39 ESSEX STREET

Medical Treatment Decisions and Incapable Persons

a presentation by

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1. The subject of medical treatment decisions taken on behalf of those lacking capacity is a large one. This talk discusses the inherent jurisdiction of the Family Division of the High Court to make declarations as regards the best interests of those lacking capacity to make those decisions. Its aim is to provide a brief summary of the general principles governing these cases and to look at some recent case law developments about the withdrawal of life sustaining treatment. This talk does not deal specifically with the issue of advance directives.

2. The jurisdiction of the Court to grant relief governing decisions relating to medical treatment, as well as residence and day-to-day care of incapable adults was clearly acknowledged in Re F (Adult Patient) [2000] 2 FLR 512. Where there is "a serious justiciable issue" the Court has the power to determine an incapable adult's best interests and to grant relief. In respect of children, there is the analogous wardship jurisdiction.

Capacity

3. The presumption is that a person has capacity to make decisions on his behalf, although this presumption is a rebuttable one (Re MB (Medical Treatment) [1997] 2 FLR 426). Babies or very young children do not have capacity to make decisions about medical treatment and parents have the right to refuse or consent to medical treatment on their behalf.[1]

4. The Court will only intervene in exercise of its inherent jurisdiction if it is shown that the person lacks capacity to consent to or refuse medical treatment. This is because a mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where the decision may lead to his own death (St. Georges Healthcare NHS Trust v S [1998] 3 All ER 673, Re B (Adult Refusal of Medical Treatment) [2002] EWHC 429).

5. The test for capacity is that set out by the Court of Appeal in Re MB (see above) per Butler-Sloss LJ at 436 - 437. In summary, a person lacks capacity if some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent to or to refuse treatment. That inability to make a decision will occur when:

[1] Although note that minors have the right to consent if they fully understand what is involved and if so, parents lose the right to consent on their behalf (Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC 112)

a) The patient is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question;
b) The patient is unable to use the information and weigh it in the balance as part of the process of arriving at a decision. If, for example, a compulsive disorder or phobia stifles belief in the information presented, the decision may not be a true one.

6. Capacity is time-specific and decision-specific. It should also be noted that the Mental Capacity Act 2005 (not yet in force) introduces a new statutory test for capacity which builds upon and expands the common law test. Under the Mental Capacity Act, persons who cannot communicate their decisions at all may be treated as incapable (s. 3(1)(d)).

7. The position of those *with capacity* was underlined by the decision last year of the Court of Appeal in the case of Burke v General Medical Council [2005] EWCA 1003 which concerned the circumstances in which artificial nutrition and hydration ("ANH") can be withdrawn from a patient and involved a judicial review challenge to guidance of the General Medical Council about withdrawal of ANH. Mr Burke suffered from a congenital degenerative brain condition known as spino-cerebellar ataxia which confined him to a wheelchair. He suffered as a result from very serious physical disabilities but had maintained mental competence and capacity. The medical evidence indicated that he was likely to maintain full cognitive faculties even during the end stage of his disease. His concern was that he wanted to be provided with appropriate hydration until he died of natural causes and did not want ANH to be withdrawn by the doctors treating him.

8. The Court of Appeal held that there was no basis for this concern. The Court stated that autonomy and the right to self-determination entitled a competent patient to refuse treatment. The corollary did not follow because autonomy and the right to self-determination did not entitle a patient to insist on receiving particular medical treatment. However, once a patient is accepted into hospital, the medical staff come under a positive duty at common law to care for the patient. A fundamental aspect of this duty is to take reasonable steps to keep the patient alive. Where ANH is necessary to keep the patient alive, the duty of care will normally require the doctors to supply ANH (although this would not override the patient's right to refuse ANH) (see paragraphs 30 to 32). Further, Lord Philips MR stated that "*it seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent's patient's expressed wish to be kept alive, with the intention of thereby terminating the patient's life, would leave the doctor*

with no answer to the charge of murder" (paragraph 34). The Court stated that there was only one situation where a doctor could override a competent patient's decision to have ANH which was where in the last stage of life, it might actually hasten death. In such circumstances, ANH might not be clinically indicated. Contrary to the Munby J's view, the Court of Appeal stated that in such circumstances a patient's wish to have ANH would not be determinative. "*Clearly the doctor would need to have regard to any distress that might be caused as a result of overriding the expressed wish of the patient. Ultimately, however, a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs. That said, we consider that the scenario that we have just described is unlikely to arise in practice*" (paragraph 55).

