

Advance directives, best interests and clinical judgement: shifting sands at the end of life

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ABSTRACT – End-of-life issues for clinical practice present complex ethical, moral and legal dilemmas that have been heightened by advances in medical technology enabling a dying patient to be kept alive for longer than ever before. Respect for patient autonomy and dignity are fundamental ethical components that engage in end-of-life decision-making. A mentally competent individual has the absolute right to refuse medical treatment for any reason and a valid advance directive for the refusal of treatment is binding in the event that the person loses capacity. In the incompetent patient, the withdrawal of life-sustaining treatment is based on the ‘best interests’ test, developed on a model that takes into account the welfare considerations of the person concerned. It is questioned whether the test should be more subjectively based, and accord greater weight to the wishes that might have been in the mind of the incompetent person approaching the end of life. The Mental Capacity Act 2005 (expected to come into force in 2007) provides a statutory framework for the law relating to advance directives, capacity and best interests. This paper examines contemporary issues surrounding end-of-life decision-making against the backdrop of the existing and proposed legal framework.

KEY WORDS: advance directives, best interests, competence, incompetence, Mental Capacity Act 2005, withholding and withdrawing life-supporting treatment

Recent advances in medical technology enable a dying patient to be kept alive for longer than ever before. Such developments have raised the need for health professionals to respect patient choice with regard to their right of autonomy. Whereas in the past, patients nearing the end of their lives might have been content with allowing doctors to make decisions on their behalf, this is now not the case. An unquestioning acceptance of a doctor's clinical judgement of a patient's best interests is no longer the norm, and can be challenged on the basis of human rights. This paper examines contemporary issues surrounding advance directives, against a backdrop

of the existing legal framework. The recent case of *Burke* in particular (both at first instance¹ and in the Court of Appeal²) has increased the media debate about end-of-life decision-making.^{3,4}

Respect for patient autonomy is a fundamental aspect of professionalism in the doctor–patient relationship and represents a key principle of medical law. Together with the sanctity of life and the need to uphold the dignity of the individual, it forms part of a cluster of ethical principles that elevate the value of human life and is the basis for the application of law to medical practice.⁵ As a matter of law, at any given time, adults are either competent or incompetent in relation to decision-making about their medical care. A competent adult has mental capacity and the ability to communicate, whereas an incompetent adult either permanently or temporarily lacks one or both of these components.⁶ The test used to determine capacity in law is whether the individual has the ability to understand, retain, believe, evaluate, weigh and use information that is relevant to a medical intervention or its withdrawal. This test has been legally endorsed on several occasions^{7–9} and these components of capacity have now been codified in the Mental Capacity Act 2005 (yet to be enforced).

Advance directives

A competent patient has the absolute right to refuse medical treatment for any reason – be it rational, irrational or for no reason at all – even though such a decision may lead to their untimely death.¹⁰ Likewise, an advance directive, or ‘living will’, that represents a patient's wish to refuse treatment, made at a time when the person was competent, and which is valid and relevant to the prevailing circumstances when he or she becomes incompetent, is binding and effective.¹¹ What is perhaps not as clear is the validity of an advance directive that requires life-sustaining or life-prolonging treatment, when this is not in accordance with clinical judgement. The nature of such a directive needs to be considered in the light of patient autonomy, clinical judgement and existing law.¹

In *Burke*¹ a number of key issues relating to end-of-life decisions were considered. The claimant has a progressive degenerative neurological disorder. The

natural history of the disease is that he will inevitably lose capacity and the ability to communicate. He expressed a wish that he wanted to be fed and hydrated until death occurred by natural causes, and he did not want doctors to take a decision on his behalf that his life was not worth living at a time when he was no longer considered legally competent. He further contended that the relevant General Medical Council (GMC) guidance on good practice in decision-making with regard to the withholding and withdrawal of life-prolonging treatment¹² was, in parts, incompatible with his rights under the Human Rights Act 1998. This case has been recently successfully appealed. The Court of Appeal has overturned the decision that the GMC guidance was unlawful.² The ancillary issues of advance directives and best interests as raised in this case, however, merit closer consideration.

