



August 2013

Newsletter No. 65

# Brain Waves



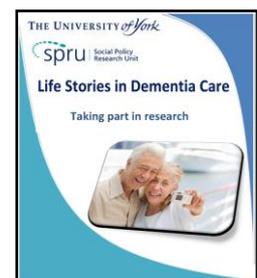
## A monthly newsletter from Innovations in Dementia CIC

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.

### Asking people with dementia about life story work

Earlier this year Kate Gridley from the Social Policy Research Unit of the University of York and Nada visited four groups of people with dementia around the country. We talked about their views and experiences of life story work.

Find out more on page 2



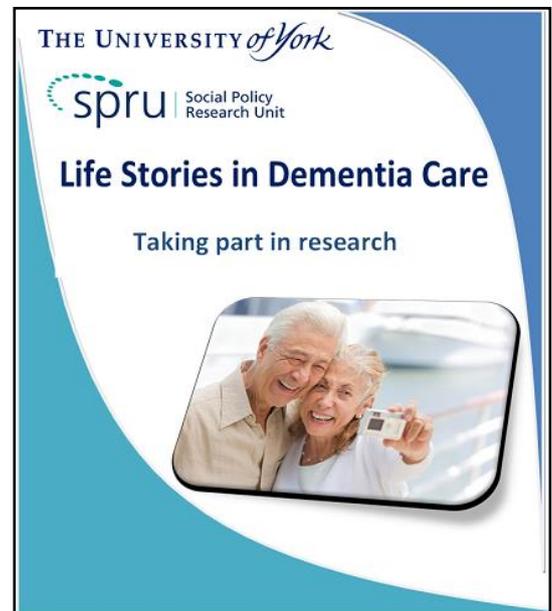
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## Asking people with dementia about the value of life story work

In the January 2013 edition of Brain Waves, we told you about how we were supporting people with dementia to play a pivotal role in a pioneering study led by researchers at the University of York. The research is into the effectiveness of using Life Stories to influence the care of people with dementia and improve their quality of life.

Earlier this year Kate Gridley from the Social Policy Research Unit of the University of York and Nada visited four groups of people with dementia around the country. We talked about their views and experiences of life story work. Kate also talked to groups of family carers and professionals.



### What Kate found out

Lots of people thought the idea of recording things about their life story was a good idea. But people with dementia should think about:

- What they want to put into a life story?
- Who they would like to read about their lives?

Workers who help people with life story work should think about:

- Giving people information about doing life story work, but not forcing anyone to do it.
- Getting to know the person well – and sharing their own life experiences.
- Respecting the person's wishes about what goes in the life story and who will read it.
- Continuing to support people with their life story work as life goes on.
- Using different techniques – music or computers as well as words and pictures.
- Helping people to talk about difficult or upsetting memories.
- Helping people to think about what might be useful for other professionals and care workers to know about their life.

## What happens next?

Kate will continue the research based on what she found out at the focus groups. She will look more closely at how life story work is used in care homes and hospitals.

In the autumn, Kate will also be sending out a survey to organisations such as care homes that might have experience of doing life story work. If you receive the survey, it would be great if you could fill it in.

This article is about emerging findings from research funded by the National Institute for Health Research Health Services and Delivery Research Programme. The views and opinions expressed here are those of the research team and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

## Brian Hennell

Last month we received some really sad news. Brian Hennell died peacefully at the Sue Ryder Hospice in Leckhampton on 22 July 2013. He was 75.

Many of you will recognise or will have met Brian. Some of us will have had the pleasure of getting to know him.

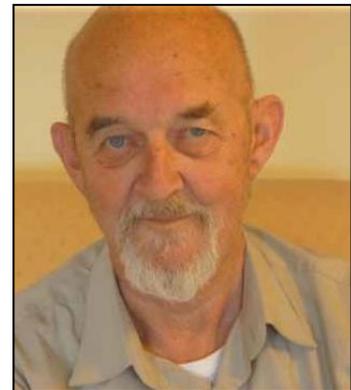
With the gentle support of his wife June, he did so much work with us, and with other organisations involved in dementia. His insight, humour, dignity and honesty has been deeply inspirational, both professionally, and personally. Steve went to Brian's funeral in Gloucester on 2<sup>nd</sup> August 2013, and it was clear that the many, many other people who had gathered in his honour felt the same way about him.

Steve was able to say a few words at the celebration dinner - and reflected how much Brian's work had helped other people with dementia to be less fearful, and to embrace the opportunities that life had to offer.

This is an excerpt from a poem Brian wrote with June, and which he read to mark World Alzheimer's Day at a service in Gloucester Cathedral in 2011.

When buds break forth each new Spring's dawn  
and birds awake to charm each morn  
I celebrate with unreserved cheer  
dementia or not, I'm still here.

It was an honour to have known Brian. He was a lovely, lovely man and we will miss him greatly.



## People with dementia working to support others

People with dementia who have come to terms with their diagnosis are in a unique position to offer support to others who are newly diagnosed.

Some pioneering organisations are recognising this and supporting people with dementia to work as peer support or advice workers.

The Kensington & Chelsea and Westminster Memory Service of Central and North West London NHS Foundation Trust is in the process of recruiting paid dementia peer support workers. This initiative followed a series of consultation events across the London boroughs of Kensington & Chelsea and Westminster. The peer support workers will work four hours a week.

The memory service believes that people with dementia who take up the peer support work will have a number of different roles, including sharing coping strategies, co-facilitate group-based discussions, helping to develop social opportunities, and signposting to relevant services and information.

By paying people with dementia to act as peer support workers the memory service hopes they will challenge ways of thinking and assumptions about dementia and demonstrate that a diagnosis of dementia is not the end of a useful life.

### **Dementia Engagement and Empowerment Project (DEEP)**



DEEP is very interested in encouraging other organisations to think about employing people with dementia.

On 30<sup>th</sup> May 2013, Nada met with members of Open Doors (Salford) and the Forget Me Nots (Kent). Both of these groups employ a person with dementia in a 'dementia advisor' role (on paid and voluntary basis). Their roles are principally about awareness raising about dementia and providing peer support.

The group discussed the kinds of qualities and support a person might need for this role. They also discussed the support that employers might give to people with dementia. This included:

- Practical support such as help with transport or arranging meetings.
- Regular review of the post and responsibilities.
- Being flexible and using the skills of the individuals involved.
- Emotional support through trusting and open relationships.

We want to hear from organisations and people with dementia who are interested in employment issues.

Please contact Nada, or you can find out more at the DEEP website [www.dementivoices.org.uk](http://www.dementivoices.org.uk)

## An opportunity to take part in research

Nottingham Trent University are looking for volunteers to take part in a photographic study exploring the role of places for identity and memory for individuals with dementia.

Participation will include taking photos of your important places and discussing them with a researcher. Cameras are provided and all responses will be kept confidential and anonymous.

For more information please contact Holly Walton

Email: [holly.walton2011@my.ntu.ac.uk](mailto:holly.walton2011@my.ntu.ac.uk)

Telephone: 0115 848 4514



**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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