

# MEDICO-LEGAL AND ETHICAL PROBLEMS ASSOCIATED WITH TREATMENT OF CHILDREN BORN WITH CONGENITAL MALFORMATIONS

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## ABSTRACT

*Recent advances in medicine and biomedical science have brought in their wake a whole array of moral, ethical and medico-legal problems. For eg, in relation to the withholding or withdrawal of treatment of neonates born with congenital malformations. While the technology to treat and thus to artificially prolong life is available, the related question of whether or not to do so and in what circumstances has to be considered. There is a paucity of cases in the courts. However, some useful principles can be drawn from a number of cases in the UK. The search for clearer legal and moral criteria has become more urgent. A way ahead appears to lie in the formation of Hospital Review Committees or some such mechanism which would enable the most appropriate decision to be taken in any one case bearing in mind the complex ethical and medico-legal issues involved.*

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## INTRODUCTION

This is the age of hand-phones, high-definition TV, micro-wave ovens and personal computers. We welcome such gadgets into our homes as the blessings of modern technology – they add to our creaturely comforts. Rarely do we question the side-effects of technology. Indeed in our technological culture, moral or ethical questions have a tendency of being pushed to the periphery, as being inconvenient, or as standing in the way of getting a job done. Such questions crop up often, though not exclusively, in medical cases, exacerbated by rapid advances in biomedical science. In-vitro fertilisation, the choice of sex of infants through genetic manipulation, surrogacy etc, have now crossed the realm of mere possibility into practical reality.

The moral and ethical questions remain, they refuse to go away, and it is in keeping with the best humanitarian tradition in medicine, that such questions continue to be raised and discussed, and not swept away under the tidal wave of technology even if the answers proffered are tentative, difficult and controversial.

Controversy, however, is not necessarily bad. Scientific controversy is an integral part of the process of discovery and refinement. Old theories are discarded, better explanations put forward, perhaps themselves to be challenged in the future and abandoned. This is the essence of the scientific quest. Scientific controversies cannot be divorced from the cultural, moral and intellectual trends of the day. So, too, with the history of medicine and medical ethics: they are best understood in the light of the total culture and world-view (*weltanschauung*).

## TWO REAL-LIFE CASES

### I In Re: J (a minor)

In order not to get too theoretical, it is best to start with an actual case: **In Re: J (a minor) (Wardship: Medical Treatment)**<sup>(1)</sup>. In

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this case, the Court of Appeal in the UK have had to deal with the question whether it would be lawful to allow a severely physically and mentally handicapped baby to die.

The facts are these. Baby *J* was born prematurely. He suffered severe brain damage at birth due to lack of oxygen. He was epileptic and was likely to develop severe spastic quadriplegia. He was blind and deaf and unable to speak. However, he had a normal capacity to suffer pain which would continue perhaps into his late teens. He had been on artificial ventilation, but was since able to breathe on his own. Baby *J* had been made a ward of court, and the parents sought the court's guidance as to his future care, in particular, that the baby should not be re-ventilated should he require it. An expert opinion concurred with this. At first hearing, Scott Baker J made an order in accordance with this expert opinion. The Court of Appeal affirmed.

The Court of Appeal reasoned that a balancing exercise is required to be done, by the courts, or the parents if the courts are not involved. This is because "to preserve life at all costs, whatever the quality of life to be preserved, and however distressing to the ward ... may not be in the interests of the ward" (per Balcombe LJ at 942). In the words of Taylor LJ, the correct approach is to "judge 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" (at 945). Lord Donaldson MR stated that the balancing exercise is to assess the course of action "to be adopted in the best interests of the child" (at 938). The test required is objective: that of the reasonable and responsible parent (per Balcombe LJ at 942).

As to be expected, the Court of Appeal adopted a cautious approach based on the strong legal policy of preserving life. Thus Balcombe LJ said there was " ... a strong predilection in favour of the preservation of life" (at 942). Taylor LJ spoke of a strong presumption in favour of taking all steps capable of preserving [human life] save in exceptional cases (at 945). In other words, the decision to withdraw or withhold treatment should only be made in *clear* cases.

