Dementia Care in the 21st Century: WE CAN DO BETTER

Dr Sam Davis
Applied Gerontology
College of Nursing & Health Sciences
Cultural Hegemony

Our tacit agreement with the way that things are…

- the process of socialisation
- our experiences with social institutions,
- our exposure to cultural narratives and imagery, and
- how norms surround and inform our everyday lives
Disease to person focus

- Dementia
- *I’m Still Me*
  - Purposeful living
  - Meaningful relationship
    - Living with dementia
    - Living beyond diagnosis
    - Stigma elimination
    - Positivity
    - Challenging
    - Engagement
  - Acceptance
  - Respect
  - Connection
  - Family
  - Journey
  - Free
  - Enjoy life now
  - Integrated wholeness
  - Changing
The nature of dementia care

- Limited exposure to/use of resident life stories
- Lack of PC leadership
- Lack of understanding personhood
- Lack of staff empowerment
- High levels of unmet need
- Staff less likely to enjoy work

Institutional Dominance
## National Australian project data

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal disruption</td>
<td>68.3</td>
</tr>
<tr>
<td>Physical aggression</td>
<td>32.0</td>
</tr>
<tr>
<td>Repetitive questions/actions</td>
<td>80.4</td>
</tr>
<tr>
<td>Resistiveness to personal care</td>
<td>68.4</td>
</tr>
<tr>
<td>Sexually inappropriate behaviour</td>
<td>13.00</td>
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<tr>
<td>Refusal to accept service</td>
<td>20.7</td>
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<tr>
<td>Problems with eating</td>
<td>60.6</td>
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<tr>
<td>Socially inappropriate behaviour</td>
<td>32.2</td>
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<tr>
<td>Wandering or intrusiveness</td>
<td>72.3</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>69.0</td>
</tr>
</tbody>
</table>
## What makes environments inadequate?

### Physical Environments
- Inadequate lighting
- Nursing stations
- Inappropriate furniture arrangement
- Lack of opportunities for spontaneous activities
- Inadequate walking pathways
- Poor/inappropriate use of colour & colour contrast
- Unsafe/unused garden areas
- Excessive noise levels
- ‘institutional’/inadequate signage
- Poor cueing/orientation

### Social Environments
- Task-oriented approach to care
- Poor overall knowledge of dementia
- Staff lack confidence in dementia care
- Misconceptions about care approaches
- Prioritising risk minimisation
- Staff at care-face have least empowerment
- Socio-emotional caring given low priority
- Poor communication
Social Institutions?
Language of ageing & dementia

Sensitivity to/awareness of appropriate language related to ageing and dementia largely disregarded
If we don’t change the language….. “we will never have dementia friendly communities, or reduce the stigma and discrimination, nor the provision of good care. It is the same as the disability community ‘demanding’ words like retard and cripple not be used 30 years ago.” Kate Swaffer

…… language can hold us back from essential learning and growing. It can reinforce our prejudices and confine us within our limitations.” John Killick (Dementia Positive)
Language & dementia care

Communication efficiency

George can’t brush his teeth

Put the toothpaste on the brush
Give the brush to George
George can then brush his teeth

Communication effectiveness

Sundowner

‘Feeds’

Toileting

“Manage”

‘Darl’
The influence of language

- Perpetuates stigma and discrimination
- Violates the rights of people with dementia as citizens
- Undermines personhood
- Generates isolation
- Frames the “experience of dementia” in the negative
Organisational culture

• it is where we have our roots and where we absorb our nourishment….soil (Brooker)
How do those involved experience dementia?
People with dementia

Study from Dementia Australia:

- 59% thought that people avoided spending time with them because of their diagnosis of dementia;
- 41% wished that they had more social contact with people in the community;
- 57% indicated that they are afraid of becoming lost;
- 48% said that they had difficulty communicating with staff in stores;

Stigma    Self-esteem    Agency
Family care partners: What the evidence says

- Knowledge/attitudes influences care partners' appraisal and reactions
- Knowledge often found in ad hoc way / volume of info can be overwhelming
- Care partners can find it difficult to integrate aspects of dementia into their understanding
- Rarely considered a terminal condition
- Unprepared for diversity of issues
How does that translate to experience of dementia?

Carers also share the lived experience of dementia

“The parent that you had is not there”

“She is the shell of a person”

“He was no longer an adult”

“They become empty”

“I feel very lucky to have this time with my mom”

“We know what valuing uniqueness and personhood is because we lived it with Pops - every person needs to be respected for who they are and the person they have always been”

(Katrina Hennell)
Healthcare Professionals Say...

- time, resources and a lack of knowledge as barriers they experience working with people with dementia

**Community setting:**
- rely on building trusting relationships to facilitate appropriate support services to enable ongoing community living
- emotional struggle - particularly in relation to decisions that impact on the independence of the person with dementia

**Acute setting:**
- often provide care with good intentions but in depersonalising ways
- lack of confidence/competence
Care home staff say…..

• Inadequately prepared for caring for people with dementia
• Role is physically and emotionally demanding
• Feel rushed by facility routines / Feel rushed by others that they work with
• Struggle to meet demand of organisation / needs of people with dementia
• Lack of recognition/acknowledgement (often a result of poor communication and negative feedback)
• Value the close relationships developed with people with dementia
• These relationships shape their experiences / kept them coming to work
Don't worry! I've done this hundreds of times!

Experience can just mean making the same mistake with increasing confidence.

- Barton

Where to from here?
Often forgotten……from Kitwood

Four global states (Based on 12 indicators of relative well-being):
• The sense of personal worth & self-esteem
• Sense of agency & ability to control person life in a meaningful way
• Sense of social confidence & having something to offer socially
• Sense of hope & relative freedom from anxiety

Senses Framework
• Security
• Belonging
• Continuity
• Purpose
• Achievement
• Significance

Experiential Pathway
• Identity
• Connectedness
• Autonomy
• Security
• Meaning
• Growth
• Joy

By us, for us
• Being me
• Being with
• Seeking freedom
• Finding balance
• Making a difference
• Growing & developing
• Having fun
“Dementia is a shift in the way a person experiences the world around her/him”

We can all do something

- Look for the positive first
- Be conscious of what you are saying
- Be conscious of what you are doing
- Be reflective
- New goal – well being!
- Positive person work

- Need to listen to the true “experts”
- “behaviours” are expressions of distress
- Abandon the assumption of ‘incapacity’
- Embrace ‘a negotiated risk strategy that promotes engagement & autonomy
- Be aware of the differing perspectives of the people involved
Contact details:

Dr Sam Davis
Email: sam.davis@flinders.edu.au