

Personho

Over the last 20 years there has been a move towards a positive and person-centred approach to dementia care underpinned by the concept of personhood. This was defined by Tom Kitwood (1997) as “a standing or status that is bestowed upon one human being by others in the context of relationship and social being”.

Before Kitwood wrote his trailblazing book, people with dementia had often been regarded as being consumed by their condition with their personality, roles and attitudes being eroded and lost (Ray 2016). But if such views are now considered misleading, what does it mean to maintain personhood in dementia?

As one possible answer to this question we present the case of Helen (not her real name), a doctor who developed early onset Alzheimer’s disease, to examine how far identity and a personal narrative can be maintained in the face of dementia (see case study on pp28-29). Our commentary on the case study aims to cast light on how the relationship between Helen and her husband/caregiver helped her to maintain that identity.

Former French president François Mitterand said at the end of his life: “I am beginning to understand the pleasure that the old experience when they sit for hours on a bench in the shade of a plane tree, doing nothing, gazing into the distance, silent, motionless, their hands folded.” This is a positive depiction of fulfilment in later life after previous roles and physical strength have been lost.

Achieving this state, however, requires a sense of personal continuity and intact psychological resources (de Hennezel 2011). In contrast, people with dementia experience a progressive diminution of psychological function and find themselves excluded from participation in mainstream social activities (Thomas & Milligan 2015). This exclusion may be unintentional and arise from the failure to communicate with people with dementia whose language skills are reduced, or failure to recognise and respond to non-verbal ways in which people with dementia communicate.

The 17th century philosopher John Locke argued that personal identity extends only so far back as one’s consciousness and memories of one’s own past. Holton (2016), however, disagrees by stressing the importance of social relations in maintaining the personal characteristics of the person

Personhood in dementia: a case study

What is personhood and how can it be maintained in someone with dementia?

Commenting on a case study of 'Helen', written by her husband and caregiver 'David' (pp28-29), **Irina Singh** and **Philip Wilkinson** argue that supporting relationships is key, both for the person with dementia and, crucially, their caregiver

with dementia. Combining these two perspectives, it might be claimed that loss of self in people with dementia can arise both from the direct impact of disease and the behaviour of those regularly involved in their lives (Sabat & Harré 1992).

Holton also points out that the types of memory (semantic and procedural) that embody identity tend to be preserved in the earlier stages of dementia, even after impairment of episodic memory sets in. For this reason, Helen "...remembered odd episodes from her school days," as the case study tells us. Helen's caregiver David (not his real name) took many active steps to maintain her status and identity, making sense of the different feelings she exhibited including loss of enthusiasm, pleasure, anxiety, and frank fear.

Accepting and adapting

David helped others to know her and accepted the new relationships that her dementia brought. He helped to preserve her previous activities as far as possible while acknowledging her emerging preference for less complex and non-verbal activities. He also recognised that the decline she experienced was not linear: "There were flashes of the old Helen which came through".

Early in her dementia, Helen experienced persecutory thinking, then frank paranoid psychosis which had a greater negative impact than her early cognitive impairment. Not surprisingly, psychotic symptoms in dementia are known to be associated with increased caregiver burden (Tampi *et al* 2011) and reduced wellbeing (Lethin *et al* 2017). Helen was prescribed antipsychotic medication, which is known to carry medical risks in people with dementia (Corbett *et al* 2014).

In Helen's case, however, this treatment brought about relief of distress, both for herself and David as her caregiver, allowing her to return home from hospital, restoring positive relationships, and helping her to engage in activities that would become important to them both. The progression of dementia, particularly that of early

Implications for practice

- A focus on personhood can help to prioritise participation in activities and bolster positive relationships for the person with dementia
- Appropriate use of psychotropic medication in dementia can help to sustain personhood
- In making the transition to becoming a caregiver, the partner of the person with dementia can also make positive changes in his activities and relationships
- In the later stages of dementia, however, the caregiver may experience loss of agency and self-esteem
- While personhood in people with dementia has been widely discussed in the literature, personhood in caregivers has been largely overlooked

onset such as Helen's, brings a loss of the skills and roles that have previously defined the person, and these losses have an increasing impact on caregivers.

Both Helen and David eventually had to give up their careers. Later, Helen's identity as a doctor was still apparent, however, in shaping the content of her delusions during her period of psychosis. Her participation in two clinical research studies, instigated by her caregiver, was congruent with her previous professional values and priorities.

Creative ways to communicate

Reciprocity in interactions with carers, family and others is important in maintaining wellbeing for all involved in the dementia journey (Ray 2016). As Helen's communication and practical skills declined, her paid carers and family members found creative ways to communicate with her, particularly through music therapy, which is said to access underexploited abilities by bypassing inhibitions and distractions.

Music therapy has also been observed to alleviate agitation, depression and anxiety (Guétin *et al* 2009, Raglio *et al* 2008) and to have specific effects on

working and short-term memory (Särkämö *et al* 2013). Emotional reactions to music are preserved even in the later stages of dementia (Johnson *et al* 2011) and in Helen's case, despite her apparent loss of awareness, this provided some connection with other people and reassurance for her caregiver.

