The University of Bradford Institutional Repository

http://bradscholars.brad.ac.uk

This work is made available online in accordance with publisher policies. Please refer to the repository record for this item and our Policy Document available from the repository home page for further information.

To see the final version of this work please visit the publisher’s website. Where available access to the published online version may require a subscription.

Author(s): Capstick, Andrea.
Title: 'This is my turn; I’m talking now': findings and new directions from the Ex Memoria project.
Publication year: 2009
Journal title: Signpost: Journal of Dementia and Mental Health for Older People.
Publisher: University of Bangor. Dementia Services Development Centre.
Link to publisher's site: http://www.bangor.ac.uk/imscar/dsdc/noticeboard.php.en
Citation: Capstick, A. (2009). 'This is my turn; I’m talking now': findings and new directions from the Ex Memoria project. Signpost: Journal of Dementia and Mental Health for Older People. Vol. 14, No. 2, pp. 14-18.
Copyright statement: © 2009 The Author. Reproduced by permission from the copyright holder.
Capstick A (2009) ‘This is my turn; I’m talking now’: findings and new directions from the Ex Memoria project. Signpost: Journal of Dementia and Mental Health for Older People, 14 (2), 14-18.

‘This is my turn; I’m talking now’: findings and new directions from the Ex Memoria project

When I last wrote for Signpost a couple of years ago I was carrying out a research project to explore the impact of using the short film Ex Memoria with students on the BSc (Hons) Dementia Studies programme at the University of Bradford (Capstick 2007). That research is now complete, so I was particularly pleased to be asked to contribute a further article, as this gives me an opportunity to outline some new educational projects and areas for future research which have all, in various ways, developed out of the Ex Memoria project.

Although training and workforce development are high on the policy agenda at present (eg DoH 2009), there has been less progress in thinking about the kind of education that might be needed in order to provide dementia care that is genuinely person-centred. A continuing obstacle here is the tendency to assume that people who have dementia are to be understood – as a group – by virtue of their shared diagnosis rather than by their lived experience, in which diagnosis is an interruption rather than the whole story. Three approaches to overcoming this obstacle that I will discuss below are arts-based learning, teaching social history awareness, and increasing the involvement of the ‘experts by experience’, people with dementia themselves.

The title quote for this article is a kind of manifesto for what follows. The emphatic statement ‘This is my turn; I’m talking now’ was made by Cynthia*, a woman with dementia, during narrative biography work in progress by David Clegg (Director of The Trebus Projects, London). It expresses, quite forcefully, the feeling that people with dementia have been talked over, talked about, and talked down to for long enough. The projects outlined below are all in various ways about people with dementia talking back. Before discussing them further, however, I will provide a brief summary of what the Ex Memoria study itself involved.
Ex Memoria (written and directed by Josh Appignanesi, 2006) is a 15-minute fiction film about the experience of dementia. The film’s development and production was funded by The Wellcome Trust through its former Sciart scheme (now Wellcome Trust Arts Awards). The central character, Eva, now living out her final years in a nursing home, appears to be re-experiencing traumatic wartime events in her native Poland. Her confusion and disorientation are exacerbated by aspects of the care home environment which are reminiscent of these earlier life experiences, during which she lost both her brother and her home. Although the main roles are played by actors, the story is based on a real-life memoir of the director’s grandmother (Appignanesi L, 2000).

The Wellcome Trust-funded evaluation reported on in my previous article in Signpost was carried out by postal questionnaire. Beyond this, I then went on to carry out a more in-depth exploration of responses to the film with 22 dementia care practitioners who were all at the time students on an undergraduate award pathway at Bradford (Certificate, Diploma or Bachelors degree in Dementia Studies). Twelve of these students were undertaking a core module ‘The Social Psychology of Dementia Care’, and wrote a coursework assignment based on Ex Memoria. The remaining 10 participants each volunteered to write a review of the film. The reviews and assignments formed the primary data for my research, but I also followed up themes that arose from analysis of this material by extending my literature search on the basis of the findings, a model of research sometimes described as ‘grounded theory’ (Glaser, 1998). I had some very enthusiastic participants, many of whom also showed the film to colleagues and family members, and everybody who took part received a certificate of research participation to thank them for their contribution to the project.

