Scottish Council on Human Bioethics

10.9.19
Position Statement on:

The withdrawal of tube-assisted nutrition and hydration from patients in permanent vegetative and minimally conscious states

The Scottish Council on Human Bioethics (SCHB) has grave concerns about medical decisions to withdraw or withhold tube-assisted nutrition and hydration in patients who are in Permanent Vegetative States (PVS) and Minimally Conscious States (MCS) as this requires the intentional ending of human life. These patients have profound brain injuries, but their death is not imminent. They are human persons with all the rights that the UK *Human Rights Act 1998* confers.

Although a feeding tube is inserted in hospital, nutrition and hydration is usually given by family members in the home or carers or nurses in a nursing home setting. If the carer or family member were to stop nutrition and hydration because they felt it was not in the interests of their loved one, there would rightly be concern and a criminal prosecution would be likely. This statement and following paper will delineate the ethical risks surrounding medical decisions to stop tube-assisted nutrition and hydration in patients with PVS and MCS.

1.The withdrawal or withholding of tube-assisted nutrition and hydration, when death is imminent and feeding is futile, is acceptable.

The withdrawal or withholding of tube-assisted nutrition and hydration in a dying patient whose death is both imminent and inevitable may be acceptable. It is good medical practice to do so if the burden to the patient of the procedure outweighs its benefit, and the intention is to relieve suffering rather than to hasten death.

2. There is an important distinction between those at the end of life and those with profound brain injury for whom death is not imminent.

The SCHB notes that any procedures should never, intentionally, hasten death, though they should not also seek to prolong the dying process. Patients in Permanent Vegetative and Minimally Conscious States have a profound but stable brain injury and are not approaching the end of their lives unless a secondary illness or complication intervenes, or their nutrition and hydration is stopped.

3. Everyone has a right to life under Article 2 of the UK *Human Rights Act 1998*.

Article 2 of the UK *Human Rights Act 1998* prohibits the intentional ending of life. Infringements of this Article are variously described as 'deprivation of life', 'ending a person's life' or 'bringing about death' but these phrases actually mean 'causing death'. In this regard, the intention in withdrawing or withholding tube-assisted nutrition and hydration may be the ending of the patient's life. Common to almost all civilised societies is the prohibition of killing persons because all individuals have the same value and worth.[1] The SCHB opposes the intentional ending of life and notes that there is a fundamental difference between making health care decisions and making value-of-life decisions.

4. Each human being has inherent human value and worth, regardless of ability, level of consciousness, contribution to society and potential.

The SCHB agrees that no person can ever lose his or her inherent value and worth. This is in accordance with the United Nations' *Universal Declaration of Human Rights*[2] which affirms in its preamble '*the inherent dignity and … the equal and inalienable rights of all members of the human*

[1] http://www.legislation.gov.uk/ukpga/1998/42/contents

[2] https://www.un.org/en/universal-declaration-human-rights/index.html

family' as *'the foundation of freedom, justice and peace in the world'.* In other words, the value and worth of all persons is:

- **Inherent** to all living human persons by virtue of their membership of the human family. Article 6 of the United Nations *International Convention on Civil and Political Rights (ICCPR)* recognises the right to life of all human beings without distinction of any kind: '*Every human being has the inherent right to life.'* Since the fundamental right to life is inherent it can neither be conferred nor removed by government or any external authority. The right to life is the basis for the enjoyment of all other human rights and is the foundation of freedom, justice and peace in the world.

- **Inclusive**, meaning that the value refers to 'everyone' and 'every person' without discrimination. The UN Declaration does not make a distinction between all members of the human family and therefore all are human persons.

- **Inalienable**, meaning that it refers to a value that cannot be removed, destroyed, transferred or renounced even by the individuals themselves, their parents or society. In this regard, Article 6 states: '*This right shall be protected by law. No one shall be arbitrarily deprived of his life.'*

- **Equal**, meaning that no human beings are 'more equal' than others but that everyone has equal rights and dignity as members of the human family. Human rights cannot be predicated on the view that certain individuals are either superior or inferior to others.

- **Universal,** meaning that the value of life is to be upheld everywhere, and at all times, irrespective of culture.

At present, human beings live in a society where inherent human value and worth is universal and where each and every person is expected to acknowledge, respect and recognise the same value and worth in others which cannot be modified or destroyed by an individual, a majority or a state. Withdrawing or withholding tube-assisted nutrition and hydration on the grounds that the patient's life has no worth would mean that society would accept that some individuals can actually lose their inherent value and have lives which no longer have any worth or meaning.

5. Patients in permanent vegetative and minimally conscious states do have interests including that of life itself.

The most important case to come before the courts was that of Tony Bland, a young man who suffered a severe head injury in the 1989 Hillsborough football tragedy in England and was assessed to be in a Permanent Vegetative State. Indeed, it had been proposed that tube-assisted nutrition and hydration be withdrawn. At the time of the case, in 1993, Lord Mustill commented in his judgement that: '*The distressing point, which must not be shirked, is that the proposed conduct is not in the best interests of Anthony Bland because he has no best interests of any kind.'*[3]

In response, the SCHB notes that Tony Bland did have interests, and in particular, an interest in life itself. For example, the *Mental Capacity Act (England and Wales) 2005* states that in the determination of best interests, there should be no motivation to bring about the person's death.
The SCHB also recognises that it may be possible to wrong someone who is not aware. For instance, when a person is absent, his or her name can be sullied, or bank account hacked. If healthcare professionals are verbally critical or abusive of a patient with dementia in a subtle or unkind way, it is still wrong, even if the patient is unaware.
The SCHB notes the outrage at the case of the rape of a woman by a care worker in PVS in the US, who subsequently became pregnant and gave birth to a healthy baby in 2018.[4] It seemed that she had certainly been wronged yet was unaware of the offence. Therefore, despite her lack of awareness, she had an interest in not being wronged in this way.

[3] Airedale NHS Trust v Bland [1993] All ER 821 (HL)

[4] https://www.independent.co.uk/news/world/americas/sex-abuse-investigation-woman-gives-birth-vegetative-state-phoenix-arizona-hacienda-healthcare-a8712781.html

Article 3 of the Council of Europe *European Convention on Human Rights* prohibits torture and 'inhuman or degrading treatment or punishment'.[5] Some might consider ongoing medical management with nursing care such as tube-assisted feeding and bowel management with daily enemas to be intrusive and demeaning to dignity. However, the SCHB maintains that these are important and common aspects of the management of illness or significant disability and need not be demeaning to the persons concerned if performed in a sensitive manner.

6. Regardless of whether tube-assisted nutrition and hydration is basic or medical care, if the intention is to bring about death by its removal, then there is an intentional deprivation of life.

