

# The Ethics of Feeding in Dementia

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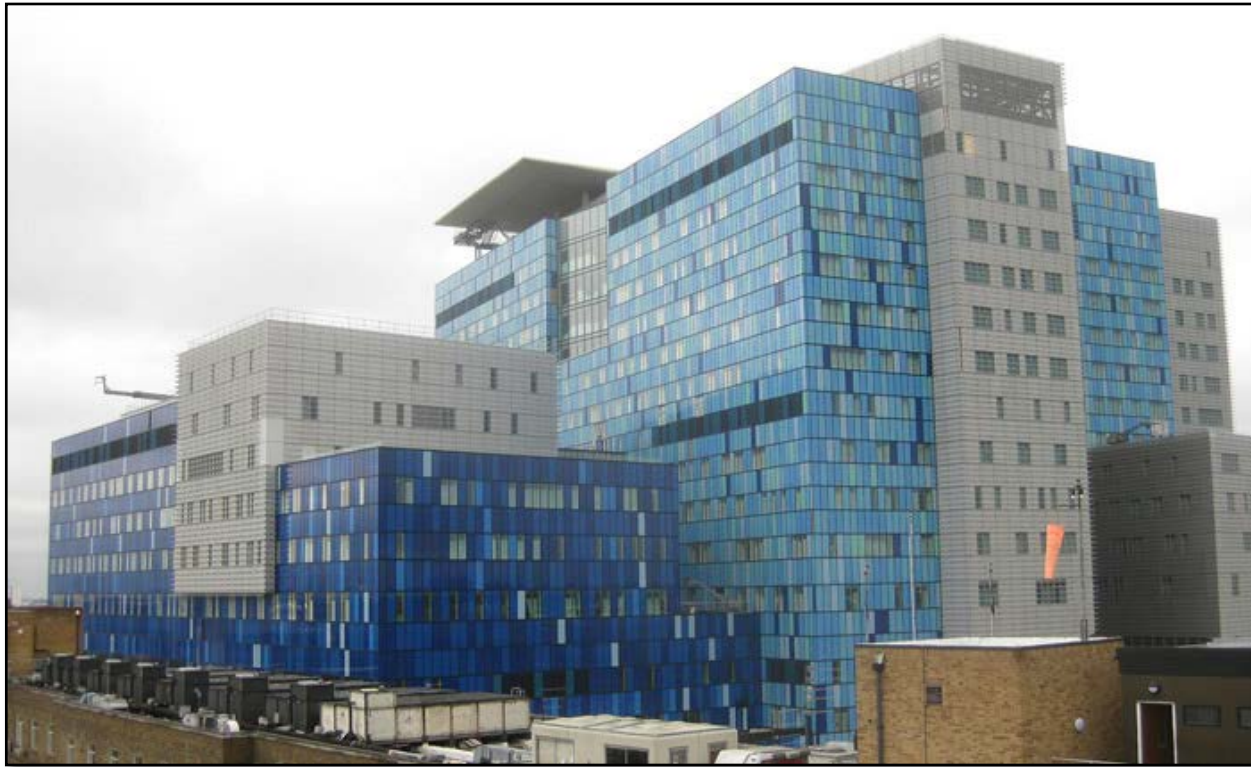


# Overview

- Background
- Case vignette
- Evidence base / best practice guidance
- Summary and top tips




# Conflict of Interests



# Context



**Dignity and nutrition  
inspection programme**  
National overview



October 2011



**AGE Concern** **Hungry to be Heard**  
The scandal of malnourished older people in hospital



**THE INDEPENDENT**

**Hungry, thirsty, unwashed: NHS treatment of the elderly condemned**

Health service stands accused of ageism



# Dementia

- Incidence 225 000
- £4.3Bn per annum
- Prevalence 850 000
  - c.1.1 million by 2025
  - > 2 million by 2051
  - 5% Age  $\leq$  65 years
- 70%  $\geq$ 1 other medical co-morbidity
  - 61% Anxiety or Depression



