The Beginning and End of the Life Cycle*

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I give this lecture with some diffidence but I hope it will be of interest to you since it raises issues of general morality and medical ethics which from time to time require decisions in English courts. These are questions which also are in the minds of and require anxious consideration by the individual and the community in many countries across the world. They raise the issue of the right to life and its obverse, the right to die, or rather the right not to be kept alive. In England in recent times, these questions have become increasingly important and relevant to more and more people. This is as a result of the advances of medical science and technology. Over the years, innovations in medical science have changed almost beyond recognition our social landscape. From birth to death, and most things in between, medical advances have transformed our expectations. Children are kept alive in circumstances in which 25 years ago they would have died at birth. The ageing population now enjoys a greater life expectancy than that of past generations; life-saving and life-prolonging technologies have made a profound difference to the treatment options available for the terminally ill. Inevitably, there will be divergent views as to the appropriateness of such treatments. Doctors sometimes disagree with patients and/or their relatives, and patients may themselves disagree with their family and friends. A doctor's devotion to preserving the life of his patients may conflict sharply with the patient's own values and wish for a dignified and humane death. These conflicting values bring into sharp focus a tension between two principles fundamental to many societies: the sanctity of life, and the individual's right to self-determination or, as it is sometimes called, personal autonomy.

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* Public Lecture delivered at the Faculty of Law of the University of Malaya, Kuala Lumpur, Malaysia, 21 November 2005.

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I have called this lecture "the beginning and the end of the life cycle" and I propose to look at the rights of three groups of people:

I. Children, particularly babies;
II. Adults with the capacity to make decisions about their own welfare; and
III. Adults who lack capacity and therefore need decisions to be made on their behalf.

I. Children

In English law, a child is not an adult until the age of 18 although he may incur obligations and responsibilities before reaching 18 years. The English child legislation is based upon the welfare of the child which, by statute (Children Act 1989), is paramount. The United Nations Convention on the Rights of the Child and the European Convention on Human Rights are also relevant to the English law on children.

Parents generally make the decisions affecting the welfare of their children. It is only exceptionally that the courts are asked to do so. Such occasions may arise in the context of medical problems affecting children. When a baby is born with serious, life threatening disabilities, the doctors and the parents may not agree over the outcome for the child and such cases come before the top tier of family judges, the Family Division of the High Court, to decide what is best for the child. The first consideration for a judge is the sanctity of life. An example of this was *Re B (A Minor)(Wardship:Medical Treatment)*, a case of a Down Syndrome baby born to elderly, first time parents with a life-threatening intestinal obstruction which could be cured by a simple surgical intervention. The doctors advised the parents to allow the child to die peacefully. The case came to court through an application by a hospital social worker and the Court of Appeal held that where the choice was between the opportunity for the child's life to be saved and inevitable death, the Court should give preference to saving the life and the operation should take place.[1]

[1] [1981] 1 WLR 1421.

More recently however there have been two cases, *Re Wyatt (A Child)(Medical Treatment:Parents Consent)*[2] concerning Baby Charlotte, and Baby Luke (unreported), where the medical prognosis for these very seriously disabled and brain-damaged children was a few months of life and resuscitation would not prolong life by more than a few weeks or months and would be of little benefit to either child. In neither case would the baby ever be able to leave the hospital. In each case, the parents would not accept the prognosis and went to court. The cases were heard by different High Court judges and each judge held that there was no benefit to the child in medical or surgical intervention which would only be likely to cause pain or discomfort and would have only a brief palliative effect. The sanctity of life did not require intrusive surgical treatment which did not benefit the child.

As a postscript, Baby Charlotte has lived well beyond expectations and her prognosis in a recent return to court was much more hopeful.

