# End of life care in dementia

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# Mrs EN, aged 89

- Care home resident
- Breathless, more confused, drowsy, poor oral intake
- Dementia, diabetes, osteoarthritis
- Temp 38.5, drowsy, RR 28, Sats 89%
- BP 110/65. No speech
- CXR patchy consolidation right base
- WCC 15, CRP 95, Urea 12.5, Lactate 2.0
- Given oxygen, IVI, tazocin (3 doses)

# Mrs EN, aged 89

- Remained drowsy and de-saturating overnight
- Seen by consultant respiratory physician – for LCP
- Transfer ward

# Mrs EN, aged 89

- Two days later
- Alert and undistressed
- Talking, sat out, ate breakfast
- Discussed with daughter, accepts she is approaching end of life, but ‘not yet’
- LCP rescinded
- Antibiotics re-commenced
- Swallow safe
- Discharged back to care home

# What went wrong?

- Failure to recognise delirium
- Failure to collect collateral information
- Failure to ascertain existence of LPA, CAD or ADRT
- Failure to consult daughter
  - Previously expressed views
  - Values and preferences
  - Any other factors she might take into account
  - Family and other carer views
- Transition to EOLC is process not event

# Mrs MM, aged 88

- Unwell 48h
- Admitted drowsy, pyrexial, breathless
- T39$^{o}$C, BP110/58, P116, $SaO_2$ 97%
- Urinary retention, faecally impacted
- Mumbled speech, generalised increased tone, fixed flexion both knees
- CRP 188, coliform in blood, bacturia and pyuria
- iv tazocin, iv fluids

# Mrs MM, drug history

- Olanzapine 20mg/d
- Simvastatin
- Ramipril
- Insulatard
- Omeprazole
- Aspirin
- Sodium docusate

# Mrs MM

- Refugee from Nasser 1956
- Husband died 20 years ago
- 5 children
- Dementia, diabetes, osteoarthritis
- Lives in NH, hoist transfer

# Mrs MM, first week

- Severe cognitive impairment, little communication
- Laxatives successful
- Eating and drinking little – refuses
- Oral apraxia, no local or metabolic cause
- Sub cutaneous fluids

# Mrs MM

Multiple conversations with family

- Oral intake, tube feeding
- Antipsychotic drug
  - previous delusions of poisoning
- Cognition worse over past year
  - forgetful, mixing languages, apraxic
- Preferences and wishes
  - talked about wanting to die, but not in hospital

# Mrs MM

… but unhappy with current nursing home

# Mrs MM

- Remained in hospital
- Oral intake remained poor, but not nothing
- Variably alert in bed
- Little communication
- Undistressed
- Died 10 weeks later

# What went wrong?

- Prognostication
- No advance care plan
- Place of care
- Difficult period for family

# What is?

**Palliative care**

is an approach that improves quality of life of patients and their families, facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

WHO 2002

# Dementia

A. Multiple cognitive deficits

1.Memory impairment

2. One or more of:
(a) aphasia
(b) apraxia
(c) agnosia
(d) disturbance in executive functioning

B. Impairment in social or occupational functioning, decline from a previous level of functioning.

C. Gradual onset, progressive decline.

D. Not due to specified other conditions…

E. … or delirium.

DSM IV

# Dementia subtypes

- Alzheimer’s disease (31%)
- Vascular (22%)
- Mixed (25%)
- Lewy body (11%)
- Fronto-temporal (8%)
- Rarities

# The problem with dementia

- Activities of daily living
- Behavioural and psychological symptoms
- Decision making
- Carer strain
- Progression to end of life care

# Experience of dementia

- Neurological impairment
- Personality
- Biography
- Mental and physical health
- Social environment and relationships

# Person-centred care

- Value people with dementia and those who care for them
- Individualised care
- Perspective of person with dementia
- Social environment

