



Dementia End-of-Life Care

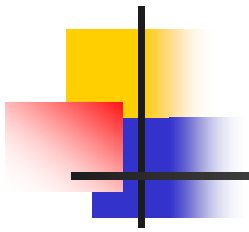
Dr. L. Badenhorst

- **Riverview Health Centre**
 - Special Care Unit
 - Chronic Care
 - Personal Care Home
- **Deer Lodge Centre**
 - Special Care Unit



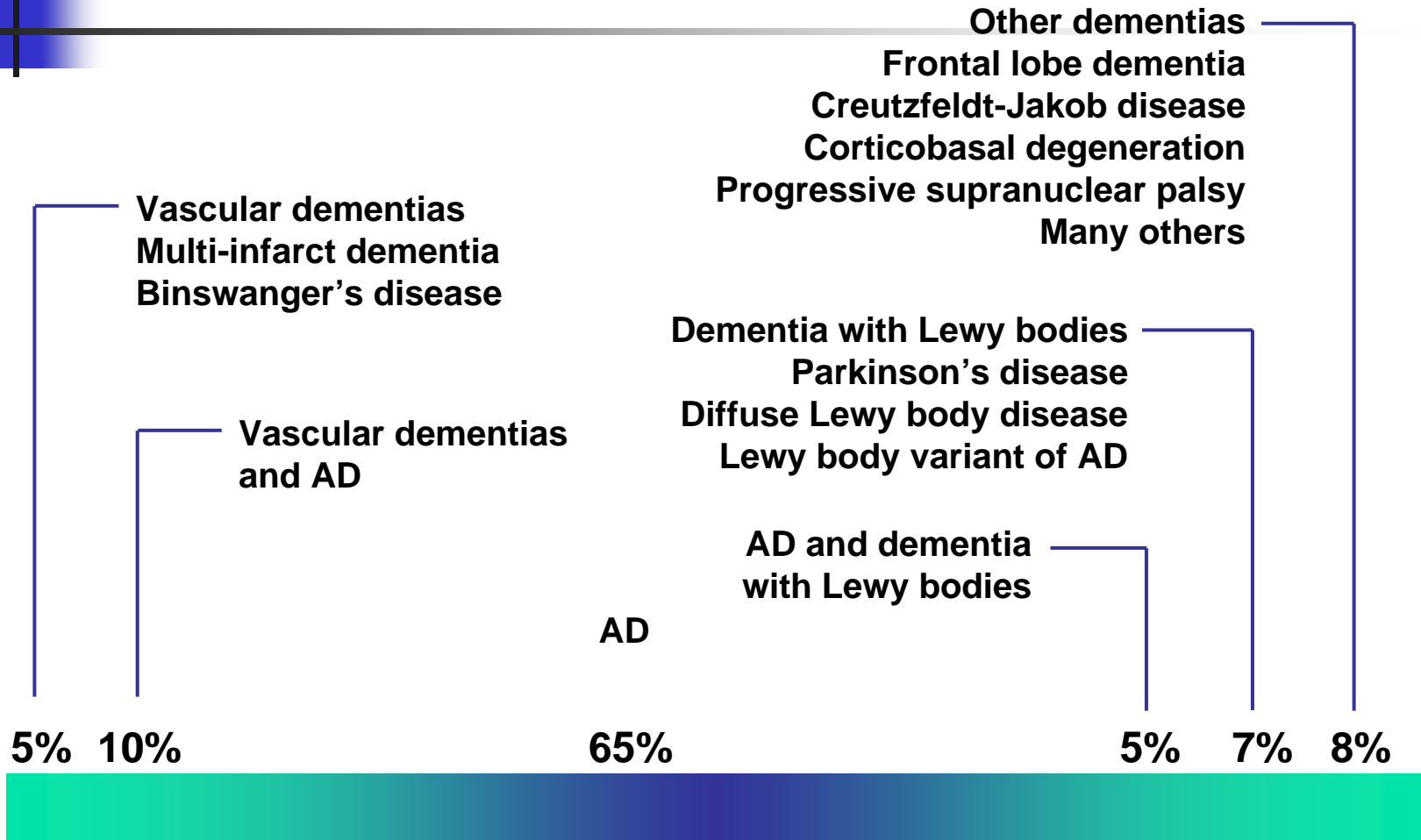
End-of-Life Care in Dementia

- ⇒ Definitions
 - ⇒ Dementia
 - ⇒ Palliative Care
 - ⇒ End-of-Life care
- ⇒ Challenges
 - ⇒ Diagnosing End-Stage Dementia
 - ⇒ Managing End-Stage Dementia
- ⇒ Conclusions
- ⇒ Discussion



