

# Managing Late Stage Dementia

Sandy Macleod



# Tithonus

- The Trojan lover of Eos (Aurora), the goddess of Dawn
- Eos laments that she will outlive her lover
- She asks Zeus for Tithonus to be made immortal
- But forgot to ask for him to be eternal youthful



# Tithonus

- Tithonus lived forever
- He became brittle, his mind deteriorated, his speech became a mere babbling
- But Eos doesn't abandon him
- She turns him into a cicada so no one will fault his mindless chirping and fragile body



# Dementia

- An insidious, global deterioration of intellect (problem solving), **memory** (short-term) and **personality** (coarsening) without impairment of level of consciousness.
- **Prevalence** – 10% in over 65 year olds, 20% in over 80 year olds
- **Decreasing incidence, increasing prevalence**

# Life Expectancy in Dementia: influencing factors

- Age of onset
- Type
- Stage
- Co-morbidity
- Cerebral reserve
- Social support
- Alcohol use
- Health care access
- ....

Median survival 4-5 years

Incurable

Dementia is a terminal illness

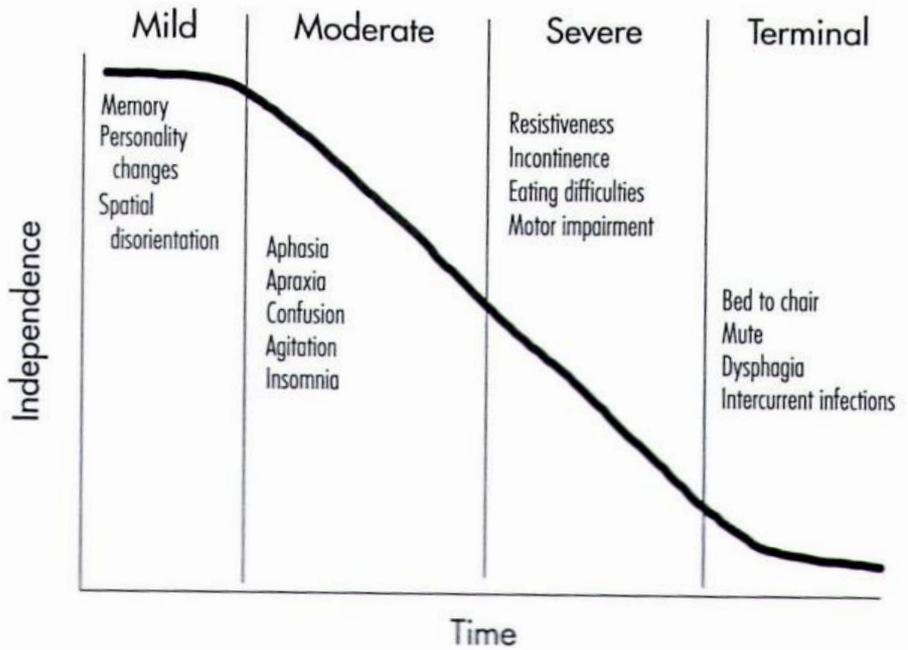


FIGURE 19-1. Course of Alzheimer disease and other progressive dementias

# Mrs H.P.

- 94 year old widow
- Advanced dementia
- Delirium - # humerus, UTI, hyponatraemia.
- Rx antibiotics, haloperidol
- Hx - # NOF, renal failure, TCC bladder, IHD, chronic pain
- Fluctuating agitation, calling out “help, help”, disorientation, hallucinations
- Rx haloperidol, olanzapine, melatonin, mirtazepine, benzodiazepines, morphine, levomepromazine
- Little clinical improvement after 3 months in-patient

## Alzheimer's Dementia

(dementia of unknown aetiology)

