



**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 & dinning 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 (Folan, 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)
 - 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 (Craig, 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

- One-to-one activities
 - Tailored, timed etc..
- Activity focused care
 - Care as an activity itself
 - Short activities while giving care

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

- 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

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

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