



Journeying through Dementia newsletter, issue 2, autumn 2017

Update

Welcome to the latest edition of the Journeying through Dementia (JtD) study newsletter. Over the past 6 months we have continued to recruit people to take part in the study and are delighted that there are, so far, 325 people living with dementia consented to take part in the study.

Participants have been recruited from 9 NHS sites across England; including Greater Manchester, Humberside, Leeds, Calderdale and Kirklees, Bradford, York, Harrogate, Leicestershire, Nottinghamshire and Sheffield.

NHS staff working in services that support people living with dementia in these regions play a key role in the study. They share information about JtD with people living with dementia so they can decide if they want to take part in the research study. The NHS staff also host the JtD groups that some of you have attended or may be attending in the future.

What activities have the local JtD groups been doing?

A key part of attending a Journeying through Dementia group is the opportunity for group members to discuss and share strategies of how they approach different aspects of living with dementia and then get the opportunity to try things out in the group. The Bradford JtD group tried out a Tai Chi session over the summer and Sarah Poll, JtD Facilitator, described the session for us:

“The tai chi session came about following discussions the group had on ‘keeping physically well’ and ‘health, well-being and activity’. The group had noticed that a tai chi session was being held in the community hall near to where the JTD group was taking place.

Facilitators approached the tai chi instructor to ask if he would host an introductory session for the JtD group in the hall. The group members were able to engage in the session according to their abilities and regardless of their experience.

The group members experienced the session as something different and one that everyone could take part in even if tai chi ‘wasn’t their usual thing’! Leaflets about tai chi were shared after the session and one group member displayed a keen interest in taking up tai chi as a result of the session.”



How we are involving people living with dementia in JTD.

People living with dementia have been involved in the development of the JtD intervention and continue to be involved in the study. Wendy, who is a member of the JtD Trial Steering Committee, tells us a little bit about her experiences:



“My name is Wendy Mitchell and I was diagnosed with Young Onset dementia in 2014. I remember so well that feeling of abandonment that many of us feel when diagnosed. However I developed a passion for research. I’m now involved in many projects, both as a participant and on advisory panels, and the Steering Group for Journeying

This study was funded by the NIHR Health Technology Assessment Programme (project number 14/140/80).

through Dementia. Yes me. A person living with dementia.

Why? Well, we all had talents before a diagnosis of dementia; we don't suddenly lose all those talents overnight.

However, even more importantly, because it's so important that people with dementia are involved from the development stage of any project as we can offer first hand advice on what might work and what might not. Otherwise how do researchers know what they're doing is right?

We can only change the future through research and the involvement of people with dementia at all stages and as willing participants is key.

It also gives me the knowledge and comfort that I may be helping create a better future for my daughters."

Wendy writes a blog about living with dementia and she invites you to take a look at www.whichmeamitoday.wordpress.com

Or follow her on Twitter
<https://twitter.com/WendyPMitchell>

In addition to Wendy's involvement in the JtD study, we have recently set up a small advisory group in Bradford made up of people living with dementia and their supporters. We will be inviting them to tell you about it in the next JtD newsletter.

We want to know how the JtD groups are going....

If you are taking part in one of the JtD groups you may be invited to take part in another part of the JtD study where we try to find out about peoples' experience of going to the groups. In the coming months, two members of the research team, Kirsty and Jules, will be visiting a small number of the JtD groups. Your facilitator will be able to let you know if your group may receive a visit.

During these meetings they will sit in with the group and take some notes to help us understand more about people's experiences of taking part in the JtD group.

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In addition, some participants, and supporters if they have one taking part in the study, will be invited to meet with Kirsty or Jules to share their thoughts on how they have found taking part in the study.

Your feedback is really important to us as it helps us to make improvements to the JtD programme.

We hope you are enjoying taking part in the study and look forward to hearing your views.

Kirsty & Jules

Kirsty



Jules



Fun Facts



The flower for the month of October is the calendula. Another name for calendula is the pot marigold. They are easy to grow and popular in gardens. Colours range from pale yellow to deep orange.



Feedback Postcard

We would love to hear your views on our newsletter so please complete the pre-paid postcard enclosed with your newsletter and post it back to us. We will share feedback and respond to suggestions in later issues. Thank you.

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 or telephone **0114 2159122**.