Best interests

9. If a person lacks capacity to make a decision, a decision had to be made in accordance with the person's best interests. Best interests must be given a generous interpretation. Lord Justice Butler-Sloss in Re A (Male Sterilisation) [2000] 1 FLR 549 stated:

"*best interest encompasses medical, emotional and all other welfare issues*."

10. In Re S (Adult Patient: Sterilisation) [2001] Fam 15 Thorpe LJ said:

"In deciding what is best….the judge must have regard to….welfare as the paramount consideration. That embraces issues far wider than the medical. Indeed it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination".

11. It is also important to note that the best interests test is different from the Bolam test. A doctor providing treatment to an incapable person must act in accordance with a responsible and competent body of medical opinion (Re F [1990] 2 AC). However, as well as so acting, the doctor must also act in a person's best interests. It is often the application of the "best interests" test which will determine which treatment option is to be preferred because a number may satisfy the Bolam test. Although in cases where an application for a declaration is made, it will be the judge and not the doctor who decides what is in the best interests of the patient (see Butler-Sloss LJ in Re A (Male Sterilisation) [2001] 1 FLR at 555 and Re S (Adult Patient: Sterilisation) [2001] Fam 15 at 27).

12. Mr Justice Hedley in Portsmouth NHS Trust v Wyatt [2004] RWHC 2247 stated that "the infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (paragraph 23).

13. As regards the proper approach to assessing best interests, Thorpe LJ in Re A (Male Sterilisation) above (at 560) stated:

"*There can be no doubt in my mind that the evaluation of best interests if akin to a welfare appraisal…Pending the enactment of a checklist or other statutory direction it seems to me that the first instance judge with the responsibility to make an evaluation of the best interests of a claimant lacking capacity should draw up a balance sheet. The first entry should be of any factor or factors of actual benefit…..Then on the other sheet the judge should write any counterbalancing dis-benefits to the applicant. ..Then the judge should enter on each sheet the potential gains and losses in each instance making some estimate of the extent of the possibility that the gain or loss might accrue. At the end of that exercise the judge should be better placed to strike a balance between the sum of the certain and possible gains against the sum of the certain and possible losses. Obviously, only if the account is in relatively significant credit will the judge conclude that the application is likely to advance the best interests of the claimant."*

14. Some of the most difficult best interest decisions fall to be made by the Courts in the context of the withholding or withdrawal of life sustaining treatment. These are cases raising fundamental principles underlying humanity: the sanctity of human life, individual autonomy or self-determination and the respect for the dignity of the human being (see discussion by Lord Hoffman in Airedale NHS Trust and Bland [1993] AC 789 at page 826). Lord Donaldson of Lymington in Re J (A minor:medical treatment) [1991] Fam 33 at 46 set out the considerations in the following way (which is a passage which continues to be quoted in recent decisions):

"*There is without doubt a very strong presumption in favour of a course of action which will prolong life, but…it is not irrebuttable…Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment…We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life….Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that*

the it is not in the best interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive."

15. Some of the most recent decisions by the Courts about best interests in the context of life sustaining treatment have concerned children. The baby Charlotte case is a well-known example (Portsmouth NHS Trust v Derek Wyatt v Charlotte Wyatt). Mr Justice Hedley delivered five judgments in the case and the Court of Appeal gave one. Charlotte was nearly one year old at the time of the first substantive judgment in the case by Mr Justice Hedley on 7 October 2004 ([2004] EWHC 2247). Charlotte has chronic respiratory and kidney problems coupled with profound brain damage leaving her blind, deaf and incapable of voluntary movement or response. The medical evidence was that she demonstrably experiences pain but no doctor knew if she could experience pleasure. She requires high levels of supplemental oxygen and at the time of the judgment in October 2004, needed to have her head covered at all times with a plastic box. The most optimistic prognosis for survival at that time was a 5% chance of survival for 12 months. This led the Judge to comment that the issue in the case was probably not whether the baby should live or die but how and when she should die.

