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- [Features](#)

How About Saying Hello? | Person-Centered Care in Dementia

by Heather Hill on September 15, 2011



As a young social worker working with mothers and babies, I could never imagine wanting to work with the elderly. It all seemed just too depressing – it seemed all about nursing home placement, sickness and death. Some years later, having trained as a dance therapist, it happened by chance that my first job was working with people with dementia(1), and in the most awful of institutional “bins” – closed down two or three years later. Dark, grim, mad – and hopeless – certainly described the institution. As for the people – well textbooks, newspapers articles all had words to describe them and their situation – “ the death that leaves the body behind”,

“a dissolution/dismantling of the self”.

As dance therapist – or “the lady with scarves” as I think the nursing caregivers regarded me – I was expected to bring in sweetness and light – and I did! But not by myself. Despite the awful environment, despite the dementia – entering a ward filled with people in various states of withdrawal and confusion was daunting – I found PEOPLE. Together we created moments that were, creative, exciting, emotional, loud, joyous, touching and sometimes fabulously funny! This was the beginning of a passion, which still burns brightly in me to this day.

My experiences in dancing with people with dementia started me on a path of questioning. How could people who had a degenerative disease which supposedly destroyed the person come to life in the dance sessions? Surely if I could find people among the grey ghostly inhabitants of this institution, others could too? I refused to believe you had to be a dancer to do this. My questioning led me to the work of Tom Kitwood, pioneer of person-centred care in dementia – a true visionary, on whose work others have continued to build and build in exciting ways. His mantra: The key psychological task in dementia care is the maintenance of personhood. Kitwood suggested that personhood is constructed and maintained in relationship, and that the relationship with the caregiver is crucial to the maintenance of personhood and the fostering of wellbeing in the person with dementia. For me this was the lightening strike. Gone was the grim determinism of the medical label; the label of “dementia” did not mean the person had “left the building”. Very importantly, it was clear that I and others working with and caring for people with dementia could indeed make a difference – and that difference was to help the person remain a person. It also reinforced my own experience in the dance sessions where seemingly “lost” people could reappear in all their vitality.

Then came more questions, how can we help people with dementia experience themselves as persons in their everyday lives, not just in the heightened moments of an arts experience? Over the years this has been accompanied by equally important questions: How can we persuade professional caregivers to move beyond the medical label and see the person. How can they be encouraged to cease to regard behaviour as a symptom of disease but rather look on it as an expression of a person’s needs and wishes? How can they be persuaded that acknowledging the person as a person is not an optional extra to the real work of physical care, that person-centred care is possible, desirable and ethical? These are the questions which continue to engage me now in my work as a dementia care trainer and facilitator.

In all these years of being with people with dementia, I have learnt so much about what it is to be a person. This is not because of any idealization of people with special needs. Absolutely not, people with dementia are as varied as everyone else in the community. Some are lovely and some are downright infuriating! The reason that I have learnt so much from people with dementia is that dementia by its very nature – as an assault on personhood – has brought me face to face with the very basics of being a person, stripped bare and uncluttered by all the things which make up our very Western, individualistic, cognitive-obsessed and materialistic lifestyle.



It has very much turned me towards relational concepts of self, that one becomes a person in relationship and continues to be a person in relationship. It has placed less emphasis on us as purely rational human beings, and highlighted the importance of feeling and emotion. It has pointed the way to not just talk of a mind/body connection (core to my work as a dance therapist), but rather of a totality. “One’s persona is in no way ‘localisable in the classical sense...it cannot be equated with any given ‘centre’, ‘system’, nexus,’ etc., but only with the intricate totality of the whole organism, in its ever-changing continuously modulated, afferent-efferent relations with the world.” (Sacks, 1991, footnote 116, p.239). Again, that word relationship comes up!

In taking a more and more relational perspective, I have come also to take into account the personhood of carers and families. “Person”-centred care is really about all-persons-in-relationship.