Another point emphasised by the Court of Appeal was that it could not (and, *a fortiori*, parents, or parents and doctors acting in concert) authorise anything aimed at terminating life or

accelerating death, but it can order such withdrawal of life-sustaining treatment so that the child died from the underlying medical condition.

"Non-treatment" should also be distinguished from "active killing". As Lord Donaldson MR explained (at 938):

"What doctors and the courts have to decide is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken which as a side effect will render death more or less likely. This is not a matter of semantics. It is fundamental. At the other end of the age spectrum, the use of drugs to reduce pain will often be fully justified, notwithstanding that this will hasten the moment of death. What can never be justified is the use of drugs and surgical procedures with the primary purpose of doing so".

This may be another way of stating the doctrine of "double effect"<sup>(2)</sup>. When in the course of treatment with the primary aim of reducing pain or discomfort, the fact that there is a secondary effect which accelerates (or runs the risks of accelerating) the patients' death, does not make the doctor guilty of culpable homicide. This is not legal sophistry. The underlying proposition is that as a matter of public policy, the courts agree that when life is intolerable, and the patient is dying, the only humane treatment left *may* be one where death is likely to result. Needless to say, controversy in this area has not abated. The court has on other occasions asserted that a defendant may intend that which it is not his purpose to achieve when he knows for certain it will occur<sup>(3)</sup>.

Since the act of the doctor may come uncomfortably close to culpable homicide, it may be instructive to consider just what is culpable homicide. Section 299 of the Penal Code<sup>(4)</sup> states:

"Whoever causes death by doing an act with the intention of causing death, or with the intention of causing such bodily injury is likely to cause death, or with the knowledge that he is likely by such act to cause death, commits the offence of culpable homicide".

And section 300 reads (in part):

"Except in the cases hereinafter excepted culpable homicide is murder—

(a) if the act which the death is caused is done with the intention of causing death;

..... "

These two sections can have no application in a case where a doctor treats in good faith and exercises reasonable care and for some reason known or unknown the treatment has not worked and led to other complications which results in the death of the patient. Thus section 89 of the Penal Code provides:

"Nothing, which is done in good faith for the benefit of a person under 12 years of age, or of unsound mind, by or by consent, either express or implied, of the guardian or other person having lawful charge of that person, is an offence by reason of any harm which it may cause, or be intended by the doer to cause, or be known by the doer to be likely to cause, to that person:

Provided that this exception shall not extend to —

- (a) the intentional causing of death, or to the attempting to cause death;
- (b) the doing of anything which the person doing it knows to be likely to cause death for any purposes other than the preventing of death or grievous hurt, or the curing of any grievous disease or infirmity;

(c) .....

In wilful, deliberate killing, no possibility exists as to recovery or a possible prolongation of life of the patient. In allowing a patient to die – withdrawing treatment, for eg. – what happens is the restoration of the situation that existed before treatment was undertaken and nature allowed to take its course. The distinction is fundamental and not a question of sophistry.

## II In Re: B (a minor)

Let's consider another well-known case: **Re: B (a minor) (Wardship: Medical Treatment)**<sup>(5)</sup>. A girl, Alexandra, was born on 28 July 1981 with Down's syndrome. She was also born with intestinal blockage (duodenal atresia) which, unless operated upon, was fatal. The parents thought that it was better for her *not* to have the operation. They accordingly informed the doctors and refused consent for the operation: they genuinely believed it was in the best interests of the child. The local authorities, Hammersmith and Fulham London Borough Council, however, thought differently. They made Alexandra a ward of court; the court ruled that the parents' wishes are to be respected. The local authority appealed.

In the words of Templeman LJ, "This is a very poignantly sad case"<sup>(6)</sup>. The evidence was that if Alexandra was not operated upon, she will die within a matter of days. If she was operated upon, then if the operation was successful her life expectancy, though short, will be 20 – 30 years; if unsuccessful, she may die within the next two or three months. This is *not* just a question of abstract statistical probability: the parents came to their decision, the court noted, with the greatest sorrow.

