Decision making at the end of life for people with dementia

Prof Rowan Harwood
Geriatrician, NUH

Mental Capacity Act 2005

Capacity presumed and facilitated

- Understand nature, purpose and effects …
- … adverse effects, alternatives, consequences of refusal
- Retain
- Use information
- Communicate a decision
- Free from undue pressure

Best interests assessment

- Involve the person
- Past and present feelings and wishes
- Beliefs and values that would likely influence the decision
- Other factors person would likely consider
- Family and appropriate others views

Mrs MW, aged 96.

- Not eating or drinking, dehydrated, ? chest infection
- Unable to take oral amoxicillin GP prescribed
- Alert, resisting examination. AMT 0/10
- AF rate 140
- Hb 14, WCC 7, Na 170, Urea 54, Cr 370, Ca 2.5
- Very dehydrated, kidney failure, uncontrolled heart rate
- Given IV fluids, digoxin, tazocin

Nurses on admissions unit:

- Pushes nurses away
- Clenches teeth
- If something in mouth, held without initiating swallow
- Urine output reasonable (after 5l IV fluids)
- No family

Nursing home

- dementia since 2008, already severe in 2008
- not well since fall last year
- immobile (wheelchair, 2 to transfer)
- mute, withdrawn
- eats little, almost nothing for 2 weeks
- doubly incontinent
- no difficult behaviours or apparent distress

Cousin (NOK, and receiver of LPA)

- Visits infrequently
- Mutual distress of non-recognition
- Seen 2 months ago at last SS annual review
- Previously discussed end-of-life decisions
- Certain she would not have wanted intervention
- Prior to dementia, dreaded prospect of dependency

Diagnosis:

Dementia-associated appetite and/or swallowing failure. Terminal illness.

Action:

- Withdraw fluids and antibiotics
- Not for feeding tube
- Discussed with NH and GP
- Returned to NH for end of life care

Questions and issues:

- Was she dying or was she just ill?
- Presumption of intervention
- Knowledge of her previously expressed wishes, and those of LPA

Case

- 93 year old woman, admitted unwell, vomiting, choking
- Multiple co-morbidities, including dementia
- Bed bound, lives with daughter
- Pneumonia diagnosed and treatment started

Case

- Remained dependent, swallow uncertain, unable to sit
- MMSE 12/30 (severe cognitive impairment)
- On day 12 referred to MMHU.

Case: reviewed by consultant

- Calcium 1.3 mmol/l (very low)
- Casenote review:
  - blind
  - vascular dementia 2006
  - hypoparathyroid following thyroid surgery years ago
- Daughter:
  - Memory mostly a problem when physically ill
  - Climbing stairs one month previously
  - Deteriorated after a week in hospital
  - Advised: very ill, may not survive
  - ‘been here many times before’

Case: to day 25

- Drowsy, resistive
- NG fed (calcium, vitamin D, thyroxine)
- Lots of discussion with daughter
- Calcium back to normal
- No other drug, metabolic or infectious process

Case: day 35

- Clinical opinion that she was terminally ill
- Daughter upset with idea of discontinuing fluids
- Declined offer of home terminal care
- Declined offer of second opinion

Sentenced to death on the NHS

Patients with terminal illnesses are being made to die prematurely under an NHS scheme to help end their lives, leading doctors have warned.

By Kate Devlin, Medical Correspondent
Published: 10:00PM BST 02 Sep 2009

Comments 447 | Comment on this article

Under the guidelines the decision to diagnose that a patient is close to death is made by the entire medical team treating them, including a senior doctor Photo: GETTY

In **a letter to The Daily Telegraph**, a group of experts who care for the terminally ill claim that some patients are being wrongly judged as close to death.

