



305/16-18 Cambridge St Epping NSW 2121

Phone: (02) 9869 0866 Facsimile: (02) 9869 0722

Record

383

Author:

The National Health and Medical Research Council

Title:

The ethics of limiting life sustaining treatment - a

discussion paper

File Number 10338

Original source:

The Lamp

Resource type:

Written

Publication Date:

01/05/89

Publisher info:

Abstract

This paper discusses the ethics of limiting life sustaining treatment for infants who have very low birthweight, infants with spins bifida and people who are elderly and sick. Its author, the National Health and Medical Research Council states that not all aspects have been covered, nor is the paper a comprehensive one. It is designed to raise issues and stimulate further discussion. It should be read in conjunction with "Lives of great value" (File number 10339) and "Euthanasia and refusal to treat" (File number 10340) which were written in response by a number of organisations. Keyword: Ethics

•

The Ethics of Limiting Life Sustaining Treatment

a discussion paper

The National Health and Medical Research Council

In recent years increasing interest has been shown in, and increasing publicity given to, the ethics of limiting life sustaining treatment. This paper aims to widen and extend this discussion by Australians. Whatever the views of individual physicians, ethicists, philosophers, theologicans and lawyers, good ethical decisions can only be made by knowing the needs, and reasonable judgments of the community at large.

The term 'life-sustaining treatment' refers to a variety of often complex procedures, such as mechanical ventilation of the lungs. However, at times, even provision of food and water by artificial means will come into this category.

To facilitate presentation, some specific ethical problems have been chosen and some definite statements made. No attempt has been made to cover all aspects, or to comprehensively cover those aspects selected. National Health and Medical Research Council as yet has no policies in this area. Depending upon public response, this exploratory approach may lead to some suggested principles and guidelines from NHMRC.

In the situations under discussion appropriate ethical decisions are being made between patients, their families and their doctors every day. In the event of uncertainty or discomfort, any of these parties may seek a "second opinion". Resort to or involvement of third parties (eg lawyers, ethics committees) is rarely considered. Nevertheless many

questions arise which need more attention:

- New technologies allow maintenance of life (as distinct from health) where previously this has not been possible. When are doctors and patients obliged to use them, and when not?
- 2. The cost of health care is increasingly questioned. How are resources to be apportioned? Who should be rationed?
- 3. What is to be done when the best ethical decision appears to be in conflict with the law, or where there is confusion as to how the law applies to a particular situation?
- 4. Who should decide for those unable to decide for themselves? Upon what criteria should the decisions be made?
- 5. Can the medical profession maintain its own standards, or do governments need to appoint regulatory bodies to safeguard the public? If needed, how would such bodies operate and would they be effective?
- 6. How can ethical decision-making

"keep-up" with changing community attitudes?

NHMRC has undertaken a preliminary study of three groups:

- extremely low birth weight infants
- infants with spina bifida
 - the sick elderly

Some of the questions to follow are particularly relevant to these groups.

1. Extremely low birthweight infants: what problems?

By definition, these infants weigh less than 1,000 grams at birth. Those below 750 grams have a low survival rate and many who live will have serious life-long handicaps. Prior to development and refinement of modern intensive care for newborn infants, low birth weight infants between low birth weight infants. between 1,000 and 1,500 grams also suffered a high death rate and many problems in survivors; this group now generally does well and poses few ethical problems. In regard to extremely low birth weight infants, then -

- (a) A few survivors will be entirely normal but they cannot be identified early. However accurate information is available on the statistical probabilities of death and disability in most situations likely to be encountered.
- (b) Aggressive treatment of all such

infants is very expensive; some infants may die only after months of treatment.

- (c) the cost of neonatal intensive care is measured not only in financial terms, but also in serious stresses on parents and careers.
- (d) In future, parents may have to take more financial responsibility for their handicapped infants. Is it appropriate for parents to make a "nontreatment" decision where there seems to be a very high chance of death or growth disability?

The dilemma is whether all such infants should receive all possible ζlife-sustaining treatment for the sake of a few intact survivors.