The court held that the operation should proceed: it was not a question of how happy or how much suffering the child would have to undergo.

Templeman LJ said (at 1424):

"... the duty of the court is to decide whether it is in the *interests of the child* that an operation should take place. The evidence in this case only goes to show that if the operation takes place and is successful then the child may live the normal span of a mongoloid child with the handicaps and defects and life of a mongol child, *and it is not for this court to say that life of that description ought to be extinguished* [emphasis added]".

Agreeing with Templeman LJ, Dunn LJ puts it in a slightly different way though (at 1424):

"[the court] cannot hide behind the decision of the parents or the decision of the doctors; and in making the decision *this court's first and paramount consideration is the welfare of this unhappy little baby* ....  
.... *there is no evidence that this child's short life is likely to be an intolerable one*. There is no evidence at all as to the quality of life which the child may expect [emphasis added]".

In summary, the legal propositions laid down in this case are:-

- (i) the best interests of the child are paramount;
- (ii) the parents' wishes, though the court would bear them in mind, are not in themselves decisive.

There is a happy sequel to **In Re: B**. The operation was successful and the baby was cared, first by foster parents, and subsequently brought home to her natural parents<sup>(7)</sup>.

It must be stressed the issue in **Re: B** was *not* whether there should be a right to withhold normal treatment from a defective

child on the basis of a subjective assessment of his/her future quality of life or extent of suffering. Medically, all the evidence was in favour of the operation, and there was no need to do a balancing test. But in **Re: J**, a balancing test was required to be done.

## EFFICIENCY vs HUMANITY

In today's world, 'efficiency' has become a by-word such that to be 'inefficient' is almost a criminal act. Efficiency, among other things, means 'cutting-down-on-costs'. Waste, of course, is hardly a virtue. In a resource-scarce world, being efficient basically means reducing waste in order to achieve a better all-round utilisation of resources.

Preoccupation with cost-effectiveness and profits does not readily encourage the exercise of ordinary considerations of humanity, care and compassion. The Good Samaritan, already a rare creature, is further threatened with extinction. Efficiency and effectiveness goals themselves presume certain values, namely, economic, and not all will agree it should be the overriding consideration in every case.

Nonetheless, the hard truth is that medical resources - doctors, nurses, laboratory technicians, pharmacies, counsellors, hospital beds, etc - are not unlimited, and it is the practice that medical treatment, consciously or not, is parcelled out or allocated based on a number of factors, inter alia -

- (i) its prospect of success;
- (ii) its immediate usefulness;
- (iii) the views of parents and general social values;
- (iv) its call on existing resources;
- (v) (and increasingly) the ability of patients to pay.

## I Quality of Life

To this list is now added the "quality of life". "Quality of life", like the well-known slogan "pursuit of happiness"<sup>(8)</sup>, is an elusive idea. One definition runs like this: "it [ie quality of life] must relate to individuals, is likely to vary with time, and will depend on past experience and future expectations. It will be concerned with a whole range of dimensions, not just the physical aspects of the illness. In simple terms quality of life describes the difference between the hopes, dreams and aspirations of an individual, and their present situation. The gap measures the quality of life and is multi-dimensional<sup>(9)</sup>". This said, it is not uncommon to hear the argument that it is better to withhold treatment of neonates born with congenital malformations (eg Down's Syndrome) in some cases, especially when combined with some other physical handicap, because their "quality of life" would be, it is alleged, dismal.

A number of questions arise. Firstly, does it make sense for a completely healthy person, eg a doctor, to decide on behalf of a Mongol what the quality of life of the Mongol *should* be? The assessment is necessarily subjective. Secondly, shouldn't we be concerned with what *this* patient would feel and think, rather than make comparisons with another person born without those defects? Thirdly, the concept "quality of life" is itself vague and ambiguous - we are not quite sure as to its content. Fourthly, is there any basis, moral, philosophical, or legal, that would differentiate between a handicapped neonate and a handicapped adult? It does not take a sharp mind to apprehend that if treatment can be withheld from a handicapped neonate on the ground of physical handicap alone, where would a handicapped adult stand? Fifthly, doctors perhaps have been bearing a disproportionately large burden in having to make or initiate the decision to withhold or to withdraw treatment in clearly medically indicated cases - but why only doctors?

