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No water, no life[1]

Withholding or withdrawing clinically assisted nutrition and hydration in prolonged disorders of consciousness.

By Rick Thomas

Tony Bland loved soccer. He particularly loved Liverpool FC. On 15 April 1989, he was in Sheffield at the Hillsborough Stadium to watch his side play Nottingham Forest for a place in the FA Cup final. He got there early to secure a place close to the pitch, but as a mass of late arrivals pushed to get into the stadium, Tony was crushed against the perimeter fence and suffered severe oxygen deprivation. Over 90 people died in the disaster, but Tony didn't quite die. Although his cerebral cortex was irreparably damaged, his brain stem survived and continued to function at a rudimentary level, sustaining respiration and circulation without need of a ventilator. He was in a deeply comatose state, apparently unresponsive to any external stimulus but still able to breathe, digest food and excrete waste in a condition known at the time as persistent vegetative state (PVS). For the next three years, Tony's body was nourished by liquid food delivered to him via a tube into his stomach. Eventually, when it seemed that there was no longer any realistic hope of improvement in his condition, Tony's family and doctor sought permission from the courts to withdraw feeding. The case ultimately went to the House of Lords and resulted in a landmark decision.[2] The Law Lords ruled that in the circumstances, assisted nutrition and hydration should be seen as 'treatment', conferring no therapeutic, medical or other benefit upon Tony, and that such treatment could be legally withdrawn. It was withdrawn and Tony died some days later.

For the first time, a profession charged with the responsibility to relieve the suffering of their patients could now choose to achieve this by intentionally ending their life in their 'best interests'. The question was, would the precedent now set extend inexorably to other groups of patients whose lives were also deemed to be 'not worth living', whose care was too costly to continue indefinitely, or whose families pressed for their 'release'? In the end, whose 'best interests' would be served?

The unfolding story

The Bland case gave rise to a great deal of debate at the time. The Royal College of Nursing distanced themselves from the verdict, preferring to view nutrition and hydration as part of basic nursing care, rather than as medical treatment.[3] In the first court ruling, Sir Stephen Browne said:

'To his parents and family he is 'dead'. His spirit has left him and all that remains is the shell of his body.'[4]

Leaving aside whether the eminent lawyer was qualified to determine when spirits leave bodies, his comments certainly precipitated some spirited correspondence, like this in the *BMJ* from Andrew Fergusson of the Christian Medical Fellowship:

'If the concept of Tony Bland being dead already is accepted in law, we will have moved the goalposts medically, legally, ethically, philosophically and theologically'.[5]

For philosopher Peter Singer, the ruling was nothing less than such a watershed moment. He suggested it might come to be seen as '*the precise moment when the old ethic gave way*'.[6] The old ethic he was referring to is the traditional Western ethic of the *sanctity of life*, described by John Keown as the basis of Hippocratic medical ethics and English criminal law, both of which have long held that '*because all lives are intrinsically valuable, it is always wrong intentionally to kill an innocent human being*'.[7] Singer welcomed the Bland judgment as allowing consideration of quality of life in determining whether that life should be prolonged, and as accepting as lawful a course of conduct that has as its aim and object, the death of an innocent human being.[8]

Of course, the Bland ruling did not automatically give doctors freedom to withdraw treatment from all patients in PVS. A separate application to the Court of Protection for 'declaratory relief' was recommended as a matter of good practice in each case, where there was no valid consent on the part of the patient in the form of an advance directive (though at the time, these directives did not have legal status).

However, that application process proved to be both cumbersome and sometimes costly for families.[9] Clinicians who were ill-informed about the diagnosis and prognosis of prolonged disorders of consciousness (PDOC) states avoided raising the question, and cash-strapped NHS trusts were reluctant to embark on them. The result was that in the 22 years following Bland only 44 such applications were reported (though, it is estimated there may have been at least 100 cases, with over half of them unreported).[10]

The relatively few applications may also reflect an intuitive unease amongst families and/or medical professionals at the thought of withdrawing food and fluids from someone who is not in the final stages of a terminal illness, nor dependent on a ventilator, but who seems very much alive, albeit comatose.

Recent change in the law

The legal picture changed significantly on 30 July 2018 when, in the case of Mr Y,[11] the Supreme Court ruled that there is no need to seek Court of Protection approval for the withdrawal of CANH, providing the provisions of the Mental Capacity Act (2005) have been followed and the family and medical team agree on what is in the best interests of the patient.[12] In determining 'best interests', the Court emphasised the need to take into account the patient's feelings, beliefs and values, as best they could be known.

