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Nurse Helen Cowan talks about starvation, dehydration and death in hospitals.

“Kill by mouth” read a recent headline in the Sun newspaper. Readers were informed that “malnutrition was mentioned on the death certificates of 297 patients who died in hospital during 2015; dehydration was cited for 429 patients. For care homes, the figures were 54 and 76 respectively.”

The newspaper was quick to blame understaffing, resulting in overworked staff forgetting or not having the time to feed patients, and I have indeed seen this first hand. As a nurse I have noticed other reasons for malnutrition and dehydration, however: patients who simply can’t or won’t eat – or, most worryingly, are not allowed to eat.

## Those who can’t eat

Disease, dysphagia, dysgeusia (impaired taste), drugs and dentition are five of the main reasons why patients struggle to eat. More than 250 medications are known to affect smell and taste, including some antibiotics, ACE inhibitors and beta blockers.

Some diseases that I have come across have made eating impossible. The first patient that I ever nursed had gastrointestinal scleroderma and could manage very little orally; another had poorly controlled COPD and the chronic cough, excessive mucous production, wheezing and shortness of breath severely restricted his ability to eat, whilst his weight plummeted as he expended extra energy in his laboured breathing.

I have nursed several patients with Parkinson’s and learnt that it’s not only the hand tremor that may interfere with feeding: poor saliva control, loss of smell, constipation and depression are less well known but relatively common symptoms.

Sometimes simple solutions can improve nutrition: I remember the young lads with muscular dystrophy who overcame their physical inability to hold a pint glass by using long twisted straws that reached from the glass on the table to the tip of their tongue; when I worked on a neurosurgical ward, nasogastric and PEG tube feeding could

overcome limitations imposed by dysphagia.

In the nursing home setting, the oral route is often the only route available, and so food can be thickened, softened, pureed and fortified to promote nutrition.

## Those who won't eat

Despite best intentions and inventions, many patients have flatly refused to eat or drink.

I have observed more than one frail elderly person for whom life seemed to have become an excessive burden, and lack of food intake a chosen method to exit life. Mary was fiercely independent, and used to laugh in my face when I offered food, endlessly repeating, "I don't want it".

Food can also be refused because it's unpalatable and unattractive. Chef James Martin is on a mission to improve standards of hospital food; broadcaster Loyd Grossman and chef Albert Roux are calling for legally binding hospital food standards. Even something as simple can help as bringing pureed food back to life by using food moulds to make the turkey dinner resemble just that again, and not an artist's palette with over-thick paints. Moulds exist to reshape pureed food into piles of peas, carrot batons, slices of meat and swirls of mashed potato; appetite and dignity somewhat restored.

For elderly patients, dementia often robs them of their appetite and ability to eat: food becomes a foreigner, chewing and swallowing a lost skill. Anne became convinced that her food was poisoned; Derek insisted on paying for his meals upfront; John often argued that he had already eaten.

## Those who aren't allowed to eat

Linda was in the end stages of life, Alzheimer's having reduced her to a shell of her former self. She hardly ate, slept often and grew weaker by the day. On the rare occasion when she woke up, she would accept a spoonful of yoghurt or a cup of milk. Her family asked why we kept feeding her, prolonging the inevitable.

Sue lay unconscious for many years after a stroke. At 6pm each evening, I would switch the news on the television, talk about the day's events and start her overnight PEG tube feeding. When Sue became unwell with a chest infection, her family decided that it would be in her best interests not to administer antibiotics: a decision that I could accept. What was more difficult was the request to no longer administer her enteral feed.

A study by the National Institute of Aging reported that insertion of PEG feeding tubes in patients with dementia who need feeding assistance does not improve survival (Teno et al, 2012). Taken conversely then, cessation of PEG tube feeding in a patient with an acute illness (such as chest infection) is unlikely to hasten death (the family's request, never mine). Proving that it does not cause feelings of hunger and thirst is more difficult.

Jewish and Catholic authors give a very high priority to preservation of life. They maintain that tube feeding comprises part of "proper, moral care" and have written that withholding such feeding "ultimately results in starvation, dehydration and death".

Others suggest that withholding enteral feeding is neither painful nor uncomfortable, but that "people adapt physiologically to starvation, and studies show that dying patients who stop eating and drinking rarely experience discomfort due to hunger. Dehydration usually precedes starvation, causing hemoconcentration and hyperosmolality followed by azotemia, hypernatremia, and hypercalcemia. These metabolic changes are thought to have a sedating effect on the brain prior to death, and some think dehydration may increase comfort and minimize pain during the dying process" (Friedrich Nutrition Counseling, 2013).

Whether and when tube feeding should be stopped near the end of life remains controversial. The GMC writes that "the current evidence about the benefits, burdens and risks of these techniques as patients approach the end of life is not clear-cut. This can lead to concerns that patients who are unconscious or semi-conscious may be experiencing distressing symptoms and complications, or otherwise be suffering either because their needs for nutrition or hydration are not being met or because attempts to meet their perceived needs for nutrition or hydration may be causing them avoidable suffering."

## Let them eat cake

For as long as I continue to nurse, I hope to be able to administer food as a form of comfort, orally or enterally, as long as it can be done safely. And it doesn't always have to be healthy eating: fancies can be indulged. I bought a plate of hot chips for a severely malnourished, anaemic patient soon after heart surgery, and administered a daily diet of pink doughnuts to a teenager dying of facial cancer. I soaked a mouth sponge in Guinness for a patient recovering from a stroke; I pour an evening glass of sherry to help a lady in the nursing home to swallow her night-time medication.

When clinical care has reached its limits, comfort and compassion should come to the fore. And nursing homes should stop the tradition of hanging paper skeletons from the rafters for Halloween: it's in very bad taste.




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