Nutritional Aims for the Dying Patient

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Outline

• Definitions
• Mental Capacity Act
• Making decisions
  – Oral intake
  – Artificial feeding
• Case study
• Final points
Palliative Care  (WHO, 2008)

- Patients with advanced progressive illness
- Provide relief from pain and other distressing symptoms.
- Integrate the psychological and spiritual aspects of patient care.
- Offer a support system to help patients to live as actively as possible until death and to help the family cope during the patient’s illness and in their own bereavement.
- Neither hasten nor postpone death.
- Use a team approach to address the needs of patients and their families.
The Dying Patient

• A dying patient is a living person
• Prognosis in the terminally ill patient is estimated to be weeks to short months
• The goals of care at this time:
  • The alleviation of suffering
  • The optimization of quality of life until death ensues
• The provision of comfort in dying stage
End of Life

• At the end of life (or actively dying) the prognosis is estimated at days

• At this stage in the illness whatever food taken by whatever route, will not be metabolized
Why Is Nutrition Important For The Dying Patient?

• More than just fuel for the body also has an important role:
  – Psychologically
  – Socially
  – Spiritually
  – Culturally
Why Is Nutrition Important For The Dying Patient?

• Quality of life

• Ability to carry on activities of daily living

• Control

• Represents normality
House of Lords (BMA, 1999)

Where death is believed imminent & unavoidable, treatment would not be the action taken to preserve the life, health or wellbeing of the patient & could, in fact, be contrary to his or her best interests by providing the burden of the treatment without any benefit.
What the BMA (2007) States…

• Normal food and fluid is basic care and should always be provided unless actively resisted by the patient.

• It should not be forced upon a patient where it causes unavoidable choking or aspiration.

• Artificial nutrition is considered a medical treatment and can be withheld if in the best interests of the patient.
The Mental Capacity Act 2005

Five Key Principles

1. A presumption of capacity
2. Individuals being supported to make their own decisions
3. Unwise decisions, just because it seems an unwise decision, a person should not be treated as lacking capacity
4. Must be done in the Best Interests of the person
5. Least Restrictive Option
What the Mental Capacity Act States…

• One of the key principles of the MCA is that any act done for, or any decision made on behalf of a person who lacks capacity must be done, or made, in that person’s best interests

• This principle covers all aspects of financial, personal welfare & healthcare decision making and actions
Exceptions to the Best Interest Principle

- Advance decisions – where someone has previously made an advance decision to refuse medical treatment while they had the capacity to do so

- The involvement in research in certain circumstances
Best Practice Suggests…

• Assess capacity to make decisions & document
• Valid consent must be obtained before starting nutritional support
  – Voluntarily
  – Informed
  – Comprehend & retain the information
  – Only the patient can consent, apart from a doctor who feels it is in the best interests
  – Patients cannot insist on feeding
What The MCA States Regarding Lack Of Capacity…

• If the patients does not have capacity & their wishes are not known then if it is practical & appropriate to do so, consult other people e.g.
  • Close relatives or friends, anyone engaged in caring for the patient, anyone named by the patient as someone to be consulted on the decision in question or on similar issues
  • Any attorney appointed under Lasting Powers of Attorney made by the patient, any deputy appointed by the Court of Protection to make decisions for the patient
A Decision Should Be Made by Taking Into Account...

1. Clinical condition, capacity, prognosis & aim of treatment

2. Dietetic assessment
   - Identify problems or barriers to food
   - Explore nutritional concerns & patient wishes
   - Establish dietary goals appropriate and achievable

3. Integrate care & ensure compatibility with medical & nursing objectives

4. Regularly reviewing progress & capacity, evaluating the effectiveness, modifying them as necessary
   - It should be validated, documented with a date for review
Barriers To Food

- Loss of interest
- Loss of appetite
- An array of symptoms
- Obstruction
- Previous surgical intervention
- Post treatment
Nutritional Concerns

• Poor nutritional intake
• Wound healing
• Weight loss
• Cultural and ethical issues
• Food preference
Making Decisions…

• Decisions should be based on the potential risks and benefits, and on the patient’s and family’s wishes.
  