The most difficult case that came before the English courts was that of conjoined twins who shared a single heart, *Re A (Children)(Conjoined Twins)*.[3] The strain on the single heart was such that the babies would both die unless separated, in which case the weaker twin would die in the course of the operation. The parents came from Gozo, an island near Malta, and were advised by their church to let nature take its course. However they decided to come to England in order that the complicated operation might be performed in an English hospital. Court proceedings were instituted to try to stop the operation from going ahead which came before a Family Division judge and the Court of Appeal. One of the major issues was how to resolve the rights and welfare of each child since they were in conflict with each other. The weaker twin was being kept alive by the stronger twin but to save the life of the stronger twin by an operation would be to kill the weaker twin. After much heart searching, the Court of Appeal held that, in balancing the welfare of both children, the only one with any chance of survival was the stronger twin and her welfare

[2] [2004] EWHC 2247, [2005] 1 FLR 21.

[3] [2001] 2 WLR 480.

overrode that of the weaker twin who would die shortly in any event. The operation was performed and the surviving twin is doing well.

The High Court has also had to consider whether life-saving operations should be carried out on older children, such as heart transplants or kidney transplants, or whether drugs, untested on humans, should be given to terminally ill vCJD[4] teenagers. In each case, the test applied was that of the welfare of the child, looked at in the widest context and not limited to medical welfare.

One issue which may become of greater importance in the future is the medical treatment of older children, aged 15 to 17 who have the capacity to understand the medical issues. By English law, a child of 16 years may seek medical treatment even if the parents refuse consent. The situation is not so clear where the older child does not want the treatment, such as a Jehovah Witness whose religion does not allow blood transfusions. In the decided cases, the Family Division judges have held in favour of preserving life by ordering blood transfusions for older children, even those at the age of 17. This may be seen in modern times as a somewhat patronising attitude to young people particularly at the age of 16 or 17. The Court of Appeal has recently indicated that much more attention should be paid to the views of those under 18. This may well include, in the future, the accepting of the decision of a teenager not to undergo surgery or other invasive medical treatment. This presents a most difficult balance between upholding the sanctity of life and the right of someone who is nearly adult to make a fundamental decision about his own life. I think however it will be difficult for a judge faced with a seriously ill young person under 18 whose life could be saved by an operation, not to direct that the operation be performed and the life saved.

II. Competent Adults

By English common law, over many centuries, no one can touch or interfere with the person of a competent adult without the consent of that person. This rule of personal autonomy is of particular signifi-

[4] Variant Creutzfeldt-Jakob Disease (Editor's note).

cance in medical cases where the consent to medical or surgical treatment is obligatory if the person is able to give or refuse consent. The issue which has come to the court in a number of cases has been whether the patient was capable of giving consent. In one case, *S v St George's Hospital Trust*,[5] a pregnant woman decided that she would deliver her baby in a barn, when she was suffering from severe pre-eclampsia and in the absence of a caesarean operation, both she and the baby would die. She was treated as incapable of giving consent and a caesarean section was performed. The Court of Appeal held that she was clearly competent to decide whether to have an operation and that the actions of the hospital were unlawful and she had the right to refuse treatment and allow herself and her unborn child to die. English law, like the law in a number of other countries, does not protect the foetus before birth.

An issue which has arisen in a number of cases is the right to bring to an end treatment which is keeping a person alive. In *Re B (Adult:Refusal of Treatment)*,[6] Miss B was a middle aged woman who became quadriplegic and was kept alive in an intensive care unit of a hospital by an artificial ventilator. She went to the High Court to enforce her right not to have treatment to which she had not consented. The doctors had assumed that she was not competent to make a decision. The Family Division judge held that she was competent and that it would not be lawful for the hospital to keep her on the ventilator without her consent. It was turned off and she died.

In another case, *Pretty v UK*,[7] Mrs Pretty suffered from an advanced form of motor neurone disease and was unable to do anything for herself. She wanted to end her life but required the help of her husband to do so. Although suicide is no longer a crime in English law, assisting a suicide is a crime.[8] Mrs Pretty and her husband asked for assurances from the Director of Public Prosecutions that Mr Pretty would not be prosecuted if he caused her death. The Director refused.