The impact of visual methods

When I began the research, I was primarily concerned to find out whether the use of film would have advantages over text-based learning materials. Our Dementia Studies courses are provided by distance learning, and when we started out in 2001
the core study materials were provided entirely in printed form. Over the last few years, however, we have been moving increasingly to mixed-media and on-line delivery, including audio-visual material. A number of recent studies recommend the use of film in health and social care education (eg Alexander et al 2005) and this is clearly a way of adding variety and interest to the learning process. I also anticipated that visual material would heighten students’ observation skills and increase their empathy with Eva.

It was clear that most viewers found Ex Memoria visually profound, and the students who took part made some very astute comments on the film’s style and technique; for example, on the use of sound and visual imagery

*The gun fire in the opening scene helps prepare us in some way for what’s to come...it conjures up pictures of fear and flight*

*Individual people are kept in single ‘cells’ along a very long, stark corridor adding to the sense that Eva is in jail, or being kept against her will*

There was also considerable evidence of enhanced observation and empathy. As one viewer noted, in relation to a scene set in the bathroom of the care home

*It made me cringe. It’s very hard to watch, because it makes you think ‘What must she be feeling? What does she think is happening to her?’ But I know I could walk past on the corridor in my own [care] home while that was going on...and just think ‘Oh, she’s playing up today...’*
Viewers also made connections between past and present in explaining Eva’s current actions, showing a move towards a broader perspective than the standard paradigm model of ‘challenging behaviour’, in which behaviour is viewed solely as the result of brain pathology (Kitwood, 1997).

The home makes her feel as she did in the war, so she tries to create change by drawing upon the skills she used then.

Viewers often ‘read into’ the narrative in order to construct Eva’s background and identity. There is, for example, a lot of speculation about whether Eva is waiting to meet someone in the woods at the beginning of the film. Some viewers suggest that she may even have betrayed her brother to the Gestapo. Although this was not an intentional theme, it was remarkably common for viewers to read Eva’s ‘secret lover’ into the story. Among other things, this makes it clear that viewers become fascinated by the historical ‘back story’ of Eva’s life, which intersects with the major historical events of the mid-20th century.

The film’s strong visual impact, and particularly the camera’s insistent ‘foregrounding’ of the central character, by remaining on Eva’s face and recording her reactions in minute detail, appears to have instilled a strong sense of curiosity in viewers. In the process Eva’s life history becomes something of a ‘life mystery’, and the clues to solving this puzzle are revealed as lying less in the day-to-day life of the
care home, than in historical events of 60 years earlier. Detailed analysis of students’ writing showed that the most often used words were all related to these earlier events. In particular, gunfire, lipstick, cigarettes, misidentification, and ‘papers’ (Eva’s possibly forged wartime identification documents) were mentioned by almost all viewers.

Ex Memoria: Eva’s ‘escape’

Peoplpe with dementia as historical subjects

As we learn from a comment made by Eva’s daughter in Ex Memoria, Eva managed to avoid the ghetto ‘somehow’ and she now appears to associate the late 20th century care home with the ghettos and concentration camps of 50 years earlier. Occasionally viewers have suggested that Eva’s experience as a Holocaust survivor was so extreme that it couldn’t be generalised to other people with dementia. This seems, however, to be a striking example of what Jacoby (1996) refers to as ‘social amnesia’, since all those who survived the war years of the first half of the 20th century are now in their 80s and 90s and the likelihood is that at least one in five will have dementia. Of the 35,000 Holocaust survivors living in Australia, for example, it is estimated that almost half now have dementia.

Sources which advocate a person-centred approach to dementia care often appear to place their main emphasis on the quality of interpersonal relationships and care
practice in the here and now. In the process, it is easy to overlook the broader sweep of historical events which all older people who now have dementia have, in some way or other, lived through. Even those practitioners who have a detailed knowledge of their clients’ personal life histories, may know much less about the national and social history that has formed a backdrop to their clients’ lives. The increasing diversity of both client group and workforce makes it even more important, however, to ensure that careworkers are aware of this dimension. As Joan, a woman with dementia, drily commented when telling her own life story, ‘None of these people working here would even know there had been a war’.