50%

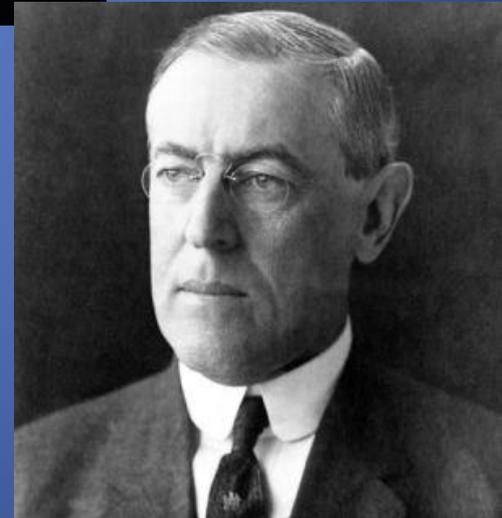
*Ronald Reagan*



## Vascular Dementia

20 - 30%

*Woodrow Wilson*



# Korsakoff's Psychosis Alcoholic Dementia



**Lewy Body Dementia (15%)**

Robyn Williams

**Multiple Sclerotic  
Dysmentia**

Jacqueline du Pré

**Huntington's Dementia**

Woody Guthrie

**Chronic Traumatic  
Encephalopathy (CTE)**

Howard Hughes

**Fronto-Temporal  
Dementia (MND/ALS) (5%)**

Chairman Mao

**HIV Dementia**

Rudolph Nureyev

Paraneoplastic, post-  
encephalopathic, hypothyroid,  
depressive pseudodementia...



# Principles of Dementia Care

- Mild – Moderate

Focus on Quality of Life, maintenance of function and independence.

- Moderate - Severe

Maximisation of Comfort.

Avoid overly aggressive, burdensome or futile treatments.

Allow Natural Death (AND)

# Symptoms of Terminal Dementia

- BPSD (Behavioural & Psychological Symptoms of Dementia) 100%
- Urinary incontinence 72%
- Pain 39-64%
- Constipation 59%
- Anorexia 57%
- Dyspnoea 46%
- Aspiration 41%
- Pressure ulcers 39%

Mitchell, *NEJM* 2009; McCarthy 1997

# Behavioural and Psychological Symptoms of Dementia (BPSD)

## Behavioural

- Personality changes (up to 90%)
- Wandering, shadowing (60%)
- Aggression (20–50%)
- Catastrophic reactions
- Screaming
- Hoarding
- Culturally inappropriate behaviours

## Psychiatric

- Depression (up to 80%)
- Agitation, restlessness (60%)
- Delusions (20–73%)
- Hallucinations (15–49%)
- Anxiety (12–50%)
- Misidentification (23–50%)
- Mania (3–15%)

# Neuropsychiatric Symptoms of Dementia

- Loss of insight/judgement
- Neglect of personal hygiene
- Fatigue ++
- Apathy
- Loss of appetite/cachexia
- Language / Linguistic regression
- Psychological regression
- Loss of independence, autonomy, personhood
- Loss of immunity
- Reverse sleep pattern
- +/- Depression
- Confusion/delirium
- Aggression/violence
- Agitation/irritability
- Impulsivity / Falls
- Disinhibited behaviours
- Catastrophic reactions
- Wandering
- Paranoia/psychosis
- Hallucinations
- Startle reflex
- Sundowning
- Rejection of care
- Enhanced will to live

# Philosophy of Clinical Management at the bedside

(in Medicine, particularly Psychiatry and Palliative Medicine)

- Identify symptoms
- Formulate the pathological processes of the bodily organ accounting for the symptoms  
(in disease we need a theory of why symptoms become manifest)
- **Investigations** (unlikely to be helpful, usually unnecessary)
- Intervene, if feasible

# J. Hughlings Jackson (1835-1911)

## Doctrine of Dissolution (after Spenser)

- CNS evolved on evolutionary principles
- organic injury results in re-adaptation at lower and less evolved level of functioning to maintain homeostasis
- more primitive functioning 'released' (positive or compensatory symptoms)
- negative (loss) symptoms and positive (compensatory) symptoms



# Neuropsychiatric Symptoms of Dementia

## Symptoms of Loss

- Loss insight/judgement
- Neglect of personal hygiene
- Fatigue
- Apathy
- Loss of appetite/cachexia
- Language / Linguistic regression
- Psychological regression
- Loss of independence, autonomy, personhood
- Loss of immunity
- Reverse sleep pattern
- Depression

## Compensatory Symptoms

- Confusion/delirium
- Aggression/violence
- Agitation/irritability
- Impulsivity / Falls
- Disinhibited behaviours
- Catastrophic reactions
- Wandering
- Paranoia/psychosis
- Hallucinations
- Startle reflex
- Sundowning
- Enhanced will to live
- Rejection of care

The aged / damaged brain does not  
have the plasticity to allow  
anatomical / functional repair:

Reversal of / treatment of  
loss symptoms is futile.