  Nitenberg & Raynard, 2000

• Nutritional support should only be undertaken when the therapeutic aim is to prolong life, not when the effect is to prolong the period of dying.
  
  Lennard-Jones, 1998
Dietary Goals

1. Sustaining or improving nutritional status
2. Improving quality of life
3. Providing life sustenance because the patient and/or family are entitled to demand it

Planas & Camilo, 2002
Goals Not Met

• If patient not displaying symptomatic problems e.g. thirst, hunger then patients comfort & dignity is the first priority
• If patient distressed then reassess & formulate new plan/goals
• If relatives distressed this needs careful handling, with competent & professional intervention
The Aims Of Nutritional Support

• To retain pleasure from food
• To retain physical strength long enough to fulfil final wishes
• To retain some control over the disease process
• To die with dignity and not as a result of starvation
Oral Nutritional Support Advice

• Is the same as for those patients having active treatment
  – fortifying foods
  – supplements

• The aim is quality of life and patient comfort
  – e.g. relax the advice for diabetics
Points for Consideration…

• Patients have the right to refuse food and fluid

• Always explore why food is being refused

• Always document if food is refused
Supplements

• Can be useful

• But can divert patients from the foods they want to eat

• Do not always like them & may feel guilty if they are unable to take them (Hill & Hart 2001).
Artificial Nutrition

• Does have a role in palliative care

• Allows for good quality of life

• To fulfil final wishes

• Patients with capacity have the right to make their own decision
Nutritional Targets

- What is appropriate for the individual
- What are you trying to achieve
- Patient comfort and quality of life are paramount
- A patient with advanced disease will lose weight regardless of the nutrition given
Always Consider

• Am I neglecting my patient’s need for fluid or nutritional treatment?

• Am I prolonging death rather than promoting life?
Case Study

- 23 years old
- Diagnosed Mediastinal Neuro-endocrine Tumour with cranial metastasises
- Haemorrhaged post craniotomy & debulking (16 weeks pregnant)
- Profound neurological deficit – prolonged period of sustained intracranial pressure
- Complete unawareness of self or the environment (Glasgow Coma Score is 3/15)
On Arrival At The Hospice

• 5 weeks post caesarean section
• NG fed, but not easily reinserted if dislodged
• Vomiting periodically due to medication & brain damage
• Doubly incontinent – doesn’t tolerate catheters.
• Prognosis unclear – palliative but ?days-short months
Following Admission

• Dislodged the NG over the weekend

• SLT review – silent aspiration and unlikely to improve.

• MDT discussion took place regarding future nutritional support
What Would You Do?...

1. To not replace NG

1. To keep replacing NG when dislodged

1. To have a PEG inserted

1. Other
A Decision Tree – How To Feed

Maria

To not replace the NG

- Benefit: Non invasive
- Burden: Patient may suffer thirst or hunger

To reinsert a nasogastric tube

- Benefit: Can be done at the bed side. Less invasive than a PEG
- Burden: Already proven difficult to insert. Is likely to keep becoming dislodged. Should only be used for 2-4 weeks

To insert a percutaneous gastrostomy

- Benefit: Less likely to become dislodged. Long term feeding solution
- Burden: Invasive, Maria will have to go to another hospital, can cause distress during the insertion, she is unable to consent
MDT Decision

• To PEG feed as:
  – Unclear prognosis
  – NG’s would have kept being dislodged
  – Family had not yet come to terms with the situation and wanted full medical intervention
  – Patient had made no informal advance decisions
  – All decisions are based on trying to arrive at the best interests of the patient
Outcome

- Maria remained at the Hospice for 3 months
- Continued to vomit periodically
- On entering the dying phase, and in discussion with her family, the feed was reduced then discontinued to promote comfort
- She died peacefully within a couple of days due to her disease and aspiration pneumonia
Case Study - On Reflection

• **Right to feed**
  – Gave family time to come to terms with the situation
  – Maria had not been dying imminently
  – Unable to determine hunger

• **Wrong to feed**
  – ?Prolonged suffering
  – No improvement seen in the individual
  – ?Quality of life
Conclusion

• Ultimately the benefit of any intervention must outweigh the burden and risks it presents to the patient and carer, and this will vary from individual to individual.