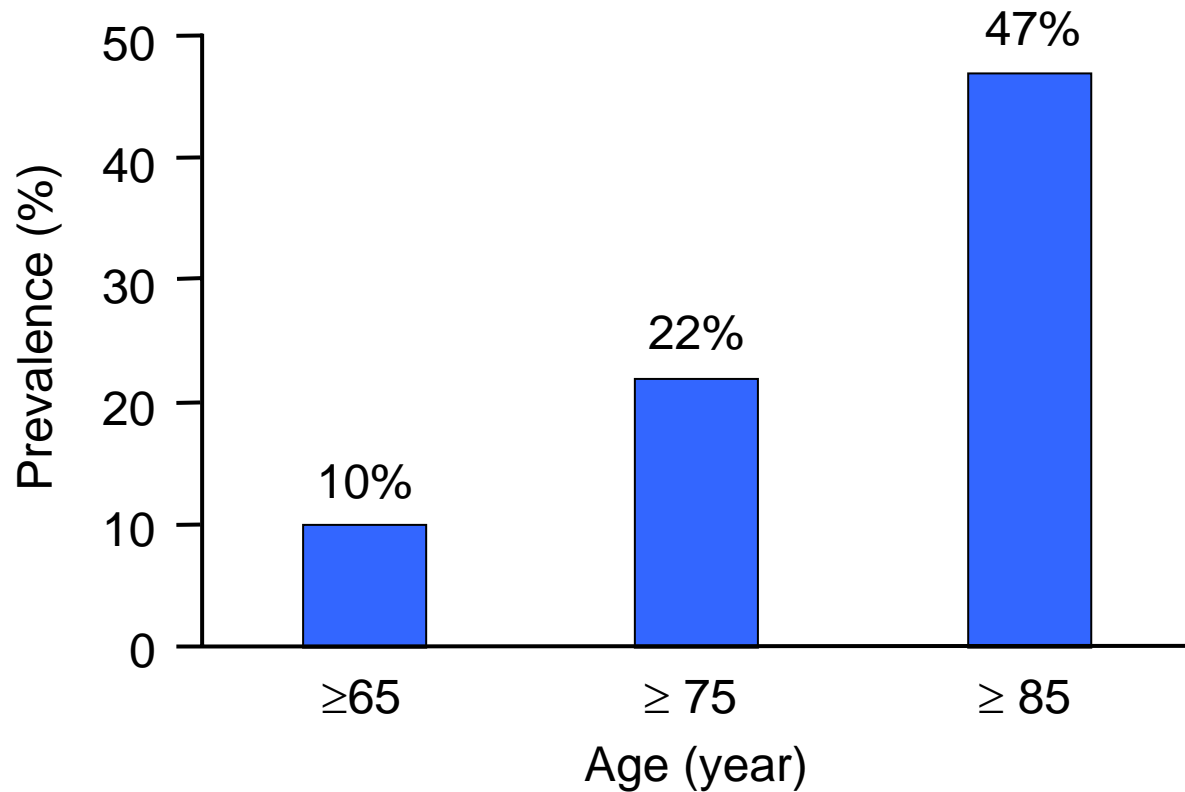
Dementia is a global impairment of every aspect of the intellect, memory and personality without alteration of consciousness.