Best interests

- Involvement: unable, too ill
- Current wishes: refusing oral feed, and resisting NG
- Previous wishes: ‘didn’t want to die’
- Family opinion: hydrate to avoid possible thirst
- Least restriction: probably non-intervention

Case

- Died 13 days later on day 49

Issues

- Was this persistent delirium? How long do you wait?
- Conflicting factors in best interest assessment
- Do we treat a patient or a family?
- ‘There is a war on, you know’

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
- Diagnosis: Sepsis with delirium
- 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
- Nutrition
- No advance care plan
- Place of care
- Difficult period for family

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

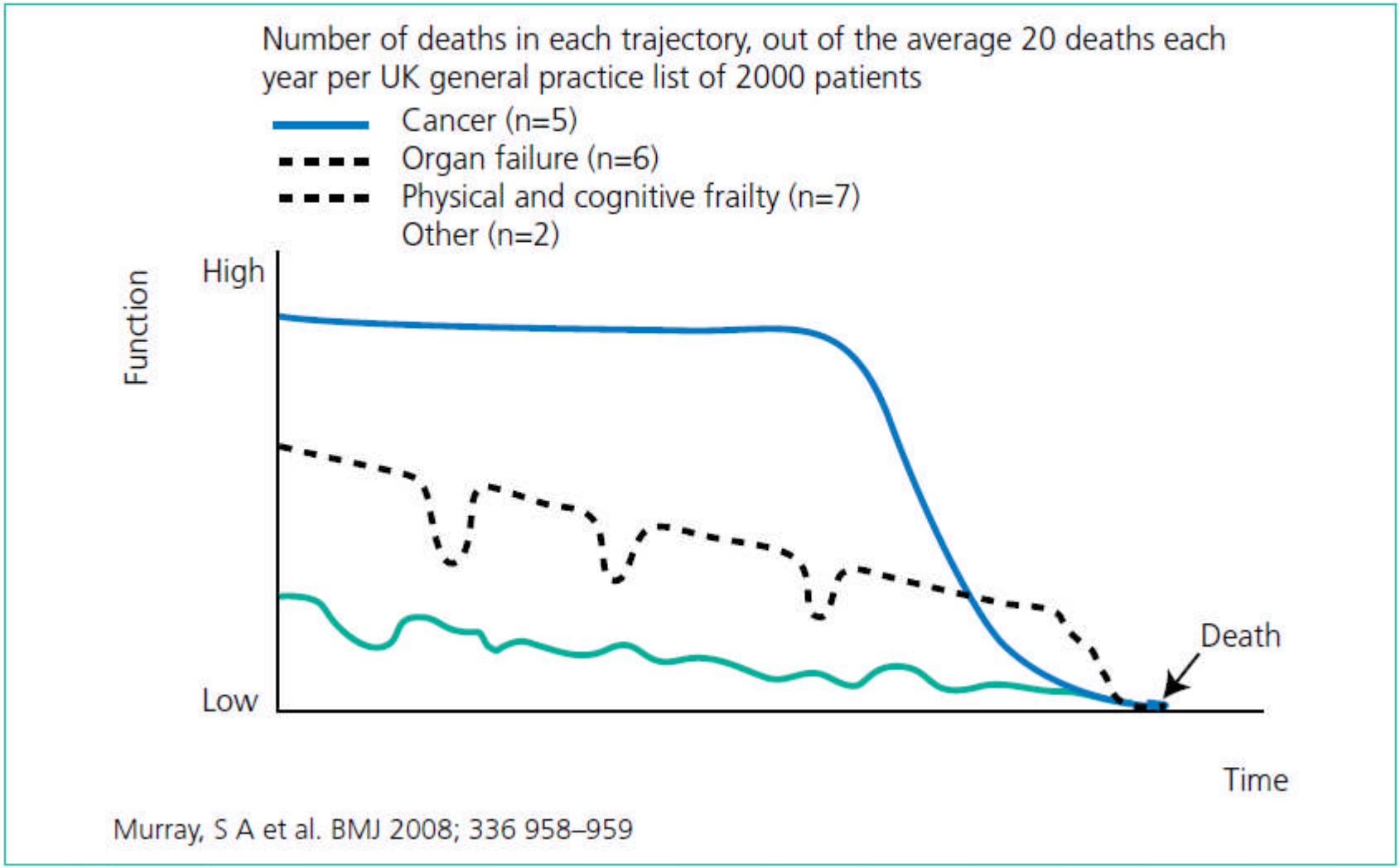
Survival in dementia

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

Poor outcomes six months later

- 31% dead
- 27% did not return home
- 18% 30-day readmission, 42% 6-months readmission
- 42% recovered to pre-acute illness level of function
- 16% spent >170/180 days at home

