

Ethical Dilemmas in Artificial Nutrition Support- A practical approach

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Ashby & Stofell, 1995

“The purpose of medical science is to benefit the life and health of those who turn to medicine.

It surely was never intended that it be used to prolong biological life in patients bereft of the prospect of returning to an even limited exercise of human life.”

What this is not

- Exhaustive review of basic principles
 - Remember
 - Beneficence
 - Non-maleficence
 - Autonomy
 - Justice
 - Acknowledge the concept of ‘sanctity of life’
 - Not analagous to ‘vitalism’
 - Human Rights

When you think you have an ethical dilemma

- **What** is being proposed?
 - What are the medical issues?
 - Risks, benefits, alternatives
 - Case and statutory law
- **Who** are the stakeholders?
 - Patient, family, medical staff, hospital, state
 - Cultural and religious concerns
- **When** does this need to be done?
 - Emergency exceptions to informed consent
- **Why** is an ethical dilemma being created?
 - Conflicts between decision makers, law and ethics
- **How** can this be resolved?
 - Meeting(s), buying time, consultation(s)

Who are the stakeholders?

- Patient
 - Quality of life, autonomy, spiritual needs
- Family
 - Proxy decision makers, quality of life
- Physician
 - Risk management concerns
- Medical profession
 - Standards
- Hospital
 - Policies, accreditation, affiliations
- State
 - Resource allocation, legal regulation

What are the Medical Issues?

- Diagnosis, nature of treatment proposed, risks, benefits, prognosis with and without treatment, alternatives
 - Evidence-based decisions
- Rule Number 1
 - We are doctors, not moral philosophers or lawyers
 - Know your medicine!

Human Rights

- **Fundamental right to life**
 - Does not mean bare existence
 - Existence that has a minimum quality & as free as possible from distress & pain

Best Interests

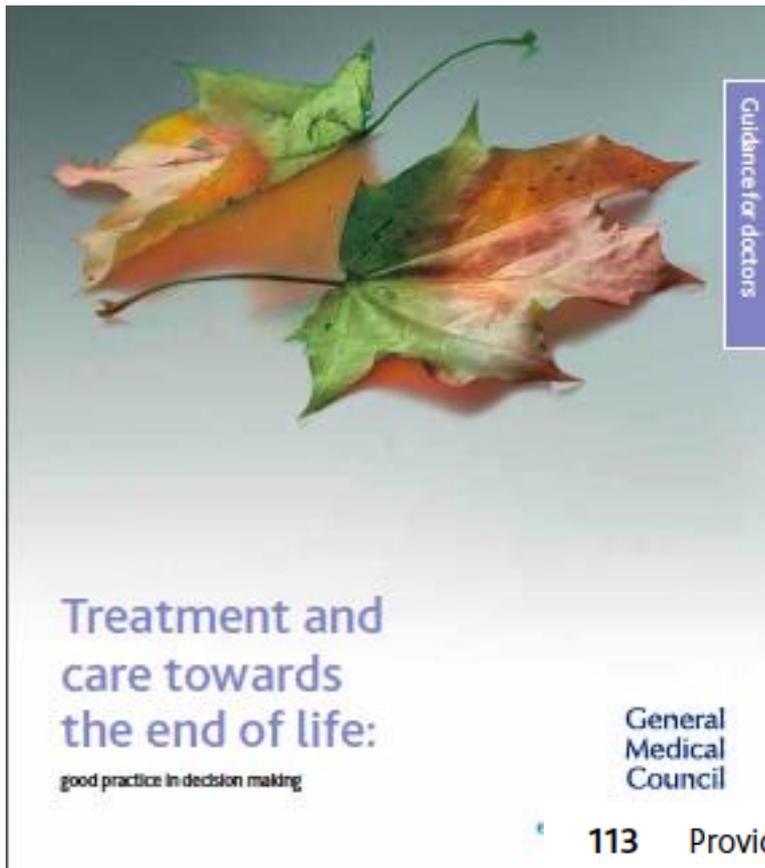
- England & Wales
 - Value judgement
 - “what a reasonable person similarly afflicted would choose”
 - Mental Capacity Act (2005) into effect in 2007
 - Appoint a donee a lasting power of attorney
- North America
 - Substituted judgement
 - “what the patient would have wanted for herself, had she been capable of choosing”



