



Artificial
Nutrition & Hydration:
Clinical, Legal & Ethical Issues

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Overview

- Clinical/ physical considerations
 - Methods
 - Clinical benefits/ burdens
- Why are ANH decisions difficult in practice?
- Case
- Key ethical issues
- Framework for making good decisions

Methods of Nutrition and Hydration



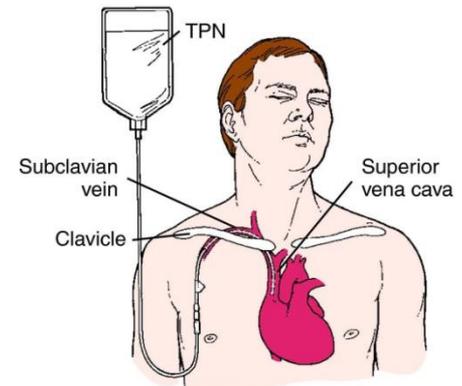
Unable to eat



Intact gut



Impaired gut



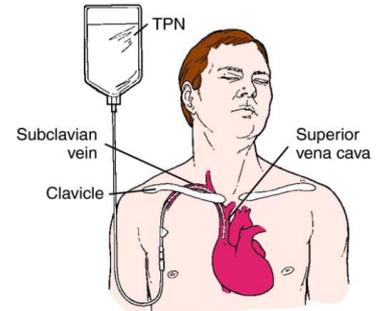
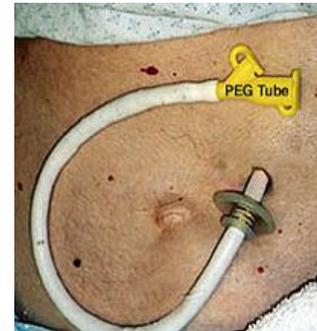
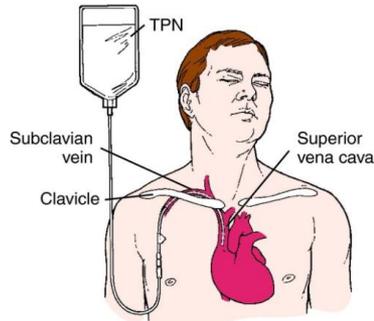
Methods of Nutrition and Hydration



Short term



Long term



Quiz; Case A

- Eileen, a 78 year old woman, is admitted after an embolic stroke. She has a dense left hemiparesis and is unresponsive with a GCS of 9. She is not suitable for thrombolysis and is transferred to the stroke unit.
- For nutrition and hydration would you suggest:
 1. PEG
 2. NG and iv fluids
 3. TPN
 4. iv fluids only

Quiz; Case B

- Frederick, a 61 year old man, with squamous cell carcinoma of the base of tongue is due to undergo prolonged radical radiotherapy. There is high risk of severe mucositis and secondary fungal infection that could make eating and drinking very painful.
- What would you suggest to aid nutrition and hydration?
 1. PEG
 2. NG
 3. TPN
 4. SALT and dietician review
 5. Mouthwashes, analgesia, proactive treatment of oral thrush

Quiz; Case C

- Susan, a 50 year old lady, has recurrent colorectal cancer and has started eating and developed uncontrolled 'short gut syndrome' with high stoma output after an extensive second bowel resection.
- In the post-surgical period, prior to resuming oral intake, would you suggest:
 1. iv fluids only
 2. NG feed & fluids
 3. TPN feeding & fluids via central line
 4. PEG feeding

Clinical Benefits

Clinical Burdens

Symptom relief:

- 1. .
- 2. .
- 3. .
- 4. .