Differential Diagnosis of Dementia



Dementia

Prevalence Increases with Age

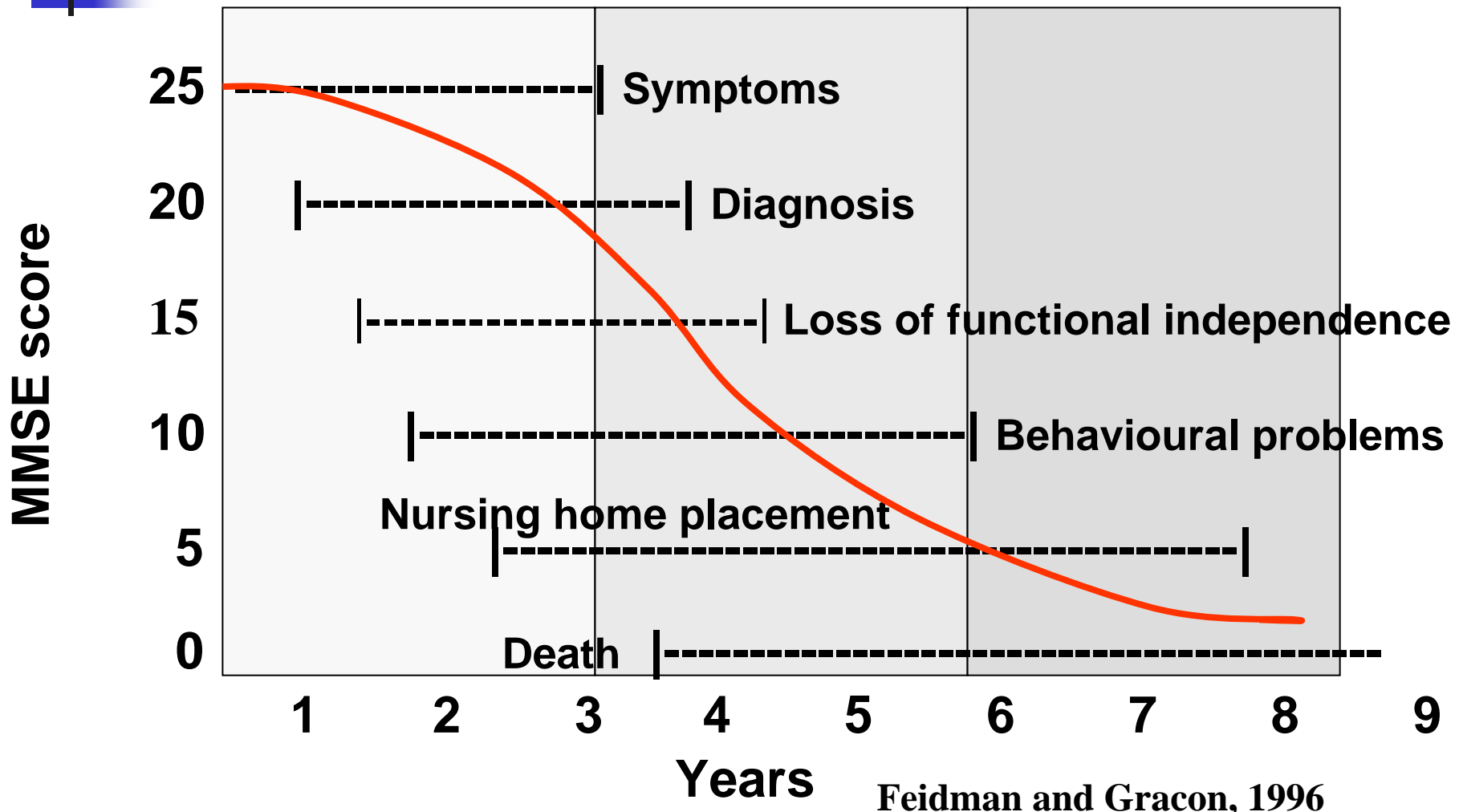




Alzheimers: Overview

- Progressive, degenerative CNS disorder
- Characterised by memory impairment plus one or more additional cognitive disturbances
- Gradual decline in three key symptom domains
 - Activities of daily living (ADL)
 - Behaviour and personality
 - Cognition

Alzheimers: Progression





Hospice Palliative Care

Definition:

- ⇒ Relief of suffering and improved quality of life for persons who are dying or are bereaved.
- ⇒ Comfort, dignity and best quality of life for both the person and family.
- ⇒ Physical, psychological, social, cultural, and spiritual needs.