Clinical cases - Neonatal

James and Matthew, 2 unrelated boys, are born the same day at a large city obstetric hospital. Both are 16 weeks premature, weigh around 700 grams, require resuscitation immediately upon delivery and require mechanical ventilation from the first day. Both transiently improve but at 31/2 weeks, after a variety of setbacks, both still require life-support treatment including mechanical ventilation and intravenous feeding.

On the most reliable information available, James and Matthew would die if life-support treatment were stopped. Even continuing all possible treatment, they each face a 60 per cent chance of dying within the next few months. In the event of survival,

though the mother is very concerned degree of urinary incontinence. about the possibility of long-term

Matthew's parents are both 26. They have four other children, the oldest suffering cerebral palsy and a moderately severe intellectual handicap following meningitis at the age of 10 months. Both parents are unemployed and the family lives in rented accommodation in an outer suburban area. Even with all possible social security benefits, they find the Urinary control may be achieved by regular catheterisation or by surgical urinary diversion.

(b) Severely affected children are at best wheelchair bound, have urinary incontinence and often bowel problems and many are severely intellectually handicapped. Most adult males are sexually impotent.

(c) It is possible to identify children at birth who will be severely

"In the management of the terminally ill, the patient's over-riding right to die in comfort (if possible) and with dignity, must be paramount."

special needs of the oldest child a great strain. This latest pregnancy was unplanned. Matthew is the first boy in the family, and his father, a keen footballer, was initially excited at the prospects of having a son. Both parents have been involved in detailed discussions about Matthew's treatment and possible outcomes. and both are deeply concerned and depressed about his chances of survival, and the chances of severe handicap, were he to survive.

From an ethical point of view, are there any differences between these two examples? Note that were both infants to survive with significant handicap, there may be a large cost to the community, less so in the case

handicapped and intellectually retarded.

(d) Renal failure develops in at least 10 per cent of survivors. This is not directly related to the degree of spinal abnormality.

(e) There is a 5 per cent recurrence risk in subsequent children. Antenatal diagnosis is possible and termination is offered.

(f) With expectant management at least two-thirds of affected children will die by one year of

Non-intervention is proposed for severely affected children with the intention of reviewing that decision at six months of age. Nonintervention with sedation and withdrawal of nutrition has also been practised. Some clinicians recommend active treatment for all. Should other options be considered?

no-longer useful, and who next?"

"Others fear that any such discussions

open the way to killing the aged, the

the likelihood of cerebral palsy, intellectual handicap and/or blindness and/or deafness will be about 30 per cent. The degree of intellectual handicap, if present, would vary from mild to profound.

James' parents have no other children and have been trying for nine years to have a child. James was born after their 3rd IVF attempt. They are in their mid-30s, emotionally stable, devoted and wealthy. They have been involved in detailed discussions about James' treatment and the possible outcomes. Neither parent has had any previous experience with a handicapped individual. Both want all possible treatment to continue at this stage,

of James as his parents would contribute some of their own resources.

2. Infants with spina bifida

Spina bifida is an abnormality of the spine and spinal cord which leads to varying degrees of loss of function of the legs, the urinary bladder and the bowels. The spectrum of severity is related to the extent of involvement of the spine and the presence of hydrocephalus at birth -

(a) Mildly affected children are of normal intelligence, able to walk and have bowel control when stools are formed but have some Case Report

Julie is 48 hours old. She is the first child of a 38-year-old accountant and a 33-year-old primary school teacher. The pregnancy was planned. She has an open spina bifida defect extending to the low thoracic region. She has no obvious movement of her legs. Her hips are dislocated. She is constantly dribbling urine and has a patulous anus. Her face is normal and she appears to see. She has a normal head circumference. She sucks well. She moves both arms, has a normal grasp and normal Moro reflex.

She fulfils the criteria for nonintervention as she will not survive with less than severe handicaps.

