

We are pleased to reprint Dancing With Change and Adventure Not Dementia Club. Written by Heather Hill, these two articles were published in the Australian Journal of Dementia Care. They involve the use of dance as a metaphor and the application of the knowledge that a DM Therapist holds is used in a different context. As reported in Aus Moves (p.32), they provide us with yet another approach to DMT.

Dancing with change

Heather Hill

In the first of these two articles, Heather introduces the concept of dance as a model for creating a positive approach to supporting people with dementia and their family carers. It is based on the concept that the qualities required in dance – creativity, improvisation, awareness and the ability to adapt to change – also apply to dementia care

In our Western society, we tend to turn to scientific metaphors for guidance, explanation and solutions and so the metaphor of ‘fighting’ dementia has gained currency in recent years.

However, at the practical level of living with dementia, this is not necessarily a very helpful metaphor, and in a recent presentation to people with a diagnosis of dementia and their family members I chose to offer a different metaphor – ‘dancing with change’ – as a more positive and empowering concept.



Many of the skills and forms of awareness required in dance, such as the ability to adapt, improvise and appreciate the moment, are also useful for the families of a person with dementia

‘Dance’, in its broadest sense, suggests drawing on one’s own strengths, accommodating one’s weaknesses, being in the moment and working with what is, being flexible, being creative and being co-creative. Dance (unless you are doing a specific set of steps) has no roadmap – you make it up as you go along – and the landscape may indeed change each time you revisit it. Sometimes you end up in a dead end, other times it leads to unexpected moments of wonder.

My original presentation was prepared with couples in mind and in this article I also include family. However, it is important to point out the significance of relationships beyond families, namely friends and the wider community.

Diagnosis as the ‘pointing-bone’

“My life changed dramatically when I faced the shock of diagnosis. It feels like a curse when the doctor says, ‘You have dementia. There is no cure’. It’s like the pointing-bone of a traditional [Aboriginal] curse, and what is said often leads to a terrible depression.” – Christine Bryden (Bryden, Friedell 2001).

The pointing-bone is a traditional indigenous Australian artefact which is used in rituals of cursing to condemn a person to death. The tool is, in effect, a spiritual/psychological focus of fear, and the arbiter of a self-fulfilling prophecy. A diagnosis of dementia, with all its associated stigma and anticipations of grief, can act in the same way.

For some, the diagnosis, the label of dementia, comes as a relief. It helps to have an explanation for what has been inexplicable, and in our Western society a medical label is often what we feel we need. But it can also be a trap. From the moment of diagnosis a whole cascade of changes occurs. The wife or husband now becomes the carer and the person with dementia the cared for.

Suddenly the person with dementia is perceived to be incapable, possibly much more broadly than

is actually the case. Medical appointments become more frequent, and any activity the person with dementia participates in is now labelled therapy. Everything is scrutinised through the lens of dementia. Even walking ceases to be viewed as a normal activity – it is now ‘wandering’.

The carer can feel incapable, unsure how to respond to a spouse they have known for 40 years. Now they feel they need to check with those who ‘know’ (namely the medical professionals). Friends feel awkward and stay away, and the couple themselves find social situations hard to navigate. In other words, dementia becomes the focus of the couple’s life, with their relationship, relationships with others and every aspect of their lives disrupted and changed.

When I meet couples living with dementia I am often struck by the ‘disease’ in their relationship – the struggle to hold things together and the desire to keep things the same. I wonder if, in focusing on understandings of dementia-as-disease and dementia ‘management’, we place too little emphasis on the relational aspects and how we may best support couple and family relationships.

‘Fighting’ dementia may well be an apt metaphor for the battle between medical interventions and a disease, but it does not offer a vision for how people and their families can best navigate their way through dementia.

If the metaphor of dance is applied to the experience of dementia for the person and their family, then the work of supporting families may involve a greater focus on relationship and on skills in navigating change.

Personhood

While, to a greater or lesser extent, we dementia care professionals are aware of person-centred approaches, couples and families may be less so. Indeed they are likely to feel quite overwhelmed by the label of dementia and its connotations of pathology, victimhood and hopelessness. The carer/cared for roles suggest an inequality in the relationship, and while it is true that in one sense there is an increasing inequality as dementia progresses, I believe it is important to try husband/wife (or mother/son etc). This reinforces personhood.

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

PERSON.” – Richard Taylor, diagnosed age 58 with Alzheimer’s disease (Taylor 2007).

In our society, personhood is often defined by the capacity for reason, with much emphasis on verbal abilities, especially speech. This is a hangover from the Enlightenment period, where reason became paramount as a signifier of consciousness. However, cognitive neuroscientists such as Antonio Damasio (1994) are beginning to see that thinking is not limited to cognitive processes, that reason works in an integrated way with emotion and that human functioning is indeed a holistic process involving mind, body and feeling/emotion.