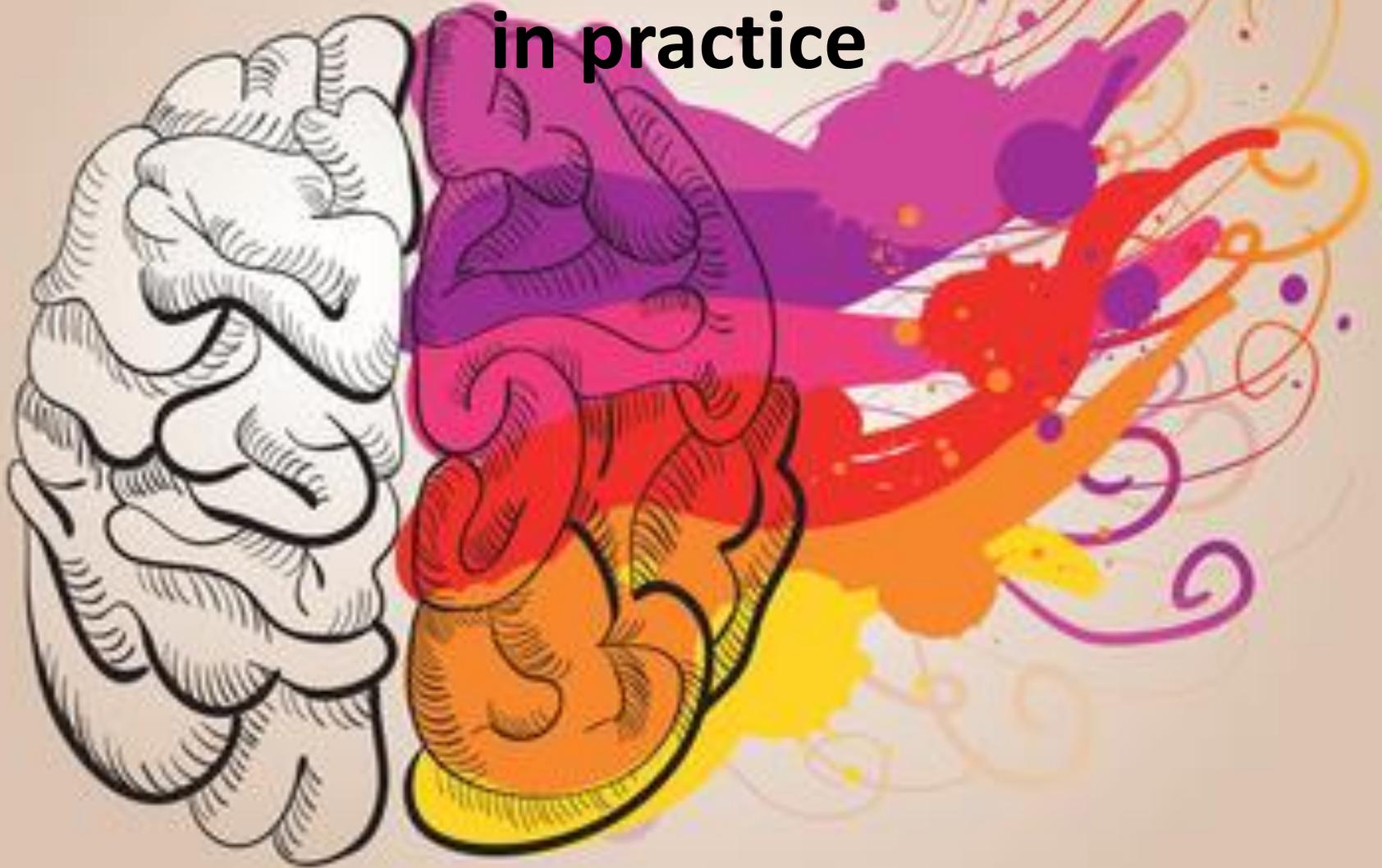
- 1. .
- 2. .
- 3. .

Allowing recovery:

- 1. .
- 2. .

- 4. .
- 5. .
- 6. .

The Clinician's View: Making difficult decisions about ANH in practice



Case Discussion: Alice

You are an F1 doctor, working on MAU. You see that Alice, an 85 year old lady with a diagnosis of advancing dementia has been admitted. You have seen her twice before in the last 3 months, diagnosing her on both occasions with an aspiration pneumonia. You go to clerk Alice in. You know Trevor, Alice's son and Karen, her daughter-in-law, with whom Alice lives and you greet them all as you pull the curtains round the bed. You can see from the end of the bed that Alice's respiratory rate is high and she is pulling at the oxygen mask that has been put on her.

Trevor and Karen tell you that Alice has been short of breath for a few days, is continuing to choke on her food despite their following instructions from the Speech and Language Therapist about the consistency of the meals they give Alice, and thickening the drinks they give her. Alice is also experiencing drooling and having difficulty swallowing the medication given to manage this undignified symptom.

You introduce yourself to Alice and gently examine her, take blood and order a chest x-ray. Your clinical diagnosis is of another aspiration pneumonia. You discuss with Alice and her family that whilst you can treat the infection the bigger picture is that Alice is being frequently admitted with the same problem and it would be good to think through what to do when Alice next develops a pneumonia. You find that Alice does not have capacity to make a decision at the time of your conversation and Trevor tells you that Alice does not have an Advance Care Plan and has not made an Advance Decision to Refuse Treatment (under the MCA).

Trevor and Karen then ask if it would be possible for Alice to have a PEG tube inserted to try and reduce the risk of Alice's food 'going down the wrong way', causing an infection resulting in her being repeatedly admitted to hospital with a pneumonia?