The sick elderly

The sick elderly consume the largest proportion of the health care

This article is made available by the Institute for Family Advocacy & Leadership Development and cannot be used except for the sole purpose of research and study

File Number 10338

Page 2 of B

budget. They occupy the most beddays in secondary and tertiary hospital facilities. They are less resilient to injury and disease than the younger age-groups and therefore deserve special consideration,

There has been debate about the appropriateness of some active interventions in this age group. The over-zealous use of life supporting treatment is not uncommon and over-treatment occurs among these patients. On the other hand, there is a a tendency in our society to "put away" our frail elderly into nursing homes with only nominal medical supervision. Relative social attitudes to ageing may sometimes result in less sensitive care, and lowered expectations regarding quality of ⊂life. Both over and under-treatment of the elderly is ethically i unacceptable.

In addition to these two extremes, there are two other broad groups of patients - the competent (albeit with disease or disability) and the incompetent including both those patients who are demented and those who are permanently confused. Ethical considerations in the treatment of patients who are incompetent are different in important ways since the wishes of

the patients may not be known, family members may not be able or willing to make treatment decisions on the patient's behalf and the attending physician may feel unable to make hard decisions which would benefit the patient.

Two other important matters might be considered - the ethical implications of the management of the terminally ill and the matter of

euthanasia.

the different circumstances which have been described.

Case 1

Mr J.G.S. is a 97-year-old man. fully cared for in a nursing home, having been admitted seven years ago following a severe stroke. He is bedfast and requires total nursing care. He has no apparent awareness of the world around him and is unable to communicate. His family

"Both over and under-treatment of the elderly is ethically unacceptable."

In the management of the terminally ill, the patient's overriding right to die in comfort (if possible) and with dignity must be paramount. The physician's skills in relieving pain and distress must be matched by the compassion needed to withhold "burdensome care" ie where the management is either a burden and an inconvenience or is the means by which the inevitable end (which will be welcomed by both the patients and their families) is prolonged.

Some philosophers have argued that there is no ethical difference between active and passive euthanasia - ie between aiding death and "allowing" it to happen. However, there is legal debate about this premise and difference of opinion among medical practitioners. It is important and appropriate that these matters continue to be debated by all members of society, as is presently the case. (The provision of fluids and food for routine care for any patient, is seen to be outside the consideration of treatment intervention.)

The following ethical principles of treatment would apply:

- The elderly patient has a right to competent and sensitive medical
- 2. Where they are known, the patient's wishes must be considered.
- Treatment should be used to improve the quality of life for the patient, ie the expected result is improved physical comfort, restoration of function, return to independence and a dignified lifestyle.
- 4. The wishes of family members and in many circumstances, the nursing staff involved in care, must be sought and carefully considered.

Two clinical cases may illustrate

ceased visiting four years ago and their whereabouts are unknown.

The general practitioner is called to see him in the middle of a winter flu epidemic. He has a cough and temperature and signs of pneumonia. The doctor discusses the case with the nursing staff. Increased fluids are ordered and aspirin for fever. Antibiotics are NOT ordered. The patient succumbs to pneumonia four days later.

Case 2

Mrs R. M. This 74-year-old widow has mild Parkinsonism well controlled with drug treatment. She suffers angina following a heart attack 10 years ago. She lives alone, relying on a daughter for shopping and outings. She is involved in local senior citizens and church groups. In addition, she has strong family ties and keeps in touch with several grandchildren.

Her mobility and independence are threatened by increasing pain in both hips due to arthritis. Her medical advisers have suggested bilateral hip operations. Her heart disease makes this prospect hazardous.

Her general practitioner calls together her family members and the matter is discussed. The patient strongly argues for operation despite the risk. The family and the doctor concur.

She suffers a heart attack on the second day after operation and subsequently a stroke necessitating ventilation in intensive care. If she shows no improvement in mental function over the next four weeks should ventilation be continued. Would the patient wish to continue living like this?

4. Refusing treatment? Withdrawing treatment?

The Medical Treatment Bills, recently passed into legislation in laws give protection to doctors acting in accord with their patients' wishes; on the other hand, beginning or continuing atreatment against patients' wishes becomes an offence.

Introduction of this Bill produced considerable appropriate public discussion and controversy. Public opinion polls suggested strong majority support for the right to refuse treatment in defined situations.