Palliative Care Delivery

Primary Care

**Secondary
Care**

**3^o
Care**



Curative vs. Palliative Care

**Curative
Care**

**Palliative
Care**

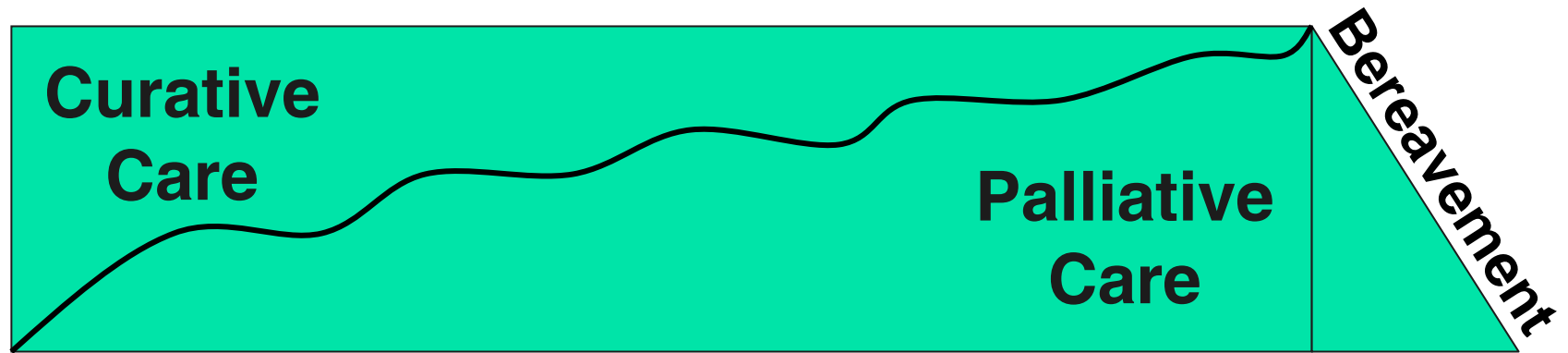
Diagnosis

Death

Disease Trajectory



Curative vs. Palliative Care



Diagnosis

Death

Disease Trajectory



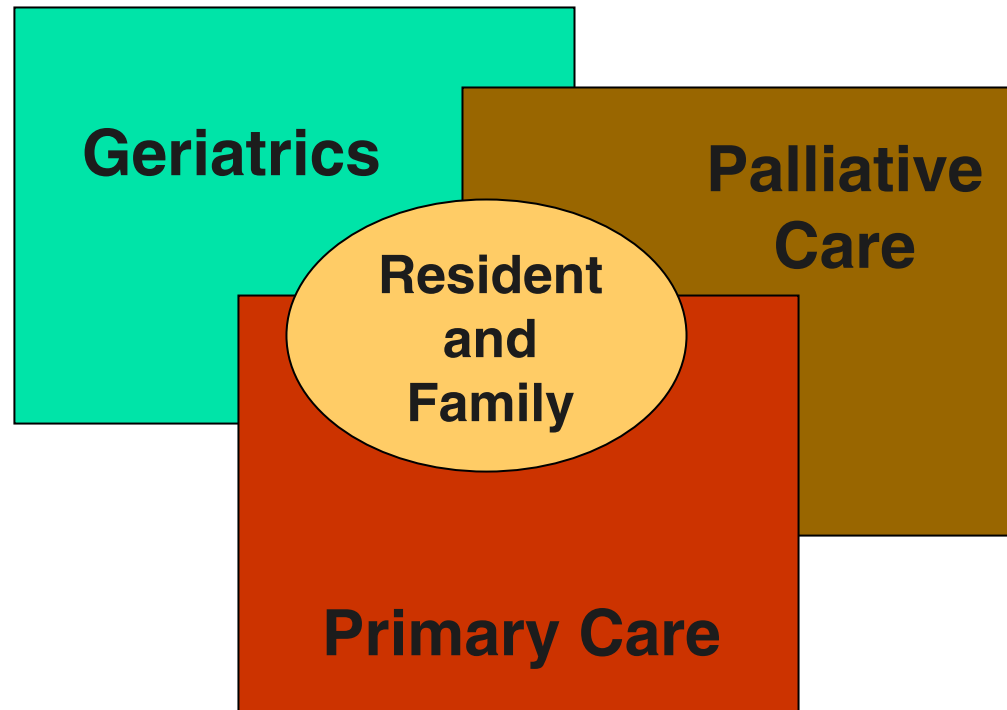
End-of-Life Care for Seniors

- requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions.
- is sensitive to personal, cultural and spiritual values, beliefs and practices.
- encompasses support for families and friends up to and including the period of bereavement.



