STAYING CONNECTED WITH THE PERSON
Cecilia Craig November, 2013

Some Myths about Dementia - they …
• They don't know what's happening …
• Dementia is a normal part of ageing …
• They don't know what they want …
• They are aggressive & violent …
• They behave like children …
• Only older people get dementia …

Impact of Dementia
- The experience of dementia involves many losses: role, skills, identity, memories etc…
- However …
The psychosocial environment can either compound or alleviate that impact:
‘... social care practices interact with the process of neurological change to weaken the [person’s] sense of self …’
(Cheston & Bender, 1999, p.167)
- Responsibility to help maintain a connection lies with those that are caring
- Social care

Propose 3 Ways of Connecting:
1. Creating a positive-living environment
2. Preserving their identity
3. Relationships

1. CREATING A POSITIVE-LIVING ENVIRONMENT

A well designed physical setting contributes to the person’s well-being BUT …

A well planned psychosocial environment also contributes to their well-being

Dinning
- Dinning & dining area as a catalyst to a person-centredness (Chaudhury et. al., 2013)
- A supportive one fosters:
  • functional ability
  • orientation
  • safety and security
  • familiarity and home-like
  • optimal sensory stimulation
  • social interaction
  • privacy and personal control
Direct contact with nature  Examples...

Aquarium
• The presence of an aquarium in the dining area significantly increases food intake in individuals with dementia (Edwards & Beck, 2012-R)
  • Increased food intake
  • Increased weight

Pets
• The presence of a dog, has been shown to increase social behaviors, including smiles and laughs, in individuals with dementia (Filan, 2002-R)
  • Pet-owning people with dementia experience fewer episodes of aggression and anxiety than non-owners (McCabe, 2002-R)

Gardens
• A source of multi-sensory stimulation & therapeutic value (Sempik et. al., 2003)
  • Indoor gardening (Lee & Kim, 2007)
  • Increased food intake
  • Increased weight
  • Improved sleep
  • Decreased agitation
  • Enhanced cognition
• However, ... A review of UK regulatory framework for residential care environments found ... (Chalfort, 2011-R)
  • Requirements for safety tended to keep residents indoors
  • Standards - not far enough to ensure accessibility to outdoor spaces
• Questions to ask: Is there a garden? How accessible is it?

Psychological approaches e.g...

Cognitive Stimulation therapy (CST)
• Standardised group sessions – stimulates cognition
• CST led to significant benefits in cognition (Spector et. al., 2003-R)
• CST is cost effective (Knapp et. al., 2006-R)
• Significant increases in MMSE Scores & Improvements in QOL observed (Coen et. Al, 2010-R)

Reminiscence
• Improvements in mood, communication & cognition (MMSE) (Haight et. Al., 2006-R)

Montessori based programming
• A way of presenting & making activities
  • Increased adaptive behaviours, engagement & mood (Jarrott et. Al., 2008-R)

Non-tangible

Time
• The person with dementia lives in the moment (Cheston, 2010)
  • Orientation in time may be more important to others
• What that person does with that time is important
• How the person uses their time is dictated by the institution (Coig, 2010)
  • Routine, task focused & order
• Institutional perspective: the day is ‘timetabled’
  • ‘Pockets of organised activity’ occur usually in the afternoon – activity programme
  • Spontaneity is curtailed
• Everyday tasks can be transformed into opportunities for engagement

Routine
• Routines are important in life
• Organisations need structure however …
  • Risk that … routine becomes the main focus of carer activities
• A person with dementia needs routine
• Routines associated with long term memory
• Short term memory is the first to go with a person with dementia
• Therefore – maintain their own routine

Examples:
• Always got up at 12 midday & never went to bed before 3am
• Had their main meal at 6pm each day
• Went for a long walk just after breakfast – bought newspaper
• Worked from 8am – 5pm
• What will the organisation do to help maintain his/her well-being?
Atmosphere
• A person with dementia finds it difficult to ‘read’ what’s going on
• Dementia affects …
  • Rate of thinking
  • Reasoning ability
  • Planning ability
  • Judgment etc..
• Relies on non-verbal assessment of their environment
• Sensitive to the atmosphere of the place

• Familiarity
  • Key to helping a person to function well in their surroundings
  • Physical environment
    • Familiar objects e.g. kitchen
  • Familiar activities, voices, senses etc…
  • E.g.
    • Smells bring back memories & trigger conversation
    • Turf fire example

2. PRESERVING IDENTITY
• Identity is about having a sense of self
• Self does not cease to exist just because someone can’t recall their memories or doesn’t appear to have a sense of who they are. (Matthews, 2006)
• For carers or those who KNOW the person well - elements of individuality still remain
• Responsibility lies with carers to help the person to maintain their sense of identity