189 people over 70 with cognitive impairment admitted to hospital

Bradshaw et al, 2012

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%

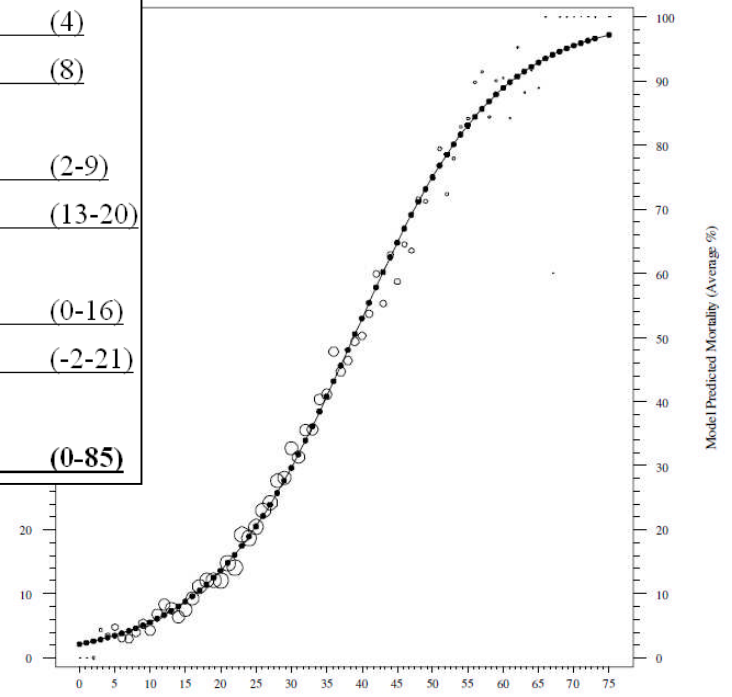


Figure 1 Observed and Predicted Six Month Mortality by MMRI-R Score - Validation Data. Open circles denote observed mortality. Dots denote model-predicted average mortality and MMR-R value.

