Dr. Anne Slowther
Director
UK Clinical Ethics Network Support Programme

UK Clinical Ethics Network

History

The UK Clinical Ethics Network was established in 2001 following the publication of a Report on Clinical Ethics Support in the UK (funded by the Nuffield Trust) which identified twenty clinical ethics committees in NHS Trusts in the UK. In the past six years the Network has expanded with the development of clinical ethics committees in other NHS Trusts currently there are
70 ethics committees in NHS Acute Trusts
10 CECS in Mental Health Trusts
2 CECs in Primary Care Trusts

The role of the Network is to:

- Offer support and advice to developing and established clinical ethics groups
- Provide networking facilities including a newsletter, electronic mailing and network website
- Facilitate training for members of clinical ethics groups (the Network has recently produced a discussion document on core competencies required for members of clinical ethic committees).
- Support regional initiatives
- Organise an annual conference
- Produce a database of useful and relevant information for clinical ethics groups
- Establish links with clinical ethics groups internationally

Clinical Ethics Support Project

The Clinical Ethics Support Project is part of the Ethox Centre's core activities and has been running since 2001. It is led by Dr Anne Slowther and has received funding from the Department of Health, the Institute of Medical Ethics and the Ethox Foundation (which is its major funder). The project's aim is to develop clinical ethics support within the UK through a series of complementary approaches. These include:

- Providing administrative and academic support to the UK Clinical Ethics Network.
- Developing and maintaining the Clinical Ethics Network website (www.ethics-network.org.uk), a publicly accessible source of information and educational resources on clinical ethics.
- Developing and running educational workshops and on-line resources for members of clinical ethics committees.
- Producing a Network newsletter.
- Liaising with national organisations to promote dialogue on ethical issues relating to patient care between these organisations and health professionals in practice through clinical ethics committees.
- Provision of an electronic response service to queries form CECs and facilitation of shared experience between CECs.

第３章－３

WITHDRAWING MEDICAL TREATMENT
－THE UNITED KINGDOM POSITION

（治療の中止　―　英国の見解）

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Withdrawing Medical treatment-the united kingdom position

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マクリーン教授紹介

今回、グラスゴー大学シーラ・マクリーン教授に本研究班のため、特別に寄稿頂いた。マクリーン教授は医療における法・倫理分野国際弁護士連盟議長であると共にグラスゴー大学医療・法・倫理学の長として数々の研究を行っている他、WHO ヨーロッパ評議会顧問として活動してきた。現在はエジンバラ王立内科医師会等の名誉会員でもあり、医療法に関する著書も多数ある。今回は終末期における治療の中止に関して法的・倫理的課題について、英国事例をもとに執筆頂いた。

序文（訳）：医療の中でも終末期に関わる医療、特に医療従事者が治療中止の決定に直面する現場ほど議論を呼び、かつ慎重を要するものはない。この問題は如何様な状況下でも起き得るが、まずは定義が必要である。中止が目的の医療とは何なのか？英国では、以下に述べるように、貴族院は栄養と水分の人工補給は医療であるとしている。即ち、その医療の提供、或いは中止は職務上の規則として、当然ながら法の遵守の下での医者の判断に委ねられている。人間性の諸相から栄養と水分の人工補給は医療と見なすべきでないと著者は常に論じてきているが、目下のところ英国裁判所はこれを医療行為と見なしていることは明白であり、我々はこれに則って行動せねばならない…。

本論：（概略）遷延性植物またはそれに近い状態の患者の治療中止の判決、作為不作為に関る議論と裁判所の対応、治療の差し控えと中止の区別に関する議論、患者にとっての最善の利益の社会的判断について論ずるとともに、法整備の可能性と実用性、事前指示書の持つ意味、児童における意思決定の司法判断（治療に関して医療従事者と両親、あるいは保護者の間で語彙が見られない場合など）について述べられている。