Much of the debate surrounding tube-assisted nutrition and hydration was whether it could be considered as a medical treatment. If it is, it is argued that it can be given or taken away only in the 'best interests' (England and Wales) or 'benefit' (Scotland) of the patient. By contrast, all patients must be given basic care such as warmth, shelter, hygiene and the offer of food and water. The UK General Medical Council advises doctors that tube-assisted nutrition and hydration have been considered medical treatment in law since the *Bland* case when it was described as a means of substituting a function that had naturally failed.[6,7] However, the academic medical lawyer, Sheila McLean, disagreed:

> *The mere fact that nutrition and hydration are delivered by artificial means is insufficient to make it any more of a clinical matter than is the routine provision of food in a hospital. While the insertion of a nasogastric tube requires a degree of skill, it has already been suggested that other, non-medical, personnel could be trained to do this. The fact that something is generally done by someone with medical expertise does not necessarily make it medical*.[8]

She also indicated that failure to offer antibiotic treatment to patients in PVS who at some stage would require the provision of such services and which undoubtedly are medical treatments could have been a solution adding that it would offend '*less acutely those who maintain that food and water are basic care; not medical treatment.*'[9]

It is important that the initial responsibility of the feeding tube should remain with the doctor or a specialist nurse given the high level of training and experience required for inserting the tube and undertaking safety checks.[10]
However, the SCHB would argue that a distinction exists between the insertion of the tube and the administration of the nutrition and hydration in liquid form.[11] Thus, the initial insertion and verification of the position of the tube may constitute medical treatment, but the day to day administration of the nutrition and hydration may be considered as ordinary care. This can be managed safely in the community by trained carers and does not require medical supervision. However, naso-gastric or stomach tubes can easily become dislodged and need repeated insertion and this does require repeated medical intervention. But they are usually a short-term measure.
However, this technical matter is not one on which the whole case turns. As the appeal judge in the *Bland*, case, Sir Thomas Bingham, found, *'whether or not this is medical treatment it forms part of the medical care and I cannot think that the answer to this depends on fine definitional distinctions'.*[12]

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[5] http://www.legislation.gov.uk/ukpga/1998/42/contents

[6] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

[7] Airedale NHS trust v Bland 1992

[8] Sheila A.M. McLean, From *Bland* to *Burke:* The Law and Politics of Assisted Nutrition and Hydration, In First Do No Harm – Law, Ethics and Healthcare, Edited by Sheila A.M. McLean, Ashgate, Aldershot, 2006, p.432.

[9] Ibid p.445.

[10] Good Practice Guideline for the National Nutrition Nurses Group. Safe Insertion and Ongoing Care of Nasogastric (NG) Feeding Tubes in Adults.

[11] Treloar A. and Howard. P. Tube Feeding: Medical treatment or basic care. Catholic Medical Quarterly Aug 1998

[12] Airedale NHS Trust v Bland [1993] 1 All ER 821

The Bland decision crossed a legal rubicon. Withdrawing nutrition and hydration from non-dying patients with the explicit intention of ending their lives is euthanasia by omission. As Lord Browne-Wilkinson observed in 1993: '*What is proposed in the present case is to adopt a course with the intention of bringing about Anthony Bland's death. As to the element of intention or mens rea, in my judgement there can be no real doubt that it is present in this case: the whole purpose of stopping artificial feeding is to bring about the death of Anthony Bland.'*[13]

7. The distinction between acts and omissions.

There is little doubt that tube-assisted nutrition and hydration are an effective means of providing sustenance to patients who cannot swallow, with some patients surviving many years.[14] In a medical context, there is a moral duty for the physician to undertake what is reasonable to save and preserve life. If a physician consciously refuses to initiate certain lifesaving interventions with the primary intention of bringing about the death of a patient, then this could be considered as murder. However, if a physician follows good medical practice in the best interests of the patient and does not initiate burdensome interventions and this, as a side effect, shortens the patient's life, then no objections would normally be brought against the physician. The critical distinction between murder and good medical care is related to the physician's intention, which is an extremely important concept in law.

There is a difference in legal and actual definitions of withdrawal of treatment – withdrawal legally is an act of omission, whereas practically it involves the action of flicking the switch to turn off a life support machine or physically removing the feeding tube.
Of course, the distinction between 'acts' and 'omissions' is sometimes artificial when viewed in a clinical context where physicians have a duty of care. Indeed, s 15(2) of *The Mental Capacity Act (England and Wales) 2005* defines an 'act' to include 'an omission and course of conduct'. The SCHB prefers the use of the term 'course of conduct' to cover both acts and omissions as this is more in keeping with everyday clinical practice where clinical pathways usually involve a succession of acts and omissions along the patient journey depending on the course of the disease and response to treatment.

8. As the state has an interest in the protection of life, the withdrawal or withholding of tube-assisted nutrition and hydration when a patient is not dying should be referred to the Courts.

In 2018 the UK Supreme Court gave its judgment in the case of Mr Y stating that a court order need no longer be sought for the removal of tube-assisted nutrition and hydration for patients in Persistent Disorders of Consciousness (PVS and MCS) in England and Wales.[15] However, the SCHB is concerned that there seems to now be a normalisation of the breach of the preservation of life and that the safeguard of court review should remain in place.

9. As decisions for patients in permanent vegetative state and minimally conscious states may affect other further vulnerable groups, the courts have an interest in the preservation of life.

There has been a significant progression of events since the *Bland* case in 1993. Indeed, the original decision was for Bland who had no awareness. Subsequent cases were described as 'minimally conscious' and now the blanket term is 'persistent disorders of consciousness.' Experts suggest there will always be a degree of uncertainty around the diagnosis of persistent disorders of consciousness.[16] It is not a binary state but rather a spectrum from raised awareness to complete unawareness. It is impossible to definitively prove awareness as there is no medical test and is therefore reliant on human observation. Charles Foster, Professor of Law in Oxford, concludes:

> *The uncertainties surrounding the nature of [prolonged disorders of consciousness] and the relationship of the neural correlates of consciousness to identity (and hence to best interests) are*

[13] Ibid.

[14] Quill, TE. Terri Schiavo- A Tragedy Compounded. *N Eng J Med* 2005 352 1630-1633
[15] https://www.bbc.co.uk/news/uk-45003947

[16] Wade, D. J Med Ethics 2017; 43: 439-445 Back to the bedside? Making clinical decisions in patients with prolonged unconsciousness

such that it cannot be concluded that the presumption in favour of the maintenance of life is displaced and that it is in the best interests of a patient in such a state for life-sustaining treatment to be withdrawn.[17]

The SCHB is concerned that other groups, such as those who are profoundly disabled but undoubtedly conscious, would eventually be considered for a withdrawal or withholding of nutrition and hydration and would urge caution to err on the preservation of life.

10. Acceptance of the withdrawal or withholding of tube-assisted nutrition and hydration may lead to calls for lethal injection to avoid a prolonged death by dehydration.

The SCHB agrees that if a patient is not dying and a health care professional withdraws or withholds nutrition and hydration from him or her with the intention of bringing about his or her death, then this could be considered as euthanasia and a violation of the right to life under the *European Convention on Human Rights*. Moreover, because dying by starvation or dehydration may be distressing, it might lead to requests for euthanasia by other means such as lethal injections.
Thus, if the withdrawal or withholding of assisted nutrition and/or hydration did become acceptable medical practice, then those who advocate euthanasia may eventually campaign for lethal injections as a more humane approach than death by starvation or dehydration.

