First Report on Inquiry into Options for Dying with Dignity

Incorporating a Discussion Paper: A Range of Views on Options for Dying with Dignity

March 1986
PARLIAMENT OF VICTORIA

SOCIAL DEVELOPMENT COMMITTEE

FIRST REPORT ON

INQUIRY INTO OPTIONS FOR DYING WITH DIGNITY

INCORPORATING A DISCUSSION PAPER:
A RANGE OF VIEWS ON
OPTIONS FOR DYING WITH DIGNITY

Ordered to be printed
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The SOCIAL DEVELOPMENT COMMITTEE, appointed pursuant to the provisions of the Parliamentary Committees Act 1968, has the honour to report as follows:-

1. FUNCTIONS OF THE SOCIAL DEVELOPMENT COMMITTEE

Under the Parliamentary Committees Act, 1968, Section 4E, the functions of the Committee are to inquire into, consider and report to the Parliament on:

(a) any proposal, matter or thing concerned with the social development of the people of the State;

(b) how the life of individuals, families and communities in the State may be improved; and

(c) the role of Government in promoting the welfare of the people of the State.
2. TERMS OF REFERENCE

The Social Development Committee received a reference from the Governor in Council dated 17 December 1985:

To invite public submissions, especially from those who care for patients, to consider, make recommendations and make a final report to Parliament before 11 September 1986, having regard to the greatly increased technological capacity to sustain life, on:

(1) whether it is desirable and practicable for the Government to take legislative or other action establishing a right to die,

(2a) the fundamental question as to whether, and under what circumstances, if any, a person should have a right to die,

(2b) what is an acceptable definition of "death",

(3) the right of an individual to direct that in certain circumstances he or she be allowed to die, or assisted in dying and the form which such a direction should take,

(4) the right of an individual who has not and is incapable of giving such a direction to be allowed to die, or assisted in dying,

(5) protection for medical, nursing and other professionals who allow an individual to die, or assist an individual in dying, including the need for guidelines for carers in the use of life sustaining equipment and procedures and the need for continuing counselling and after care,

(6) relevant literature, legislation, judicial decisions and other relevant developments in Australia and overseas including, but not limited to:

   (i) the Quinlan case in the U.S.A.,
   (ii) the Barendregt case in the Netherlands,
   (iii) the Californian and South Australian Natural Deaths Acts, and the Yale Legislative Services Model Bill: Medical Treatment Decision Act, 1978,
   (iv) the ongoing work of the Victorian Law Reform Commission,

but not to consider any issue associated with the termination of pregnancy.
3. APPROACH TO THE INQUIRY

The Committee is required to invite public submissions on the terms of reference of the inquiry. It has decided to publish this Discussion Paper at the same time as it advertises for such submissions. Its purpose in so doing is to assist those individuals or groups who wish to participate in the Committee's inquiry. The function of this document is to provide an insight into some of the highly complex matters raised by the terms of reference.

The Discussion Paper has been prepared using the contributions of eminent experts from a variety of backgrounds who are in day to day contact with issues and matters raised by the inquiry. It is intended that the views of the panel should form a focus, stimulus and catalyst for the general public.

The Committee has noted the intensity of public interest and wide community debate surrounding the complex issues raised by its terms of reference. It desires at this stage to inform Honourable Members and place before them material prepared as a basis for discussion of the various issues raised by the inquiry.

It should be very clearly understood that this Discussion Paper is not intended to be exhaustive or conclusive, and that the contributions of the panel are not necessarily the opinions or views of the Committee. The Committee does not, by publishing the Report, signify its endorsement of it or of any of its conclusions. This Discussion Paper is published in accordance with the Committee's policy of assisting the public to participate in its Inquiries. The Committee recommends that all those interested in making submissions to the Inquiry should first read this Discussion Paper. By this method the Committee hopes that the terms of reference will be fully addressed in an informed manner.

Committee Room,
19 March 1986.
The authors of the following contributions come from a variety of backgrounds and professions and this provides an illustration of the many perspectives from which people may debate matters raised by the Inquiry.

In setting up the consultant panel the Committee has been aware that it is not possible to represent all shades of opinion, nor all occupational groups caring for patients, in its Discussion Paper. Those members of the public who feel there are significant omissions or an unfair balance in the overall effect will, of course, have the opportunity to rectify the matter by making a submission to the Inquiry. At the forefront of the Committee's considerations has been the practical problem of putting together a variety of views in a succinct and publicly useful document, while allowing the panel the chance to provide a worthwhile and stimulating contribution.

The deadline for receipt of submissions to the Inquiry is Friday, 30 May 1986. Submissions addressing the terms of reference should be forwarded to:

    The Secretary  
    Social Development Committee  
    1-15 Little Collins Street  
    Melbourne, 3000  

The Committee's final report to be tabled in the Victorian Parliament prior to September 11, 1986 will indicate the Committee's recommendations and major findings of the Inquiry.
DENIAL AND ACCEPTANCE

REV. HOWARD C. AINSWORTH
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Summary

This paper argues that denial of death has been a fundamental force in civilisation. It gives a Judaeo-Christian basis for relativism rather than absolutism. Legal recognition of hastening death would improve the doctor/patient/relatives relationship. The patients' right to information should be improved.

The concept of a "right to die" is rarely workable. Legislation is desirable but difficult to achieve satisfactorily. The dilemma of malformed babies raises the need for legal recognition of the doctors' and parents' responsibility to decide.

We need a statutory definition of death. Brain death is the death of the person.
FACING THE QUESTIONS

At least for those of us who are not living with specific and immediate portents of our dying, there is something offensive about facing up to the question of whether or not our laws should be changed to allow death or hasten death willingly in certain of our fellow human beings.

The question threatens something fundamental about religion, morality and ethics - something fundamental about civilisation itself.

We need to explore the nature of this threat if we are to address the question in ways which are sensitive and helpful.

Apart from death, the other universal human experience is birth. The two are not separable. At the psychological level, our first death occurs at birth. We are expelled from the womb, the all-supplying foetal cord is parted and our first statement is normally a yell of protest. That yell is also a gulp of our oxygen supply. We die to the womb and with varying degrees of success we adjust to ever-changing environments. The adjustments are all accompanied by the experience of having our being or well-being threatened. Pain accompanies hunger so we yell for the breast or the bottle. When our stomachs can't cope with what we have consumed, we hurt and feel threatened. Life is a continual oscillation between threat and pleasure, loss of well-being and satisfaction, need and fulfillment.

What do we do to cope with the threatening aspect of our universe?

We vest the powers of our universe in persons, objects and ideas. Thus, from birth, the energy with which we relate with our environment is the energy of the psyche to survive by denying that we are vulnerable and mortal. Our lives depend on our capacity to be possessed by others - other people, other objects, and by ideas. The power of our denial-needs is the power of being possessed by the other. Herein is the energy for relationships, creativity and social organisation.

To generalise: our amazingly complex systems of human relating, organising struggling, loving and creating are formed by our need to deny our vulnerability as flesh and blood organisms in a physically implacable universe.
To quote some great thinkers:

"Few people can be happy unless they have some other person, nation or creed."

(Bertrand Russell)

"Neurosis is the way of avoiding non-being by avoiding being."

(Paul Tillich)

"The cave-man looks out into the darkness listening to the sounds of the deadly animals and the cries of his hungry children and starts to 'people the sky with gods and god the sky with people'."

(Edward Stein)

We are possessed by the systems and relationships in which we stake our security. We are pursuing our need to deny that we are mortal. Our "downfall" is also our "salvation".

So to question whether striving against death should in some instances be suspended is superficially to threaten both the source and the raison d'être of all relationships. No wonder we feel offended by the need to address the question.

**Judaean-Christian Background**

Christianity inherits and upholds the Judaistic ethic of the sanctity of human life. This sanctity derives from the intimacy of the relationship between God and persons. Herein is a theological basis for the respect for persons and especially for persons who are unable to look after themselves.

But while respect and protection for human life is a basic principle for Christians, the absolute value of human life is not. The question of the absoluteness of the value of physical human life cannot be considered in Christianity without reference to the physical death of Christ himself. The death of Jesus happened in the context of Jesus' struggle with what it means to be faithful to the character of God. Obviously, in the experience of Jesus, absolute value of human life was not consistent with the nature of God. Jesus gave his life, including his physical life.
In Judaeo-Christian experience, the basic human condition is seen as "creatureliness". The problem of consciousness is represented in the myths of the Fall, the expulsion from Eden and the doctrine of Original Sin. In Christian tradition the ultimacy of the power of our need to deny our creatureliness has been removed by Christ. He made clear a faith-relationship between creature and Creator. He embodied the alternative to all the gods spawned of the human need for denial. So relativism is closer to the Christian position than absolutism. There is a relativity between the quality (sacredness, from intimacy with God) and the physical continuance of life.

**LOVE YOUR NEIGHBOUR**

"Love your neighbour as (you would love) yourself" is an honoured precept. It hinges on the way we love ourselves.

I can say without any doubt that I can think of circumstances in which I would choose to die and I would be choosing in a spirit of love for myself, my environment and God. Many people who are experienced in the care of extremely debilitated, pain-wracked terminally ill people are confident in their choice of what they would want for themselves. They rarely however assume that is what their patients choose. Familiarity in this field does not often breed contempt. Rather it refines one's respect, care and awareness that every person is a unique individual.

The parable told by Jesus to illustrate his meaning for the Golden Rule indicates that one's relationship with the person who becomes one's neighbour is, at its best, based on need and personal responsibility. Creed, religious rule, temperament, ideology and culture are all transcended by the relationship of personal responsibility. This process of transcendent love is nowhere more common than in the relationship between a helpless, dependent, hurting person and those who have the care of him or her. Both transference and projection, in the Freudian sense, are also transcended in true responsibility.

Just as denial of creatureliness is a universal human characteristic, so is the potential for admission of creatureliness. We need our self-protective ideology but we can transcend it when we no longer avoid vulnerability in ourselves and the other person.
THE CULTURAL PROBLEM

It is very common for persons accepting the probability of their own death in the near future to remain concerned with THE WAY they will die - "Death itself does not worry me; it is HOW I will die that I worry about". We have come to expect a generally high standard of humanity in our healing professions. Normally there is congruence between the feelings/thoughts of dying persons and the medical treatment they are receiving. As we develop life-sustaining technology there are more individuals for whom there is a clash between them and the treatment they are receiving. A weary, terminally ill eighty-year-old lady, too weak to speak, wonders what all the fuss is about as the Surgical Registrar phones the Consultant to weigh the question of yet another operation. The patient has good reason to wonder whether she will ever again have a quiet minute or two with her loved ones free of tubes, pain and an oxygen mask. After her death two days after surgery her relatives and attendants are left to wonder whether she would have preferred to die the way she lived - graciously and with dignity.

Sometimes the clash is painfully obvious to the treatment-givers but the treatment is technically and ethically mandatory. At other times the clash is apparent to the few who know the patient well, but the treatment continues because of lack of personal communication between the decision-makers and the dying person and his/her intimates.

The conditions which lead to this lack of communication exist in our culture and codes. Culture takes too long to catch up with and "handle" technology. For most of us, those who are competent in their field of technology are beyond our field of communication - "They know what's best". There is a real sense in which the medically qualified person stands between me and my mortality, so I need to feel that he/she is competent in more than just the technologies of medicine. To think of questioning whether or not the doctor should actively treat me is to allow a threat to the codes which I normally trust to stay alive and well, and the codes to which the doctor is committed.

So to pursue the concerns as to how one will die is to trespass in an area which is culturally taboo. Many dying persons have gone ahead of our normal codes and in acceptance of their mortality have welcomed death as an appropriate and positively meaningful prospect. They have been rather alone in their journey, leaving the rest of us behind with our very different prospect. These "pioneers"
remind us that we are not just ethical and social beings; we are also physiological and existential individuals. They encourage us to consider carefully our responsibilities to those whose lives are maintained artificially and who can or cannot say what they are prepared to tolerate in order to stay alive.

If the energy with which civilisations are constructed is really the energy of our psychological defence against mortality, then the person who is dying is in a sense moving beyond the normal constructions of civilisation. In dying we are on the frontier of civilisation where customary religion, morality and law are clumsy and inadequate.

We would know of more exceptions to the rule of denial if we were to acknowledge our denial-needs and listen to those who are coming to the end of their lives in ways that are lively and authentic. Too often our treatments preclude any possibility of a person living out their dying in their own way. In the best professional practice and in the best of family support the moral being of the dying person is attended to with as much consideration as his/her physical condition. Public morality, expressed in law, sometimes overrides the moral being of the individual.

If a person is known to have other terminal and potentially distressing diseases the medical information alone suggests the appropriateness of asking whether, in a heart attack the person should be actively resuscitated. Respect for the person requires that the choice should be considered. It is a professional responsibility to consider whether or not the patient should be consulted, but the training for such responsibility is still lacking. Death remains defined as the "enemy" to be avoided without question. We often act as though every patient, without being consulted, will choose to suffer pain, indignity and even a vegetative state rather than allow the dying process to continue.

In effect, we hold the privilege of technical medical information in a context of conventional morality as though every individual conforms to the convention. In fact, given the information, some people integrate their terminal condition in a way that makes their dying process a life-affirming "closing of the curtain". To have withheld the information and to have failed to involve them in decision-making, would have deprived them and their attendants of the humanity and deeper values of a lived dying process.
How many more people could die this way if we learnt the finer responsibility of trusting in the capacity of persons to handle what is really their own most personal business? The right to refuse medical treatment is effectively denied a person if he/she is not given all the information available by which to decide whether or not a treatment is wanted.

