Food for thought
Eating, drinking and dementia

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With thanks to
Stephanie Dyson, 4th Year Medical Student

“Let us eat and drink; for tomorrow we shall die.”

Isaiah 22: 13

“While you live, drink!

For, once dead, you never shall return.”

The Rubaiyat of Omar Khayyam, XXXV

Mail Online

Elderly patients are being 'deprived of food and drink so they die quicker and free up bed space', claim doctors

Six doctors say the 'care pathway' practice could be being used in UK hospitals to ease pressure on resources

9/7/2012

Case - Withdrawal of clinically assisted nutrition

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NG fed & Keppra administered via NG.

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Discussion with daughter re implications of no PEG and withdrawal of clinically assisted feeding.

- She understood that the consequences would be palliative care and eventually that her mum would pass away.
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Discussion in stroke MDT –

- MDT in agreement that withdrawal of NG feed would be appropriate given the patient's wishes.
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Topics to cover

- Ethics, Values and Law
- Eating, drinking and dementia
- Clinically assisted nutrition and hydration (CANH)
- Case examples

What do we mean by ethics?

- Utilitarianism (Jeremy Bentham)
  - The most happiness for the most people
  - Based on the outcome of actions
- Virtue ethics (Aristotle, Thomas Aquinas)
  - Doing the right thing for its own sake
  - Based on individual morality and character
- Deontological/Duty ethics (Immanuel Kant)
  - Following rules, duties and obligations
  - Based on duties of the person and the rights of others

Principles of biomedical ethics

- Beneficence – Doing good
- Non-maleficence – Doing no harm
- Autonomy – Rights of the individual
- Justice – Rights of others/society

Doing good > causing harm = **Best Interest**

Beauchamp and Childress (1985)

Human Rights Act 1998

Several articles relevant to medical care

- 2 – Right to life (beneficence)
- 3 – Prohibition of torture (non-maleficence)
- 5 – Right to liberty and security (justice)
- 8 – Respect for private & family life (autonomy)

Values – it's not about you

- We all have our own values and beliefs
- So do our patients and their families
- Difficult decisions are often more about values than facts
- It is the patient's values that are the most important and it is the role of the family to try and represent this
- You ***will*** make decisions that may not be what you would do if this was your family

Consent / Refusal of treatment

- To grant or withhold consent prior to examination or treatment is a person's legal and moral right
- Autonomy generally takes precedence over 'best interest'
- A competent adult may refuse treatment, even if life-saving
- However, they may not demand treatment that is likely to be futile.
- Intervention without consent may amount to an assault

Consent / Refusal of treatment

- A doctor has a duty to explain the nature, purpose and risks of the proposed procedure in non-technical language
- Consent must be freely given, without duress
- Competence (Capacity) is assumed in law unless there is evidence to the contrary
- Presence of a mental disorder does not necessarily preclude competence
- Mental capacity is decision-specific

Assessment of Capacity

- Can you ***understand***, in simple terms, what is proposed and why?
- Can you ***retain*** the information
- and ***use*** it to reach a decision?
- Can you ***communicate*** your decision?

What if you lack capacity?

- How can you retain autonomy when unable to express your wishes?
- Temporary loss of capacity
  - Can it wait?
- Permanent loss of capacity
  - Clearly expressed prior wishes
  - No clear prior wishes
- Advance statements

Independent Mental Capacity Advocate

- Extra safeguard for the very vulnerable
- Duty on Trusts and LA's to provide the service
- Should be provided if a person without capacity has no one (family, carer) to support them and has an important decision to make regarding medical treatment or accommodation
- Can be used if a person's family/carer is unable or unwilling to assist in Best Interest decision

Independent Mental Capacity Advocate

- Independent Mental Capacity Advocate
  - Represent that person's feelings, wishes, values and beliefs so far as these can be ascertained
  - Communicate those views to the professionals
  - May challenge a professional's decision
  - They do not make the decision or give 'consent'

Eating, drinking and dementia

- It is not unusual for people with any advanced disease to have a reduced desire or ability to eat and drink
- Disease can affect:
  - Appetite
  - Food preparation
  - Chewing and swallowing
  - Respiratory function
- Dementia can affect any or all of these

Assisted nutrition & hydration (ANH)