11. Physicians should not be afraid to give tube-assisted nutrition and hydration.

There is a risk that some health professionals may be reluctant to begin tube-assisted nutrition and hydration, because of concerns that they cannot be withdrawn. This could result in some patients failing to receive nutrition and hydration for their own benefit. Thus, the best interest of the patient should be re-evaluated regularly.
In addition, the legal and moral equivalence of withholding and withdrawing treatment was expressed by the judges, Lord Goff and Lord Lowry, in the in the *Bland* case, with the latter indicating:

I do not believe that there is a valid distinction between the omission to treat a patient and the abandonment of treatment which has been commenced, since to recognise such a distinction could quite illogically confer on a doctor who had refrained from treatment an immunity which did not benefit a doctor who had embarked on treatment in order to see whether it might help the patient and had abandoned the treatment when it was seen not to do so.[18]

12. There is no benefit in being dead.

The SCHB disagrees with the manner in which benefit is defined in the UK when it is understood in the context of the deceased. Indeed, the Oxford English Reference Dictionary[19] indicates that the noun 'benefit' is defined as a 'favourable or helpful factor or circumstance'. However, being dead cannot be considered in any philosophical, rational or logical manner as a favourable or helpful factor or circumstance since death represents the ending of the existence of the person. Thus, from a rational and logical perspective, a 'favourable or helpful factor or circumstance' cannot exist when the subject to which it refers does not exist. Therefore, the concept of benefit cannot apply to a deceased person.[20]

[17] Foster C. J Med Ethics 2019 45; 265-70 It is never lawful or ethical to withdraw life-sustaining treatment from patients with prolonged disorders of consciousness
[18] *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

[19] The Oxford English Reference Dictionary, Second Edition, Edited by Judy Pearsall and Bill Trumble, Oxford University Press, 1996.

[20] However, some look forward to death, as it is perceived as reaching peace or at least a pain free existence in an afterlife. For example, the various faiths place different interpretations on reaching death, such as achieving certain goals. Even a consequent possible longing for death, does not imply a desire to expedite it. On the contrary, there is very much a duty to preserve life and respect the time given.

13. The dangers of voluntary palliative sedation with the aim of bringing about death.

The legal framework for the withdrawal of tube-assisted nutrition and hydration with medical sedation sets a precedent for a withdrawal of any nutrition or hydration with supportive medical sedation and would be a form of doctor-assisted suicide which the SCHB would oppose.

In 2013, the Professor of Bioethics, Julian Savulescu, suggested that persons seeking assisted suicide in countries which prohibit such a procedure, may circumvent the law through 'voluntary palliated starvation'.[21] This entails the starvation of consenting patients whilst under heavy sedation. He indicates that *'any competent person has the right to refuse to eat and drink, leading to their death. And given that they will certainly die if they do not eat and drink, they are entitled to relief of their suffering as a part of medical treatment as they die. This can be achieved through palliative care involving sedation and analgesia ... This could be called Voluntary Palliated Starvation.'*

He also indicates that: *'The conjunction of the right to refuse food and fluids and the right to relief of distress through provision of medicine (in this case, palliative care), may be tantamount to a right to assisted dying. This applies not only to people who have a terminal medical condition but also to people ... with a severe non-terminal physical illness.'*
Savulescu finally notes that: *'According to medical ethics, competent people have the well-established right to refuse medical treatment now and in the future by the formation of advance directives or living wills. This principle should apply to the refusal of food and fluids in advance ... This could be called a starvation advance directive.'*

It is important to note that if the provision of tube-assisted nutrition and hydration is considered as a medical treatment, then there would be no basis, in many European legislations, to stop persons who are not dying asking for such a treatment to be interrupted with the view of ending their lives through Voluntary Palliative Starvation.
Thus, the provision of continuous deep sedation to a person (who is not immediately dying[22] and is of sound mind with decision making capacity) before he or she interrupts his or her life sustaining treatment with the aim of bringing about his or her death should also be prohibited. This is because:

- It would anticipate the death of the patient (who is not dying) and would mean that the healthcare professional agrees to participate in making this happen.

- There is no clinical reason to sedate a person who is in a stable situation. The artificial creation of a situation in which the life of a patient becomes dependent on life sustaining treatments with the aim of then interrupting these treatments to cause, with intention, the death of a person is not acceptable.[23]

- The refusal of a specific treatment by a patient who is of sound mind with decision making capacity may terminate some of the physician's associated obligations towards this patient[24] including the provision of additional treatments such as sedation. It also absolves the physician of any liability. The physician may, however, continue to provide other treatments to the patient for different ailments if they both agree that this is appropriate and acceptable.

When patients ask for information that might encourage or assist them in ending their lives, healthcare professionals should explain that they cannot respond because providing such information would mean breaking the law in the UK. Similarly, in respecting a patient's decision, healthcare

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[21] Julian Savulescu, A simple solution to the puzzles of end of life? Voluntary palliated starvation, *Journal of Med Ethics*, Published Online First: [18 July 2013] doi:10.1136/medethics-2013-10137

[22] Persons who are dying could correspond to '*persons approaching the end of life*' defined by the General Medical Council as individuals who are likely to die within the next 12 months. Persons who are dying would certainly include persons whose death is imminent which usually means that they are likely to die within the next few hours or days.

[23] French Conseil d'État, La révision des lois de bioéthique, May 2009, http://www.conseil-etat.fr/cde/media/document//etude-bioethique_ok.pdf

[24]Timothy E. Quill and Ira R. Byock, Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids, Ann Intern Med. 2000;132(5):408-414.

professionals are not required to provide treatments which they consider are not of overall benefit, or which will harm the patient. Respect for a patient's decision-making capacity cannot justify an illegal action.[25]

Healthcare professionals would also find themselves in a very difficult position if an individual started to suffer unbearably (of starvation and thirst) because they stopped eating and drinking (i.e non-assisted) with the aim of bringing about his or her own death.[26]

14.The *Bland* ruling on the lawful intention to terminate life should be overturned.

The most serious of the legal implications of the *Bland* case is the ruling that, provided it is not a 'positive action' and is adopted because it is considered to be in the best interests of the person, it is lawful to adopt a 'course of conduct' with the intention of terminating life. No person, whilst providing medical or nursing care, should omit anything with the intention of terminating a patient's life.

[25] GMC, Consultation on Assisting Suicide Allegations Guidance, GMC, 2012, p.8. http://www.gmc-uk.org/Assisted_suicide_consultation_version_3_pub_0001.pdf_47681132.pdf

[26] It may be the case that the courts in Scotland would demand that sedation be provided to stop the individual experiencing unbearable suffering. Alternatively, it may be the case that a healthcare professional may be considered as assisting the suicide of a person in the above case. In this regard, it should be noted that the concept of assisted suicide is not defined in Scottish law and would be regarded as culpable homicide (a common law offence).

Scottish Council on Human Bioethics

10.9.19 Position Paper on:

The withdrawal of tube-assisted nutrition and hydration in permanent vegetative and minimally conscious states

1. Definitions and general information

Approaching the end of life: Individuals are approaching the end of life when they are likely to die within the next 12 months.[27] This definition from the UK General Medical Council (GMC) may include those whose death is imminent (hours or days) but also those who have advanced, progressive incurable conditions; those with general frailty such that they may be expected to die within the next year, those at risk of dying from a sudden acute crisis in a chronic condition and those with life-threatening conditions caused by sudden catastrophic events. The term 'approaching the end of life' can also be used for extremely preterm neonates whose prospects for survival are known to be very poor.

The GMC guidance also includes a final category for those in a '*persistent vegetative state for whom a decision to withdraw treatment and care may lead to their death*.'[28] This is a contentious definition as the reason for these patients approaching the end of life, as stated in the definition, is not a clinical but a technical or legal one. These patients may survive many years if nutrition and hydration were continued. It is also a troubling precedent since the phrase could also be substituted to include '*patients with dementia for whom a decision to withdraw treatment and care would lead to their death'* or even '*patients with any disability for whom a decision to withdraw treatment would lead to their death*.'