GUIDE TO PROFESSIONAL CONDUCT AND ETHICS FOR REGISTERED MEDICAL PRACTITIONERS

19 Nutrition and hydration

19.1 Nutrition and hydration are basic needs of human beings. All patients are entitled to be provided with nutrition and hydration in a way that meets their needs. If a patient is unable to take sufficient nutrition and hydration orally, you should assess what alternative forms are possible and appropriate in the circumstances. You should bear in mind the burden or risks to the patient, the patient's wishes if known, and the overall benefit to be achieved. Where possible, you should make the patient and/or their primary carer aware of these conclusions.



P54-59

- 113 Providing nutrition and hydration by tube or drip may provide symptom relief, or prolong or improve the quality of the patient's life; but they may also present problems.^{xxvii} The current evidence about the benefits, burdens and risks of these techniques as patients approach the end of life is not clear-cut.^{xxviii} This can lead to concerns that patients who are unconscious or semi-conscious may be experiencing distressing symptoms and complications, or otherwise be suffering either because their needs for nutrition or hydration are not being met or because attempts to meet their perceived needs for nutrition or hydration may be causing them avoidable suffering.

Oral feeding difficulties and dilemmas

A guide to practical care,
particularly towards the end of life

Report of a Working Party

January 2010



87 Pages

Airedale Trust vs. Bland (1993)

Anthony Bland



- Age 17
- Crushed in the Hillsborough stadium disaster
- Persistent vegetative state for over 3 years
- Completely insensate with no hope of recovery
- His doctors, with the full agreement of his parents, wished to withdraw the means of intensive care

Airedale Trust vs. Bland (1993)

- **High Court:** declared that the withdrawal of hydration and feeding would be unlawful
- **Court of Appeal:** supported the High Court
- **House of Lords:** dismissed the Court of Appeal judgement
 - The provision medical treatment could no longer provide the chance of recovery
 - Therefore medical treatment could be withdrawn

Important rulings after Bland

- **Best interests**
 - Medical decisions for a mentally incapable patient should be made in the best interests of the patient
 - If a decision to withdraw or withhold life prolonging treatment is in best interests of the patient then it is lawful (i.e. **best interests can include death**)
- **Feeding**
 - Artificial nutrition & hydration are medical treatments
 - Feeding against a patients wishes constitutes assault
- **Withholding and withdrawing treatment**
 - There is no legal difference

Essentials for life

Oxygen - minutes

Water - days

Food - weeks

(Reproduction - years)

**There is a duty to provide these essentials
for life when caring for a patient**

Consequences

- Water Deprivation
 - Survive 3-14 days
- Food deprivation
 - Survive up to 10 weeks
 - Simple starvation versus anorexia cachexia syndrome
- Malnutrition causes
 - Lethargy/ Apathy/ impaired muscle function
 - Immobility/ hypostatic oedema/ pressure sores/pneumonia

A framework

- There are 2 aspects to management
 - Is artificial feeding necessary for adequate nutrition or can sufficient for basic needs be taken orally?
 - If artificial nutrition is necessary, what is the best method?
 - When ANH is required the aim should be to improve the overall condition of the patient
 - Set criteria in advance of a trial of nutrition e.g.
 - Reversal of confusion
 - Increased capacity for rehabilitation
 - Improved healing of pressure ulcers
 - Decrease in discomfort/ symptoms as medication can be given

What you need to consider

- What is the underlying diagnosis?
- What are the goals of care?
 - Cure/ maintain/ rehab/ palliate/ futile?
- What is the mechanism of the oral feeding problem?
- Can the person eat and drink, and if so, at what risk?