"THE RIGHT TO DIE"

These words require discussion. We could say, "this person has a right to die" and on that basis bring about death. In strict fact, the idea of the person having any rights at all may be academic in the sense that he/she does not have any capacity to exercise or assert any rights. In fact the great majority of situations in which the right to die is an issue are cases where the person is unable to validly state any wish or thought. A right to die may refer to the rightness of dying. The rightness may be asserted by the person whose death is in question or it may be asserted by those who are responsible for him or her. Whether we like it or not, our responsibility for ourselves varies from total to nil. It is normally shared. The way we exercise responsibility is the focus of the need for changes in law.

THE LAW. DO WE CHANGE IT?

Any surveys of the status quo and of attempts to reform the law concerning dying lead inexorably to the view that the status quo has worked well so long as doctors have been able to break the letter of the law without being challenged in a court. Attempts to reform the law to make legal what has been humane, professionally correct but illegal, have been tentative and difficult. A healthy wariness of abuse of legal freedom has usually prevailed. The right to refuse treatment has been a workable concept on which to write law, but the right to die is not workable in most cases. We can anticipate that however much a law is refined before it is proclaimed, it will not meet all the situations which it is designed to meet. It is neither desirable nor practicable to regulate by law what happens in a professional caring relationship. At present, however, statutory definitions of murder, assault and negligence can be used to regulate professional decisions even though these definitions were related only to protection from criminal acts.

There is thus a need for laws to enable good professional decisions to develop free of the risk of inhumane legal interference. The difficulty is in making sure the enabling law cannot also become the instrument of inhumane interference or licence.
Both the South Australian Natural Deaths Act and the Victorian Refusal of Medical Treatment Bill seem to be attempts to legislate in one area where the right to die could be a workable legal concept.

The South Australian Act has gained some approval in the early stages of its operation. As it applies only to people who have already been diagnosed as terminally ill it leaves less scope for undesirable misapplication.

The Victorian Bill in attempting to give a person a legal right in the event of terminal illness, would, if successful, correct the present imbalance between the perception of "good" practice on the part of doctors and the perception of "good" practice on the part of individual members of the community.

However laudable the aims of the Bill, it is difficult to see how it can be made workable. One major problem is that the Declaration must be revocable. Once the declarant is physically incompetent, revocation on his/her own behalf is not possible. The declaration could then be challenged, even though a relative or agent can revoke it.

It would be necessary to write into the Declaration a statement that the declarant is aware that he/she may become unable to revoke the declaration even if he/she wishes to.

The difficulties may not be insurmountable provided we accept that the process of review and refinement may have to continue indefinitely once it is commenced.

MALFORMED BABIES

As I contemplate the dilemma of those responsible for the fate of severely deformed babies I have to acknowledge my distance from their situation before I can begin to appreciate the realities they are wanting us to share with them. I have no doubt about the rightness of providing legal recognition of the need to allow doctors and parents of severely malformed babies to decide whether or not the child should live. We expect parents of malformed children to "carry their cross" so that we don't have to carry it with them. The cross, for many, is the decision taken at birth. The decision to end the life of the child can be as heavy as
the prolonged effort of maintaining the life. We live with the possibility that we made the wrong decision either way.

The prevailing advantage of legal protection for those who may have to end the life of a malformed child is that we can then provide proper counselling and a more supportive environment for those who are involved – parents, doctors, nurses, and the "grey area" babies who are given continuing life. The community is more likely to share responsibility for the consequences of each choice if it provides legal freedom to make the choice. Legal freedom would increase the quality of the choice. People could discuss it more confidently and thus weigh all the factors more carefully for the child, the parents and society. A choice freely made is more likely to result in a wholesome commitment to the consequences. At present the stress experienced by some families of malformed children is increased by resentment of what they feel is expected of them. They are often isolated in a world which revolves around the needs of their most demanding child. The rest of the community scarcely knows how to reduce the isolation. One step in reducing the isolation is for the community to give parents and doctors legal support at the most critical moment to choose for their child and then to support them more sensitively in their commitment.

The law should set out the right of parents to state their wishes after being told all relevant information and reasonable predictions. There should be provision for the doctor to take responsibility for the decision after consultation with appropriate others. The law should commence with enactment of safeguards for the interests of the child per se.

Guidelines should allow time, wherever medically possible, for parents to come to terms with the realities they are facing so that their decision-making, and possibly their grieving, can be as natural as possible. At present too many mothers are seemingly expected to pretend that it was not a real child they were carrying. This is especially important in cases where the malformation was not diagnosed or disclosed to the mother before delivery.

Finally, there is no way of avoiding the need for trust in the practitioner's aim to do his/her best in the professional tasks. When the law recognises the need to end the lives of some malformed babies it will be easier for educators to equip their
students better for the medical and pastoral care of all concerned including medical and mursing staff. Obstetricians and gynaecologists may more freely share their observations and experience towards improving the quality of care and decision-making.

DEFINING DEATH

The realities of personhood demand of us that we accept that when the brain is dead the person is dead.

With machines maintaining lung activity, the blood circulating and maintaining body-temperature it may not be easy for on-lookers to accept that a brain-dead person is actually dead.

Death is best seen as a process; not a moment in time. Establishing the reality of death is the task of determining that the process is complete. Whilst the classical definition of cessation of circulatory and lung function still stands, modern technology also requires that brain-death be synonymous with actual and legal death whether or not there is heart and lung function.

There was no need for a statutory definition of death until the advent of human tissue transplantation required it. It is now generally agreed that insurance companies, coroner’s courts, courts of criminal law as well as surgeons require a legal definition of death.

Morally and ethically there is a need for a definition of death which has been arrived at quite independently of any consideration other than that of the need to enable people to agree that the moment of completion of dying has arrived and that the condition of death is irreversible.

The development of a standard set of practicable diagnostic procedures could well be agreed upon and publicised by the medical profession so that the community as a whole can come to terms with brain death as soon as possible.

It is my impression that doctors are finding it easier to communicate with relatives now that brain death has been defined legally. This new-found confidence removes what was once a difficult problem in helping people in the initial stages of grief.
There remains the task of defining death independently of any contingency issues even though the second definition will almost certainly be the same as the first.

CONCLUSION

This paper commenced with a thesis concerning a universal need to deny that we ever die at all.

I conclude with a (gratuitous) warning: As our dilemma's challenge us to admit our denial-needs and the endless means we have developed to meet those needs, we will be tempted to despair if we don't also learn faith. One symptom of despair is to rationalise ourselves into regarding a human being, even one's self, as "fit only for the scrap-heap".

Whatever public policy is adopted, we should set up processes to monitor the effects of the policy. Public discussion of the quality of the dying process should help create a climate in which more complete notification of terminal care decisions can be given. Trends could then be monitored in an atmosphere of trust.

At present our ethical/legal structures embody a reluctance to regulate medical practice any more than is absolutely necessary. This principle is no more precious than in the relationship between a terminally ill person and his or her carers. These people are at the frontier where ideology and legalism often clash with our sanctity.

Gradually we are learning, from those who have been there, that we can, with care, discard the products of our need to deny that we die.
Summary

Most people caring for critically ill babies believe they should have "the right to die with dignity" when high technology treatment does nothing except prolong the dying process or cause survival with severe permanent handicaps. Despite this general consensus, there is much disagreement over what kinds of conditions warrant withholding treatment, and what mechanisms for withholding treatment are permissible.

There is thus no uniformity in the practice of selective non-treatment. This leads to arbitrariness and injustice. The legality of some non-treatment decisions is unclear. Decisions are made by doctors and parents alone, and while doctors believe this is how it should be, they acknowledge that it is undesirable that the community at large has no formal mechanisms for supervising or influencing the decision-making process.

A scheme is suggested which would leave individual decisions to doctors and parents while at the same time ensuring some overall control and input into decision-making processes for other experts, the law, and the community at large.
Just as in adult medicine, advances in knowledge and technology are achieving cures or amelioration of diseases in babies which in the past resulted in death or permanent severe handicap. But there are still conditions in which modern techniques are less successful. In some, technology achieves little more than delaying death. In others death is prevented, but survival results in severe handicaps and invalidism.

Caregivers - doctors, nurses and parents - vary in their attitudes to these less successful outcomes. Those to whom the sanctity of life is paramount, acknowledge that much pain and suffering can result from unsuccessful modern technology, but they can see no solution apart from improvements in treatment regimes. Others question the value of new technology when it appears to them to achieve little whilst prolonging pain and suffering. These caregivers advocate selective non-treatment - withholding or withdrawing treatment from babies when it appears to them to do more harm than good. They maintain that society must develop mechanisms for ensuring some babies the right to die with dignity. The debate resulting from these varying views is the same in essentials as that in adult medicine, but it differs in details:

1. The strongest case for "dying with dignity" in adults arises when a competent adult with a terminal disease insists on his or her right to die. This situation never obtains in babies: all decisions are by third parties, claiming to act on the baby's behalf.

2. Accurate prognosis - being quite sure how things will turn out - can be difficult in newborn conditions. With adults, towards the end of life, with terminal diseases, outcome is usually much clearer.

3. Continuing survival of a severely handicapped baby can have a much greater effect, lasting much longer, on the baby's parents, brothers and sisters, and society, than is the case with surviving adults.

Some of the issues in selective non-treatment can be clarified by examples. Important terms used in the examples first need explanation.
Mechanical ventilators are machines which perform a patient's breathing when the patient cannot. The machine pumps oxygen in and out of the patient's lungs many times per minute, day and night. Ventilators can keep babies alive, even when their brains are dead or severely damaged, for months or years. Operating ventilators requires sophisticated nursing and other complex technologies. Ventilators achieve very good results with babies who have diseases which temporarily prevent them from breathing properly - the machine maintains life until treatment and Nature allows the baby to recover and resume breathing. Dilemmas arise when babies are kept alive on ventilators without any prospect of eventually recovering their ability to breathe. Being on a ventilator involves many painful and distressing experiences throughout each day.

Permanent severe handicaps involve various combinations of mental deficiency, body paralysis, blindness and deafness. Mental deficiency means varying degrees of unconsciousness, lack of self-awareness, and inability to show social or emotional responses. Body paralysis means varying degrees of lack of control of body and limbs, with resulting immobility and dependence on others for feeding, toileting, and other of life's basics.

Survival of a baby with permanent severe handicaps has a serious effect on its family. Marital breakdown is frequent; the mother is usually left to cope as a single parent. There is a high incidence of psychiatric disturbance in parents. Other children in the family can suffer emotional hardship and deprivation as a result. A handicapped child can destroy the family.

For some families though, the care of a severely handicapped child can be an experience of moral growth and enrichment. Most parents - especially mothers - develop an extraordinary bond of love for a handicapped child, even when its existence leads to so much hardship. Indeed, to the outsider, the loving sacrifice by parents of self and family interests to the handicapped child is a central part of the tragedy.

Feeding means different things in newborn intensive care. Some babies can suck from breast or bottle despite severe brain damage or other illness. Others cannot, and if they are not to starve, must be fed through a plastic tube passed into the stomach - tube-feeding. Intravenous feeding is a complex technology by which
chemical nutrients are given directly into the bloodstream. With this technique babies can grow normally for months or even years without any food by mouth. This procedure has frequent distressing complications, some lethal. It achieves wonders when babies have bowel diseases that prevent feeding for weeks or months, but which eventually heal. It creates dilemmas when it keeps babies alive when there is no hope that they will ever be able to be fed naturally.

ANENCEPHALY is a malformation in which a baby's brain and head fail to form properly. Babies with anencephaly have virtually no brain - they look as though the head has been sliced off just above the eyebrows. They are often born dead. If alive, most live only a few minutes or hours.

If such babies were kept warm, put on mechanical ventilators when they breathed inadequately, and fed via a stomach tube or intravenously, some could live for months or years. It is assumed, though, that anencephalics are incapable of consciousness, self-awareness, and thought. Virtually all caregivers believe that treatment which artificially prolongs life is unwarranted - the babies are better off dead.

There are about 30 anencephalics born in Victoria each year: 10 to 15 of these are alive. The condition can be diagnosed in early pregnancy by a simple test and termination of pregnancy performed if desired.

MAJOR GENETIC ABNORMALITIES - Trisomy 18: Trisomy 18 is typical of many conditions caused by abnormalities in the genetic material - the chromosomes - of the sperm or ovum. Genetic abnormalities are very basic, affecting all the developing tissues of the unborn child.

Most fetuses with Trisomy 18 are aborted naturally early in pregnancy. The few that survive to birth have severe abnormalities. The brain is malformed as are head, body and limbs, kidneys, lungs and occasionally heart. Fifty percent die within the first three months. Very few survive to one year.

They probably have no consciousness or self-awareness, although they cry and grumble. Some cannot feed at first. Most have convulsions, frequent stop-breathing attacks, and choking episodes from milk or saliva. If the heart is malformed they become distressed from breathlessness.
A tiny minority of caregivers have advocated that, since life is possible for many months, all care should be given, including mechanical ventilators when they stop breathing or choke, and even heart operations. Most caregivers believe that their potential is so poor that treatment likely to prolong life should be withheld. But decision-making cannot be so simple. Specific decisions must be made - should secretions or milk in the babies' throat be sucked out when they are causing choking episodes (both the episodes and the sucking out procedure are distressing)? Should the baby be fed? Should a stomach tube be used if the baby cannot suck? Without feeds starvation will result. With feeds, a life of choking spells and other distresses may be prolonged for months. Is it legal to withhold feeds which prolong distressing life? Should medicine and oxygen be given to relieve symptoms of heart malformation?

A few caregivers advocate giving pain relievers and sedatives to ensure avoidance of distress; these will usually shorten life. Others believe anything which prolongs life, including feeding, is inhumane, and should be withheld. Others advocate active euthanasia.

There about about 20 babies born with Trisomy 18 in Victoria each year, and unknown numbers of other severe genetic abnormalities. Some can be diagnosed and terminated in early pregnancy, but not by simple, widely applicable tests.