Kitwood 1997, Brooker 2007

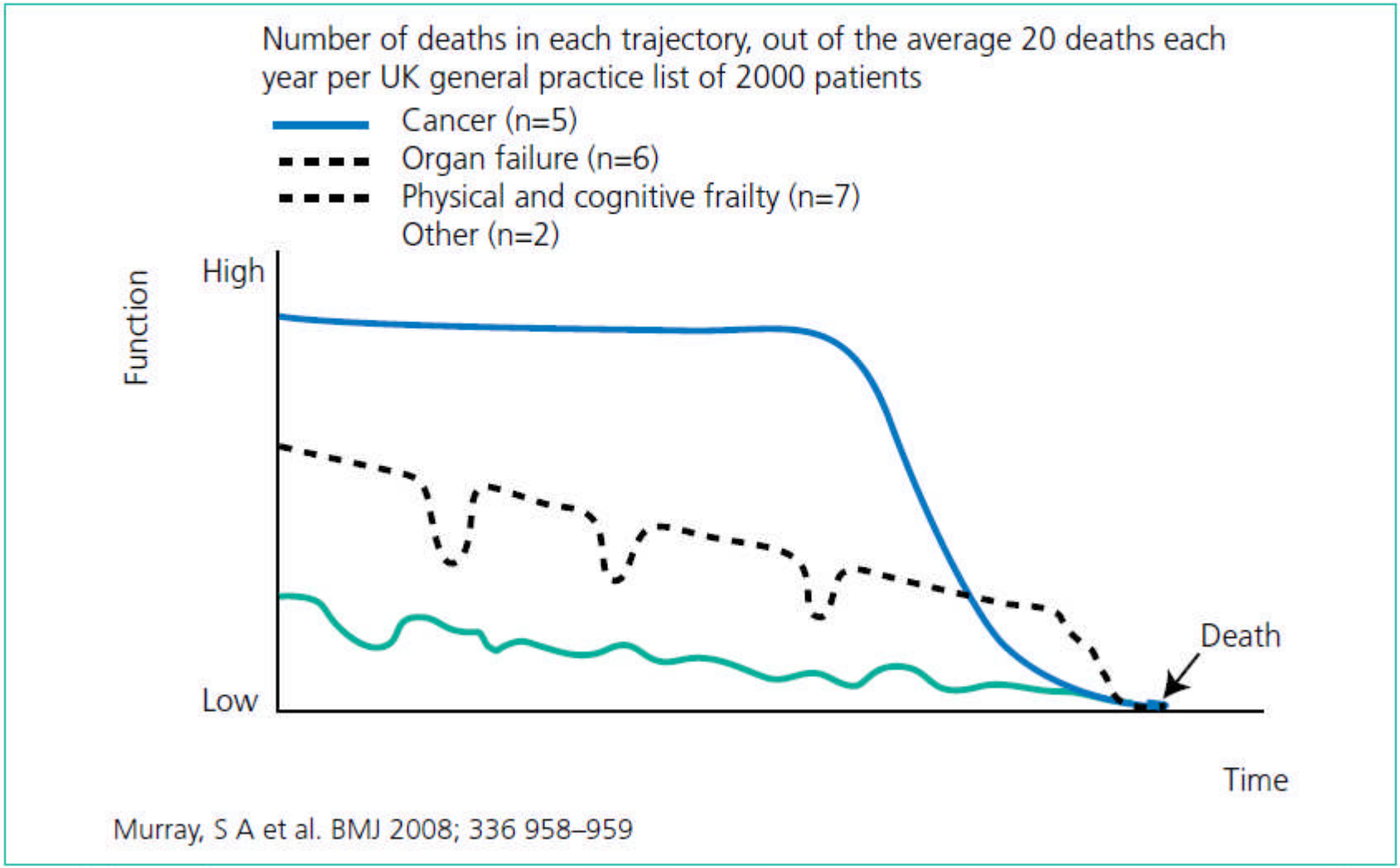
# Survival in dementia

| Age at onset | Median survival |
|---|---|
| 65-69 | 10.7y (24) |
| 70-79 | 5.4y (12) |
| 80-89 | 4.3y (6) |
| 90+ | 3.8y (4) |

(general population life expectancy in brackets)

CFAS

**Figure 1: The three main trajectories of decline at the end of life**




Murray, S A et al. BMJ 2008; 336 958–959

# Prognostic indicators

- MMSE <18, hip fracture or pneumonia: ½ patients die <6m
- MMSE <12: median survival = 1.3y
- Care home admission: 71% die <6m
- Hospital admission: 31% die <6m

- Appetite and swallow failure
- Immobile, no communication, dependent in ADL, weight loss
- Recurrent hospital admission, recurrent infections