Understanding the disease process

- Oral feeding problems in specific conditions
 - Alzheimer's Disease
 - Cortical Dementia
 - Physical functions (swallow/ mobility) preserved til late stage
 - Pre-oral stage vulnerable to change in conduct
 - Intra-oral and voluntary swallow initiation vulnerable to apraxia of face, lips and tongue
 - Swallowing and coughing reflexes preserved

Understanding the disease process

- Oral feeding problems in specific conditions
 - Brain Stem Stroke
 - Pre and intra-oral disruption: nausea/ vomiting/ oropharyngeal anaesthesia
 - Reflex phase compromised if Xth nerve involved- larynx cant close and coughing compromised
 - Takes weeks to months to improve
 - Left Middle Cerebral Artery Stroke
 - Initial stages low GCS?
 - Sitting posture/ head control/ weakness and/or dyspraxia face, lips, tongue or palate
 - Voluntary components affected
 - Resolves in days to weeks

Understanding the disease process

- Oral feeding problems in specific conditions
 - Motor Neuron Disease
 - Upper motor neuron predominant
 - Voluntary motor control
 - Reflex coughing very well preserved
 - Lower motor neuron predominant
 - Profound weakness and wasting
 - Huntington's Disease
 - Slowly progressive dementia and chorea limbs and tongue
 - Pre-oral and intra-oral phases affected early
 - Good reflex coughing
 - Well trained carers can continue oral feeding til late stage

Complications of tube feeding

- Aspiration pneumonia (0-66%)
- Tube occlusion (2-35%)
- Local infection (4-16%)
- And
- 23% mortality during the hospital admission of placement with median survival of 7.5 months (Rabaneck et al, Lancet 1997)

Tube feeding in Dementia

- It doesn't prevent aspiration pneumonia (Finucane et al, JAMA 2003)
- No evidence in domains of functional status, nutritional status, or prevention of infections
 - In the FOOD trial pressure sores were increased in the PEG fed group (Dennis et al, Lancet 2005)
- Doesn't improve survival
 - 50% mortality at one month; 75% at 6 months (Sanders et al, Am J Gastroenterol 2003)

Which dementia patients get tube fed?

- Patient factors
 - Younger age; male sex; recent decline in functional status; divorced; non-alzheimers; no advance directive
- Institution factors
 - Private institutions; urban areas; larger (>100 beds); no dementia specific unit

(Mitchell et al, JAMA 2003)

Ethical Dilemma in Dementia

- Patient benefits are unclear
- Procedure has risks
- Patient's ability to consent is reduced
- Main benefits are to others

Legal considerations

- Hand to mouth feeding is an ordinary intervention and cannot be withheld unless something else is put in place
- Tube feeding is an extraordinary (or medical) treatment and can be withheld

Decisions should be

- Made by the patient when competent
- Take into account pre-existing wishes of the patient were available
- Informed by the evidence
- Have input from the family
- Independent of the wishes/ beliefs of the treating staff
- Independent of financial considerations
- And be clearly documented

Dealing with disagreement

- Clinician obliged to make decision in patients best interest
- Family must contribute on basis of PATIENTS views/ beliefs/ situation- not their own
- A fixed trial of NG feeding with assessment against pre-defined clinical goals

Dealing with Disagreement

- In making a decision- consider
 - Is there an advance directive
 - Ethical principles
 - Legal or financial concerns (nursing homes and PEG versus NG)
 - Emotional factors- information to avoid later guilt
 - Cultural background
 - Religious beliefs
 - Need for a family meeting

A word on families

- Does PEG feeding improve QoL?
 - Before event 66% said yes
 - After- 44%
- Will it improve the course of the underlying disease?
 - Before event 56% said yes
 - After- 25%
 - (Lada et al, Dig Dis 2002)