結論（訳）：（子供と精神障害者にかかる法律を除けば）裁判官は治療中止の決定の合法性を予見して法を解釈してきており、それが一般的であると言える。ブランド訴訟の裁判官の中には立法による介入の必要性を説いた人たちもいたが、判決後二十年余りが経過してもその動きはない。この分野での適切で適用し得る法律の立案は極めて難しいことではあるが、このままでは判例は多数の可変要素の対象となる。まず、栄養と水分の人工補給は医療の範疇なのかどうかの問題がある。これは（患者が）成人でも子供でも決定に関係する。次に、法は最善の利益という、どちらかと言えば無意味なほど漠然としていて簡単に反論できる余地があることを重視し、特に裁判所が（患者にとっての）最善の利益については医師たちの見解を受け容れる傾向がある点は（問題）である。欧州人権条約が英国法に採択されてもなお裁判官がこの司法見解に重きを置いている。この見解が維持されるべきかどうかは常に論点になるだろう。それだけではない。（イングランドとウエールズでは）治療中止の認許を裁判所に求めるのはPVS患者の場合のみである。他のケースでの治療中止の決定は病院で一連の手順として行われ、患者の医療者と親族の間で意見不一致がない限り、（判例と）同様な徹底調査の対象にならない。このように、死が結果となる多くの決定は裁判所の（全く無効とは言えないが）有効性のない決定手順上でも報告されずにある。こうなると、全く法整備がない方が人権法理学はより安全措置を強化する方向になるのかもしれないと仮定したくなるが、現実にはそういうことにはなっていない。

Introduction

Few areas of medical practice are as contentious and sensitive as those which arise at or towards the end of a life, particularly when healthcare professionals are confronted with a situation where treatment withdrawal is contemplated. Such problems can arise in a variety of circumstances, which for ease will be dealt with separately in what follows. First, however, it is necessary to define our terms. Just what is medical treatment for these purposes? In the United Kingdom, as will be seen, the House of Lords has accepted that assisted nutrition and hydration amounts to medical treatment, thus leaving decisions about its provision or removal firmly in the hands of doctors acting within their professional constraints and, of course, the law. I have argued elsewhere that assisted nutrition and hydration should be separated from medical treatment in the interests of humanity,[1] but for present purposes it is clear that courts in the United Kingdom will regard it as equivalent to medical treatment and we must proceed on this basis.

Patients in a Permanent Vegetative State (PVS)[2]

The first case heard in UK courts concerning the management of a patient in PVS was the case of Airedale NHS Trust v Bland. [3] The case concerned a young man who was diagnosed as being in PVS some three years after he had received traumatic injury in a football stadium incident. The medical team caring for Anthony Bland, supported by his parents, petitioned the court to allow discontinuation of his nasogastric feeding as there was no hope for recovery; no prospect of Anthony ever regaining consciousness. It should be said that, although some commentators have expressed doubts about the certainty of the diagnosis of PVS,[4] evidence in

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[1] McLean, S.A.M., 'From Bland to Burke: The Law and Politics of Assisted Nutrition and Hydration', in McLean, S.A.M. (ed) *First Do No Harm: Law, Ethics and Healthcare*, Aldershot, Ashgate, 2006, 431-446

[2] for further discussion, see McLean, S.A.M., 'Permanent vegetative state: The legal position', Neuropsychological Rehabilitation (Special Issue), Volume 15, Issue 3/4 , July/September 2005, 237-250

[3] (1993) 12 BMLR 64

[4] for a full discussion of PVS see Mason, J.K. and Laurie, G.T., *Mason and McCall Smith's Law and Medical Ethics*, (7th Ed), Oxford University Press, 2005, chapter 16

this case that he was indeed in that condition was unequivocal and not disputed.[5] Given the importance of the facts under consideration, and the decision being sought, the case went all the way to the House of Lords, which is the UK's highest civil court.

The question to be resolved by the courts was whether or not it could ever be lawful to remove the means for survival from a patient. Both euthanasia and assisted suicide are criminal offences in the United Kingdom, so a central issue was whether or not withdrawing feeding and hydration was able to be distinguished from criminal behaviour. Although the House of Lords concluded that it would be lawful to withdraw the assisted nutrition and hydration, Their Lordships took a variety of routes to reach that decision and these are worth considering.

Lord Keith attended to the argument put forward that assisted nutrition and hydration did not amount to medical treatment, but 'simply feeding indistinguishable from feeding by normal means.'[6] This, however, he found unpersuasive. Rather, he concluded, we should look at the entire regime that was keeping Anthony Bland alive which included, but was not confined to, assisted nutrition and hydration. While accepting that it would normally be unacceptable for healthcare professionals to fail to provide nutrition and hydration, in this case there was 'a large body of informed and responsible medical opinion….to the effect that no benefit at all would be conferred by continuance.'[7] He concluded, therefore, that the decision about its provision was a matter for the healthcare professionals looking after Anthony.

