



July 2011

Newsletter No. 40

# 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.

### How to describe 'Shared Lives'?

We are keen to get your views on our Shared Lives project for people with dementia.

Find out more on page 2



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## Shared Lives for people with dementia what is the best way of describing it?

We are keen to get your views on our Shared Lives project for people with dementia.

Shared Lives is a type of living arrangement where people who need support can live in family homes.

In some parts of the country people with dementia are already using this service. Most people with dementia have been using Shared Lives for a short break – during the day, overnight or for a few days. A few people live in their Shared Lives home all the time.

At the moment, Shared Lives is often used by people as an alternative to ‘respite care’ in a residential home. It is often accessed in order for family carers to take a break from caring.

However, we know that this kind of scheme works much better when people with dementia know and trust the family with whom they are spending time.

This would mean people beginning to use Shared Lives at an early stage of dementia, at a time when they are perhaps not ready to start thinking about or do not anticipate needing respite care.

### Tell us what you think

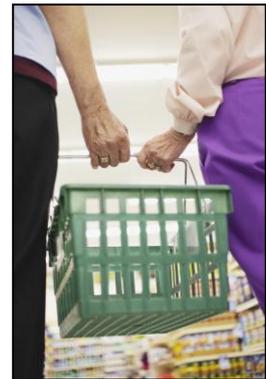
What do you think would encourage people with dementia (and their carers) to think about linking with Shared Lives early (at a time when people are ‘getting on with their lives’ rather than thinking about respite care)?

Funding is an obvious issue – but we would like you to put this to one side for the time being. This is more of a question about how Shared Lives might become part of a person’s community networks – that they can draw on in the future.

If you have any ideas or wish to discuss this further, please contact Rachael

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## Ethical issues and dementia

Back in 2009, the Nuffield Council on Bioethics published a report called 'Dementia: Ethical Issues'.



Earlier this year they held a series of 'policy seminars' to follow up issues raised in the report. Steve went along to make sure that our views were heard.

The notes from the meetings have just been published. In the notes from the meeting called "We're all in this together", it is good to see that our views and experiences were heard (even if we weren't mentioned by name).

In particular, we said:

- It is important to be thinking about dementia in terms of **rights**, just like people with other disabilities did in the 1980s - and look what they have achieved.
- We need to continue to work on making our communities more dementia-friendly so that people with dementia can remain active citizens.

You can get a copy of the notes from the meetings from the Nuffield Council of Bioethics website. Go to:

<http://www.nuffieldbioethics.org/dementia>



## Dementia and the Arts event

On 21 September 2011 in Bath

This event is jointly arranged by Arts & Health South West, the Institute of Contemporary Interdisciplinary Arts at Bath University and the National Institute for Creative Ageing. The event aims to help healthcare staff find out about how the arts are contributing to improved quality of life for people with dementia.

For more information go to the Arts & Health South West website -

<http://www.ahsw.org.uk>.

## Launch of 'Difficult Conversations' booklet

On 12 July 2011, the National Council for Palliative Care (NCPC) and the NHS National End of Life Care Programme launched a new booklet in the Difficult Conversations series. The launch took place at the joint meeting of the All Party Parliamentary Groups on Hospice and Palliative Care and Dementia at the House of Commons.

The booklet is based on fifty conversations with people with dementia, carers and former carers. It is designed to help professionals and people with dementia and their carers to open up conversations about end of life wishes, especially early on in the condition.



Many Innovations in Dementia ThinkTank members helped with the research for the booklet and it was lovely to see so many of our friends and allies at the launch event.

You can find out more about the booklet from the NCPC website:

[www.ncpc.org.uk](http://www.ncpc.org.uk)



**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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