

UTSPEAKS

THE HUMAN TOUCH

2 September 2010

**UTS: NURSING, MIDWIFERY
& HEALTH** THINK.CHANGE.DO

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The Human Touch

Is too much procedure and too
little care making life unbearable
for people with dementia?

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Outline of Presentation

- The Nature of Dementia
- Interpretation of Behaviour
- Common/usual Responses to Behaviour
- The Theory of Person-Centred Care (PCC)
- Results of PCC Research
- Reflections/conclusions—and some helpful tips

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**Evidence-based
models of care**

**...bring a
message of
HOPE amidst
the devastating
effects of
dementia.**

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The nature of dementia

- A variety of conditions with cognitive features
- Decline in two or more mental abilities, including memory, learning, orientation and attention
- Deterioration in at least one intellectual skill, including abstraction, judgement, comprehension, language and calculation
- Loosening of emotional control and/or personality change
- Difficulties in family, social and work functioning

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Impact on the person's sense of identity

- characterised by disconnectedness, along with altered self-perception, awareness and response
- may lead to disorientation, apprehension, distress, anxiety, depression, ambivalence, elation, withdrawal, perseveration
- these experiences and feelings are often expressed through behaviour, such as agitation and apathy

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Impact on carers, family...

- Sense of hopelessness
- Sense of loss of the person they knew
- Distress
- Burnout
- Irritation and anger
- Ill health

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Interpretation of behaviour

- How behaviour is interpreted will determine the response of other people.
- People live in a relational world.
- Responses of others to the person with dementia will impact on behaviour.
- When behaviour not understood as communication then quality of social interactions decreases.

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- A man with dementia is sitting in his room shouting incessantly
 - One person sees ‘verbal aggression’; reaches for the medications and eventually there is welcome silence – for now!
 - **Another sees boredom, knows he loved the Lions – puts his video of his favorite game on and his scarf on his lap. He always ate a meat pie and drank beer at the footy - so he needs some now to complete the moment.**

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- A woman with dementia hits the staff whenever they assist her with Activities of Daily Living
 - One sees ‘aggression’
 - **The other sees unrelieved pain made worse on movement.**
- A Man touches the nurse’s breasts in the shower
 - One sees sexually inappropriate behaviour
 - **Another sees a man who only ever showered with his wife and is behaving ‘normally’ according to his cues.**

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How would you feel if...

- 1.You are sick and lying in bed, but no-one is around to help you to go to the toilet, and so you wet the bed?
- 2.You are feeling really angry about something, but nobody around you will take your grievance seriously and they keep telling everything is fine?
- 3.You are asleep in your chair at home when suddenly you are woken by a person you have never seen before trying to undress you?
- 4.You are feeling bored and restless at home so you decide to go for a walk. But you find your front door has been locked and a stranger appears and tells you to go and sit down?

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- Feelings are universal, although their expression can be cultural.
- People with dementia remain able to feel.
- Although their emotional reactions and responses may be exaggerated they are usually appropriate to the situation...as they are experiencing it.
- Engaging on an emotional level can be comforting in and of itself.

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One view of dementia

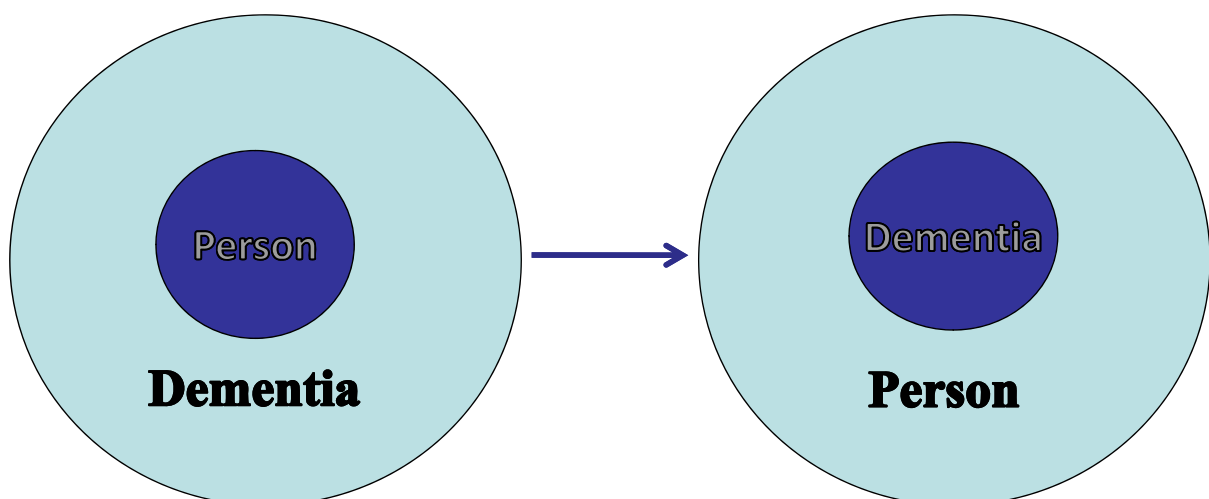
- Traditional constructions of dementia focused on neurodegenerative changes and that 'which is lost' through the illness.
- There is a belief that the 'self' is gradually lost in a dementing illness.
- This leads to a 'social death' whereby people are treated as if they are not there.