**EXTREMELY PREMATURE BABIES:** Some babies are born very prematurely, long before their bodies can cope with life outside the womb. Serious illnesses result, and survival depends on intensive nursing and complex technology. Before modern intensive care, babies born around 12 weeks early - weighing about 1000 grams (2lb,3oz) - seldom survived. With modern intensive care about 65 per cent can live.

Outcome is less satisfactory in even more immature babies. Of those born 14 to 16 weeks early - around 700 grams (1lb,9oz) or less - fewer than 10 percent survive. Of these survivors, 30 percent or more are left with permanent handicaps, many of them severe.

Such tiny immature babies require mechanical ventilators and other complex technology from birth. Without them they would quickly die. Although they represent only about 0.15% of all babies born, their care consumes up to 20% of resources available for the care of all sick babies.
Many caregivers believe that, despite their almost "pre-viability", the low chance of survival, the high risk of severe handicap, and the high cost in scarce resources, these babies should be offered all available care. They see the extremely premature infant as having the same right to life, and the same call upon medical resources, as any other person.

Other caregivers believe such babies should receive all care if they are very well at birth, and as long as their progress is smooth. But if severe complications occur which make their chance of survival even more remote, or severe handicap even more likely, then treatment should be withdrawn. This means turning off ventilators and oxygen, and withholding other treatment, including nourishment. The commonest severe complication which leads many caregivers to withdraw treatment is haemorrhage into the brain (intra-ventricular haemorrhage).

A growing number of caregivers advocate that all treatment be withheld from these extremely premature babies. They point to the virtual "pre-viability" of such babies, the poor chance of survival, the high handicap rate, and the disproportionate consumption of scarce medical resources that might be better used in other areas of health care; the days or weeks of distress suffered by many babies and their families before the baby dies, and the years of suffering when survival results in severe handicaps.

There were 152 babies of less than 700 grams (about 14-16 weeks too early) born in Victoria in 1983. Sixty-eight of these were born alive. Ten survived for 1 month - probably seven or eight survived overall. The handicap rate will be about 30 percent.

SPINA BIFIDA (Myelomeningocele): This is a malformation of the brain and spinal cord. There is a large defect (an open "wound") in the middle of the baby's back where the spinal cord - the nerves controlling the lower body's movement and functions - has failed to form properly. This results in permanent paralysis of the legs up to the waist, and absence of control of the bladder (urine) and bowels. The brain malformation results in an abnormal accumulation of fluid within the brain (hydrocephalus).

Death from infection can occur if the back "wound" is not operated on. The
surgery does not change the severity of the handicap - it only reduces infection, thus ensuring the baby will live. Hydrocephalus requires an operation (a "shunt") to relieve the abnormal fluid accumulation in the brain. Without this, progressive mental retardation would occur. Even with the shunt more than two-thirds of affected babies grow up with some degree of mental deficiency.

Life is very hard for a surviving child and its family. A few die in early or middle childhood. Most are confined to wheelchairs, with no control over urine or bowels. Numerous admissions to hospital and multiple operations are the rule. Sexual and emotional problems are added in adolescence.

Some caregivers believe that, despite the severity of handicaps involved, all babies should receive all available treatment they need, and they and their families should be given maximum support throughout the child's life. Others believe that life is so poor in quality for those most severely affected (about half) that treatment which prolongs life without improving its quality should not be given. Most babies die within 18 months without early surgery and other complex treatment, but a few live longer with handicaps worse than if all treatment had been given. To avoid this, some caregivers believe that not only should surgery be withheld, but babies should also be given pain relieving and sedative drugs, and not be fed. Managed this way, babies die within 3 to 6 weeks. A few caregivers believe that, since the justification for withholding treatment is that a handicapped life is not worth living, active euthanasia should be practised.

Many foetuses with spina bifida are aborted by Nature early in pregnancy. Between 25 and 30 are born alive in Victoria each year. The condition can be diagnosed in early pregnancy by a simple test, widely applicable, and termination offered.

There are many other newborn illnesses that present similar problems. Some babies suffer severe oxygen lack during the birth process (birth asphyxia). The worst affected sustain severe brain damage. In the past such babies died. Modern technology can avert death, but results in survival with severe handicaps. Some babies develop diseases of the lungs, so severe that survival is impossible without a
mechanical ventilator. Such babies may spend many months on a ventilator before eventually dying. Other babies develop severe infections of the brain – encephalitis – which can cause severe brain damage. In the past they usually died; now treatment may keep them alive.

Some babies develop diseases of the bowels so severe that the bowel is destroyed (necrotising enterocolitis, massive volvulus). When this happens, nourishment from eating and drinking becomes forever impossible. Such babies may live for months or years without chance of cure, on intravenous feeding, but this technique has frequent unpleasant complications.

Several points emerge from these examples:

1. Modern technology is able to maintain life - biological life - long after reasonable hope of recovery, or of what most people understand as an acceptable, bearable life (consciousness, self-awareness, capacity for social and emotional interactions), has gone.

2. Most caregivers believe in selective non-treatment of severely abnormal babies, at least in some circumstances. Withholding and withdrawing life-sustaining treatment are established practices.

3. Opinions differ widely as to what circumstances justify selective non-treatment. The main points in dispute are:

   (a) Can withholding treatment be justified only in babies who are dying anyway, in whom treatment will only prolong the dying process, or can concepts such as "quality of life", severity of handicaps, pain and suffering caused by treatment, and the great expense of treatment, be taken into account?

   (b) Should the interests of the baby be the only - or the main - consideration, or should the interests of the family, (especially brothers and sisters) or the interests of society, also be considered?

   (c) Should decisions be made by doctors, nurses, and parents alone, or should others be involved? Or should parents be excluded from
decision-making as too likely to consider self-interest, and the process be referred to independent bodies such as courts or ethics committees?

Caregivers also vary widely as to what is permissible in the mechanics of withdrawing treatment. For some, withdrawal means stopping sophisticated expensive treatments such as ventilators, operations, and intravenous feeding. If babies unexpectedly survive withdrawal this must be accepted. Others believe withdrawal includes all medical treatment likely to prolong life. Others still believe withdrawal means stopping feeds as well, and if necessary, giving pain relievers and sedatives which will incidentally hasten death. A few caregivers advocate active euthanasia.

4. As a result of this range of opinions, management of severely ill or malformed babies can be arbitrary, inequitable and unjust. It becomes a matter of chance what happens to an individual baby and its family. The care given will depend on the ethical beliefs held at the time by the doctors and nurses in attendance. In some hospitals, babies with no reasonable prospect of survival may be submitted to inappropriate life-prolonging treatments. In other hospitals, babies may have treatment withheld for insufficient reasons. The opinions or wishes of parents may be allowed no role in either situation.

5. The legal status of many acts of selective non-treatment is unclear. Some current practices are almost certainly illegal.

6. A point requiring mention that is not made clear in the examples, is that in Australia, decisions for or against treatment are currently confined mainly to doctors and parents. Others such as extended family, religious and ethical advisers and social workers play lesser roles. The law, and society at large, have only indirect inputs.

Despite the variations in views and practices, certain opinions are held in common, to a greater or lesser extent, by the majority of caregivers.

I. The lack of uniformity in criteria used for selective non-treatment, and the
arbitrariness and injustice that result, are seen as serious problems. (Of course, caregivers at the extremes of the spectrum of views would, from sincere conviction, like to see their own viewpoint prevail).

II. Most caregivers are very concerned about legal uncertainties. Those who practice selective non-treatment fear prosecution. They believe that, for a rational, compassionate approach to the most difficult newborn conditions to be possible, the law needs to be changed. There is scepticism, however, that the law can be sufficiently flexible and sensitive to allow optimal decision-making in all possible circumstances. What appear to be needed, in their view, are changes in the law which would redefine the legal status of the newborn.

Paradoxically some caregivers who practice selective non-treatment fear law reform. They argue that, although under the present law they may be at risk of a charge of murder, juries are very unlikely to convict caregivers acting in good faith. If the law is modified, however, caregivers may well be at risk of conviction on newly-defined offences short of murder. They hope that bodies reviewing the law will be sympathetic to such concerns.

III. Most caregivers believe that factors other than the babies' own interests should be taken into account in deciding for or against treatment. Factors considered very important are the interests and attitudes of the baby's family, especially the long-term welfare of the other children, the availability in the community of supporting resources for the future, and the financial cost of care.

IV. Most caregivers believe the decision-making process should be confined to doctors, nurses and parents. It is generally held that the parents' attitudes and desires are crucial and should be accorded great weight.

The parents are likely to be the best advocates of the baby's interests. They are best able to judge their own capacities to cope with whatever the future might hold: it is they who will have to live and cope with the consequences of the decisions made.
Caregivers believe that uninvolved people or groups cannot be as sensitive or as flexible as the decision process requires. The experience emerging from North America, where ethics committees and the courts are now frequently involved in individual cases, is very discouraging. Decisions imposed by committees and courts often appear to produce results far from ideal, and occasionally bizarre.

V. Caregivers acknowledge that serious problems can result when decision-making is confined to caregivers and parents;

(a) the arbitrariness and injustices that result have already been mentioned.

(b) abuses are possible: babies may have treatments withheld for trivial reasons.

(c) the community at large, and in particular those with relevant expertise such as ethicists, lawyers, social workers and religious advisers, can have little input or influence.

Thus caregivers acknowledge that mechanisms are needed:

(i) to give society some sort of overall surveillance and control of selective non-treatment.

(ii) to give society an ongoing influence in the way decisions are made. This includes helping to shape the attitudes, beliefs, and ways of thinking of caregivers and parents.

The issues involved in selective non-treatment are extraordinarily complex. Because they concern human life and death, and happiness and suffering, and because we are a pluralist, secular, multi-faceted society, ideal solutions do not exist. As others have said, we can only seek after the least worst solution.
The following suggestion is offered for discussion:

1. The Government should establish an expert committee (a statutory body?) to perform the role outlined below. Perhaps it could be called "The Advisory Council on Newborn Ethical Issues."

2. Decisions for non-treatment in individual cases will be confined to doctors and parents (and any other people they would like involved).

3. When an individual case is resolved - when the baby has died - the presiding doctor must register the case with the Advisory Council.

4. Upon registration of the case, the doctors and parents are immune from prosecution unless it is obvious they acted in bad faith.

5. Cases of selective non-treatment not registered will be subject to the full sanctions of the law.

6. Strict confidentiality would be preserved in each case. In unusual cases, doctors and parents will be asked to clarify details of their actions at a confidential hearing.

7. The Advisory Council would have formal ongoing liaison with learned bodies such as Colleges of Physicians, Paediatricians, Surgeons, Obstetricians, nursing professional bodies, Law Reform Commissions, Human Rights Commissions, faculties of Law, Philosophy and Ethics, and other relevant bodies both local, and overseas.

8. The Advisory Council would have research personnel to collate its own experience, and co-ordinate its links with other bodies. It would publish annual reports on its activities, including the nature of cases and decisions registered with it. It would receive reports and submissions from the public and community bodies.
It would be responsible for publicising the current approaches to ethical decision-making in the newborn. The Advisory Council, by all these activities, would amass vast knowledge and experience in the nature of newborn ethical problems, in our community and elsewhere, the decisions currently being made, and their suitability and appropriateness in the light of community attitudes, expert opinion, and the law. It would pass on this knowledge and experience to those involved in decision-making, to parents, and the public at large.

If individual doctors made decisions seriously inconsistent with the Council's experience, or repeated doubtful acts after warnings and advice from the Council, the Council could withdraw the doctor's future immunity from prosecution (but not retrospectively).

9. The composition of the Advisory Council could include Government representatives, representatives of medical bodies, nursing bodies, lay community representatives, lawyers, ethicists and social workers.

A system centred around a statutory Advisory Council would have many advantages:

a. It would keep control of decision-making in individual cases in the hands of doctors and parents.

b. It would give the community overall surveillance and control without interference in individual cases.

c. By registration of cases and publication of the Council's experience, a far greater uniformity of approach would be achieved and much of the present arbitrariness would disappear.

d. All interested parties - society, experts, and the law would have ongoing input into the decision-making process.

e. The potential for abuses would be curbed: the prospect of illegal behaviours would be avoided.
Caregivers and parents could be assured of the approval and support of the community for the difficult decisions they have to bear. This might be one of the greatest benefits of all - at present, making decisions in a legal, ethical and emotional no-man's land, the caregivers' and parents' lot is a lonely one indeed.

Further Reading


A RIGHT TO DIE?

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Summary

The so-called 'right to die' is part of the more general and fundamental right to moral autonomy, that is the right to control and determine one's life for oneself. A person has the right to control the duration of his or her life by refusing treatment. Although this will usually be based upon medical evidence, the decision is a moral and not a medical one. Where a person cannot exercise this right a proxy may exercise it but only on condition that it is seen as a decision of the person. In other words, it is the individual patient who must (by himself or herself or through a proxy) make the final decision about the termination of his or her own life, and not a physician or some other external agent making the decision on the basis of some kind of supposedly 'objective' evidence about the degree of value of 'quality' of a person's life. Any legislation must specify appropriate structures and procedures which would ensure that the decision is seen primarily as a moral decision and not as a medical decision, that as far as possible the decision is left in the hands of the person or proxies, and that the person or proxies receive as much support as possible in making their decision.
The Moral Perspective:

To speak of a legal 'right to die' implies that there is a moral right to terminate one's life, or to have it terminated, which needs to be protected by legislation. Whether or not there is a right to die is therefore fundamentally a moral question which can only be settled by moral discussion and argument. Scientific or medical evidence may of course be relevant to this discussion, but it can never be decisive in determining what is finally a question about the value of human life. What I may do, as a human being, and what I may and may not do with respect to the lives of others, are not matters which appeal to medical facts can possibly resolve.