# MDS Mortality Risk Index

**The MDS Mortality Risk Index – Revised (MMRI-R)**

| | | | Weighted points |
|---|---|---|---|
| Admission to nursing home in the past three months | | Yes ☐ No ☐* | (8) |
| Lost weight unintentionally in the last three months | | Yes ☐ No ☐ | (5) |
| Renal failure | | Yes ☐ No ☐ | (6) |
| Chronic heart failure | | Yes ☐ No ☐ | (4) |
| Poor appetite | | Yes ☐ No ☐ | (4) |
| Male | | Yes ☐ No ☐ | (5) |
| Dehydrated | | Yes ☐ No ☐ | (4) |
| Short of breath | | Yes ☐ No ☐ | (8) |
| Cancer (if yes – see Age and Cancer worksheet; if no continue) | | Yes ☐ No ☐** | |
| Age of patient/resident at last birthday _____ | Age score **without** cancer | | (2-9) |
| | Age score **with** cancer | | (13-20) |
| Deteriorated cognitive skills or status in the past three months | | Yes ☐ No ☐*** | |
| Activities of Daily Living score ____ | ADL score **without** cognitive decline | | (0-16) |
| (see ADL and cognitive decline worksheet) | ADL score **with** cognitive decline | | (-2-21) |
| | **TOTAL MMRI-R SCORE** | | **(0-85)** |

Score 26: sensitivity and specificity about 70%

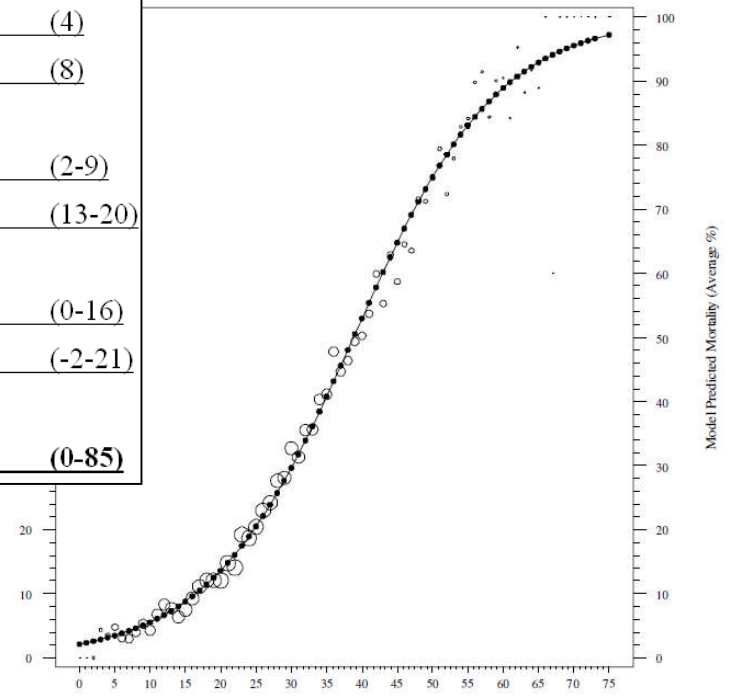



**Figure 1 Observed and Predicted Six Month Mortality by MMRI-R Score - Validation Data.** Open circles denote observed mortality. Dots denote model-predicted average mortality and MMR-R value.