It can be said, then, that such public approval adds an ethical right to the legal right. Those who disagree with it may ignore it, or publicly declare their opposition, but do not have a right to interfere with those who might exercise this right. The nature of the public discussion was in marked contrast to the most usual type of public exposure to ethical issues, viz exploitation of a tragic individual situation by newspapers and television.

While the impact of the Victorian legislation cannot yet be assessed, the legal and ethical right to refuse medical treatment has been well established in the United States for some time. There, much more attention is now being given to how non-treatment decisions can be made for incompetent individuals (the discussion to follow relates mainly to adults; the additional considerations relating to newborns are referred to below).

In contrast to the situation in Australia and Great Britain, doctors, legislators, press and the public in the United States have made

Victoria, give mentally competent reconsiderables efforts; to specify persons of 18 or more years the legal secriteria for those who must decide right to refuse medical treatment, sifon incompetent; patients. Court even life-saving treatment. The new prulings have been given, for sifor incompetent; patients. Court instance, on treatment for persons mwith progressive neurological diseases and vegetative states. A key unresolved controversy is whether or not such rulings may apply to those who are not terminally ill, for instance, those in a vegetative state, or close to this, but not requiring more than feeding and nursing care.

It may be impossible for any third party.

1. to avoid a conflict of interest

treatments which may be refused; by patients or withheld ... by their doctors.

(d) More controversial again, is the situation where the person's preferences were never stated and therefore will never be known. For this, the following have been suggested:

> To allow the family to make the decisions (considered to be fraught with difficulties and dangers by some). This system has two key faults the wishes of the

"Public opinion polls suggested strong majority support for the right to refuse treatment in defined situations."

to know what the patient would have thought

It may be impossible to be sure a third person could not materially

A variety of situations is apparent in overseas experience.

- (a) Living wills (see below) are often given legal status and acted upon. There is little awareness of the concept of a living will in Australia.
- (b) A "durable power of attorney" given to another person has been upheld, at times (leading in one instance, to cessation of feeding a person in a permanent vegetative state).
- Artificial methods of providing food and water are now included, along with more complex medical treatments, as

incompetent can never truly be known and conflicts of interest not always avoided.

- To appoint a person or (ii) persons who after discussion with relatives and friends, makes decisions based on what, it is felt, the person concerned would have preferred.
- (iii) To develop comprehensive legal guidelines and procedures to cover cessation of life-supporting treatment (whether this could be done successfully is open to doubt).

Many would prefer not to think about the options. Others fear that any such discussions open the way to

File Number 10338

Page 4 of 8

killing the aged, the no-longer-useful, and who next? (The "thinedge-of-the-wedge' argument; them "today tomorrow.) The safest noption, though, would appear to be the gradual development, sidelineation and expression of community ideas and values, at a local level initially, providing a solid basis for individual decisions. at most in the state of the state of

How do they affect ethical decision-making?

To long established rights such as freedom from assault by others, (e.g. being able to refuse unwanted medical treatment) are now added newer asserted rights in access to services (eg access to any available medical treatment).

In the situations under discussion, the following rights of the patient may be identified:

- The right to be treated in his/her best interests.
- (b) The right to life equal rights for all children and adults.
- (c) The right to dignified life a qualification of (b) above -Which recognises that there are limits to the application of medical services in support of life itself.
- , (d) The right to choose between treatment and non-treatment a right of all competent human beings.
 - The right to adequate information - a right which relates both to the general policy of any medical institution or service and to specific information relevant to the illness and likely outcomes, to enable genuine choices to be made, concerning treatment and non-treatment.
 - The right to prompt initiation of treatment where prognosis is uncertain - a right of all patients.
 - The right to cessation of treatment that is unduly burdensome - a right of all patients.
 - (h) The right to relief of pain a right of all patients.
 - The right to seek alternative diagnosis — a right of all patients to seek further professional or other judgment or opinion.

The rights of other interested parties can be summarised as follows:

(a) The right of parents - a right to judge what is in the best interests of their child (this would include treatment versus non-treatment decisions).

