Tom Kitwood Memorial Address
2018

DEMENTIA RE-CONSIDERED, REVISITED
THE PERSON STILL COMES FIRST
Theory development: Tom Kitwood

- Person centred approaches to dementia care; 1989-1997 drawing on Martin Buber and Carl Rogers
- The enriched model of dementia
- Supporting personhood through the eradication of malignant social psychology and promotion of positive person work

Dementia reconsidered *Revisited*: the person still comes first

1. On being a person
2. Dementia as a psychiatric category
3. How personhood is undermined
4. Personhood maintained
5. The experience of dementia
6. Improving care: The next step forwards
7. The caring organisation
8. Requirements of a caregiver
9. The task of cultural transformation

1. Jan Dewing
2. Julian Hughes
3. Steven Sabat
4. Dawn Brooker
5. Keith Oliver & Reinhard Guss
6. Richard Cheston
7. John Keady & Ruth Elvish
8. Bob Woods
9. Claire Surr

Foreword by Christine Bryden
Additional material from Kate Swaffer
Photographs by Cathy Greenblat

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Video message from Christine Bryden
Well-being in Dementia Chapter 1

Well-being in dementia
Having dementia does not, in itself, entail a loss of personhood. These pictures all show people with a high level of well-being, despite the presence of cognitive impairment.

• The late Peter Ashley (front right) in 2010 receiving an honorary degree from University of Worcester for services to Dementia Advocacy.

Photo is owned by University of Worcester
Well-being in Dementia Chapter 1

Caption A resident in an Australian care home enjoying time with a staff member, a sleepy rabbit, and her own stuffed rabbit, a constant companion.

- Photograph by Cathy Greenblat
Maintaining personhood

When the physical needs have been met, this is the central task of dementia care. It involves enabling choice, the use of abilities, the expression of feelings, and living in the context of relationship.

As the last step of a visit to the Matisse Museum in Nice, participants were given sketching materials and invited to try to reproduce the artist's technique. Christiane was very proud of her results, with good reason.

Photograph by Cathy Greenblat
Maintaining personhood Chapter 4

At the end of a special luncheon for six residents of the Kingwood Silverado care community, Lois charmed Sabrina, the daughter of a staff member, by placing her hat on Sabrina's head.

Photograph by Cathy Greenblat
Co-production: chapter 5

- Keith and Reinhard writing together with a lap-top each

Photograph by Keith Oliver
Dementia care as interaction
Chapter 6

Dementia care as interaction
The ‘positive person work’ in dementia care is essentially that of interaction, according to each individual’s needs, personality and abilities. This work requires a high level of ‘free attention’ on the part of caregivers.

*Pat and Michal collaborating in a shared moment, touching a wood carving of great beauty in a library in Worcester, UK*

Photograph by Cathy Greenblat
Bhanumati frequently performs a finger ritual to ward off evil spirits and also to show that she is caring and loving to all the aides at the Nightingale day program in Bangalore, India.

Photograph by Cathy Greenblat
Julian Hughes

Dementia as a psychiatric category

• Was Kitwood fair to psychiatry?

• ‘And here, in comparison to conventional psychiatry, we may find an immeasurably richer conception of the healing of the mind’ (p.144).

• A ‘paradigm in disarray’
What’s wrong with Chapter 2?

- Error
- Assertions without good evidence
- Poor arguments
Error

• Homer *et al* (1988): 34% of the people they reviewed met the clinical or neuropsychological criteria for dementia but had no pathology in their brains post mortem
• Actual statistic seems to be 3.7%
• Homer *et al* pursuing good interdisciplinary science in a self-reflective and self-critical manner
• ‘Making a diagnosis of dementia in any individual case ... is a very difficult task. It is notorious that GPs, clinical psychologists, psychiatrists and neurologists tend to differ in their opinions’ (p.26)

• So the general diagnosis of dementia is never absolutely clear...’ (p. 27, emphasis added).
Poor arguments

• ‘Clearly, then, there is no possibility of Alzheimer’s or vascular dementia meeting the key criterion of a classical disease: that distinct pathological features should be present in all cases where the symptoms appear, and in none of the cases where they do not’ (p. 25).

• Consider: arthritis, non-cardiac chest pain, PTSD, and so on...

• Consider values-based practice
A paradigm in disarray


- 1997: Dementia Reconsidered

- 1997: Donepezil licensed in the UK
The uplands

• The broader view of the person
• The importance of the psychosocial environment and malignant social psychology
• Sabat (2001): Malignant positioning
• Sabat (2001): Defectology (what would Kitwood have made of MCI?)
So now...