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Our experiences of common care practices

- **DISTRACTING** and/or **IGNORING** the person
- **Little or no attempt to ENGAGE** with the person's feelings and needs
- **DISBELIEF** that care practices contribute to distress and problematic behaviours
- **NO REALISATION** that care environment can lead to ill-being and problematic behaviour
- **LITTLE** attempt to draw on the person's unique profile in care planning.

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A typical scenario in residential care?

- Con Soulos reluctantly transferred to his new “office” accommodation and having trouble settling in
- Con guards his “office”, refusing staff entry
- Con attacks staff who try to provide personal care, especially the younger ones who he believes have no manners, are bossy and have no right to undress him
- The staff are so afraid of his anger and aggression they tend to avoid him and his care needs are being neglected
- Con is so debilitated by his need to remain vigilant against intruders he is losing weight and in a constant state of anxiety

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How can staff prevent Con’s aggression & reduce incidences?

1. Continue to keep others away from his “office” area?
2. Employ a consultant to teach selected staff how to care for him in a safe way?
3. Develop policies and procedures that staff must adhere to in all interactions with Con?
4. Ask Con’s wife, or only a few staff, to shower and attend other aspects of personal care each day?

While some of these approaches might help for a while, they will not stop Con from being aggressive to anyone he believes is encroaching on his territory, or insulting him.

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Is this an issue of concern in older age?

- Olive Beach moved to the aged care home 6 months ago following a stroke which left her unable to walk, use the right side of her body, speak clearly, and self-care.
- She has become socially withdrawn, unhappy, critical of staff, resistant when care and social activities are offered, and lost the desire to eat
- She constantly talks about wanting to be left alone and occasionally, to let her die.

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What can staff do to try to help Olive?

1. Ask Olive not to talk about death?
2. Ignore any mention of death?
3. Turn the subject to something more cheerful?
4. Remind Olive she has a loving family, friends, a lot to live for?
5. Try to distract her with activities or care?

None of these responses will help Olive to express her feelings, acknowledge her personhood, take her situation seriously, or give her any sense of hope for a brighter future

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What matters to the person with dementia?

- A sense of security-feeling safe
- A sense of continuity- experiencing links between the past, present and the future
- A sense of belonging- having a “place”
- A sense of purpose- having direction
- A sense of fulfilment- feeling of getting somewhere meaningful
- A sense of significance- feeling you matter

(Kitwood 1993/7)

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Psychosocial Theory of Personhood in Dementia (Kitwood 1993)

- **Derived from Roger's Person-Centred Therapy** - client is provided with unconditional positive regard in all therapeutic encounters
- **Proposition**- the distinctive psychosocial environment surrounding the person, including care and communication, can lead to an increase or reduction of 'personhood'
- **Personhood**- involves feelings, action, belonging, attachment to others, identity, and achieving one's potential
- If the **quality of interactions** is not good at a psychological level the person with dementia will move downwards into some stage of enduring ill-being, a situation where personhood cannot be expressed

Improving life for Con

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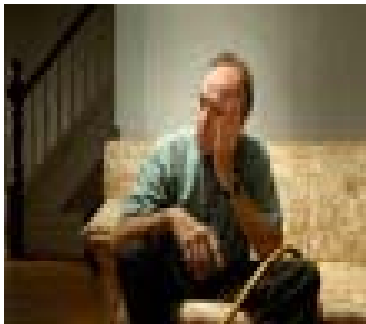
1. Consult with Con's wife for advice
2. Greet Con respectfully using his surname
3. Explain what is required, ask permission to enter 'his office'
4. Allow choice for all activities
5. Use active listening, smiles, warmth
6. Provide thanks and praise assistance
7. Invite Con and his wife to social activities
8. Invite Con to maintain valued CEO role