- (b) The right of relatives and close friends to assist in judgments about the best interests of patients for whom they have care.
- The right of physicians and (c) helping professions to act in accordance with professional standards.
- (d) The right of physicians and helping professions to refuse to offer or participate in treatment to which they conscientiously object.

challenged, what, instead, should take its place?

6. Living Wills — what value? na na che Carron del

Living Wills, which are also known as Advance Written Directions, are a means by which individuals may direct in writing that they do not wish to receive certain treatment if in the future they become terminally ill or severely impaired.

The concept first received legal acceptance in the 1976 Californian Natural Death Act which was passed

"Patients also have duties and responsibilities, including cooperation and compliance with agreed forms of treatment provided by their carers."

- (e) The right of physicians and helping professions to assist in judgments about the best interests of the patient.
- The right of society the right to determine by the allocation of resources, the setting of general rules and standards and other means how far the interests of various kinds of patients can be

In addition to these identified rights, it should be acknowledged that patients also have duties and responsibilities, including cooperation and compliance with agreed forms of treatment provided by their carers. The exercise of personal rights of patients may sometimes be in conflict with responsibilities to other individuals and to society as a

In any particular situation, it is likely there will be conflicts between the rights of various interested parties and also between rights which may be asserted in regard to the individual patient. None of these rights will be of over-riding importance in any and every situation. Where there is a conflict of rights or claims, a conscientious judgment must be made about the appropriate ones on which to act.

Traditionally, the chief responsibility for such judgment has almost always rested with the physician to whom society delegates this responsibility in the expectation that he or she will take full account of the interests of the parties and the significance of the values at stake. If this traditional responsibility is to be

as a consequence of a number of right-to-die cases including the Karen Ann Quinlan decision in 1975. The majority of American states now have similar legislation.

The South Australian Natural Death Act (1983) provides that a person of sound mind above the age of 18 years who desires not to be subjected to extraordinary measures in the event of suffering from a terminal illness may make a direction in the prescribed form. The direction must be witnessed by two persons. The Act defines both "terminal illness" and "extraordinary measures '

This useful concept has prompted consideration of a number of issues:

- (a) The rights of terminally ill patients to refuse treatment.
- (b) Definition of "terminal illness", 'life sustaining procedures' "extraordinary measures" and other key terms in the legislation.
- (c) Appropriate and inappropriate application of medical technology.
- (d) The criminal and civil liability of physicians and other health care providers who comply with a patient's advance written direction.
- (e) Guidelines for physicians regarding the termination of life support systems.
- (f) The impossibility of a patient knowing all future conditions, including personal circumstances, when an advance written direction is made
- (g) The degree of formality required to make an advance written direction valid.

7. Who should decide for newborns?

While doctors have traditionally made "life and death" treatment decisions for newborns with no clear obligation for consultation, there is an increasing community expectation that parents should have a

HARD BOOK BOKEN

between 'ordinary' and 'extraordinary' treatment measures helpful. 'Ordinary' treatments are usually held to be obligatory, while it is generally accepted that decisions need to be made regarding 'extraordinary' measures. 'Ordinary' treatments are those which are well established, likely to

"Should the lives of extremely low birth weight and/or severely disabled infants be sustained simply because we have the technology to do so?"

central role in this process. It is, after all, the family that must live with the consequences of the decision. Others have suggested various roles for Newborn Ethics Committees in a consultative and advisory capacity or as the final adjudicator where a conflict exists. Legal action has rarely been necessary and is usually viewed as a last resort.

Each of these parties may have a contribution to make in deciding what is "in the best interests" of the infant and a consensus decision can usually be reached. Ethical dilemmas are most likely to arise when the parents and doctors disagree about the appropriate course of action, usually in a situation where the chances of death or significant disability are high. Such decisions involve qualitative judgments about the infant's prospects and some people would argue that the principle that "everyone is equal and all treatment should be applied' should always apply. Most would agree, however, that a point can be reached where futile and aggressive overtreatment becomes a more serious concern. Upon what criteria should such decisions be made? Should the lives of extremely low birthweight and/or severely disabled infants be sustained simply because we have the technology to do so?