16. There was no dispute in the case that Charlotte should be maintained in her current condition. The issue was whether she should be given artificial ventilation were she to deteriorate to a state where she would require it. The medical evidence was that she would almost certainly deteriorate to that extent. The unanimous medical opinion (given by five paediatric consultants) was that artificial ventilation would not be in her best interests on the basis of the minimal prospects of her life and the costs to her. Even if she were recommended for a tracheostomy, she may not survive transfer to another hospital where the operation had to be performed or the anaesthetic. If ventilated, there was a risk that her lungs would be fatally damage. The evidence was that she had no sense of sigh or sound and is and will remain without volition. Hedley J concluded that it was highly probable that she did not experience pleasure although it could not be excluded as a possibility. Charlotte's parents were of the view that it was in her best interests to receive artificial ventilation. He felt discomfort at overriding the views of the parents and allayed that by taking account of the fact that her parents know her best when assessing best interests. Hedley J determined that he did not believe that further aggressive treatment, even if necessary to prolong life, was in Charlotte's best interests and he made declarations to that effect. "*I know that that may mean that she may die earlier than otherwise she might have done but in my judgment the moment of her death will only be*

slightly advanced." (paragraph 38). He arrived at the decision by asking himself "what can now be done to benefit Charlotte?" and concluded that there were only three answers: to give her as much comfort and little pain as possible, to give her as much time to spend in the presence of and contact with her parents and to meet her end in the TLC of those who most love her. In this he gave considerable weight to what he describes as the best interests of any person at a risk of imminent death to sure a good death "not in the course of painful and futile treatment but peacefully in the arms of those who love her most" (paragraph 28). He also found that further invasive and aggressive treatment would be "intolerable" to Charlotte (following the "intolerability" test suggested by Taylor LJ in re J (a minor) (Wardship: medical treatment) [1991] Fam 33), although he said he preferred to determine the case on the basis of a finding as to what is the best that can be done for her (paragraph 38). He emphasised that he was granting was only permissive and did not prevent the giving of the treatment if the doctors and parents considered this appropriate at the material time.

17. The case came back before Mr Justice Hedley in April 2005 [2005] EWHC 693 because one of the doctors then supported trying invasive aggressive treatment in the event of an overwhelming respiratory infection but the Judge followed the majority medical opinion and found that aggressive intervention would not be in her best interests. He also, contrary to the wishes of the parents ordered that the declarations should continue, albeit that they related to a future situation which might change because he was dealing with a precisely anticipated medical emergency and because the stress and volatility of the relationship between the parents and the medical staff made this appropriate.

18. This decision was appealed to the Court of Appeal by the parents ([2005] EWCA Civ 1181) who refused permission to appeal on the best interests issue and also refused the appeal on the "timing" issue i.e. that Mr Justice Hedley should not have continued the declaratory relief at that time but left the matter open for a decision to be made as and when artificial ventilation became necessary. What the Court of Appeal was keen to emphasise was that the case was not about the withdrawal of treatment in order to allow Charlotte to die (paragraph 9). The case was about "*what should happen if Charlotte contracts an infection or suffers some other crisis which is likely to lead to her death and thus requires her to be ventilated if she is to stand any chance of remaining alive*" (paragraph 11). The Court (whose judgment was given by Wall LJ) also discussed the "intolerability test" mentioned by Hedley J and derived from the Court of Appeal decision in Re J (which also concerned whether a young baby should be artificially ventilated). It noted that it was only Taylor LJ (and neither of the other two Lord Justices) in that case

who had described the correct approach of the Court as involving the court judging the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child. The Court of Appeal concluded that it was right to say that the concept of "intolerable to the child" should not be seen as a gloss on, much less a supplementary test, to best interests. It is, however, "a valuable guide in the search for best interests in this kind of case" (paragraph 77). It is to be noted that the Court of Appeal in the Burke case (above) also stated that the touchstone of best interests in the context of life-prolonging treatment was not "intolerability" and that Munby J at first instance was wrong to say so and that test of what is in someone's best interests will depend on the circumstances and took the view that there was no "single test" applicable to all circumstances (at paragraphs 62 and 63).