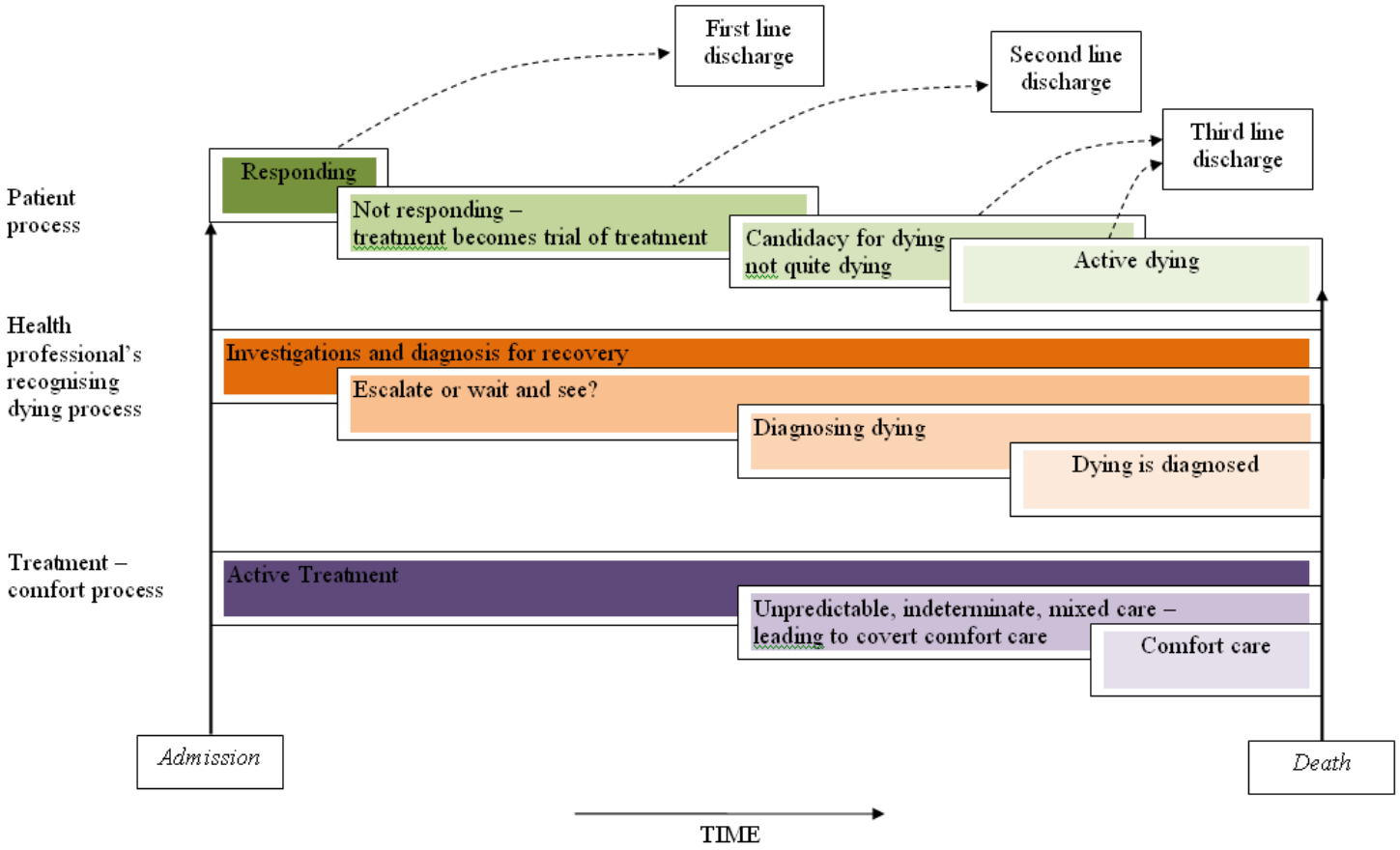
End of life care in dementia

An exercise in managing uncertainty

Louise Robinson

Candidacy

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



Davina Porock

Ethics

The science of morals (good or bad, right or wrong); moral principals, rules of conduct

Wikipedia

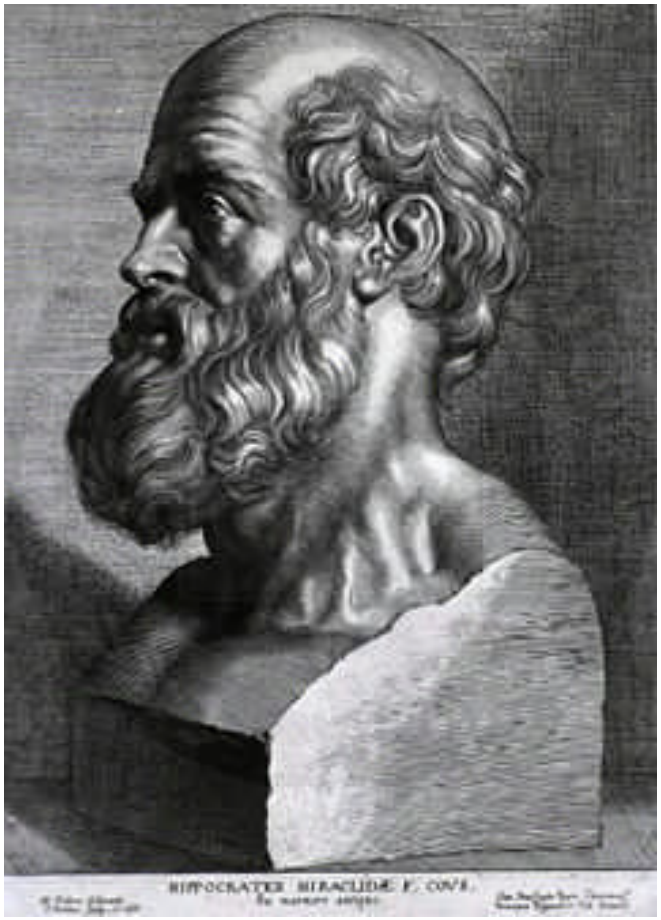
How do you do ethics?