It is important to note that the GMC sees the need to include PVS explicitly within the end of life definition, yet acknowledges it is held within that definition only by virtue of legal decision, not clinical deterioration.

Capacity: Is the ability to make a decision. The *Adults with Incapacity Act (Scotland) 2000*[29] presumes that adults (those over the age of 16) are capable of making personal decisions for themselves and of managing their own affairs. The starting point is a presumption of capacity and this can only be overturned where there is medical evidence stating otherwise.

Incapacity: Means incapable of acting or making decisions or communicating decisions or understanding decisions or retaining the memory of decisions. *The Mental Capacity Act (England and Wales) 2005*[30] states that a person lacks capacity in relation to a matter if at the material time he or she is unable to make a decision for himself or herself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

Benefit: The Oxford English Reference Dictionary[31] indicates that the noun 'benefit' is defined as a *'favourable or helpful factor or circumstance'*. Thus, it may be considered as the clinical advantage or the net gain that a person may receive through a particular intervention.

[27] Treatment and care towards the end of life: good practice in decision making. GMC guidance for doctors www.gmc-uk.org

[28] Ibid p. 87

[29] https://www.publicguardian-scotland.gov.uk/adults-with-incapacity-(scotland)-act/definition-of-incapacity

[30] https://www.legislation.gov.uk/ukpga/2005/9/section/2

[31] The Oxford English Reference Dictionary, Second Edition, Edited by Judy Pearsall and Bill Trumble, Oxford University Press, 1996.

Overall benefit: Defined by the GMC as: '*the ethical basis on which decisions are made about treatment and care for adult patients who lack capacity to decide. It involves an assessment of the appropriateness of treatment and care option that encompasses not only potential clinical benefits, burdens and risks of those options, but also non-clinical factors such as the person's personal circumstances, wishes, beliefs and values*.'[32] The GMC guidance on overall benefit is consistent with the legal requirement to consider whether treatment benefits a patient in Scotland.

Best interests: The highest level of well-being that is achievable for a specific person. Best interests include medical benefit as well as respect for the wishes and beliefs of the patient including his or her spiritual and religious beliefs. Best interests relate to the reasonable hope of benefits without disproportionate burdens of treatment and should never reflect a judgement that the patient's life is not worth living. To act in someone's best interests is to act so as to benefit someone.[33]

The Mental Capacity Act 2005 (England and Wales) does not define 'best interests' but rather the process by which they are determined. It stipulates that the decision-maker must consider a number of factors, both clinical and non-clinical as well as 'all relevant circumstances' in making a determination of best interests (s.4(6)(7)). This therefore is a subjective process. Once a decision has been made in the patient's best interests, the decision-maker is free of liability if he has reason to believe that he is acting in the patient's best interests (S4(9)).

It is interesting to observe that both *The Mental Capacity Act 2005 (England and Wales)* and the *Adults with Incapacity (Scotland) Act 2000* involve ethical decision-making processes which weigh heavily on respect for individual autonomy (rather than doing something in someone's best interests because it is the right thing to do). It should be noted that *The Mental Capacity Act 2005 (England and Wales)* clearly specifies that there must be no motivation to bring about the person's death in the context of life-sustaining treatment.[34]

Intervention in the health field: Any intentional activity, withholding of activity or the withdrawal of activity in the health field. Interventions include:

Medical treatment: Any positive intentional activity designed to address a specific physical or mental disease or disorder in the best interests of the person. Medical treatment will always have some identifiable therapeutic or palliative function. Nutrition and hydration are not generally recognised as treatments since they do not address an underlying disease or disorder (however, since the Bland case (1993) in England and Wales, tube-assisted nutrition and hydration can be considered, in law, as a form of treatment).

Ordinary measures:[35] Ordinary treatments as '*all those treatments that hold reasonable hope of benefit… and can be obtained without excessive expense, pain or other inconvenience'*.

Extraordinary treatment: Any treatment which:

- holds no reasonable hope of benefit;

- would place disproportionate burdens on the patient in relation to likely benefit;

- is too expensive for the healthcare service in relation to its possible benefit, in the context of scarce resources.

It is worth noting that the same procedure can sometimes be considered as either an ordinary or extraordinary measure at different stages of an illness.

[32] Ibid.

[33] https://www.collinsdictionary.com/dictionary/english/to-act-in-someones-best-interests

[34] s.4(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death'.

[35] Markwell, H. End of life: The Catholic View. The Lancet 2005; 366:1132-35

Basic care: Any positive healthcare activity which addresses the fundamental needs of a person and does not specifically address a physical or mental disorder. The benefits of receiving nutrition and hydration are the essential elements required to stay alive and can be considered as a form of basic care. Thus, food and water should be given to all patients, except if the patient is conscious and refuses or if the patient is in the last stages of a terminal illness and the intention is to relieve suffering rather than to hasten death. Advance directives do not generally include refusal of basic care, which is considered to always be necessary in order to provide humane assistance.

The UK General Medical Council accepts that there is no legal or commonly accepted definition of basic care nor of what is covered by the term. In the medical profession it is most often used to refer to procedures or medications which are solely aimed at providing comfort to a patient or alleviating that person's pain, symptoms or distress. It includes the offer of food and water by mouth. However, a distinction is generally made between 'artificial' (by tube) and 'oral' (by mouth) nutrition and hydration, the latter being regarded as part of basic care.[36] Others, however, disagree with this distinction.

In English law, basic care might be regarded either as 'care' or 'personal care' for the purposes of continuing healthcare funding. Moreover, there are different statutory definitions of care, including social care, personal care and nursing care which may not coincide with the ordinary English usage or clinical and ethical definitions. This means that discussions may become very difficult. For example, tube feeding through an established PEG tube is regarded as 'medical treatment' according to the Supreme Court judgment in *Re Y 2018*.[37] (This was a case which decided that it was no longer necessary to involve the courts in the removal of tube feeding if the medical team and family were in agreement). But there is uncertainty whether this means that only doctors or nurses can provide tube feeding. If feeding is given for 8-12 hours per day in a domestic setting does this mean that the patient or non-clinical carers are providing 'medical treatment'? There is further uncertainty whether it means that patients and carers can make decisions regarding 'medical treatment'.

Life-sustaining treatments: treatment necessary to sustain life. This term is understood to mean mechanical ventilation, cardiopulmonary resuscitation, life-saving antibiotics and tube-assisted nutrition and hydration.[38]

Clinical: The Oxford English Reference Dictionary indicates that the adjective 'clinical' relates to the treatment of a patient.[39] A clinical or medical action can be determined as a response to a pathological disturbance of health. In this regard, a treatment can vary in its complexity from something requiring extensive technological experience to a procedure which can be applied by any person in society. At present, for example, a treatment can sometimes be provided by a person himself or herself which, in the past, could only be provided by a physician or a nurse. In other words, the term 'treatment' is not defined by the person who applies it. A 'clinical treatment' does not always need to be applied by a clinician. Instead, it reflects the reality that an individual may require assistance and support from a drug or application in addition to what is naturally provided by his or her body.