Helen's caregiver benefited from the support of the Young Dementia UK worker and care home staff in sharing responsibility for care and activities. They gave helpful feedback on the approaches he was taking. Caregivers find the need to provide positive interaction at all times to be burdensome but enabling them to recognise their own strengths and vulnerabilities can enhance their sense of agency and satisfaction (Chung *et al* 2017). Clinicians play an important role in supporting the caregiver in this way, as they do by fostering relationships in the dementia community.

Impact of loss over time

Perhaps the biggest impact over time is on a caregiver who has known the person before the onset of dementia and who accompanies them through the slowly progressive illness. Caregivers make the journey despite the fact that the person who is known and loved gradually recedes from them, becoming someone whose mind and sense of history share few common roots with the caregiver.

David was left to carry their memories which, 10 years after diagnosis, might also have been experienced as a burden, given the loss of their future together. As Helen reached the later stages of her dementia, her personal memories, connection with loved ones and previous activities were lost to her, but they remained alive for David. The gradual shift from the role of husband in a mutually loving relationship to caregiver for a person who viewed him as a stranger much of the time was profound, particularly given that his wife's understanding would not improve.

While there are recognised ethical and legal obligations on a lifelong partner or family member to provide care for a loved one during the dementia decline, little

attention has been paid to the needs of the carer over the long course of dementia. Are there obligations to care for the carer beyond occasional respite care? If so, on whom are those obligations conferred? These questions will become all the more important in the light of medical efforts to slow the dementia decline. While this is likely to have important benefits for the healthcare system and for people with dementia, we need to recognise that it could inadvertently increase the burden of caregiving on family members and other carers.

Until there are biomedical advances in the prevention and treatment of dementia it will remain a progressive disorder with a considerable impact on people with dementia and those close to them. As stated by Holton (2016), "keeping a personality going in dementia, demanding as that is, is a job for us all". We argue that approaches arising from the concept of personhood have contributed much to the care of people with dementia and, as our case study demonstrates, they can at the same time help caregivers re-shape their skills, status and relationships.

Benefits for caregivers do not endure, however, once the dementia has reached its later stages and the paths of the person with dementia and the caregiver have diverged. Further understanding of how to

foster a caregiver's sense of identity and self-esteem in these later stages of dementia is therefore required. ■

■ Ilna Singh is professor of neuroscience and society in the Department of Psychiatry, University of Oxford, and Philip Wilkinson is honorary senior clinical lecturer in the Department of Psychiatry, University of Oxford, and consultant psychiatrist at Oxford Health NHS Foundation Trust

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An account by David, Helen's husband and caregiver*

At the age of 54, my wife Helen wasn't quite right – not as on the ball as others of her age. She seemed to be losing her characteristic enthusiasm and drive. She could not manipulate the spreadsheets she used to or complete her tax return, and she spent long hours playing solitaire on-screen, which now seemed to be the peak of her achievement even though previously she had enjoyed doing cryptic crosswords. She would buy dozens of garden plants in pots that lay outside unplanted, dying for lack of water.

Helen seemed very stressed at work – she was a doctor - and complained that her colleagues were ganging up on her. I got very angry with her sometimes because she seemed almost wilfully stupid. It was all out of character, so I began to wonder if it may be an illness. Surely it would be treatable? Helen herself felt something to be wrong; she knew she had good days and bad. Her GP and family thought it was stress-related and she was started on an antidepressant. But the bad days steadily increased.

Early-onset Alzheimer's disease: David's story

Two years after her problems started, Helen became seriously lost on familiar roads and was driving erratically. One evening she left from work, about 30km away, but did not get home till three in the morning. I was frantic, but she could not explain where she had been and it did not seem to worry her. Nonetheless, she sought further help from her GP and was referred for neuropsychology tests.

In the tests, she could not draw a clock face, getting all the numbers bunched up in one place, and failed catastrophically on all the spatial skill tests – matching blocks, copying line drawings etc. This was our first formal and objective evidence that Helen was truly unwell and it was hard to take in. She was put on long-term sick leave with a provisional diagnosis of potentially treatable depressive pseudo-dementia and we hoped that a different antidepressant would work.

But it didn't, and Helen never returned to work. She was then referred to an old age psychiatrist who diagnosed early onset dementia of the Alzheimer's type. Her particular problem was not so much memory loss as loss of executive function – organising and managing tasks. Helen was upset by the diagnosis. I was still working full-time but Helen now stayed at home. She started to tell me things that I knew not to be true – that her business colleagues were having an affair and that her best friend had married our son. She drove to her previous workplace and told her colleagues that I had died.

By the age of 57, Helen's ideas were more and more far-fetched. She believed she had been appointed as chief executive of the organisation she had worked for, and she was convinced that I had AIDS and was trying to poison her. She was physically violent towards me and her delusions and hostility became so intense

that she was admitted as a psychiatric inpatient for assessment under the Mental Health Act. She stayed in hospital for three months and, after treatment with an antipsychotic drug, she was discharged and seemed improved, although I took partial retirement to spend more time with her. She could not make her own lunch, so I left a sandwich on the days I went to work.