19. On the timing question, the Court of Appeal concluded that the Judge was right to continue the declarations, although they acknowledged the tension between the concept of a declaration designed to state what is lawful in the current circumstances and a situation which was sufficiently fluid to render it likely that the circumstances might change and the legality of the conduct called into question. They relied in particular on the fact that a court order did not dictate what clinicians should do and did not absolve them of their duty to act in the best interests of a child and that until the court had ordered otherwise, the clinicians would have to follow the instructions of the parents and so without a court order, they would have to resuscitate while the hearing was being sought and proceeding which would to a large extent make it unnecessary. The Court also bore strongly in mind that the Judge found that nothing had changed in her underlying condition. The Court did, however, counsel caution in making declarations involving seriously damaged or gravely ill children and said that the Court was not to be used as a "general advice centre" and it is not the function of the Court to "oversee the treatment plan for a gravely ill child" (paragraph 117).

20. Hedley J proceeded to act in accordance with this advice in October 2005 ([2005] EWHC 2293) when he reviewed the case again. At that stage there was evidence of "real progress" in Charlotte's condition and her consultant paediatrician indicated that he could see circumstances where he was prepared to ventilate her but it was impossible for him to define those circumstances in advance. In those circumstances, Hedley J refused to grant any declaratory relief (contrary to the requests of the doctors) commenting that the Court could not be used to oversee treatment plans. He also took the opportunity to discuss the duty of the treating clinician when he disagrees with the parents of a child and recognised

the principle that a doctor cannot be required to act contrary to his conscience or do or not do something which in his bona-fide clinical judgment is not in the best interests of the patient (at paragraph 32). Although a further declaration was later made by him that it was in Charlotte's best interests for the medical profession to refrain from artificial ventilation when she developed a rasping cough in February 2006.

21. The following points can be made about the various judgments in this case:

a) This case, as was particularly emphasised by the Court of Appeal, was not concerned with whether the existing treatment regime to prolong life should be withdrawn. It was about what should be done in Charlotte's best interests if her condition were to deteriorate where she required artificial ventilation i.e. if there were a crisis in the future, should treatment be withheld. It could be said that this is not a valid distinction in circumstances where the medical evidence was that it was highly likely that she would develop an infection where artificial ventilation was required. Although, on the facts, the crisis did not actually arise during the course of litigation and as we know from recent developments reported in the press, she is now well enough to be discharged home from hospital. In assessing what was in Charlotte's best interests, he found that securing a good death in the arms of her loved ones as opposed to undergoing further painful and futile treatment;

b) At all times, the Court followed the majority opinion of the medical professionals as to best interests – as often/usually will be the case;

c) The concept as to whether or not the life was "intolerable to the child" is not a gloss nor a separate test. The test is simply "best interests" which will depend on all the circumstances. It is not surprising that the Court moved away from a test that so obviously seeks to assess the quality of person's life in cases which will often be dealing with children with profound disabilities;

d) The jurisdiction of the Court to grant declaratory relief in cases which are not one-off decisions (e.g. whether a person should be sterilised or whether life support should continue for a patient in a PVS) but relate to decisions in the future should be used sparingly. The Court will not act as an advice centre or a general overseer of the care of a patient. In this case there was a precisely anticipated medical emergency and at the time when the declarations were made, there was no evidence that the underlying medical condition had changed;

e) The effect of the declarations were permissive only. They did not prevent a doctor providing treatment which he considered to be in the best interests of someone at the material time, even if contrary to a declaration authorising him to do so. Hence, the

Court is not interfering with nor relieving medical professionals of their duties to make clinical decisions in accordance with their duties to their patients. The Court cannot require a medical professional to act contrary to his conscience;

f) The particular role that parents have to consent or to refuse medical treatment on behalf of their children places a particular responsibility on clinicians to work in partnership with them and to accommodate their views and opinions except in cases where to do so would be an affront to their conscience. Given that parents have the right to consent or to refuse medical treatment, it can be said that their views carry greater weight than family members of incapable adults. In cases of dispute, the Court will have the last word.

22. A recent case where the Court did not follow the views of the medical professionals in reaching a decision about a baby's best interests was the decision of Mr Justice Holman in An NHS Trust and MB and Mr and Mrs B [2006] EWHC 507 (heard in March 2006). That case concerned an 18-month year old baby boy "M" who suffers from spinal muscular atrophy ("SMA"). He suffers from the severest form of SMA amongst those who are not dead. It is a degenerative and progressive condition which affects the voluntary muscles (but not the involuntary muscles such as the heart). The involuntary muscles include the respiratory muscles and death is inevitable unless, after a certain point, artificial ventilation is commenced. He had reached the point that save for movement of his eyes and possible slight but barely perceptible movement of his eyebrows, corners of his mouth, thumb, toes and feet, he cannot move at all. He had not been able to breathe unaided since July 2005 and required positive pressure ventilation via an invasive endo-tracheal tube since October 2005. However, brain damage or impairment or loss of cognitive functions (i.e. the ability of the brain to think or operate in a normal, age-appropriate way) are not normal features of SMA, even in its severest forms.

