Artificial Hydration and Nutrition at the end of life
Providing effective mouth care

Dr Sarah Human & Catherine Hughes RN
“Dying is not only a physical event – it is the conclusion of a life defined in its nature, content and connections within a society and its cultures that are every bit as important as the mechanism of how dying happens.”

End of Life Care Strategy: promoting high quality care for adults at the end of their life. July 2008
‘Death pathway’ to be scrapped by NHS
System has failed the vulnerable, says inquiry

By Daniel Martin
Whitehall Correspondent

THI controversial Liverpool Care Pathway is to be phased out within 12 months after an independent review found shocking examples of abuse across the NHS.

Care Minister Norman Lamb will announce on Monday that he is to scrap the scheme, which allows doctors to stop treating those deemed to be close to death.

It follows a review that heard allegations of the vulnerable being put on the pathway without consent, that they were being unreasonably sedated and that others were being denied food and water.

The Neuberger inquiry also found “numerous examples of poor implementation and worrying standards in care” that meant the LCP needed to be replaced.

The Mail has led the way in campaigning against the so-called “Death pathway”, highlighting how hospitals were being paid bribes by the NHS to hit targets.

The Department of Health will also reveal that these incentive payments will be scrapped.

Last night Mr Lamb vowed that the replacement will definitely not be called a “pathway”.

He said: “We need a whole new system of better end-of-life care tailored to the needs of individual patients and involving their families. I took the decision to launch this review because concerns were raised with me about how patients were being cared for and how families were being treated during this difficult and sensitive time.”

The care pathway has been described as “futile” and “fruitless”, with patients often dying in hospital instead of being able to die at home.

Ministers order an inquiry into the care pathway payments

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

April 3, 2013

November 27, 2012

Ministers order an inquiry into the care pathway payments

The report found no evidence of misuse, but Mr Lamb said the “bribes were such a bad impression that they should be stopped”.

Michelle Mitchell, of the charity Age UK, said: “Any decision on the future of the Liverpool Care Pathway has to be based not just on what the guidance says but also on the reality of hope it is being implemented.

“A society, we must be able to ensure that people at the end of their lives are treated with compassion and dignity.”

Hospitals bribed to put patients on pathway to death

The money was partly tied to delivering an LCP figure of 45 per cent against a target of 30 per cent. South Staffordshire CCG Trust had LCP-linked payments halved for failing to hit targets.

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“One chance to get it right”

The Five Priorities for Care of the Dying Person

- Recognise
- Communicate
- Involve
- Support
- Plan and do
Care of adults in the last days of life
NICE guidelines December 2015

- Recognising dying
- Communication
- Maintaining hydration
- Pharmacological interventions
- Managing pain

- Managing breathlessness
- Managing nausea and vomiting
- Managing anxiety, delirium and agitation
- Managing noisy respiratory secretions
- Anticipatory prescribing
Care of adults in the last days of life
NICE guidelines December 2015

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Pensioner placed on Liverpool Care Pathway WITHOUT family's permission dies after spending eight days without food or water

- Susan Phillips said father Robert Goold, 69, was left to slowly deteriorate
- She claimed doctors said there was no record in his notes about LCP
- He died without being able to say goodbye to his wife of 51 years
- Addenbrooke's Hospital said it will investigate the family's claims

By LEON WATSON
PUBLISHED: 13:04, 6 March 2013 | UPDATED: 17:06, 6 March 2013

A grieving daughter has lodged a complaint against a hospital which left her father to die on a 'barbaric' end of life pathway for eight days without her permission.

Susan Phillips said her 69-year-old father Robert Goold was left to slowly deteriorate for more than a week on the controversial Liverpool Care Pathway.

