

# **Dementia Care in the 21<sup>st</sup> Century: WE CAN DO BETTER**

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**Flinders**  
UNIVERSITY

inspiring achievement

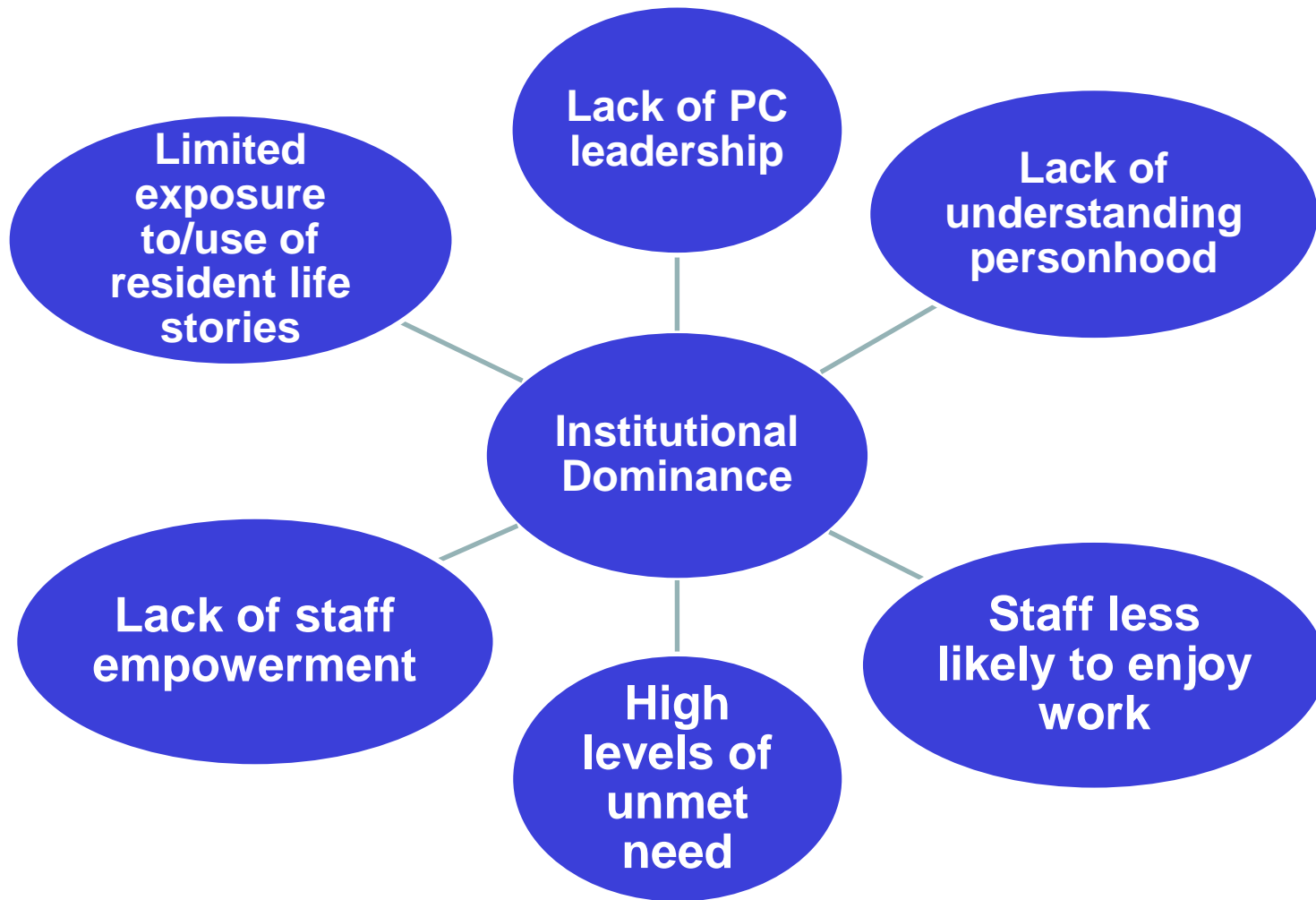
# Cultural Hegemony

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



# The nature of dementia care



# National Australian project data

Verbal disruption	68.3
Physical aggression	32.0
Repetitive questions/actions	80.4
<b>Resistiveness to personal care</b>	<b>68.4</b>
Sexually inappropriate behaviour	13.00
Refusal to accept service	20.7
Problems with eating	60.6
Socially inappropriate behaviour	32.2
Wandering or intrusiveness	72.3
Sleep disturbances	69.0

