THE LEVESON CENTRE
for the study of
AGEING, SPIRITUALITY AND SOCIAL POLICY

www.leveson.org.uk

Understanding Dementia

The three speakers at the Leveson seminar held on 14 June 2006 have kindly made available to us the headings they used for their presentations.

Dementia: what is it? Dr Daphne Wallace

Slide 1 Confusion

- Disorientation - in time
- Disorientation - in place
- Disorientation - in person
- Memory loss - recent (common)
- Memory loss - past
- Misinterpretations
- False perceptions or beliefs

Slide 2 Dementia - What is it

- Dementia is an illness associated with gradual failure of the functions of the brain. This can in turn affect bodily functions and activities of daily living.
- Dementia is usually a progressive condition although the rate of progression varies from one individual to another and in relation to the underlying cause.

Slide 3 Dementia - Who does it affect?

- Mainly older people, but some younger people
- 2% total population
- 3.7% over 60 and under 75
- 10.5% over 75
- 20% (or more?) over 80
- Dementia is NOT just old age - it is a disease

Slide 4 Dementia - Some facts

- 650,000 people with dementia in the UK
- Dementia can affect younger people - 17,000 people in the UK under 65 have dementia
- After 65 the likelihood of developing dementia rises sharply
- Dementia affects 2 in 100 people between 65 and 75 years
- Dementia affects 1 in 5 people aged over 80

Slide 5 Is it dementia?

- Is a ‘confused’ person suffering from dementia?
- Is it dementia or delirium?
- Is it depression?
- Is it psychosis?
- Is it just eccentricity?

Slide 6 Delirium or dementia ?

Clinical features of delirium
- Sudden onset/impaired cognition
- Fluctuating awareness/severity
- Perplexity/anxiety/fear
- Hallucinations (especially visual) and misinterpretations
- Occasional aggression
- Impaired attention/concentration
- May be hypoactive or hyperactive

Slide 7 Causes of delirium

- Infection
- Metabolic cause eg Thyroid disease, diabetes
- Medication eg painkillers, L-Dopa, benzodiazepines, anticholinergic drugs
- Alcohol
- System failure - cardiac, respiratory

NB Old and frail people are particularly vulnerable

Slide 8 Dementia or depression?

- Cognitive impairment is common in depression at all ages
- Depression may mimic dementia - pseudodementia
- Need for clear history of onset
- Possible empirical trial of anti-depressant
- A lots of recent research has looked at the relationship between dementia and depression. Certainly early onset of dementia is often heralded by depression. I believe that sub-consciously the person realises that they are not coping as well as usual which is threatening

Slide 9 Dementia or psychosis

- Delusions and hallucinations may be described by relatives and carers as ‘confusion’
- Cognitive impairment may occur in psychosis
- Paranoid ideas may be expressed in early dementia

Slide 10 Eccentricity

- Someone who hoards, does not wash or eats a bizarre diet may not have dementia
- If the person’s behaviour seems odd, it is essential to establish what they were like in the past

Slide 11 Common dementias

- Alzheimer's Disease - 50%
- Vascular dementia - 15-20%
- Lewy Body dementia - 15-20%?
- Mixed dementia
- Dementia in Parkinson's Disease

Slide 12 Less common dementias

- Alcoholic dementia: Korsakoffs Psychosis/Wernicke's Encephalopathy
- Creutzfeld-Jacob's Disease (CJD)
- Huntington's Disease
- HIV/AIDS
- Sub-cortical dementia associated with high BP
- Pick's Disease/ frontal Lobe Dementia

Slide 13 Alzheimer's Disease - risk factors

- Increasing age
- Genetics - familial type/Downs Syndrome
- Unhealthy life style
- High Blood Pressure
- ?Education

Slide 14 Alzheimer's Disease - diagnostic features

- Gradual progression
- Cortical atrophy (on CT scan)
- Ventricular enlargement (on CT scan)
- Senile plaques (Amyloid)
- Granulo-vacuolar degeneration
- Neurofibrillary tangles

Slide 15 Clinical features - early

- Insidious onset
- Gradual decline in cognitive state
- Memory problems (especially encoding new memories)
- Indecision and vagueness
- Word-finding difficulties