# Nutrition & Dementia

- Progressive weight loss
  - 1-4% per annum
- Exacerbated by co-morbidities
- Sarcopaenia
- Osteopaenia
- Frailty



# Malnutrition & Dementia

- Morbidity ↑
- Mortality ↑
- Quality of life ↓
- Carer burden ↑



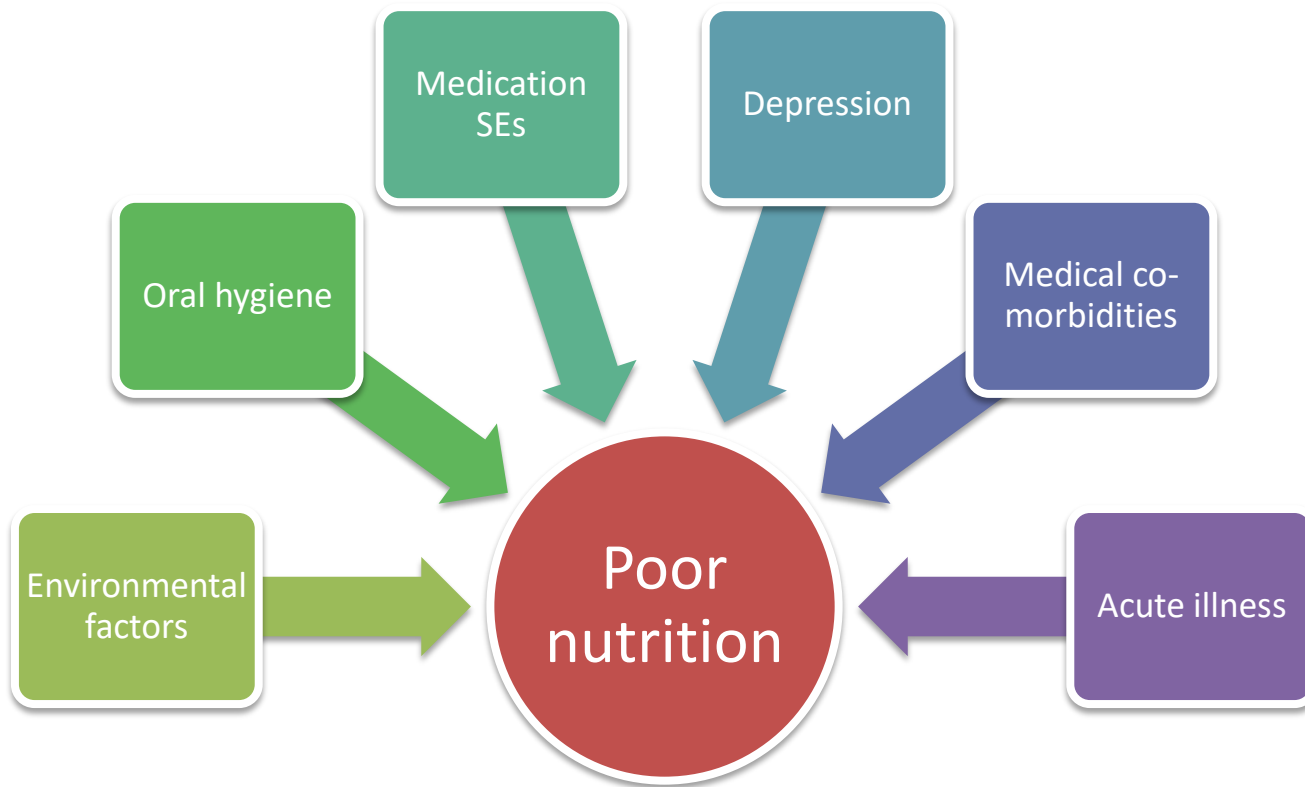
# Nutrition & Dementia

Nutritional problem	Stage of dementia
Olfactory and taste dysfunction	Preclinical and early
Executive planning difficulties (shopping, preparing food)	Mild to moderate
Attention deficits	Mild to moderate
Dyspraxia	Mild to moderate
Agnosia	Mild to moderate
Behavioural problems	Moderate to severe
Oropharyngeal dysphagia	Severe
Refusal of eating and drinking	Severe