The discussion of a so-called 'right to die' has for the most part taken place in a medical context with the advent of new medical techniques which can prolong the lives of human beings, so that the question has arisen as to the moral, legal and professional obligations of doctors to utilise these life-prolonging techniques, and the rights of patients to refuse (or to have refused on their behalf by proxies) their application in certain circumstances. Again, whereas in the past most people died in their homes, the vast majority now die in institutions governed by the medical profession. Death (like childbirth) has become a medical business. Thus, a recent American report has noted:

"As medicine has been able to do more for dying patients, their care has increasingly been delivered in institutional settings. By 1949, institutions were the sites of 50% of all deaths; by 1958 the figure was 61%; and by 1977, over 70%. Perhaps 80% of the deaths in the United States now occur in hospitals and long-term care institutions, such as nursing homes." 1

However, while the right to die debate has mainly taken place within a medical context, it raises, as I have been insisting, ethical or moral issues which can be appropriately discussed only within the framework of ethics or moral philosophy.

It may seem that I am labouring the obvious in making this point, but in fact there is a good deal of confusion over these matters. Thus, some people imply that the 'quality of life' of a patient is primarily a matter for medical determination, as though one could judge how much specifically human worth or value a person's life had solely by 'objective' medical observations and tests, very much in the same way that one can medically diagnose whether or not a person has AIDS or Alzheimer's disease. (Some exponents of the 'quality of life' rhetoric seem indeed to think that the value of a human life can be determined in an almost quantitative way as though we could place the respective lives of, for example, an anencephalic child, a Karen Ann Quinlan, an insane person, a conscious person suffering from a painful and debilitating disease, and a fully conscious and healthy person, on a kind of graduated scale with one person having 'more' or 'less' human life than the other). Again, by assuming that the issues related to dying are primarily medical issues, one is led to a distorted view of the physician-patient relationship whereby the physician comes to be seen as the main agent in decisions about death and dying - the master of his patient and not his servant.

The recognition that the discussion of whether or not we have a right to die is basically of a moral or ethical kind does not mean that all those - medics, nurses, patients, parents and families of patients, lawyers, social workers and politicians - who have interests in this area have also to be professional moral philosophers or ethicists, or at least to have done a short course in ethics before they enter the field. It does mean, however, that they have to be aware that they are entering a distinct field of inquiry which has its own requirements and rules, its own 'logic' and style of thinking and argumentation and proof, and its own intellectual history and traditions. As Aristotle pointed out, you cannot argue and reason about ethical matters in the same way as you argue and reason in mathematics and, we might add, you cannot proceed in an ethical inquiry as you might proceed in a scientific or medical inquiry.

A central requirement of moral inquiry is that we must have some kind of general moral theory about what kind of beings human beings are and what is good for them - a theory from which we can derive criteria for making particular moral judgements and decisions. 'Plain blunt man' pragmatists and exponents of inspired commonsense usually decry the need for moral theory, but in actual fact they tend to rely surreptitiously upon a half-baked utilitarianism (whatever brings about the greatest amount of human happiness is good), or a simple-minded theory of ethical
intuitionism (one just knows, or most rational or educated people just know, that such and such is good), or again they end up by espousing a wholly inconsistent set of ad hoc principles. (As a 19th century moralist observed, such people think they can summon up and then dismiss moral principles very much as one whistles up and dismisses a hansom cab).

Sydney Smith once remarked to two harridans shouting at each other from their respective doorsteps: 'Ladies, you will never agree since you are arguing from different premises.' A good deal of disagreement, particularly in the area we are concerned with here, is of this kind, that is, it springs from an undisclosed and often unacknowledged difference at the theoretical level about the nature of human beings and what is good for them. It is of course, absolutely necessary to look at particular cases, especially at 'hard cases', but the mere contemplation of such cases, no matter how heart-wringing, will not finally enable us to decide how they should be interpreted and evaluated. My differences with the position of Singer and Kuhse, for example, about the treatment of severely handicapped newborns, are not basically at the factual case level - I can understand and appreciate the terrible moral dilemmas Singer and Kuhse present and upon which their arguments rely for their force - but at the level of moral theory. In other words, I disagree with them about the nature of human beings and what is good for them. 2

At this level also, it is important that we recognise the cultural factors that shape the way in which we view death and dying. Other cultures see death "as a distinctively social event and of the dying man and those around him as fulfilling social roles". 3 As a consequence, "if there is a right time to die, and a time which it is not open to one to choose, then one can have no right to bring about one's own death prematurely." 4 In contrast to such cultures, it has been claimed,

4. Ibid. p.80.
"our dominant culture lacks any coherent concept, and perhaps any concept at all, of a right way to die or a wrong way to die, of a good death or a bad death." 5 Whatever the truth about this, it is true that our modern Western view of death and dying is embedded within a complex network of cultural beliefs and attitudes and has a certain degree of cultural relativity. We should therefore be reticent about assuming that our view is the only, or even the best, view. 6

Does a person have a moral right to die?

A recent American report on life-sustaining treatment dilates at some length on what it calls "the disservice done by empty rhetoric." Discussions in this area, the Report complains, have been confused by the use of slogans and code words such as "right to die", "death with dignity", "quality of life", "euthanasia", etc. whose meanings have become hopelessly blurred. 7 "In recent years", the Report goes on, "many have commented on the claim that patients have a 'right to die with dignity.' Much can and should be done to ensure that patients are treated with respect and concern throughout life. Insofar as 'death with dignity' means that the wishes of dying patients are solicited and respected, it is a concept the Commission endorses. Many who use the phrase seem to go well beyond this, however, to a vision in which everyone is guaranteed a peaceful and aesthetically appealing death. This is clearly beyond reach; a fair proportion of dying patients are confused, nauseated, vomiting, delirious or breathless. Avoiding these distressing symptoms is not always possible; likewise, naturalness may have to be sacrificed since mechanical assistance is sometimes required to ensure comfort at the end of life. Thus, the apparent appeal of the slogan 'dignified death' often disappears before the reality of patients' needs and desires. Comparable problems arise with other slogans that are frequently heard in discussions on life-sustaining treatment." 8

5. Ibid., p.77.
7. Foregoing Life Sustaining Treatment, p.24
8. Ibid.
We must, therefore, look very closely at the expression "right to die" and try to be clear about what it really means and involves. At the most basic level, we have, as human beings, the right to control or determine the course of our own lives and to decide how we shall live (subject, of course, to our not infringing the rights of others to do the same). It flows from the fact that I am a human person that I must freely decide for myself and be responsible for all aspects of life within my control. Others, of course, may deplore the choices that I make and the personal morality and style of life I adopt, but they must admit my right to make my own decisions and, so to speak, go to hell in my own way. Even traditional Christian theologians admitted the right of a person to follow his or her conscience even if, objectively speaking, that conscience was morally awry or misguided. The right to moral autonomy or self-determination is in fact the basis of all other rights in that it would make no sense to speak of "rights" at all unless we were able to decide freely for ourselves and be responsible for our lives. (It is indeed so much a part of what we mean by being a human person that it seems otiose to speak of it being a "right" - as though it were a distinct right among other rights).

This right to moral autonomy carries with it the subsidiary right to control the duration of one's life either by deliberately exposing oneself to certain death or by "sacrificing" one's life, or by refusing treatment which would prolong one's life, or by directly terminating one's life. With regard to the latter, there may well be religious reasons or socio-cultural reasons which make one reject the possibility of directly terminating one's life, (in the mainstream Judaeo-Christian tradition suicide has always been considered to be morally reprehensible), but from a purely moral point of view, it is difficult to deny that one does have a right to terminate one's life when there are serious reasons for such a course of action. (The older Christian moralists always assumed that suicide was committed either from cowardice, or from despair or a lack of proper "self-love", or from an attempt to "play God" with one's own life: but it is of course quite possible that I should choose to "lay down" my life or terminate my life out of proper self love, or love for others, or even out of love and respect for God.)

If I have such a moral right then

(a) I ought not to be penalised for exercising it, and
(b) I may reasonably ask another to assist me in terminating my life either by not giving me certain treatment or by helping me in directly bringing about my own death.

For that assistance, the other ought not to be penalised for acting as my servant. If it is not, in certain circumstances, morally wrong to terminate my own life, it cannot be morally wrong for another to assist me in this act. As the English moral philosopher, Philippa Foot, puts it:

"It does not seem that one would infringe someone's right to life in killing him with his permission and in fact at his request. Why should someone not be able to waive his right to life, or rather, as would be more likely to happen, to cancel some of the duties of non-interference that this right entails? (He is more likely to say that he should be killed by this man at this time, in this manner, than to say that anyone may kill him at any time and in any way). An objection might be made on the ground that only God has the right to take life but... religion apart, there seems to be no case to be made out for an infringement of rights if a man who wishes to die is allowed to die or even killed."  

Within this context, my "right to die" is part of my right to moral autonomy, that is my right to control and determine and be responsible for my life; in fact the phrase "right to die" adds nothing to the latter. Indeed, the suggestion that there is a distinct and separate right to die might lead to a misconception of the doctor-patient relationship. Here I would like to endorse the argument of the American moral theologian, Richard A. McCormick  

Speaking of 'living will' legislation, McCormick says:

"the very fact that a law is deemed necessary implies, and therefore tends to reinforce, an erroneous pre-supposition about the locus of decision-making in the physician-patient relationship."  

11. Ibid. p.405.
Apropos the Karen Ann Quinlan case, McCormick argues that the problem there arose because it was assumed that the physician "had a right to treat a patient unasked - indeed opposed." "We reject that premise," he goes on. "We believe that, both philosophically and practically, proposed laws on death with dignity or living wills tend to enshrine the notion that physicians are masters of their patients and not their servants". 12 In fact, he says, "the individual, having the prime obligation for his own health care, has also thereby the right to the necessary means for such basic health care - specifically, the right of self-determination in the acceptance or rejection of treatment. When an individual puts himself into a doctor's hands, he engages the doctor's services; he does not abdicate his right to decide his own fate." McCormick cites a statement by Pope Pius XII in 1957 making the same point:

"The rights and duties of the doctor are correlative to those of the patient. The doctor, in fact, has no separate or independent right where a patient is concerned. In general, he can take action only if the patient explicitly or implicitly, directly or indirectly, gives him permission." 13

As I have said, it is only if we see the so-called "right to die" as part of the right of the individual to control his or her own life processes that we will also see the relationship between patient and doctor (and medical institution) in its correct light.

The situation I have just been discussing, where a fully conscious person, for serious reasons, terminates his or her own life, either alone or with passive or active cooperation from another, is a relatively simple one. Situations similar to that which prevailed in the Karen Ann Quinlan case, however, are more difficult. In the latter a proxy must exercise the patient's right to moral autonomy for her and make the decision to terminate her life. On what grounds does the proxy make that decision? It is important to get the perspective right here: it is not precisely because the medical evidence irresistibly and "objectively" points to the patient enjoying such a low degree of "quality of life" - in other words, her life having such a low degree of human value that her life is not worth prolonging - that the proxy

13. Ibid.
makes the decision to allow her life to be terminated; rather, it is because one reasonably supposes that the patient, had she the power to make a decision about prolonging her life, would in the circumstances see the prolongation of her life as morally pointless. Here the proxy must take account not just of the medical evidence but also of the patient's moral (and religious) views about the value of human life and the process of dying. For example, one could envisage someone holding, on religious grounds, that a person is still a full person even though in a "vegetable" state, and that it is the will of God that a person should continue to live in such a state in the expectation of some kind of future life after bodily death. This is, in fact, a traditional Jewish view: thus, according to the Halacha,

"hastening death in order to relieve pain is not allowed, and the shortening of a dying patient's life is forbidden even if he suffers terribly. One may not be released from pain at the cost of one's life... The doctor has no authority to decide on lethal treatment for his critically ill patient, and he will be regarded as a murderer if he kills the patient in order to save him from further suffering. Finally, no one is entitled to ask his neighbour to kill him, as one has no power to appoint an agent for the fulfillment of something that one is not authorised to fulfill oneself." 14

In the case of a patient who held such views, it would clearly be wrong for a proxy to impose his or her own view about the value of life and the process of dying on the patient and to make a decision on her behalf that was contrary to her moral and religious views. Finally, if the proxy's decision is (as best as it can be) "reasonable" in that it is a judgement about her life that she, the patient, might have made had she been capable of exercising her right of self-determination, then it seems to me that another (for example, a doctor) might licitly be asked to assist in the termination of her life. Karen Ann Quinlan is in effect saying, through her proxy: (her parents) "I wish my life not to be prolonged and I ask you to assist me in this as my servant."