# Management of Loss Symptoms

- Supportive care - maintenance of function entirely dependent on external assistance and benign maternalism/paternalism
- Environmental care- simple, safe, secure
- Education & Support of Family
- **Pharmacotherapy** — deprescribing medication regime (statins, antihypertensives ...), thiamine for alcoholics, ?melatonin, cholinesterase inhibitors and psychostimulants ineffective (except in very early stage)



**Lightening at End-of-Life does  
not occur in Advanced  
Dementia**

# Management of Compensatory Symptoms

- Environmental care and safety
- Supportive Interpersonal care – attentive nursing care
- Falls prevention (cease benzodiazepines, supervision ...)
- Raise deliriant threshold, Rx delirium
- Pharmacotherapy
  - Major tranquillizers for psychotic symptoms
  - ? Major tranquillisers for aggression
  - ? SSRIs for agitation / aggression
  - Cyproterone/SSRIs sexual aggression
  - Opioids, benzodiazepines for agitation

# Suffering in End-stage Dementia

- High 63%, Intermediate 30%, Low 7%

Using the 'Mini Suffering State Examination' (Aminoff , 2004)

- 54% died peacefully (relatives' opinion)

(de Roo 2015)

“How people die remain in the memory of those  
who live on” Dame Cecily Saunders



5

# Clinical Course of Advanced Dementia in Nursing Home Residents

Mitchell *NEJM*, 2009

- 54% died over 18 months
- Probability of – pneumonia 41%, febrile illness 53%, eating problem 86%
- 6 month mortality and cause of death - pneumonia 47%, febrile illness 45%, eating problem 39%

**6 month mortality 25% (= metastatic breast cancer)**

# Predictors of Death in Dementia within 6 months (Sachs 2004)

- Non-ambulation
- Loss of meaningful conversation
- Dependent on ADL assistance
- Weight loss >10%
- Recurrent infections
- Multiple pressure areas
- Hip fracture
- Pneumonia

# Signs and behaviours of dying with dementia

Regnard and Hockley 2003

- Deterioration day by day, or faster
- Increasing drowsiness or torpor
- Increasingly bedbound
- Peripherally cyanosed and cold
- Diminishing food, fluid or oral medication
- Altered breathing pattern

# Stage 7, Dementia

Reisberg, NYU, 2010

- Requires continuous assistance with ADLs
- Speech limited/lost
- Loss of independent ambulation
- Loss of independent sitting without arm rests
- Loss of ability to smile
- Loss of ability to hold up head without assistance
- Physical rigidity, contractures
- Primitive reflexes

# Causes of Death in Dementia

- **Inanition** (Latin *inanis*, empty) (genug syndrome, Zahl Kam Rauf , vital exhaustion, brain stem neuronal death)
- **Pneumonia / infections**
- **Cachexia**
- **Falls**
- **Medical misadventures**
- **Self-neglect**
- **Suicide**
- .....

# Place of Dementia Death

- Home - 1985-91, 25%
  - 1992-98, 15% (Kay, 2000)
- Residential/Nursing Homes
  - 1985-91, 14%
  - 1992-98, 32% (Kay, 2000)
  - 1997, 41% (McCarthy, 1997)
- Hospital
  - 1985-98, 56% (Kay, 2000)
- Institutional Care at death 76% (Keene, 2001)

# Management Controversies in Advanced Dementia

# Dementia and Social Death

- “socially he is already dead, though his body remains biologically alive” (Glaser & Strauss, 1966)
- “death-in-life” (Kastenberg, 1988)
- ? loss of personhood = death

? definition of death

Sweeting & Gilhooly, 1997

# Dying with 'Dementia and Dignity'

- Multiple losses, including autonomy
- Social death
- Institutional care
- ....

Is “Dying with Dementia and Dignity” an oxymoron?

# Delirium and Dementia

- Delirium worsens dementia severity
- Delirium a strong risk factor for incident dementia and cognitive decline in the elderly

Davis et al., *Brain* 2012

**Delirium should be aggressively treated**

# Efficacy of Antipsychotics for Dementia

Corbett, *BMJ* 2014

- 16% receive antipsychotics in UK (and reducing)
- Modest clinical benefit for aggression with risperidone < 2 mg
- No benefit for non-aggressive symptoms, including psychosis
- High placebo response
- No evidence for quetiapine, or other neuroleptics
- Best practice guidelines suggest 12 weeks of Rx

!!!

Only risperidone registered for use in dementia

Olanzapine preferable w.r.t. efficacy, adverse effects (ADM)

# Medication Adverse Effects

- **Antipsychotics:** neuroleptic sensitivity (DLB), parkinsonism, akathisia, sedation, peripheral oedema, chest infections, accelerated cognitive decline, stroke risk, hypotension.
- **Benzodiazepines:** sedation and falls risks.
- **Antidepressants:** hyponatraemia, serotonin syndrome, anticholinergic (delirium, urinary retention, postural hypotension, constipation... avoid tricyclics).