[http://www.espen.org/presfile/Volkert\\_2014.pdf](http://www.espen.org/presfile/Volkert_2014.pdf)



# Slight caution



# Case study

## 78 years old seen in the Emergency Department Friday 6pm

- Lives in a nursing home
- ‘Chesty’ cough
- Drowsy
- Spiking temperatures
- PMHx
  - Dementia
  - Hypertension



# Additional information

- Recently admitted to nursing home
- Diagnosed with dementia 18 months ago
  - Probable vascular dementia
  - CT showing multiple small lacunar infarcts
- Decline in function in the last 12 weeks pre-empting admission to nursing home
- Approx. weight loss of 10% in last 6 months



# Important Information

- Pre-existing wishes of the patient
- Extent of end organ damage
  - Respiratory failure
  - Renal failure
  - Cardiac failure
- ABG: pH 7.29 pO<sub>2</sub> 7↓ pCO<sub>2</sub> 7↑ BE -10↓
- CXR: Focal consolidation right lower lobe
- Bloods: Urea 34↑ Creat 196 ↑ K<sup>+</sup> 5.9 Na<sup>+</sup> 153 ↑



# Vote now....



# To feed or not to feed?



# Artificial nutrition & hydration

Barts Health  
NHS Trust



**ANH constitutes medical treatment\***

**There is no distinction between passing and feeding  
via an NG tube**

\* It is considered part of basic care for neonates



# Four ethical tenets

## “Basic Human Right”

Article 25(1)

- Autonomy
- Beneficence
- Non-maleficence
- Justice

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including **food**, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control

<http://www.un.org/en/documents/udhr/>



# Assessing capacity

- Understand in simple language what the medical treatment (or research intervention) is, its purpose and why it is proposed.
- Understand its principle benefits, risks and alternatives.
- Understand in broad terms what will be the consequences of not receiving the proposed treatment.
- Retain the information for long enough to make an effective decision.
- Make a free choice without pressure.

BMA & the Law Society



# Lacking capacity

- Legally ANH is a medical treatment
  - You cannot be compelled to prescribe ANH
- Mental Capacity Act 2005
  - Advance Statement / Decision
  - Engage “those close to the patient”
  - Donee with Lasting Power of Attorney for Personal Welfare
  - Independent mental capacity advocate (IMCA)
  - GP or consultant are legally responsible for decision
- Deprivation of Liberty