Improving life for Olive

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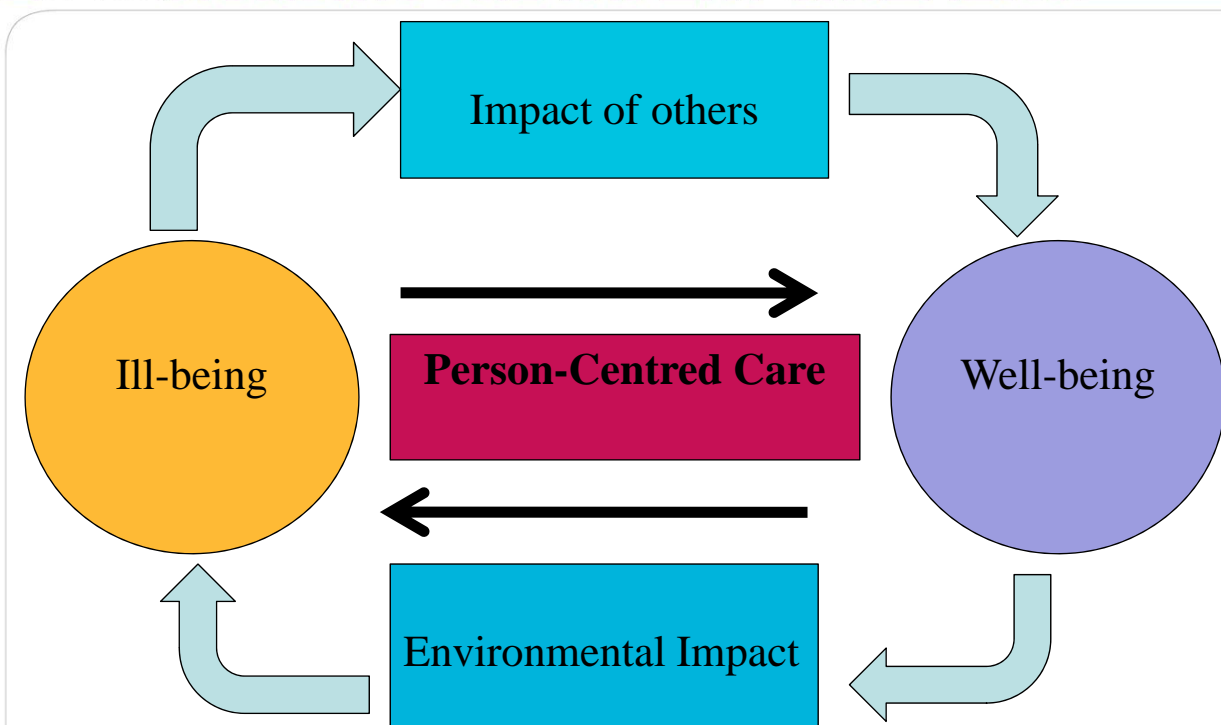
1. Listen to Olive, show empathy for her feelings
2. Ask Olive what she would like to do before dying
3. Managers encourage & support staff's involvement in fulfilling Olive's wishes
4. Staff and family assist Olive to achieve wishes
5. Staff, residents, visitors recognise Olive's talent and success
6. Staff support Olive to help other residents

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Central to providing person-centred care is looking beyond the brain damage to acknowledge, value and enable the uniqueness of each person, his/her previous personality, biography, achievements, values, preferences and life story

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**UTS Person-Centred Program of Research
CADRES, PerCEN, EN-ABLE**



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Caring for aged dementia care residents study (CADRES)

Grant agency:

The Australian Health Ministers Priority Research Grant,
administered by the NHMRC

In-Kind support:

UTS, UNSW, SESIAHS, 15 aged care services across Sydney, NSW

Project Manager

Yun-Hee Jeon-USyd

Research Team:

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Research Team Assistants:

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Statisticians:

Georgina Luscombe (USyd), Dr Patsy Kenny (UTS-CHERE)

