

March 2008

Newsletter No. 1

Brain Waves

A monthly newsletter from Innovations in Dementia CIC

The aim of this newsletter is to keep people with dementia and their allies informed about the work of Innovations in Dementia Community Interest Company.

Do you like this newsletter? We need your help

This is the first newsletter of Innovations in Dementia CIC. Innovations in Dementia is an organisation that works **with** people with dementia.

The next issues of this newsletter will be designed with the help of people with dementia. We need people with dementia to help us with the design and content of future issues of this newsletter

Please contact us if you want to help us or know of any individuals or groups of people with dementia who might like to get involved (see page 4 for details).



In this newsletter:

What is Innovations in Dementia CIC?	p2
Get involved with Innovations in Dementia	p2
Start making sense	p3
The rights of people with dementia	p4

What is Innovations in Dementia CIC?

Innovations in Dementia is a community interest company (CIC). Community Interest Companies are limited companies with special additional features. This means that the company is for community benefit not for private advantage.

Innovations in Dementia community interest company provides consultancy, advice and training to organisations to help them think creatively about how they can support and involve people with dementia.

Innovations in Dementia is a national organisation that tests opportunities that enable people with dementia to live life to the fullest. We promote a positive view of dementia.

What makes Innovations in Dementia different?

We aim to work with advisors who are themselves diagnosed with a type of dementia.

We believe that people with dementia should:

- Be able to experience all that life has to offer.
- Receive appropriate and sensitive support to access opportunities and learn new skills.
- Be part of opportunities and decisions that affect their lives.

Get involved with Innovations in Dementia CIC

It is important to us that all our work is based on what people with dementia want. This means that we want people with dementia to be fully involved in our organisation and we want to find out the views of people with dementia about lots of things.

How do people with dementia work with Innovations in Dementia?

People with dementia can get involved in our work in a number of ways:

- We can arrange small discussion meetings with 3-4 people or we can talk to people individually if they prefer.
- We can telephone or email people to ask for views or experiences on specific issues.
- We can keep people informed of our work by post.

Working in partnership

We are also interested in working in partnership with commercial and statutory organisations that work with people with dementia or vulnerable older people to test out other innovative projects.

Consultancy and training

Innovations in Dementia CIC is happy to work with organisations that need specialist advice and/or training around dementia issues. Our work is underpinned by the voices and experiences of people with dementia who are directly involved in our work.

Start making sense

Many people find information hard to understand. People with dementia may find information more difficult to understand as their dementia progresses.

One reason for this is brain damage, caused by dementia. **But** another reason is that information is poorly written or laid out.

Innovations in Dementia is starting a project called 'Start Making Sense' to:

- Find out how information can be provided in a way that is helpful for people with dementia.
- Encourage people with dementia and their allies to ask for accessible information.
- Make people aware of the rights of people with dementia to accessible information.

Complaining about information that you can't understand

Innovations in Dementia CIC has produced a guide to help people with dementia complain about information that they find difficult to understand.

Under the Disability Discrimination Act, service providers have to make sure that their services are easier for disabled people to use. People with dementia qualify as 'disabled' under the Act so long as the dementia has an effect on their ability to carry out 'normal day-to-day' activities.

There are three steps to making a complaint:

- Step 1 - talk to the organisation that is providing the information.
- Step 2 - write a formal letter.
- Step 3 - take the matter further.

The guide includes sample letters for making a complaint. These can be downloaded from the website and adapted.

For more information visit the Innovations in Dementia website - www.innovationsindementia.org.uk.

Ideas for future work

We know that poorly produced information can be a barrier to people with dementia taking part in decisions about their own lives or taking part in their communities. We would like to investigate this further. For example:

- We would like to hear from people who have complained about information that is difficult to understand.
- We would like to investigate different ways of providing information to people with dementia.

We are looking for people with dementia and partner organisations that might be interested in working with us. If you are interested please contact us.

The rights of people with dementia

The theme of the rights of people with dementia runs through all the articles in this newsletter.

Innovations in Dementia believes passionately that people with dementia have the same rights as the rest of us. We also believe that many people with dementia will have additional legal rights as disabled people under the Disability Discrimination Act.

This Act makes it unlawful for service providers to unreasonably discriminate against disabled people. Since the Act was introduced, things have improved for many people with disabilities. Services that discriminate unfairly against disabled people face the wrath not only of the law, but of new generations of disabled people prepared, encouraged and empowered to fight for their rights. We would like to see people with dementia among them.

However, we know that the rights of people with dementia can seem to slowly disappear after the diagnosis. This can happen in small ways. For example people in authority including health and social care professionals may only consult a carer and may make assumptions about what people with dementia want.

We want to challenge this.

First steps

We want to hear from people with dementia about their views of their rights and how these might have changed after their diagnosis.

Please contact us for more information.



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 Telephone 01392 420076

Innovations in Dementia CIC, PO Box 616, Exeter, EX1 9JB

Website www.innovationsindementia.org.uk

If you wish to receive (or stop receiving) copies of this newsletter email newsletter@innovationsindementia.org.uk

Registered as a community interest company No. 06046815