The cases concerning gravely disabled newborns introduces a further complexity since here it seems to be quite artificial to suppose that they have any kind of right to self-determination or moral autonomy because they have not ever had the capacity for self-determination or for framing any views about the value of life,

and in some cases, will never come to have that capacity. These are obviously radically anomalous cases and in order to bring them within the purview of normal moral criteria, we have to deem them to fall within a category with which we can deal. One could say, quite brutally, that although these newborns are humanoid, they are not really human persons in any significant sense; they therefore do not have any rights and the termination of their lives should not be seen as equivalent to killing a human person. As Singer puts it: "Killing a defective infant is not morally equivalent to killing a person". In fact, "very often it is not wrong at all.\(^{15}\)

This, however, is an impossibly severe view since it would mean that very young infants (even though normal), the insane, the senile, etc. have no rights, and therefore no right to life, because they do not also have the power of self-determination. I therefore agree with those thinkers who argue that it is more appropriate to classify gravely defective newborns as potential persons and to treat them as though they will eventually become fully actualised persons in the normal course of events. This way of deeming the status of defective newborns at least escapes the unacceptable consequences of Singer's position. \(^{16}\)

Given that grossly disabled newborns are to be seen and treated as (potential) human persons, proxies may therefore make decisions on their behalf with regard to prolonging or terminating their lives. Here, although the criterion is a vague and general one, it is "the best interest of the child" that must be the primary ground for treatment or non-treatment. \(^{17}\)


\(^{17}\) On the 'best interests of the child' criterion see *Foregoing Life-Sustaining Treatment*, pp. 134-5.
What I have tried to bring out in the discussion above, is that it is the individual patient who must (by himself or herself or through a proxy) make a final decision about the termination of his or her own life, and not a doctor or some other external agent making the decision on the basis of some of supposedly "objective" medical evidence about the degree of value or "quality" of the patient's life, or on the basis that the prolongation of the patient's life would be a social burden. It is not very helpful to make loose and gratuitous comparisons with Hitler's euthanasia program in the 1930's, but it is worth remembering that under that program, some 275,000 people were judged on quasi-scientific grounds to be "socially useless" and then gassed in centres which were the prototypes of the extermination camps for the Jews and other "racially inferior" peoples. As one commentator has written:

"In Germany the exterminations included the mentally defective, psychotics (particularly schizophrenics), epileptics and patients suffering from infirmities of old age and from various organic neurological disorders such as infantile paralysis, Parkinsonism, multiple sclerosis and brain tumours. In truth, all those unable to work and considered non-rehabilitable were killed." 18

Once we move away from seeing the decision to terminate life as a moral decision belonging to the individual patient, and as being grounded in the patient's right to moral autonomy, to seeing it as primarily a medical matter, or a social matter (taking into account, for example, whether the prolonged life of a defective newborn would be a burden upon its parents or on society at large), then we are indeed on a "slippery slope". 19

19. One might think that those who raise the possibility of allowing gravely handicapped newborns to die as a form of 'medical management' have already taken a step on this slippery slope. For a discussion of the matter, see Dennis J. Horan, 'Euthanasia as a form of medical management' in Death, Dying and Euthanasia, Dennis J. Horan and David Mall (eds.), Washington, University Publications of America, 1980, pp.196-221.
Expression of the "right to die" in legislation:

Any legislation concerned with a "right to die" must emphasise that procedures sanctioned under such legislation relate essentially to the patient's right to moral autonomy, and, in the case of severely handicapped newborns, to the "best interests of the child". Extraneous considerations, for example whether the continuation of a patient's life is a burden on parents or family or on society in general, should not be taken into account. Legislation must make it clear that it is the patient, or the patient's proxies, who are making the decision (though of course with the benefit of medical advice) to terminate life, and not the doctor or the agents of medical institutions. To make this effective, the legislation should specify appropriate structures which would ensure that the decision is seen as a moral decision (based on medical and other evidence) and not a medical decision, that as far as possible the decision is left in the hands of the patient or his or her proxies, and that the patient (or proxies) receive as much support as possible in making their often horrendously difficult decisions. (In my view, the following recent statement by a group of eminent American physicians places the emphasis in exactly the wrong place: thus, after acknowledging that "the patient's role in decision-making is paramount", the group then goes on to say,

"the patient's right to accept or refuse treatment notwithstanding, the physician has a major role in the decision-making process. He or she has the knowledge, skills and judgement to provide diagnosis and prognosis, to offer treatment choices and explain their implications, and to assume responsibility for recommending a decision with respect to treatment."  

This makes it appear as though the decision is primarily a medical one and not, as I have been insisting, a moral decision based on medical evidence.)

By 1983 there were some fifteen pieces of "natural death" legislation enacted in various American states and on the basis of experience with that legislation Robert Weir has made some useful suggestions about decision-making procedures which would help to safeguard and promote the interests of the patient rather than of, say, the interests of the parents, the family, the hospital, or society at large.  

Weir is mainly concerned with decisions about defective newborns, but what he says also applies to decision-making apropos other patients. After detailing criteria which proxy-decision-makers should satisfy - they should have relevant knowledge and information, be impartial, not be under severe emotional stress, and be consistent - Weir argues that although parents of newborns will of course play a major part in proxy decisions, they have only a defensible right to make decisions for their child.

"All parents simply do not promote the best interests of the birth-defective children born to them. In fact, it is a false assumption to think that all parents in these circumstances have the capacity to be either altruistic or impartial toward the handicapped newborns in their families." 22

The attending physician also, according to Weir, has a right to play a part in the decision-making process, but the physician's contribution, along with the views of the parents or other proxies, ought to be considered finally by a special committee comprising a physician and a nurse, a patient advocate, a parent advocate, an ethicist, a social worker and a lawyer. 23 If need be, appeal can be made from the committee to a court of law, although this should be a rare occurrence. Weir goes on to specify three safeguards that should accompany any decision in favour of non-treatment:

"(a) The proxies in a case should consult with appropriate medical specialists and other professionals before making a decision to deny treatment;
(b) The decision should not be carried out for a set period of time (perhaps a week) to allow for greater emotional stability by the parents and the possibility of a custody hearing, should that be warranted;
(c) The attending physician should provide written reasons concerning why the diagnostic condition was not treated, or why treatment in this case was judged to be optional." 24

22. Ibid. p.259.
23. Ibid. P.272.
24. Ibid.
In effect, in Weir's scheme, parents, physicians and committee would constitute a kind of collective "proxy".

Although these provisions may appear to be over-elaborate and cumbersome, I believe that something like them is necessary if we are to maintain the fine but crucial line between, on the one hand, the termination of life as an expression of the patient's right of moral autonomy (and his or her consequent "right to die"), and on the other hand, "socially useful" killing.
DYING WITH DIGNITY: A NURSE'S VIEWPOINT

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Summary

The theme of this paper reflects a belief that every person has rights including a right to die with dignity and a right to be involved in decision making about his/her future. It does not condone active euthanasia but rather emphasises the need to present options for care particularly relating to the control of distressing symptoms; nor does it suggest that one solution will suffice in all situations.

The meaning of dying and death is explored, the dilemmas confronting patients, families and health care professions with respect to life-sustaining measures are described and the emergence of "living wills" examined.

Finally several possible actions to facilitate options for dying with dignity are presented for consideration.
INTRODUCTION

Regardless of age, social, physical, psychological or economic status, all people have a right to a quality of life, a right to make decisions about their own destiny and a right to die with dignity. Indeed, two public opinion polls conducted in Australia have revealed that there is widespread support in this country for the right of a person to die with dignity¹.

Some people are afforded a dignified final phase of life while others die with much suffering and indignity. Many dilemmas beset patients, relatives and health professionals when decisions are required about the use of life-sustaining or life-prolonging measures, or the decision of a patient to refuse medical treatment.

The right to die has been legislated for in one Australian State and elsewhere²; similar legislation has not yet been enacted in Victoria although an enabling Bill was first introduced into State Parliament in December, 1980³.

This paper will examine the care of persons who are dying, the significant dilemmas confronting patients, families, health professionals, legislators and the community, and some possible options for the future.

THE MEANING OF DYING AND DEATH

Death is perceived differently by different people whether they be patients, relatives, doctors, nurses, chaplains, philosophers, legislators or others in the community. The definition varies according to the responsibilities exercised and the functions performed⁴. The traditional signs of death have been described as:

- cessation of heart beat,
- cessation of respiration,

². Natural Death Acts of South Australia and California.
pupils no longer responding to light,
clouding of the cornea,
decreased intro-ocular tension,
fragmentation and stasis of blood in retinal blood vessels,
no response to sound, pain, touch stimuli,
pallor and, later, changes to skin colour,
reduced body temperature.⁵

In some instances such criteria have been found to be unreliable since a number of premature burials, particularly during epidemics, has been reported⁶.

With the advent of sophisticated medical technology a number of countries and States of the United States of America have formally defined "brain death". For example, in France, brain death is said to have occurred when an electroencephalograph (EEG) tracing is a straight line for ten minutes while in Germany a person is said to be brain dead if unconscious for twelve hours and has a straight line EEG for a period of one hour. In Minnesota and New York, brain death is deemed to have occurred when spontaneous breathing is not sustained during a three minute period while the patient is off a respirator and during a repeated episode twelve hours later; structural brain damage, absence of brainstem reflexes, fixed pupils and lack of motor responses must also be evident⁷.

The above describes the biological definition of death but what of a definition of social death? Some people could be said to be socially dead because they do not wish to communicate or interact with other members of society and express the feeling of being "dead". This is particularly so with some people who live alone and who, for a variety of reasons, describe their day-to-day existence as intolerable. On the other hand an individual who has gross deformities or incurable illness and is unable to communicate in a normal manner may not feel socially dead since meaningful interactions can and do take place. They may have a strong will to live and an effective support system may be available to ensure this desire is facilitated.

⁵. Ibid.
⁷. Cited in Thompson, op.cit.
While a person is dying he or she is also living. Until four decades ago decisions about dying patients primarily involved the provision of comfort and reassurance for the patient and family. Since the advent of sophisticated medical technology and other intensive treatment procedures, decisions regarding the care of dying people have become more complicated, have resulted in considerable debate and have caused dilemmas for patients, health care professionals and families.

During any phase of living people have a right to privacy, a right to know the options relating to health care, a right to refuse or accept treatment, a right to feel safe and secure and a right to a "good death". Apart from suicide and sudden death, a patient depends on others to facilitate a "good death". Terminal care of a high standard is necessary if this objective is to be achieved.

Pain is what the patient feels but despite advances in the knowledge and use of pain control measures they are not always applied properly. Many patients die having experienced unnecessary physical and emotional suffering. To die with dignity requires freedom from pain and discomfort, needs continuing emotional support, maintenance of self respect and a feeling of being loved and loveable; the patient should feel in control of his/her situation. This presupposes that care in the terminal stage of life, no matter the duration of that stage, is available at the appropriate time, in the appropriate manner and, if possible, in the appropriate place.

All people have a right to refuse treatment even though this may hasten the dying process. At times, particularly for unconscious or mentally incapable patients and children, the decisions to treat or otherwise rests with others, primarily their families. However in all situations the expressed desires of patients must be taken into account and must override those of the family and health care professionals.

The traditional mandate of doctors is to cure. The significance of death has changed in our society and in recent years institutionalised medicine has attracted enormous funds to research patient care technology and treatment. The achievements have been so significant that, at times, death seems avoidable. But, as more patients are hooked up to more and different machines the stress of patients, families and health professionals increases.

8. Thompson, op.cit.
The euthanasia debate has spanned many centuries and although it is defined as a "gentle and easy death" it also suggests assistance to hasten the dying process. The concept is not clearcut and various types have been described and may be viewed along a continuum from passive (inactive) euthanasia to active euthanasia. The former, often referred to as "letting die", involved the withholding or cessation of treatment aimed at prolonging life and allows a person to die with dignity. Active euthanasia involves the provision of specific means to a person to enable him to kill himself or involves another person instituting direct means to bring about a death. In our society active euthanasia is a criminal offence. Nevertheless, when the quality of life is reduced to an intolerable level, the temptation to seek this course of action is understandable.

A patient who, given sufficient information about the available options, decides he/she wants no further treatment should be supported in this decision even if it means a shortening of the life span. However, specific action to terminate the life of another is not supported and for others to make such a decision or take such action is unacceptable. Euthanasia is not supported particularly if such a decision is made independently of the patient. Treatment for those in a terminal situation should aim at relieving pain and distress rather than prolonging life or hastening death.

Numerous cameos could be presented to describe the dilemmas arising from living and dying and death. Four only are presented:

1. A third year student of nursing, only months away from the final examinations, was knocked off her motorcycle by a car and sustained a fractured collar bone which required an operation to stabilize the fracture. This procedure is generally straightforward but while under the anaesthetic in the operating room her heart stopped beating. The cause was not identified but she was transferred to the intensive care unit where she remained in total physical and metabolic support for three months before being allowed to die. At no time during this period could she breathe.

without mechanical assistance and a number of straight line EEG's were recorded.

**Comment:**
The nursing staff who were constantly in attendance believed the life of this person after the cardiac arrest was futile and was without dignity. The devoted parents maintained eternal hope as the medical staff struggled to find the solution.

2. A young man (engaged to a student of nursing) suffered 85-90% burns to his body associated with a petrol explosion and fire following a motor car accident. He was fully conscious on admission to hospital, was hydrated with intravenous fluids and given strong analgesics to control his pain. His fiance and family were consulted frequently and were supported during the nine days he was alive. His life was not prolonged nor was it suddenly terminated by human intervention. It was considered by his family, fiance and the staff that he had been involved as much as was possible in decisions about his treatment and that he had been allowed to die with dignity.

**Comment:**
The circumstances described in the above two situations related to young people who were being cared for by other young people, particularly nursing staff. In such instances staff identify closely with patients and find it difficult to be objective.

3. A seventy-five year old lady living alone who had painful arthritis and expressive dysphasia following a series of minor strokes had often expressed to her doctor and friends her desire not to live. Following an emergency admission to hospital for an acute episode of pulmonary oedema she was treated with a multiplicity of life sustaining measures including a two week period in an intensive care unit. At no time was she given the opportunity to accept or reject treatment. She recovered but is maintained on numerous medications which she threatens not to take and now pleads with her friends to help her end her life.

**Comment:**
The life-sustaining treatment given to this lady was not compatible with her expressed wishes. It is not known if her desires were communicated to the health professionals caring for her or, if so, whether they were taken into account.
4. A sixty year old lady was receiving chemotherapy for cancer as an inpatient. Following a meeting of the team caring for her, she was informed that further treatment was unlikely to be effective. She agreed with this decision, her family was informed and the staff were prepared to give them all the support they required. Within twenty-four hours a second team offered her "another chance" with a different chemotherapeutic agent which she readily accepted. This treatment did not have the desired effect with respect to controlling her symptoms or prolonging her life. She died within four days.