- Normative ethics
  - Consequentialism (Bentham, Mill): utilitarianism, egoism
  - Deontology (Kant): rights and duties
  - Virtue ethics (Aristotle): traits, capacities and dispositions
  - Ethics of care (Gilligan): relationships and emotions
- Applied ethics

Rights and duties

- Right to life
- Equality
- Freedom from inhuman or degrading treatment
- Respect for family life
- Information
- Consent (autonomy)
- Fidelity (truth telling)
- Proxy decision maker appointment
- Confidentiality
- Use resources wisely

Medical ethics



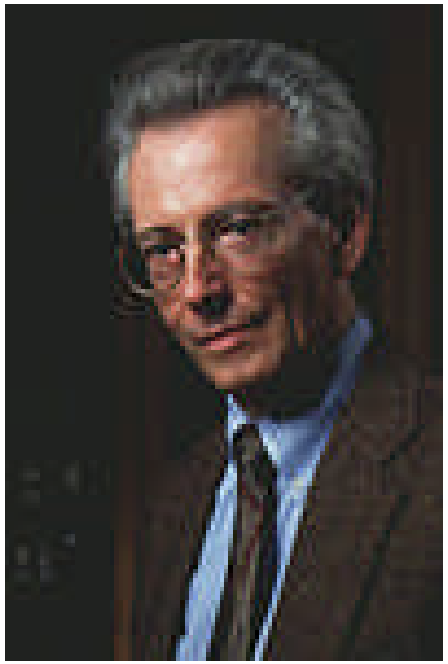
Hippocratic utility ...

- beneficence
- non-maleficence

Put better...

- benefits
- burdens and risks

Principalism



James Childress

Principles of Biomedical Ethics

Childress & Beauchamp 1979

Consequentialist (outcome)

- Benefits
- Burdens and risks

Deontological (rights and duties)

- Autonomy
- Justice

‘Universal and across all cultures’

The problem with principalism

- Principals can conflict
- Autonomous decision making compromised
- Ethics is everywhere

Ethics is everywhere

- Numerous decisions every day
- Easier to make formulaic for cognitively intact

Ethics is everywhere

- Medical treatment decisions
- Preventative drug use
- Physical and mental state examination
- Investigations
- Rehabilitation
- Discharge destination
- Risk taking
- Meal choices
- Hygiene and personal care
- Bed time
- Engagement in activities
- Visitors – when and who
- Co-patients, single sex
- Property
- Ward moves

Problems at end of life in dementia

• 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
- Location of care
- Unwanted hospitalization
- DNAR
- Dementia not seen as life threatening
- Delirium
- Uncertainty
- Carer strain

Beware delirium

Disorder of cognition and attention or arousal with an identifiable physical cause

- Disordered thinking - incoherent, illogical flow
- Hallucinations, delusions/paranoia
- Hypoactive, lethargic or depressive forms

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

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

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

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

Alternative ethical approaches

Reject ethical absolutes

- Virtue ethics
- Ethics of care (feminist ethics)
- Perspectivism
- Discourse (communication) ethics
- Narrative ethics

Hughes and Baldwin 2006

Virtues

- Charity
- Truthfulness
- Compassion
- Faithfulness
- Generosity
- Prudence (practical wisdom)
- Humility
- Fortitude
- Justice

Ethics of care

- Emphasises uniqueness of situations, vulnerability, caring as a disposition
- The ethical solution is the one that creates and maintains healthy relationships

Gilligan 1982

Perspectivism

- There are many perspectives from which judgement of truth or value can be made.
- No way of seeing the world is definitively ‘true’, although all perspectives may not be equally valid.

Alternative ethical approaches

Moral theory	*Approach*	*Themes*
Consequentialism	Discourse	‘Being with’
Deontology	Narrative	Communication
Principalism	Feminist/care	Concern
Virtues	Perspectivism	Conscience
		Empathic understanding
		Relationships
		Situated personhood

Hughes and Baldwin 2006

Principals of palliative care

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

Practical steps

- Communication
- Relationships
- Empathic understanding