The ruling will mean that the NHS will be saved the considerable expense of seeking the approval of the Court. However, it also removes the Court's supervision of the PDOC diagnosis as a matter of proof. Some will argue that this was always an inappropriate role for the Court, but others that it provided vital accountability such that its removal puts the best interests of vulnerable people at risk.

The case of *Briggs v Briggs* [13] for the first time confirmed that CANH could be withdrawn from a patient suffering a prolonged disorder of consciousness on the basis of that patient's own views, beliefs and feelings, where those views could be ascertained with certainty. In this case, the Court gave great weight to the patient's pre-accident stated view that life on a 'life support machine' would 'not be living', agreeing with his wife that he would not have wanted to continue life in a minimally-conscious state (see box). Against the preferred option of the treating clinicians, the court held that CANH could be legally withdrawn – possibly a seminal moment in rebalancing the relative weighting given to the sanctity of life and self-determination.

Death in 'best interests'

It has long been held as good medical practice to withhold or withdraw intrusive treatments from some patients in selected circumstances, when the burden imposed by those treatments outweighs any benefit. [14] It is not always clinically appropriate to continue CANH in some imminently dying patients. However, stopping CANH in brain-damaged patients who are not imminently dying, with the intention that they will then die from dehydration and sedation, is much more controversial.

For doctors, intent has long been seen as the arbiter of action. Treatment that might incidentally shorten life is permissible so long as the intention is to relieve pain and suffering – the so-called 'principle of double effect'. However, until very recently a physician acting with the primary intent to end life would be guilty of murder, no matter how compassionate his motive. In this view, the 'best interests' of a patient could not include their intentional killing.

Yet this is precisely the guidance from the British Medical Association (BMA) in the light of the 2018 Supreme Court ruling. [15] Their guidance focuses on three categories of patients where CANH is the 'primary life-sustaining treatment being provided' and who 'lack the capacity to make the decision for themselves': those with degenerative conditions; those who have suffered a sudden-onset, or rapidly progressing brain injury and have multiple comorbidities or frailty; previously healthy patients who are in a vegetative state (VS) or minimally conscious state (MCS) following a sudden onset brain injury. Significantly, the BMA guidance also extends to include those suffering with severe strokes or other neurodegenerative conditions with a 'recogniseed downward trajectory', not just those in PDOC.

As a result, many more patients could be affected in the long term. The guidance also proposes that the certified cause of death in such cases should be the underlying condition, not dehydration resulting from withdrawal or withholding of CANH. As a result, official statistics will not indicate the number of people whose deaths are caused in this way – it will be impossible to track the effects of the guidance in practice.

The guidance makes crystal clear that it does not cover patients who are imminently dying and 'expected to die within hours or days' but rather those who 'could go on living for some time if CANH is provided'. Dehydrating someone to death in these circumstances is justified as being in their best interests. In this view, 'best interests' is determined by the quality of life it is deemed a particular patient would find acceptable. [16] Otherwise continuing to provide CANH would be tantamount to 'forcing them to continue a life they would not have wanted'– a form of abuse. [17] Families wishing to resist the trajectory towards so-called best interest decisions, inevitably leading to recommended withdrawal of CANH, face an increasing challenge.

In retrospect, one wonders if the RCN got it right in 1993, commenting on the Bland case, when they insisted CANH should be understood as part of basic nursing care – a human right, not a form of medical treatment – and its removal from non-dying patients as unethical. [18] But that ship has sailed. The battle now is to prevent the new guidance from being extended to a wider group of patients.

Many will see this new legal landsape as allowing the potential for back-door euthanasia to develop. British parliaments have consistently refused to legalise euthanasia or assisted suicide, principally to protect vulnerable people. Because of the Supreme Court ruling and subsequent BMA guidance, the call to replace starvation and dehydration with a lethal injection on the grounds of compassion for the patient and their relatives will be harder to resist. Thereafter, the case for refusing assisted suicide to those who are themselves not imminently dying and do not lack capacity will be equally hard to sustain. [19]

States of disordered consciousness

Even with the best techniques available today it can be very difficult to make an accurate diagnosis in PDOC. An acquired brain injury (ABI) may be followed by one of three, currently recognised forms. These are defined by the Royal College of Physicians (RCP)[20] as coma, vegetative state (VS) or minimally conscious state (MCS) – see box.