Despite the difficulties, the notion of "quality of life" can be

of some use. Such a quality "... can and must include whatever the value sciences, medicine and public policy agree upon concerning the essential quality or qualities of a human person; and the decision can and must be in the first instance by, and for the benefit of the patient and no one else<sup>(10)</sup>". This point could hardly be overstated.

## II A Question of Values

Inescapably, "value considerations", not just medical prognosis, come into play. By "value considerations" I mean questions like "What is a person?" Is there such a thing as a right to life? How does one "trade-off", weigh costs and benefits? That these are difficult questions do not absolve the medical practitioner, parents and other health care workers from having to make a decision in a concrete case. It can be agonisingly difficult. As these are ethical questions, the doctor also has no monopoly of insights, although to ignore his insights, born of front-line interaction with patients, would be imprudent, if not perverse.

Two such tests on whether or not to withhold treatment from infants born with congenital malformations have been formulated. I am not sure how helpful they really are. For example, Professor G.R. Dunstan has suggested that where:-

"a reasonable hope of benefit, without excessive expense, pain or other serious inconvenience exists, treatment should be continued"<sup>(11)</sup>.

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioural Research (US) formulated the criterion that:

"such permanent handicaps justify a decision not to provide life-sustaining treatment only ... when they are so severe that continued existence would not be a net-benefit to the infant"<sup>(12)</sup>.

An infant with Down's Syndrome with a surgically correctible blocked intestinal tract would, in the Commission's view, be entitled to treatment. Those conditions that by current medical knowledge are clearly untreatable, eg extreme prematurity or anencephaly, should arouse no controversy. What is controversial is the grey-area of treatable conditions but whose prospects of success are by no means guaranteed. Another equally difficult category is this: patients with malformations not inconsistent with long and often enjoyable life (eg Down's Syndrome) but whose parents request withholding or withdrawal of life-sustaining treatment.

We have been using the carefully chosen words "withholding or withdrawal of treatment". But we must not forget the end-result of such a course of action. The result is death for the patient. And this is where the criminal law, which makes no distinction - correctly in my view - between an act of commission or omission if the end result is death - comes in<sup>(13)</sup>, as alluded earlier. According to **R v Gibbins**<sup>(14)</sup> a parent who fails to perform his duty to preserve the child's life, with the object of bringing about the death of the child is guilty of murder<sup>(15)</sup>. Doctors are not a special category which are accorded extra protection from the ambit of the criminal law.

Farquharson J in his summing up to the injury in **Re: Arthur**<sup>(16)</sup> said:

"There is no special law in this country that places doctors in a separate category and gives them extra protection over the rest of us. It is undoubtedly the case that doctors are, of course, the only profession who have to deal with these terrible problems". Some consolation here!

In **Re: Arthur**, a paediatrician was charged, and acquitted, of

the attempted murder of a 3-day old boy born with Down's Syndrome. Dr Arthur had consulted the boy's parents, who made it clear they did not wish him to live, whereupon Dr Arthur prescribed a drug DF 118 (a pain reliever, which the manufacturers, Duncam Flockhart, advised is not to be given to children under four years old), and ordered "Nursing Care Only". No feed was given. Needless to say, the boy died – 67 hours after birth.

Where the issues are complex, cutting across medicine, law, morality, philosophy and economics, it would be foolhardy for any one person or profession to take upon itself the whole burden of having to come to a considered decision – specifically, in our discussion, whether to withhold or withdraw treatment from infants born with congenital malformations.

