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Dementia

Dr Maria Foundas
Consultant Physician

Training support • Skills development • Competency • Assessment •
Scholarships • Education

Training to care for people with dementia



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Preamble and disclaimer

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Use of this material should be acknowledged



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Outline of Presentation

- Overview of Dementia
- Neuroanatomy and functional correlates
- Dementia subtypes
- Assessment for dementia
- Options for care and treatment
- Support for carers
- Palliative care



Dementia

- **Definition** - progressive, largely irreversible clinical syndrome characterised by global impairment of mental function
- As the condition progresses - some/all of the following:
 - Memory loss
 - Language impairment
 - Disorientation
 - Personality change
 - Difficulties with ADLs
 - Self-neglect
 - Psychiatric symptoms
 - Behaviour change



Epidemiology

In **Australia:**

- 2008: 227,300 persons with dementia.
- 9,600 cases **under 65 years of age.**
- 57,000 new cases expected to be diagnosed in 2008
- 2050: 731,000 cases projected.
- 1 in 15 aged 65+ (prevalence rate)
- 1 in 9 aged 80 - 84
- 1 in 4 aged 85+
- Affects the lives of nearly 1 million Australians (carers)
- Prevalence in Australian Aboriginals 5x higher
- 1 in 8 Australians with dementia from NESB

SOURCE: Alzheimer's Australia. Dementia Facts and Statistics. Updated January 2008.



A Costly Challenge

- 2002: \$6.6 billion total financial cost of dementia.
- 2051: Anticipated 3.3% GDP
- Family carers provide 80% of value of informal care, without financial compensation.
- Half of persons with moderate to severe dementia live in community settings, half in residential care facilities.



A Complex Problem: Morbidity and Mortality

Complex care needs

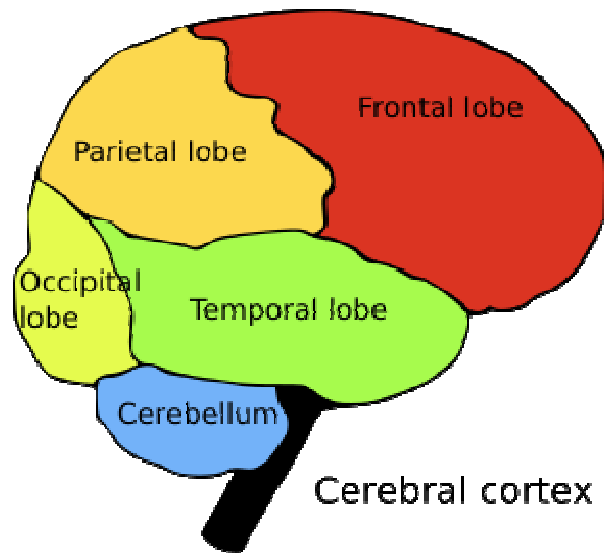
- Dementia 2nd to depression in disability burden *(Access Economics 2003)*
- With disease progression, can present behaviours of concern such as aggression, restlessness and wandering, incontinence psychotic symptoms and mobility problems.

Mortality

- Fourth leading cause of death in age 65+.
- Survival 4-8 years, depending on age at diagnosis, severity at diagnosis, other medical conditions, gender.



Functional Neuroanatomy



- Frontal Lobe- reasoning, planning, parts of speech, movement, emotions, and problem solving
- Parietal Lobe- movement and perception, orientation, recognition
- Occipital Lobe- visual processing
- Temporal Lobe- auditory perception, memory, and speech



Neurological Conditions Causing Dementia

- Alzheimer's disease* (50–70%)
- Vascular dementias* (10–20%)
 - Multi-infarct dementia
 - Binswanger's disease
- Dementia with Lewy Bodies (DLB)
 - Diffuse Lewy Body disease
 - Lewy body variant of AD
 - Parkinson's disease
- Other less common dementias
 - FTD, CJD, PSP, NPH, HD, alcohol.

*Mixed Common



Alzheimer's Neuropathology

- Neuritic plaques
 - Core of amyloid, abnormal neurites and glial cells
 - Amyloid is diagnostic of AD
- Neurofibrillary tangles
 - Extracellular phosphorylated tau protein
 - Not specific for AD (80% of people > 80y)
- Other findings
 - Cortical neuronal loss
 - Amyloid angiopathy



Alzheimer's Disease

- Asymmetric onset usually seen
- If dominant (usually left) hemisphere affected first then language problems early
- If right hemisphere first - tend to have problems organising activities in space and flattening of expressed feelings
- In some patients personality changes and psychoses prominent early (limbic and/or frontal areas)
- Ultimately a global process



Vascular dementia

- **Multi-infarct dementia**
 - Most common form of VD
 - Multiple strokes
 - Location determines deficits
- **Binswanger's disease**
 - Subcortical vascular dementia
 - Related to chronic hypertension
 - Pathological changes greatest in the cerebral white matter, especially in the territory of the long penetrating arteries.
 - Subcortical dementia with gait dyspraxia, hyperreflexia and personality changes in a patient with vascular risk factors.