# What it doesn't mean....

capacity

→ does not need formal assessment as

i) will take considerable time to assess

ii) won't affect decision for RIG





**BAPEN**

*Putting patients at the centre  
of good nutritional care*

REGISTERED CHARITY NO. 1023927

**NHS**

**Barts Health  
NHS Trust**

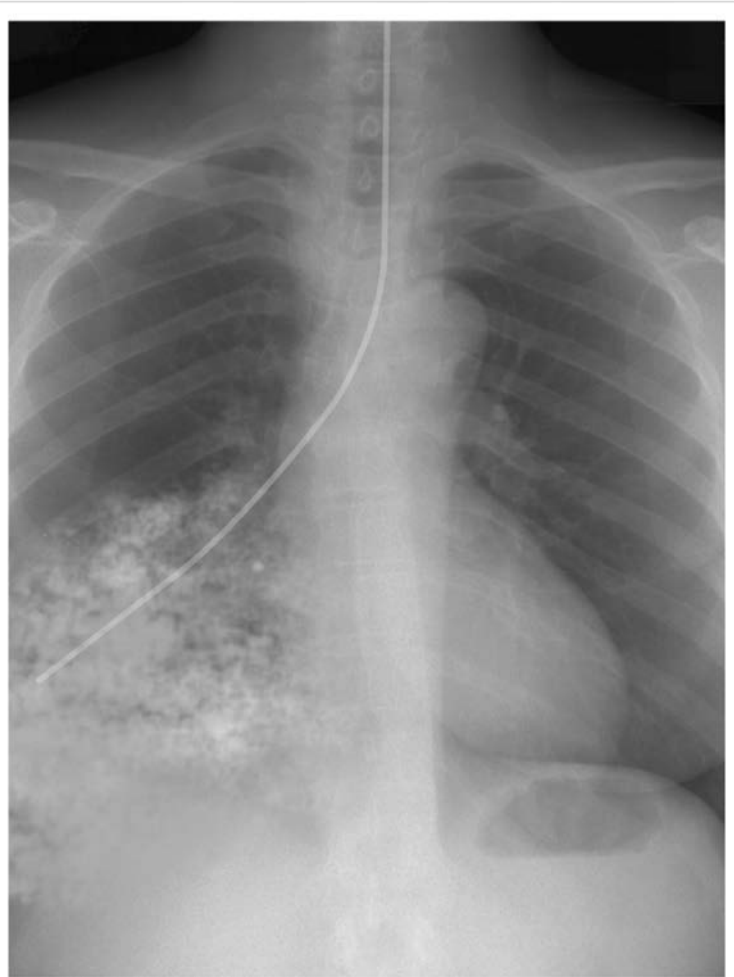


Figure 3. Chest Radiograph Representing  
Nasogastric Feeding Tube in Lower Lobe of  
Right Lung with Infiltrate



# PEG Evidence / Guidance

- Does not improve nutritional status
- Does not prevent or lower the risk of aspiration pneumonia
- Does not reduce skin breakdown or pressure ulcers
- No difference in life expectancy compared with assisted oral feeding
- **But studies are small and methodology could be improved**