**burden v. benefits**

# Antipsychotics / Major Tranquillisers

stroke risk increased 3-fold  
mortality increased 1.5-fold  
accelerated cognitive decline  
(probably similar risk with all antipsychotics)

Do they merely enhance loss symptoms  
(and maybe improve Quality of remaining supported Life)  
but accelerate dying ?

# Managing Dementia Violence

Violence secondary to: frustration, misunderstanding, disinhibition, impulsive, characterological, situational, personal grievances, paranoid / psychotic ideations, hallucinations, loss of autonomy ....

- Defusing techniques
- Pharmacology
- Restraint

Should staff tolerate physical assaults in the workplace?

# Resuscitation

- CPR – x 3 less likely to be successful in cognitively impaired (similar to that in metastatic cancer)(Ebell, 1998)
- CPR associated with harm
- CPR undignified (in dementia care facilities)
- Futile (1% of residents with dementia discharged alive from hospital following CPR)

CPR should not be the default position in dementia units

# Pneumonia

- Pneumonia mortality in severe dementia 53% c.f. controls 13% (Morrison & Siu, 2000)
- No difference with antibiotics (Fabiszewski, 1990)
- Discomfort eased with antibiotics (van der Steen, 2002)

Is pneumonia “old man’s friend”?

# *On Certain Features in the Prognosis of Pneumonia – W. Osler, 1896*

- 124 cases
- “no other disease kills from 1/4 to 1/3 of all persons attacked” (3/4 to 2/3 survived pre-antibiotics)
- “so fatal is it, that to die of pneumonia is said to be the natural end of elderly people”
- “pneumonia is a self-limiting disease, and it runs its course uninfluenced in any way by medicine”

# Hastened Death in Dementia

- Suicide risk low (Haw 2009), risk not increased (Draper 2015)
- Exception: Huntington's Disease (X3 risk), highest risk within 3 months of diagnosis and young onset (?HIV/AIDS)
- Impaired competence is protective against suicide, except if depression or alcohol complicates (Harris, Barraclough 1997)
- Requests for euthanasia in dementia extremely rare

I know of 2 HD suicides, and 1 HD patient requesting hastened death in 33 years of practice

# Artificial Nutrition in Dementia

Eating Problems – loss of appetite, loss of hunger, dyspraxia, swallowing difficulties, cachexia

- Tube feeding does not improve survival (Finucane, 1999)
- Associated with patient harms – aspiration pneumonia, infected PEG sites

Appropriate only if dysphagia temporary (Gillick, 2000)

# Dementia and Pain

- Decreased likelihood of analgesia
- Stoical elderly describe “aching”, “soreness”, “discomfort” – but not “pain”
- Pain tolerance enhanced in AD (pain processing impaired), not pain thresholds (feel pain, but experience it with less / different distress)
- Verbal expressions of pain & self-rating scales difficult to interpret – facial, (atypical) behavioural indicators  
**If in doubt prescribe (initially low dose) analgesia**

# Common procedures and pain

(10-point numeric rating scale)

In last 3 months of life 41% underwent at least 1 burdensome intervention (Mitchell, 2009)

Procedure/experience	Mean pain rating
Nasogastric tube	6.9
Phlebotomy	4.6
Indwelling urethral catheter	4.3
Intramuscular injection	3.9
Mechanical restraints	2.4
Movement (chair to bed)	2.0
Chest radiograph	1.4
Vital signs taken	1.3
Waiting for a procedure	1.1

# Advance Care Planning in Dementia

- Timing of documentation – needs to be pre-illness
- Disability paradox – change of decision when a disease is experienced
- Organic regression induces survival behaviours
- EPoA is reliant upon a sensible surrogate
- Hastened death without an explicit request 1.7% Belgian deaths 2013 (0.4% NLDs 2005). How many had dementia?

Theoretically a great idea but...