End-of-Life Care for Seniors

Delivery Model:





Successful Ageing?

- The success in ageing has led to viewing these aged individuals (successful in their efforts) as a “burden” to society
- This is especially the case for frail elders suffering from dementia



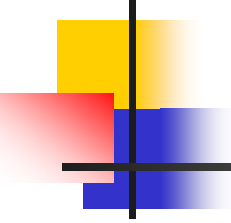
Challenges in End-of Life Care

- Co-morbidities
- Cultural issues
- Directives for care
- Effects of aging
- Grief and Loss

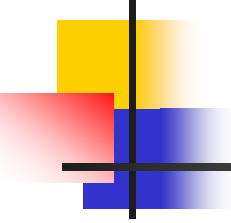


PCH scenario

- Changing patient population
 - Multiple pathology
 - Increased frequency of dementia,
 - Reduced length of stay
- No change in staffing
- Non-adaptive environments

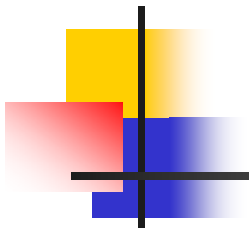


If you were dying, would
you choose to die in
your institution?

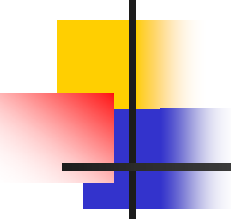


If your mother was dying,
would you want her to die
in your institution?

Your partner?

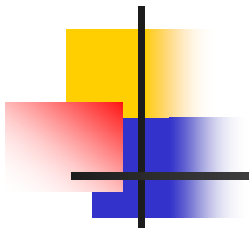


If your mother or partner had dementia, would you want him or her to die in your institution?



The dying need the friendship of the heart . . . its qualities of care, acceptance, vulnerability; but they also need the skills of the mind - the most sophisticated treatment medicine has to offer.

Dame Cicely Saunders



Dementia
is a
Terminal Illness



Diagnosing Terminal Dementia

- Denial of terminal illness
- Inability to predict the time of death
- Health care financial incentives



Mild AD (MMSE 21-30)

IMPAIRMENT

Cognition

- Recall/learning
- Word finding
- Problem solving
- Judgement
- Calculation

Function

- Work
- Money/shopping
- Cooking
- Housekeeping
- Reading
- Writing
- Hobbies

Behavior

- Apathy
- Withdrawal
- Depression
- Irritability



Moderate AD (MMSE 10-20)

IMPAIRMENT

Cognition

- Recent memory (remote memory unaffected)
- Language (names, paraphasias)
- Insight
- Orientation
- Visuospatial ability

Function

- IADL loss
- Misplacing objects
- Getting lost
- Difficulty dressing (sequence and selection)

Behavior

- Delusions
- Depression
- Wandering
- Insomnia
- Agitation
- Social skills unaffected



Severe AD (MMSE <10)

IMPAIRMENT

Cognition

- Attention
- Difficulty performing familiar activities (apraxia)
- Language (phrases, mutism)

Function

- Basic ADLs
 - Dressing
 - Grooming
 - Bathing
 - Eating
 - Contenance
 - Walking
 - Motor slowing

Behavior

- Agitation
 - Verbal
 - Physical
- Insomnia



End-Stage Dementia: Diagnosis

A. Cognition

B. Function

C. Behaviours



A. Cognition

- Amnesia
- Agnosia
- Aphasia
- Apraxia
- Loss of executive function



B. Function

- IADL & ADL
- Nutrition
- Continence
- Sleep



C. Behaviour

- Paranoia
- Misidentification
- Agitation
- Pacing
- Insomnia



Predicting End of Life...

A risk score based on 12 variables from the MDS estimates 6-month mortality for nursing home residents with advanced dementia with greater accuracy than existing prognostic guidelines.