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- ❖ **Randomised controlled trial**, two year pre/post-test/follow-up design, 5 Person Centred Care (PCC) treatment sites, 5 Dementia Care Mapping (DCM) treatment sites, 5 control sites (Usual Care, UC)
- ❖ **Hypotheses- Compared with DCM and UC, PCC will:**
 1. reduce behaviours, accidents, injuries, hospitalisations, psychotropic medicines
 2. improve well-being/quality of life
 3. improve quality of care
 4. be cost effective

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Demographics, clinical data, dependency- RCS

Dementia staging- FAST, GDS

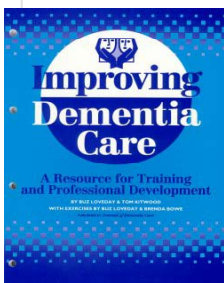
Behaviour incidence & severity- CMAI, NPI

Quality of life- QUALID, DCM-WIB scores

Accidents/injuries/hospitalisation/treatment –
behaviour

Care quality- QUIS, DCM- PE, PD scores,
physical restraint, psychotropic medications

Economic analysis

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Improving Dementia Care: A Resource for Training and
Professional Development. (1998)
Loveday, B., Bowe, B. and Kitwood, T.

PCC

2 day PCC training for 2 staff x 5 PCC sites
6 hours x 2 site visits direct supervision/care planning
Assistance with PCC care planning for selected residents
Ongoing telephone support for staff

DCM

5 day DCM training and exam for 2 staff x 5 DCM sites
8 hours of DCM observations for all recruited residents
Feedback of DCM scores and recommended changes in care to
all staff/managers, assistance with PCC care planning
Ongoing telephone support for staff

UC usual care

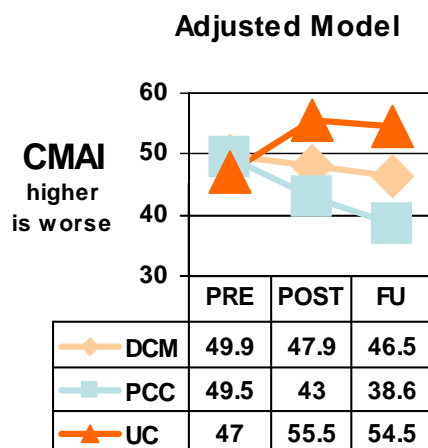
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PCC and DCM training/support focus

1. Pay attention to the person's feelings, not behaviour
2. Acknowledge the person's perception of their own reality- know when/how to draw them into your reality if relevant
3. Attend to the person's total needs
4. Focus on well-being in all interactions and relationships
5. Help the person to maintain meaningful function
6. Create an enriched environment
7. Avoid triggers for distress

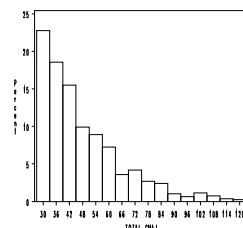
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Effect on Agitation (CMAI)



Full scale range: 29-203

Obs range: 29 – 119



P values

Tm't x tm 0.0013

Time trends PCC 0.0037

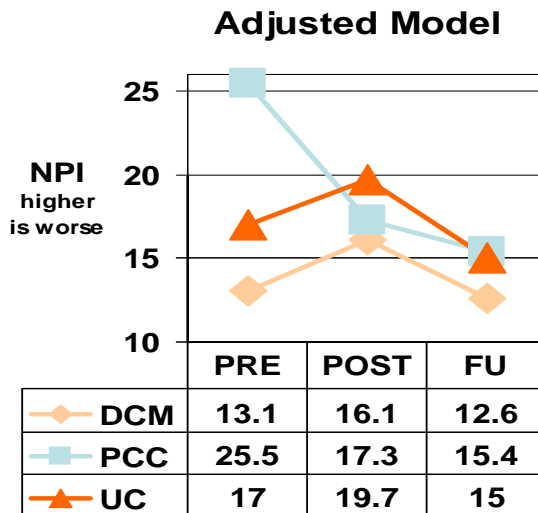
DCM 0.026

SE (means) ~ 5.2, CI +/- ~10

PCC Significant group by time interaction

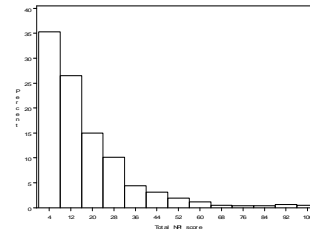
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Effect on psychological/psychiatric symptoms (NPI)



Full scale range: 0-144

Obs range: 29 – 102



P values

Time 0.12
 Tm't x time 0.14
 Time trend PCC 0.015

SE ~ 4.5 (adj), CI +/- ~ 9

No significant group or time effects overall, but...