## NEED FOR MORAL FRAMEWORK AND CLEAR CRITERIA

### I Establishing Legal Criteria

The key issue is, in my view, not so much whether doctors, or doctors in consultation with parents, decide – since it is patently clear someone must make a decision – but the moral framework within which such a decision is taken. In other words, are there established criteria or guidelines for making a decision? There is an equally important and related question: who sets these criteria? We cannot avoid the morality question. On the other hand, we should be careful not to go the way of the absolutist, in holding, for example, that there is an absolute obligation to treat each and every baby, whatever the consequences, whatever the prospects. I doubt if there is a hospital anywhere in the world who would treat whatever the cost, whatever the prognosis, on the basis of the absolutist principle. Indeed extraordinary but futile treatment which only delays inevitable death is inhumane.

Those of you who are looking for unequivocal guidance on the law may be disappointed: the law in this area is uncertain and still developing. Courts decide on a case-by-case basis; the cases are few and far in between; the issues complex. No single all-embracing principle can be laid down; it is doubtful if one exists. What we are faced with is a conflict between equally valid moral claims or principles, viz right to life, right to autonomy, right to respect, and some would argue, right to die in a dignified manner.

By and large, courts in the US have allowed a large measure of parental discretion concerning treatment of children and are hence reluctant to intervene. The law presumes that parents generally act with the best interests of their children in mind. This accords with common sense. There are of course cases where the court has intervened in ordering life-saving treatment over the objection of the parents; but it does so hesitantly, especially when life is not in imminent danger<sup>(17)</sup>.

In June 1992, the Court of Appeal (UK) had to consider the question of "Who decides?" In *Re: J (a minor)*<sup>(18)</sup>, the fundamental issue there was, as Lord Donaldson MR framed it (at 662): "... whether the court in the exercise of its inherent power to protect the interest of minors should ever require a medical practitioner or health authority acting by a medical practitioner to adopt a course of treatment which in the bona fide clinical judgement of the practitioner concerned is contradicted as not being in the best interests of the patient." His unequivocal answer was that it would be an abuse of power for the Court to *require* the practitioner to act contrary to his own best clinical judgement. Lord Donaldson took the opportunity to reaffirm what he said on this point in *Re: J (a minor)*<sup>(19)</sup> and *Re: R (a minor)*<sup>(20)</sup>.

The facts in *Re: J (a minor)* are these. *J* had a fall when he was about a month old. He had severe injuries on his head, as a result of which he suffered severe microcephaly, and has a severe form of cerebral palsy. He also had cortical blindness and is prone to fits. He has to be fed largely by a nasogastric tube. The expert

medical opinion was that he would not be able to develop beyond his present level of functioning; his expectation of life, which is uncertain, was short.

On the basis of *J*'s consultant paediatrician's report – confirmed by two other paediatricians – the local authority sought and were granted leave to invoke the inherent jurisdiction of the High Court<sup>(21)</sup> to determine whether *J* is to be resuscitated mechanically should a life-threatening event occur. Overruling the recommendation of the doctor involved in treating *J*, Waite J answered the question in the affirmative.

The Court of Appeal overturned Waite J's decision basically on two counts: firstly, no doctor could be forced to treat his patient against his own best clinical judgement; and secondly, the lack of certainty of what was actually required of the health authorities as the order did not take adequately into account whether the health authority had the resources to treat the patient.

To wait for the courts may be a long wait. The alternative is legislation. But this is inconceivable at the moment: it is too hot a potato! At any rate, votes are more likely to be lost than won on this score. The only way out is, in my view, to have some kind of code of practice. They do not, and should not, have the force of law; but if adhered to in good faith, they will go a long way to mitigate – I say mitigate for it would not extinguish the need for individual deliberation, which is often a very painful or distressing exercise, even for the doctor – the burden on one person having to make the decision and allow community expectations, restraints, values and, hopefully, wisdom, to prevail in the overwhelming majority of cases.

The fact that there is uncertainty in prognosis also does not preclude the attempt for articulating clear rules for guidance. After all, as I Kennedy has written:

"We all work on best estimates. And, in a society subject to the rule of law, we develop guidelines for conduct on the basis of those estimates<sup>(22)</sup>".