Slide 16 Clinical features - late

- Disorientation in time, place and person
- Restlessness and agitation
- Failure to recognise home/relatives
- Hallucinations (frequent but not usually evident)
- Apraxias/ Dysphasia/ Incontinence

Slide 17 Vascular Dementia

Various types, very variable in symptoms and speed of progression

- After big stroke
- After several small strokes (multi-infarct dementia)
- Small vessel disease

Slide 18 Vascular Dementia - risk factors

- High Blood Pressure
- High cholesterol
- Diabetes
- Unhealthy lifestyle - sedentary, smoking, alcohol
- Family history of vascular or heart disease
- Men more than women
- Indian Sub-continent/ Afro-Caribbean ethnic origin

Slide 19 Symptoms of Vascular Dementia

<u>Stroke - related dementia</u>

- Depends on area of brain affected eg visual cortex leads to cortical blindness/ hallucinations
- Symptoms of stroke - weakness/paralysis
- Memory problems
- Speech problems
- Fits
- Step-wise progression - multi-infarct dementia
- Depression is common

Slide 20 Symptoms of Vascular Dementia

<u>Small vessel disease</u>

- Problems with concentration
- Problems with communicating
- Memory problems (often NOT first symptom)
- Symptoms develop slowly and gradually
- May be associated with walking problems
- Deterioration in specific skills

Slide 21 Lewy Body Dementia

- Different pathology to AD but similar to Parkinson's Disease
- Presence of Lewy bodies in brain

<u>Symptoms</u>

- Hallucinations especially visual - often the first symptom
- Communication problems
- Fluctuating confusion
- Stooped posture and later walking problems

Slide 22 Fronto-temporal Dementia

- Various forms - Pick's Disease, dementia with Motor Neurone Disease, Frontal Lobe degeneration
- More common in those under 65
- Symptoms include personality and behavioural change, loss of judgement and planning, loss of language skills

Slide 23 Driving and Dementia

- At present, despite much work by a working party on which I sat, it is not clear when someone with dementia should stop driving
- Driving is not appropriate in the presence of severe dementia
- Despite the DVLA Guide for Doctors, memory impairment, which is offered as a symptom to look for, is not a very good guide for driving ability in early dementia

Slide 24 Investigations

- Routine tests of blood, electrocardiograph, chest x-ray etc are used to check for common physical problems - a sort of MOT. Most, if not all, can be arranged by GP
- GPs can also do a simple cognitive test if memory and other mental functions
- Referral to pyschogeriatrician or neurologist should follow if there are changes with no obvious cause

Slide 25 Specialist investigations

- More sophisticated and detailed cognitive tests can be done by a neuropsychologist
- A detailed history from informant(s)
- Routine tests (if not already done)
- CT scan of head which will indicate if there are particular abnormalities due to blood supply problems, stroke etc

NB Alzheimer's Disease shows only increased brain shrinkage - not really specific

Slide 16 Implications

- How dementia presents is different in every individual
- However severe the disability the PERSON is still there
- Dementia can affect the person's ability to copy eg with hospital administration, bereavement, worries etc
- Fear may develop with uncertainty and recognition of loss of control or misunderstanding

Slide 17 Treatment

- There is currently no cure
- Vascular dementia is treated by treating the blood pressure ie reducing the risk factors
- Alzheimer's Disease and Lewy Body Dementia may respond to cholinesterase ihhibitors (aricept etc or ebixa)
- A good active lifestyle, mentally and physically, helps all types
- Person-centred care is good for all

Slide 18 Some useful terms - 1

Delusions - false beliefs not understandable within the culture of the individual concerned

- Persecutory - paranoid delusions
- Guilt - delusions of guilt
- Poverty - delusions of poverty
- Religion - religious delusions

Slide 19 Some useful terms - 2

Hallucinations - false perceptions

- Auditory eg music / machines / voices
- Visual eg rats / insects / people / cats
- Olfactory eg bad smell / food
- Tactile eg touching in night / infestations
- Gustatory eg unpleasant taste

Slide 20 Some useful terms - 3

Dysphasia - difficulty with language. My be:

- Expressive - cannot find words or names for things. Cannot find correct words / jumbled speech
- Receptive - cannot understand what is said to them eg questions or instructions

