Bridging the gap in Good Dementia Care
A question of leadership?

Copenhagen October 2012

Professor Dawn Brooker
Association for Dementia Studies
University of Worcester UK
Starting points

Thanks
Humility
Principles not prescription
Solidarity
From theory to practice to evidence
The Association for Dementia Studies at Worcester University

- Established 2009
- Aim to make a substantial contribution to building evidence-based practical ways of working with people living with dementia and their families that enables them to live well.
- Research, education, practice development and policy advice
Modern dementia care

The move from

The death that leaves the body behind

to

Living well with dementia
Professor Tom Kitwood, 1937-1998

- Person centred approaches to dementia care; 1989-1997
- “Dementia Reconsidered: the person comes first” 1997
- The enriched model of dementia
- Supporting personhood through the eradication of malignant social psychology
Person centred care & Personhood...

Person Centred Care are the processes by which we maintain the Personhood of those who have dementia.....

“Personhood is a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust....”

Kitwood, Dementia Reconsidered 1997
Kitwood’s concern for 2010

“It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 might be as bad as it was in 1970, except that it would be varnished by eloquent mission statements, and masked by fine buildings and glossy brochures”

Tom Kitwood Dementia Reconsidered (1997) p 133
The Sisyphean Task
Good dementia care

Dementia-ist society
Lack of resources
Lack of political will

Institutionalisation
Task centred care culture
Us and them divide

Lack of skills
Lack of leadership
Lack of clarity

Thanks to Paul Whitby for Sisyphus
Person centred care fit for VIPS

V = Values people
I = Individuals needs
P = Perspective of service user
S = Supportive social psychology
National Guidelines (NICE-SCIE) on Dementia 2006

- **V**alues and promotes the rights of the person
- **I**ndividualised care according to needs
- **P**erpective of the person with dementia
- **S**ocial environment enables the person to remain in relationship
Guiding Principles

• Do my actions show that I respect, value, and honour this person?

• Am I treating this person as a unique individual?

• Am I making a serious attempt to see my actions from the perspective of the person I am trying to help? How might my actions be interpreted by them?

• Do my actions help this person to feel socially confident and that they are not alone?
PCC: It’s what you do and it’s the way that you do it ...

V = *Values* people

I = *Individual’s needs*

P = *Perspective* of service user

S = *Supportive* social psychology

- A music group
- Aroma therapy session
- Helping someone eat
- Inserting a catheter
- Doing a cognitive assessment
The Person-Centred Care Provider who leads what?

<table>
<thead>
<tr>
<th>VALUING; The directors, senior team</th>
<th>INDIVIDUALISED; clinical leads</th>
</tr>
</thead>
<tbody>
<tr>
<td>V1 the vision is clear</td>
<td>I 1 care pathways and planning</td>
</tr>
<tr>
<td>V2 human resource management</td>
<td>I 2 regular reviews</td>
</tr>
<tr>
<td>V3 management ethos</td>
<td>I 3 personal possessions</td>
</tr>
<tr>
<td>V4 training &amp; staff development</td>
<td>I 4 individual preferences</td>
</tr>
<tr>
<td>V5 the service environments</td>
<td>I 5 life story work</td>
</tr>
<tr>
<td>V6 quality assurance, improvement &amp; governance</td>
<td>I 6 activity &amp; occupation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PERSPECTIVE; shift leaders</th>
<th>SOCIAL/PSYCHOLOGICAL; everyone</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1 skilled communication</td>
<td>S1 inclusion</td>
</tr>
<tr>
<td>P2 empathy, risk &amp; decisions</td>
<td>S2 respect</td>
</tr>
<tr>
<td>P3 physical environment managed</td>
<td>S3 warmth</td>
</tr>
<tr>
<td>P4 physical health needs</td>
<td>S4 validation</td>
</tr>
<tr>
<td>P5 challenging behaviour, BPSD</td>
<td>S5 enabling</td>
</tr>
<tr>
<td>P6 advocacy</td>
<td>S6 family &amp; community</td>
</tr>
</tbody>
</table>
www.carefitforvips.co.uk

Care fit for VIPS website
Question?

• Why do some homes provide good quality care whereas others do not?
The Sisyphean Task
Good dementia care

Dementia-ist society
Lack of resources
Lack of political will

Institutionalisation
Task centred care culture
Us and them divide

Lack of skills
Lack of leadership
Lack of clarity

Thanks to Paul Whitby for Sisyphus
Organisational Culture

• Organisational culture, (the assumptions, values and norms shared by and influencing how members of an organisation behave and interact) is argued to play an important role in shaping the care experience

• Often at a pre-conscious or outside conscious awareness, not written down but people who work in the care home know the rules
Care Home Organisations Implementing Cultures of Excellence (CHOICE)

Examining the relationship between organisational culture and the quality of care
Anne Killett, Diane Burns, Dawn Brooker, Jenny La Fontaine, Isabelle Latham, Alison Bowes, Michael Wilson, Nick Jenkins, Fiona Kelly, Martin O’Neill and Heather Strange
Acknowledgements

This research is funded through the PANICOA programme by the Department of Health and Comic Relief. The views expressed in this presentation are those of the authors and do not reflect those of the Department of Health or Comic Relief.

With special thanks to:
• The care homes (including residents, relatives, visitors and staff) who volunteered to take part the project
11 in-depth case studies

- PIECE-dem observational framework gave detail of care experience of residents with advanced dementia/complex needs.

- Ethnographic data collection (interviews, observations and documents/artefacts) answered questions from PIECE-dem.

- Each case study analysed to identify key practices and cultural elements influencing care experiences.