The opposite pole, ie responding as the situation demands (situation ethics), without any clear (albeit not perfect) guidelines is also to be avoided. The truth is that it is not the situation that dictates the decision: people, with their values, attitudes, prejudices, do. It is important we know what those values and attitudes are. A cavalier attitude towards life, whether of the newborn (or of the unborn) will show itself, often devastatingly, in the other dimensions of human interaction and community life, and may well lead to a tacit acceptance of the most abhorrent social policies (eg Hitler's Final Solution). We still hear of killing of female infants in parts of rural China where the male child is prized.

Parents' choices cannot be decisive for the child because every liveborn child who enters into civil society acquires certain independent rights, chief among which is life itself.

### II Providing adequate care

Section 4(1) of the Children and Young Persons Act<sup>(23)</sup> provides that parents who neglect their child –

"... in a manner likely to cause that child ... unnecessary suffering or injury to his health ... shall be guilty of an offence ... and for the purposes of this section a parent or other person legally liable to maintain a child or a young person shall be deemed to have neglected him in a manner likely to cause injury to his health, if he wilfully neglects to provide adequate food, clothing, medical and or lodging for the child and young person".

What if parents act in concert with doctors to withhold or

withdraw treatment of the severely handicapped child? Would their decision always be unimpeachable? I venture to say No. The reason is it is not so much who makes the decision, as to what legal principle by reference to which the treatment decision is reached. The legal principle is that doctors do not owe the same duty of care to severely disabled children as to other children<sup>(24)</sup>. This is the content of the doctor's and parent's duty. It is, first, a matter of legal principle as to how the child may be categorised, and then a matter of medical evidence.

There is a similar provision in the UK. Retired paediatric surgeon RB Zachary opines: "... failure to obtain or administer available medical treatment which has a very good chance of success must come into this category, particularly if the failure to obtain or give such treatment will result in the unnecessary death of the child." I tend to agree.

Everything hinges on what is meant by "wilfully neglecting" to provide adequate medical care. In a House of Lords decision, **R v Sheppard**<sup>(25)</sup>, Lord Keith said:

"The words "adequate", as applied to medical care, may mean no more than "ordinarily competent" ... it is related to the prevention of unnecessary suffering or injury to health ... There could be no question of a finding of neglect against a parent who provided ordinarily competent medical care, but whose child nevertheless suffered further injury to its health, for example paralysis in a case of poliomyelitis, because the injury to health would not in the circumstances have been unnecessary, in the sense that it could have been prevented through the provision by the parent of adequate medical care. There can be no question of a finding of neglect against a parent who had provided ordinarily competent medical care ... Failure to provide adequate medical care may be deliberate, as when the child's need for it is perceived yet nothing is done, negligent, as when the need ought reasonably to be perceived, but was not, or entirely blameless, as when the need was not perceived but was such as ought to have been perceived by an ordinary reasonable parent'. (at 417-8).

However, this passage is not very helpful in the case of having to decide whether or not to withhold treatment of neonates with congenital malformations which on its face would reasonably require medical care.

#### **HOSPITAL REVIEW GUIDELINES – A WAY FORWARD**

Attempts have been made in various neonatal institutions to deal with the question of withholding or cessation of treatment of neonates with congenital malformations<sup>(26)</sup>. The starting point, according to paediatrician A. Whitelaw, is to have an acceptable test for non-treatment and he suggested: "near certainty of death or no meaningful life" as the benchmark. "No meaningful life" is further elucidated as "a virtual certainty" not just of handicap, but of total incapacity – eg, microcephaly, spastic quadriplegia, and blindness.

In describing the method of review in Hammersmith hospital, Whitelaw writes that after verifying the baby's condition, there must be an unanimous decision of the treatment team that a baby be selected for non-treatment. The parents are then called in for a discussion. If they agree to non-treatment, the policy is followed; if not, then the baby is treated. This process of course does not eradicate the difficulty of choice, but at least it provides a practical framework for making decisions. If anything, advances in life-sustaining therapy will increase, not reduce, the scale of the problem.