- Healthcare is able to provide some means to provide or supplement intake via a non-oral route (e.g. drip, NGT, gastrostomy)
- Purpose may be to improve symptoms or to prolong life, *sometimes* both
- Evidence for benefit is limited, as is the evidence for any burden from this approach
- Debate as to whether ANH is a medical treatment or essential care

Evidence in favour of ANH

- No useful RCTs
- Observational studies flawed

- Some evidence that cognitively intact patients with impaired swallow experience more pain and distress in the absence of nutrition
- Patients with dementia often resist assisted feeding but this may be reflex when really they would want to be fed

Evidence against ANH

- In palliative care settings, there is some evidence that patients only experience brief sensations of hunger and thirst and can gain comfort from very small amounts of food/drink
- Dehydration is a common *mode* of dying and leads to reduced alertness, therefore reduced hunger and thirst
- Ketones may have a central anaesthetic effect
- Dry mouth can be managed without a drip

NICE Guidance

- Clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may cause other problems
- It is uncertain if giving clinically assisted hydration will prolong life, or extend the dying process
- It is uncertain if not giving clinically assisted hydration will hasten death

NICE Guidance

- No evidence that long term feeding prolongs life in patient with severe dementia
- Consider short term tube feeding in patients with dementia who have dysphagia if this is thought to be reversible or temporary
- Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration is inadequate
- Involve patient and families

Withdrawing and withholding treatment

- BMA Guidance
  - Medical treatment cannot always provide a net benefit to the patient
  - No justification for providing or prolonging treatment that is not beneficial
  - Increasing technological means to maintain life
  - Priority is to protect a person's dignity, comfort, wishes and rights
- Withdrawing = withholding legally and ethically

Withdrawing and withholding treatment

- What to do
  - Consultation and communication
  - Clinical evaluation
  - Consider time-limited trial of treatment
    - Assess benefits, risks and burdens
  - CANH requires particular care
    - Must be an independent senior clinical decision
    - Agreed with patient/family
    - Consider court approval in certain situations
  - **Support family** for as long as they need

National Audit of Care of the Dying in Hospital

- An assessment of the need for clinically assisted (artificial) hydration (CAH) was recorded for 59% of patients, but discussions with the patient were recorded in only 17% of those thought capable of participating in such discussions. There was documented discussion with relatives and friends in 36% of cases. CAH was in place in 29% of patients at the time of their death.

- An assessment of the need for clinically assisted (artificial) nutrition (CAN) was recorded for 45% of patients, but discussions with the patient recorded in only 17% of those thought capable of participating in such discussions. There was documented discussion with relatives and friends in 29% of cases. CAN was in place in 7% of patients at the time of their death.