- Cross case analysis to compare and contrast case studies. Identify common practices and cultural elements.
Findings: Care experiences

In the 11 homes we found examples of:

• Homes providing excellent care
  Consistently inspiring, creative, and sensitive approaches to residents

• Homes working hard to provide good care but...
  Examples of impoverished care:
  - Little engagement for long periods
  - Neglectful practices
  - Insensitive support
Findings: relationship to culture

Positive care experience was facilitated by
- Shared norms of practice, shared values and assumptions about care delivery
- Similar aspects of culture carried out at different levels
- Poor care experiences were unusual and infrequent

Poor care experience occurred when
- Lack of shared values and assumptions and inconsistent norms of practice
- Fragmentation of culture
- Positive care experiences dependent on individual staff action

University of Worcester
Managers ensure external pressures do not have negative impact on care delivery.

A sense of community between all involved in the care home.

Staff empowered to take responsibility for resident well-being through active management processes.

Shared purpose in providing the best person-centred care.

Norms of care:

- Openness to change for the benefit of residents
- Using the care home environment for the benefit of residents
- Person-centred activity and engagement is integral to care work

Person-centred activity and engagement is integral to care work.
In a positive culture...

Beliefs and values
• Shared purpose in providing the best person-centred care
• A sense of community between all involved in the care home
• Staff are empowered to take responsibility for resident well-being through active management processes
• Managers ensure that external pressures do not have a negative impact on care delivery

Norms of care
• Openness to change for the benefit of residents
• Using the care home environment for the benefit of residents
• Person-centred activity and engagement is integral to care work
Key beliefs & values care home leaders

(1)

• All who live here have a life worth living. I am open to change and value staff who are open to this.

• The function of this home is to help residents to feel relaxed, at home, that they are connected to others, they are cared about, and comfortable.

• Person-centred activity and engagement is integral to care work.
Key beliefs & values care home leaders (2)

• I value staff who act in the best interest of residents and I will support them in doing this.

• All who work here have a part to play and I value their contribution. I believe it’s important that I look after them.

• I welcome families and friends into this home and want them to feel at home here too.
Key behaviour of leaders (1)

• Clearly articulates the purpose of the home and help all involved share the vision.
• Clear on staff actions that are consistent with this vision.
• Reinforce and praise actions that promote best interests of residents
• Do things that help create a sense of shared community between all involved in the care home, staff, residents and visitors.
• Help all people feel that they belong.
Key Behaviour of leaders (2)...

- Demonstrate and model commitment to putting resident needs as the top priority
- Ensure staff are empowered to do this on a day-to-day basis.
- Present & hands-on management style
- Create an environment where external pressures such as inspections and paperwork do not have a negative impact on care delivery.
Norms of practice for staff...

Norms of care

• I am on the lookout for ways to improve the quality of my residents' lives. I put the needs of the residents first and act in their best interests.

• I use the care home environment and its facilities for the benefit of residents. I help them feel relaxed, cared for and not alone.

• Resident activity and engagement is part of my job. I don’t wait for an activity coordinator to help residents engage in life.
### The Person-Centred Care Provider who leads what?

<table>
<thead>
<tr>
<th>VALUING; The directors, senior team</th>
<th>INDIVIDUALISED; clinical leads</th>
</tr>
</thead>
<tbody>
<tr>
<td>V1 the vision is clear</td>
<td>I1 care pathways and planning</td>
</tr>
<tr>
<td>V2 human resource management</td>
<td>I2 regular reviews</td>
</tr>
<tr>
<td>V3 management ethos</td>
<td>I3 personal possessions</td>
</tr>
<tr>
<td>V4 training &amp; staff development</td>
<td>I4 individual preferences</td>
</tr>
<tr>
<td>V5 the service environments</td>
<td>I5 life story work</td>
</tr>
<tr>
<td>V6 quality assurance, improvement &amp; governance</td>
<td>I6 activity &amp; occupation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PERSPECTIVE; shift leaders</th>
<th>SOCIAL/PSYCHOLOGICAL; everyone</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1 skilled communication</td>
<td>S1 inclusion</td>
</tr>
<tr>
<td>P2 empathy, risk &amp; decisions</td>
<td>S2 respect</td>
</tr>
<tr>
<td>P3 physical environment managed</td>
<td>S3 warmth</td>
</tr>
<tr>
<td>P4 physical health needs</td>
<td>S4 validation</td>
</tr>
<tr>
<td>P5 challenging behaviour, BPSD</td>
<td>S5 enabling</td>
</tr>
<tr>
<td>P6 advocacy</td>
<td>S6 family &amp; community</td>
</tr>
</tbody>
</table>
“all needs, no mobility, not eating”

6 days after admission to a person centred care home.....

Mrs May Williams, Lady Forester Home
“all needs, no mobility, not eating”

1 month later – baking

Mrs May Williams, Lady Forester Home
“all needs, no mobility, not eating”

1 month later – baking

Mrs May Williams, Lady Forester Home
“all needs, no mobility, not eating”

6 weeks later – Italian meal

.....
“all needs, no mobility, not eating”

6 weeks later
tea and
teddy
“all needs, no mobility, not eating”

2 months later – head massage.
“all needs, no mobility, not eating”

2 months later – old skills returning.....
“all needs, no mobility, not eating”

2 months later – silk scarves.....
“all needs, no mobility, not eating”

3 months later — dancing to music....
“all needs, no mobility, not eating”

3 months later Mexican celebration
Interventions to reduce BPSD for May Williams

- **Interventions**: Person centred animal therapy, baking, eating, knitting, teddy, dressing up, silk scarves, head massage, dancing, pain relief
- **Outcomes**: Alive, weight gain, happy, active, having fun, no BPSD
Thank you for listening!

Professor Dawn Brooker
University of Worcester
Association for Dementia Studies
d.brooker@worc.ac.uk

http://www.worc.ac.uk/discover/association-for-dementia-studies.html