Dementia with Lewy Bodies

- Lewy bodies are neuronal inclusion bodies
- Lewy bodies found most often in the temporal lobe, in the cingular gyrus, amygdala and insula.
- Memory loss may be more subtle than in those with AD.



Fronto-temporal dementia

- Degeneration of the frontal +/-or temporal lobes of the brain
- Includes FTD, Progressive non-fluent aphasia, Semantic dementia and Pick's disease
- Progressive aphasia - begins left hemisphere, language problems dominate initially
- Right temporal onset -prominent change in personality
- Both frontal lobes initially -problems with organising and planning, may also show disinhibited behaviour and word finding problems; Pick bodies in some cases.



Alzheimer's Disease

- Most common cause of dementia.
- Regarded as a syndrome.
- May coexist with other causes of dementia.

DSM-IV Diagnostic criteria for AD (1994)

- Multiple cognitive deficits
 - Short and long term memory impairment
 - One or more of the following:
 - Aphasia
 - Apraxia
 - Agnosia
 - Disturbance of executive function
- Gradual onset, functional impairment, continuous decline
- Decline from previously higher level of function
- Exclusion of other possible causes.
- No evidence for delirium.



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Alzheimer's Disease

NINDS-ADRA Criteria (preferred by NICE)

PROBABLE AD

- Dementia
- Deficits 2 or more cognitive domains
- Progressive worsening memory and other cognitive functions
- No disturbance consciousness and absence of other systemic disorders.
- Onset between 40 and 90 years of age.
- Progressive worsening of specific cognitive functions.
- Impaired ADL.
- Associated behavioural abnormalities.

POSSIBLE AD

- Dementia syndrome in the absence of other neurological, psychiatric or systemic disorders sufficient to cause dementia, and in the presence of variations in the onset, in the presentation, clinical course.

UNCERTAIN/UNLIKELY AD

- Sudden onset
- Focal neurological findings.
- Early seizures or gait disturbance.



Clinical Course of AD

- Slowly progressive disease.
- Mild (MMSE 21-30), moderate (MMSE 11-20) and severe (MMSE 10 or below)
- Pathology begins years before any symptoms or functional compromise manifest.
- Early - memory impairment, personality changes, gait and posture normal, anomia, impaired abstraction, behaviour indifferent or delusional.
- Later - global cognitive impairment evident, gait impaired, behaviour agitated, stuporous or delusional.



Common Medical Problems in AD

- Falls and fractures
- Incontinence (urinary/faecal)
- Malnutrition with sarcopaenia
- Immobilisation with contractures and rigidity
- Depression
- Infections
- Delirium
- Seizures
- Other medical comorbidities - stroke, heart attack, arrhythmia



Vascular Dementia

- Distinguishing from AD
 - Onset - in multi-infarct dementia may be abrupt deterioration in cognitive functions or fluctuating stepwise progression of cognitive deficits.
 - Cardiovascular risk factors, previous stroke or TIA.
 - Focal neurological deficits.
 - Multiple infarcts on imaging.
 - In Binswanger's, subcortical pattern



Dementia with Lewy Bodies

Classical features to assist diagnosis:

- Parkinsonian type symptoms (may be mild)
- Visual hallucinations
- Memory loss (may be subtle) leading to very severe dementia.
- Fluctuating cognition
- Executive function deficits.
- Severe visuo-spatial deficits.
- Neurolept sensitivity (EP and cholinergic side effects)



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Parkinson's Disease and Dementia

- PD - progressive disorder of the CNS characterised by tremor, rigidity, bradykinesia.
- 60-80% of elderly patients with PD develop dementia after 10 years
- Possible causes:
 - Dementia with Lewy Bodies (DLB)
 - Dementia associated with PD - "subcortical dementia" (PD-D)
 - Alzheimer's disease (AD)



Dementia Diagnosis

- Memory assessment services
- History
- Cognitive and mental state examination
 - MMSE - be aware of limitations.
 - Other standard tests eg clock drawing
 - Assess affect
- Physical examination
- Review of medications (including OTC)
- Appropriate investigations
- Formal neuropsychological testing
 - Mild dementia, unusual features