• The debate is about citizenship

• And yet and yet ...
Keith Oliver

• Hope...
  ✓ Understanding
  ✓ Inspiration
  ✓ Learning
  ✓ Improved care
  ✓ Relationships
  ✓ Truth
  ✓ Kitwood flower is reality
• The Privilege of the Flower Chapter
• Relationship and Trust
• A multitude of possibilities and Services
• The post code lottery
Changes in use of Language

- Language affects thinking, experience, emotion
- The emergence of stories of coping and thriving
- Professional’s use of language, better lies?
- The erosion of “person centred care”
- A Kitwood Test for the future
Well-being at Work
Ruth Elvish
<table>
<thead>
<tr>
<th>Kitwood</th>
<th>Quote from staff using well-being service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisations should give people ‘permission’ to ask for support when they need it</td>
<td>“I think that has...been such a huge added bonus...having sessions that have been so easily accessible through work…”</td>
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<td></td>
<td>“It’s enabled me to have those discussions in a really open way, but...not with....a line manager, not with someone who has got a different agenda, really. It’s allowed me to be very vulnerable in a way that perhaps you can’t be in those other relationships.”</td>
</tr>
<tr>
<td>Kitwood</td>
<td>Quote from staff using well-being service</td>
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<tr>
<td>Staff need to understand their own scripts, and challenge them where necessary</td>
<td>“We talked a lot about the underlying....assumptions that I might have had...we call them...schema. You know, some of the key stories that I tell about myself. And so, we briefly put in a lot of work about where those stories have come from and how they might be impacting and also how I can deal with them on a day-to-day level...”</td>
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<td></td>
<td>“…she enabled me to do my job better, she enabled me to actually see things, to gain some confidence and to have an opportunity...”</td>
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“Among all the changes that have occurred, one fact stands out above all others. It is that men and women who have dementia have emerged from the places where they were hidden away; they have walked onto the stage of history, and begun to be regarded as persons in the full sense.” (Kitwood 1997)
The Inclusive Culture

Beyond being a full person to

A society where people living with dementia are full and equal citizens

The 3 Nations Working Group contribute their expertise and personal knowledge of dementia to society.

Photograph by Peter Paniccia
The inclusive culture

<table>
<thead>
<tr>
<th>New culture</th>
<th>Inclusive culture</th>
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<tbody>
<tr>
<td>Dementia should be seen as a disability</td>
<td>Those who live with dementia are full and equal citizens and included in all aspects of society.</td>
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<tr>
<td>How a person is affected depends crucially on the quality of care</td>
<td></td>
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<td>The people who possess the most reliable, valid and relevant knowledge ...</td>
<td>... people living with dementia and their family members</td>
</tr>
<tr>
<td>... are skilled and insightful practitioners of care.</td>
<td></td>
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<tr>
<td>The inclusive culture</td>
<td>New Culture</td>
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<tr>
<td>-----------------------</td>
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<tr>
<td>Via research there is a great deal that can be done ...</td>
<td>...through the amplification of human insight and skill.</td>
</tr>
<tr>
<td>In providing care for those with dementia ...</td>
<td>...caring is concerned primarily with the maintenance and enhancement of personhood.</td>
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The inclusive culture

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<tr>
<td>It is important</td>
<td>... the best and most successful approaches to including and empowering all those living with dementia to express their priorities, needs and wishes.</td>
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<tr>
<td>to have a clear</td>
<td>... a person’s abilities, tastes, interests, values, forms of spirituality.</td>
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<td>understanding of ...</td>
<td></td>
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<tr>
<td>Sustainability and</td>
<td>Our societal response needs to be able and willing to evolve rapidly based on what people tell us is needed. There is always room for improvement</td>
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<tr>
<td>change ...</td>
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The future ....

“While we have yet to achieve even the basics of Kitwood’s vision for a New Culture on widespread basis, our aspirations for what could be achieved have far surpassed this. What we must ensure is that we continue to strive to achieve our ambitions and continually renew our vision of what is possible.”

Keith Oliver and his wife Rosemary representing the case for persons living with dementia at the United Nations Committee on the Convention on the Rights of Persons with Disabilities in 2017 in Geneva, Switzerland

Photograph by Keith Oliver
Final words and acknowledgements

Thank-you to Tom Kitwood for writing such a marvellous book and to his family for giving permission for the second edition.

Thanks to all at the Journal of Dementia Care and UKDC for fanning the flames year on year.