about dementia but has also authored some academic papers.



She writes:

“The three things that keep me going: my friend, my faith, and my talks. The reason I do talks is because of my past career and the skills I acquired during that time, which I can use to educate people about living with dementia.”

“As a person living with Alzheimer’s disease, it is very easy to lose one’s feeling of worth; giving talks enables me to realise that I still have a lot to offer than can benefit others.”

“It is difficult to explain the problems caused by Alzheimer’s disease, because to the listener they may appear strange. Public perceptions and understandings of Alzheimer’s disease are often related to short-term memory loss. However, some people have problems with understanding and adding up.”

“The effect created by someone talking about how the symptoms affect him or her makes it all personal and real. The audience often becomes emotionally and personally attached to the speaker.”

“It is important to educate others as to how to care emotionally, as well as physically”

“Teaching people with dementia to use strategies to overcome their problems is vital.”

## Read more

These quotes are taken from this published article

Learning Lessons: how I live with my Alzheimer’s  
The Journal of Mental Health Training, Education and Practice,  
Volume 5, Issue 3, pp7-9 (published September 2010)

## John writes about his thoughts about getting dementia as a gay man

John is a member of OLGA (Older Lesbian, Gay, Bisexual and Trans Association). He writes about his thoughts about his care should he develop dementia.

He writes:

“For whatever reasons, some of us in the lesbian, gay, bisexual, and transgender community can be far removed from those who are normally expected to be our carers - our blood family. But we may be cut off from our blood family by distance or rejection.”

“Some people still believe that we deserve dementia as well as other diseases due to our sexuality. Will our supporting friends or partners be allowed to have input into our care or be able to take on our personal or financial concerns? Human Rights legislation may exist but the gay community can be ignored, barred or have to wage long battles to be able to include input from those we care about or who care about us.”

“I want the people who I have accepted into my life to care for me as dementia progresses. If we plan ahead there is light at the end of the tunnel. I have been fortunate to find and develop a “family of choice”. These are the individuals who will be with me and help me identify the early signs of dementia and other medical conditions.”

“We need not live in doom and gloom. Personally I plan to live each day with hope and happiness. I would like to travel as long as I am able and to be found face up in an Archaeological Museum in a beautiful city. That’s just me. If something else does happen just take me there.”

## Find out more

OLGA is a voluntary organisation and a National Community Network based in Scarborough and Ryedale. In addition to supporting their members, OLGA offers advice about equality policies and the use of all inclusive, appropriate language. OLGA also delivers awareness raising workshops on issues surrounding lesbian, gay, bisexual and trans and receiving health and social care.

Find out more from OLGA’s website: [www.olga.uk.com](http://www.olga.uk.com)





**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