



JOURNEYING through DEMENTIA

## Journeying through Dementia newsletter, issue 3, spring 2018

### What's the purpose of Journeying through Dementia (JtD)?

Journeying through Dementia is a large research study designed to find out whether attending a 12-week community programme assists people in the early stages of dementia to live as well as possible with the diagnosis.

Thirty people with dementia living in Sheffield previously took part in a similar programme (which involved a mix of group and individual meetings). The indications were that this helped people to keep independent and continue to enjoy life. This feedback led to the current Journeying through Dementia study.

### How is the study going?

So far, 403 people living with dementia have agreed to take part and 272 family members have also agreed. This includes people from Yorkshire, Greater Manchester, Nottinghamshire, Leicestershire and Humberside. About half of those we recruit are offered the Journeying through Dementia programme. Some programmes have now ended and new ones will be starting in Lincolnshire, Newcastle, Northamptonshire and North Staffordshire later in the Spring.

### We'd like to know how you are getting on.....

Everyone who volunteers to take part is invited to meet with a researcher three times to answer some questions about their health and well-being.

Some of you who are reading this newsletter may have been contacted recently to arrange to meet with a researcher. These visits are really important and we would be delighted if you were

able to continue to take part in the study in this way.

So that the researcher can remain impartial please don't tell them if you attended the programme or not. Thanks!

**Thanks for your feedback on the last newsletter.** Your feedback is really valued and will help us create a more informative and useful newsletter.

**You said, we did...** You told us that you enjoyed hearing about how the study is progressing and the sort of things that are happening - **we will include an update on the study in each edition of the newsletter.**

You asked for reminders about the study - **we will provide a short reminder on what the study is about in each newsletter.**

You also wanted to see more for carers – **we have included an item written by a carer in this newsletter.**

You also told us you enjoyed the article by Wendy in the last newsletter - **we will continue to include items written by people living with dementia in future editions.**

You asked for information and groups available in your local area. – **this newsletter includes the details of two national organisations that support people living with dementia, and their supporters/carers. They can advise what is available locally to you.**

**Thoughts from the Experts by Experience JTD group members.....** Our panel of Experts by Experience shared their views on a recent meeting. Those who took part were asked to give us feedback on the interview questions we were planning to use with people that have

taken part in the Journeying through Dementia programme. We met in the Science and Media Museum in Bradford.

*“Kevin and I enjoyed the meeting at the Media Museum to discuss the Journeying through Dementia. We both like to feel that we can contribute in some small way to make life as easy as possible for people with dementia. I think the main contribution at this meeting was very simply just changing some of the words to make it easier to understand. We were made very welcome and comfortable and also enjoy a general natter with other people in similar situations to us. We would definitely welcome the opportunity of taking part again, when the opportunity arises”.*

Another group member told us about their experience of advising on this and other studies we are involved in at Bradford University; *“I’m usually really pleased to be asked to take part in any Dementia Studies, if they are relevant to us and especially Experts by Experience as I feel we make a real difference. The main reason is the people we are talking to listen to us and take note of what we say and CHANGE things. This gives you an enormous feeling of satisfaction that you are contributing to something that makes it easier for someone who’s going to be in the same boat as you at some point.*

*The documents we were shown at the Media Museum meeting were written very well and easy to understand on a University level but to normal people like us some of the words were a bit clinical and needed to be made warmer, more human. It’s great to be in a group looking at things like this as we all spark of each other. Someone usually makes a suggestion, it starts a discussion and we come up with a solution that everyone agrees with. Job done.*

*Living with Dementia can be a bit isolating at times so joining in with groups is a good way of getting out and meeting up with the friends you have made from being involved with various projects. The “making a difference” element is so beneficial as sometimes when you are a full time carer you feel as if you don’t count. Being able to*

*contribute in this way is invaluable to your self-esteem.”*

It is vital that people living with dementia and their families work in partnership with us and advise us on the way this and other studies are run. We are very grateful to all those who continue to contribute.

### **Organisations that support people living with dementia, and their supporters/carers...**

AGE UK and the Alzheimer’s Society can tell you what advice and support is available in your local area.

**AGE UK** - AGE UK dementia advisors can support friends and family of those with dementia with information and advice about navigating local services and applying for benefits. **Please call 0800 678 1174** or speak to your local Age UK to organise an appointment.

**Alzheimer’s Society** - the Alzheimer’s Society has a national Dementia Helpline that you can contact if you are looking for information, support or advice about dementia. **Their helpline is there for you on 0300 222 11 22.**

**Spring has sprung!** Researchers working at the Universities of Bradford and Nottingham have captured their interpretation of spring on campus. We hope you enjoy the photos and the season. (Now it has stopped snowing!)



**Need to get in touch?** If you wish to contact the Journeying through Dementia team to advise us of a change in your circumstances, or that you no longer wish to take part in the study, then please contact us **via email to [jtd@sheffield.ac.uk](mailto:jtd@sheffield.ac.uk) or telephone 0114 2159122.**