In considering the legal status of a competent patient's expressed wish that treatment be continued at a future time when that patient becomes incompetent, the judge in the first *Burke* case, Mr Justice Munby, analysed this on the basis of rights protected by the Human Rights Act 1998, which has had a major impact on medical practice.¹³ Munby J's intellectually powerful reasoning was sustained on the interaction between the right to life, the prohibition of degrading or ill treatment, and autonomy (as encompassed respectively within Articles 2, 3 and 8 of the European Convention of Human Rights). The scope of Article 8 in particular is wide, and covers the physical and psychological integrity of the person as well as how a competent person may choose to pass the closing days of life.¹⁴ Respect for human dignity and the prohibition of ill treatment or degrading treatment is a fundamental right protected by Article 3. The threshold for the engagement of Article 3 is low and has been described as a level that arouses feelings of fear, anguish or inferiority of a humiliating or debasing nature that may erode the physical and moral resistance of the victim against his will.¹⁵ Recognition of such fundamental rights and their need for protection under the Human Rights Act 1998, led Munby J to provide a strongly flavoured rights-based discourse to support the view that a competent patient is entitled to the provision of life-prolonging treatment such as artificial nutrition and hydration (ANH), and that an advance directive that is valid and relevant will be binding¹ and therefore should be accorded the same legal status as an advance refusal of treatment. He concluded that in specific circumstances an advance directive requiring treatment would be determinative.

The Court of Appeal did not accept the proposition that an advance request for treatment would be determinative. Whilst the rights-based analysis of Munby J was not refuted, the Court drew on two different strands to support its view.² The first was the analysis of the House of Lords in *Bland*, which was concerned with withdrawal of life-supporting treatment from a patient in a permanent vegetative state (PVS). In ancillary considerations the House of Lords concluded that an advance directive refusing life-supporting treatment in the circumstances of a PVS should be respected. The Court of Appeal's inference from *Bland* was that it did not therefore follow that the reverse decision should necessarily hold true. In other words, the decision in

Bland did not require a patient to be kept alive because he might have made an advance directive to that effect. Therefore an advance directive requiring life-prolonging treatment would not be binding as an advance refusal. Furthermore, the Court of Appeal considered that the proposition of an advance requirement for life-prolonging treatment would not be compatible with the provisions of the Mental Capacity Act 2005. Whilst section 26 of the Act will require compliance with a valid advance directive to refuse treatment, section 4 does no more than require that such a directive be taken into consideration in the determination of best interests of the incompetent patient. The caveat is, however, that this point has as yet not been tested in court. In *Burke*, a written advance directive to the effect of requiring life-prolonging treatment was never actually made by the claimant, and therefore this point remains moot. What the Court of Appeal has emphasised is that any doctor who deliberately brings a competent patient's life to an end by discontinuing the supply of ANH when the patient indicates his or her wish to be kept alive through the provision of ANH, would not only be in breach of duty, but would also be guilty of murder. This clarification is not new law, and arguably was not the most salient concern for the claimant. However, from a clinical perspective an exception to this general rule might lie in the rare circumstances where the provision of treatment such as ANH might be harmful or even hasten death for the patient.

Best interests

Doctors owe a duty of care to provide treatment which is in the 'best interests' of the incompetent patient.¹⁶ Traditionally, doctors have veered towards a 'medicalised' perspective that has been heavily dependent upon clinical judgement. The legal requirement for the determination of best interests encompasses a wider evaluation of the patient's interests, of which the medical perspective is but one component. In determining what is in the *medical* best interests of a patient, a doctor must act in accordance with a responsible and competent body of relevant

Key Points

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End-of-life decisions represent complex ethical and moral dilemmas that are likely to increase with advances in medical technology

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A competent person has the absolute right to refuse medical treatment and a valid and relevant advance directive is binding

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In an incompetent person the withdrawal of life-sustaining treatment is based on the 'best interests' approach

.....
An advance directive requesting the provision of life-sustaining treatment is not binding

.....
The Mental Capacity Act 2005 will provide a statutory framework for the law relating to capacity, advance directives and best interests

professional opinion. The starting point is one that must be *Bolam* defensible.¹⁷ The role of the physician is to inform with respect to the patient's prognosis and probable consequences of receiving or not receiving certain kinds of treatment or care. Having considered the available medical options and their relative merits, the next stage in the determination of best interests is a wider evaluation of the 'welfare' of the patient which must incorporate broader ethical, social and moral considerations. In the event of uncertainty or disagreement, it is for a judge and not a doctor to make this determination for the incompetent person.¹⁸