The pensioner, who had dementia, got weaker and weaker as doctors took food, water and oxygen away from him but survived longer than they expected.
The issues

• Symbolic value of food and fluid: HOPE
• Fear of “dying badly” while suffering from hunger and thirst: COMFORT
• Is denying ANH a medical act that is the same as euthanasia?
Emotive issues

- ‘My Father is not drinking enough. Why aren’t you giving him extra fluids?’

- ‘If she doesn’t eat will she starve to death?’

- ‘Can’t you give her calories into a drip to make her better?’

- ‘Will my Dad die of dehydration if he can’t drink?’
Emotive issues

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• ‘Will my Dad die of dehydration if he can’t drink?’
What happens when people stop eating and drinking?

HUNGER

- Studies in voluntary fasting
- Northern Ireland hunger strikers
- Anorexia Cachexia Syndrome
- Other conditions e.g. dementia, MND, MS, heart failure
What do we mean by “dehydration”?
The evidence?...

Few studies in dying patients. Dry mouth, thirst and respiratory secretions are unrelated to level of hydration¹. 45% of patients admitted to hospice have dry mouth when asked. No proof that withholding of fluids interferes with length of remaining life or comfort.

The evidence?......

• Only ½ of patients show any biochemical evidence of dehydration in final 48h of life.

• No evidence thirst/dry mouth improves with artificial fluids.

• More fluids may lead to fluid on lungs, increased secretions, increased vomiting and uncomfortable urinary output.

• Terminally ill cancer patients who declined food and drink did not generally experience hunger or thirst.\textsuperscript{2}

• Stopping food and fluids in terminally ill patients is not associated with pain.\textsuperscript{3}

Ethical considerations:

- Is killing the same as allowing to die?
- Is withholding or withdrawing artificial nutrition or hydration the same as denying food or drinking?
Ethico-legal considerations:

- **Basic care**: All patients are entitled to food and drink (by mouth) and to help with eating and drinking.

- **Medical treatment**: Artificial (tube) feeding is a medical treatment in law.

- **Withholding/withdrawing** hydration/nutrition (in terminally ill) is morally and ethically distinct from euthanasia or assisted suicide.
Ethico-legal considerations

• Withholding and withdrawing treatment
  – When is it legal?
• Mental Capacity
• Best Interests decisions
Ethical considerations:

- **Beneficence (Doing Good):** Will fluids/nutrition help the patient?

- **Non-maleficence (Avoiding harm):** Will giving or not giving fluids/nutrition cause the patient harm?

- **Autonomy (Self determination):** Does the patient want to continue with fluids/nutrition?
Benefits, burdens and risks
When might artificial nutrition and hydration be appropriate in the palliative care setting?

Nutrition and fluids

- Head and Neck tumours/oesophagus – in preparation for treatment
- Some patients with MND or other progressive neurological disorders
- What about dementia?

Fluids

- Potentially correctable situations (to prolong life)
  - D+V
  - Sepsis
  - Overmedication
  - Hypercalcaemia
- To treat symptoms of thirst
  - Bowel obstruction
  - Dying phase?
- To treat the family????????
Potential problems with artificial hydration in last days or so of life

- Abnormal fluid accumulation e.g. peripheral oedema, ascites, vomiting, pleural effusions, pulmonary secretions, full bladders
- Burden/discomfort of cannula/blood tests – it is intrusive
- Limits choice in terms of place of care?
- Prolongs dying process?
- Interferes with acceptance of dying?
Things to consider

- Prognosis/Life prolonging treatment
- Capacity/Incapacity
- “What are we trying to achieve?”
- “Who are we treating?”
- Weigh up potential benefits against potential harm
- Duty of Care
- Quality of Life

Artificial Hydration and Nutrition; guidance in end of life care for adults.
2007
What to say to families?

• Managing difficult conversations is central to the provision of good end of life care.
• Listen and acknowledge first.
• Be open to hearing concerns.
• Put aside personal beliefs.
• If you feel unable to answer questions, commit to finding someone who can.
What to say to families?