Assisted nutrition and hydration:[40] The provision of nutrition and/or hydration by artificial means in order to overcome a pathology (disability) in the swallowing mechanisms of a patient. It includes giving nutrition and hydration by using:

- A drip through a small tube through a vein or the skin.

[36] General Medical Council, Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making, August 2002, http://www.gmc-uk.org/standards/default.htm

[37] https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf

[38]https://mydecisions.org.uk/help/life-sustaining-treatment

[39] The Oxford English Reference Dictionary, Second Edition, Edited by Judy Pearsall and Bill Trumble, Oxford University Press, 1996.

[40] Treatment and care towards the end of life: good practice in decision making p54 GMC guidance for doctors www.gmc-uk.org

- Feeding tubes:

    - via the nose (naso-gastric or NG tube) or

    - a tube placed in the stomach by the doctor (a Percutaneous Endoscopic Gastrostomy or PEG tube)

Assisted nutrition or hydration does not generally include helping patients eat and drink such as with a spoon or lidded cup.

Tube-assisted nutrition and hydration: The means of providing nutrition and hydration through a tube to someone who cannot take them by mouth. It bypasses the natural mechanisms of eating and drinking and requires initial clinical intervention. Nevertheless, the administration of nutrition and hydration, even when provided by artificial means, represents a natural means of preserving life, and is not itself a medical act. For this reason, it is better to talk of tube-assisted nutrition and hydration.

The insertion of a naso-gastric (NG) tube is not technically difficult but is usually done by an experienced nurse. The tube is passed by hand via a nostril into the back of the throat and slides down the gullet into the stomach. However, the key issue is the position of the tube. It is possible for the tube to miss the gullet and instead arrive in the lungs via the bronchi. This is similar to 'something going down the wrong way' causing choking when eating. If the naso-gastric tube is in the bronchial tubes and feeding begins, then fluid pours in the lungs and causes aspiration pneumonia. This can be fatal in a debilitated patient. There have been several patient safety alerts, advising that 'checking tube placement is essential in preventing harm.'[41] It is imperative to check the position of the tube by X-ray and also by removing some fluid and measuring its acidity level.

The insertion of a PEG tube in the stomach by the doctor is undertaken using an endoscope (telescope via the mouth) which crosses the abdominal wall and exits through a hole made in the skin. The PEG tube is then placed through the hole with the help of the endoscope.

Once the tube has been placed, feeding is normally undertaken by the patient or a carer. Hence, the provision of hydration and nutrition once a tube is in situ, is basic care or ordinary treatment. The overwhelming majority of tube feeding occurs in a domestic setting or care home.

Euthanasia The British House of Lords Select Committee on Medical Ethics defined euthanasia in 1994 as '*a deliberate intervention undertaken with the express intention of ending a life, to relieve intractable suffering*'.

Coma:[42] A state (lasting more than 6 hours) in which a person cannot be awakened, fails to respond to painful stimuli, light or sound, lacks a normal sleep-wake cycle and does not initiate voluntary movements.

Vegetative State (VS): A state of wakefulness without 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.[43] People with persistent vegetative state (PVS) may live for many years. There are estimated to be between 1,000 and 5,000 patients with PVS in Britain today, but, so far, only a few dozen have died after court rulings allowing tubes to be removed.

Minimally Conscious State (MCS): A state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated. [44]

[41] National Patient Safety Alert. Nasogastric tube misplacement and the continuing risk of death or harm

[42] Persistent Disorders of Consciousness. National Guidelines. Royal College of Physicians (2013)

[43] Ibid

[44] Ibid

This different states are summarised in the table below:

	Awake	Aware
Coma	No	No
Vegetative State	Yes	No
Minimally conscious state	Yes	Minimally

Experts use the term 'Persistent Disorders of Consciousness' to cover both permanent or persistent vegetative and minimally conscious states.[45]

2. Principles and Purpose

Patients in Permanent Vegetative States and Minimally Conscious States have profound brain injuries though their death is not imminent. This means that any intention to withdraw or withhold nutrition and hydration would end their lives. But such patients have a similar inherent value and worth to all other human persons and should, therefore, be treated as such. In other words, these patients should not be deprived of their lives intentionally. Thus, the SCHB opposes the withdrawal or withholding of nutrition and/or hydration with the intention of ending life.

Where a patient's death is imminent (expected within hours or days) and tube-assisted nutrition and hydration are already in use but are considered to no longer be of benefit, it usually will be appropriate (and good medical practice) to stop providing the nutrition and hydration. In this case the means of death is the disease itself. However, it can be very difficult to judge how long a patient may live. In a 2008 study from a hospice in Manchester, no group of health care professionals got the prognosis right more than 50% of the time.[46] In addition, it has been suggested that there was sometimes a misjudgement by a matter of months.[47] But even though prognostication is difficult, it is generally easier when patients approach the last days or weeks of life.

Persistent Vegetative State is characterised by a complete lack of awareness despite being awake and was first described in 1972. New methods of life support were allowing the survival of patients who would have previously died, such as those with massive brain injury, stroke or oxygen deprivation.[48] Experts described the syndrome as 'the lack of a working mind' caused by profound damage to the cerebral cortex but the brainstem is intact allowing lower breathing and circulation to be preserved. The cortex is required for all types of thinking, sight, motor and sensory activities. There has been an increase of cases of PVS largely because of increased availability of cardio-pulmonary resuscitation as this permits restoration of circulation and breathing after a period when they have stopped which allows survival despite significant brain damage.

The phrase 'Minimally Conscious State' was first coined in 2002. It described patients like those in PVS but who had some verbal or purposeful gesture such as appropriate smiling or crying or response to external stimulus. There has been growing understanding of the medical diagnosis and management of these disorders and they are now described as a continuum of Persistent Disorders of Consciousness (PDOC). The UK Royal College of Physicians published National Clinical

[45] Ibid

[46] Feargal Twomey, O'Leary N, O'Brien T. Prediction of patient survival by healthcare professionals in a specialist palliative care inpatient unit: a prospective study. American Journal of Hospice Care, Vol 25 No 2. April/May 2008, p139-145. DOI:10.1177/1049909107312594

[47] Dr. Gillian Craig, consultant geriatrician, Innovative approaches and ethical issues associated with end of life care, 9th December 2008, Westminster Health Forum papers.

[48] Jennet, Bryan, and Plum, Fred. (1972). 'The Persistent Vegetative State after Brain Damage: A Syndrome in Search of a Name.' *Lancet* 1: 734–737.

Guidelines on the Management of PDOC in 2015. This document enabled the recent transition of decision-making about end of life to return to the bedside in England and Wales. The UK Supreme Court decided in 2018 that, as there is now sufficient professional experience and guidance in place, in conjunction with relevant legislation, that it is no longer necessary to seek additional judicial review of medical decisions to withdrawal or withholding of tube-assisted nutrition and hydration in England and Wales.