Comment:
The patient and family had renewed optimism having been previously resigned to a "no further treatment" situation. The staff found the changed situation difficult to cope with and the distress of the family and staff was evident for many months beyond the time of death.

These four cameos illustrate the complexities which are faced by those involved in the process of dying and clearly indicate that no one solution can be defined for all situations. Likewise, dilemmas arise when a patient wants to live despite expert medical opinion that extraordinary means should not be instituted. A recent such case, described by Kearney and Greany10, tells of a young married man with one child who, while not accepting the prognosis of his cancer, pleaded with the doctors to "try again". All told he had more chemotherapy treatments than would normally be expected but he had a certain amount of control over his destiny and in the end died with dignity.

LIVING WILLS

Whether or not it is appropriate and practicable to legislate for the right to die, a mechanism should be available to individuals in our society who, for whatever reason, wish to exercise a right to die. This not only relates to individuals who have (for example) a terminal illness or who have been badly injured, but also to those who simply do not wish to live because their quality of life has been reduced to an intolerable level. The emergence of "living will" debate and legislation in this and other countries have arisen by artificial means. This is not thought always to be meaningful or of benefit to the patient and his/her family. Briefly, the idea of a "living will" is that a person gives a written and witnessed direction regarding the use of life sustaining measures in the event of terminal illness or injury.

Many people have very strong views as to what they want done or not done to them in specific circumstances and are able to articulate their wishes with little difficulty. The problem arises when their authority and autonomy are in conflict with those of others. It may be that the attending practitioners do not meet an individual's stated wishes, the relatives do not communicate these desires or the intent is not understood. When people, faced with life threatening situations, are able to verbalise their desires at that time, their chances of goal fulfilment are greater. However, when an individual is unable to communicate or has not communicated his/her desires, others must make the decisions.

The South Australian and Californian Natural Death Acts provide that adults who do not wish to be subjected to extraordinary means in the event of terminal illness or injury may give direction to that effect in a prescribed form. The South Australian Act retains the right of an individual to refuse or accept treatment and ensures that the medical practitioner incurs no liability for decisions made in good faith. However, it does not allow an accelerated death. It has been said that "living wills" cannot cater for all contingencies and that the way a person feels at a particular time may change in the future. Further, to activate the desires

II. Natural Death Acts, op.cit.
expressed in living wills would be difficult if, for example, a person was in those defined circumstances without a copy of the "will" readily available.

In Victoria, a Refusal of Medical Treatment Bill was introduced into Parliament in December 1980, and in September 1981 had its second reading. Prior to the third reading it was referred by the then Minister of Health to the Health Advisory Council for consideration. A Sub-committee was established to conduct an enquiry, submissions were subsequently called for and representatives from selected organisations were invited to meet the Sub-committee. The report to the Minister in July 1983 concluded that "there were no substantial objections to the proposed Bill on religious or moral grounds" and that the Bill "did not depart materially from the philosophy behind the common law right to refuse medical treatment"12.

Despite all the knowledge doctors, nurses and other health care professionals have, it is often difficult for them to come to terms with patients who, for whatever reason, refuse medical treatment.

THE RIGHTS OF INDIVIDUALS

All people have rights to health care, to be informed, to consent to treatment, to refuse treatment, to confidentiality, to access to persons of their own choice, to compensation and to maintenance of dignity. These rights should not determine the nature of health care but rather should present available options. For instance it is desirable that the number of "carers" summoned to care for one person should be kept to a minimum. Up to 27 different "carers" have been known to have been involved in the care of one person at home. This kind of situation becomes confusing for the patient and inevitably leads to fragmentation of care. The optimum exercise of such rights, involving the choice of rational and realistic options, should therefore result in the most appropriate health care being made available.

Two major components of the decision making process regarding the future of people are information and communication. Traditionally the health care

professional has known what is "best" for the patient, has usually been at an advantage having the greater knowledge and experience, and knows the available options. The patient on the other hand must rely on information and explanation. It is imperative not only that the information be given but that the explanation is in a form which can be understood. A further consideration is that during the process of explanation the patient is often so anxious that he/she does not listen effectively and later turns for answers to queries and concerns to others who may not have appropriate knowledge.

Although a number of people live in isolation, the majority interact with other people whether they be family, friends or others. They may share their concerns, fears and plans. Although they may not agree with them, it is these other people who know their desires for the future and must heed them when life threatening circumstances arise.

There must be protection in the case of minors and for those deemed incapable of making rational decisions or unable to clearly articulate their desires. It should not be assumed in all situations that these people cannot be involved in the decision making process. Communication not only involves the exchange of spoken or written words but incorporates a wide range of body movements and other expressions which can be equally meaningful to those who understand and who share life's experiences.

Inevitably there will be difficulties in interpretation of the wishes of individuals and when no clear direction is given or when it produces conflict for the carers an alternative mechanism should be found whereby all human beings have the opportunity to exercise their rights as individuals particularly when it involves dying or "letting die".

In some instances the patient may be considered to be more valuable while living than if declared dead. It can be argued that maintaining life by extraordinary means until such time donor organs (for example, corneas and kidneys) are collected will improve the quality of life of someone else. Even in these situations the patient has rights and if explicit directions have not previously been given in this regard, the collection of donor organs should take place only after full consideration of all the facts.
Health care professionals also have rights and as previously stated they should be protected provided a duty of care is exercised. At no time should these carers be required to undertake any action for which they are not experienced or about which they are philosophically or morally opposed.

Medical decisions about the use of extraordinary means of life support should be made only after full consultation with the staff caring for the patient, particularly the nurses, the patient (if able) and the family. Huttinan\textsuperscript{13}, a nurse, has poignantly described a situation where the wishes of a patient (the nurse's mother) were not taken into account resulting in considerable conflict between the nurse and the medical staff and significant stress for the patient and her family.

For the protection of hospital staff, decisions made not to institute extraordinary means in the event of a patient's condition deteriorating should be clearly documented and communicated to all staff. Problems of interpretation may arise if all appropriate staff are not informed nor involved in the decision making process. It is their right to know and such knowledge will reduce the possibility of distressing situations for all involved.

Any debate relating to the rights of individuals involved in the process of dying will invariably bring out the widely differing community views. The contentious decisions of cases such as that of Karen Quinlan\textsuperscript{14} draws much media attention. This in turn "can harass and impede the judgement of those charged with the duties of compassionate decision making ... and ... assaults the privacy of families at a time when their burden is already too much to bear"\textsuperscript{15}.

\textsuperscript{13} Huttman, B.R. Not murder - just nothing. \textit{American Journal of Nursing} December 1985, 959-960.


ACTION REQUIRED AND OPTIONS AVAILABLE

The theme of this paper reflects a belief that every person has a right to be involved in, and should be central to decisions made about his/her future. It does not endorse the notion of active euthanasia. Emphasis is placed on care for the dying person rather than on the decision to treat or not to treat.

Dying, like birth and living, is part of the continuum of human existence. It is essential that the public should be aware of the options and resources available with respect to the right to be allowed to die. This requires an active education programme. In particular, the public should know that people can die with dignity, that their symptoms can be controlled, that they can make a choice about their treatment. If this information is not readily offered to the community there should be encouragement to actively seek it out.

The decisions about where people die are difficult at this time when available resources do not adequately meet the needs. Those people who wish to die at home should be allowed to do so but it is incumbent on society to ensure that the required human and physical resources are made available. Invariable the family needs considerable assistance, including emotional support, to ensure that its members are able to fulfil the patient's needs.

Many people do not wish to die at home but prefer to be admitted to an inpatient facility. Others initially express a desire to die at home but later indicate a wish to be admitted to hospital; some, because of their condition, cannot be cared for at home. In recent years the hospice movement has emerged to provide specialised care for the dying. However, there are not enough programmes to meet the demand and often people who are dying are admitted to hospitals where care is technically sophisticated and aimed at cure.

The range of physical aids and human resources is vast and the knowledge of care of the dying is increasing. Care of the dying person must be planned if resources are to be used effectively and efficiently. The patient is central to the family unit of care, the planning for which will depend on the particular needs of that unit.
Since, at this time, we all have a common law right to refuse medical treatment and providing symptoms are controlled in every respect (physical, social, spiritual and psychological), there should be no reason to legislate for the right to die. However, things do not always go according to plan – there is the dilemma of those who have given no direction or who are unable to have a say in their plan of care (especially those diagnosed as brain dead) and difficulties arise when a person's wishes are in conflict with those of the family or "carers". It will always be difficult to know when to cease technically sophisticated treatment particularly with respect to the use of life support machines. "Miracles" have been reported and likewise many tragic situations have resulted from what might be described as heroic medicine.

The notion of an independent tribunal or advocate group should be explored to deal with these situations. The group would need to be convened at very short notice to meet with the patient and those closely involved in his/her care and be prepared to act quickly. Patients should have direct access to the group. In the case of those declared brain dead, mentally incapable or minors, "carers" and family should have direct access to the group. The implementation of such a procedure would minimise the publicity surrounding difficult decisions about the right to die and would help to maintain the dignity of all concerned.

At this time, many patients and family caregivers know their rights but for a variety of reasons are unable to enforce them. It is up to others with "legitimate authority" in the direct care situations, particularly nurses, to become more active in patient advocacy.

All caring institutions and authorities should be required to have bioethics committees to examine the ethical implications of their treatment programmes. Such committees should also facilitate relevant education opportunities and provide support for staff involved in difficult situations. Input to these activities should also be encouraged from patients and relatives. The membership of bioethics committees should be largely independent of the institution or authority and should include specialists with relevant knowledge in ethics as well as patient representatives.
The concept of a patients' bill of rights\textsuperscript{16} and following this a dying patients' bill of rights\textsuperscript{17} should be explored by legislative authorities.

Protection of "carers" involved in decisions about dying and "letting die" is essential. The duty of care principle has been upheld over time and, providing future technological development is carefully controlled, no further legislation should be necessary in this regard. However, the situation should be closely monitored and it is essential that health care professionals be afforded every opportunity to actively seek out and understand their rights and responsibilities. Plans of care, including directions for life support and resuscitation measures, should be explicitly documented to avoid confusion.

**CONCLUSION**

As a member of the nursing profession I believe:

\begin{itemize}
  \item all people have the right to die with dignity;
  \item life sustaining and life prolonging measures should only be used with the consent of the patient or, in certain circumstances, the family;
  \item "living wills" are useful in such situations;
  \item active euthanasia cannot be condoned and should not be contemplated as pain and distress can be relieved;
  \item passive euthanasia is acceptable where the patient decides against measures to prolong life;
  \item urgent attention should be given to the adoption of a patients bill of rights and the creation of a tribunal to deal with situations where there is conflict over the right to die;
  \item the situation of health care professionals involved in decisions about life sustaining or life prolonging measures should be formally recognised;
  \item health care institutions should have bioethics committees to monitor treatment programmes, to facilitate education opportunities and to support staff involved in difficult situations.
\end{itemize}

\textsuperscript{16} Royal Australian Nursing Federation (Victorian Branch) Patients' Bill of Rights, 1980.

\textsuperscript{17} Davis, op.cit.
When considering the options for the right to die no one solution will suffice in all situations. It has been said that "the whole subject is almost impossibly difficult". People can and do die with dignity; their physical, social, psychological and spiritual needs can be met. The sad fact remains the options are not equally available to all.

"... a person's last great freedom is to decide when he or she has had enough pain and suffering, of upsets, of hardship, indignities, life itself."19

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Acknowledgement is also given to my colleagues particularly those at the Peter MacCallum Hospital, family and friends who shared their experiences so willingly with me.
SOME OBJECTIONS TO EUTHANASIA

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Summary

Objections to euthanasia have relied to a significant extent on certain more or less subtle distinctions. The relative merits of these are considered. First, a distinction between killing and letting die is defended and its importance assessed in terms of human motivation and intention. Some limitations of the distinction are acknowledged, such as its inability to distinguish between different kinds of omission on the part of human agents. In drawing attention to the influence of intention on the meaning of human acts, however, the distinction between killing and letting die invites sensitivity with regard to our fellow humans and sensibility in the quest for social policy.

Next, the distinction between active and passive euthanasia is compared with that between killing and letting die, and the former is found to lack the subtlety and helpfulness of the latter.

A more subtle distinction is considered to be that between ordinary and extraordinary means of treatment. The way this distinction draws attention to the well-being of the patient, and not just to kinds of treatment is noted. It is nevertheless suggested that additional formulae, such as 'only caring for the dying,' will be helpful in clarifying human responsibility in terminal cases.

Some of the risks which, it is suggested, will unavoidably be associated with a public policy that permits voluntary euthanasia are noted before consideration is given to a fourth distinction, that between negative rights of liberty and positive rights of access to resources. The importance of this distinction is related to an alleged 'right to die.' The paper concludes with the suggestion that the positive right of the dying is to receive care that is on-going.
One of the strongest cases that can be made for euthanasia concerns a dying patient who freely requests that his or her life be shortened for reasons related to health and those aspects of well-being that are relevant to the practice of medicine, e.g. the pain or the indignity of a particular way of dying.

Such a case is clearly analogous to that of a person giving free and informed consent to participation in a medical experiment, or to acceptance of a particular course of medical treatment.

Yet there remain serious and, I believe, over-riding objections to the practice of euthanasia, deliberately bringing on the death of a person, even in the kind of case I have outlined.

Many of these objections turn on some more or less subtle distinctions which have been drawn in the past as means of clarifying debate about euthanasia. It is with these distinctions that I begin, then, in order to approach what seems to me to be 'the heart of the matter.' As this brief outline suggests, I shall be arguing that the distinctions are of relative importance, in that they are more or less useful guides to what is basically at stake in the treatment of people who are dying.
1. **KILLING VERSUS LETTING DIE**

I consider this to be one of the two most important distinctions we have received from the past but before explaining why, it should be noted that a few have doubted whether, as a matter of fact, the distinction can be maintained. The reason for such doubt would be that, either way, the death of a person is envisaged and achieved. To this the rejoinder is, simply, that the ways are not the same. To push a drowning person under for the proverbial third time is not the same as refraining from diving in to help.