Slide 21 Some useful terms - 4

- Mild dementia - slight confusion and forgetfulness or change in behaviour
- Moderate dementia - inability to cook, lapses in personal hygiene, short-term memory poor, word finding difficulties, easily upset or flustered
- Severe dementia - lack of recognition of friends or family, home and surroundings, may wander, be anxious. Communication problems. Cannot do simple everyday tasks

Dementia Care in the Community: a person-centred approach Jan Roberts

Slide 1 Magic Eye

Illustration of a complex picture

- Are we able to look beyond and through an image
- Can we make sense of a confusing picture

Slide 2 Classic images of older age

- Impassive
- Sleeping
- Little or no interaction
- Unresponsive
- No motivation
- Disengaged

Slide 3

We need to see the PERSON with dementia and not the person with DEMENTIA

Slide 4 Person-centred: exploring the concept

- Person-centred - evolved
- Person-centred concept / philosophy / approach
- Leaders on the person-centred concept: Carl Rogers, Tom Kitwood, John Killick

Slide 4 Personhood - a term coined by Tom Kitwood

“Instead of seeing a set of defects, damages and problem behaviours which effectively turn the person into an object…we need to work on the basis of seeing the person as a whole…we should understand a person’s dementia as being a complex interaction between their personality, physical health, biography or life history, social psychology, their neurological impairment”
Tom Kitwood 1993

Slide 5 McGregor and Bell (1993)

“ Given the opportunity, people with dementia are able to function as valuable members of their social group and have the potential to regain control over their own lives…the stumbling block to achieving this may well be our limited conception of what is, and what is not, possible for them.”

Slide 6 Key word / phrases in this statement

- Opportunity
- Valuable members
- Regain control (own lives)
- OUR limited conception

Slide 7 A person-centred approach requires us to:

- enter their frame of reference - their inner world
- accept that each person is unique
- see the person as a whole
- acknowledge the human need to fulfil potential

Slide 8 A person-centred approach requires us to:

- appreciate the importance of feelings and emotions and positive regard
- understand the importance of inter-personal relationships
- adopt a non-directive approach - working as an enabler or facilitator NOT controller

Slide 9 Finding our way through the maze…

- employing lateral thinking
- being undeterred when our way is barred
- picking up clues from others in or around the maze
- when you reach the centre, being able to start all over again

Slide 10

"How you relate to us has a big impact on the course of the disease. You can restore our personhood and give us a sense of being needed and valued"
Christine Bryden 'Dancing with dementia' p127

Slide 11

Effective communication is key to a person-centred approach

Slide 12 Tragedy

"Our evidence suggests that people with dementia residing in care are offered few opportunities to engage in direct communication, and when the opportunity does arise, care workers employ various strategies to maintain a focus on the care task at hand"
Richard Ward et al Journal of Dementia Care Nov/Dec 2005 pp16-19

Slide 13 Kitwood and Bredin's twelve indicators of well-being in dementia

- Assertion of will or desire
- Ability to experience and express emotions
- Initiation of social contact
- Affectional warmth
- Social sensitivity
- Self-respect

Slide 14 Slide 13 Kitwood and Bredin's twelve indicators of well-being in dementia

- Acceptance of other people with dementia
- Humour
- Creativity and self-expression
- Showing evident pleasure
- Helpfulness
- Relaxation

Slide 15 A Zulu saying

A person is a person through others

Working with people who challenge us in the context of dementia: implications for practice Andrew Papadopoulos

Slide 1 Defining challenging behaviour

- What do we mean?
- Numerous and inconsistent terminology:
  BSPD (Behavioural and Psychological Symptoms of Dementia)
  Behavioural disturbance
  Disruptive behaviour
  Difficult behaviour
  Agitation

Slide 2 Definitions

- Behaviour which is challenging is viewed as behaviour which while largely (but not always) being designed to meet need, results in significant degrees of distress and or disturbance for others within that person's environment and frequently for the person themselves. Abnormal behaviour does not necessarily mean challenging behaviour

Slide 3 Demography

- Figures relate to biomedical definitions, BPSD
- 90% of people with dementia will suffer from some degree of behavioural disturbance (Ballard and Oyebode, 1995)
- Rates vary depending on the population studied
- Cache County USA (Lyketsos et al, 2000), 5000 older people studied including 329 people with dementia:
  61% had at least one sympton of BPSD
  32% had a score of 6 points or more on the NPI indicating at least a clinically relevant level of disturbance