Lord Goff, while accepting that Anthony was legally alive, nonetheless described his condition as a 'living death'.[8] He noted that although the principle of the sanctity of life was fundamental, it was not absolute. In this case, he argued, 'there is no absolute rule that the patient's life must be prolonged….regardless of the circumstances.'[9] Nonetheless, he was at pains to draw a distinction between withdrawing treatment and administering a lethal injection. Although the outcome would be the same – the death of the patient – for Lord Goff the two were different classes of behaviour. The first could lawfully form a part of medical judgement; the latter was always a crime. In order to justify this difference, Lord Goff accepted that withdrawing

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[5] Indeed, Lord Keith in the House of Lords described Anthony's brain as having 'degenerated into a mass of watery fluid' – see, *Airedale NHS Trust v Bland, supra cit*, at p. 106

[6] at p. 106

[7] at p. 107

[8] at p. 111

[9] id

treatment amounted at an omission, whereas administering a lethal injection was an act. This is an important distinction since it is a general rule that we are culpable for our acts but not our omissions. However, it is arguably also a distinction without a difference when a duty of care exists between the parties concerned. Thus, it was necessary to consider whether or not Anthony's doctors could reasonably be held to owe him a duty to maintain his existence. This decision rests in part on an assessment of what is in the patient's best interests; a test which was described as 'broad and flexible'.[10] In Anthony's case, 'the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged…'.[11] For Lord Goff this question was answered in the negative. Indeed doubt was expressed about whether or not it would be lawful to continue to provide treatment to Anthony in the absence of his consent.

Lord Lowry agreed with the analysis of his colleagues that withdrawing treatment was indistinguishable from not providing it in the first place. Failure to agree to this, he argued, would be perverse since '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.'[12] Moreover, Lord Lowry expressed the view that:

> Even though the intention to bring about the patient's death is there, there is no proposed guilty act because, if it is not in the interests of an insentient patient to continue the life-supporting care and treatment, the doctor would be acting unlawfully if he continued the care and treatment and would perform no guilty act by discontinuing.[13]

Perhaps the most interesting and thoughtful judgements were delivered by Lords Browne-Wilkinson and Mustill; thoughtful, in that each of them took a broader view of the decision they were being asked to make. Lord Browne-Wilkinson, for example, clearly appreciated that 'behind the questions of law lie moral, ethical, medical and practical issues of fundamental importance to society.'[14] This decision was, therefore, bigger than a straightforward legal one and engaged with a variety of other aspects of society. In addition, he

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[10] per Lord Goff at p. 121

[11] per Lord Goff at p. 115

[12] at p. 121

[13] at p. 123

[14] at p. 124

questioned whether it was for judges or for Parliament to 'reach its decisions on the underlying and practical problems…',[15] concluding that it was for Parliament. Nonetheless, the House of Lords was obliged to reach a conclusion in the absence of relevant legislation. He also asked how it could be acceptable to dehydrate someone to death when it would not be so to help him die quickly by, for example, a lethal injection, particularly since it was clear that 'the whole purpose of stopping artificial feeding is to bring about the death of Anthony Bland'?[16]

Lord Browne-Wilkinson was, however, persuaded that failing to provide continued nutrition and hydration was an omission rather than an act. Indeed, he argued that even if the removal of the feeding tube could be considered an act, it could not be regarded as a positive act bringing about death as the 'tube itself, without the food being supplied through it, does nothing.'[17] He also concluded that, if it was not in Anthony's best interests to continue to be fed, then his doctors could not lawfully continue to treat him without his consent. He concluded, therefore, that '[u]nless the doctor has reached the affirmative conclusion that it is in the patient's best interest to continue the invasive care, such care must cease.'[18] Given his concern about the proper role for the courts in such cases, he resorted to existing principles, derived from the case of Bolam v Friern Hospital Management Committee,[19] and concluded that 'the court's only concern will be to be satisfied that the doctor's decision to discontinue is in accordance with a respectable body of medical opinion and that it is reasonable.'[20]

Lord Mustill also expressed his concern about the decision the court was being asked to reach, because the 'authority of the state, through the medium of the court, is being invoked to permit one group of its citizens to terminate the life of another.'[21] The case, he declared, raised 'acute problems of ethics',[22] but also was 'exceptionally difficult in point of law…'.[23] Interestingly, however, Lord Mustill was not comfortable taking the route which his colleagues had adopted; namely, basing his judgement on the distinction between acts and omissions. Indeed he

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[15] *id*

[16] at p. 127

[17] at p. 128

[18] at p. 129

[19] [1957] 2 All ER 118 The test derived from this case is referred to as the *Bolam Test*