# 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

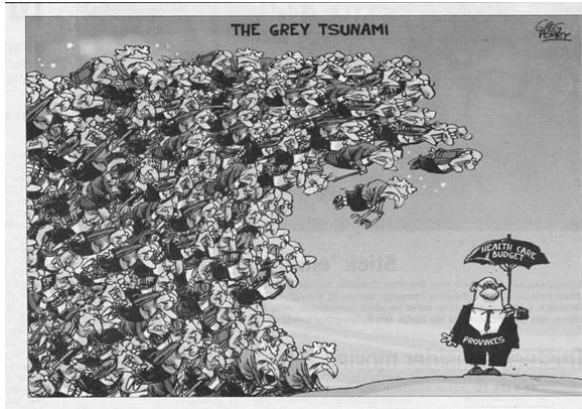
## Social Environments

- 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



## The Dementia Tsunami



Sensitivity to/awareness of appropriate language related to ageing and dementia largely disregarded



# Language Matters

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



**'Feeds'**      **Sundowner**  
**Toileting**  
**"Manage"**      **'Darl'**

Communication efficiency

*George can't brush his teeth*

Communication effectiveness

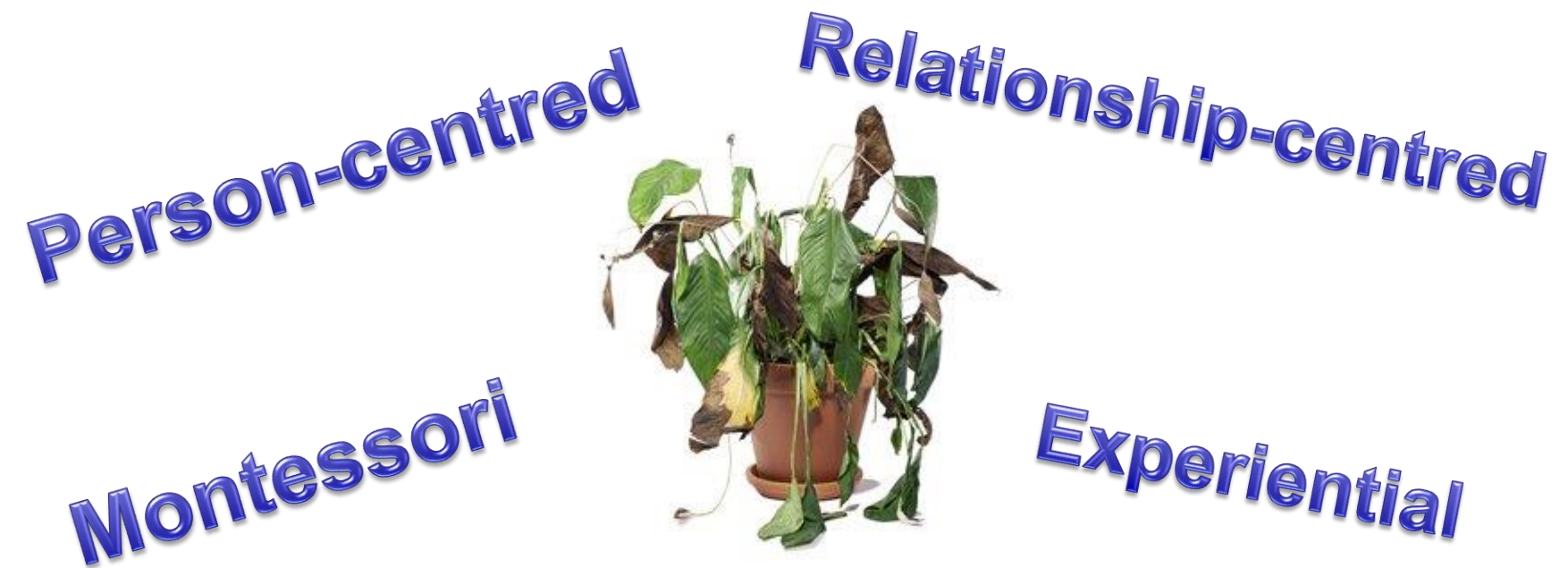
*Put the toothpaste on the brush  
Give the brush to George  
George can then brush his teeth*

# 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

# 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”***

Power, G. A., & Taylor, R. (2014). *Dementia beyond disease: Enhancing well-being*. Health Professions Press, Incorporated. p 19

# 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



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