



September 2014

Newsletter No. 78

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.

Steve's report from Australia

Steve has been over in Australia for the last couple of weeks. He met many inspirational people with dementia.

Read Steve's report on page 3.



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Dementia and truth-telling: call for evidence

The Mental Health Foundation has launched a major new inquiry exploring the issues of truth-telling, lying and finding meaning in the often different realities or different perceptions of people living with more severe dementia.

The terms “hallucinations”, “delusions” and “confusion” have been used to capture a whole range of different experiences that people living with dementia may have. For example:

- Believing that a deceased parent is alive and wanting to visit them;
- Gaining comfort by holding a doll, believing it to be a real baby;
- Not recognising a spouse or partner, or being convinced that a spouse or partner is an imposter or constantly deceiving them;
- Wishing to leave a care home and “go home” when the care home is where they now permanently live;
- Seeking activities/roles that replicate jobs or activities the person did prior to developing dementia.

We want to explore the meaningfulness of these experiences to people living with dementia. Can we rethink dementia to enable responses which are supportive, therapeutic, and possibly even empowering for people living with dementia?

The survey is open until mid-November. Please go to:

<https://www.surveymonkey.com/s/DementiaInquiry>

The survey can be completed in less than 10 minutes.

If you would like to know more about the Inquiry or need help completing the survey please contact:

Kirsten Morgan at the Mental Health Foundation

Tel: 020 7803 1188 Email: kmorgan@mentalhealth.org.uk

Find out more at:

www.mentalhealth.org.uk/our-work/research/dementia-truth-telling

Steve's report from Australia

Steve has been over in Australia for the last couple of weeks. **Here's his report:**



I was invited by the Alzheimer's Association of Australia to talk about our work on dementia friendly communities.

I started in Sydney, and then moved on to Kiama, Port MacQuarry, Melbourne, Hobart, Brisbane, Canberra, Adelaide and finally, Perth.

My main points were:

- People are the most important thing in dementia-friendly communities.
- People with dementia and their carers are the real experts, and must be involved from the start.

Everywhere I went I met people inspirational people with dementia.

Kate Swaffer is a great and inspirational advocate for people with dementia in Australia, and beyond. She often talks about what she calls "prescribed disengagement". By which she means the way she feels people with dementia are almost encouraged to give up their lives and interests. She is feisty, clever, and fun. She also took good care of me - thanks Kate.

Graeme Atkins is a really talented singer songwriter. His songs about dementia are very moving but also very witty.and for the musically minded out there - not a minor key in sight. He was also a lovely chap - strong words softly spoken. A pleasure to meet you Graeme.

And many many others.

What really struck me about Australia was the warmth and friendliness of the people. I believe this gives them a really good basis from which to grow and sustain dementia-friendly communities. It's all about the people, after all.

I want to mention one more person with dementia.

Breeda - (I'm sorry I didn't catch your surname) was diagnosed at the age of 40. Now in her 70s she has been a volunteer for the Alzheimer's Association for many years. Breeda has to be one of the most positive people I think I have

ever met. She was clearly feeling the effects of her dementia, especially as the day wore on, but to say she was bursting with life would be an understatement. One incident sticks in my mind.

I was introduced to a young woman who was clearly still reeling from her recent diagnosis, as was her husband. I only had a few minutes before I had to leave for the airport, but just had time to introduce her to Breeda. When she told the young woman that she had been living with dementia for more than 30 years the look on the younger woman's face spoke volumes. The germ of hope perhaps? The birth of an idea that, as we say, a diagnosis of dementia might be life-changing but need not be life-ending.

It confirmed in my mind the belief of the power and strength that people with dementia can draw from each other. Breeda - you are inspirational. Thank you.

Women and dementia: exploring a feminist perspective

For the last nine months we have been collecting of the experiences of women affected by dementia.

We are now holding a special event on 6th November 2014 in York, which will be an opportunity to:

- Share the thoughts and experiences of women living with dementia, women who are caring for family members with dementia, and the female workforce.
- Debate the underlying issues about dementia from a women's perspective.
- Decide what more needs to be done to change attitudes, policy and practice.

Get involved:

- Join us on 6th November in York.
- Write a piece for the project website – www.dementiawomen.org.uk
- Make a pledge to improve the lives of women who are affected by dementia.

For more information contact Nada – nada@myid.org.uk

Engagement and empowerment – a personal view

The September/October 2014 issue of the Journal of Dementia Care includes an article by Keith Oliver. Keith is the Dementia Service User Envoy for Kent and Medway Partnership Trust (KPMT). In the article he describes what getting involved in dementia work means to him, and how he is working with others through his local group, The Forget Me Nots to make things better for people with dementia. He also describes how the voice of the Forget Me Nots has been amplified by being part of the wider network of the Dementia Engagement and Empowerment Project (DEEP).

You can read the article on the Journal of Dementia Care website.

Go to: <http://www.careinfo.org/journal-of-dementia-care/>

The same issue has an article about another DEEP group – the Hope and Doodle group in Lewisham.



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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