Focusing on the Person
• Language conveys our thoughts, intentions, attitudes etc..
• Attitude towards the person with dementia
• As attitudes change – our language should change too
• E.g.
  • How many dementias have you?
  • The ‘feeds’
  • The ‘washes’
  • The ‘walkers’ etc…

New attitude:
• Focus on the PERSON and ‘park’ the DEMENTIA
• New language
  • The person with dementia
  • Assisting the person to eat & drink
  • The person who walks about …
• Treat with respect and equality
• Keep the person in mind

Personalising the living area
• Name on the bedroom door
• Family photos
• Furniture from home
• Personal ornaments
• Arranged in a familiar manner
Life Story Work
• Life story work – a tangible record of someone’s life and experiences
  • Identity
  • Understanding for Carers
• Meaningful
• Resource for reminiscing & activity development
• Use their language

• User friendly presentation
  • Booklets, boxes, notice boards etc..
• Use themes & topics from what the person says
• Guiding frameworks/booklets – use with care only
• Storage
• Not all memories

John’s Stories
John’s Shed
His garden shed was his pride and joy – organised with tools that were there ‘just in case’ they’re needed!
He would spend a lot of his time in the shed ‘fettling with things’.

John worked in a chicken factory for awhile:
‘I had to pluck those feathers off the chickens’ and then ‘we would hang them on the racks, upside down – alive and all’.
‘I wouldn’t eating those burgers if I was you!’
To this day he will not eat chicken at all!

Women Golfers
John remembers the time when women obtain the right to become golfers.
‘Didn’t seem right – it was no place for a woman and they caused havoc at the club being associate members’.
A balanced life history may be one of the most important tools available for recreating the real story and representing the real identity of the person…”

Egan et al., 2007 (p.26)

**Living their life**
- Activity is in all our lives
  - A sense of purpose & satisfaction
  - Enjoyment
  - Social contact
- Need for occupation in life
- Activities need to be suitable to the needs and abilities of the individual
- Group activities
  - Reminiscence, Physical exercises, Sonas etc...
  - Not suitable for all people with dementia

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**3. RELATIONSHIPS**
- Social beings
  - Through others that we preserve our identity
- The person’s QOL & the stress of the carer are associated with the quality of the relationship (Woods, 2011-R)
- Person-centred approach
  - Nolan et. Al., (2004) suggest that a relationship-centred care approach might be more appropriate
  - Builds on person-centeredness
  - This focuses on the interactions as a foundation of any therapeutic or healing activity (Tresolini et. Al, 1994)
  - Provides the context in which caring occurs
  - Interpersonal & intrapersonal relationships ...
  - Enhancing their sense of well-being

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- Forming relationships with those with advanced dementia is also possible (Ericsson et. al., 2011-R)
  - Assigning time
  - Establishing security and trust
  - Communicating equality ...
  - ... all lead to establishing a relationship
  - Triadic relationships ...
    - Each are involved in an ongoing process of ‘negotiating the balance’ (Quinn et. Al., 2012)
• Relationship centred approach ...

• **Senses framework** (Nolan, 1997; Davies et al., 1999; Nolan et al., 2001, 2002) Captures the experience and the individuals’ perceptions of the relationship and the interpersonal processes.

• Proposes that healthy relationships should involve a sense of...
  
  Security  
  Purpose  
  Belongingness  
  Achievement  
  Continuity  
  Significance

**Summary**

• Staying connected with the person

• Creating a positive-living environment
  
  • Direct contact with nature
  
  • Psychological approaches

• Non-tangible

• Preserving their identity
  
  • Focusing on the person
  
  • Personalising

• Life story work

• Living their life – occupation

• Forming therapeutic relationships

**References**

• Chalfort, G. (2011) *Connection to nature at the building edge* Saarbrucken: LAP Lambert Academic Publishing

• Chaudhury, Hung & Badger (2013) Hun *The role of physical environment in supporting person-centered dining in long-term care – a literature review* AM J ALZHEIMERS DIS OTHER DEMEN August vol. 28(5) 491–500


• Ericsson, I., Kjellstro, S. & Hellstro, J. (2011) *Creating relationships with persons with moderate to severe dementia* Dementia 12(1) 63–79


• BE MY FRIEND .. FOR I NEED ONE. BUT DO NOT BE MY MANAGER.

REMEMBER ME AS MY LIFE & IDENTITY ERODE [FROM ME] AS A PERSON NOT AS A CASE.

J. OSSOFSKY, 1993

• Sempik, J. et al. (2003) Social and therapeutic horticulture: evidence and messages from research (Literature review) Loughborough: CCFR.


• http://www.youtube.com/watch?v=9uJi30HNb-Q Montessori
• http://www.youtube.com/watch?v=FLDwzgRTbVA