The important question, then, is not whether a factual distinction between ways or means of dying can be made, but whether this distinction between bringing death on, and letting it occur, really matters from a moral and social point of view.

I suggest that it does in a basic, albeit minimal, kind of way. For it draws attention to different ways of acting that are to some extent indicative of human motivation. It reminds us that human actions are the embodiments of meanings so that, among other things, they are the conveyors of messages among and between persons. It does all this by rightly indicating that deliberately bringing about the death of another person usually, or at least very often, betrays the malice of murder whereas letting another person die usually, or at least very often, does not. Thus it begins to help us in discriminating among difficult cases.

Of course it does not take us very far. It does not indicate whether there are kinds of killing in which malice is not usually found. It does not distinguish between omissions that are due to a lack of ability or resources on the part of human agents, and those which are due to comparative lack of care. Both the 'good' Samaritan and those who passed by on the opposite side, for example, were capable of rendering assistance to the injured traveller. Beyond these limitations, with regard to motive, it is also to be noted that the distinction is not always clear about the classification of certain kinds of acts. In particular, it does not, of itself, determine how we are to regard, in a non-moral sense, the act of withdrawing measures of life support from a dying person.
Is this a matter of doing something to bring about death or, as some would put it, of 'letting nature take its course'? Or is it a bit of both?

Having acknowledged these limitations, however, it is important to reiterate that the rather blunt but basic distinction between killing and letting die does amount to a first and quite sizeable step in sorting out ways in which the living are morally and socially related to the dying. Despite its bluntness and other limitations, then, it represents an invitation to sensitivity in an area of human relations where sensitivity is especially needed. For the way we are to treat those among us who are dying is not just a matter of public concern about which there may be a case for developing and implementing public policy. It is also a matter of private concern in which the deepest of personal and communal beliefs, values, attitudes and feelings are brought to expression, often in great anguish. Sensitivity to the depth and range of feeling and meaning that human beings find in death and dying must be matched then, by a sensibility in the quest for a moral and social policy in this area. In particular, as much respect as possible must be given to the dignity of persons as bearers of meaning and to their freedom to bring this to expression. Emphasizing the freedom of the parties involved means keeping legislation to a minimum so that room is made for conscientious judgment and decision in difficult cases. This, in turn, means allowing for different judgments and decisions to be arrived at in cases which are in many respects similar but the moral tradition of the Western world has long recognized that it is possible for men and women to disagree in good conscience and to act accordingly. Military service is one area in which public policy has acknowledged this and I am convinced that death and dying should be another.

The process of making conscientious judgments and decisions about treatment of the dying may be assisted by attention to some received distinctions less blunt than that between killing and letting die. Before examining these, however, I want to dismiss a purported distinction made in the past.
2. **ACTIVE VERSUS PASSIVE EUTHANASIA**

It has been suggested that a distinction between active and passive euthanasia simply corresponds to that between killing and letting die and this may well have been the intention of those who introduced this way of talking about euthanasia. For the person who kills another is clearly playing an 'active' role, whereas one who allows death to occur is playing a more 'passive' role. The two distinctions are not the same, however, because one is concerned with what is done - killing or letting die - whereas the other is concerned with how this is done - in an active or passive manner. The former, as I have argued above, requires some account to be taken of the motives which influence and find expression in different ways of treating the dying, whereas the latter diverts attention from the social and moral importance of motivation by focussing upon euthanasia as the supposed aim of both active and passive forms of treatment.

If the distinction between active and passive euthanasia is not to be equated with any other, neither is it to be regarded as very helpful. For one thing, it is a truism to say that the purpose to be served in dealing with a person who is dying is to bring about, as far as possible, a good death. The crucial issue is what constitutes a good death and, in seeking criteria by which to determine this, a distinction between active and passive measures does not take us very far at all. Beyond this, the suggestion that our aim in every case should be to bring about a good death is open to misinterpretation. At a time when, for various reasons there has been an increase in the psychological propensity to regard death as 'the last enemy' and to combat it at all costs, such a suggestion might well be taken to justify treating the dying as only means to an end, namely, that of proving that we can engineer what we determine to be a good death for them. This kind of attitude is reflected in the rather horrid way in which some people have recently begun to talk of 'euthanasing' others.

It is of the utmost importance for the debate about treatment of the dying that the idea of allowing a person to die not be confused with that of passive euthanasia. It suits those who advocate that certain classes of dying persons be 'put out of their misery' to pretend that the two ideas are the same because this allows them to dismiss both with arguments which tell only against one. Advocates of passive
euthanasia may fairly be accused of allowing their own scruples about killing to prevent an early release for dying persons who would choose this and, even worse perhaps, to prolong the suffering of infants or incompetent adults who are doomed to die quite soon anyway. Such accusations do not tell against those who prefer to let others die instead of killing them, however. For this policy is an expression of motives and intentions which are ignored by all who approach dying with a preoccupation about good death, euthanasia. Those who are not so preoccupied, who are prepared to let their fellows die when hope of saving their mortal bodies is vain, also find room to express concerns and serve purposes which relate, not to a thing called death, but to persons with names who are dying. In order to appreciate some of these concerns and purposes it will be helpful to introduce another distinction, one which at first sight appears exceedingly blunt.

3. **ORDINARY VERSUS EXTRAORDINARY MEANS** (of treatment)

The main reason for the subtlety, and therefore the helpfulness, of this distinction is that it is not so much substantive as reflective. In other words, it does not attempt to lay down once and for all what is ordinary treatment on the one hand, and extraordinary on the other. Rather does it invite the dying and those who attend them to consider the circumstances of the case and reflect, as one commentator has put it, on what treatment would and would not be 'unduly burdensome' for the patient. Such reflection will range over a variety of matters, from the prospect of recovery to the financial resources of the patient, and in so doing, it seems to me, it cannot wholly exclude the concerns of persons close to the patient, especially relatives, although the patient will always be the primary focus of concern. If, upon such reflection, it is found that a proposed treatment offers the patient a reasonable prospect of benefit without being unduly burdensome, then it can be said that the treatment is not out of the ordinary and so is obligatory or, as I would prefer to put it, appropriate. (I prefer to put it this way because, in accordance with what was said earlier concerning respect for the dignity and freedom of the parties involved, I think the patient always retains a right to refuse treatment, regardless of whether others think it would be foolish or wrong to exercise that right in the circumstances of the particular case.)

Properly understood, then, the distinction between ordinary and extraordinary means escapes the criticism that it focusses too much on the kinds of treatment available and not enough on the intention with which these are to be used, namely,
the well-being of the patient. In view of possible misunderstanding, however, it is helpful to clarify the meaning of the distinction by reference to the formula of 'only caring for the dying'. By clearly making human intention paramount, this formula helps to explain why it can be appropriate to shorten the life of a patient by administering pain-killing drugs.

For proper care clearly involves relief from debilitating pain and suffering so that the dying may proceed on their way in as much peace and with as much capacity for communication with people around them as circumstances permit. If the drugs administered for this purpose also have the effect of shortening life, then that is acceptable, although not the chief aim of the treatment. Furthermore, it has been pointed out that the trauma of severe pain can bring an early end to life and so it is often difficult to be sure in advance whether or not a drug to be administered to a particular patient is likely to end life more quickly. Having said all this, however, it should be noted that the idea of 'only caring for the dying' is not without its limitations. It could, for example, be taken to mean that doctors have no responsibility to use their resources so as to ascertain whether a dying patient can be set free from the dying process. I have therefore proposed a further distinction between (merely) arresting the process of dying and significantly postponing death, with the suggestion that the former would not constitute appropriate treatment whereas the latter would. I must admit, though, that postponing death for a reasonable period of time may not be of much benefit to a person who will lose all autonomy for this period.

We would look in vain for a distinction or formula that was entirely adequate and not in need of qualification or even correction, in the face of the difficulties that can arise in dealing with the dying. In drawing attention to human intention, and to the relation between ends and means, however, some of these formulae also point to a connection between what we do and what we are taken to mean in doing it. It is this that underlies the concern that has often been expressed about the social consequences of permitting any kind of euthanasia. Even if it were only a question of voluntary euthanasia and even if the voluntary were very carefully and narrowly defined, its authorization would still be taken to mean that a healing profession was now also a death-dealing one, and the society in which this could take place,
one that discriminated between citizens whose lives were worth retaining and those which were not. In a situation such as this the trust that is so vital in relations between doctors and their patients is not just likely to decline, but bound to do so, with undesirable consequences of uncertainty and anxiety for all concerned. For actions mean not only what we intend, but also what they say.

In view of the fact that some people have begun to speak of a 'right to die' in connection with euthanasia, it is appropriate to refer to another distinction that has been made in the past, not so much in discussion of medical practice as in debate about human rights.

4. LIBERTY VERSUS WELFARE

This distinction between the civil liberties prized in the West and the economic, social and cultural privileges emphasized in the Soviet bloc, is by no means as neat and clear as some have claimed but it does indicate that the provision of freedom is not always the same as the provision of resources. I have already suggested that room should be made for the dying to refuse treatment and thus allowed a right to die, in the sense of a negative right of freedom from interference. This is not to concede, however, a right to die in the sense of a positive right of access to certain resources.

In an era of technological advance that has increased the dependency and impersonality of the condition in which some people die, it is understandable that persons should seek to assert themselves by claiming that instead of their being placed at the disposal of professionals and their technology, these resources should be placed at their disposal. The response that is thus proposed to the undue power that the medical profession and medical technology sometimes exercise over the dying is, however, unnecessary. It would suffice for lessons to be drawn about the abuse of power and about restraining its exercise in accordance with the needs and choices of patients. There is no need for the profession to be co-opted by the dying in such a way that it sacrifices its responsibility by placing its agency under their control. The best answer to power is not always revolution.
There is, however, a positive right to which the dying lay claim and this corresponds to our responsibility to care for them. This requires not only the application of appropriate materials and techniques, but also the devotion of human time and attention. In a society where technology works to increase rather than decrease the pace of life and most of us become more rather than less busy it is the giving of time, especially to those who may soon be gone, that is often the most difficult. There may be an important parallel between the impatience, or at least discomfort, that some feel in dealing with them and that which is aroused when people are asked to attend to careful distinctions of the kind I have discussed with regard to voluntary euthanasia. Just as the latter call in question a premature judgment, so the former call out for something other than a final solution. Patients who are dying must rely on the patience of the living whose responsibility is best summed up as follows:

Seek not to end the living of the dying but rather to tend the dying in their living.
INQUIRY INTO OPTIONS FOR DYING WITH DIGNITY

THE HON. MR. JUSTICE M.D. KIRBY

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Of necessity, this paper can examine only a few of the moral and legal dilemmas presented to the law today by life and death. The realm of discourse is bioethics and the law. The paper will proceed from a few words on a number of riddles now being presented to our legal systems by advancing medical technology as it affects the beginning of life, to the issue of death and the law. It will examine some aspects of death, particularly of the unchoosing very young and very old. In the course of this examination, attention will be called to recent cases and to some legislative developments both within the Commonwealth and beyond. Finally, a few words will be offered in relation to the institutional problem of lawmaking that is posed by the variety and speed of the presentation of bioethical dilemmas.

The Neonate

A number of cases in Britain in recent years have required the courts to examine the right to die or to let die. Three of the cases have concerned very young babies. These babies are undoubtedly human persons in the eye of the law, because fully born and therefore entitled to the law's protection, whatever controversies may exist in respect of the 'humanness' of the unborn child, foetus, embryo or oocyte:

* In August 1981 the Court of Appeal in England had to decide an appeal from a decision delivered by Mr. Justice Ewbank concerning the performance of an operation on a child born with Down's Syndrome. The child also suffered from an obstruction which, without operation could be fatal. If the child had been intellectually normal, the operation would have been instantly and routinely performed. But the parents did not consent to the operation. They believed, and their doctors supported them, that it was in the child's interests that she should be allowed, under sedation, to die naturally. The Court of Appeal, reversing Mr. Justice Ewbank's decision, made the child a ward of court, and ordered the operation to be performed.¹

¹ In Re B (A Minor) [1981] 1 WLR 1421.
In November 1981 a specialist obstetrician, Dr. Leonard Arthur, was acquitted by a jury in the Leicester Crown Court in England of the charge of attempting to murder a mentally retarded newborn baby, John Pearson, who had been rejected by his parents. The doctor had ordered a course of 'non-treatment' for the child, prescribing a pain-killing analgesic which also sedates and depresses appetite. As reported, there was evidence that with 'normal treatment' the child had an 80 per cent prospect of living to adulthood. The defence case was that the drug merely eased the child's inevitable progress towards death. A statement reportedly issued after the verdict by the British Medical Association, the Royal College of Nursing and the Medical Protection Society urged that it was 'the parents' responsibility to decide what was best for their child. It was the doctor's job to advise and help them.' The same statement claimed that the verdict showed that the public was right in allowing doctors considerable freedom in coping with the burden of handicapped babies. Yet it claimed that 'parents may find it a great deal harder to reach a tacit agreement with the doctor that the child should be left to gradually slip out of life'.