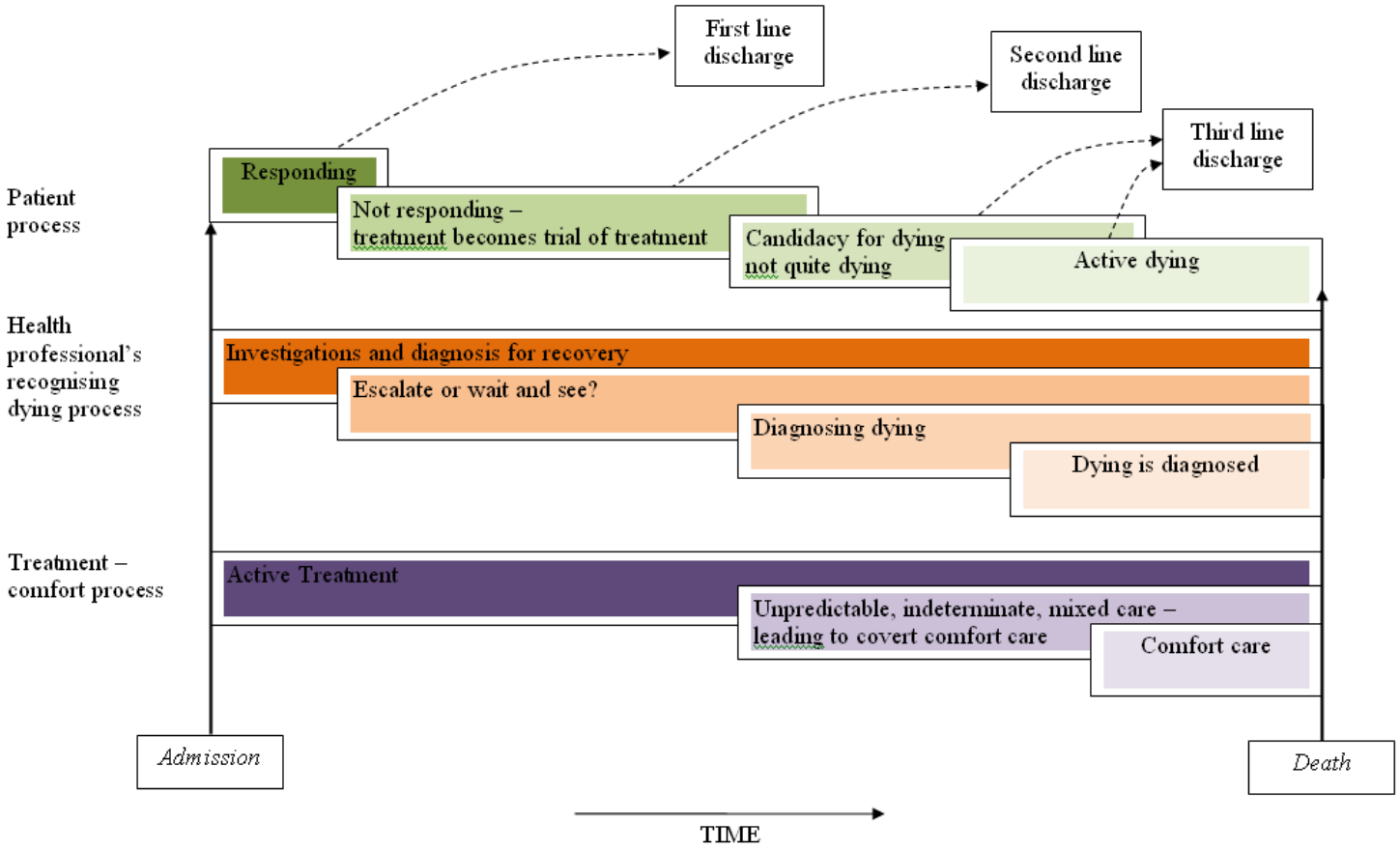
# Prognostication

3.22 For many conditions it may be difficult or impossible and potentially unhelpful to estimate prognosis precisely

DH EOLC Strategy 2008

# Candidacy

Figure 1. The Process of Recognising Dying and Transitioning to Comfort Care in Hospitalised Older Adults




Davina Porock

# Principals of palliative care

- Meticulous management of symptoms
- Open communication
- Psychological, emotional and spiritual support of the patient and those close to them

# Problems

| | |
|---|---|
| • Confusion | 83% |
| • Urinary incontinence | 72% |
| • Pain | 64% |
| • Low mood | 61% |
| • Constipation | 59% |
| • Poor appetite | 57% |

Regional Study of Care of the Dying 1997

# More problems

- Swallowing failure
- Immobility, falls
- Behaviours
- Infections
- Delirium
- Carer strain
- Dementia not seen as life threatening
- Location of care
- Unwanted hospitalization
- DNAR
- Uncertainty

# Beware delirium

- Disorder
  - of cognition and attention or arousal
  - with an identifiable physical cause
- Look for:
  - Disordered thinking - rambling speech, incoherent, irrelevant, illogical flow
  - Hallucinations (often visual), delusions/paranoia
  - Hypoactive, lethargic or depressive forms

# Delirium causes

- Anything medical
- Often multiple
- Think...
  - drugs, drug withdrawal
  - brain diseases
  - infection
  - metabolic disorder
  - hypoxic disorders
  - post operative

# Slow recovery

Persistence

- 61% after 24h
- 45% at discharge
- 33% at 1 month
- 26% at 3 months
- 21% at 6 months

Cole 2009 systematic review

# Swallow and appetite

*Causes of poor appetite*

- Metabolic
- Drugs
- Infections
- Depression, dementia
- Constipation, nausea, pain
- Cancer
- End of life

