

July 2008

Newsletter No. 5

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.

New logo and look for Innovations in Dementia

This is a sneak preview of our new logo. All our documents and our website will soon have this logo, which was designed with the help of the Forget-me-not group.



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Valuing the contribution of people with dementia

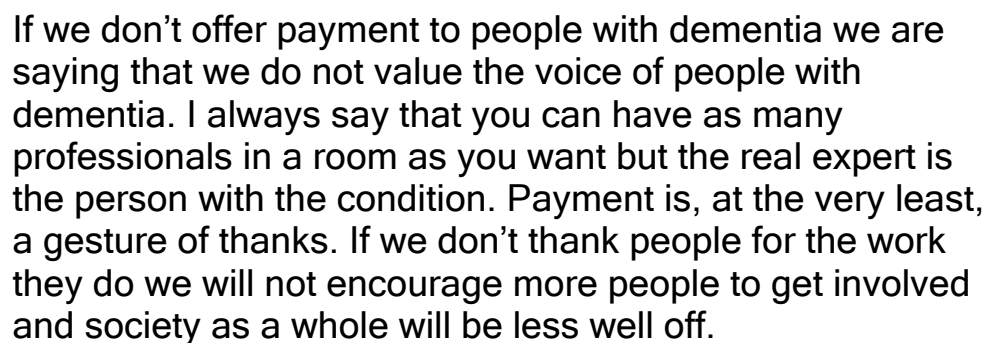
At Innovations in Dementia, we want people with dementia to be at the heart of everything we do. We are developing way in which this can be achieved. This includes:

- working with individuals with dementia
- making links with established groups or organisations. Some of these groups may not yet have thought about getting involved in the wider dementia field.

We are drawing up policies around the ways we involve people with dementia in our work. A key issue is how we value the contribution that people make. Although we are a social enterprise, we charge for our services. We believe that people with dementia should be rewarded for any work they undertake with us.

We are starting a process to gauge the views of people with dementia. We are asking people for their views round **incentives** and **payments** for people with dementia.

Peter Ashley has Lewy Body dementia. Peter is an associate of Innovations in Dementia.



If we don't offer payment to people with dementia we are saying that we do not value the voice of people with dementia. I always say that you can have as many professionals in a room as you want but the real expert is the person with the condition. Payment is, at the very least, a gesture of thanks. If we don't thank people for the work they do we will not encourage more people to get involved and society as a whole will be less well off.

He says:

Tell us what you think

Email: ideas@innovationsindementia.org.uk. Telephone: 01392 420076.

Disability, discrimination and dementia

We believe that there are lessons to be learned from the disability movement by both people with dementia and their allies.

The introduction of the Disability Discrimination Act 1995 was due in very great part to the pressure from generations of disabled people no longer happy to accept the status quo.

Most people with dementia are likely to qualify as 'disabled' under the Act. However, very, very, little attention has been given to the way in which the Act might be used to protect people with dementia. One of the main problems is that many people do not see dementia as a disability.

Innovations in Dementia (CIC) has started in a very small way to encourage people with dementia to exercise their rights under the Act. For example, we are putting together a project to work on accessible information for people with dementia.

The disability movement has also challenged the predominantly negative cultural stereotyping of disability in which disabled people are portrayed as either villains, monsters, victims, or as heroes who 'overcame' their disabilities to achieve greatness.

While far from perfect, the cultural representation of disabled people has improved considerably. This has had a great impact on the level of stigma that was formerly attached to disabled people.

However, people with dementia are still portrayed negatively in the press. For example, a few months ago the Observer ran a two-page feature on dementia with the headline 'the living death that faces 700,000 Britons'.

Even charities, who you might think should know better, do not help with statements like this: **'Alzheimer's is more than a vile and vicious disease. It robs people of their identity, spirit and soul like no other does'** (A celebrity astrologer launching Alzheimer's Awareness Week for a major dementia charity)

Innovations in Dementia is currently working with a group of people with dementia to explore issues of identity and stigma in dementia.

Would you like to help us in this work?

Please contact Steve

Email: ideas@innovationsindementia.org.uk. Telephone: 01392 420076.

Contact us

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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