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[5] [1998] 2 FCR 685.

[6] [2002] 2 FCR 1.

[7] (2002) 35 EHRR 1.

[8] Suicide Act 1961, s 2.

Mrs Pretty took her case through all the tiers of English courts including the final court of appeal, the House of Lords, and to the European Court of Human Rights, the United Kingdom having applied the European Convention on Human Rights to English law. All the courts, including the European Court, were sympathetic to the plight of Mrs Pretty but upheld the decision of the Director of Public Prosecutions.

In the arguments advanced by the lawyers for Mrs Pretty, it was submitted that a person's right to life under Article 2 of the European Convention incorporated a right to choose whether or not to go on living, that the State has a positive obligation to protect people from inflicting inhuman or degrading treatment, and that her right to self-determination encompassed the right to choose when and how to die.

The European Court rejected all of those arguments. It held that the right to life does not have a negative corollary, and cannot be distorted so as to confer the diametrically opposite right, namely a right to die. Although Mrs Pretty had had her right to privacy infringed in being prevented by law from exercising her choice to avoid what she considered would be an undignified and distressing end to her life, such interference is justified, because it is "necessary in a democratic society" for the State to regulate through criminal law such activities as are detrimental to the life and safety of other individuals. The purpose of the Suicide Act, the Court said, is to protect the weak and vulnerable, especially those not in a condition to take informed decisions against acts intended to end life or to assist in ending life. For the few circumstances in which assisted suicide might be appropriate, it said, the Director has a discretion not to prosecute, and the court has a discretion in the sentence it imposes.

The result of these cases is that the individual has the right to make decisions for himself about his own death, and the right to instruct others to refrain from treating him, but he does not have the right to ask for anyone else's assistance. In this way, the law makes a somewhat technical but absolutely fundamental distinction between a failure to treat (which is termed an "omission"), and a positive act designed to bring about a person's death. The former is permitted, but the latter

is not. To aid, abet, counsel or procure a person's suicide remains an offence. In one sense it is difficult to justify the decision in *Re Be (Adult: Refusal of Treatment)* since someone else had to turn off the artificial ventilator. It was however treatment to which she did not consent and which she was not obliged to receive. Mrs Pretty had the misfortune not to be kept alive by artificial means.

Patients are entitled to give advance refusals of medical treatment by, for example, giving their doctors an order not to resuscitate. This is sometimes done by making a "living will". In a recent case, *R (Burke) v DRC*,[9] Mr Burke went to court to uphold his right to continue to have treatment by way of artificial nutrition and hydration even if he were not at a later stage able to ask for it. In the Court of Appeal, the appellate court considered that Mr Burke was at no risk of being deprived of such treatment by doctors treating him in the last stages of his illness. It supported the guidance given to the medical profession by the General Medical Council and held that, were any doctor to withdraw artificial nutrition and hydration from a competent patient without his consent, then not only would that be a breach of his duty of care to the patient, it would also constitute murder. The Court also held that a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs. It is an interesting judgment of the court which deals with many questions which I have no time to set out here.

A number of people in a position similar to Mrs Pretty have gone abroad to Holland or to Switzerland to euthanasia clinics which perform assisted suicides. One such case, *Re Z Local Authority v Z*,[10] came to the High Court recently and the judge refused to intervene but warned the husband that, in taking his wife to Switzerland to the clinic, he faced the risk of prosecution on his return. To my knowledge, no one has yet been prosecuted for assisting a spouse to go abroad for this purpose. Euthanasia remains, however, contrary to the law of each part of the United Kingdom.

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[9] [2005] EWCA Civ 1003.

[10] [2004] EWHC 2817 (Fam).

III. Vulnerable Adults

Adults without the capacity to make their own decisions about their welfare, nonetheless, have rights which require to be protected. Very recently a new Act has been passed, the Mental Capacity Act 2005, which provides for the day to day welfare of a vulnerable adult without sufficient capacity to be formally managed by others appointed to this task. This is a great improvement on the somewhat haphazard previous arrangements for this group of people. It does not however resolve certain life and death issues which will continue to require decisions by High Court judges.