[20] at p. 130

[21] at p. 131

[22] *id*

[23] *id*

expressed his 'acute unease'[24] about adopting this route because of 'the sensation that however much the terminologies may differ, the ethical status of the two courses of action is for all relevant purposes indistinguishable.'[25] Nor was he persuaded by the argument that it was not in Anthony Bland's best interests to continue the provision of nutrition and hydration. For Lord Mustill, while what the doctors proposed would alleviate the distress of his parents and caregivers, it made no sense to suggest that Anthony had any interest in this happening. As he said, '[t]he distressing truth which must not be shirked is that the proposed conduct is not in the best interests of Anthony Bland, for he has no best interests of any kind.'[26] Although more critical than the other judges of the question before the court, Lord Mustill was ultimately persuaded as follows:

> Now that the time has come when Anthony Bland has no further interest in being kept alive, the necessity to do so, created by his inability to make a choice, has gone; and the justification for the invasive care and treatment together with the duty to provide it have also gone. Absent a duty, the omission to perform what had previously been a duty will no longer be a breach of the criminal law.[27]

From this somewhat lengthy discussion of the House of Lords judgement it is clear that the ultimate conclusion that assisted nutrition and hydration could be withdrawn from Anthony Bland was reached by a variety of routes, not all of them obviously compatible with each other. One thing, however, on which their Lordships were agreed was that subsequent decisions of this sort would require court authority. Only one year later, the courts were again invited to deal with a similar case, although in this case the hospital took advantage of the fact that a feeding tube had become dislodged and the court granted permission not to reconnect it.[28]

In Scotland, the first case to be presented to the courts was Law Hospital NHS Trust v Lord Advocate.[29] This case involved a woman, Janet Johnstone, who had lapsed into a PVS following an unsuccessful suicide attempt. In similar vein to the courts in the Bland case, the Inner House of the Court of Session concluded that its decision should rest on the issue of best

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[24] at p. 132

[25] *id*

[26] at p. 141

[27] at p. 142

[28] *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403

[29] 1996 SLT 848

interests; of whether or not any benefit could be obtained from continuing assisted nutrition and hydration. However, the Scottish court went further than its English counterpart in indicating that court authority was not inevitably needed when such decisions are to be taken. Following this, the Lord Advocate (Scotland's senior prosecuting officer) declared that no prosecution would follow if a doctor first obtained the authority of a court before discontinuing treatment, although equally he did not state that prosecution would necessarily follow should such approval not be obtained. This somewhat ambivalent position has been criticised by Mason and Laurie who argue that the 'situation has now arisen where the doctor may be required to second guess the criminal law – a position that is hardly desirable.'[30] Not only is this potentially problematic, it may also run counter to Article 6 of the European Convention of Human Rights which was incorporated into UK law by the Human Rights Act 1998. Article 6 guarantees the right to a fair hearing, and arguably in the absence of the impartial scrutiny of a court, this is denied to patients in PVS. Nonetheless, in the leading case in which the human rights issue was raised (albeit not Article 6), the court held that discontinuation of assisted nutrition and hydration was indeed compatible with the terms of the Convention.

In NHS Trust A v Mrs M, NHS Trust B v Mrs H,[31] the court was invited to test the lawfulness of withdrawing assisted nutrition and hydration from two patients in PVS against a number of Convention Articles, specifically Article 2 (the right to life), Article 3 (prohibition of cruel and inhuman treatment) and Article 8 (the right to respect for private and family life). In this case, the court declined to find that any of these rights had been breached. In respect of Article 2, the judge was of the opinion that 'the phrase 'deprivation of life' must import a deliberate act, as opposed to an omission….'.[32] Very much in line with the judgements in Bland, the judge in this case held to the distinction between act and omission which Lord Mustill had described as leading to a position where the law was 'both morally and intellectually misshapen.'[33] As for Article 3, the judge held that for someone to be subject to cruel and inhuman treatment they must be able to experience it.[34] Clearly, patients in PVS were unable to do so; therefore, their Article 3 right was not breached. In terms of Article 8, the court held that the right to autonomy which is protected by this Article would in fact be breached by continuing unconsented to

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[30] *Mason and McCall Smith's Law and Medical Ethics, supra cit*, at p. 590, para 16.128

[31] (2001) 58 BMLR 87

[32] at p. 95

[33] *Airedale NHS Trust v Bland, supra cit*, at p. 132

[34] interestingly, this conclusion was challenged by Mr Justice Munby in the case of *R (on the application of Burke) v General Medical Council* (2004) 79 BMLR 126

treatment. Mason and Laurie challenge this conclusion, arguing that '[t]he error lies in the failure to appreciate that it is respect for the human being that is required, not only (or necessarily) respect for her 'right to choose'.'[35]

