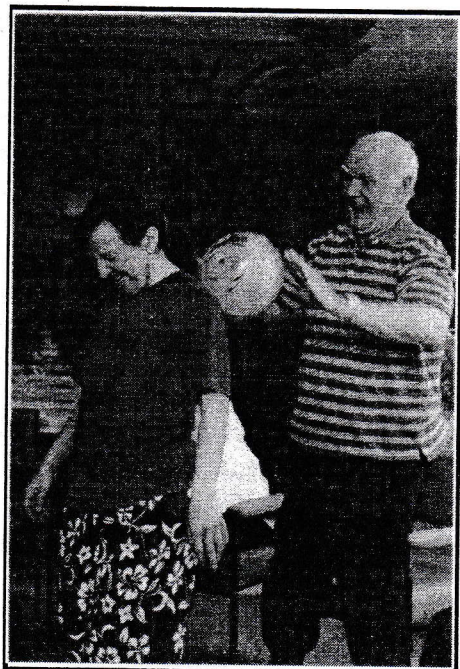


Dementia – Changing Perspectives



Heather Hill

When I began to work as a dance therapist in the field of dementia, I saw ways of caring which very much reflected the traditional model outlined here. This seemed very out of step with the philosophy and practice of dance therapy, so it was wonderful for me to come across person-centred care – a model of care which seemed much more philosophically attuned to my work. I now am doing a PhD in person-centred dementia care and trying to teach some of the skills and wisdom of dance and the arts to professional carers.

The traditional model of care in the field of dementia is grounded in our western model of health which in turn reflects our society and a culture influenced by philosophers like Descartes who espoused ideas such as: that mind and body are separate, that the mind is the core of the self (cogito, ergo sum -I think, therefore I am), that rational thought is the only valid form of thinking, that we live in a mechanistic universe of cause and effect, and that “objectivity” is the cornerstone of knowing.

The traditional, biomedical views of dementia are that:

- * Dementia is the result of disease which attacks the brain.
- * It is progressive and ultimately results in loss of personhood.
- * The behaviour of the person with dementia is a symptom of pathology.
- * Until such time as a cure is found, all that can be offered is physical care and management (control) of difficult or threatening behaviours.

* staff are the professionals and know what is best. Patients are the passive recipients of care.

However in the last 10 years or so psycho-social models have emerged, particularly thanks to the work of the late Professor Tom Kitwood (in England). Similar work has been carried out by Professor Elery Hamilton-Smith and Sally Garratt here in Australia.

Key aspects of psycho-social approaches to dementia can be summed up as follows:

- * While acknowledging the effects of brain pathology, it is important to recognise that the experience of dementia is affected by many other factors such as: personal history, personality, coping skills, culture, environment and relationship with carers.
- * The behaviour of the person is not merely a symptom of disease but is meaningful in terms of the person’s efforts to make sense of their new reality.
- * With personhood under threat, the responsibility of carers is to support the person’s own efforts (empower), help maintain personhood and help the person achieve a sense of wellbeing.
- * There is an emphasis on the openness of staff to the person with dementia - listening, empowering, working with *rather than* treating, managing, controlling.

Kitwood’s concept of personhood is essentially relational – it is through relationship that the person with dementia can maintain his or her personhood. Instead of “malignant social psychology (infantilizing, etc.), we can carry out “positive person work” which he lists as recognition, negotiation, collaboration, play, stimulation (working with the senses), celebration, relaxation, validation, holding, facilitation, offering opportunities for creating and giving. Person-centred care therefore requires that the carer is able to engage in a fully human way, which is flexible and sensitive to the person in the moment. Buckland (1995) concludes:

Person-centred care is not mechanical. We cannot diagnose a particular problem of dementia, and thus prescribe a certain action to treat the problem. It is more of an art, requiring imagination and creativity.

Diagnosis as Destiny – “Pointing the Bone”

Within the biomedical model, diagnosis is seen as determining the experience and course of a disease. In the case of dementia, it means a hopeless and inevitable decline in all areas of function, a descent into oblivion and a loss of self. While a diagnosis of dementia can

come as a relief for people who then at least have an answer to the troubling experiences they have been having, it can also have negative consequences. It can become a self-fulfilling prophecy and it can adversely affect relationships with family and others, who begin to interpret everything the person does in terms of the disease. The following is an extract from a presentation made by Christine Bryden and Morris Friedell, at the National Conference of the Alzheimer's Association in Canberra in 2001. Both have had dementia for a number of years and have been strong advocates for having the voices of people with dementia heard. – HH

The diagnosis of dementia is the confirmation of suspected losses, and has a toxic power analogous to that of "bone-pointing" in Aboriginal culture. It generates extreme fear of further loss. We experience a defeat of spirit and hope. The medical prognosis is believed – there is nothing that can be done, all that lies ahead is inevitable decline.