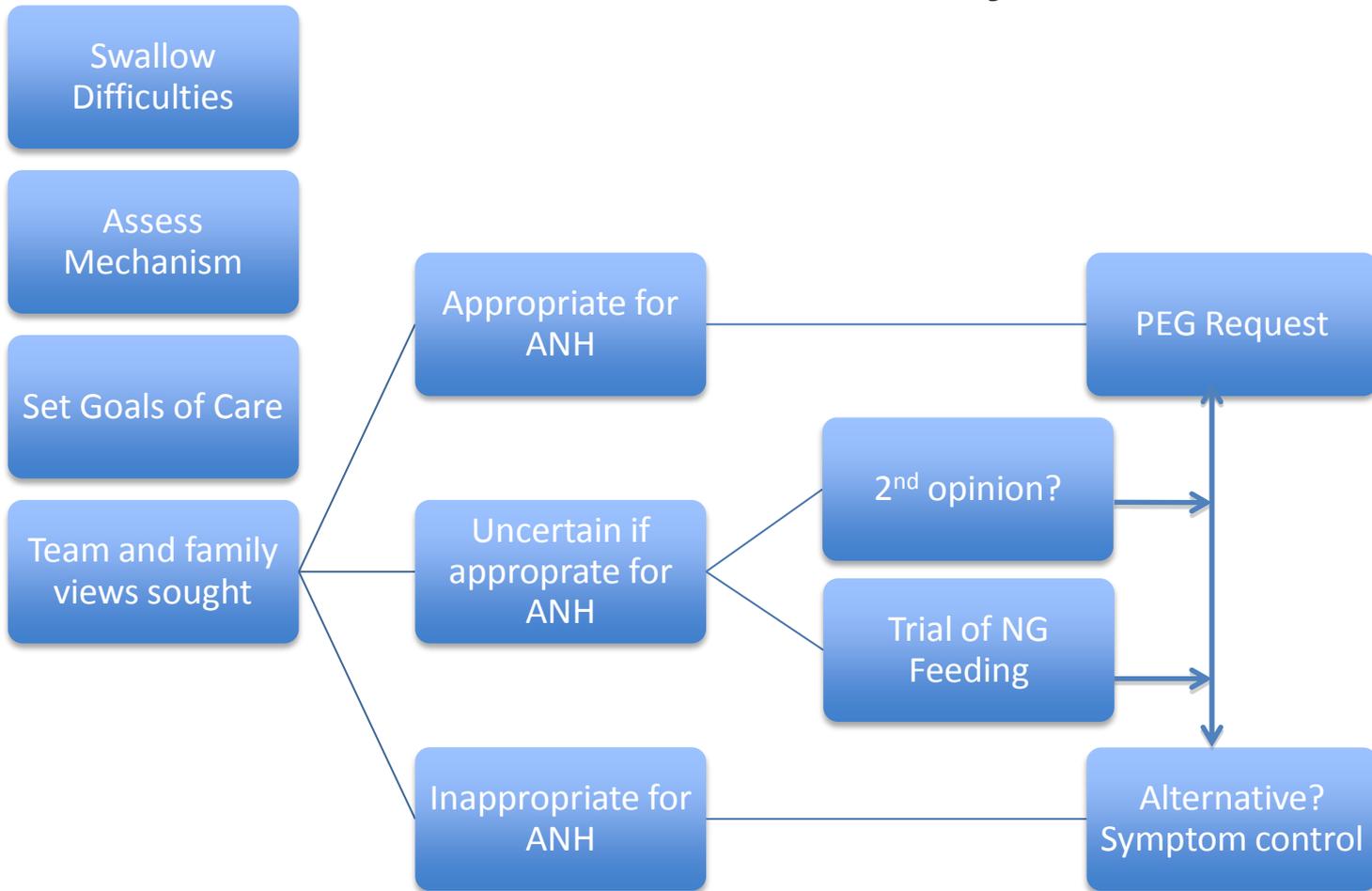
A Case

- Mrs CH- 84 year old nursing home resident
- MMSE 19/30; Barthel Index 13/20 baseline
- Admitted with aspiration pneumonia/
delirium
- Manages thickened fluid and semi solid diet
but takes approx one hour to feed her
standard sized meal
- Nursing home will take her back with a
feeding tube but not without
- One son wants tube; one daughter opposed
on basis of mums previously expressed wish

Case continued

- She is fit enough for a PEG
- Gastro judge it technically feasible
- she has been in one week, is off antibiotics, vitally stable
-and the swine flu season is upon us
- What should you do?
- What would you do?

Summary



1. Alternatives: Continue eat/drink; alter food consistency; spoon feed; patient support
2. Clear documentation



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