Patients in 'Near' PVS

Whatever one's views about the reasoning which led to the deaths of Anthony Bland, Janet Johnstone and others, there is no doubt that many believed this to be the desirable outcome. Moreover, arguably the English requirement that cases should always be brought before a court was designed to offer an additional layer of protection for the incapacitated individual. However, subsequent cases suggest that this has not been the case. Indeed, Mason and Laurie suggest that 'one cannot avoid the impression that the precedents laid down in their cases are being extended to include less well defined conditions than was intended at the time.'[36]

That this is the case seems clear from one subsequent case. In Re G (adult incompetent: withdrawal of treatment),[37] the court was asked to consider authorising the withdrawal of nutrition and hydration from a woman who had suffered serious anoxic brain damage, was not in PVS, but was said to have no prospect of recovery. Her family wanted her to be allowed to die by removing her assisted nutrition and hydration and also claimed that she would not want to continue existing in her current circumstances. Despite her inability to express an opinion, Dame Elizabeth Butler-Sloss granted the application authorising removal of sustenance.

Mason and Laurie regard this decision 'with a degree of concern....'[38] because it depends so heavily on medical opinion rather than on a 'principled approach to individualised human and patients' rights....'.[39] yet, as we have seen, such dependence on medical assessment is inherent in the use of the Bolam Test to adjudicate on matters of life and death. In other words, using a responsible medical opinion to answer the question as to whether or not assisted nutrition and hydration can lawfully be withdrawn places too much emphasis on doctors' views about the point of continuing a patient's existence and gives insufficient weight to that patient's potential right to life.

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[35] *Mason and McCall Smith's Law and Medical Ethics, supra cit*, at p. 587, para 16.117

[36] *Mason and McCall Smith's Law and Medical Ethics, supra cit*, at p. 595, para 16.141

[37] (2001) 65 BMLR 6

[38] *Mason and McCall Smith's Law and Medical Ethics, supra cit*, at p. 587, para 16.120

[39] *id*

One additional case, however, seems at odds with this judgement. In the case of W Healthcare NHS Trust v. H and others, [40] the family of a woman who had been incapacitated for many years gave evidence that their belief was that she would not wish the tube that was delivering nutrition and hydration to be reinserted after it had fallen out. In the Court of Appeal, Brooke LJ declared that the judge in the lower court had been:

> ....correct in finding that there was not an advance directive which was sufficiently clear to amount to a direction that she preferred to be deprived of food and drink for a period of time which would lead to her death in all circumstances. There is no evidence that she was aware of the nature of this choice, or the unpleasantness or otherwise of death by starvation, and it would be departing from established principles of English law if one was to hold that there was an advance directive which was established and relevant in the circumstances in the present case, despite the very strong expression of her wishes which came through in the evidence.[41]

As we will see below, the position of advance statements has now been clarified, at least when they are executed within the terms of the Mental Capacity Act 2005. However, when deciding on what is in the best interests of a patient who has not left clear directions behind, these cases seem to pose as many questions as they answer. However, it is of interest that in the latter case the medical staff caring for the patient wanted the tube reinstated, just as those in Re G took the opposite position. It may well be, then, that yet again the decision as to what was in the patient's best interests was dominated by medical opinion.

A Legislative Response?

The treatment of incapacitated patients has recently been the subject of legislative review. In Scotland, the Adults with Incapacity (Scotland) Act 2000 replaced the previous legal framework. However, this does not affect the question of withdrawing assisted nutrition and hydration, since the legislation is designed to facilitate the provision of treatment, not its withdrawal. The Act authorises treatment of an incapacitated adult only if 'the person responsible for authorising or effecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without the intervention.'[42] Despite the fact that the Act

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[40] [2004] EWCA Civ 1324

[41] at para 21

[42] s.1(2)

is concerned with providing treatment, it has been argued that 'a jurisprudence relating to negative treatment will develop around this recent legislation....'[43] since a second opinion, and even ultimately a court decision, is available should a doctor decide to continue or withdraw treatment.