23. The view of the NHS treating doctors was that it was not in M's best interests for them to continue artificially to keep him alive and that his endo-tracheal tube should be withdrawn. Sedatives would be used so that he could have a peaceful, pain free and dignified death. Eight consultants who were all part of the treating team gave evidence that "*Although ventilation is keeping him alive, it is not restoring his health. We believe that every day that we continue with his ventilation is adding to his distress. The treatments currently provided for M are futile and sadly will not change the outcome of his illness"* (at paragraph 26). Further, four expert witnesses had been appointed (all consultants, including one by M's parents) who all agreed with the treating doctors as to

diagnosis, prognosis, current and future pain and distress to M and that his ventilation should be withdrawn (paragraph 29). The Guardian also supported the withdrawal of ventilation.

24. However, as Holman J noted, M was not unconscious nor in a permanent vegetative state. He was conscious and it was probable and had to be assumed that he continued to see and to hear and to feel touch and to have awareness of his surroundings and in particular, of people who are most close to him, his family and to have the normal thoughts and thought processes of a child of 18 months (paragraph 10). The Judge stated that although there had been cases about withdrawal of life support from brain dead or severely brain damaged children and cases about advance approval not to embark upon particular treatment (e.g. Charlotte Wyatt) "*So far as I am aware, no court has yet been asked to approve that, against the will of the child's parents, life support may be withdrawn or discontinued, with the predictable, inevitable and immediate death of a conscious child with sensory awareness and assumed normal cognition and not reliable evidence of any significant brain damage* (paragraph 11).

25. Contrary to the opinions of all the medical professionals, Mr Justice Holman reached the view that it was not in M's best interests for ventilation to be discontinued with the inevitable result that he would die, even taking into account predicted deterioration. He went further and held that it was positively in M's best interests to continue with continuous pressure ventilation and the nursing and medical care that go with it including suctioning and replacement of the tube and physiotherapy and he accepted that he could not and did not make an order to that effect (see paragraphs 89 – 90). Although he accepted that there were certain procedures which should be withheld in his best interests if they were required which included cardio pulmonary resuscitation, ECG monitoring, the administration of intervenous antibiotics and blood sampling. He found that these involved additional pain and as regards CPR also aggressive intervention and little dignity in death (see paragraphs 96 to 98). He emphasises that the declarations were only permissive and should not deter or prevent a doctor or staff from giving any of them if thought fit at the time.

26. As to the balancing of the benefits and burdens, he accepted that M would probably die in about a year and had "*almost relentless discomfort, periods of distress and relatively short periods of pain (deep suctioning). It is indeed a helpless and sad life*" (paragraph 101). However, his life did include benefits:

"*Within those benefits and central to them is my view that on the available evidence I must proceed on the basis that M has age appropriate cognition, and does continue to have a relationship of value to him with family, and does continue to gain other pleasures from touch, sight and sound….*

It is impossible to put a mathematical or any value on the benefits. But they are precious and real and they are the benefits, and only benefits, that M was destined to gain from life. I do not consider that from one day to the next all the routine discomfort, distress and pain that the doctors describe (but not the ones I have now excluded) outweigh those benefits so that I can say that it is in his best interests that those benefits, and life itself, should immediately end. On the contrary, I consider that as his life still has benefits, and is his life, it should be enabled to continue, subject to excluding the treatment I have identified" (paragraphs 101 – 102).

27. The Judge described how he used to smile and react positively to his family when he could and there was not reason to assume that he now derives any less pleasure from their company and the relationship. Given the long times spent with him by members of his family, this was not a short lived or occasional pleasure. He still had what is most probably the single most important source of pleasure and emotion to a small child, "his relationship with his parents and family" (paragraphs 66 to 69).