4.England and Wales-Legislation, Case Law

4.1 Developments

Tony Bland

The key legal case of the withdrawal of tube-assisted nutrition and hydration concerned Tony Bland, a 17-year-old football supporter catastrophically injured in the Hillsborough tragedy of 1989.[49] He sustained punctures to his lungs and interruption to the oxygen supply to the higher centres of his brain leaving him in a condition then known as Persistent Vegetative State. This meant that although he had periods of wakefulness, he had no awareness of himself, nor of his surroundings. His brain stem was intact and so was able to breathe unaided while his heart was strong and healthy. However, he could not feed himself, and as his swallow was impaired, he was fed via a nasogastric tube. After four years in this tragic situation, the hospital with full support of his family, sought legal declarations that they might stop all life-sustaining treatment and medical support including ventilation, nutrition and hydration by artificial means. This was granted by the High Court and supported by the Court of Appeal in England and the UK House of Lords. It was held that:

1. The object of medical treatment was to benefit the patient.
2. Naso-gastric feeding was a medical treatment, substituting a function that had naturally failed.
3. A large body of medical opinion held that mere existence for a patient in PVS was not a benefit.
4. Mere prolongation of his life in PVS was not in his best interests, Lord Mustill held he had 'no interests at all'.
5. The principle of the sanctity of life was not absolute and was not violated by stopping medical treatment to which he had not consented and conferred no benefit.
6. Bland himself did not have capacity to make the decision, but his family said he would not have wanted to be kept alive in his current state.

Whether artificial nutrition and hydration constitutes medical treatment or basic care was one of the central questions considered by the House of Lords in the *Bland* case. The view of three of the five Law Lords who considered this case was expressed by Lord Goff as follows:[50] *'There is overwhelming evidence that, in the medical profession, artificial feeding is regarded as a form of medical treatment; and even if it is not strictly medical treatment, it must form part of the medical care of the patient'.*

This classification of tube-assisted nutrition and hydration as medical treatment was eventually adopted in other subsequent cases in England and Wales[51] and is now established common law. But until a body of experience and practice had built up around sensitive cases such as these, it was recommended for the protection of patients and reassurance of the public, that they should be brought before the Family Division of the English High Court. In addition, the Court required a second opinion from a senior clinician.[52]

[49] Airedale NHS Trust v Bland [1993] 1 All ER 821

[50] Ibid

[51] See, for example, Frenchay Healthcare NHS Trust v S [1994] 1 WLR 601, Re D (Medical Treatment) [1998] 1 FLR 411.

[52] General Medical Council, Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making, August 2002, http://www.gmc-uk.org/standards/default.htm

Other PVS cases

In subsequent cases of PVS, it was found not to be unlawful to withdraw tube-assisted nutrition and hydration, on the basis that its provision was not in the best interests of the individual patient.[53,54] In *Frenchay Healthcare Trust v S* in 1994 the court permitted the medical team not to replace a gastrostomy tube which had become displaced for a young man in likely PVS. This was a rushed decision due to clinical need and has been criticised for the lack of clarity of evidence of diagnosis of PVS.[55]

In the *re G* case in 1995, a medical team and wider family requested withdrawal of tube-assisted nutrition and hydration but was opposed by the patient's mother. It was of interest because the courts sanctioned the withdrawal of nutrition and hydration despite her opposition.[56]

In *Swindon and Marlborough NHS Trust v S* a blockage of a PEG tube had occurred in a patient in PVS looked after at home. Further treatment would have required hospitalisation. The court found that it was not in the best interests of S to have the tube replaced.

The impact of *The Human Rights Act (1998)* in England and Wales was assessed in *NHS Trust A v Mrs M* and NHS Trust B v Mrs H [2000].[57] Dame Butler Sloss found that the decision to withdraw life support in a case of PVS was not a breach of the patient's human rights. The three human rights she examined were Article 2 (the right to life) Article 3 (the right not to be subjected to degrading and inhuman treatment) and Article 8 (the right to a private life). She stated that a person must be able to experience the degrading treatment before Article 3 could be engaged, although this is arguable.

Minimally conscious state

In 2014, *W v M* was the first occasion in the UK when an application was made for a patient in a Minimally Conscious State.[58] The judge found that the removal of artificial nutrition and hydration was not in M's best interests because of her right to life saying, '*M was recognisably alive in a way that a patient in PVS was not*.' The second factor was previous wishes and feelings. Although her family felt M would not have wanted her current situation, in the absence of an advance decision, this was not compelling. The judge weighed up her suffering of pain, enjoyment of life, prospects of recovery as well as her dignity together with the wishes and feelings of family members and carers. In the judgement, the importance of preserving life was the decisive factor in the case. It would not be in M's best interests for tube-assisted nutrition and hydration to be withdrawn.

However, in subsequent cases in 2015 such as *M v Mrs N*, the Court of Protection did authorise the withdrawal of tube-assisted nutrition and hydration.[59] In *United Lincolnshire Hospitals NHS Trust v N* it was held not in the best interests to re-insert a PEG tube to feed the patient. Although the same process was followed as in *W v M* in the weighing up of the advantages and disadvantages for the patient, the judge emphasised that not all factors held equal weight with the most important element being Mrs N's past feelings and wishes.[60]

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[53] British Medical Association: Withholding and Withdrawing Life Prolonging Medical Treatment: http://www.bmjpg.com/withwith/ww.htm

[54]By the end of September 2000, 23 such cases had been considered by the Courts and two were heard in early October 2000 in which the court confirmed that withdrawing or withholding artificial nutrition and hydration in such circumstances did not contravene *The Human Rights Act 1998*.

[55] [1994] 2 All ER 403; (1994) 17 BMLR 156, CA

[56] [1995]3 Med Law Rev 80

[57] NHS Trust A v M; NHS Trust B v H [2000] 58 BMLR 87

[58]W v M [2011] EWHC 2443 (Fam); [2011] WLR (D) 283

[59] N v Mrs M [2015] EWCOP 76

[60]https://www.mills-reeve.com

Leslie Burke

Leslie Burke suffered from a chronic neurodegenerative disorder and in 2004 sought a declaration from the courts that he would be provided with appropriate feeding and fluids until he died of natural causes. He did not want any withdrawal of tube-assisted nutrition and hydration and any decision to be taken by doctors that his life was no longer worth living.[61]
Initially, the High Court judge ruled in his favour, stating that '*If life-prolonging treatment is providing some benefit it should be provided unless the patient's life, if thus prolonged, would from the patient's point of view, be intolerable*. *If there remains any doubt in the matter it should be resolved in favour of life.* In other words, if patients have not made a 'living will' and lack capacity to decide, doctors should presume treatment should be given and apply the '*intolerability*' test.[62]

However, the English Court of Appeal ruled in favour of the General Medical Council in 2005, arguing physicians could be put in an impossible position. Given tube-assisted nutrition and hydration had been defined as a treatment by *Bland*, doctors would have had to provide treatment which they knew would be of no benefit or could even be harmful.[63]

The Court of Appeal also dismissed the test of 'intolerability'. This test had meant that in deciding whether treatment should be withdrawn (if there had been no specific request for life-sustaining treatment), there was a strong presumption in favour of preservation of life. This presumption could be overruled but only if it could be demonstrated that any continued life would be intolerable. The Court of Appeal modified this test by indicating that: '*The test of whether it is in the best interests of the patient to provide or continue [tube-assisted nutrition and hydration] must depend on the particular circumstances.*' However, 'circumstances' are much more elastic test than 'intolerability' and commentators suggest that the new test will be much more difficult to police.[64]

Deep sedation

A further question is that of the use of deep sedation. Patients capable of expressing their will may, for example, ask for sedation with any subsequent tube-assisted nutrition and hydration being stopped. Such a request can be made by those who have intense psychological or existential suffering or who, for any reason, refuse all care and request an ending of their lives.[65]

However, in this case, legislation would also have to account for the legal provisions on assisted suicide. The Director of Public Prosecutions for England and Wales in 2010[66] indicated that a prosecution is more likely to be required if '*the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not]*'.