Whitelaw also argues that there is no need to invoke legal procedures in cases where thorough medical investigation have led the medical team and the parents to choose withdrawal of treatment; the decision to treat or not is essentially one between doctors and parents. This may be a way of saying that the institutional decision-making as adopted by him and his team is sanctioned by the law. But, I would stress, the criteria for decision-making must be determined by the law, and should be defensible under existing law. This means regular review to take into account advances in technology and outcomes in treatment. No hospital should come up with treatment guidelines based only on traditional or administrative practice alone.

On the lawfulness of clinical decisions by doctors, in *Airedale NHS Trust v Bland*<sup>(27)</sup> Lord Goff puts it this way:

"It is nevertheless the function of the judges to state the legal principles upon which the lawfulness of the actions of doctors depend; but in the end the decisions to be made in individual cases must vest with the doctors themselves. Mutual understanding between the doctors and the judges is the best way to ensure the evolution of a sensitive and sensible legal framework for the treatment and care of patients, with a sound ethical base, in the interest of the patients themselves."

In **Re: Karen Quinlan**<sup>(28)</sup>, Hughes CJ supported the formation of a Hospital Ethics Committee as it would provide "... a regular forum for more input and dialogue in individual situations and to allow the responsibility of these judgements [of treatment or non-treatment] to be shared. To apply to the courts to confirm such a decision – in this case, turning off life support system in an adult comatose patient – was a 'gratuitous encroachment upon the medical professions' field of competence ...'. However, some judges are more intrepid; **Re: B** may be such a case<sup>(29)</sup>.

Still, the buck has to fall somewhere, and someone, or perhaps, some committee has to decide. The need for a Hospital Ethics Committee has been suggested and should be seriously explored<sup>(30)</sup>. It should be broad-based, including non-medical personnel like social workers, theologians, ethicists, etc in order to bring a multi-disciplinary approach to bear on the problem. It should be flexible enough to allow for emergency decisions to be taken expeditiously. However, the tendency for such a committee to be conservative is strong, perhaps unavoidable, and it may also lead to a broadening rather than a sharpening of responsibilities.

The law, in order to be fair to each person, has developed the well-known and time-tested phrase that all relevant factors and circumstances must be considered. A decision to withhold or to withdraw life-sustaining therapy should only be made with the utmost care and trepidation and only after having considered all the circumstances in any particular case.

#### **CONCLUSION**

Legal and ethical discourse can unwittingly lapse into the abstract and unreal. We must not forget that ultimately we are concerned with a person's life so the person's voice must be heard. Especially in the case of those born with congenital malformations, someone has to speak out for them<sup>(31)</sup>.

The Committee of Bioethics of the American Academy of Paediatrics sums it up, in my view, authoritatively:

"Withholding or withdrawing life-sustaining treatment is justified only if such a course serves the interests of the patient. When the infant's prospects are for a life dominated by suffering, the concerns of the family may play a larger role. Treatment should not be withheld for the primary purpose of improving the psychological or social well-

being of others, no matter how poignant those needs may be"<sup>(32)</sup>.

To close with a real-life story.

Janet was a 14-year-old girl with severe spina bifida which required numerous operations. She spent her waking hours in a wheel chair. Paediatric surgeon RB Zachary recounted how he met her in town one day after she had been watching a television programme which advocates that those babies with spina bifida should be put down directly after birth. "I'm glad they didn't do that to me," Janet said, "because I have had 14 years of love"<sup>(33)</sup>.

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- [1992] 4 All ER 614.
- Supra*, note 1, at 934.
- [1992] Fam 11 at 22, 26.
- Section 100 of the Children Act (UK) 1989.
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## 2ND ANNUAL SCIENTIFIC MEETING

### Theme: Medicine without Frontiers

organised by Tan Tock Seng Hospital

Date: 6 – 9 October 1994

Venue: Raffles City Convention Centre  
Westin Hotel, Singapore

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