*Causes of poor swallow*

- Neurogenic
  - stroke
  - degenerative
- Decompensation, weakness
- Oral apraxia
- Oral candida
- Poor dentition
- Mechanical obstruction
  - stricture, tumour
  - pouch

# Tube feeding

- NG uncomfortable
- Relatively minor risks and problems
- Little evidence of benefit in dementia
- Can be useful (drugs, recurrent aspiration)
- Fully respect decision making process
- Fine line to passive euthanasia
- Rarely appropriate, but don’t be dogmatic

# Why assessing pain can be difficult

- Forgetful
- Poor abstract thinking
- Poor receptive and expressive language problems
- Outpacing, overwhelming questions
- Co-morbidities (deaf, vision, delirium)
- Reliance of proxy (collateral) reports

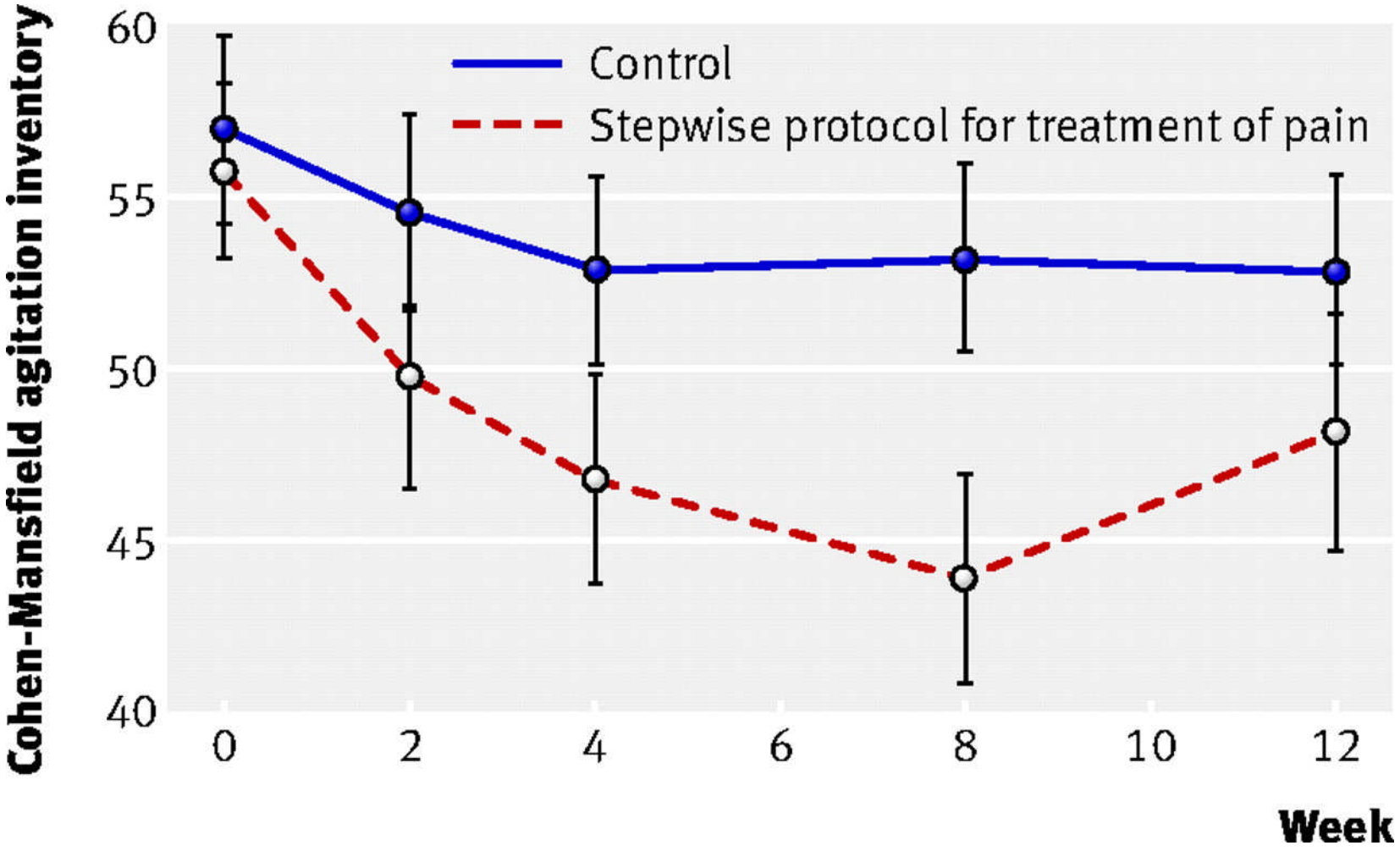
# Abbey Pain Scale

| | | | |
|---|---|---|---|
| **Vocalisation** – expressions of pain without using words e.g. whimpering; crying; groaning; gasps; sighs; grunting | | | |
| Absent 0 ☐ | Mild 1 ☐ | Moderate 2 ☐ | Severe 3 ☐ |
| **Facial expression** – e.g. wincing; tension; frowning; narrowed eyes; tight lips; teeth clenched; distorted expressions; looking frightened | | | |
| Absent 0 ☐ | Mild 1 ☐ | Moderate 2 ☐ | Severe 3 ☐ |
| **Changes to body language** – e.g. rocking; guarding part of the body; withdrawn; clutching or holding tight to things | | | |
| Absent 0 ☐ | Mild 1 ☐ | Moderate 2 ☐ | Severe 3 ☐ |
| **Behavioural changes** – e.g. confusion or increased confusion; restlessness; refusing food or fluids; irritability / agitation or withdrawal; resistance/pushing away | | | |
| Absent 0 ☐ | Mild 1 ☐ | Moderate 2 ☐ | Severe 3 ☐ |
| **Physiological change** – e.g. altered temperature or BP outside usual pattern; perspiring; flushing; pallor; cold & clammy | | | |
| Absent 0 ☐ | Mild 1 ☐ | Moderate 2 ☐ | Severe 3 ☐ |
| **Physical changes** – e.g. skin tears/bruising; pressure ulcers; arthritis; contractures; other injury (e.g. fracture); potential injury (e.g. recent fall) | | | |
| Absent 0 ☐ | Mild 1 ☐ | Moderate 2 ☐ | Severe 3 ☐ |

**Match acquired pain score in the table below:**

| | | | |
|---|---|---|---|
| 0 – 2<br>No Pain (0) | 3 – 7<br>Mild Pain (1) | 8 – 13<br>Moderate Pain (2) | 14 +<br>Severe Pain (3) |