If he were to “lose his marbles” he would want his wife,  
with the help of his GP, to “end things”

Bob Hawke

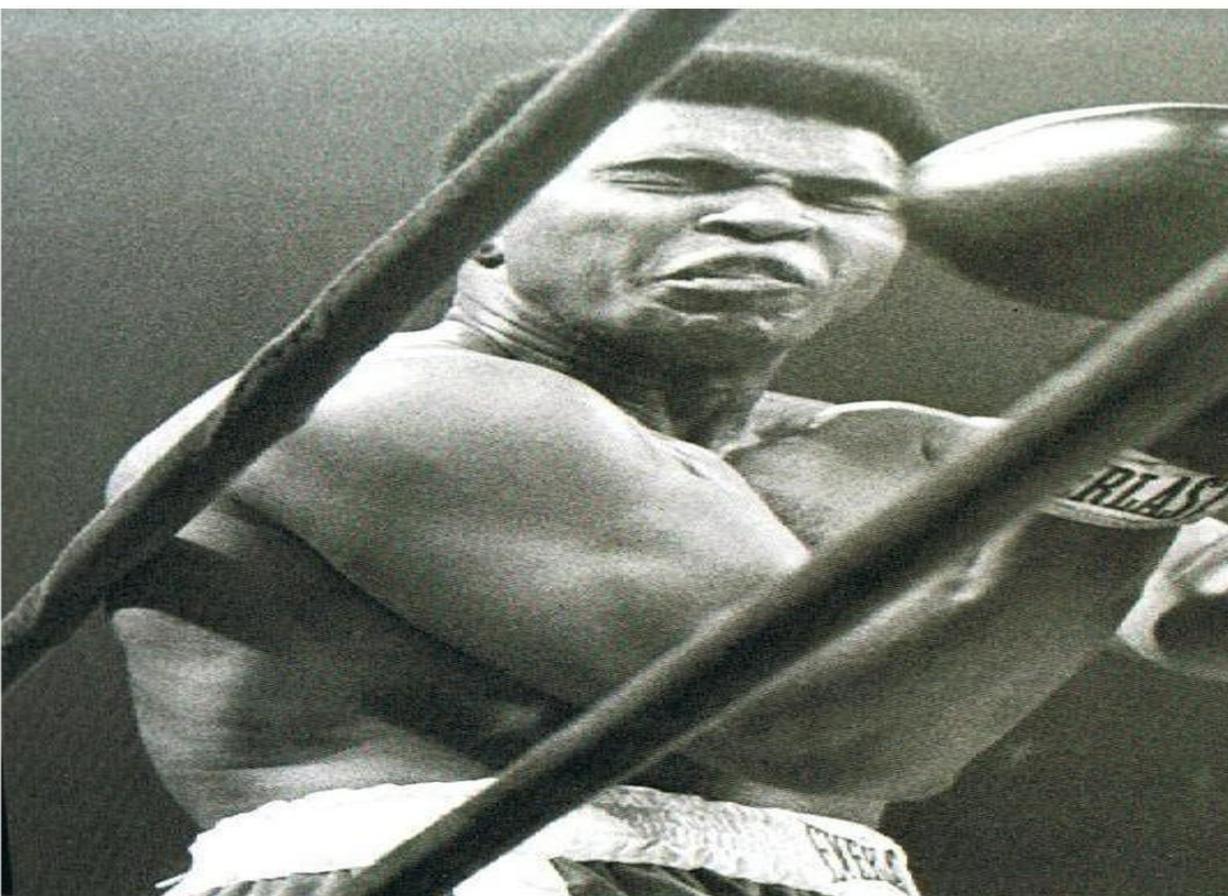
RN Breakfast, ABC 14/04/16



# The obligated, obdurate carer

# Parkinson's Dementia / Dementia Lewy Body

- An emerging “epidemic”
- Williams SS. The terrorist inside my husband's brain. *Neurology* 2016; 87: 1308-11.



# Palliative Sedation in Dementia

- Decision influenced by prognosis, staff and relative's opinions, but not the patient's opinion as they are incompetent
- Indications in dementia – ?, delirium, pain, ~~dyspnoea, nausea, haemorrhage, existential distress~~
- Risks – DVT, aspiration pneumonia, decubitus ulcers
- Tendency to marginally prolong life

? definition of '*intractable suffering*' in dementia

# Mrs H.P.

- Morphine 40mg
- Clonazepam 1mg
- Levomepromazine 12.5 mg
- SC pump over 24 hours
- Comfortable
- Died 21 days later



# “Dying of Cancer is the Best Death”

## Types of Death

- Sudden - difficult for survivors
- Dementia – “long, slow and may be the most awful”
- Organ Failure – “too much in hands of doctors”
- Cancer – time to complete tasks, reflect, prepare , say goodbye

**Richard Smith** ex-editor BMJ, 2014 blog



# Thankyou

Does good care enhance quality of remaining life  
or prolong dying of dementia?