

# Communication & Care-giving in Dementia: a positive vision

## Outline for the 4 day course for professionals / caregivers: "Communication and Care-giving in Dementia: a positive vision"

(Why positive? It is always possible to help a person, including being a 'symbolic presence'.) –

By: Dr. Gemma MM Jones (HBSc, BSN, CVT, PhD.)



### Aims:

- to cover key aspects of the developing knowledge-base for professional dementia care
- to provide a conceptual framework for understanding dementing illnesses, behavioural changes and the range of options for care, communication, and environmental intervention

### Vision:

- Stage-specific, dementia-specific, bespoke dementia care

### Goal:

- Encourage abilities that are spared- support and intervene for those that are weakened

### Assumptions:

- "All behaviour has meaning."
- "A caregiver's presence is often symbolic."
- "Lucid moments can occur in all stages."
- "Home is a feeling- not just a place."

### Day 1 Theme: Sensory changes in normal aging (and additional implications for dementia) /

(What does the world look/feel like to older people and people with dementia?)

- introduction to the course, course notes, vocabulary, key concepts of dementia care, 'The Wide Spectrum' mnemonic for describing the course, and guiding principles for dementia care
- different types of memory: factual, emotional, and sensory (bookcases in a library metaphor)
- attentional changes in dementia (blackboard metaphor)
- additional visuo-perceptual changes that can occur in Alzheimer's disease (a visuo-cognitive illness)
- getting the balance right between over and under-stimulating the senses
- a first look at the 'Communication Dilemmas' exercise

### Day 2 Theme: Dementing illnesses- the range of cognitive abilities that can be affected /

(In what ways do people try to adapt and cope with their difficulties?)

- how aging senses can affect the perceived world (implications for assessment and care interventions)
- design considerations for dementia care environments - supporting changing abilities and perceptions
- what is and isn't dementia? (double umbrella model) [ more than 100 types of dementing illness]
- crash-course on 'the brain and behaviour' to help replace some common myths about dementia
- what range of cognitive and other abilities can be affected in dementing illnesses?
- extended case study of vascular dementia (51 letters of complaint written to a Chef in a Care Home) [early stage fluctuations in ability, benefits of early diagnosis, advantages of being able to talk openly]

### Day 3 Theme: Understanding how dementia progresses (behaviour changes and stage-specific care) /

(What can good care interventions achieve?)

- difference between: 'pathology', 'symptoms', 'consequences', and 'emotional responses to consequences'
- the purpose of various 'staging models' to understand 'where' someone is in the course of an illness
- the 'Behavioural Staging' model (for Alzheimer's Disease and progressive Multi Infarct Dementia)
- noticing 'fear/discomfort' behaviour - versus - 'feeling safe/comfortable', in each stage
- language changes (learning to understand and speak a new language in each stage to stay connected)
- examples of typical misunderstandings – versus - good care practice, for each stage [ verbal and DVD]
- attachment behaviour in dementia (Miesen's work expanding Bowlby's theory)
- use of 'Split-Staging' when the Behavioural Staging doesn't fit rarer or more complex dementing illnesses

### Day 4 Theme: Tools for communication, care-giving, and forming care partnerships with family /

(What examples have helped you most to enhance your practise?)

- stage-specific activities and interpersonal approaches
- more than ten communication options to choose from (and appropriate use of humour)
- discussion of the 'Communication Dilemmas' to solve from Day 1, in light of the new framework
- understanding families: subjective versus objective perception of burden; stages of grieving and guilt
- helping families to keep contact in each stage: adjusting care and visiting strategies [DVD]
- how to develop genuine 'care partnerships' with family members
- ideas for documentation and care planning
- course evaluation and Certificates of Attendance

Since course participants vary widely in their work remits (assessment, liaison, commissioning, teaching, care, management, advocacy), background and experience- these objectives are generic.

After this course, it is expected that the course participant:

- can explain differences in care approaches for the 'frail elderly' versus 'people with dementia'
- can name the most common types of dementing illness (and that they are not 'normal aging')
- knows about other illnesses/ injuries/conditions that can cause cognitive difficulties (and further exacerbate dementia symptoms)- is aware they need to be documented, reported and investigated
- has a core knowledge base about dementia and dementia care (vocabulary, concepts, models, examples), and possible interventions (care, communication, activity-based, and environmental)
- understands that many factors- besides brain damage- affect behaviour and need to be assessed for (personality, life history, support, losses, current grieving, past/ concurrent illness/disability, and medication)
- has a framework for describing the variety of changes that can occur in dementing illnesses (sensory-perceptual, cognitive, emotional, behavioural and physical)
- knows how each sense characteristically changes in normal aging (and that additional difficulties can occur when memory, attention, problem-solving, and 'reality-testing' are reduced)
- is alert to progressive visual difficulties in Alzheimer's disease; how to enhance important cues
- can provide examples of how 'fear' and 'what is (mis)perceived' can affect a person's behaviour
- can relate why early stage dementia is often missed - and specific ways in which people try to cover up and deflect mistakes to save face (confabulation/ lying/ blaming/ hiding/ poor excuses)
- can assess for 'fear' versus 'contentment' behaviour in each Behavioural Stage
- can anticipate the variety of 'disinhibited behaviours' possible, and at what point they may occur
- can illustrate how people with dementia differ from children, though behaviours may be similar
- can identify when 'perceptually appropriate' and 'emotionally comforting' interventions may take precedence over 'age appropriate' ones (in relation to disorientation / attachment behaviour)
- can choose and adapt care interventions to minimize:
  - 1) the consequences of cognitive symptoms on daily living: and,
  - 2) distressed emotional responses to those consequences
- can identify the barriers to communication and characteristic language changes in each Behavioural Stage
- can select and evaluate their own communication options to enhance their ability to make contact with a person, and to maximize and maintain whatever responses a person can still make
- knows:
  - 1) the stages of grieving and guilt that family carers can experience;
  - 2) why some carers reject/ resent the help of caregivers;
  - 3) how to help family carers adapt care/visiting strategies;
  - 4) that carers also need core dementia education;
  - 5) that providing the best dementia care possible, includes having genuine 'care partnerships' with carers