Within the range of PDOC there is a radical difference in outcomes between ABI due to trauma and that due to a loss of oxygen supply to the brain (hypoxia). RCP guidelines [21] define VS resulting from hypoxia as 'permanent' PVS only if it has persisted for more than six months. If the cause is trauma, then VS is regarded as permanent only after a period of twelve months has elapsed, reflecting the fact that a significant number of traumatic brain injured survivors will emerge from a vegetative state within that longer time frame.

Recovery of consciousness after a year in PVS is very rare, but not entirely unknown. Andrew Devine was another of those crushed in the Hillsborough Stadium who survived. He was taken to a specialist neurological rehabilitation unit and after 8 years in PVS, recovered sufficient consciousness to be able to communicate using a touch-sensitive buzzer. [22]

Patients with MCS show a similar disparity in outcomes between non-traumatic and traumatic causes of brain injury and gains over time may be much more significant, such that RCP guidelines do not suggest that MCS be regarded as 'permanent' until three to five years after onset.

FACT BOX

- **Coma**: a state of unrousable unresponsiveness, lasting more than six hours, in which a person cannot be awakened and fails to respond normally to painful stimuli, light or sound, lacks a normal sleep–wake cycle, and does not initiate voluntary actions.
- **Vegetative State (VS)**: a state of wakefulness without evidence of awareness, in which there is preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep–wake cycles and a range of reflexive and spontaneous behaviours. VS is characterised by complete absence of behavioural evidence for self or environmental awareness.
- **Minimally Conscious State (MCS)**: a state of severely altered consciousness in which minimal but clearly discernible evidence of awareness, above the level of spontaneous or reflexive behaviour, is demonstrated indicating some degree of interaction of the individual with their surroundings.

The differentiation between these states is therefore a critical part of the assessment of this patient group in determining prognosis. As there is no currently available scan that will definitively diagnose or differentiate between MCS and VS, clinical observation is required by trained observers over an extended period of time to look for behaviours that suggest awareness of self or the environment.

The latest BMA/RCP guidance however, seeks to remove this emphasis saying '*…it is increasingly recognised, by clinicians and the courts, that drawing a firm distinction between VS and MCS is often artificial and unnecessary. In practice, when assessing best interests, information about the patient's current condition and prognosis for functional recovery and the level of certainty with which these can be assessed is often more important than achieving a precise diagnosis*.' [23]

This is at odds with the RCP guidelines on management of PDOC, which delineate the significant differences in outcomes between MCS and PVS and the need to establish trajectory of change clearly, in order to establish prognosis. The BMA/RCP guidance however, seems to be suggesting prognosis can be established independent of diagnosis. The emphasis is therefore very much on potential for functional recovery – a judgement on potential quality of life and whether that level of recovery is meaningful, the arbiter of which is a 'best interests' discussion. The challenge is whether the prognosis can be established with certainty, particularly if the precise categorisation of the diagnosis is being deemed 'artificial and unnecessary'.

Assessment is complex and intricate; the trajectory of change may be very slow and diagnostic accuracy is poor in the hands of non-specialist teams. In one study, 41% of patients assessed as being in VS (unaware) were actually found to be in MCS (some level of awareness) and 10% of patients thought to be in MCS had actually emerged from this state. [24] Given the difficulty in interpreting the clinical findings in persistently comatose patients, and the occasional account of someone recovering a degree of consciousness after years in PVS, is it ever possible to say with total confidence that a vegetative state is permanent, such as to make the withdrawal of CANH 'safe'? **If it becomes normal practice to withdraw CANH from patients thought to be in VS after six or twelve months, then some of those patients will not survive long enough to see if their diagnosis was correct in the first place.**

The BMA (supported by the Royal College of Physicians and the General Medical Council) have sanctioned the delegation of the assessment and decision-making process to local teams with no evidence of any safeguards to audit outcomes and practice. Essentially, there is a reliance on families or staff invoking the Mental Capacity Act (2005), if they have concerns. Otherwise, if it *feels* like best interests it is best interests as far as the decision-making teams are concerned, and the risk of drifting into utilitarianism is high.