The underlying principle of the Mental Capacity Act and previous court decisions is the welfare test, very similar to that applied in children cases. The best interests of the patient are to be established in the widest context, having regard to social and family as well as medical considerations. As with children, the approach of the court is to preserve life unless it is not in the best interests of the patient to do so.

This issue of best interests arose in *Airdale NHS Trust v Bland.*[11] An appalling tragedy at a football match in which 95 spectators died after a stand at the football stadium collapsed was the cause of a famous case which went through each tier of our High Court and appellate courts. Anthony Bland, aged 17, was at the match; was very severely injured but did not die. He was diagnosed as being in a permanent vegetative state, sometimes called "in a twilight world", where he remained alive but without any cognitive ability and without any possibility of improvement. He was fed by artificial nutrition and hydration. After three years, his family asked that he should no longer be treated and that he would not have wanted to continue to live in such a condition. The House of Lords held that the artificial nutrition and hydration was medical treatment and that the doctors were not obliged to continue to treat patients when there was no benefit to the patient and it was futile to do so. Anthony Bland was allowed to die.

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[11] [1993] AC 835.

Both in England and in many other countries, patients in a permanent vegetative state have had their artificial nutrition and hydration withdrawn and have been allowed to die. So far to my knowledge, this has only happened in England in circumstances in which the medical profession, the family and the lawyers representing the patient have been in agreement.

These cases represent the tip of an iceberg and, despite the Mental Capacity Act and the opportunity for competent adults to direct in advance whether there should be medical or surgical intervention in the event of the loss of competence, I am certain that these problems and others we have not yet had to consider will come before the senior judges in increasing numbers as there are even greater advances in medical science and technology.

The problems can, perhaps, be summarised in the words of Isaiah Berlin:[12]

> The world that we encounter in ordinary experience is one in which we are faced with choices between ends equally ultimate, and claims equally absolute, the realization of some of which must inevitably involve the sacrifice of others ... The knowledge that it is not merely in practice but in principle impossible to reach clear-cut and certain answers, even in an ideal world of wholly good and rational men and wholly clear ideas – may madden those who seek for final solutions and single, all-embracing systems, guaranteed to be eternal. Nevertheless it is a conclusion that cannot be escaped by those who, with Kant, have learnt the truth that out of the crooked timber of humanity no straight thing was ever made.

[12] Berlin, I, *Four Essays on Liberty* (London: Oxford University Press, 1969) at pp 168-170.

Karunairajah a/l Rasiah v Punithambigai a/p Ponniah: The Need to Amend Section 95 of the Law Reform (Marriage and Divorce) Act 1976?

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Introduction

The recent Federal Court decision in *Karunairajah a/l Rasiah v Punithambigai a/p Ponniah*[1] (hereafter referred to as "the present case") could be described as one that has shattered the hopes of children above the age of 18 years who are financially dependent on their divorced parents for the purpose of completing their tertiary education. Their hopes were raised by the Court of Appeal's decision in the case of *Ching Seng Woah v Lim Shook Lin*,[2] which was followed by the High Court and the Court of Appeal in the present case. In *Ching Seng Woah v Lim Shook Lin*, the Court held that the involuntary financial dependence of a child of the marriage for the purpose of pursuing and/or completing tertiary and/or vocational education came within the exception of physical or mental disability under section 95 of the Law Reform (Marriage and Divorce) Act 1976[3] (hereinafter referred to as "the LRA") so as to entitle the child to maintenance beyond the age of 18 years.

Section 95 of the LRA stipulates as follows:

> Except where an order for custody or maintenance of a child is expressed to be for any shorter period or where any such order has been rescinded, it shall expire on the attainment by the child of the

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[1] [2004] 2 MLJ 401.

[2] [1997] 1 MLJ 109.

[3] Act 164.