"Ethical dilemmas and nutrition towards the end of life - an overview".
Life and sex.....

- “Life is a sexually transmitted disease and the mortality is 100%”
- RD Laing 1927-59 Scottish Psychiatrist
The Hippocratic Oath

I swear by Apollo Physician, Asclepius, Hygieia, Panaceia and all the gods and goddesses ...

I will apply dietetic measures for the benefit of the sick according to my ability and judgement; I will keep them from harm and injustice.
Principles of Hippocratic ethics

**Autonomy**
- principle of self-determination
- recognition of the patients rights

**Non-maleficence**
- Deliberate avoidance of harm: “Primum non nocere”

**Beneficence**
- Provides the patient with some benefit

**Justice**
- The fair and equitable provision of available medical resources to all
Medieval nutritional support
Patient with paralytic dysphagia fed for 18 days with :-

“Jellies, eggs beaten up with a little water, sugar and wine”

- By passage through a tube
Article 2

‘Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law’
History in the making - Early Fine bore NGT, 1980 & PEG - 1986
Early PEG – Foley (direct stab) 1986
Important sources on Ethics and Nutrition

www.bapen.org.uk & RCPL
Oral feeding difficulties and dilemmas
A guide to practical care, particularly towards the end of life

Report of a Working Party
January 2010

Royal College of Physicians
British Society of Gastroenterology
MDT lead by doctor (not always!)
Patient focused collaborative team, not individuals in isolation. Dietitian a crucial member of that team. Family/carers to be involved in decisions.

1st question: “What are we trying to achieve?”
Oral intake (modified as required) should be main form of Rx
Tube feeding can be complementary to oral intake.
Unsafe swallow towards end of life – risk management approach.
If in doubt – trial of Rx with NGT
NBM last resort
Nursing homes to ensure adequate staff. Cannot insist on PEG.
Clinical ethical committees helpful. Courts as last resort
Mental capacity to informed consent must be assessed.
GMC and end of life decisions, 2002 & 2010
GMC Good Practice, May, 2010

- Defines “approaching end of life” as likely to die within next 12/12
- Covers broad spectrum of age, illnesses and treatments
- Replaces “Withholding life-prolonging treatments: Good Practice in Decision – making” 2002
- Emphasise that if “clinically assisted nutrition” is not offered, patients must receive high quality care addressing all symptoms
- Deals with capacity or lack of it
MCA - New concepts

- New criminal offence of neglect or ill-treatment of those lacking capacity
- Lasting power of attorney for financial and health matters inc life prolonging treatments
- Independent Mental Capacity Advocates for incapacitated without family
- Emphasises need to assume capacity until proved otherwise & Maximising capacity before decisions
Principles of nutritional care

- Food and water by mouth = basic care
- Nutrition by tube is a treatment, not basic care
- If evidence supports use – unethical not to feed?
- If patient doesn’t want it – don’t do it! (forced feeding)
- Withholding treatment = Withdrawing it
- Futile treatments unethical
- Can hydrate without nutrition but not vice versa
- Burden not > benefit
- Don’t prolong dying
Conflicts

- Euthanasia/right to die groups/ Assisted suicide/Dignitas
- Sanctity of life/Pro-life groups - fundamentalism
- Religious/cultural views –becoming more polarised
- Resources- limited and declining
- The Law and some more new ones!
- European Court on Human Rights
- Ethics – Piggy in the middle!
- Prejudice: PEG is “devil’s work”
Withholding or withdrawing nutrition

- Ethical terms: no difference
- Emotional terms: more difficult to withdraw treatment than not to start it
- Remember patient autonomy

- Best approach is to start treatment as a time-limited trial with clear goals
“You mustn’t starve patients to death”