**Cohen-Mansfield agitation inventory scores, with 95% confidence intervals, over study period.**




**Husebo B S et al. BMJ 2011;343:bmj.d4065**

# Specific carer issues

- High levels of carer strain
- Not necessarily reduced by care home placement
- Long time frame
- Emotional burden of proxy decision makers
- Anticipatory grief
- Death may be a (guilty) relief

# National Dementia Strategy: objective 12

**Improved end of life care for people with dementia.** People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the DH EOLC strategy…

# Liverpool Care Pathway

- Comfort measures
- Anticipatory prescribing
- Discontinuing inappropriate monitoring & interventions
- Psychological and spiritual care
- Care of family

# Do we love the LCP?

- Advantages
  - Clarity of communication
  - Promotes prioritisation of comfort care
  - Drug review
  - Tailoring of observations
- Disadvantages
  - Uncertainty of prognosis
  - Time frame
  - Different problem set from cancer

# Advance Care Planning

- Statement of preferences and wishes
- Advance decision to refuse treatment
- Preferred priorities for care / preferred place of care
- Lasting Power of Attorney (Health and Welfare)

# Gold Standard Framework

- Identify (palliative care register)
- Assess needs, symptoms, preferences
- Plan - enabling people to live and die where they choose

# Triggers

- Diagnosis of life limiting condition
- Move to care home
- Multiple hospital admissions
- Death of spouse
- Making will
- Retirement

# Do we love Advance Care Planning?

- Advantages
  - Easier decision making
  - Avoidance of unwanted intervention
  - Preferred place of care
- Disadvantages
  - Too late by time of crisis
  - General reluctance in practice (care homes, families)
  - Practicalities
  - Care home uncertainties
  - Quality of alternatives

# Making things better

- Open mind, flexibility, in face of uncertainty
- Continuity
- Geriatricians, psychiatrists/CMHTs, GPs, care homes
- Integrated systems and structures
- Accept and plan for hospitals remaining a major venue for dying
- Ditto care homes
- Communication, decision making, treatment choices
- Advance care planning

# End of life care in dementia

An exercise in managing uncertainty

Louise Robinson