Exploring people with dementia's experiences using creative research methods

By Alison Ward

In 2015 I was very fortunate to win a Winston Churchill Travelling Fellowship, to visit Denmark and learn about the different ways that they work creatively with people with dementia. As part of this project, I spent time with a school in Aalborg Municipality (Aalborg Dementia School, formerly Voksenskolen for Undervisning og Kommunikation). At the school, they have developed classes which are specifically aimed at supporting people with dementia, who attend the school as students. The students with dementia take part in a range of different classes, including: cognitive training, music and art therapy and physical exercise.



I was inspired by the work of the school, having never experienced anything like their approach in the UK. The school also embodies a number of the person-centred principles which I feel have a strong place within dementia care/services. I was therefore keen to learn more about their work and through the Fellowship, was able to undertake a creative project with the students with dementia to find out about their

Alison in Aalborg

experiences of being at the school and what it meant to them.

I worked with the school and students for four weeks, and was supported by a colleague from the University College of Northern Denmark, Diana. Together, we carried out a photography and storytelling project, giving cameras to the students to take photographs of things, people and places (both at the school and at home), which had a meaning to them. We then used these photographs over four weeks to their experiences of being students. We also used some different creative approaches, including poetry, photo elicitation and storyboards to find out whether these different methods supported the students with dementia to have a voice in the research process.

Using these creative approaches was found to be an exciting way of working for the students with dementia who particularly enjoyed using the photographs. The photographs were a way to support their memory, helping them to recall places and people. They also acted as a way to bond the group, as they found pleasure in seeing other people's photographs and in sharing their own pictures.

We found that the students recalled the process of taking the photographs, for some this was even four weeks later. The students also enjoyed sharing the stories which emerged out of the photographs, both about their time at the school and their home life. This led to personal stories and shared stories, one memorable moment was listening to the group sharing their experiences of having lived in occupied Denmark during World War II. This approach proved to be a valuable way of working and was an engaging, and supportive, way for the students to tell us about their lives both past and present.



Using photographs and the different storytelling methods was not always an easy thing to do, however, as this was a challenge for the students, presenting a new way of working. Myself and Diana provided a lot of guidance and support through the process. We had spent time before each session planning the activities and making sure we had different options as backups. While this can be a very positive way of working and including people with dementia in research, I found it takes a lot of time and planning, and requires a personcentred ethos at the heart of the work to ensure that the needs of the person with dementia are always met.

A student poem about being at the school

We ended our time together with a Danish celebration, making the most of proper Danish pastries and lots of coffee – a joke shared amongst the group who had previously joked with me as an English tea drinking lady! We also created a storybook of our time together, making sure that the students had a copy of their poems, stories and all of their photographs. This was a great way to bring the project to an end and we also used it to reflect on the work we had done. The students said it had been fun and agreed that the book provided an accurate representation of their experiences.



A Danish celebration to end the project



The student's storybook

Since finishing this project, I have been fortunate to secure funding to work with the students, teachers and Diana on a new project at the school to further develop their evidence base. I was excited to return recently, especially when I heard that one of the students was still at the school and was equally excited to see me again. On my visit I received a warm hug from this student, and we had an opportunity to catch up. I was sad to hear that many of those who were part of this project had since passed away and sad to realise that while the student I re-met remembered me, thier condition had deteriorated significantly. The stark realisation of what it means to carry out research in this field was clear and has emphasised the importance of keeping my participant's voices alive through this research. I am pleased to continue my collaboration with colleagues, and now friends, in Denmark, and aim to continue to explore ways in which we can best support those living with dementia to live as positively as possible, especially incorporating creative approaches.

If you would like to find out more about my stay in Denmark and the other exciting projects I experienced, you can read my report: <u>https://www.wcmt.org.uk/users/alisonward2015</u>

Also to find out more about the Winston Churchill Memorial Trust: <u>https://www.wcmt.org.uk/</u>