It has brought to the fore for me the constant striving of human beings to make sense of their lives, to find meaning even in the darkest moments and to be happy. As someone who rejected formalised religion, I have come to experience moments with people with dementia, which I can only describe as spiritual – a sense of heightened experience, connectedness and total immersion in the moment. I have witnessed again and again the need people have for this type of experience and the power of the arts to meet this need.

I’ve learnt a lot about myself and being with another human. Persons are more than the sum of all the facts we might know about them and the person can never be reduced to file notes on the ward, descriptions of past life, interests etc. The nature of dementia requires that we connect with the person as they are in the now. The present, especially for the person with dementia, can be a second by second thing and therefore this requires a heightened attention to who the person is right now in this moment. Taking this intense and challenging journey accompanying the person with dementia has been a huge learning experience, and has challenged me to be fully human myself.

I have also come to understand that human beings are about both continuity and change – difficult as the often extreme changes of dementia can be for both the person and for their families. How do we cope with such extremes – how can we find the continuities but also be able to work with the changes. Since Kitwood first mooted the possibility of “relative wellbeing” for people with dementia, we have moved on first to “wellbeing” and now to “flourishing” and “creativity” in dementia. People with dementia can experience positive change and growth.



Further, the person with dementia need no longer be viewed as a passive recipient of the efforts of others, but as an active partner in making sense of the changes in their lives. And now many people with dementia themselves are speaking up and asserting their personhood.

Richard Taylor, diagnosed with Alzheimer's at age 58, is a strong voice for people with dementia. In a presentation (3), he declares –

I AM A WHOLE PERSON, dammit. I am not half full. I am not half empty. I am a WHOLE PERSON.

He describes how he asked his friends why they no longer visited him after his diagnosis. “We don't know what to say” – Taylor's response “well, say hello...” Indeed! I am thankful to have had the wonderful, engaging modality of dance and movement, which helped me say that “hello”.

I end with one story from my work with people with dementia (3).

Mr J in the four years he spent at the nursing home was always one of the hardest of the residents to make contact with – except in the dance. While usually closed within himself, except in those moments when suspicion and distrust of staff actions would make him lash out, he seemed to open up in the dance sessions. He would watch, smile and then even get up to dance. The unit manager commented that Mr J “lived for the dance sessions”. Time

and dementia however took their toll and eventually Mr J became quite immobilised and even further shut away in himself. He would spend the day lying in a big armchair in rigid immobility staring into space or sleeping. However he would still come to dance and often, but not always, he might have eye contact, or raise a hand to hit the ball or take a staff member's hand. One day, I felt moved to sing to him Brahms Lullaby in German, not his native language, but he was likely to know the lullaby and something of the language.

It is probably a sentimental favourite of many Europeans. As I sang, he began to cry – I just held him and gently rocked with him. When we returned to the ward, his wife was there and Mr J said something to her in his native language. It was only later that I learned he had told his wife “I’ve been dancing with tears in my eyes”.

**Notes:**

- (1) I am using the more generic term of “dementia” here. The most well known of the dementias is of course Alzheimer’s Disease, but there are at least 60 other known causes of dementia.
- (2) An excerpt from Richard Taylor’s dvd “Be with me today” can be found on his website: <http://www.richardtaylorphd.com/>
- (3) Hill, H. (2009). *Invitation to the Dance* (2nd edition). Stirling, Scotland: University of Stirling Dementia Services Development Centre.

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[Heather Hill](#) – who has written 1 posts on [The Dasein Project](#).

Heather has worked for 25 years in dance therapy with many different groups of people, but in particular people with dementia. Her masters research, a phenomenological study of the experience of dance therapy for a person with dementia, convinced her of the value of the dance therapy experience in offering the person “a space to be herself”. This then led her to doing a PhD on person-centred care. In the meantime, she has also taught dance therapy, creative arts therapy and arts-based research. However, this year Heather made the decision to do what she wanted to do ever since she finished her doctorate in 2004: to utilize her training to change the culture of care in dementia. This year she started a new business “Quality Relationships, Quality Care” which has a strong focus on relationship, and draws on embodied, action and arts modalities to help care staff really take in and integrate new ways of being with people with dementia.

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