You feel out of your depth, realising that this is a complex decision and so you speak with your Reg, Sarah, who knows the patient well from clinic. Sarah thinks that PEG feeding will not benefit Alice and carries significant risks. She cites the evidence that a PEG tube will not prolong life and could cause harm. She promises to review Alice and discuss a plan with her family regarding how to manage future chest infections.

When you go back to discuss this with the family, Karen's eyes fill with tears. Since the onset of her dementia, Trevor and Karen have been helping Alice take her meals. For over a year, Alice has continued to join the family for dinner around the table, and Trevor says that Alice smiles and appears to get a lot of pleasure from eating with her family. As Karen puts it, "dinner time is the only time that the family see the real Alice these days". Trevor and Karen themselves report how important this time is for them to show their love and care for their mother. Trevor adds that Alice has always been something of a 'bon viveur'. She has previously worked as a professional chef, and was a regular at many of London's fine dining establishments. She was proud never to have missed a single episode of Masterchef.

Trevor and Karen think that refusing a PEG tube to their mother is inhumane and ask to speak to the consultant. Should Alice have a PEG tube inserted, in line with the family's request?



Ethical Considerations

General ethical considerations

- Preferences vs. risk
 - Balance varies depending upon stage of dementia/degree of capacity?
 - Role of professional and NICE guidance?
- Subjective vs. objective quality of life
 - What is the evidential force of subjective QoL considerations in cases like Alice?
- Weight of past values and desires
 - How precisely are they relevant to the present situation?

End of life/ANH specific considerations

- Alice's narrative integrity
- 3rd party interests and the value of supporting relationship bonds
 - Broader socio-cultural perspectives on the value of food, eating, and dying?
- Meeting basic human needs
 - Is nutrition and hydration morally significantly different from other treatment interventions?
- Dignity-related considerations
 - The significance of a “natural death”?



Making good decisions

- **Legal considerations**
 - Obtaining informed consent (where possible)
 - Tempered by judgement about clinically relevant options: when should ANH be presented as a viable option?
 - Role of ACP and 'Advance Refusals': future care planning to avoid ethical 'sticking points'
 - Best interests decision making under the MCA (when capacity lost)
 - Limited guidance about how to weigh up relevant factors, and balance these against objective benefits and burdens
 - Basic care vs medical treatment
 - Bland judgement [Airedale NHS Trust v Bland (1993)] established that ANH is a treatment that can be withdrawn in line with general medico-legal principles
 - GMC guidance ("Treatment and care towards the end of life" – 2010)
 - 117: "When the benefits, burdens and risks are finely balanced, the patient's request will usually be the deciding factor." [patient has capacity]
 - 124: "If a patient has previously requested that nutrition or hydration be provided until their death, or those close to the patient are sure that this is what the patient wanted, the patient's wishes must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor." [patient lacks capacity]



A framework for decision-making

1. Determining the facts and possible options

- Given the specific details of the situation, which options are available, viable and possible?
- These facts will include information relating to the person's abilities, values, behaviours, the interests of others, clinical indications etc.

2. Which action will most respect the person's autonomy?

- Can the person participate meaningfully in the decision?
- Do we have information about what the person would have chosen, if able, in this situation?
- [Can we set in place processes to enable us to obtain such information in decisions relating to this patient's future care/other patients in similar situations?]



A framework for decision-making

3. Which action will most enhance the person's well-being?

- What are the benefits and burdens of the available options? Think about these in broad, experiential and inter-personal terms – not merely clinical

4. Are there any justice related considerations to take into account?

- Will the options involve all patients getting fair access to care and treatment?
- Will family members be unfairly disadvantaged or burdened by one or more of the options?

5. Resolving residual ethical conflict

- Is there alignment between autonomy and well-being considerations, given the options?
- If not, has our analysis given rise to new options that were not part of the original management plan?
- If not, how can we act in such a way that the resolution of this dilemma will reduce the degree of 'moral damage' that results from the ethical choice that we settle on?



Take-home lessons

- Ethical decision-making around ANH evolves quickly: be prepared to change the options being weighed up, and the decision to be made
- Collecting evidence relevant to making a good ethical judgement will require expertise drawn from all members of the MDT.
- Value conflicts & managing conflict will be a significant feature of ethical decision-making: within the MDT setting, or between the team, patient and family members
- Good ethical decision-making will involve finding imaginative solutions to problems (and pre-empting moral concerns with certain options to limit the 'moral damage')



What is patriotism but the love of
the food one ate as a child?

— *Lin Yutang* —

AZ QUOTES