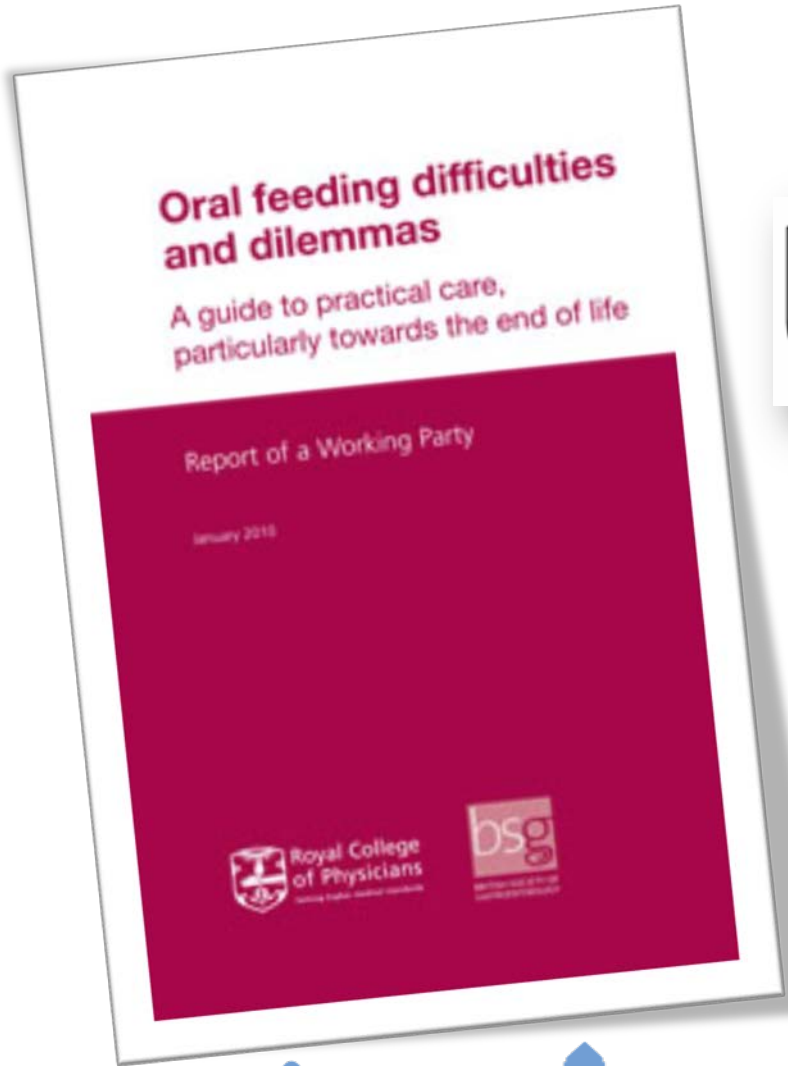
# Alzheimer's Association

## ASSOCIATION POSITION

The Association asserts that it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the person with Alzheimer's disease or dementia is in the end stages of the disease and is no longer able to receive food or water by mouth. The Association emphasizes that assisted oral feeding should be available to all persons with advanced Alzheimer's disease. Neglect in this area should not be tolerated, and concerted efforts are called for to educate and support professional and family caregivers in techniques of assisted oral feeding.

"Assisted oral and tube feeding"  
Alzheimer's Association





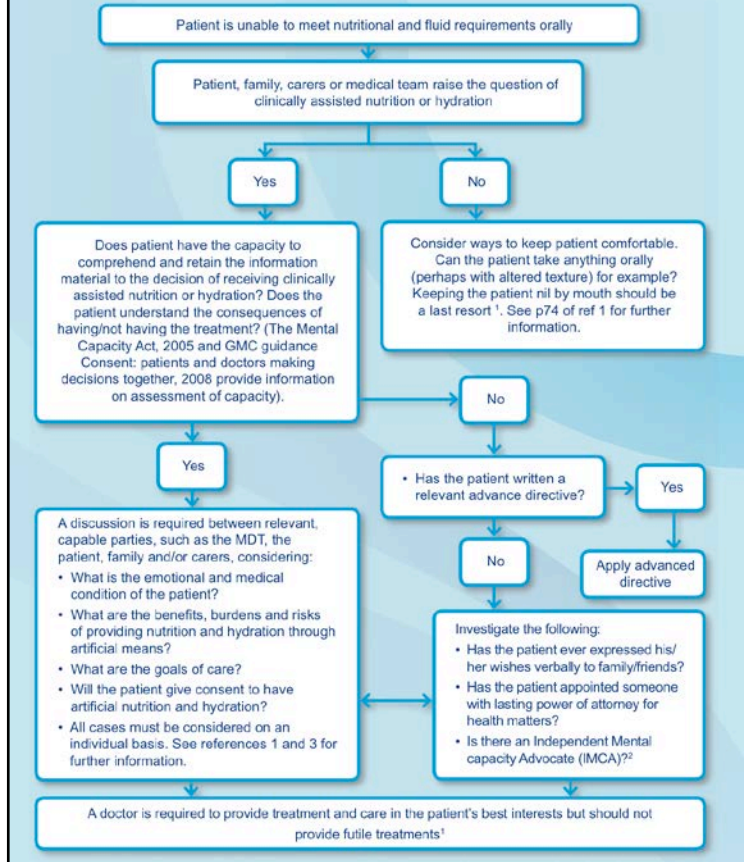
# Oral Feeding Difficulties & Dilemmas

- **The first question should be ‘what are we trying to achieve?’**
- Oral intake, modified as necessary, should be the main aim of treatment
- At the end of life, even if deemed to have an ‘unsafe swallow’ a risk management approach may offer the patient the best quality of life
  - **If in doubt, a trial of nasogastric feeding with clearly agreed objectives may be appropriate**
- When artificial nutrition and hydration are required for the medium term or longer, this should be managed by the multidisciplinary team
- Artificial feeding should never be based on the convenience of the staff or carers or be required as a criterion for admission by any institution