The legal yardstick in an evaluation of all the factors in an incompetent person's best interests is a 'balance sheet' approach that weighs potential or actual benefits against countervailing disadvantages.¹⁹ In *Burke*,¹ Munby J raised the bar to 'intolerability' as being the touchstone for best interests. In making a judgement of intolerability, the decision-maker must take into account factors such as pain and suffering, and ask whether the quality of life, if prolonged, would be intolerable for that particular individual.²⁰ Thus, a strong presumption was raised in favour of preserving life and only if the intervention in question was intolerable, would it not be in the best interests of the patient (namely ANH as in *Burke*). It remains somewhat problematic as to when the *withdrawal* of treatment is lawfully in the best interests of an incompetent patient. The Court of Appeal chose not to enlarge on this, primarily because of the perceived danger of enunciating propositions of principle divorced from a factual context, and incompetence was not relevant to Mr Burke's case at this particular time. It is somewhat disappointing that the issues surrounding withdrawal of life-prolonging treatment were not addressed.²¹

At least three pertinent clinical situations can be identified. At the far end of the spectrum is the patient who is dying, and the goal may be to relieve suffering rather than the achievement of a short prolongation of life. In this situation, the position is relatively clear. It would be lawful to withdraw treatment where it may no longer be providing any benefit particularly if there is evidence that such treatment may be detrimental. It seems that this is a decision predominantly based on clinical judgement. In the incompetent patient who is non-sentient (as in a patient in a PVS), the test is 'best interests' and it would seem that in these circumstances clinical judgement would again carry relatively heavy weight.⁵

The position, however, in the incompetent but sentient patient remains uncertain. It is established that the withdrawal of ANH does not constitute an 'intentional deprivation of life' within the meaning of the right to life under Article 2, otherwise there would be a duty imposed in every case to keep a terminally ill patient alive using all possible means.²² A positive and deliberate act is required to unlawfully deprive a person of life, as opposed to a responsible decision taken by a medical team not to continue to provide life-prolonging treatment.²³ In considering the lawfulness of the withdrawal of life-sustaining treatment, the prohibition imposed by Article 3 with respect to ill treatment or degrading treatment will apply. With respect to a patient in a PVS state, the court concluded that an insensate

patient has neither feelings nor comprehension of the treatment accorded, and therefore in these circumstances the withdrawal of treatment would not violate Article 3.²³ This view has been challenged in *Burke*.¹ The judge stated that however unconscious or unaware of ill treatment a patient might be, factors such as the actuality of suffering or treatment that is humiliating or debasing as perceived by others, would be sufficient for Article 3 to engage. Thereby it has been proposed that the ambit of Article 3 is extended. This point was not specifically addressed by the Court of Appeal,² and as yet has to be tested in court vis-à-vis a sentient but incompetent patient, although it was said that it is not possible to define, or attempt to define, best interests of a patient by a single test but that the decision will be dependent upon the specific circumstances of that case at that time.

A troublesome issue with end-of-life decision-making in the incompetent patient is deciding what is best for that individual at that particular time. It is suggested that the 'best interests' test is insufficiently robust and a better test might be one of 'substituted judgement' that has been used in some American jurisdictions.²⁴ In the application of substituted judgement, the decision-maker 'speaks' for the patient by considering advance wishes and previous thoughts that may have been communicated, either directly or indirectly, in order to determine with the greatest degree of accuracy the patient's probable wishes at that particular time, thus aspiring towards an ideal test. However, this test has intrinsic limitations in that it cannot be applied to a patient who has never been competent to express his or her wishes.²⁵ Furthermore, how those wishes may have changed with time, the progression of disease and the evolving prognosis will always remain a mystery and the best that might be achieved is a 'limited objective test'. Within this jurisdiction, the 'best interests' test is an objective test that imbues values of the decision-maker. It is arguable that 'intolerability' as a component in the decision-making process (rather than being the touchstone) might add a gloss to 'best interests' in specific circumstances.

The decision to withdraw treatment in the incompetent patient is always fraught with moral and ethical dilemmas. The analysis in *Burke* at first instance was based on the premise that the individual rights of autonomy and dignity take precedence in respect of withdrawal of ANH in the incompetent patient. This led the judge to alter the boundaries within which withdrawal of such treatment would be lawful, and as a consequence he formulated a prescriptive approach to obtaining court authorisation. Such an approach would have severely restricted the application of clinical judgement and it is reassuring that the Court of Appeal has taken a pragmatic view in overruling this. The Court of Appeal has stated that there is no legal duty to obtain court approval with regard to the withdrawal of ANH and in reaching this decision, which is clearly policy-based, was persuaded by statistics advanced by the Intensive Care Society. Evidence was provided that approximately 50,000 patients a year are admitted to intensive care units, of whom 30% die in the unit or on the wards before hospital discharge. It was calculated that if rigid criteria seeking court approval were applied, approximately ten applications a day would be made, and even

these conservative estimates would be sufficient to flood the Family Division of the High Court. However, it is suggested that in the presence of doubt or disagreement about best interests, it remains prudent practice to seek a High Court declaration that the withdrawal of life-supporting treatment in a particular instance would not be unlawful, particularly since the repercussions for unlawful withdrawal could result in criminal action for homicide, civil liability and disciplinary action.