In fact many real life examples similar to Eva’s have been noted (eg David 2003; Wong 2003) and the reality is that there are still many older people living in care homes who have experienced similarly traumatic situations earlier in life. Ironically, however, they may never have chosen to speak of these events until the onset of dementia reduced their ability to censor painful memories. I think we all find it very difficult today, to keep squarely in mind that the people we read about in accounts of the ‘hungry thirties’, the Blitz, mass evacuations, prisoner of war camps and so on, are not a different population from those who now have dementia, but the same one. As Bender (1997) points out, media representations of war-time have also led us to accept a sanitised and conventionalised version of these historical events which bears little resemblance to the reality of what many people endured.

Prisoners of war: the survivors will now be in their 80s

Compelling evidence to support this view can be found in the narrative biographies of people with dementia collected by David Clegg (Brown and Clegg, eds 2007) under the title ‘Ancient Mysteries’. These stories demonstrate – among other things - the frequency with which people who now have dementia have had traumatic early
experiences related to war, childhood poverty, the early loss of parents or siblings and other ‘social evils’ such as domestic and institutional violence.

I was in London for the celebrations...the street parties...they were alright until you started to look round then you found the realisation of it...people who you’d known for year...who’d lived next to each other...people you went to the pub and had a pint with...all dead...all dead (Sid)

It was tough...specially when you’re just twelve years of age...they’d come up behind you and bang! Smack across the ears. One time I remember they stuck a pencil clean through a kid’s hand...nothing was done to them...I was completely wrecked and ruined by my father and the Christian Brothers.

(Patrick)

Too often, however, these valuable testimonies have been subjected to forms of censorship; what is revealed can too easily be ignored or dismissed as merely the ‘confabulation’ of someone whose memory is failing. As a result, one of my subsequent projects has been to increase the historical content of the first module completed by students coming onto our Diploma and Degree programmes. Early indications are that students who have seen Ex Memoria, and discussed the major historical events experienced by people born during the first half of the 20th century, are much more likely to identify significant traumatic or historical life events when compiling a life history with their own clients.

Arts-based approaches to practitioner education

We have now used Ex Memoria as the basis of a number of creative writing workshops where we ask participants (both practitioners and service users) to re-create Eva’s story using the clues given in the film, to identify keywords that occur to them when watching it, and then to produce a group poem. Here’s an extract from one of the resulting poems that reflects something of Eva’s equivocal past, and challenges the stereotypical view of the passive ‘victim of dementia’:
I’ve been a wife. A mother. A sister. A lover.
I’ve been an adventurer,
A traveller, a survivor
An escapologist –
Long before I had
A wheelchair to escape from.

As Smith et al (2006) point out arts-based approaches to the education of health and social care practitioners have great potential for increasing our awareness of the complexity of human experience and for developing expressive and observational skills. It might also be added that judicious use of the arts is a good way of raising awareness of historical events, and their continuing impact on the experience of dementia. The novel ‘The Madonnas of Leningrad’ (Dean 2006), for example, is a moving evocation of the links between history, memory and personal narrative for a woman who lived through the siege of Leningrad and now has dementia. Ian McEwan’s novel ‘Atonement’ (2001: 240-44) provides a harrowing account of the retreat from Dunkirk, based on a contemporary memoir, which looks beyond the popular recollection of the ‘miracle of the little boats’ to the reality of what the servicemen involved actually endured.

They passed men who could barely walk for their blisters. Some were barefoot. A soldier with a bloody chest wound reclined in an ancient pram pushed by his mates. A sergeant was leading a carthorse over the back of which was draped the body of an officer, unconscious or dead...ten miles away Dunkirk burned

I find sources such as these are actually more valuable for teaching than many standard textbooks on dementia.