• Explain that the patient’s body is gradually shutting down.
• The patient’s body is unable to handle extra fluid.
• Reassure that patient will continue to be kept comfortable throughout.
• Explain measures used to avoid discomfort.
• Explain about mouth care.
What to say to families?

• Avoid words like ‘futile’ and ‘withdrawing’.

• Focus on disease process as cause of deterioration.

• Explain that time spent with patient of most importance.

• Provide written information if appropriate.

• Give family members the opportunity to provide care.
What should I do when families are unable to accept?

- Explore their concerns.
- Acknowledge family distress.
- Discuss pros/cons of artificial fluids/nutrition.
- Reassure that patient will be kept comfortable whether artificial fluids/nutrition are given or not.
- If family still unable to accept?
• Mr Black has advanced, hormone refractory Ca Prostate. He is becoming increasingly frail & is now mostly bed bound. His wife is very anxious about his nutrition & is trying to make him eat but he does not feel hungry.

• You are asked to review him. It is clear he is likely to be in the last few days of life, cannot manage his oral medications (including pain killers) and you wish to set up a syringe pump for him.

• Whilst you are talking this through with her she says…….
“Will this pump give him some fluid and food?.....he is going to die without any food......you can’t let him die of thirst.......that would be just cruel.....he is starving to death!”
Summary

• Discontinuation of food and fluid at the end of life is highly emotive.
• Basic care is a human right.
• Artificial hydration and nutrition is a medical treatment.
“Navigate the path of least regret...........”
# Chapter 16

### 16. Palliative Care

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[https://southwest.devonformularyguidance.nhs.uk/formulary/chapters/16.-palliative-care](https://southwest.devonformularyguidance.nhs.uk/formulary/chapters/16.-palliative-care)
Mouthcare

Catherine Hughes RN Education Facilitator
Good oral hygiene …

…is integral to promoting and maintaining elements of patients’ quality of life including:

- Comfort
- Nutrition
- Communication
- Motivation
- Self-esteem

Davies and Epstein (2010)
Glare et al (2011)
Saliva

• Lubricates

• A healthy individual is estimated to produce between 0.75-1.5 litres of saliva per day

• Production drops to almost zero in sleep
Assessment

Oral assessment

- Identifies baseline oral status
- Establishes preferences for hygiene routine
- Identifies changes
- Important for care planning
Nurse Assessment

Equipment for oral assessment:

- Pair of disposable gloves
- Tongue depressor
- Pen torch
- Denture receptacle, if required
- Tissues
Oral Problems

Xerostomia (dry mouth)  Candidiasis Oral Thrush

[Images of a dry mouth and a mouth with thrush]
Check for

Ulceration

• Odynophagia (painful mouth)
SLS free toothpaste

1. Weleda
2. Jack 'n' Jill
3. miessence
4. Kiss My Face
5. Jason's Sea Fresh
Mouth care for semi-conscious/unconscious patients

- Prepare mouthcare tray
- Remove any dentures as appropriate
- Wipe oral/buccal mucosa and tongue using a moistened pink tipped sponge swab
- Apply saliva replacement gel to mucosa and lips
Use of oral swabs or soft tooth brush
Lets have a go

- Split into pairs

- How did that feel?
- Would you do mouth care any differently now?
Dementia care and oral hygiene?

- Provide a calm environment
- Approach the patient at eye level and establish a rapport
- Check if the patient is accepting of touch
- Stand/sit the patient in front of a mirror and sink
- May open mouth in response to carer positioned behind, when in front of a mirror
- Give short, simple instructions
- Encourage the patient to complete the task
- If unsuccessful, ask a second carer to complete the task
A useful Guide for carers

Our ambition is for everyone across Torbay and South Devon to view this short film. The purpose of the video is to discover people's comfort in talking about death and dying. Talking about dying may not be easy, but could be one of the most important conversations you will ever have. Click on the picture to watch film.
Free access to end of life e learning