- Giving a little carbohydrate prevents adaptive protective response
- Giving fluids only will prolong life sufficiently for starvation to become more apparent
- If decision made not to feed a dying patient, give fluids by mouth to prevent buccal symptoms but don’t fully rehydrate or give antibiotics etc
- Perception of thirst and hunger very different in dying patients/advanced dementia
## Mortality of common Palliative care diseases on HETF

<table>
<thead>
<tr>
<th>Disease</th>
<th>N</th>
<th>1 yr Mort</th>
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<tbody>
<tr>
<td>Huntingdon’s chorea</td>
<td>133</td>
<td>21.8%</td>
</tr>
<tr>
<td>MND</td>
<td>925</td>
<td>62.9%</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>911</td>
<td>14.2%</td>
</tr>
<tr>
<td>Parkinsons Disease</td>
<td>37</td>
<td>32.4%</td>
</tr>
<tr>
<td>Cerebrovascular dis</td>
<td>423</td>
<td>41.1%</td>
</tr>
<tr>
<td>MS</td>
<td>4821</td>
<td>29.6%</td>
</tr>
<tr>
<td>Dementia</td>
<td>510</td>
<td>48%</td>
</tr>
</tbody>
</table>

BANS Report;1996-2000; Elia et al, 2001;20:27-
Case 1

69 year old man
Muslim
Known multi-infarct dementia
  ○ Unable to communicate = no capacity
  ○ In nursing home for 1 year
  ○ 2 admissions with aspiration pneumonia
  ○ Current inpatient

Family request for nutritional support
What would you advise?
Outcome (Case 1)

- Family confirmed wish for PEG
- 2\textsuperscript{nd} opinion sought
- Patient deteriorated rapidly
  - Further pneumonia
- Died before PEG inserted
- Family still distressed that feeding not given
Advanced dementia

- Frequently experience
  - Anorexia / loss of interest in eating
  - Swallowing difficulties
  - Aspiration pneumonia
- Often difficult to provide adequate nutrition
- Decision to insert a feeding tube – NG or PEG
- Consent for feeding/PEG often impossible due to incapacity
• No evidence of improved outcome in
  Survival
  Infections
  Q O L
  Bed sores
  Comfort
  Functional status

Finucane et al, JAMA; 1999: 282; 365-70. McNamara & Kennedy, Proc Nutr Soc, 2001; 60; 179-185
• “Should test and fully document the ability of patient with dementia to provide informed consent”
• 18% deaths had dementia
• 19% deaths “PEG FUTILE”
• 40% coexistent chest infection
• 43% deaths within 7 days
• 6% 30/7 mortality in 16648 patients
Why do we concentrate on PEG insertion?

- Real question is whether to feed at all
- Why question insertion of PEG if nasogastric feeding already being given?
- Why not debate administration of water and electrolytes?
- Why not debate administration of antibiotics?
Dementia, decision to feed and cognitive function

- Most dementia patients with swallowing difficulty have very poor cognitive function
- Evidenced by low Bartel score, dependency, inability to self care and nursing home placement
- BUT.... Are all with dysphagia severely cognitively impaired and incompetent to consent?
- Non Alzheimers dementia eg multiple infarct dementia may have better prognosis and less cognitive decline?
- Prevention of nutritional decline often neglected - an important role for dietitians?
• “NS may lead to improved nutritional status in dementia but in advanced stages dysphagia may develop and might be an indication for EN in a few cases”
• “for those with terminal dementia (irreversible, immobile, unable to communicate, completely dependent, lack of physical resources), tube feeding is not recommended”
• “It is recommended that adequate nutrition is ensured especially in the early stages of dementia to prevent undernutrition”
• Enteral tube feeding in community @£2555 p.a./patient
• 571 HETF with dementia in 2005
• = £1.5 million p.a. for feeds alone
Case 2 for discussion

- 54 yr old lady with Huntingdon’s Chorea
- Increasing athetoid/choreiform movements + cognitive decline
- Losing weight and eating very slowly
- Referred by her Neurologist for PEG
- Visited by Our nutrition nurse at home
- Husband struggling with feeding wife. Threw food over her!
2 weeks later......