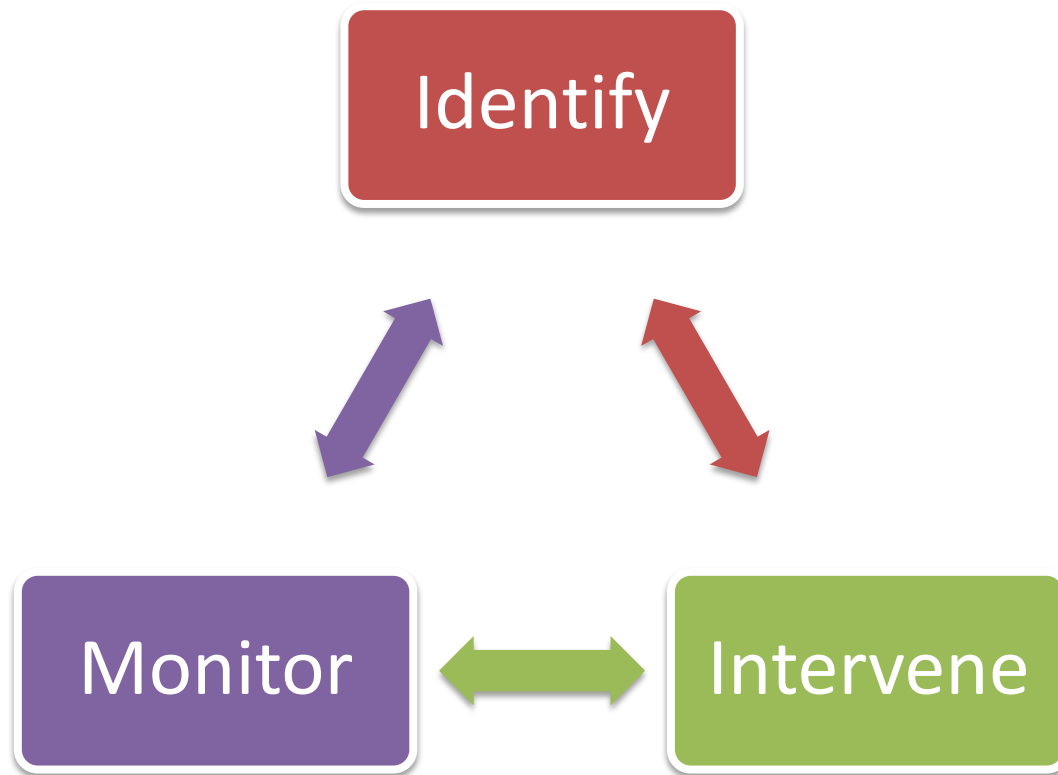
RCP / BSG Oral feeding difficulties and dilemmas 2010



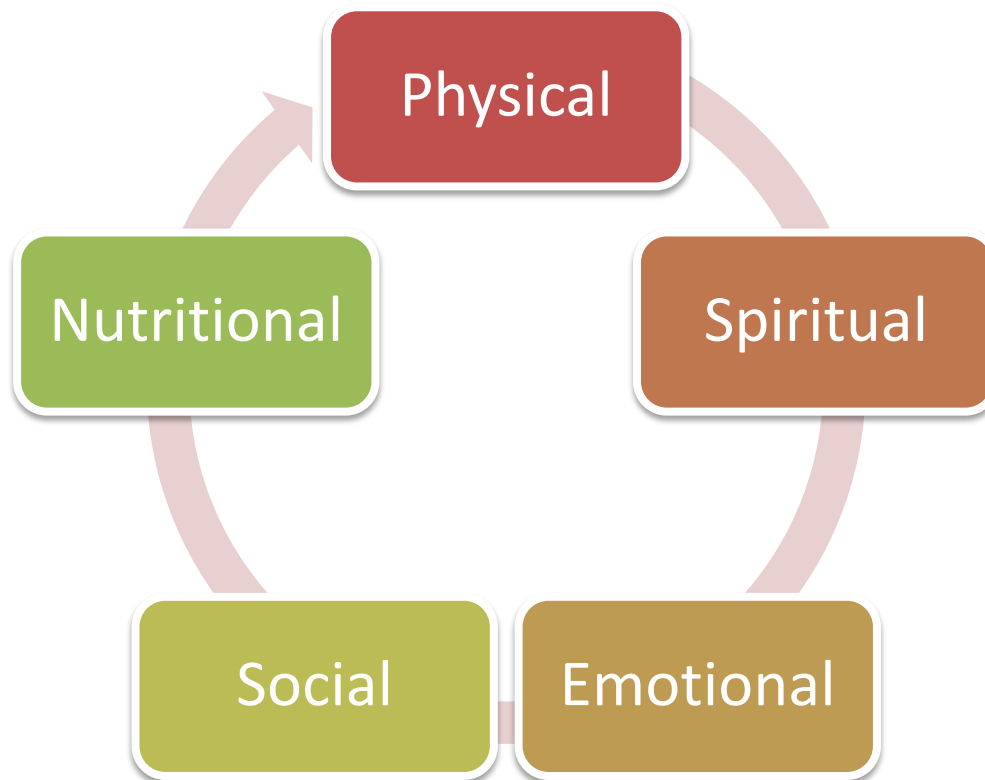
**Ethics and clinically assisted nutrition  
or hydration approaching the end of life –  
Decision Tree**