In this regard, it is difficult to see healthcare professionals deliberately considering such a chain of events with respect to the interruption of nutrition and hydration with suicide as the outcome. It would also be unethical and irresponsible for healthcare professionals to put someone into deep sedation when more appropriate clinical alternatives are an option.

61 R (Burke) v General Medical Council [2004] EWHC 1879 (Admin)

62 Alexandra Frean, The new line separating life and death, The Times, Saturday 31 July 2004.

63 Burke, R (on the application of) v General Medical Council & Ors [2005] EWCA Civ 1003.

64Charles Foster, Triple Helix - Autumn 2005, The Leslie Burke debacle - Fixing what ain't bust (p14), http://www.cmf.org.uk/literature/content.asp?context=article&id=1692

65 This is an option that is increasingly being accepted by bodies such as the Swedish National Council on Medical Ethics. See: Swedish National Council on Medical-Ethics, Patient autonomy in end-of-life decisions, November 2008, Reg. No14/08. See also: The patient's possibility to decide about his/her own death, November 2008, Reg. no14/08, http://www.smer.se/Bazment/337.aspx

66 Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide Issued by The Director of Public Prosecutions, Crown Prosecution Service, February 2010, http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.pdf

Related case law

A number of legal judgments on the withholding and withdrawing of treatment indicate that the English courts do not consider that protecting life always takes precedence over other considerations. The case law establishes several relevant principles. The outline below reflects some of the key points:

• An act where the doctor's primary intention[67] is to bring about a patient's death would be unlawful.[68]

• A competent adult patient may refuse treatment even where it may result in harm to himself or herself even if this means death.[69] If a doctor objects, they must refer the patient to another doctor.[70]

• Life prolonging treatment may lawfully be withheld or withdrawn from incompetent patients when commencing or continuing treatment is not in their best interests.[71]

• There is no obligation to give treatment that is futile and burdensome.[72]

• Where an adult patient has become incompetent, a refusal of treatment made when the patient was competent must be respected, provided it is clearly applicable to the present circumstances and there is no reason to believe that the patient had changed his or her mind.[73]

• For those who lack capacity to decide, in reaching a view on whether a treatment would be more burdensome than beneficial, assessments of the likely quality of life for the patient with or without the treatment may be one of the appropriate considerations.[74]

• The 'intolerability' of treatment is not the sole test of whether treatment is in a patient's best interests which encompasses medical and all other factors relevant to the patient's welfare.[75]

• A patient's best interests may be determined as meaning that a patient should not be subjected to more treatment than is necessary to allow him or her to die peacefully and with dignity.[76]

• All reasonable steps should be taken to overcome challenges in communicating with or managing the care of patients with disabilities, to ensure that they are provided with the treatment they need, and which would be of overall benefit to the patient.[77]

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[67]ii R v Cox (1992) 12 BMLR 38.

[68] For a rare exception in the case of conjoined twins see Re: A (Children) (Conjoined twins: surgical separation) [2000] 4 All ER 961.

[69]iv Airedale NHS Trust v Bland [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Also, Re JT (Adult: Refusal of Medical Treatment) [1998] 1 FLR 48 and Re AK (Medical Treatment: Consent) [2001] 1 FLR 129.

[70]vi Re Ms B v a NHS Hospital Trust [2002] EWHC 429 (Fam).

[71] Airedale NHS Trust v Bland [1993] 1 All ER 821.

[72] Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930.

[73] Airedale NHS Trust v Bland [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Re T (Adult: Refusal of Treatment) [1992] 4 All ER 349 and Re AK (Medical Treatment: Consent) [2001] 1 FLR 129. W Healthcare NHS Trust v H [2005] 1 WLR 834

[74]Re B [1981] 1 WLR 421; Re C (A Minor) [1989] All ER 782; Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930; Re R (Adult: Medical Treatment) [1996] 2 FLR 99.

[75]Wyatt & Anor v Portsmouth Hospital NHS & Anor [2005] EWCA Civ 1181. Burke v GMC [2005] EWCA Civ 1003. An NHS Trust v MB [2006] EWHC 507 (Fam).

[76]NHS Trust v Ms D [2005] EWHC 2439 (Fam). Burke v GMC [2005] EWCA Civ 1003.

[77]An NHS Trust v S &Ors [2003] EWHC 365 (Fam).

• Where clinicians and a child's family are in fundamental disagreement over the child's treatment, the views of the court should be sought.[78]

• If a patient requests a treatment which his or her doctor has not offered, and the doctor concludes that the treatment will not provide overall clinical benefit to the patient, the doctor is not obliged to provide it, although he or she should offer to arrange a second opinion.[79]

• Where tube-assisted nutrition and hydration are necessary to keep a patient alive, the duty of care will normally require the doctor to provide it, if a competent patient wishes to receive it.[80]

• Tube-assisted nutrition and hydration may be withheld or withdrawn where the patient does not wish to receive them; or where the patient is dying and the care goals change to palliation of symptoms and relief of suffering; or where the patient lacks capacity to decide and it is considered that providing tube-assisted nutrition and hydration would not be in the patient's overall interests.[81]

• Responsibility rests with the doctor to decide what treatments are clinically indicated and should be provided to the patient, subject to a competent patient's consent to treatment or, in the case of an incompetent patient, any known views of the patient prior to becoming incapacitated and taking account of the views offered by those close to the patient.[82]

• When the Court is asked to reach a view about withholding or withdrawing a treatment, it will have regard to whether what is proposed is in accordance with a responsible body of medical opinion. The Court will determine for itself whether treatment is in the patient's overall interests.[83]

4.2 Present situation

In 2018, the UK Supreme Court gave its judgement in the case of Mr Y where it found that there was now no need to go to court in England and Wales to seek approval, each time, for the withdrawal or withholding of tube-assisted nutrition or hydration. This was provided that the provisions of *The Mental Capacity Act (England and Wales) 2005* are followed, the relevant guidance is implemented and the family and treating clinical team are in agreement.[84]

The new guidance from the Royal College of Physicians, the UK General Medical Council and The British Medical Association states that decision makers should start from the presumption that it is in the best interests of the patient to prolong life but there is no obligation to prolong life irrespective of the quality of that life or of the patient's own views.

5. Scotland- legislation, case law.

5.1 Developments

The classification of tube-assisted nutrition and hydration as medical treatment has been adopted in Scotland since the case of the *Law Hospital NHS Trust v Lord Advocate* (1996). Thus, the withdrawal or withholding of tube-assisted nutrition and hydration for patients in PVS is now established common law.

[78] Glass v the United Kingdom (ECHR, 2004).

[79] Re J (A Minor) (Child in Care: Medical Treatment) [1992] 2 all ER 614; Burke v GMC [2005] EWCA Civ 1003.

[80] Burke v GMC [2005] EWCA Civ 1003.

[81] Burke v GMC [2005] EWCA Civ 1003. NHS Trust v Ms D [2005] EWHC 2439 (Fam)

[82]Re J (A Minor) (Child in Care: Medical Treatment) [1992] 2 All ER 614; and Re G (Persistent Vegetative State) [1995] 2 FCR 46.

[83]Re A (Male Sterilisation) [2000] FCR 193; and Re S (Adult: Sterilisation) [2000] 2 FLR 389.