- Arrives on GI Unit with Husband and daughter
- Both are (more) concerned about technical aspects of home enteral feeding
- Patient thought to lack capacity to understand issues
- Patient became distressed on learning she was coming to new hospital for PEG - ? significance
Case 2 continued

- Should endoscopist place PEG?
- Who should make decision?
- What would you do?
- What else would you like to know?
Additional history

- Patient had made it clear to her family 6 years ago that she would want a PEG if her swallowing deteriorated.
- Husband strongly disagreed - he had seen her 2 sisters die of HC
- Dietitian visited her at home - Patient evidently still eating and drinking food if prepared by other than husband eg chocolate trifle, mashed potatoes and salmon
- Urine output good
Final decision?

- Not to insert PEG despite patient’s wishes (expressed verbally 6 years before) on grounds that she is still able to take oral nutrition and fluids.
- Offer to review if choking occurs.
- Swallowing maintained late in Huntingdon’s
36 year old lady

- Hydrocephalus & poor cognitive function since birth
- Resident in special unit for congenital learning difficulties
- Mother alive but not involved or able to advise
- She is finding swallowing difficult & tiring
- SALT advises artificial nutrition
- Recurrent chest infections and fits
- Carers say that her QoL is deteriorating
- Referred for PEG by her psychiatrist
April 2007: Domiciliary visit

- Consultant gastroenterologist with 7 professional carers present
- Consultant felt that
  - Patient was largely unaware of the visit and cognitive function severely impaired (carers disagreed)
  - Patient was obviously losing weight (5%)
  - Distorted anatomy on trunk & neck
  - No peripheral vein access
  - PEG placement reluctantly agreed, with many cautions
  - No “exit” policy considered by carers (who become distressed)
Case 3 - hydrocephalus

- I agree to place PEG with many cautions
- Who must give consent?
- Nurses on GI Unit worried and visit her
- All agree to try to place PEG
- Arrives on GI unit and 10 signatures plus statement from Advocate (MCA, 2005)
- I fail to place PEG using oral midazolam syrup due to distress
- What next?
Case 3. What Next?

Case conference

- Hospital staff, advocate & GP
- Felt that QoL worse since feeding difficulties developed. Nutrition to blame?
- *Decision: try again for PEG under general anaesthetic, with temporary central line*

But anaesthetist not sure......
Case 3. Anaesthetic opinion

- Assessed by consultant anaesthetists
- CVC placement very dangerous due to anatomical deformities even with USS control
- Refuses to give GA with no venous access

- So what next?
2nd Case conference, June, 2007

- Full care team and patient also present
- Option of no feeding discussed
- 2 Advocates (one from pre MCA and one IMCA advocate) disagree with each other!

What are the options?
Options available

1. High risk PEG/other gastrostomy insertion
   - Will have to find anaesthetist
   - Risk to be explained to the carers

1. Withdraw offer of artificial nutrition
   - In view of deteriorating quality of life
   - Inevitable decline
   - Concentrate on limited oral nutrition with altered texture
   - Accept risks inherent in this approach
   - **OR** – go to legal opinion???
The case v artificial nutrition (AN)

- Objective of improving cognitive function unlikely
- PEG or NGF will not present aspiration
- Patient is in unrelenting decline
- Artificial nutrition will cause distress & prolong dying
- AN will not improve QoL as interpreted by carers
- Carers too involved?
- Best interest is to allow natural history to progress
- Patient already lived much longer than expected
- Risk:benefit ratio adverse

- Best interest is to provide nursing/palliative care with oral fluids & thickened fluids/appropriate analgesia/sedation
Case 3: Outcome

- I heard no more until a few months later....
- Admitted via A&E but Nutrition team not notified.
- Died after fitting age 37.
Twilight over Mont Blanc
The end of life – our greatest challenge?