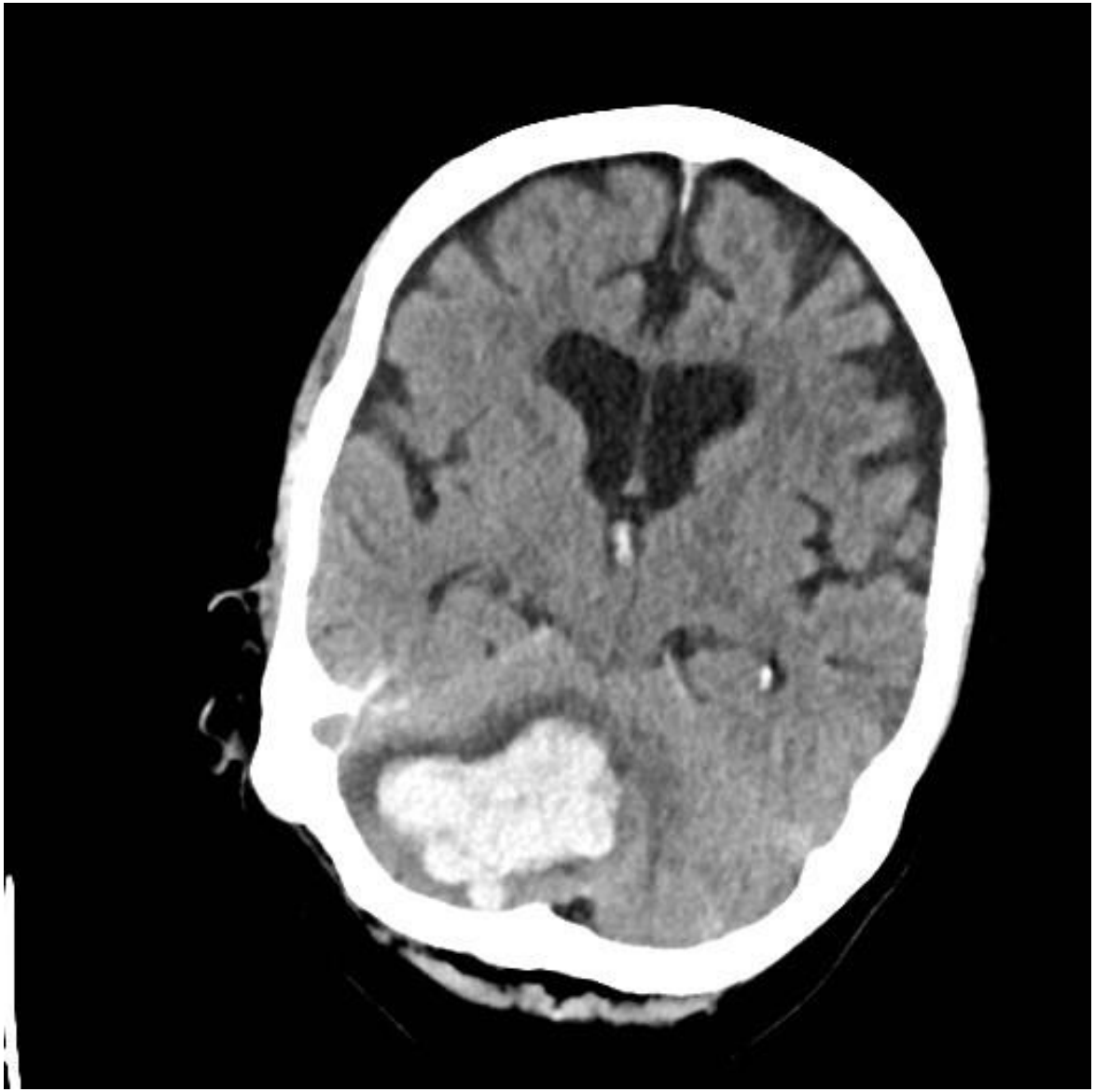
National Audit of Care of the Dying in Hospital

- Only 39% of bereaved relatives reported being involved in discussions about whether or not there was a need for CAH in the last 2 days of the patient's life.
- For those for whom the question was applicable, 55% would have found such a discussion helpful.

Cases

Case - RV

- 74 M
- Lives with wife
- Alzheimer's disease with mild dementia
- Usually able to give a good account of himself, mobile and self-caring
- Admitted in June with 3 week history of headache, unsteadiness and several falls