In England and Wales, the Mental Capacity Act 2005 now covers treatment of people who are mentally incompetent. A person lacks capacity if 'at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'[44] The Act requires that decisions taken on behalf of such a person must be made in his/her best interests.[45]

Advance Directives

One way of resolving problems concerning how best to identify the appropriate course of action in treatment withdrawal cases would, of course, be to identify what the patient him or her self would want. Although in many cases, such as those referred to above, such information may be unobtainable, some patients will have made an advance directive[46] which explains the circumstances in which they would not wish treatment to be imposed or continued. Although historically there was some doubt about the precise effect of such directives, it was widely assumed that a directive which was clear and applicable to the circumstances should be respected by healthcare professionals. The British Medical Association proposed that the following could be concluded from case law:

- An advance refusal of treatment is legally binding if:
    - the patient is an adult and was competent when the directive was made and
    - the patient has been offered sufficient, accurate information to make an informed decision and
    - the circumstances that have arisen are those that were envisaged by the patient and

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[43] *Mason and McCall Smith's Law and Medical Ethics, supra cit*, at p.591, para 16.129

[44] s. 2(1)

[45] s.4

[46] also referred to as a living will or advance statement

- the patient was not subjected to undue influence in making the decision.[47]

These conclusions could be derived at that time in large part from the case of Re C.[48] This case was essentially about whether or not a man with a clinical diagnosis of paranoid schizophrenia could legally refuse life-sustaining treatment, but the judgement went beyond this. C also asked for, and was granted by the court, a prohibition on doctors imposing the treatment in the future should he become incompetent; in other words, a court endorsed advance directive. Also, in the case of AK (adult patient)(medical treatment: consent)[49] a young man who was suffering from motor neurone disease made it known that he wished treatment to be withdrawn 2 weeks after he finally lost the ability to communicate and this was upheld by the court. The terms of the Mental Capacity Act 2005 now make it clear that advance directives do carry legal weight so long as they are written, signed, witnessed and applicable to the circumstances.[50] The legislation also recognises the validity of an advance refusal of life-sustaining treatment if the person making the directive has specifically referred to this.[51]

In Scotland, since the relevant legislation did not deal directly with advance treatment refusals, the common law position maintains. That is, it is likely, but not inevitable, that a competently executed advance directive will be honoured, even when its effect is to expedite the death of the patient. It should be noted in passing that advance directives can only cover refusal of treatment; they cannot force doctors to provide treatment which they regard as futile or inappropriate.[52]

The Case of Children

When a child is very young (and not, therefore, competent) decisions about whether or not treatment should be withheld or withdrawn will obviously require third party involvement. The most notorious of such cases in the United Kingdom was the case of R v Arthur.[53] In this case, a child born with apparently uncomplicated Down's Syndrome was rejected by his parents who

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[47] *Medical Ethics Today: The BMA's handbook of ethics and law*, (2nd Ed), London, BMJ Books, 2004, at p. 114

[48] *Re C (adult: refusal of medical treatment)* (1993) 15 BMLR 77

[49] (2001) 58 BMLR 151

[50] see Mental Capacity Act 2005 ss 24-26

[51] s. 25(5)

[52] *R (on the application of Burke) v General Medical Council, supra cit.*

[53] (1981) 12 BMLR 1

did not want him to survive. The consultant, Dr Leonard Arthur, prescribed 'nursing care only' and the child was not nourished or hydrated (and was also given a powerful tranquilliser). Dr Arthur was originally charged with murder, but this was reduced to attempted murder when evidence was led that the child suffered from a range of other problems which could have contributed to his death. Dr Arthur was acquitted following directions from the judge and evidence from a number of eminent paediatricians that they would have done the same as Dr Arthur. This case is not now regarded as good law.[54]

The Arthur case was preceded in the same year by a case heard in the civil rather than the criminal courts. In the case of Re B (a minor),[55] the parents of a child with Down's Syndrome refused their permission for relatively minor surgery to remove an intestinal blockage. In the event, Templeman LJ said that the test was whether or not the child's life would be 'demonstrably so awful' that she should be condemned to die.[56] In this case, the balance was in favour of treatment. A number of other cases followed Re B, but it still seems broadly to represent the legal position.[57]

One recent case in particular points to the difficulties involved in making treatment decisions in this situation, particularly – as is generally the case – when there is a disagreement between healthcare professionals and parents/guardians. In the case of Charlotte Wyatt,[58] the baby in question was profoundly disabled and not expected to survive. Although this case concerned withholding rather than withdrawing treatment it is of interest for what it tells us about the law's approach. Consistently, the court involved refused to endorse Charlotte's parents' opinion that she should receive all available treatment, preferring instead the prognosis of her doctors in whose view the application of invasive and possibly painful or uncomfortable ventilation would not serve her best interests. Charlotte's parents repeatedly petitioned the court to insist on ventilation should she require it, as they believed Charlotte was showing signs of improvement.

