

NON-INTERVENTION IN CHILDREN WITH MAJOR
HANDICAPS: LEGAL ASPECTS

AUSTRALIAN COLLEGE OF PAEDIATRICS
ANNUAL SCIENTIFIC MEETING

May 1983

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SURFERS' PARADISE, QUEENSLAND, 18 MAY 1983

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The Hon Mr Justice M D Kirby CMG
Chairman of the Australian Law Reform Commission

LAW REFORM AND MEDICAL PRACTICE

Although the issue before this Annual Scientific Meeting is one of acute legal and ethical concern, it is not one which has been referred by the Federal Attorney-General to the Australian Law Reform Commission. The Commission has tackled and is tackling important issues touching medical practice. They include:

- * Human tissue transplants. Our 1977 report on transplantation, now accepted as the basis of the law in all States of Australia, save Tasmania and New South Wales. A Bill is before the New South Wales Parliament.
- * Privacy and confidentiality. The examination of the law of privacy and confidentiality of personal information, including medical information. A report on this subject goes to the printer within a month.
- * Evidence : medical privilege. We are working on reform of the Federal laws of evidence. As demonstrated by recent events in Britain, an acute issue to be considered is the extent to which medical practitioners should enjoy a privilege against having to disclose patients' confidences, even to courts of law.¹
- * Standing. The right of special interest groups, not immediately involved, to bring legal questions before the court in order to test the legality of conduct and its compliance with the law of the land.

The numbers of problems that are presenting themselves at the interface between law, morality and medicine, continue to increase apace. In vitro fertilisation, genetic engineering, artificial insemination, transexualism, euthanasia and living wills, surrogate motherhood and human cloning are just some of the issues that require a major new effort of medical law reform. The number and complexity of the questions may even require new institutions for law development. The Australian Law Reform Commission's multi-disciplinary effort in its report on Human Tissue Transplants shows that success can be achieved. You will therefore understand my support for the call in the report of the Working Party of the College for the encouragement of 'informed public debate ... on the various complex and contentious issues that are involved in establishing the criteria of acceptable quality of life'.² That call goes on to assert, however, that such exercise of free speech:

should not be confused with the right of litigious intervention in an individual situation.³

It is next to impossible to outline the legal issues raised by non-intervention in children with major handicaps in a space of 15 minutes. Necessarily, my remarks must appear superficial and dogmatic where exactly the opposite is what is needed. But my primary point is that a stone has been turned and attention is now being paid to an aspect of medical practice. Until now this has been left very largely to the idiosyncratic judgment of doctors and hospitals, sometimes reinforced by the decisions of parents. A spate of litigation has broken out in a number of countries. It signals community and legal concern. It will require us in Australia to take the difficult path of searching for a more consistent and publicly stated set of rules that govern decisions of life and death made in these tragic situations.

TURNING THE STONE

Until the past few years, there was relatively little medical and still less legal writing about the problem of dealing with neonates born with gross physical or mental handicaps. Dr Raymond Duff and Professor Alexander Campbell conducted their study in 1973 of the case histories of 299 babies who had died in the intensive care unit of the Yale-New Haven Hospital, to see what treatment they had been given. The report was that in 43 cases, ie 14%, some treatments were withheld or stopped with the knowledge that early death and relief from suffering would result.⁴ The doctors decided, effectively, that 43 babies should die and of course they did. In 1980 an anonymous British paediatrician disclosed in The Lancet his personal code of conduct:

I assess babies with the more severe chromosome disorders ... and even straightforward Downs Syndrome ... I offer the baby careful and loving nursing, water sufficient to satisfy thirst and increasing doses of sedative. A few days after the baby has died, I write offering a date for the parents to come and see me.⁵

That this practice exists in Australia was asserted by Sir Macfarlane Burnet⁶ and is virtually acknowledged in this College's Working Paper.⁷

It is now ten years since the decision of the Supreme Court of the United States in Roe v Wade.⁸ In the same time there have been important changes in abortion law in Australia, as a result of legislative changes or judicial interpretations. The result is, apparently, a greater community acceptance of abortion which the common law formerly regarded, after the 'quickening' as a serious criminal offence. Twenty five percent of the surgery conducted in the United States is now abortion surgery. This change in community, medical and legal attitudes in the case of abortion may well reflect something deeper, including changing attitudes to infanticide in the case of defective neonates. Quite possibly, the majority of the community supports their death and would favour precisely the medical practice disclosed by the anonymous writer in The Lancet and urged on Australians by Sir Macfarlane Burnet. The only difficulty for those who hold that view is that the law, as it presently stands, does not appear to countenance such an approach. Furthermore, some moral philosophers have begun bluntly to ask whether it would not be kinder to give such neonates a needle rather than hypocritically waiting for them to die for want of nourishment, slowly under sedation. This question poses the blunt issue which must ultimately be faced in this debate. Does and should the law defend and uphold every form of human life, no matter what its quality, what burdens it places on the victim, the parents, the relatives, nurses and society? Until now the law has tended to see the issue in black and white terms. Perhaps that is why it has taken so long for these painful questions to come to public notice. But come they now have. And a series of recent cases shows how.