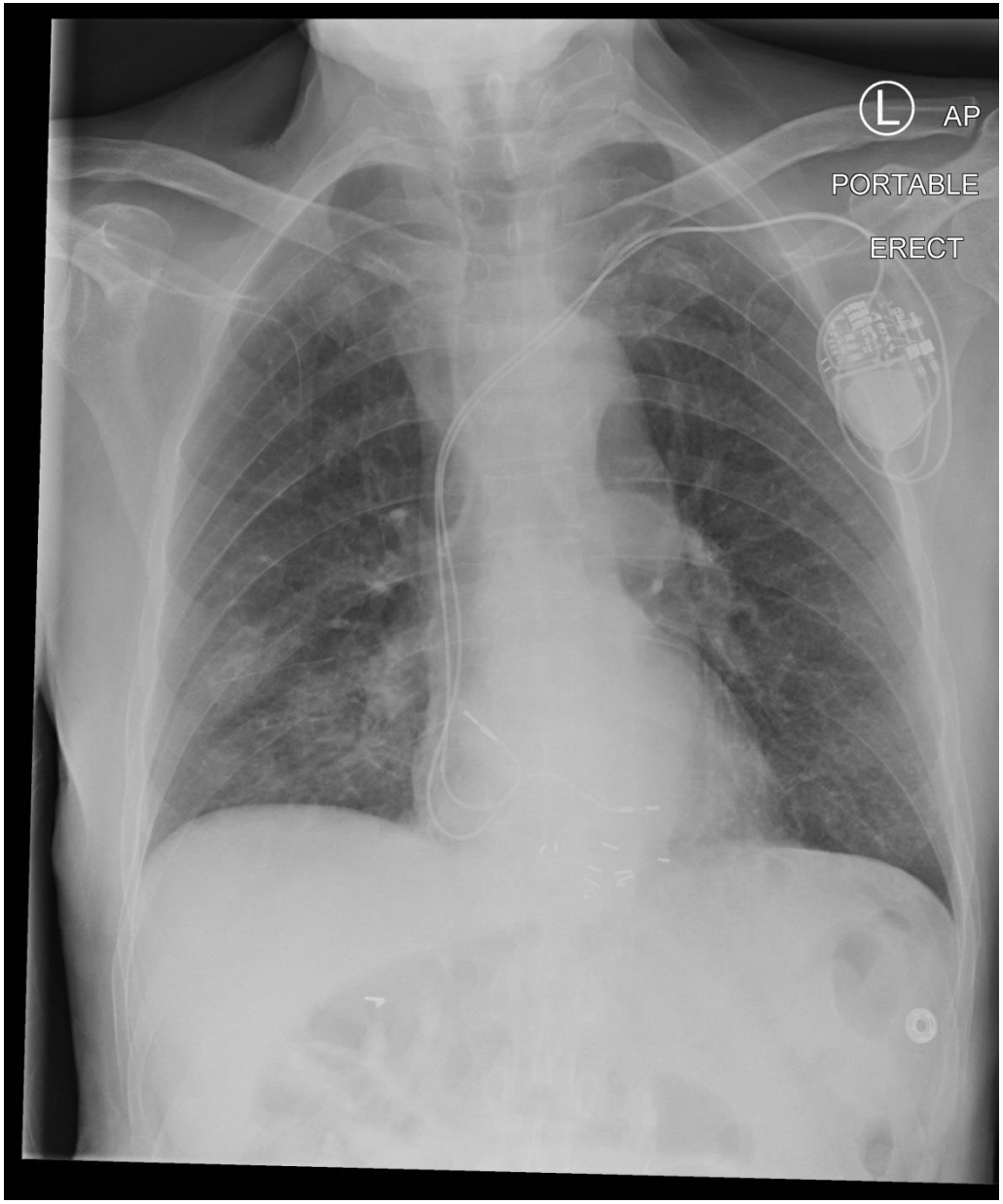
Case - RV

- Large right acute cerebellar haematoma
- Treated non-operatively
- Period of rehabilitation
- Mobile with frame and supervision
- Variable level of confusion, flat affect
- Some difficulty eating and drinking – poor appetite, hiccups and dysphagia – thickened fluids (Speech and Language Therapy advice)

Case - RV

- Discharged after 5 weeks
- Felt to be at high risk of becoming dehydrated and undernourished but family wanted to try him at home. BMI 18 (had been 21)

- Readmitted the next day – vomiting, unwell
- Poor oral intake, no appetite, some evidence of aspiration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Case - RV

- Treated for aspiration pneumonia
- Difficulty eating, seemed to be multifactorial
  - Dysphagia
  - Hiccups
  - Appetite
  - Depression/apathy
- Input from Speech and Language Therapists and Dietitians

Case - RV

- Trial of anti-depressant
- Encouraged to eat and drink but not meeting requirements

What we did

1. Assessed capacity for NGT v no change in Rx
2. MDT and family discussion of best interest
3. NGT difficult to insert at bedside
4. NGT inserted by ENT under direct vision
5. NGT ‘came out’
6. This happened a couple of times

What we did next

- Reassessed capacity for NGT with nasal loop
- Further MDT and family discussion
- NGT with nasal loop (“bridle”)
- Continued NG feeding for an agreed period

- Reassess clinical condition, MUST, food diary
- Weight unchanged, MUST 4, food intake poor

What we did after that

- Reassessed capacity
  - for gastrostomy v NGT v Feed ‘at risk’ (FAR)
- Further MDT and family discussion
- Review by Nutrition Team
- PEG inserted
- Not gaining weight, yet
- Further aspiration pneumonia