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[54] for further discussion see McLean, S.A.M. and Elliston, S., 'Death, Decision Making and the Law', Juridical Review 2004, Part 3, 265-293

[55] (1981) [1990] 3 All ER 927

[56] at p. 931

[57] see, for example, *Re J (a minor)(wardship: medical treatment)* (1990) 6 BMLR 25; *Re C (a minor)(wardship: medical treatment)* [1989] 2 All ER 782; *Re C (a minor)* (1997) 40 BMLR 31; *A National health Service Trust v D* (2000) 55 BMLR 19

[58] this case reached court on a number of occasions. See *Portsmouth NHS Trust v Wyatt* [2004] 1 and *Portsmouth NHS Trust v Wyatt* [2005] EWHC 117

Indeed, in one hearing of the case, Hedley, J. (who has heard each of the cases raised by the parents) noted that doctors had changed their position somewhat and indicated that there could conceivably be circumstances in which they might decide that ventilation was appropriate.[59] Despite the doctors' gloomy prognosis, Charlotte continues to survive and is able to be discharged from hospital.

In the case of older children, differences emerge between the various jurisdictions in the United Kingdom. In England and Wales, a child reaches full maturity at the age of 18. Between the ages of 16 and 18, treatment decisions are subject to the terms of s. 8 of the Family Law Reform Act 1969 which on its face appears to give these mature children the same rights as adults to agree to or reject medical treatment. However, s 8(3) of the Act also says that 'Nothing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted.' Cases interpreting this section have held that this must mean that, where a child refuses treatment, his/her refusal can be overridden by parents or the courts.[60] In Scotland, a child reaches full maturity at the age of 16,[61] so that their decisions are given full force of law. Under the age of 16 in both jurisdictions a child may be deemed to be competent, following the case of Gillick v West Norfolk and Wisbech Area Health Authority[62] but clearly this is limited by the nature of the decision being taken, at least in England and Wales. For example, in the case of Re M (child: refusal of medical treatment)[63] a fifteen year old girl refused to accept a heart transplant. Her decision was not endorsed by the court which believed the surgery to be in her best interests; a decision which has been said to 'represent the outermost reaches of acceptable paternalistic practices.'[64] In Scotland, in terms of the Age of Legal Capacity (Scotland) Act 1991, a young person of 16 years personally enter into any legal transaction,[65] which would include decisions about medical and dental treatments or procedures.

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[59] (2005) 87 BMLR 183

[60] e, for example, *Re R* (1991) 7 BMLR 147; *Re W (a minor)(medical treatment)* (1992) 9 BMLR 22

[61] Age of Legal Capacity (Scotland) Act 1991

[62] [1985] 3 All ER 402 (HL)

[63] (2000) 52 BMLR 124

[64] *Mason and McCall Smith's law and Medical Ethics, supra cit*, at p. 373, para 10.54

[65] s.1(1)(b)

Conclusion

It can be seen that (with the exception of legislation concerning children and the mentally incapacitated) it is common or judge made law that predicts the lawfulness of withdrawal of treatment decisions. Although some of the judges in the Bland court called for legislative intervention, this has not occurred some two decades after the case was decided. While drafting appropriate and applicable legislation in this area would undoubtedly be difficult, this leaves such decisions subject to a number of variables. First is the categorisation of assisted nutrition and hydration as medical treatment, which permeates all decisions whether about adults or children. Second is the law's emphasis on the best interests test which is open to the objection that it is so vague as to be relatively meaningless, particularly when one considers the final point; that courts have tended to accept doctors' views as to what amounts to best interests. Not even the incorporation of the European Convention on Human Rights into UK law has caused judges to deviate from that position. Whether this position can be maintained indefinitely is moot. Moreover, the requirement (in England and Wales) that withdrawal of treatment requires court authority applies only to patients in PVS. Other decisions about withdrawing treatment are routinely made in hospitals but are not subject to the same scrutiny unless there is a dispute between those caring for the patient and relatives. Thus, many decisions which result in death are not informed even by the (arguably) flawed decision-making of the courts. It might have been tempting to presume that human rights jurisprudence would have led to a tightening of safeguards where no legislative regime is in place, but this does not seem yet to have occurred.

第３章－４

Ethical Framework for End of Life Decisions in Intensive Care In The UK.

