

Outline for the four-day course:

“Communication and Care-giving in Dementia: a positive vision”

for professionals / paid caregivers, (there is a separate version for family carers)

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Why positive? There's always something you can do to help a person – including being a 'symbolic presence' and anchor of safety for people with dementia.

This course has been attended by:

- **nurses** working in the community and in all types of services /units /wards of acute care hospitals, residential, nursing homes specialist dementia units, assessment centres, day centres, day hospitals, memory clinics
 - students of all health care professions
 - Sheltered Housing Managers and staff
 - residential and nursing-home inspectors
 - Social workers
 - Occupational therapists
 - Physiotherapists
 - Alzheimer Café leaders and volunteers
 - Family physicians, old age psychiatrists,
 - Pastors and pastoral care workers
 - Radiology staff
 - Community Team In-reach workers
 - Architects/ designers of dementia care environments
 - Inspectorate staff and assessors
 - (paid) Care-givers, care assistants and ancillary staff, receptionists, chefs, maintenance, laundry and housekeeping staff
 - Managers, directors, finance and administrative heads
 - Personal and Domiciliary Care coordinators and staff
 - Commissioners of health and social care services
 - Carer Support Workers
 - Speech and language therapists
 - Activity therapists and social events coordinators
 - Befrienders
 - Psychologists, psychotherapists, music therapists
 - Paramedics and ambulance staff
 - Hospital porters and orderlies
 - Police and Fire department staff
 - Phone Help-line staff
 - Staff and volunteers with dementia support services
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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 interventions

Vision bespoke, stage-specific, dementia-specific, dementia care

Goal Encourage abilities that are spared; support and intervene for those that are weakened

Assumptions “All behaviour has meaning.” “Home is a feeling- not just a place.”

“A caregiver's presence is often symbolic.” “Lucid moments can occur in all stages.”

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 describes the course; guiding principles for dementia care
- Exercise: Everyday communication dilemmas in care settings
- Introduction to dementia; What is and isn't dementia? [more than 100 types of dementing illness]
- Different types of memory: factual, emotional, sensory (*bookcases in a memory library*)
- Attention changes in dementia (shrinking attention *blackboard model*)
- Visual changes that can occur in Alzheimer's disease (a visuo-cognitive illness)
- The changing senses; getting the balance right between over and under-stimulating the senses

Day 2 Theme:

Dementing illnesses - the range of cognitive and that can be affected (In what ways do people try to adapt and cope with their difficulties?)

- Updating and replacing common myths about dementia
- What range of cognitive abilities can be affected in various dementing illnesses?
- How aging senses affect the perceived world (implications for assessment and care interventions)
- Supporting changing abilities and perceptions: design considerations for dementia-care environments
- Extended case study of vascular dementia – *“Letters of complaint to a Chef in a Care Home”* (early-stage fluctuations in ability; paradoxical patterns of difficulty; the benefits of early diagnosis, and advantages of talking openly)

Continued -

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'
- '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 (understand and speak a new language in each stage to stay connected)
- Using '*Split-Staging*' when the Behavioural Staging doesn't fit rare/ complex dementing illnesses
- Examples of misunderstandings and good care practice for each stage

Day 4 Theme:

Communication and caregiving tools care-giving; forming care partnerships with family carers (What examples will most enhance your practise?)

- Stage-specific activities and interpersonal approaches
- The Ten-plus Communication Options Model (Jones); choosing your options
- Understanding families: perception of burden; stages of grieving and guilt
- Helping families to keep contact in each stage: adjusting care and visiting strategies
- Developing genuine 'care partnerships' with family members
- Revisiting the 'Communication Dilemmas' from Day 1 – any changes in your thinking
- Ideas for documentation and care planning
- Written and verbal course evaluation; distribution of Certificates of Attendance

Teaching objectives for this version of the four-day course

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

After this course, it is expected that a 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 knows that they are not 'normal aging')
- knows about other illnesses/ injuries/conditions that can cause cognitive difficulties (and further exacerbate dementia symptoms) – and is aware of the need for documenting, reporting and investigating behaviour changes
- has a core knowledge-base about dementia and dementia-care (vocabulary, concepts, models, examples), and ideas for possible interventions (care, communication, activity-based, and environmental)
- understands that many factors - besides brain damage - affect behaviour and need to be assessed for (e.g., sensory changes, 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 (e.g., 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, and logical thinking abilities are reduced)
- is aware of the types of progressive visual difficulties that can occur in Alzheimer's disease; how to enhance important cues
- can provide examples of how 'fear' and 'visual misperceptions can affect a person's behaviour
- can explain why early-stage dementia is often missed; - specific ways in which people try to cover up and deflect mistakes to save face (confabulation/ lying/ denying/blaming/ hiding/ using excuses)
- can assess what Behavioural Stage a person is in (or select a 'split-stage' description for them)
- can assess for 'fear' versus 'contentment' behaviour in each stage
- knows the variety of 'disinhibited behaviours' possible in dementia, and when 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-seeking behaviour)
- can select from and adapt care interventions to minimize the distressed emotional responses of a person with dementia
- can identify the barriers to communication and characteristic language changes in each Behavioural Stage
- can select, utilize and evaluate from a range of 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:
 - the stages of grieving and guilt that family carers can experience
 - why some carers reject/ resent the help of caregivers
 - how to help family carers adapt care/visiting strategies
 - that most carers need core dementia education
 - that providing the best dementia care possible, includes facilitating genuine 'care partnerships' with family-carers