The future

The Mental Capacity Act 2005 (expected to be enforced in 2007) will provide a statutory framework for, *inter alia*, the law relating to advance directives and best interests. The Act has its basis in the Law Commission Report Number 231 on Mental Incapacity as well as extensive Government consultations. The Act aims to clarify several legal uncertainties and to reform and update the current law on surrogate decision-making. The Act establishes a new statutory scheme for lasting powers of attorney (LPA), which may extend to personal welfare including healthcare decisions. Under section 11 a donee of a LPA (the person who has the power to make decisions on behalf of an incompetent person – a power granted at a time when the donor is competent to make healthcare decisions) can be given power to refuse to give consent to life-sustaining treatment on behalf of the donor. Under the Act a person may also make an advance directive to refuse treatment. Sections 24–26 provide a number of safeguards in relation to life-sustaining treatment. The advance directive must be in writing, signed and witnessed. The directive must be both valid and relevant to the treatment or intervention that is contemplated. The doctor must be further satisfied that the decision has not been revoked, that the person has not done anything to indicate a change of mind, and that the circumstances have not altered in a way that might reasonably have changed the person's decision. Furthermore, sections 6(7) and 26(5) provide that action can be taken to preserve life and prevent serious deterioration while the court resolves any dispute or difficulty.

Section 3 of the Act deals with persons who are unable to make treatment decisions for themselves. The determination of incapacity may not be reached without the relevant information having been presented to the person in a way that is appropriate to his or her circumstances and the person must be able to retain this information long enough to make a decision. These provisions largely reflect the current position at common law. However, those who are completely unable to communicate their decision (but who may still be sentient) would be regarded as not having capacity under the provisions of the Act.

Section 4 deals with best interests and builds on the existing common law whilst offering further guidance. An evaluation of best interests must not be based on potentially discriminatory factors such as age, appearance or assumptions founded on the person's condition or behaviour. It requires a determination to be made by applying an objective test that incorporates all relevant circumstances, none of which are to be accorded greater priority or weight. Relevant factors to be considered are provided in sub-

section 11 but this list is not exhaustive. The decision maker must consider whether the individual concerned is likely to have capacity at a future date, and must consider (as far as can be ascertained) past and present wishes and feelings of the individual concerned. Subsection 7 specifies those who should be consulted, in so far as this is 'practicable and appropriate'. This includes anyone who has been named as an informal carer, family and friends and others who care for the person in a professional or voluntary capacity.

Conclusion

End-of-life issues for clinical practice in the twenty-first century present complex dilemmas with ethical, moral and legal facets. In asserting the right of self-determination, a competent patient may refuse any treatment, even where the decision may lead to an untimely death. The same holds true with respect to an incompetent patient with an advance directive, made when that patient was competent and which is valid and there is no reason to believe that the patient has changed his or her mind. These legal principles are incorporated in the current guidance offered by the British Medical Association (BMA)²⁶ and GMC.¹² If life-sustaining treatment is withdrawn from a competent patient against their wishes, such an action would constitute a criminal offence unless such treatment is actually causing iatrogenic harm.

In an incompetent patient, the withdrawal of life-sustaining treatment requires an evaluation to be made to ascertain that patient's best interests. The common law has evolved to develop a model that is wider than medical interests and takes into account the welfare interests of the patient. The provisions of the Mental Capacity Act 2005 will consolidate and update existing law with respect to advance directives as well as when decisions need to be taken on behalf of those incapable of deciding for themselves. The Act will govern decision-making on behalf of adults both where an incapacitating condition has been present since birth and where the individual loses capacity at some point in his or her life. Whilst there is, as yet, no legal duty imposed upon doctors to seek a declaration of best interests in every case where withdrawal of life-sustaining treatment from an incompetent patient is contemplated, certain situations still exist where such an action may be prudent; for example, if there is disagreement within the healthcare team or between health professionals, carers and the family.

A greater reliance upon a rights-based discourse by the courts in recent decisions has bolstered the position of autonomy and dignity of the patient in end-of-life decision-making that pertains to the incompetent patient. Clinicians must be conscious of the inevitable sea change that has occurred in the court's attitude to the evolution of patient rights. The sands have now shifted and the paradigm will continue to evolve.²⁷

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