[84] Decisions to withdraw clinically assisted nutrition and hydration (CANH) from patients in PVS or minimally conscious state (MCS) following sudden onset brain injury. Interim guidance for health professionals in England and Wales. General Medical Council. British Medical Association. Royal College of Physicians www.bma.org.uk accessed 20 Nov 2018

The Scottish Law Commission also said that there was no requirement to bring all such cases to court, but decisions could be made on medical grounds. It also indicated that only the treating doctor need make the decision and a second opinion was not required. There should be recourse to the courts only in the case of dispute.[85] This was not enacted in primary legislation. In 1996 the Court of Session stated it was not necessary to bring every case of PVS in Scotland to court. However, the Lord Advocate responded stating that only if the court had been involved, could he guarantee immunity from prosecution for the doctors, so the position remained uncertain.

5.2. Present situation

The withdrawing or withholding of tube-assisted nutrition and hydration is not specifically mentioned in the *Adults with Incapacity (Scotland) Act 2000*. However, Section 47 (4) of this Act states that: '*[A] medical treatment includes any procedure or treatment designed to safeguard or promote physical or mental health*'. As such, it is very likely that the giving of nutrition and hydration may be considered as medical treatments since they would safeguard or promote physical health.

And in this respect, para 2.34 of the Code or Practice indicates that:

> *Generally, treatment will involve some positive intervention in the patient's condition. Simple failure to do anything for a patient would not be treatment. However, a decision not to do something is still an intervention in terms of section 1 principles and must accord with those principles. It is difficult to conceive of circumstances in which a medical practitioner would take no steps at all in relation to a patient.*

Moreover, Section 83 (1) of the Act states that:
'It shall be an offence for any person exercising powers under this Act relating to the personal welfare of an adult to ill-treat or wilfully neglect that adult.'

In para. 2.62 of the Code of Practice it is indicated that:

> *Nothing in the Act authorises acts or omissions which harm or are intended to bring about or hasten the death of a patient.*
> *During Parliamentary debate on the Act there was extensive discussion of this matter. Ministers made it absolutely clear that the Act does not permit any form of euthanasia, which remains a criminal act under Scots Law.*
>
> *As the then Deputy Minister for Community Care, Iain Gray, said in the Scottish Parliament, 'Any health professional, like any individual, who acted by any means – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law.'*
>
> *All interventions under the Act (including some omissions to act) must comply with the general principles that all interventions must benefit the adult, and that any intervention must be the least restrictive option in relation to the freedom of the adult. Clearly, an intervention under Part 5 of the Act which adversely affects the well-being of an adult or causes harm or even death to that adult cannot be described as bringing a benefit to that adult.*

Finally, para 3.2. of the Code of Practice indicates that:

> *'while proxies can legitimately object to particular courses of medical treatment, they may not act unreasonably by, for example, refusing fundamental care procedures.'*

6.Other jurisdictions

6.1 International

[85]Jennet, B. Should Cases of permanent vegetative state still go to court? BMJ 1999;319:796–7

- United Nations Convention on the Rights of Persons with Disabilities[86] (legally binding). This entered into force on 3 May 2008. The UK has ratified this Convention in 2009. This states under Article 25 (Health) that:

> *States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.*
> *In particular, States Parties shall … Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

- Council of Europe Convention on Human Rights and Biomedicine, ETS - No. 164[87] (legally binding). Entered into force on 1 December 1999 (the UK has not signed nor ratified this instrument). This stated under Article 5 (General rule) that:

> *An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.*
> *This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.*
> *The person concerned may freely withdraw consent at any time.*

Case Law:

In the case *X. v. Germany, no. 10565/83,1984,* the European Court of Human Rights indicated that a State was entitled to force-feed a prisoner on hunger strike. This may be of considerable interest in relation to *Bland* as it indicates an interest in preserving life for its own sake. The assertion in *Bland* that autonomy extends to refusals 'however unreasonable'[88] needs to be qualified in that Strasbourg has affirmed the state interest in preserving life even in the face of determined efforts of individuals to end their own lives. An important factor in such considerations was the specific vulnerability of those in care of the state.

Diane Pretty

Diane Pretty suffered from motor neurone disease and requested that her husband not face prosecution if he helped her to die. But the House of Lords said that the right to life did not include a right to die. The European Court of Human Rights agreed that Article 2 of the European Convention on Human Rights is there to protect life itself.

Vincent Lambert

In 2015, Doctors were given permission to remove assisted fluids and nutrition from Vincent Lambert, a severely brain-damaged, 38-year-old Frenchman. After a long legal battle, the European Court of Human Rights ruled that ending artificial nutrition and hydration did not violate Article 2 of the European Convention on Human Rights, which guarantees the right to life. His family had been divided with his wife indicating that he would not have wanted to be kept alive in a vegetative state, but his parents wanted him to be kept alive.
Twelve of the judges in the ECHR voted to allow Lambert to have his tube-assisted nutrition and hydration stopped. However, there were five who strongly dissented. They pointed out that he was not brain-dead, he could breathe on his own, he could digest food, was not in pain and was not in a terminal situation. The legal decision to stop treatment in Mr Lambert's case has now been taken five times and each time been contested. The latest decision was overturned by the Paris appeals court in May 2019 which eventually brought about his death.[89]

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[86] UN Convention on the Rights of Persons with Disabilities, entered into force on 3 May 2008, The UK has signed but not ratified this Convention, http://www.un.org/disabilities/default.asp?id=259

[87] Convention on Human Rights and Biomedicine, ETS No.164, http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc

[88] Airedale NHS Trust v Bland

[89] https://theconversation.com/vincent-lambert-what-are-the-legal-and-ethical-issues-117577

6.2 Other countries

United States
The US courts have permitted the removal of tube-assisted nutrition and hydration in the situation of permanent vegetative state in the case of Mrs Terry Schiavo. However, this was based on the decision-making process. Rather than the courts deciding in the best interests of the patient, as in the UK, in the US the courts ask the nominated deputy or surrogate what they believed the patient would have wanted. This is the 'substituted judgement' standard and was particularly difficult, in this case, as Mrs Schiavo's husband (the surrogate decision maker) and her parents disagreed, requiring intervention at almost every level of the US legal and political system before her feeding tube was removed. One of the concerns was that Mr Schiavo might benefit financially from his wife's death.

Italy
Eluana Englaro was an Italian woman who was in a permanent vegetative state for 17 years after a road traffic accident. Her father campaigned for her feeding tube to be removed as she had previously expressed wishes not to be kept alive in such a state. The case caused great political upset in Italy with debate in the Italian Senate and intervention from the Prime Minister and Health Secretary. She died in 2009 after the tube was removed in a private clinic with court permission.
Subsequently, the Italian parliament adopted an *Advance Directives Bill* in 2009 prohibiting any form of euthanasia and the interruption of treatment, nutrition and hydration for patients at the end of their lives. Guaranteeing the right to life in its terminal phase, and in cases where the person is not able to understand or to express their will, the bill reaffirmed that human life is inviolable.[90] However, in 2017 a further law, Law 219/2017 on the 'Provisions for informed consent and advance directives', was passed that gave the option to refuse life-sustaining treatments, including tube-assisted nutrition and hydration.

[90]Moratti, S. Cambridge Quarterly of Healthcare Ethics (2010), 19, 372–380. Cambridge University Press, 2010.