（集中治療における終末期医療上の倫理的枠組み－英国の場合）

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（概要）

英国では医療上での父権主義は過去のものとなり、明確な倫理的枠組みによる考え方が一般的となってきている。これは四つの原則、自主性（autonomy）、無害性(Non-maleficence)、有益性（beneficence ）、公正性（justice）から成り立つ。総ての決定はこの四原則がバランス良く為されなくてはならないが、自主性こそが最優先原則であり、これは「患者の同意」の重要性を反映している。治療行為を実施するかどうかは臨床医側の決断であるが、自主性ある患者がその治療に同意するか拒否するか判断できるようにしておかなければならない。それ故、治療のリスクと利益について患者が情報・知識を有していることを確実にしておくことが肝要である。治療を拒否したことが原因となるあらゆる被害は患者の責任となる。患者に意思決定能力が欠如している場合、つまり救急治療の際や、病気の経過や治療によって患者が意思決定能力を喪失した事態では治療に関して事前に患者の同意を得る義務は流動的になる。

「患者の同意」と「患者の最善の利益」、また治療の「必要性」、救急現場における治療の差し控えと中止に関る倫理的原則、ダブル・エフェクトの原則（苦痛の緩和などの有益な作用が同時に有害な副作用（呼吸抑制など）をもたらすことなど)、倫理委員会と医療従事者の啓蒙、司法や宗教との関連、集中医療開始時の判断の根拠と治療効果がみられない場合の倫理的ジレンマについて、生存見込みのない患者を３段階に分類した対応方法について述べる。

ETHICAL FRAMEWORK FOR END OF LIFE DECISIONS IN INTENSIVE CARE IN THE UK.

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In the UK there has been a move away from a paternalistic model of medicine. A clearer ethical framework has now evolved. It is accepted that four main ethical principles currently guide medical practice. These are autonomy, non-maleficence, beneficence and justice (1). *Autonomy* is the principle of self-determination. This is equates to the right to consent or refuse treatment. A doctor also has autonomy and cannot be compelled to provide treatment not clinically indicated. Nor can a doctor be obliged to provide treatment to which he has a moral or religious objection.
Non-maleficence signifies avoiding doing harm. It is originally known as "primum non nocere" or "first do no harm". This principle accepts that many beneficial therapies also have unwanted harmful side effects. Non-maleficence means that the potential harm of any therapy should be less than its potential benefit. *Beneficence* is the intention to do good. This is principle is secondary to non-maleficence in that the primary aim must be to minimise harm. *Justice* refers to the equitable distribution of healthcare resources. There is no consensus on how this should be achieved. Different methods have been proposed such as needs based, utilitarian (maximising benefit), egalitarian (equal share to each person). Unfortunately each of these methods of equitable distribution can discriminate against particular groups of patients. For example, the elderly or those with chronic disease may be at a disadvantage in an egalitarian system (2).

Although all decisions should attempt to balance all 4 principles, autonomy is the leading principle. This is reflected in the importance placed on the patient's consent. The decision to provide a treatment lies with the clinician. The autonomous patient is then able to consent to or refuse. It is therefore important to ensure that the patient is informed of the risks and benefits of treatments. Any harm that occurs because of a refusal is the responsibility of the patient. The obligation to obtain a patient's consent in advance of any therapy changes when the patient lacks mental capacity. This may occur during emergency treatment or where the disease process or treatment renders the patient incapacitated.

Consent, best interests and necessity

It is common for critically ill patients to lack the ability to give or withhold consent. This may be due to the disease process or its treatment. Under these circumstances it is common practice to discuss the various treatment options with the family of the patient. In some jurisdictions the relatives may actually have the authority to consent on behalf of an adult patient (see later). In the United Kingdom relatives may give assent, which means that they agree to the proposed treatment but it is not a legal requirement. The discussions with relatives are of most value because they may help to give an indication about the patient's own attitudes and values concerning treatment.

When the views of the patients are known then they should be used to guide decision making. It is common that the patient's precise wishes are unknown and therefore decisions must then be made on the basis "best interests". A person's "best interests" are difficult to define. The concept is based on the responsibility of parents to act in the best interests of their children. It was assumed that parents do, generally, act in their children's best interests and that the state should not interfere unless the parents actions were to have serious adverse consequences for the child. It was because no best interests to the patient could be demonstrated that the practice of of electively ventilating severely head injured patients until they became brain stem dead, so increasing the availability of organs for transplantation, was not allowed to continue. This was deemed illegal because there was no benefit to the patient from the ICU admission (3).

In an emergency situation doctors are allowed to commence treatment on the basis of necessity. This allows the initial treatment to save a life or limb but does not give the authority to undertake non life saving treatment. This is based on the reasonable assumption that most people would wish to have life saving treatment.

Ethical principles around withholding and withdrawing

With the advances in critical care and medicine it has come accepted that maintaining life is not the sole aim.

> *'the prolongation of life ...does not mean a mere suspension of the act of dying, but contemplates at the very least, a remission of the symptoms enabling return towards a normal, functioning, integrated existence' (4).*

Medical futility has been used to justify stopping or withholding medical therapies that can