

'I will tell you something

Helen Gregory describes an innovative project that brought together the arts and social sciences to tackle questions of stigma and personhood for people with dementia

I will tell you something of my own.

*I will still be what I am,
I will still be on the slide.*

I want the same as life.

I want the same.

From 'The same as life' by
Olwen Jones and Karen Hayes

I Will Tell You Something of My Own is a project which uses social scientific research and innovative artworks to explore the everyday lives and selves of people with dementia. The project is funded by Arts Council England and NHS Gloucestershire, and supported by Age UK Gloucestershire. Its aims are twofold: to understand better what it is like to live with dementia and to help combat the stigma which people with dementia face daily, by illuminating the continuing humanity and competencies of those who live with this condition. This article explores the background, rationale and method of 'I Will Tell You Something of My Own', considering how it unites the arts and science to help improve the lives of people touched by dementia.

Dementia, personhood and stigma

The interpersonal needs of people with dementia are often overlooked (see for example Alzheimer's Society 2007). This neglect is partly due to the limited resources available to those who care for people with dementia, but we cannot afford to ignore the impact which dementia stigma has on this care and on the daily interactions of people who live with dementia.

Unfortunately, Kitwood's (1997) landmark work on personhood has far from

extinguished fatalistic descriptions of dementia as 'a slow unravelling of the self' or the 'living death' (Beard, Knauss & Moyer 2009). As Sterin's (2002) revealing autobiographical account observes, the dementia label remains "the kiss of death" (p8) for many social interactions. People with dementia often find that others speak for them, talk about them as though they are not there or otherwise avoid engaging them in conversation (Killick & Craig 2012). This leads to a loss of agency, identity and social connectedness which could at the least be seen to exacerbate the symptoms of dementia and at most be viewed as an alternative explanation for these 'symptoms' (Kitwood 1997).

Related to this is the commonly held view that people with dementia lack insight into their condition, being unable to recognise or articulate their own needs or desires. Accounts such as Sterin's question such claims however, and there is increasing recognition that people with dementia have greater awareness than they are typically credited with. This moves the onus onto us to provide the conditions which enable people with dementia to express these thoughts, needs and desires (Killick & Craig 2012).

Introducing the project

This belief in the competency and value of people with dementia lies at the heart of 'I Will Tell You Something of My Own'. The project takes as its starting point (and for its title) a collection of poems co-written by Karen Hayes for the 'Try to Remember' project (see

Gregory *et al* 2012 a, b). In 'Try to Remember', Karen worked with people with dementia to create poems about themselves and their lives. The poems were then read back to co-authors, their carers and their family. Many of the professional carers who were interviewed about the project said that these poems changed their view of those in their care, emphasising clients' humanity and personhood (Gregory 2011).

'I Will Tell You Something of My Own' seeks to make these poems available to a broader audience and to develop a wider collection of artworks with people with dementia. The project brings together Karen's poems with photographs by Viv Jones, sculpture by Elisabeth Turfrey, songs by Benita Johnson, poetry-song fusions by Yaffle (Benita Johnson and myself), and a collection of 3D collages, selected and narrated by myself and people with dementia.

These artworks were initially displayed in a six-week long exhibition in Stroud between December 2013 and January 2014. Over this time, we recorded 894 visits (some of which were repeat visits), and many more people engaged with the exhibition project indirectly via newspaper articles, radio broadcasts, internet platforms and other routes. Visitors with experience of dementia were invited to contribute something of their own to this exhibition, adding photographs to a collaborative album or placing objects on a central sculpture formed from a jumble of old coffee tables. This collaborative collection lives on through the project's website and in the exhibition brochure (see www.tinyurl.com/somethingofmyown).

Art and science

'I Will Tell You Something of My Own' is not only an artistic exploration of dementia. It is also a scholarly, (social) scientific exploration. The confluence of these two elements is aptly demonstrated by the collages (referred to above). These contain objects selected in semi-structured one-to-one interviews with four people with dementia.

In the first of two sessions with each participant, I talked to them about themselves, their life and their experience of dementia. We also started to talk about salient objects that might help tell the story of their life/selves to others.

The second interview focused on the objects, which participants felt told a story about their life or represented something that was important to them. In three cases, participants worked with family members between sessions to pick the final selection of objects. In the fourth case, however, the participant had no one to work with between sessions. Further, living in a care home meant that she had few personal possessions from which to draw. This participant thus chose objects from a larger group of items which were bought by myself to represent key elements of her life.

The transcripts from all interviews were then analysed using thematic analysis and this analysis was used to construct a narrative to accompany each framed object or collection of objects. The narratives describe the frame's objects in the words of the participant, using the objects to illuminate the lives, selves and experiences of people with dementia. They also

of my own'



share participants' insights into what it is like to live with dementia. One participant, Lewis, for example, contends that dementia is "the background", rather than the essence of his identity, saying: "It's not me ... it isn't who I am. It's part of my situation." These dialogues demonstrate participants' awareness both of their condition and of how others respond to them. Thus, another participant, Joyce complains that people, "...treat me like I'm old sometimes. You know, 'Oh she won't remember' or whatever."

This initial data analysis will be developed further using a method called interpretative phenomenological analysis (IPA), which aims to elucidate the inner world of participants in depth (see for example Smith & Osborn 2008). IPA will be applied to the creative session interviews and to additional interviews with people with dementia. This data will be combined with visual analysis of items and photographs contributed to the core collection. The aim of this research is to better understand what it is like to live with dementia and to further the overall project aim of combatting stigma around dementia, by telling the stories of people with dementia within the academic community. I plan to write at

least one journal article about the project and present the project at one or two academic conferences this year.

Moving forward

Unfortunately, stigma around dementia remains all too prevalent. Many people continue to believe that individuals with dementia have no insight into their condition and cannot adequately express their own needs or desires. There is also a great deal of fear and shame around dementia. 'I Will Tell You Something of My Own' represents the attempts of four artists and one artist/academic to tackle this stigma.

This is an ongoing project. The project artworks will live on via the website, exhibition brochure and collaborative photo album, while the interview data still has much to reveal about life with dementia. In addition, both artworks and scholarship have inspired the project team to continue work in this area, and the offshoots of this project are likely to continue to grow for some time to come. The message that this wider body of work seeks to spread is that people with dementia are competent, valuable human beings, and that we must create a space in which their potential can be fully realised. As Benita Johnson sings in a piece commissioned for this



Project Lead Dr Helen Gregory, with Violet and her daughter Janet, who contributed objects to the exhibition collection. Lewis's frame

project and inspired by the words of its participants: "Sometimes I need somebody to lead me through the dark. Won't you feel your way to me, feel your way to my heart."

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Feedback from the exhibition

[The launch gave] a voice to the old who may be unable to express [themselves] artistically, it gave them a voice and a stage and celebrated individuality rather than being a plea for pity. *Email from participant's daughter*.

The 'poems' really did the business in given an insight to the conversations we have with people living with dementia. It was good to see these represented in a really imaginative way - and they gave me pause for thought over the many conversations we've had with both my mother and Jane's Dad [who have dementia]. *Email from visitor*.

[The exhibition has helped me to develop] an understanding that there is no barrier to achieving what a person wants to achieve even if they have got dementia." Feedback questionnaire.

"What a great exhibition - I really hope lots of people will come and visit. It's so important to be able to see the rich lives of people living with dementia and not just see their illness." *Guestbook comment*.