Mitchell, Kiely, et al

JAMA 2004;291:2734-2740



Functional Assessment Staging

- 7 major stages
- 16 successive stages and substages
- National Hospice Organization suggests FAST stage 7c as cutoff to enroll.
 - Patient had to have progressed through all the previous stages of the FAST scale *sequentially*.



Comparing apples with apples...

- Variables chosen from MDS to most closely match the description of FAST stages 6 through 7c
- 11430 (6799/4631) participants
- At least 65 years old
- All with advanced dementia
- New admission to nursing home



Variables: Diagnoses

- Diabetes mellitus
- Congestive heart failure
- Asthma or emphysema/COPD
- Cancer
- Pneumonia or other URTI
- Cardiac dysrhythmias
- Any fracture in previous 3 months
- Septicemia



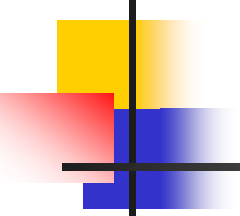
Variables: Other health conditions

- Edema
- Hallucinations or delusions
- Recurrent lung aspirations
- Bowel incontinence
- Weight loss (>5% previous 30 days;
>10% previous 180 days)
- Dehydration
- Insufficient fluids (not consume almost all liquids previous 3 days)



More health variables

- Fever
- Pressure ulcers (some loss of skin integrity)
- Shortness of breath
- Chewing or swallowing problems
- No more than 25% eaten of most meals
- Not awake most of day
- Need for oxygen therapy in previous 14 days
- Body Mass Index



Multivariate Proportional Hazards Model of Characteristics Associated With 6-Month Mortality Among Residents With Advanced Dementia in the Derivation Cohort (n = 6799)

Characteristic	HR (95% CI)
Activities of daily living score = 28*	1.9 (1.7-2.1)
Male sex	1.9 (1.7-2.1)
Cancer	1.7 (1.5-1.9)
Oxygen therapy	1.6 (1.4-1.8)
Congestive heart failure	1.6 (1.4-1.7)
Shortness of breath	1.5 (1.3-1.9)
<25% Food eaten	1.5 (1.4-1.7)
Unstable medical conditions	1.5 (1.3-1.6)
Bowel incontinence	1.5 (1.3-1.7)
Bedfast	1.5 (1.3-1.7)
Age _83 years, median	1.4 (1.3-1.6)
Not awake most of day	1.4 (1.2-1.6)

Abbreviations: CI, confidence interval; HR, hazard ratio.

*Total activities of daily living score (0-28) is the sum of scores in each of 7 domains of function including bed mobility, dressing, using the toilet, transfer, eating, grooming, and locomotion. Each is scored on a 5-point scale (0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence). A score of 28 represents complete functional dependence.



Mortality Risk Index Score

- Point value according to hazard ratios in final multivariate model from derivation cohort.
- Summed for each resident
- Rounded to next higher integer
- Ranged 0 to 19
- Scores with similar mortality rates combined



Mortality Risk Index Score

- 0 ➤ 8.9%
- 1 - 2 ➤ 10.8%
- 3 - 5 ➤ 23.2%
- 6 - 8 ➤ 40.4%
- 9 - 11 ➤ 57%
- ≥ 12 ➤ 70%

Proportion of Residents With Advanced Dementia in Each Risk Category and Those Who Died Within 6 Months of Nursing Home Admission in Derivation (n = 6799) and Validation Cohorts (n = 4631)

<i>Risk Score*</i>	Total No. (%) Residents		No. (%) Residents Who Died	
	<i>Derivation Cohort</i>	<i>Validation Cohort</i>	<i>Derivation Cohort</i>	<i>Validation Cohort</i>
0†	272 (4.0)	56 (1.2)	4 (1.5)	5 (8.9)
1-2	938 (13.8)	278 (6.0)	79 (8.4)	30 (10.8)
3-5	3141 (46.2)	1755 (37.9)	666 (21.2)	407 (23.2)
6-8	1795 (26.4)	1727 (37.3)	732 (40.8)	698 (40.4)
9-11	517 (7.6)	648 (14.0)	332 (64.2)	369 (57.0)
>=12	136 (2.0)	167 (3.6)	109 (80.1)	117 (70.0)

*Risk score is based on point assignments from hazard ratios obtained from the derivation cohort.