FOUR CASES

Four cases, in three countries, illustrate what is happening:

- * A needed operation. The first concerned a little girl born in London in July 1981. She was suffering from Downs Syndrome but also from an intestinal blockage that would be fatal unless operated upon. The parents thought it would be unkind to perform the operation. They thought nature should take its course. The doctors contacted the local authority who made the child a ward of court. The child was

moved to another hospital. But the doctors there would not perform the operation without the parents' consent. A judge of the High Court of Justice in England was asked to order the operation. He declined to do so. On appeal, later in the same day, the English Court of Appeal ordered the operation performed. It pointed out that the test to be applied was the best interests of the child, not the judgment of the parents or the doctors. The judges did offer an exception to the overwhelming prejudice in favour of life, namely where 'the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die'.⁹ Commentators claimed that this exception was more significant, legally, than the order for the operation to be done in the particular case.

- * Trial of a doctor. In November 1981, following reports and protests from a Right to Life group in a hospital, a respected paediatrician, Dr Leonard Arthur, was placed on his trial, ultimately, for attempted murder of a baby boy, John Pearson. The boy had been born with severe mental handicaps. Dr Arthur had ordered a regime involving no food, simply water and sedatives. The child died within days. Evidence of normal practice in these cases was given at the trial. The jury acquitted Dr Arthur. However, the debate about his 'treatment' of the child continues in the medical and popular press.¹⁰ In the Australian Law Journal too, there has been comment. Dr Paul Gerber of Brisbane put it thus:

Once the foetus has become a living human being, [it] had all the rights belonging to a human being including, of course, the pre-eminent right not to be killed by neglect. I have no objection to infanticide — provided it is sanctioned by Parliament.¹¹

- * Appeals to Washington. In April 1982 a storm broke in the United States. The resultant case was taken to the Supreme Court of that country. A child, known in the court records only as the Infant Doe, was born severely mentally retarded. The parents, whose names were not released, authorised doctors to withhold food. The Supreme Court of Indiana upheld the parents' rights to do this. But the County Deputy Prosecutor, Mr L Brodeur, flew to Washington. He sought to contest the Indiana ruling before the Supreme Court. Before the Supreme Court could consider the matter, the child died, just two weeks old. Subsequently, the Reagan Administration invoked a Federal rule requiring that hospitals, receiving Federal funds in the United States, must put up notices that withdrawing care from handicapped infants is a violation of Federal law. The notices included a new Government toll-free telephone number for reporting to Washington suspected cases of child neglect in hospitals. However, on 14 April 1983 Federal Judge Gerhard Gesell disallowed the rule on the grounds that there had been inadequate public comment before it was put into effect. He said that the rule involved 'complex and controversial questions of ethics and public policy'.¹² The United States Government has announced an appeal.

* A Canadian case. On 18 March 1983 Mr Justice McKenzie in the Supreme Court of British Columbia had to hand down a decision in the case of Stephen Dawson, aged seven. Shortly after birth, Stephen suffered profound brain damage through meningitis. It left him with no control over his faculties, limbs or bodily functions. At the age of five months, life support surgery was performed implanting a shunt to drain excessive cerebro-spinal fluid. The boy was blind, partly deaf, incontinent and could not stand, walk, talk or hold objects. Early in 1983 a blockage in the shunt was detected. The parents initially gave consent for remedial surgery. After a day's reflection they withdraw their consent on the ground that the boy 'should be allowed to die with dignity rather than continue to endure a life of suffering'. The Superintendent of Family and Child Service sought an order that the child was in need of protection. The trial judge considered that the exercise of the incompetent boy's right to refuse life-sustaining treatment rested with the family in consultation with their doctors. She considered that the operation was 'extraordinary surgical intervention' and not necessary medical attention. The Superintendent appealed. Mr Justice McKenzie in the Supreme Court of British Columbia ordered the operation to be performed. He reverted to the test in the English case in re B. The decision in this case was complicated by the uncertainty that death would follow promptly and painlessly a refusal to remedy the shunt. The judge said this:

I cannot accept [the parents'] view that Stephen would be better off dead. If it is to be decided that 'it is in the best interest of Stephen Dawson that his existence cease', then it must be decided that, for him, non-existence is the better alternative. This would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it is not worth preserving. I tremble at contemplating the consequences if the lives of disabled persons are dependent upon such judgments. To refer back to the words of Templeman LJ, I cannot in conscience find that this is a case of severe proved damage 'where the future is so uncertain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion'. I am not satisfied that 'the life of this child is demonstrably going to be so awful that, in effect, the child must be condemned to die'. Rather I believe that 'the life of this child is still so imponderable that it would be wrong for [him] to be condemned to die.¹³

CONCLUSIONS

It should not be thought that this debate whether in courts or conferences is a simple battle between religious conservatives and medical progressives. One of the chief opponents of the 'Baby Doe' rule before the United States Senate Committee on Family and Human Services was Father John Paris, a well known Jesuit Professor of Ethics, who called the rule 'a tragic mistake', 'too vague', 'open to misunderstanding' and 'too blunt'.¹⁴ Some opponents of the current silent practice, including here in Australia, are humanists who would go further, eugenics supporters who would go much further or just simple citizens who worry about the toll that bringing up severely handicapped child will involve, on the parents, on institutions when the parents are gone and on the community purse.

It does seem clear that at least in some hospitals (possibly most) in Australia, the practice that has been disclosed overseas goes on quietly and in apparent defiance of the letter of the present law. The choices before us are three:

- * to leave well alone on the basis that these problems are just too difficult or too painful to confront and inappropriate for laws and litigation;
- * to enforce the law, strictly, rigidly, vigorously, and to encourage toll-free numbers and alert groups in our hospitals to do just that;
- * or, thirdly, to confront the problem frankly and to seek to draw up clearer new rules. These would relieve doctors and hospital staff, parents and others involved of the universal burden and risk of criminality. They would provide clearer guidance for more uniform decisions : so that these choices of infant life and death do not depend upon the personal moral convictions of particular doctors or particular hospitals; but are laid down (as matters of life and death typically are) by the law of the whole land. They would need to uphold the primary prejudice in favour of life, whilst conceding that in some cases, according to given tests and criteria, life alone is not enough. Obviously such tests would have to contemplate scope, for judgment, discretion and wisdom.

It will be no surprise to you that I favour the third course. It is unreasonable to impose upon busy judges, in the midst of pressing courtroom dockets of diverse cases, the obligation to solve these great moral quandaries usually in the space of hours. Typically, they will not have before them the whole range of expertise. Typically, they must focus on the interests of the litigants, without necessarily having advocates for the public interest or other interests affected. Typically, they will be unaided by philosophers, social scientists and theologians. All too often they may unconsciously reflect, in their hasty decisions, their own moral precepts which may or may not reflect those of a changing community.

It is a good thing that your College has brought these sensitive questions out into the open. It will be better still if that initiative can produce an informed, public debate leading to laws made not by the judges but by our Parliaments, sensitive to the views of an anxious but kindly community.

FOOTNOTES

1. The reference is to the Police and Criminal Evidence Bill 1982 (GB). See [London] Times, 15 April 1983, 1.
2. Australian College of Paediatrics, Non-Intervention in Children with Major Handicaps : Legal and Ethical Aspects, Report of Working Party, March 1983, mimeo, 16.
3. ibid.
4. In R Lindley, Handicapped Babies, The Listener (BBC), 12 November 1981, Vol 106, No 2735, 558, 559.
5. ibid.
6. M Burnet, Endurance of Life, 1978, 113 ('To put it bluntly, this means killing the product of conception as soon as its inadequacy to face life is known with certainty ... This may be spoken of as mercy killing or compassionate infanticide, but legally it is murder. However, in my own mind I am confident that within less than a hundred years such action will be accepted as socially necessary, morally acceptable, and perhaps even compulsory under law').
7. Report, n.2 above, 5-6.
8. Roe v Wade, 410 US 113 (1973).
9. In Re B [1981] 1 WLR 1421.
10. See discussion in The Lancet 1981; 2, 1101-2 and (1982) 56 Australian Law Journal 141.
11. (1982) 56 Australian Law Journal, 141.
12. Reported, The Advocate (Melbourne), 28 April 1983, 17.
13. The Superintendent of Family & Child Service v Dawson, decision of the Supreme Court of British Columbia, mimeo, 18 March 1983, McKenzie J, 22-3.
14. The Advocate, n.12 above. 17.