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Psychological/psychiatric symptoms - all 12 domains NPI

Statistically significant effects (0.015)

Appetite & eating disorders, disinhibitions, sleep

Borderline effects

NS for Group, Time & Grp-by-Time, but $p < 0.1$ for time trends

PCC improved over time

Delusions ($p=0.04$), anxiety ($p=0.07$), irritability/lability ($p=0.09$)

DCM improved at POST, but declined over time

elation/euphoria ($p=0.02$)

UC improved over time

apathy/indifference ($p=0.09$)

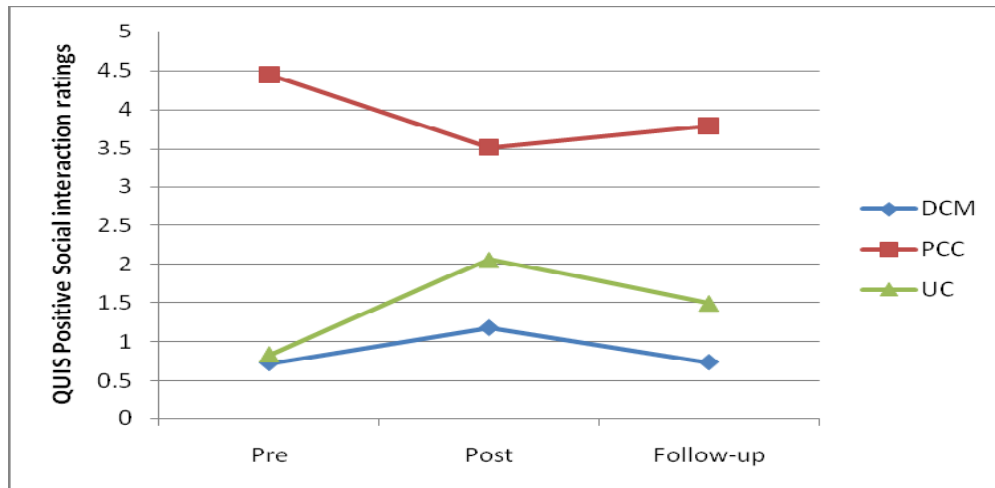
No effect

hallucinations, agitation/aggression, depression/dysphoria, aberrant motor behaviour

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Effect on CARE QUALITY – QUIS Positive Social ratings

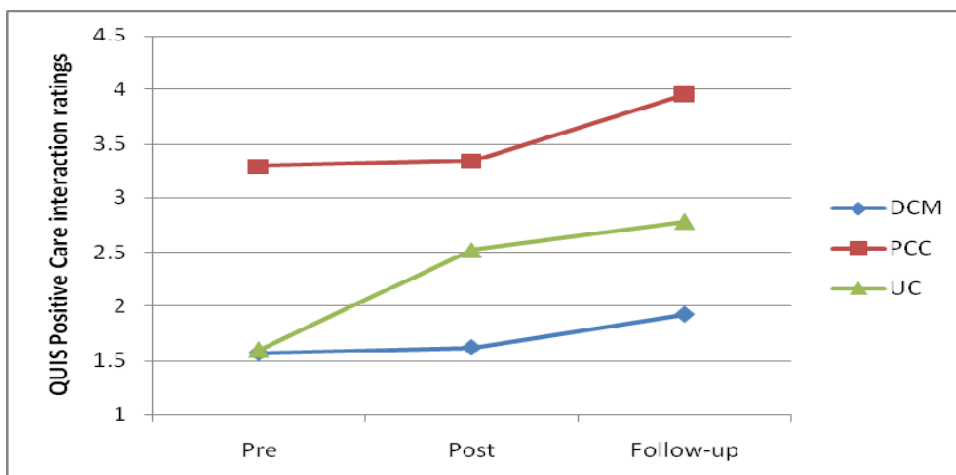
Significant overall effect of group ($p = 0.001$) but not of time ($p = 0.56$), nor group by time interaction ($p = 0.08$) (adjusted).