Having said this, there is clearly a need for caution when using some ready-made sources, and this is due to the frequency with which mainstream film, TV programmes and novels perpetuate stereotypes about people with dementia. Ex Memoria was essentially tailor-made to facilitate new ways of seeing a person with dementia. In ‘made-for-box-office’ films, by contrast, the focus is often a carer’s
eye view of dementia as merely the disintegration of former personality and the burden of caring.

As the next section demonstrates, people with dementia themselves resist stereotyping; they are not a single homogenous group defined by their diagnosis. In fact the more we engage with people like Cynthia, Joan, Edwin and Patrick, whose voices are present throughout this article, the more apparent it becomes that we should not be making generalising claims about ‘the person with dementia’ at all. Hearing the individual voices of people with dementia helps to challenge stereotypes, inform care practice, and discover previously unwritten histories.

*Recovering censored testimonies*

Cayton (2004), Williams and Keady (2006) and Baldwin (2006) among others have all drawn attention to the need for a ‘narrative turn’ in work with people with dementia. Although life history work and reminiscence are now widely recognised as a therapeutic activity for people with dementia, there is less recognition that the things people with dementia have to say are uniquely valuable as social and historical testimony. Long-term memory often stays relatively intact in dementia, and events from the past that are highly emotionally charged can return with great force.

Cynthia, for example, describes herself as ‘a six footer’ (unusually tall for a woman of her generation); she also talks of her experience as a sergeant in the ATS during the WWII, and later as a nurse.

> *I ended up as the youngest Company Sergeant Major in the British Army. I remember the bombing and the air raid warnings and that’s all I wish to say about that…that I remember those days clearly.*

Cynthia’s story challenges stereotypes, not just about people with dementia, but also about the roles of ordinary women during the first half of the 20th century. It highlights the centrality of wartime experience and the major social upheavals experienced by people who are now in the 75-and-over age group.
Experts by experience

People with dementia are often able to give their opinions on the quality of the services they receive, and thus to inform care practice and the education of practitioners. Here Joan, a former schoolteacher, comments on an approach to care practice that she doesn’t approve of:

*I think she’s taking over the rather strict teacher convention that we’re all naughty, naughty schoolgirls…..Today’s education needs brushing up a bit…looking after people and so on.*

Joan goes on to model her own view of good care practice, providing reassurance as another resident walks up and down the corridor

*Look what you can see now…this is nice…look at this nice red jumper…look at the people…shake hands with them, by all means…what can you see? Lovely flowers…lots of people. Do you need to use the loo? You’d look important in that big chair over there. There’s a paper for you to read*

So older people with dementia are not just experts on the experience of dementia, or care services, they are also experts on life. As Joan demonstrates, people with dementia can also be our teachers, and they can be providers of care as well as recipients.
Other extracts from the narratives collected by David Clegg reveal how people with dementia often remember things that society as a whole would prefer to forget. Edwin, for example, talks about people living 12 to a house in the 1930s, and notes how during the Second World War, bad news from the front line was often followed by vicious attacks on prisoners of war. These are the kinds of things that, whilst they happened literally ‘within living memory’ are much more comfortable for those of us born in the post-war period to pretend never happened.

Over the last couple of years, we have begun to develop a range of strategies for involving people with dementia in the development of learning materials, teaching, assessment, and course evaluation on the Dementia Studies programme at Bradford. We now have experts by experience directly involved in course management and module delivery. Service user consultations have been done through outreach work in the community, in dementia cafés and at a local day centre for younger people with dementia. Where people with dementia have cognitive difficulties which make their direct involvement less feasible we use case study material based on observation in care settings, and audio-visual material. This summer I will be starting to make a rather different kind of film from Ex Memoria, one which – in keeping with the
principles of participatory video (Lunch and Lunch 2006) - is directed, scripted, filmed and edited by people with dementia themselves. I hope to be able to share the outcomes with you in due course.

Acknowledgements:

With thanks to David Clegg, Cynthia, Joan, Edwin, Sid and Patrick for material from The Trebus Projects (* the names of all people with dementia mentioned in this article have been changed), and to Professor Cathy Greenblat for permission to use the photograph on page x

References:


http://www.baycrest.org/If_Not_Now/Volume_4_Fall_2003/default_7108_7169.asp.