Of course, even those few PVS sufferers who have eventually recovered some degree of awareness remain severely disabled and still dependent on CANH, such that it is argued they would have been 'better off' had they remained in the full PVS state, and thus been 'eligible' for withdrawal of CANH. The difficulty with so much of the debate about the treatment of PDOC is that such quality-of-life judgments threaten to obscure and displace the painstaking, costly and possibly inconclusive attempts to assess a patient's level of awareness using the best methods available to us.

If further advances in technology enable us to say with complete confidence that there is irretrievable loss of consciousness, the pressure for medicine to adopt a definition of death based on death of the cortex (but not necessarily of the brain stem) will be intense. Were cortical death to become the defining criterion, many patients in PDOC would be seen as dead already and CANH as inappropriate, despite the persistence of normal heartbeat and respiration mediated by a functioning brainstem.

Putting a value on human life

In Christian thinking, the value of a human life is not measured by its productivity or by subjective experience. Value derives from being created in God's image [25] and for his pleasure. [26] As the objects of divine love, simply by virtue of our humanity, value is conferred upon us regardless of how flawed or disabled our life may be – a '*radical equality*' as John Wyatt terms it:

'*We may be able to judge whether a treatment is worth giving, but we can never judge whether a life is worth living*'. [27]

This view of the intrinsic value of every human life is no longer an uncontested influence upon healthcare provision in this country, which is increasingly weighed on functional, quality-of-life scales. It seems unlikely in a resource-stretched NHS that life-sustaining treatment for permanently unconscious patients will continue to be made available indefinitely, even if that be the family's wish.

Is there an ethical distinction to be made between active and passive euthanasia? Removing Tony Bland's tube was a decisive act, but withholding food and fluids is a passive one. Lord Mustill, one of the Law Lords in the case, admitted '*however much the terminologies may differ, the ethical status of the two courses of action is for all relevant purposes indistinguishable*'. For him, the judgment they reached served only to emphasise '*the distortions of a legal structure which is already both morally and intellectually misshapen*.' [28]

Should CANH be considered a 'treatment' or a basic human right? The place of CANH in the final stages of terminal care is hotly debated. Palliative care physicians tend towards the view that hydration can be withdrawn at the end of life and that terminal dehydration is not associated with thirst in cancer patients. Indeed, they have long held that there can be a significant risk of fluid overload in some of these patients when given CANH.[29] Other physicians suspect that where CANH is withheld, dying patients do experience distress but that this is masked by the use of palliative sedation.[30]

Recent studies[31, 32] of patients in PDOC with functional MRI and EEG recordings suggests that sentience of some sort may be present in a small proportion of PDOC patients. This remains an experimental area, but the available evidence suggests there should be caution about assuming there is no experience of distress in this patient group.

The latest change in the law and the newly issued BMA guidance represents a major shift in practice, now placing the burden of decision-making on to local teams. A second opinion is required, but whilst it is recommended that this should not be a member of the treating team and that they should be 'able to act independently', there is no requirement for external peer review or audit of such decisions nationally over a prolonged period. It is recognised that local culture within institutions can have a huge impact on decision-making in end of life care, producing significant variation in mortality rates between institutions.[33] There is a risk that a culture of 'nihilism' could develop unchecked in organisations driven by leadership styles or resource pressures. Sadly, the situation faced by patients in Mid-Staffordshire and Gosport suggests this is not merely a theoretical issue.

The definition of CANH as a 'medical treatment' in PVS, and the recent deregulation of treatment withdrawal decisions, open the way for a concept-change that could, over time, be applied to those with other disabling conditions. If we conclude that life is not present in patients with PVS, or that their quality of life is not worth living, then it is possible that we shall extend that view to include much larger groups of patients, such as the victims of severe stroke or those with advanced dementia, especially as pressure on resources grow and the prevailing values of our culture continue to change.

If we say 'yes' to intentional killing by omission, the risk is that it will eventually lead to more widespread, non-voluntary and active euthanasia. Conversely, we must 'grasp the nettle' of defining when treatment has become futile, and what appropriate palliative care looks like in those circumstances. This debate must be continued. It is too easy to lose sight of the fact that, whilst maintaining the bodies of PVS sufferers with CANH as part of basic care is costly, it serves to 'draw a line in the sand'. By doing so, we invest with dignity and value the most disabled and affirm that to be human is to be intrinsically special and deserving of such apparently extravagant care.

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