28. The Judge later emphasised that this was a fact specific decision and was not a policy-based judgment designed to have implications. The critical circumstances were that he had already been and is no ventilation and has already survived to 18 months, is assumed not to be brain damaged and is in a close relationship with his family (paragraph 107). Even though his remaining life was short (probably only about 1 year), the benefits of a good "death" did not outweigh the benefits of survival and life itself. The circumstances and benefits of a "good death" will depend very considerably on the role and involvement of the parents

29. The important points to note from this decision are:

    a) That it was a case where the doctors were seeking to withdraw existing life-sustaining treatment which would result in immediate death. Unlike the Wyatt case, it did not concern the withholding of future new treatments in a crisis situation. Although there is no legal distinction between withholding or withdrawing life support (both are omissions see Bland per Lord Goff at 867 and Lord Lowry at 875) and the best interests test applies in both circumstances, in reality, it is more difficult for a Court

to be persuaded that it is in a child's best interests for existing life support to be withdrawn leading to immediate death. It is arguably easier for a Court to conclude that future treatments are too painful and/or have insufficient prospects of success to be in the child's best interests;

b) M was not brain damaged but a conscious and sentient being assumed to have normal cognitive abilities for a child of his age. It is clear that this was an important factor in Holman J's reasoning. It is to be noted that in the Wyatt case, Hedley J found it probable that Charlotte did not experience any pleasure;

c) Given that M was conscious and sentient, he was able to enjoy and derive pleasure in particular from his relationship with his family which was found to be a close one. In cases concerning profoundly brain damaged children, their ability to derive pleasure and emotion from contact with their loved ones is usually much more limited or non-existent. Holman J referred in his judgment to the case of Re C (A minor) (Medical Treatment) [1998] Lloyd's Law Reports Medical page 1 where approval and permission was given for artificial ventilation to be discontinued to a baby of 3 months who had serious brain damage, could not see or hear and had a very low awareness of anything, if at all;

d) The decision is an example of the application of the very strong presumption that life should be preserved. It was a "helpless and sad" life but the only life that M was ever destined to have. Looking at the situation from M's point of view, there were real benefits and pleasures to his life, even though it might not seem so from the perspective of non-disabled child. The strength of the presumption in shown by the fact that the Judge overruled the opinions of the all the medical professionals in the case. In cases involving conscious and sentient children, it is likely only to be in extreme circumstances where there is evidence of considerable pain and suffering and/or lack of pleasure in life or from family relationships, that a Court will sanction the withdrawal of existing life sustaining treatment leading to immediate death.

30. The same approach has been adopted by the Court when considering the position of incapable adults who are sentient and not in a PVS. The House of Lords in Bland [1993] AC 789 held that it was futile to provide medical treatment, including artificial nutrition and hydration, to a patient with not awareness of self or environment and no prospect of recovery. However, when the Court has been asked to consider whether life-sustaining treatment should be continued for a patient with some awareness of self or environment, it has not permitted the withdrawal and resultant immediate death of the patient.

31. In the case of KH (W Healthcare NHS Trust v KH [2004] EWCA Civ 1324) Mr Justice Coleridge decided that it was in the best interests of a 59 year old woman with multiple sclerosis that the treating doctors re-inserted at percutaneous gastronomy tube (PEG) into KH in order to allow her nutrition to continue on a permanent basis. Her physical condition was such that she required feeding by PEG for five years and she was in a state described as pitiful. She was conscious but not more than that, disorientated in time and place, did not recognise anybody even members of her close family. Her family's position was that her life was intolerable and she was not being allowed to die with dignity. The Judge refused to accede to the requests of the relatives stating that the Court cannot in effect sanction the death by starvation of a patient who is not in a PVS state other than with their clear and informed consent or where their condition is so intolerable as to be beyond doubt. "*This patient is sufficiently conscious and sentient to appreciate and experience the effects of death by starvation over weeks…and so I cannot say that life prolonging treatment (in this case feeding via the PEG) would provide no benefit*." He saw death by this route might be even less dignified than the death she will more probably face in the future.

32. The Judge's decision was upheld by the Court of Appeal. This was not a case where KH was said to be gaining positive benefits or pleasure from her life. However, the benefit lay in avoiding death by starvation which she was sufficiently conscious and sentient to experience. The Judge was in this case supported by the opinions of all medical professionals. It is accordingly only in situations which can truly be described as "intolerable" where a Court is likely to find that the withdrawal of life-sustaining treatment is in the best interests of someone who is not in a PVS and has some degree of awareness of himself and his environment.

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