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JOURNEYING THROUGH DEMENTIA – RESEARCH PROJECT

Journeying through Dementia is a research project which is looking at how people living with dementia can be empowered to live well and as independently as possible.



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It has been created in partnership with people who have recently received a diagnosis of dementia. They told us that people can benefit from assistance to adapt to life with dementia, and how important it is to learn how to compensate for poor memory. People also told us that they can still learn new skills and that they want to remain involved in life.

KEEPING YOU INFORMED

Journeying through Dementia involves taking part in 12 weekly group sessions of around two hours each at a community venue. During these groups people are encouraged to share experiences and solutions. The sessions are designed to be interesting, fun and informative.

Each participant also has four one to one sessions with one of the group facilitators to explore what they want to personally achieve and how.

Some of the topics which can be explored during the group sessions

- Understanding dementia
- Adapting to dementia
- Planning for the future
- Memory maintenance
- Building and maintaining friendships
- Managing finances
- Hobbies and leisure

The research

Journeying through Dementia is a randomised controlled trial which means that some people will be selected at random to take part in the 12 week programme and some will not. All participants in the study will receive regular visits from a researcher and receive regular updates about the study by newsletter. Everyone participating in the Journeying through Dementia study will be making an important contribution, helping us to understand how we can improve the lives of people living with dementia in the future.

The study is taking place in a number of locations including Bradford, Middlesbrough, York, Hull, Harrogate, Leeds, Sheffield, Nottingham and Leicestershire. We are in the process of recruiting people to take part in the study.

We hope that staff in the National Health Service (NHS), social care and voluntary services who work with people recently diagnosed with dementia will share information about Journeying through Dementia. So far over one hundred people have agreed to take part in the study.

People who are randomised to take part in the 12 week programme will be encouraged to choose topics of importance to them during the weekly group sessions (two examples are continuing with hobbies or supporting memory).

Participants can choose to attend some of the group sessions with a family member or friend if they wish.

Each person who is randomly selected to be part in the Journeying through Dementia programme will be visited by one of our facilitators before the group starts. They will talk with each person about what they might expect to happen in the group and enable them to discuss any concerns.

They will also meet monthly on a one to one basis with a facilitator to work on what they would like to achieve in life and how.

Support to take part

Living with dementia can sometimes impact on our ability to get around. To try and help with this we have done our best to ensure that the venues for the 12 week programme of sessions are in an easily accessible location such as a community centre or library. Getting to the venue is the first important step and we do not underestimate the challenges this can bring. One of our facilitators will work with each individual to look at the best options for how they might get to the group such as using community transport links and other options in their locality.

Concerns about taking part

Some people may have concerns about taking part. This is perfectly normal. Our facilitators will do their best to ensure that each person is able to relax, and have fun.

Those who have taken part in similar groups in the past have told us how helpful it can be to share experiences. They realised that their difficulties were not unique and found it valuable to connect with people in a similar situation.

Taking part in Journeying through Dementia does not mean that people cannot continue with the activities they are already involved in such as Cognitive Stimulation Therapy and other therapies. It does however mean that it is not possible to take part in another research study until the Journeying through Dementia study is completed.

Being involved – what it means to people living with dementia

Kevin has been involved in several aspects of our research.

“I’ll say yes to anything lots of the things that happen are not just for dementia, they’re for everyone – everything. Buses, information, everything. When they ask me to do it (get involved) it makes me feel that I’m helping them, that I can do things because I’m getting old. If they ask me to come, certainly I will. Just once I’d like to meet the younger people, the younger students. Just to say hello – let them find out what they’re doing as well. It’d probably surprise some people, they’d probably be surprised, they probably wouldn’t know the difference.”

Diane and Trevor have also helped with research for the University of Bradford and other Organisations’ such as the Alzheimer’s Society.

“We like to feel that we’re helping others, in the future. It’s usually enjoyable although we prefer it when things sent to us are written in plain English. Everyone’s very nice to us and really helpful. We’ve met some great people too and even got involved in other activities through it.”

Liz and Derek have just recently joined our research advisory panel and said they enjoy being involved.

Liz said “We find it really interesting and want to do all we can. I’ve learnt a lot from it myself. It also helps us to feel connected. Everyone treats us well and we’ve even made some new friends. As long as it’s a date we can do then we’re happy to take part.”

Our Team

Journeying through Dementia is a collaborative project between several universities. These are the University of Bradford, University of Sheffield, University of Nottingham, Sheffield Hallam University, University of Hull and University of Manchester.

Here are some of the members of our team...



Above – from left to right Dr. Jessica Wright, Alisha Patel, Zoe Furniss and Benjamin Thomas (Sheffield Clinical Trials Research Unit, University of Sheffield)



Above - from left to right Dr. Claire Craig, (Sheffield Hallam University), Professor Gail Mountain, (University of Bradford), Clare Mason, (University of Bradford).



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