Personhood is more than reason and speech; it involves emotions, perception, senses and physicality. For both the person with dementia and their spouse and family, it is so important to emphasise ongoing personhood and to refocus on the strengths and competencies that still remain.

Most importantly, I believe, is for the family to realise that in a very important area, the absolute core of human interaction – the experience of feeling or emotion – the person remains very much present to the end. This, I believe, provides reinforcement to the possibilities of ‘keeping in touch’.

Contrary to the great Western myth of the strong individual, we are all in fact formed and developed through our relationships (Gergen 2009) and not by our solitary capacity for rational thought. We are persons-in-relationship. Define someone as being incompetent, and they will begin to live ‘down’ to the definition. Relationships and the perceptions of others are core to human health and well-being. For that reason, the quality of relationships will be crucial to how well or badly people live with dementia.

Change

Without minimising the impact of the major and uninvited changes which occur with dementia, it is important to remember that change is part of life. We all struggle with change, especially big changes, and we want to keep the known, the familiar and the pleasant constant in our lives. It is a human trait to seek continuity, but this can’t work with dementia, which is fundamentally a process of change. In fact, it doesn’t work in life in general. Time changes people and circumstances. Ultimately, we need to keep in touch with change and work with it.

It is of course easier for professionals to say that the best way to deal with the changes of dementia

is to accept and work with them, but a lot harder to do when the person involved is your parent, wife or husband. But this is the way one needs to go, I believe, if one is not to be torn further and further away from one's roots and the lived experience of those relationships. This is where, I think, Jane Crisp's (2004) idea of 'keeping in touch' can be helpful: *"It means continuing to be in contact with the other person and to interact positively with them. It can mean simply being there for them as a friendly presence as someone who cares. This is the essence of keeping in touch with anyone whether they have dementia or not."*

Crisp emphasises 'keeping in touch' – rather than trying to keep things the same – keeping in touch with the other, so you can move on together and find pleasure in each other's company. While there will be changes, *"What counts most is being in touch – still giving attention to and responding to each other – how ever simple or minimal the content of our interactions becomes"* (Crisp 2004).



This is about:

- Having the relationship – what happens between you – as the prime focus.
- Keeping in touch through and despite the changes.
- Keeping in touch with the past self as well as the present self.
- Keeping in touch for the long haul – looking after yourself (bearing in mind that the relationship involves two people).

The latter point is probably the hardest for family carers to acknowledge, but is an important one. The focus is not directed solely at the person with dementia, but rather looks to the health of the relationship.

Keeping in touch requires flexibility, being where you are in the moment, working with what's presented to you – new skills in some ways, but in other ways, not.

Couples, in particular, need to be reminded that they have done this to a greater or lesser extent all their lives; they have life experience to draw on as they deal with this new change. What's more, they have their relationship which does not suddenly become a stranger upon the diagnosis of dementia. Their job is to keep alive to this relationship and as with the best of relationships, keep in touch and adapt.

Beyond labels

There is no way to deny the impact of dementia on couples and families. But I think that while this new metaphor of 'dancing with change' offers no easy solutions, it does bring the focus to where I believe it should be – namely on supporting relationships as they are bent, stretched and at times over-stretched through change.

This support can take many forms. There is an educational component focusing on person-centred perspectives of dementia (personhood and relationship), but this needs to be supported not only by accepting these ideas on an intellectual level, but also embracing them at an experiential level. This is the challenge – to help families see beyond the label of dementia to the person and to retain a sense of relationship and partnership with the person throughout.

Many of the skills and forms of awareness required in dance are useful for the families of a person with dementia:

- Mindful presence – learning to be present to the other in the moment, but also present to one's self. This is about being able to respond to who the person is now, and it is also about self care.
- Flexibility – going with the flow and adapting, which links to the next point;
- Improvisation – working with what's there (rather than what you wish was there), while at the same time drawing on experience and skills built up over years.

- Quality of experience – appreciating the moment. Opening oneself to possibilities of joy, new discoveries, transformation. Another task for health professionals is to take off our expert hat and to draw out from families the skills, strengths and experience they have accumulated over the years and through multiple life changes. They already have many of the tools required to navigate change.

Christine Bryden, the author and advocate who was diagnosed with Alzheimer's disease at the age of 46, talks about how family often fall into a role of denier or carer (of a helpless victim), but also how they can reframe their place:

"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 roles as 'denier' or 'carer' and can walk alongside us as we rediscover who we can be with dementia" (Bryden, Friedell 2001).

'Dancing with change' suggests all of the above, but offers something more – it suggests the possibility of joy and transformation as we engage meaningfully with each other and with life!

References

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Dr Heather Hill is a facilitator/trainer in dementia care and has worked for 25 years in dance therapy and movement, in particular with people with dementia.

Pictures:

p. 35, Tomas Castelazo
p. 37, Ignas Kukenys

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