Predictive information can never be totally conclusive and it is perhaps inevitable that mistakes will be made. There isn't necessarily a "right" or "wrong" choice — often a decision must be made on what is "the least undesirable" option. The pain of treatment, subsequent quality of life, social considerations and cost all have some bearing on the final decision of how aggressive treatment should be.

Many people find a distinction

be effective and not too painful or burdensome to the patient, while "extraordinary" measures are those which go beyond some or all of these criteria. At a time of rapid technological advance and escalating costs, this distinction cannot always be clear.

"Extraordinary" treatment has also been defined as that which would prolong the dying process, so that when death is inevitable or highly probable, employing all available technology could be regarded as "extraordinary". Such distinctions imply that if the physical, emotional or financial costs of continuing treatment are unbearable, one is not obliged to

and the parents would be appropriate, the ultimate decision should be theirs. Parents would often equally claim this role, feeling a moral if not a legal - right and obligation, to make, judgments concerning their infant's welfare. In fact, while parents appear to have the right to informed consent to their infant's treatment, they do not have a right to what might be called "informed dissent". Their rights to control over their newborn's treatment effectively cease when they make choices which are regarded as "unacceptable" by their infant's doctors as well as in extenuating circumstances such as serious mental illness or when the parents cannot reach agreement between themselves.

Parents do however have the right to seek alternative opinions and careers. Both parents and doctors have a responsibility to care for the infant, and each would similarly feel an obligation to protect the newborn from harm. Who should decide when doctors believe treatment is justified and necessary while the parents involved believe that the proposed treatment is futile and perhaps cruel and abusive?

While it is unlikely that a solution satisfactory to all concerned can be found in every situation, some believe that there is a role for a "Patient Care Ethics Committee" (see Section 9, below).

"Predictive information can never be totally conclusive and it is perhaps inevitable that mistakes will be made."

pursue it if there are very few likely benefits.

Many suggest that ideally, the responsibility for a decision to withhold or withdraw treatment from a newborn should be shared—undue emphasis should not be placed on an individual doctor's assessment and parents should not have to bear the anxiety, guilt and grief alone. Parents will almost always want what is best for their children; however there will always be occasions when parents and doctors do not arrive at the same conclusion. Who should then decide on the "best interests" of the infant?

Some doctors feel that their role is one of "advocate" for their patients and that while consultation with their medical and nursing colleagues

8. Costs and who pays

This discussion would be incomplete without some acknowledgement of resource constraints and of the finite funding of the health care system. As a society, we already know how to provide people who would benefit from them with more services, procedures, tests and medication than we can afford to pay for — and we are inventing new tests and drugs all the time.

Many of the new procedures and treatment regimes are extraordinarily expensive and could not be afforded by the majority of individuals, so that government, or society, has to pay for them. Every time we provide an expensive

This article is made available by the Institute for Family Advocacy & Leadership Development and cannot be used except for the sole purpose of research and study

File Number 10338

Page 6 of 8

procedure or treatment to a person it is at the expense of something else ic something has to be foregone.

For many of the interventions in the health care system, there is no argument that people will benefit and it is what we should be doing. However, when we are considering providing very expensive treatment which has very little chance of a successful outcome, we should also be considering whether it would be wiser and more compassionate, as a society, to spend our money elsewhere. We cannot afford to do everything.

This refers to costs only in money terms. In addition, there are those costs which are other than financial - the costs of time, the social costs and those of distress, anxiety, pain, suffering experienced by all the people involved in these difficult decisions - family, friends, health professionals and others.

9. Patient care ethics committees: what role?

Many larger Australian hospitals have patient care ethics committees whose work largely relates to the ethics of proposed research. The usually included: physicians, nurses, membership and workings of such committees reflect this role. By their nature, such committees are empowered by their hospital executives to make binding decisions. Such committees will often be quite inappropriate (both in personnel and approach) for the very different task of discussing individual ethical problems involving

Patient care ethics committees were first suggested in the USA in the '70s and arose from the notion that individual physicians could or should not make decisions about withdrawing life-sustaining treatment on their own.