Update

- 1 year later
- Continues PEG feed
- Small amounts of Stage 2 fluids orally
- Living at home with wife
- Carers bd
- Mobile with stick
- No further hospital admissions

RV – learning points

- Dementia and stroke
  - Different reasons for reduced food intake, often managed differently
- Good practice to give a limited trial of feeding
  - Uncertainty about prognosis (swallow and overall)
- Involvement of patient, family and MDT
- Formal MDT meeting not essential

Case - RG

- 86 M
- Lives with wife
- Severe dementia
- Recent and rapid decline in condition
  - Agitation, reduced food intake, falls
- Coughing and excess secretions
- Presents to ED with fall and head injury while at day centre

Case - RG

- Seen in ED
- CT head scan – no bleed
- Discharged home
- Re-presents 3 days later after another fall
- Laceration to left arm
- Increasingly agitated
- Hyperactive delirium

Case - RG

- Definite history of deterioration in dementia
- No clear reversible cause found
- Could be a prolonged delirium
- Initially stable, mobile on the ward
- Worsening swallow with weak voice and cough
- SALT review - High risk of aspiration

Case - RG

- Assessed capacity – FAR v NBM
- Discussion with wife and daughter (nurse)
- Wife volunteered that she did not feel RG would want or tolerate tube feeding
- Agreed that FAR was in best interest
- SALT advice on least unsafe oral intake
  - Stage 2 fluids, pureed diet

Case - RG

- A few days later, RG develops pneumonia
- Treated with iv antibiotics and fluids
- Initially drowsy but improved
- Still has weak cough
- Wife reaffirms preference for FAR and also does not want further antibiotics or drips
- Sudden rapid deterioration the next day
- Palliative care

RG - Learning points

- Important to recognise when a person is reaching the end of life
- Different decisions with different priorities of care
- (almost) Always listen to the family
- Tubes and drips are what hospitals do but may not always be right for that person

Case - GD

- 85 F
- Lives in Nursing Home
- Mild vascular dementia
- Recent possible small stroke
- Also has severe heart failure and history of recurrent bowel obstruction
- Admitted with severe constipation and reduced oral intake

Case - GD

- Constipation treated
- Impaired swallow with poor oral intake
- SLT review – risk of aspiration
- Failed attempts to pass NGT (patient resisted)
- Daughter wants her to be fed
- Despite medical problems, not about to die

Case - GD

- Assess capacity – for FAR and for tube feeding
- MDT discussion with daughter
- Daughter - wants to continue FAR and also consider feeding tube
- Medical team - FAR will not meet nutritional need, not sure a tube is appropriate
- Appeared to be an impasse

Case - GD

- Asked for second opinion:
- What is the main issue here – comfort, risk of aspiration, or nutrition?
- Not dying of anything else just now so could die of starvation if underfed
- Proposed that tube feeding would be the only way to meet nutritional need
- Also, definite pleasure from oral intake

Case - GD

- As resistant to NGT, proceeded directly to PEG
- Continued FAR with stage 1 fluid and fork mashable diet, administered by daughter, not by staff

Case - GD

- Over 3 years later
- One admission for 24h with constipation
- Still alive, good quality of life in NH

GD – Learning points

- Guidelines are only guidelines
- If a patient isn't dying of anything else, could they die of starvation
- While it is usually not going to be beneficial to consider long term tube feeding in a person with dementia, there are exceptions
- Anyone can have short term NGT feeding but long term feeding needs a bit of thought

What if it goes wrong?

- Unmanaged expectations
  - If this is short term feeding or a ‘trial’ of feeding, everyone needs to know this at the beginning
- Inappropriate treatment
  - Stuck with an NGT forever
  - Not fed when they ‘should’ have been
- Unhappy patient, family, MDT
  - Complaints, litigation (rare)
  - Demoralised team (less rare)

Protect yourself

- Assess capacity and document this
- Feeding rarely an emergency decision
- Best interest discussion essential

- Document everything

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Final thought

When considering CANH – ask 3 questions

- What are you expecting to achieve and are goals realistic?
- Do relatives have realistic expectations of what it can achieve?
- What does the patient want (or what would the patient have wanted)?

Thank you

Further reading:

“Use of modified diets to prevent aspiration in oropharyngeal dysphagia: is current practice justified?”

O’Keeffe BMC Geriatrics (2018) 18:167