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Effect on care quality Positive Care ratings - QUIS

Non- significant contrast between pre and post-test



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Outcomes of PCC for residents

Statistically significant improvement

1. Incidence of agitation, anxiety, sleep, eating, disinhibition
2. Incidence of falls
3. Well-being (DCM-WIB scores)
4. Care quality - social conversation, positive communication in care events

Non-statistically significant improvement

1. Quality of life scores (QUALID)
2. Care quality- physical care
3. Recreation activity- dose
4. Physical restraint use

No change

1. Psychiatric symptoms, eg hallucinations, severe aggression
2. Hospitalisation rates
3. Psychotropic medication use

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Implications for health services

Organisation

focus primarily on the person and their needs

Managers

provide staff with education and support to provide evidence-based care

Staff

- make efforts to understand, identify and meet individual needs
- value, recognise & respect person to develop trust
- show empathy and aim for well-being
- reinforce strengths and positive attributes, not weaknesses
- encourage and allow choices and personal decision-making

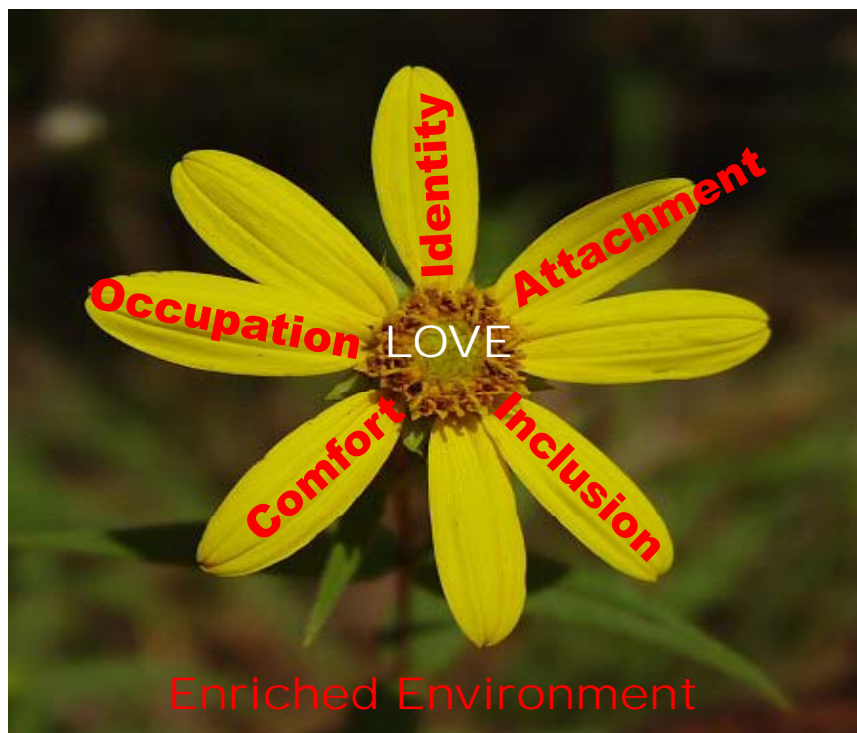
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Chenoweth L, King M, Jeon YH, Brodaty H, Stein-Parbury J, Haas M et al. 2009 Caring for aged dementia care residents study (CADRES) of person-centred care, dementia care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*. 8(4):317-325.



Best Practice Dementia Care—Helpful Tips

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Sample of evidence supporting the PCC model

Brooker D & Duce L 2001 Well-being and activity in dementia. *Aging & Mental Health*, 4:356-360

Chenoweth L, King M, Jeon YH, Brodaty H, Stein-Parbury J, Haas M et al. 2009 Caring for aged dementia care residents study (CADRES) of person-centred care, dementia care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurology*. 8(4):317-325.

Cohen-Mansfield J & Werner P 1998 The effects of an enhanced environment on nursing home residents who pace. *The Gerontologist*, 38 (2): 199-207.

Cohen-Mansfield, J., Libin, A., Marx, M. 2007 Non-pharmacological treatment of agitation: a controlled trial of systematic individualised intervention. *J Gerontol A Biol Sci*, 332:758-61 62: 908-16.

Fossey J, Ballard C, Juszczak E et al. 2006 Effect of enhanced psychological care on antipsychotic use in nursing home residents with severe dementia: a cluster randomised trial, *BMJ*,

Kitwood T 1997 *Dementia reconsidered. The person comes first*. Buckingham: Open University Press.

Sloane PD, Hoeffler B, Mitchell CM et al. 2004 Effect of person-centred showering and the towel bath on bathing-associated aggression, agitation and discomfort in nursing home residents with dementia: a randomised controlled trial, *J Am. Geriatr. Soc.*, 52:1795-804.