At this time, we had our first contact with the charity Young Dementia UK. Helen was assigned a support worker to take her out once a week. They found fun things to do, visiting gardens and museums, going for long walks and always ending up with tea. The support worker's visits, when I was at work, made a big difference to Helen. Gradually she was weaned off the antipsychotic and was able to make her own lunch again.

Things seemed to improve but, sadly, this was only temporary. Helen could not now do any gardening. She could not work out the dead-heading or the weeding, and if she dug a hole to plant something she filled it right up with soil again instead of the plant. One dark wet winter evening she went missing from home when I was at work. I called the police who mobilised a helicopter and found her a few hours later. She was 6km from home, believing she was to attend a wedding reception.

When she was 57, Helen stood for hours in the cold and the dark outside the house waiting for taxis she believed she had ordered. When they did not come, she tried to steal my car keys. I could not now go to work as it was unsafe to leave her on her own. I locked us in the house together, but she got physically violent when contradicted or restrained. The GP prescribed the antipsychotic again, but Helen refused to take it so she was again detained under the Mental Health Act in a psychiatry inpatient unit for her own safety. At this point I was relieved, but also realised that I had lost for good the old Helen – it was a tearful time for me.

Helen at first believed she was in the inpatient unit to monitor the performance of staff. Eventually, she accepted a long-acting antipsychotic injection and began to calm down. She took part in ward-based gardening and swimming activities and seemed to gain some understanding of her illness. She was prepared for discharge and I had her at home on occasional afternoons or took her out for longer and longer periods. After discharge, Helen was calm but unable to do anything she used to do, such as wash herself or go to the toilet unaided.

Helen now had places at two day centres, which enabled me to go to work



Helen and David

just half a day a week and gave her the stimulation of mixing with other people. She started one-to-one music therapy, which seemed to tap into something she still enjoyed. She loved to sing along with familiar music, and we were able to go out to concerts as we had once done. She was quiet and had little conversation, although she understood that she could not do her past activities. But she had no insight into why.

When she was 59, Helen entered a year's drug trial of memantine, which had positive effects. I was sure she was not on the placebo! She became more alert, less stressed, smiled a lot more and was an easier, friendlier, person to have around. Just occasionally there were flashes of the old Helen which came through – she would laugh at some punning word play, for instance. She became more aware of her environment, noticing flowers, birds and sunsets.

At 61, Helen had her first week in residential respite care while I went away on my own. Later we had a week away visiting friends and relatives and she coped pretty well, but without any conversation or real connection to anyone. Over the next three years she needed gradually more help with eating; she walked more slowly and managed steps less easily.

Helen was recruited to a positron emission tomography (PET) study for detection of amyloid plaque in the brains of living subjects which meant a couple of long sessions at the hospital. She coped well and managed to lie still for the crucial 30 minutes while the scan was done. It was good that we could contribute by taking part in such things – as a doctor this is what Helen would have wanted.

By the time Helen reached 66, I had been caring for her for 10 years. She no longer engaged significantly with me, with friends or family, or with her home environment. She enjoyed music and her one-to-one music therapy sessions, but she no longer liked the crowded environment of concerts and I felt there was little more I could do for her. I felt worn out by being on duty 24 hours a day.

It seemed to me that Helen would be as happy in a care home as she was with me, and we have a high-quality dementia home not far away.

The family encouraged me to take this route. Helen settled happily in the home, but even months later I was still finding it hard to come to terms with. The 'ambiguous loss' and the guilt at being inadequate remained with me – irrationally, I felt that if only I had worked harder as a carer, I could have made Helen better. I was pleased, therefore, that the care home offered me support and counselling.

I visited Helen frequently and helped her eat at mealtimes, which was maybe more for my benefit than hers, though she smiled and laughed occasionally, apparently at what I had to tell her. So maybe she took in more than I realise? I like to think Helen's quality of life was now better than it would have been just staying with me at home. There were kind people with her all the time and she definitely responded well to the care home staff.

For my part, I needed to re-invent myself in the outside world as a 'real person' with an identity of my own and no longer as simply 'Helen's carer'. Who indeed was I now? After 10 years, this would be a challenge.

Helen is now 68 years old and it is hard now to think of her psychotic days 10 years ago. In some way, she seems to have been through all that and come out the other side as a much more relaxed person. In that regard, she is more reminiscent of when I first knew her exactly 50 years ago, except that she has lost all her energy and enthusiasm and initiative, of course. I am sure the psychotic phase was in some way an interaction between that energy and enthusiasm and the dementia.

Two years after she moved to the home, I am gradually reaching an accommodation with my situation. In many ways these two years have been harder than the previous 10. Watching Helen decline is the saddest part. Our plans for what we might do in our later lives have not been realised – no holidays abroad together, few trips out, no big household projects engaged and completed.

There is an almost total loss of meaningful shared companionship and friendship. Helen could not help at all with house and garden projects which she once initiated and enjoyed. It is hard to stay enthusiastic about things when there is nobody else around to appreciate or share them. ■

** Names have been changed.*