Investigations

- “DEMENTIA SCREEN”
- MSU if delirium a possibility
- Consider CXR if indicated.
- Lumbar puncture not routine.
- Radiology – MRI preferred, CT more readily available
- Other imaging – SPECT
- Other tests if indicated eg EEG
- APOE, neurobiological markers (research)



Communicating results to patient and family

- Determine client and carer's expectations and preferences
- Remember the general principles of "breaking bad news"
- Offer supporting material (including further appointment and written information)
- Sometimes it will be a relief to "have an answer"



Options for care and “treatment”

- Pharmacotherapy usually forms a small component of the treatment plan.
- All carers and relevant staff should have access to dementia care training (including volunteers)
- Environment
 - both in residential care (dementia-specific) and home
 - Assistive technologies to maintain independence



Care Options

- Medications: blister packing, prompts & supervision.
- Cognitive stimulation programs.
- Services - HACC, CACP, D-EACH.
- Day Centres
- Respite (residential, in-home)
- Permanent care - or planning for the future.
 - 50% low care, 90% high care with cognitive impairment.



Behaviours of concern

- includes calling out, aggression and risky behaviours
- Often stressful for carers
- Resources such as DBMAS
- Judicious use of medications to treat anxiety, psychosis or depression



Cultural, ethnic and social issues

- Consider schooling and cultural factors in assessment, utilising professional interpreters when required
- Consider culturally appropriate services
- Consider persons social strengths



Pharmacotherapy

- Cholinesterase inhibitors
 - PBS prescribing criteria restrict therapy to certain groups
- Memantine
 - Very specific PBS criteria
- Antidepressants
 - Modern agents (eg SSRI) safer and better tolerated
- Antipsychotics
 - Try non-pharmacological interventions first (behavioural strategies, music, massage, aromatherapy) for challenging behaviours.
 - Increased risk of cerebrovascular accidents and death
 - Very cautious use in DLB (extrapyramidal toxicity).



How effective are the dementia drugs?

- Modest improvements in cognition, ADL and global function.
- About 50% of patients can be considered positive responders
- superior to placebo at 6 - 12 months.
- NICE guidelines revised to state consider use for mod-severe AD (MMSE 10-20), not milder.
- Possibly slows down progression of dementia and reduces nursing home admission ?also neuroprotective effects.



Other therapies

- Insufficient evidence to recommend Gingko biloba, vitamin E, anti-inflammatory medications, oestrogens
- Social supports are **the** most important management strategy.



Multi-disciplinary care

- Holistic care requires input from multiple professions and non-professional groups
- Peer support is often as valued as professional input
- Different perspectives may be critical at different points in the dementia journey



Care planning

- Health care (“Living Wills”)
- Financial
 - Testamentary capacity
 - Enduring power of attorney (EPA)
- Social
 - Respite for client and carer
 - Accommodation options
 - Driving - risks, testing
 - Risk of abuse - physical, financial



Addressing Caregiver Burden

- Identify any psychological distress and psychosocial impact on the carer.
 - Regular reassessment
- Individual or group education.
- Peer support with other carers.
- Support via telephone or internet.
- Psychological counselling (or CBT) if needed.
- Training courses about dementia, services and benefits, communication and problem solving.
- Involve the person with dementia if appropriate.
- Practical offerings - transport, services, Day centres, respite.
- Am I at risk? - genetic counselling, education (Mind Your Mind)
- Maintaining quality of life for the carer



Palliative Care

*Palliative care approach from time of diagnosis
until death (NICE Clinical Guideline 42)*

- Support QOL, death with dignity in place of own choosing.
- Access to palliative care services.
- Artificial feeding generally not beneficial in persons with severe dementia.
- Infections.
- Resuscitation status.
- Pain relief.
- Try to keep previously expressed preferences in mind. Discuss with carers and relatives.



Quality of life for patient and carer

- Improvement of quality of life (QoL) in dementia is a high priority for care and research
- Many people with dementia can report their QoL
- Utility of informant rating of QoL uncertain
- QoL does not necessarily decline as dementia advances (perhaps due to changing insight)



Enabling approaches

- Traditional time limited restorative rehabilitation approaches may have limited benefit for people with dementia
- Alternative adaptive strategies
- Enabling retained abilities to encourage independence and quality of life
- Enabling environments



Dementia and co-morbidities

- preventing complications and/or recurrence
- Optimising control of vascular risk factors
- Maintaining physical health and cognitive strengths
- High risk of delirium with intercurrent illness



Prevention

- Control of vascular risk factors
- Maintenance of physical health including physical activity
- Cognitive Activity



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