†Residents with a risk score of zero did not have any of the characteristics included in the final prognostic model.



Estimate 6-month Prognosis

- ADL Scale = 28
- Male gender
- Cancer
- Congestive Heart Failure
- Need for oxygen therapy
- Shortness of breath
- Less than 25% of most meals eaten
- Unstable overall condition
- Bowel incontinence
- Bedfast
- Age over 83
- Not awake most of the day



Management of End-Stage Dementia

- Accommodate *Cognition*
- Optimise *Function*
- Modify *Behaviour*



BPSD

- Biological triggers
 - neuro-chemical
 - delirium
- Psychosocial triggers
 - Premorbid personality
 - Prior psychiatric illness
 - Change in social milieu



Meds associated with BPSD

- Antipsychotics
- Paxil
- TCAs
- Steroids
- Stimulants
- Anticonvulsants
- Anti-histamines
- Anti-parkinsons
- Narcotics
- Alcohol



Meds associated with BPSD

- Diuretics
 - Furosemide
 - HCT
 - Triamterene
- Digoxin
- Theophylline
- H2 blockers
 - Ranitidine
- Isordil
- Nifedipine
- Warfarin



Environmental Interventions

- Calm consistent environment
- Emphasize cognitive strengths
- Music / Light / Pets
- Occupational planning
- Programming
- Safe environment for wandering



Clinical Interventions

- Treat pain
- Manage constipation
- Correct sensory impairment
- Pharmacotherapy



“Pharmaco-resistive” symptoms

- Resistance with personal care
- Wandering, pacing and exit-seeking (including door pounding)
- Inappropriate sexuality
- Inappropriate voiding
- Inappropriate verbalising (calling out, screaming, foul language, repetitive questions)



“Pharmaco-sensitive” symptoms

- Aggression
- Anxiety
- Depression
- Insomnia
- Physical and/or spiritual discomfort



Pharmacotherapy in Dementia

- **START LOW, GO SLOW and CHECK OFTEN!**
- Combine with non-pharmacologic assessment and management
- Tolerability to agents is often different depending on age, body mass, gender and diagnosis
- **REVIEW and REDUCE!**



Medications...

- Anti-psychotics
- Anti-depressants
- Benzodiazepines
- Anti-convulsants
- Others



Anti-psychotics...

- Good evidence for their use
- Atypicals less risk of TD
- Fewer side effects/more tolerable
- Examples:
 - Risperidone 0.25 to 1.0 mg per day
 - Olanzapine 2.5 to 5 mg per day
 - Quetiapine 25 to 300 mg per day



Anti-psychotics...

- Typicals have higher risk of TD
- More side effects
- Examples:
 - Haldol 0.5 mg to 5 mg per day
 - Nozinan 5 mg to 100 mg per day
 - Loxapine 5 to 50 mg per day
 - Chorpromazine 25 to 100 mg per day



Anti-depressants...

- Evidence for treatment of comorbid depression, anxiety, obsessions, and some irritability
- SSRI's are first line
- Choice vs side-effects



Benzodiazepines...

- Good for short term relief and anxiety
- Some evidence for restless legs, myoclonus
- Problems:
 - Tolerance to effects
 - Worsens cognitive status
 - Paradoxical agitation
 - FALLS!!!



Anti-convulsants...

- Good evidence for treatment of mood lability, aggression, agitation
 - Carbamazepine 50 to 600 mg per day
 - Valproate 125 to 750 mg per day
 - Gabapentin 300 to 1800 mg per day
- Multiple Interactions



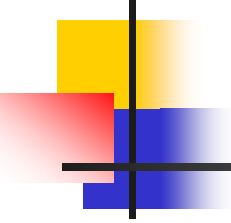
Others...

- ACEI's
 - Not usually initiated in terminal dementia
- Hormones
 - Provera 150 mg weekly or monthly
- Trazadone
 - 25 to 100 mg as sedative



Food for Thought

- Ageing is the 20th century success story
- Goal: increase quality of life not just life expectancy
- Individuals with dementia present a special challenge



“the life span of any civilization can be measured by the respect and care that is given to its elderly citizens and those societies which treat the elderly with contempt have the seeds of their own destruction within them”.

Arnold Toynbee