# Getting the basics right

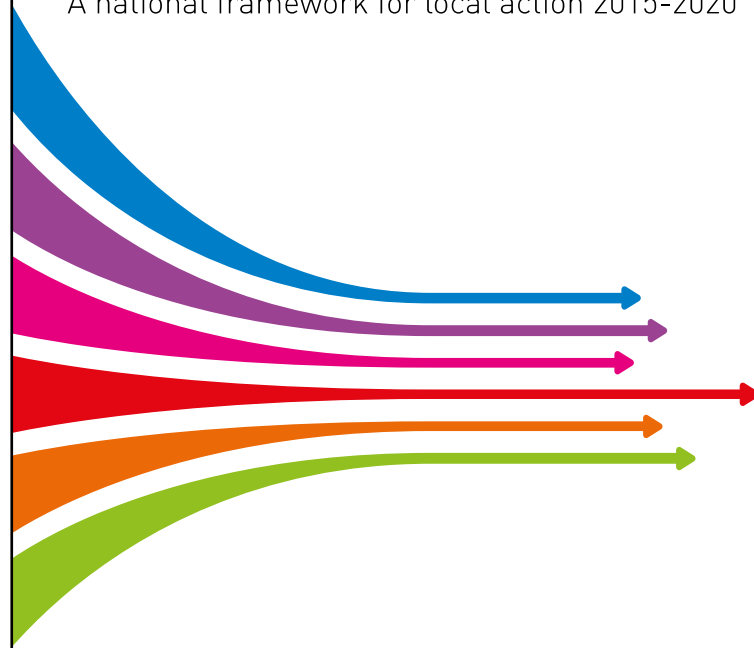


# Quality of Life



# Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership  
[www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk)



# Challenges

## Staff

Training

Staffing levels

Motivation

## Patients

Illness

Self awareness

Visibility

## Systems

Documentation

Continuity

Culture

Pressures



# Summary

- The ethics of feeding is complicated and challenging
- The first question should be '*what are we trying to achieve*'?
- ANH can be appropriately given on a trial basis
- A multi-disciplinary approach is essential



# Final Thoughts...

“One overlooked reason that many families and physicians continue to opt for artificial nutrition is that the case for feeding tubes is a moral one not a scientific one.

What may be at issue for families is how best to demonstrate ***caring***, and caring is not readily amenable to empirical study.

A better approach to family members who want feeding tubes for the demented is to acknowledge the symbolic value of nutrition for them and to seek an alternative means of satisfying the need to feed”

Gillick M, Volandes A  
<https://doi.org/10.1016/j.jamda.2008.03.011>



# Key References

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- The National Council for Palliative Care: *Artificial nutrition & hydration, guidance in end of life care for adults.* London, 2007
- <http://bma.org.uk/practical-support-at-work/ethics/withdraw-withhold-artificial-nutrition-and-hydration>



# Any questions?

