Caring for people who are dying: implications of the Burke *vs* GMC case

The General Medical Council (GMC) has successfully appealed against a court ruling which would have had far-reaching effects not only for doctors, but for society at large. In effect, the GMC (2002) is vindicated in its carefully considered guidance on withdrawing and withholding life-prolonging treatments. If the appeal had been unsuccessful, doctors would have been obliged to administer treatments which they considered to be futile.

Why did the GMC guidelines alarm Mr Burke enough to go to court?

Mr Burke is a man in his mid-40s who has degenerative spinocerebellar ataxia. It is expected that at some stage he will develop dysphagia and lose the ability to articulate his wishes verbally, even though he will retain full mental capacity. As he understood matters, he might or might not receive artificial nutrition and hydration (ANH) according to the whim of the attending doctor at the time. In consequence, he expressed the very reasonable fear of being left to die, hungry and thirsty.

In reality, of course, taking the GMC guidance in totality and not isolating paragraphs out of context, there was already every provision to give reassurance to Mr Burke that he would not suffer in the way in which he feared. Indeed it has been suggested that a doctor following the GMC guidelines would have treated Mr Burke with ANH for longer than the court ruled would be obligatory (Gillon, 2004).

Why was there so much at stake in the original Burke *vs* GMC case?

The original ruling made by Mr Justice Munby in 2004 (Dyer, 2004) would have given patients the right to demand ANH and possibly other life-prolonging treatments. This would negate the doctor's clinical judgment to act in the patient's best interests, even if the doctor felt that the particular treatment was wholly inappropriate and might exacerbate suffering or simply prolong the dying process. Essential paragraphs in the GMC's guidance on life-prolonging treatments would have been deemed unlawful. The judge indicated that life-prolonging treatment could be withheld only if continuation of that life would be 'intolerable'. A further declaration in the judgment was that all disputes about life-prolonging treatments should be referred for the court's decision in those cases where the patient lacked capacity.

The importance of whether the patient has capacity

Perhaps the first question involving life-prolonging decisions is whether the patient has capacity. Capacity implies the ability to understand the nature and implications of the treatment, the ability to remember this information, and to weigh up the benefits and burdens of any given treatment. Thus the patient with capacity, sometimes called the 'competent' patient, is able to make an informed choice. Clinicians must respect the wishes of competent patients who consistently refuse to have life-prolonging treatment, provided that they are fully aware of the potential benefits and burdens of that treatment. Patients who decline life-prolonging treatments should receive optimum care aiming to prevent unnecessary pain and suffering until death occurs naturally.

Patients who are near the end of life often do not have capacity, commonly because of organic delirium, medication or unconsciousness. Capacity in this context may be intermittent, and will vary according to the complexity of the dilemma for the patient. Thus it may be easy for a confused patient near the end of life to accept water given orally, but it may be beyond the capacity of that individual to consent to having a feeding gastrostomy tube fitted.

When do these dilemmas arise?

Disease trajectories vary according to the underlying condition, and the question of ANH may arise at a much earlier stage in some conditions. Starting ANH may well be appropriate in neurological diseases where swallowing is compromised, even where the disease will progress inexorably over the ensuing months or years. Individual patients may rate their quality of life surprisingly highly, especially where they have had many years to adapt to diminished independence. Equally, the patient who is unconscious following an intracerebral bleed may make at least a partial recovery, strengthening the case for all supportive and life-prolonging care. In advanced malignancy, artificial hydration usually neither prolongs nor shortens life, and a dry mouth is better treated with good mouth care (National Council for Hospice and Specialist Palliative Care Services, 1997).

When death is imminent within the next few hours or days, then any life-prolonging treatments will usually be deemed futile. At this stage, it is important to make the diagnosis that the patient is dying, recognizing that this is sometimes a complex process (Ellershaw and Ward, 2003). This will allow time to prepare and support the patient's loved ones.

How does the doctor proceed compassionately and within the law?

Each case must be assessed on its own merits, and any decisions should be reviewed, daily if necessary. Thus the patient with advanced lung cancer who has had a succession of frightening complications from his illness may opt not to have any further chest infections treated with antibiotics. On the other hand it is preferable to discuss the option of gastrostomy feeding with patients who have motor neurone disease many months before swallowing is significantly compromised, and before speech is lost.

For those patients who lack capacity, then the doctor should seek the views of 'those close to the patient' including family members and informal advocates, as well as clinical staff caring for the patient.

It will be the patient's prior wishes which count most, including views on dignity, suffering, sanctity of life, rather than necessarily the personal wishes of those being consulted. Ultimately, the responsibility for making a decision about life-prolonging treatments rests with the clinician responsible.

While there is a strong bias towards providing life-prolonging measures, the doctor is under no ethical or legal obligation to provide a treatment which he/she feels provides no net benefit to the patient. This should take into account the likely positive outcomes and burdens for the patient. Incidentally, stopping ANH need not be associated with patient distress (Chamberlain, 2005). Furthermore, insertion of gastrostomy tubes in advanced diseases carries its own mortality and morbidity.

Finally, although there is no absolute guidance for every scenario, there is considerable good practice around the country, and it is usually possible to obtain the best outcome for the patient after seeking opinions of all those involved in the patient's care. If dispute still remains, it is appropriate as in the GMC guidelines to ask for the opinion of another senior clinician experienced in these matters, or to seek legal advice from one's defence society or the legal department of the hospital trust.

Patients need to know that their doctor will always put their interests first, and that relief of unnecessary distress, and appropriate use of life-prolonging treatments is a responsibility which doctors take very seriously. BJHM

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KEY POINTS

- The Leslie Burke *vs* the General Medical Council high court ruling of 2004 would have obliged doctors to provide artificial nutrition and hydration to all dying patients requesting it, even if the doctor felt this was not in the patient's best interests. This ruling has been overturned.
- Patients with capacity can refuse life-prolonging treatment.
- For patients without capacity, the clinician in charge should make thorough enquiries from all 'close to the patient' before deciding what is in the patient's best interests.
- Every case should be assessed on its own merits and decisions reviewed as necessary.

Chamberlain P (2005) Death after withdrawal of nutrition and hydration. *Lancet* **365:** 1446–7
Ellershaw J, Ward C (2003) Care of the dying patient: the last hours or days of life. *BMJ* **326:** 30–4
General Medical Council (2002) *Withholding and withdrawing life-prolonging treatments: Good practice in decision-making.* General Medical Council, London
Gillon R (2004) Why the GMC is right to appeal over life-prolonging treatment. *BMJ* **329:** 810–11
National Council for Hospice and Specialist Palliative Care Services (1997) *Ethical decision-making in palliative care: artificial hydration for people who are terminally ill.* A paper produced by an ethics working party. National Council for Hospice and Specialist Palliative Care Services, London (http://www.ncpc.org.uk/index.html)