Many possible roles for patient care ethics committees have been suggested and include educating hospital staff in ethics, developing policies and procedures to promote ethical decision-making, acting as a resource of expert information, discussing ethical options following consultation and on request, counselling care-givers, patients and families. The composition of ethics committees has been widely argued. Some or all of the following are

ethicists, lawyers, clergy including theologians, philosophers, patient representatives and administrators.

Should patient care ethics committees make decisions about patients? Such committees don't have legal authority, but there may be value in spreading the burden of responsibility amongst (presumably) capable and respected professionals. Members of the committees may be unable to agree or they may tend to veer towards a "safe" decision eg safer for themselves or the institution. Inevitably such decisions will be influenced by the feelings. experiences, prejudices, family background and religious beliefs of committee members. But should such factors supersede the patients' own rights and responsibilities to accept or reject treatment or in the case of a child or incompetent adult, the family's feelings about the situation?

In most difficult ethical situations, there is a range of options, often with little to choose between them. Trends here and overseas are for patients and/or their families to make their own choices after comprehensive discussion. The only

File Number 10338

Page 70-8

exceptions are where the family goes beyond the limits of acceptability, ie wishing to do what will not be tolerated by society such as allowing a child with otherwise excellent prospects to die by refusing a surgical operation or blood transfusion.

For further discussion, then, it is suggested that patient care ethics committees in hospitals should be available to provide information, discussion of options, expert

in exceptional circumstances, eg with major congenital where for instance, the infant is abnormalities, it is likely that likely to die soon anyway or will suffer life-long pain and distress, but not just because, for instance, there may be some degree of mental handicap in the future. In the legal view, it appears that short of "no life at all" quality of life is not a relevant criterion which doctors

may weigh up when deciding

"There may be value in spreading the burden of responsibility amongst (presumably) capable and respected professionals."

opinions and counsel for both patients and care-givers, but should never determine and direct what is to be done in any situation.

10. Horse-and-cart laws for space-age medicine?

Australian laws applicable to limiting treatment were in place decades before modern lifesustaining techniques became available. Australian and English laws are essentially the same in this area and often differ considerably from American laws. It would appear, then that -

- (a) Contrary to popular belief and expectation, parents do not have a legal right to determine that their infant, severely compromised already, be refused treatment, without which the infant would die.
- (b) Courts of law, once involved in such situations, are likely to determine that life-sustaining treatment must be given except

whether to undertake aggressive or expectant treatment.

- A doctor who omits to undertake routine treatment, which any doctor of average competence would have undertaken, when such omission can be shown to have caused the death of the patient, may be charged with manslaughter. Where such omission was deliberate, intending to cause the death of the patient, such omission may constitute murder. On the other hand, the law would not appear to require heroic measures in all situations.
- (d) It is probably true that the law would prefer the medical profession to maintain its own standards, which would also satisfy public expectations, but once involved, judges would have no option but to interpret the law as they saw it.

In cases of extremely low birthweight babies and some infants

both doctors and parents at present occasionally make decisions which may not be acceptable under present Australian laws yet which would miprobably be considered reasonable by most Australians.

(e) Acts of omission are seen in exactly the same light as acts of commission in this regard. The law is concerned about the intent in the minds of those involved.

Generally the law should facilitate appropriate ethical practices rather than being prescriptive. Rigid definitions of required practices in particular situations would only hamper appropriate ethical practices.

There are obviously differences of opinion both within and between professional groups and among members of the public. These differences clearly indicate the need for wide and extensive discussion.

The Following Questions Must be Asked

Can the law be made more interpretable or should we await "test cases" to define particular situations?

Are any changes in laws required, so that the interests of the people are best served?

The aim of this document is to stimulate further discussion of important ethical issues within the community. If you wish to comment on how this aim could be achieved or on any other specific issues raised above, write to.

National Health and Medical Research Council, GPO Box 9848, Canberra, ACT 2601.

This article is made available by the Institute for Family Advocacy & Leadership Development and cannot be used except for the sole purpose of research and study Page 8 of 8

File Number 10338