By some accident of genealogy, I recently found myself flying to an Arabian Gulf state to act as the next-of-kin and surrogate advocate for a relative who had suffered a catastrophic brain stem infarction. My uncle, a 71-year-old lifelong bachelor still in active employment, had been admitted to a private hospital with massive bilateral verteobasilar artery thrombosis. CT scans showed widespread infarction of the cerebellum, brain stem, and occipital cortex. He developed coning, at which time my sister, who lived in the region, was contacted to give consent for surgery. Having already discussed the details with me, she attempted to refuse but was told that this was not an option and that surgery had to be performed.

The operation notes, which in part read like a Gothic horror novel, confirmed visible, widespread ischaemia with marked tissue oedema. The surgery report detailed debridement of visibly necrotic areas of the brain stem.

QUALITY OF LIFE

I attended to a body totally unresponsive to any stimuli, immobile, externally ventilated, parenteral nutrition in place, bladder catheterised. The neurosurgeon greeted us amicably but did become slightly confused when asked what he had hoped to achieve by his interventions, in particular the removal of necrotic brain tissue from a sensitive area like the brain stem. He was more relaxed when the question was rephrased as to what he had hoped the prognosis would be. He immediately replied that the patient was likely to be quadriplegic and, when pressed, further agreed that the patient might also be unable to talk, swallow, breathe, or see. He agreed with my own literature search on the poor outcomes of brain stem infarction.

I summarised our discussion and concluded by saying that, because we both agreed that even the most optimistic prognosis seemed to offer little in the way of any quality of life, then the best interests of the patient would be served by initiating the process for defining brain death and subsequently withdrawing assisted ventilation. The surgeon was visibly shocked at my suggestion and immediately stated that he could not comply with my request. When he continued to demur I suggested that, rather than withdraw therapy, we would prefer that they should no longer actively medically intervene in managing any further complications. The doctor was discomfited by these suggestions and could only respond by stating that if he complied with our wishes then he would likely be sued (not by us I assured him), that he would be struck off the medical register (though not in the UK), and that, above all, it was against the law of the country and he would likely be imprisoned. Subsequently we proceeded to cover a host of issues, the dialogue later repeated with the hospital’s medical and finance directors, on all of which we profusely differed.

I failed in my mission to modify my relative’s treatment in any way and left the country 2 days later. Since my visit, my uncle has had numerous chest infections treated, two blood transfusions, and further limited surgery. He remains largely unresponsive to any stimuli.

BEING ALLOWED TO DIE WITH DIGNITY

The tragic case of my uncle raised during the varied conversations a number of ethical and philosophical issues that were personally discomfiting and surprisingly difficult to address. However, there was only one overriding conclusion and that was that the society in that region would not condone any situation where a doctor would be allowed to not treat an illness, regardless of the personal circumstances surrounding the patient. In effect, a ‘natural’ death would only be countenanced once all life-prolonging interventions had failed.

I confess that the sole purpose of my visit to see my uncle was the arguably humanitarian one of seeking the withdrawal of life-prolonging treatment in order that he could die with dignity following a catastrophic stroke. I naively, in retrospect, thought that I would be welcomed and supported in this endeavour by clinicians who took a holistic approach to their patient and his likely quality of life after such an event. I failed in my attempt to convince them to do so and therefore feel that I failed my uncle in the one time when I could have repaid all the help that he had provided our family in the past. My failure and his continuing distress wakes me nightly.

THE WISHES OF THE INDIVIDUAL

I was ultimately frustrated by a non-secular law conflicting directly with my secular views regarding medical practice. Because of this divergence in beliefs, a gentle, humble, ascetic, and, above all, independent man will be forced to exist, due to the persevering actions of dedicated professionals, in a state of total dependency on others.

Currently, in the UK, the wishes of the individual tend to hold primacy over those of the state. Consent for medical treatment is enshrined in medical ethics. However, this may not be so in other societies where a conflicting view can be encouraged by advances in medical science and technology.

Some years back, in a short essay published by the BJGP entitled ‘Whither mortality,’ I suggested that advances in medical science were moving public opinion to where it would no longer countenance death by natural causes.

This case highlights what can happen if we allow ourselves to travel down the road towards an over-weaning, some might feel utopian, vision of our clinical capabilities.

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The age of the patient described in this article has been altered for anonymity reasons because the patient is unable to provide consent in the usual way.

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