Slide 4 Demography

- Relating these figures to Birmingham which has approximately 10,600 people with dementia of all ages
- 6350 will have t least one BPSD symptom
- 3330 will have BPSD of clinical relevance requiring varying levels of specialist mental health interventions
- Younger people with dementia are known to have higher rates of disturbance with an increased risk of institutionalisation
- Around 100 people with dementia will have symptoms so severe that they will require residential support in some form of unit with direct specialist mental health intervention *Bentham, 2005*

Slide 5 Brodaty et al Seven Tiered Model (Adapted to Birmingham, Bentham, 2005)

- Tier 1, no dementia
- Tier 2, Dementia, no BPSD. Estimated number in Birmingham 4134, mainly in own home
- Tier 3, Dementia, mild BPSD. Estimated number 3074, own home to residential care
- Tier 4, Dementia, moderate BPSD. Estimated number 2120 residential care or own home
- Tier 5, Dementia, severe BPSD. Estimated number 1060, nursing or EMI home, own home
- Dementia, extreme BPSD. Estimated number 5, specialist external placement

Slide 6 Demography

Impact on caregivers
- High levels of physical and psychological morbidity in family caregivers where person has dementia
- 39% of carers had GHQ scores of 5 and above where they were caring at home (RIS, 1997)
- 33% of those visiting loved ones in institutions had GHQ scores of 5 and above (RIS, 1997)
- Behavioural problems are a high predictor of psychological morbidity
- Harvey et al found that 50% of carers of younger people with dementia had significant psychological morbidity
- Coope et al (1995) 29.4% of carers had case levels of depression

Slide 7 Perspectives

Biomedical
- Considers challenging behaviour as symptomatic of dementia
- As arising from a progressive decline in normal executive function of the fronto-temporal cortex and related pathways (dis-executive syndrome)
- As being informed by pre-morbid dominant personality characteristics
- As becoming attenuated via the presence of neurotoxins, co-morbid mental health difficulties or other secondary medical problems

Slide 8 Perspectives

Psychological
- Considers challenging behaviour as a goal-directed response (functional and purposeful)
- As arising from external / internal challenges - needs a trigger
- As being mediated by neuropsychological factors / impairment
- As being elicited in context-dependent situations

Slide 9 Perspectives

Social
- Considers challenging behaviour as being socially constructed
- Culturally specific
- Having a social function
- Arising out of discrimination and dehumanisation
- Constructed within the context of relationships
- Environmental influences

Slide 10 Interventions
- “In recent years, interventions have been pharmacological, which has largely been influenced by a limited focus upon the person with minimal attention paid to the mult-faceted and multi-causal contact in which behaviour occurs” (Bord et all, 2001)
- Recognition of the dangers of inappropriate use of medication to suppress behaviour
- Similar behaviour can occur in two people for entirely different reasons
- Behaviour may be viewed as problematic for environmental reasons, or because of the psychological difficulties experienced by the caregiver rather than because it is abnormal in itself (Bird et al, 2001)

Slide 11 Interventions

- Informed by a bio-psycho-social framework ie draws together all three frameworks in an attempt to formulate an understanding of the person and their behaviour
- Based upon person-centred principles ie what do we understand to be the personal experience of the individual, their ‘world’ and our role in that world which informs our understanding of, and response to, their behaviour?
- Should involve multi-disciplinary, multi-agency and multi-layered appraoches required
- Assessment is crucial (shared fomulation)

Slide 12 Interventions

Considerations in assessment

- Personality (assertive / submissive; secure / insecure; extrovert / introvert; principled / easy-going)
- Neurological impairment (insight, memory, attention, concentration, social and personal awareness, communication, emotion)
- Physical and mental health (pain, disability, loss of valued functioning, mood, motivation, psychosis)
- Biography and early life experiences (adaptation to losses, abuse, exploitation, likes, dislikes)
- Relationship dynamics
- Environment (physical and pscho-social)

Slide 13 Interventions

- Respond to the identified need, not to the behaviour
- Develop alternative ways of communicating (you may be part of the problem!)
- Remove or change the threat ie that which seems to be triggering the behaviour
- Consider use of distraction or meaningful activities
- Work with or seek help from others eg specialist mental health services
- Work with, but don’t rely on, medication