This is a further assault on our sense of self, in particular the dread of the future. We are experiencing existential fear, and a threat to fundamental self-object relations on a continuing basis. A key emotional reaction in dementia is "existential terror" (Cheston & Bender, 1999, p.155).

It is at this point that our psychic resources are important in how we will continue to experience this label of being a victim of dementia. Will we accept or deny it? Will our families accept or deny it?

- If our family accepts the diagnosis, adopting the role of 'carer', in this dysfunctional social context we exhibit learned helplessness. This augments our predisposition to experience the diagnosis as "bone-pointing".
- If our family denies the diagnosis, another dysfunctional social context arises – that of victim and 'denier'. We maintain a shell of normalcy, rather than deal with the deeper issues. We accept our family's covert message – dementia is too dreadful to be constructively dealt with.

They suggest that like other "survivors" of trauma, they and their families need a supportive environment ...

in which to be challenged in regard to our dysfunctional beliefs and defensive behaviours. Should we accept that we no longer have any neuro-plasticity – that we can no longer restore any function? Why do we rule out rehabilitation for dementia, yet consider it for strokes? Is this a psycho-social phenomenon that we – the victims and our carers, as well as professionals and the medical profession – are all captured by?

What if we could regain lost function? What if we could throw off the role of victim? What if we could stop

pretending, and address the challenge of dementia?....

With trembling hand, we are encouraged to open the door to a wider world of possibilities. No longer enclosed in our prison of being a helpless victim or hopeless pretender, we can find a new identity as a survivor. Our family is released from a roles as 'denier' or 'carer' and can walk alongside us as we rediscover who we can be with dementia.

Three overlapping phases of rehabilitation are recovery of function, validation of pain, and the discovery of a 'survivor mission' (Friedell 2000). Martin Luther King, Jr. spoke to black Americans who suffered from a "degenerating sense of nobodiness". We persons with dementia know what that's like. He inspired them to a mission.

If you will protest courageously and yet with dignity and Christian love, when the history books are written in future generations, the historians will have to pause and say: there lived a great people – a black people – who injected new meaning and dignity into the veins of civilisation.

Extract from the Conference Proceedings of the national Conference of the Alzheimer's Association "Together on a Journey", Canberra, March 2001. Reprinted with kind permission of the Alzheimer's Association ACT, tel. (02) 6254 5544.



Photographer: Rae Saleeba

RESOURCES:

On dementia:

Boden, C. (1998). Who will I be when I die? Melbourne: Harper Collins.

(An account of her personal experience of dementia.)

Buckland, S. (1995). Well-being, personality and residential care. In T. Kitwood & S. Benson (Eds.), The new culture of care (pp 30-34). London: Hawker Publications.

Cheston, R. & Bender, M. (1999). Understanding dementia: the man with the worried eyes. London: Jessica Kingsley.

Garratt, S. & Hamilton-Smith, E. (1995). (Eds.) Rethinking dementia: an Australian approach. Melbourne: Ausmed Publications.

Kitwood, T. (1997). Dementia reconsidered: the person comes first. Buckingham: Open University Press.

The Arts and Dementia

Hill, H. (2001) Invitation to the dance. Stirling: Stirling University.

Available at the Eltham Bookshop, Tel. 9439 8700.

Innes, A. & Hatfield, K. (Eds.) (2001). Healing arts therapies and person-centered dementia care. London: Jessica Kingsley Publishers.

Killick, J. (Ed.) (1997) You are words: Dementia poems. London: Hawker Publications.

John Killick, currently research fellow at Stirling, has worked extensively with people with dementia, listening to and writing down their words

Internet Resources

<http://www.stir.ac.uk/dsdc> It is definitely worth checking out the literature available from Stirling University's Dementia Services Development Centre, especially as they are doing a lot of work on dementia and communication through the arts.

<http://www.brad.ac.uk/acad/health/bdg.htm> This is the website of Bradford University Dementia Group, who also put out various publications and carry out research on dementia.

<http://www.basingbooks.com.au> Based in Sydney, Basing House Books have a wide range of books of publications both Australian and from overseas on aged care and on dementia (including some of the Stirling University range).

<http://www.DASNInternational.org> Website of the Dementia Advocacy and Support Network

<http://members.aol.com/MorrisFF/index.html> Morris Friedell's home page which contains several articles he has written on dementia.