In February 1982, the Court of Appeal in England had to consider whether a child could bring an action against medical authorities alleging 'wrongful life'. In the United States, actions have been brought by children and parents against doctors, even by children against parents themselves, claiming 'wrongful birth', or 'wrongful life'. Wrongful birth cases involve the assertion of negligence in allowing pregnancy (incompetent sterilization) or in permitting or causing a defective birth. 'Wrongful life' cases involve the claim that the life of physical or mental handicap to which the child is condemned from birth is such that reasonable parental and medical precaution, before birth, would have required termination of the pregnancy. The Court of Appeal in England in 1982 dismissed such a claim on the basis that the common law of England did not recognize a cause of action against doctors for allowing the child to be born deformed. The court said that to impose a duty to terminate the child's life would make a further inroad into the sanctity of human life, which would be against public policy.

2. As reported Sydney Morning Herald, 7 November 1981, 4. See also British Medical Association, Handbook of Medical Ethics, para 5.10.
The opportunity for controversy about these cases is virtually limitless. Both in Britain and in Australia discussion in the legal and other journals has examined whether death caused by the deliberate withholding of sustenance or of normal medical treatment, withheld with the intention to cause death, can constitute murder or manslaughter. The suggestion by medical organisations that such painful decisions can simply be left to the decision of parents, guided by their medical advisers, may be sensible, practical and upheld by juries. But it may not give sufficient attention to the law's insistence that the criterion is not the best interests of the parents nor the protection of the public purse, let alone any social interest in eugenics. In the first case above, Lord Justice Templeman stated the law's approach:

"At the end of the day it devolves on this court in this particular instance to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die. There may be cases, I know not, of severe proved damage where the future is so certain 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, but in the present case the choice which lies before the court is this; whether to allow an operation to take place which may result in the child living 20 or 30 years as a mongoloid or whether (and I think this must be brutally the result) to terminate the life of a mongoloid child because she also has an intestinal complaint. Faced with that choice I have no doubt that it is the duty of this court to decide that the child must live. The judge was much affected by the reasons given by the parents and came to the conclusion that their wishes ought to be respected. In my judgement he erred in that the duty of the court is to decide whether it is in the interests of the child that an operation should take place." 8

These observations and the consequential obligation to perform the life saving operation received words of approbation in the popular media. But they were denounced by many medical observers. For example, a Professor of Paediatrics said that society was indulging in hypocrisy in insisting on a life-saving operation. Three hundred spina bifida babies were allowed to die each year in the United Kingdom. In the 1950's and 1960's heroic efforts had been made to sustain such babies. Now, most of them grown into adulthood, they languish in nursing homes, frequently unloved, unvisited and 'a costly burden to themselves and to society'.

The Arthur trial and the other English cases have generated a serious debate in Australia, and doubtless, in other Commonwealth countries. They have lifted a stone and revealed a largely unknown world of medical practice affecting the life of defective neonates. Sir Macfarlane Burnet asserted as a fact that in Australia 'compassionate infanticide' was 'standard practice where the product of birth is such as to justify the term "monstrous"'. The course followed by Dr. Arthur in Britain is apparently not at all uncommon in hospitals in Australia. If it happens, it occurs either with indifference to the law of murder (deliberate omissions intended to kill) or by turning a blind eye in the comfortable knowledge that such decisions will rarely become known, where they become known will rarely be prosecuted and, where prosecuted, will rarely result in a jury conviction. It is not too much to say that decisions of the kind that are apparently regularly made by doctors in the case of neonates born with gross physical or mental disabilities are at present left to the vicissitude of unstructured, possibly idiosyncratic determinations varying from individual to individual and from hospital to hospital. Such decisions appear to be made without any guidance of principle, or at best with the help only of a closed hospital committee or an appeal to 'the traditional medical way of doing things'.

11. See e.g. the statement of Dr. J. Bebridge, Director of the Prince of Wales Children's Hospital, Sydney, Sydney Morning Herald, 7 November 1981, 1.
The decision of the Court of Appeal quoted above was assailed because it required medical intervention to save the retarded child. But it has been equally criticised, from the opposite point of view, because it was not sufficiently uncompromising. The door was left ajar for the termination of the child's life, if it had been shown that its life was 'demonstrably going to be so awful that in effect the child must be condemned to die.' 12 In some ways this exempting phrase is more significant than anything else in the decision. The law's tendency to retreat to simplistic and absolute rules, respecting the sanctity of every human life, may seem unrealistic in the messy business of a hospital crisis. It may be out of touch with majority community values, certainly in Britain and Australia. For example, an opinion poll in Australia found that two out of three respondents believe that doctors should be allowed to permit a badly deformed new born child to die, rather than to try to keep it alive. 13 The present state of the law is unsatisfactory. Plainly it is not being observed. Clearly it is offering little guidance in daily decisions of life and death in many hospitals. Attempts to improve it would be more likely to succeed if they were developed by law reforming agencies. This is no reflection upon the hard pressed judges who, in urgent cases amidst other busy duties, have had to respond immediately to the dilemmas posed by the cases I have mentioned. I shall return to this point.

The Mature Adult

Space does not permit consideration of all the legal implications of euthanasia, of so-called 'mercy killing' 14 or of reform of the law of suicide which, years after its amendment in England, remains unreformed in many other parts of the Commonwealth of Nations. 15 These and other issues are addressed in a 1982 working paper of the Law Reform Commission of Canada, Euthanasia, Aiding Suicide and Cessation of Treatment. 16

12. [1981] 1 WLR 1421, 1424, Templeman L.J.
The Canadian Commission recommended that existing prohibitions in the Canadian Criminal Code concerning homicide should be maintained to forbid active euthanasia in any form. It did not favour the complete decriminalisation of aiding or counselling suicide. Nor did it favour enactment of legislation to permit a patient suffering a terminal illness to forbid prolongation of medical treatment. Such legislation has been enacted in a number of States of the United States. In Australia, Private Member's Bills were introduced in two State Parliaments along similar lines.

The law on 'euthanasia' was examined in a recent decision of the English courts. The case involved the prosecution of two members of the British Euthanasia Society EXIT. They were charged with aiding and abetting suicide. The jury convicted the secretary of EXIT, an Oxford don aged 34, and a 70 year old man who had been sent to visit eight people contemplating suicide. Six of the people visited died by their own hand soon after these visits. The Secretary of EXIT was sentenced to be imprisoned for two and a half years. Sentencing him, the trial judge said that he had flouted the law and 'using the Society, the object of which is to get the law changed, to jump the gun'. As he was led from the dock at the Old Bailey to serve his term, he denounced 'the idiocy of the present law', claiming that the law should be changed to allow doctors to give a 'peaceful death' to people in great distress and suffering from terminal illness. An appeal resulted in reduction of the sentence.

Support for voluntary euthanasia, at least in the case of the seriously ill, incapacitated and dying, is not a notion of a few disturbed cranks. A national opinion poll in Australia in November 1982 revealed that 69% of the people polled believed that if an adult has a terminal or chronic illness and wished to end his life, a doctor should help him to die if asked to do so. Only 24% considered the doctor should refuse, 8% being undecided. Critics of euthanasia have tended to isolate the issue of active euthanasia from the issue of the right of a terminal patient to

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18. See e.g. Natural Death Act 1983 (SA); Refusal of Medical Treatment Bill 1980 (Vic.)

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refuse extraordinary care. But public opinion indicators suggest that the law\'s rigid
defence of human life and its refusal to countenance moves to expedite the active
termination of life (whatever its quality and whatever the distress and pain being
suffered) are simply not accepted by a large majority of the population. The
difficulty for reform is bringing such a distressing topic into the open and providing
useful criteria and procedures that will be properly defensive of human life, but at
the same time be respectful of individual autonomy, attentive to the relief of pain
and distress and accepting of the natural processes by which we eventually move
out of this life.

The Very Old

In the United States, more than in Commonwealth countries, decisions to withhold
life-prolonging treatment from very old or incompetent patients have tended in
recent years to move in increasing number from families and physicians into the
courts. In 1977, in the case of Saikewicz\(^20\) the Massachusetts Supreme Court
firmly rejected the approach adopted by the Supreme Court of New Jersey in the
Quinlan case when it ruled that such decisions were to be made by the patient\'s
family and physician, subject only to review by the hospital\'s ethics committee.\(^21\)
The assertion of the function of the courts, as guardian of very old or incompetent
persons, to make decisions on life and death has generated a flood of literature in
medical, philosophical and legal journals.\(^22\) Courts in the United States are now
appointing guardians \textit{ad litem} to represent incompetent persons and to conduct an
adversary hearing on the issue of whether treatment should be terminated, where
the termination will probably result in death. A typical recent case involved Earle
Spring, a 78 year old senile hemodialysis patient whose final year of life was
marked by continual court battles and banner headlines as his wife and son moved
from court to court in a vain struggle to terminate treatment which they believed
Earle Spring did not want. Adhering to the Saikewicz decision, the probate court in
Massachusetts appointed a guardian \textit{ad litem} to represent Earle Spring, conducted

\(^20\) Superintendent of Belchertown State School v Saikewicz, 370 N.E. 2d 417
\(^21\) In Re Quinlan 70 N.J. 10, 355 A.2d 647 (1976).
\(^22\) See e.g. A. Relman, 'The Saikewicz Decision: A Medical Viewpoint' 4
an adversary hearing and issued an order to terminate the treatment. The guardian appealed. The Court of Appeals approved the probate judge's order. The guardian appealed again to the Supreme Court of the State. That court determined that "it was an error to delegate the decision to the attending physician and the ward's wife and son". The matter was then remitted to the judge at first instance. He ordered the guardian "to refrain from authorising any further life prolonging treatment until further order of the Court". Earle Spring was allowed to die.

Lawyers have defended the case as the assertion by the law and the courts of the ultimate respect for human life: providing legal protection for an incompetent person to make a decision that he would have made himself had he been competent and had he known all the facts. Such a view coincides with the insistence in the English Court of Appeal:

"Fortunately or unfortunately, . . . the decision no longer lies with the parents or the doctors, but with this court". 24

Medical practitioners and theologians are not so sure. Spring's physician was highly critical of the way the case had been handled:

"If you must go to court every time a treatment is to be stopped, the implications are mind boggling. These decisions . . . are made perhaps hundreds of times a day in Massachusetts . . . I do not think courts of law can draw the line . . . The decision that it is up to the courts to say when treatment ends, was a very bad mistake". 25

23. *In Re Spring, Mass 405 N.E. 2d 115 (1980).*
And a theologian reflected:

"Earle Spring suffered an additional year of hemodialysis. His family experienced that suffering and endured the pain and cost of litigation, headlines, murder accusations and the agony of a public dying. The benefits for them: bitterness and financial ruin. For the public: a Supreme Court opinion that evidences little sophistication, sensitivity to medical realities, or tight legal reasoning, one that will serve only to exacerbate the already existing tensions among patients, physicians, families, lawyers, and courts". 26

Cases such as this may illustrate the need to defend the right to die and to uphold the duties of medical practitioners to lessen suffering instead of concentrating on prolonging for the longest possible time - using any means and under any circumstances - a life which is no longer fully human and which is drawing naturally to its close. 27

Death has been described as the last great taboo of the 20th Century. Cases such as Quinlan, Saikewicz and Spring in the United States and the recent cases in England alert lawyers to the fact that they may ultimately be forced to address, not merely the definition of death, but also the proper balance between the right to live and the equal right, in due time, to die naturally and with dignity, harassed neither by heroic doctors nor officious lawyers.

Institutions

The points of this paper are essentially two. The first is that medical science and technology are presenting to the law in our generation a large number of complex and intriguing puzzles. They require moral and ethical judgments. But they also require legal judgments, for they affect human life and traditionally the law has sought to guard and defend this precious, mysterious and fragile phenomenon. Whether we should rejoice in the moral choices that are posed for us is beside the point. The choices that must now be made challenge many assumptions of the legal system and pose issues that have never previously had to be considered.

The second point is illustrated by the variety of cases cited. Bioethical questions are increasingly coming before our courts. With little guidance from the legislature, judges in the midst of busy and more familiar tasks, are required to offer decisions of principle in complex questions of life and death that baffle philosophers and theologians. When does life begin? Should a life sustaining operation on a deformed infant take place? What principle distinguishes insisting on treatment in such a case and withholding it from the aged and chronically ill? Is withdrawal of sustenance to a deformed baby, murder? Should there be an action for 'wrongful life'? Who should have standing to challenge a decision to terminate treatment? What is 'death'?

Living with the new biology can be exciting. It will extend the intellectual horizon of lawyers and lawmakers throughout the world. But if our solutions are to escape the criticism of superficiality and unsophistication, or adherence to values no longer shared by our communities, and if we are to provide legal principles that make some pretence to keeping pace with the technology, it seems to me that we will need to do better than we have been doing. It is asking too much of the judiciary and the common law system, of the adversary trial and the limits of the curial process to afford the next generation appropriate and satisfactory legal principles on these subjects where these are needed.

It is here that the law reforming agencies, which have sprung up in all parts of the Commonwealth of Nations have an essential role to play. Such institutions, by painstaking and interdisciplinary research, by public consultation and community education, as well as all-party Committees of Members of Parliament, can help our legislators to face up to hard questions that will otherwise be ignored or fudged, to the danger of the rule of law. It is just as important to define where the law should not intrude as to try to state the community's standards in rules that are relevant to the problems of today. If pressed, the common law system and the courts will provide answers to the new problems of life and death. But the questions are so hard and the answers so uncertain that it will be safer and wiser to address the problems in bodies which have more time, wider sources of information and opinion and in which the voices of scientists, theologians and philosophers will be at least as loud as the voices of lawyers.
ACTIVE AND PASSIVE VOLUNTARY EUTHANASIA

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Summary

The ultimate questions for this inquiry are: what makes human life valuable and on what principle or principles should life and death decisions in the practice of medicine be based? Initially these questions may seem too abstract, too difficult and too controversial to be of any help in solving the practical issues raised by the birth of a severely handicapped infant, or by the request of a terminally ill patient for help in dying. And yet, many of the day to day decisions taken by medical professionals in the modern hospital setting, presuppose that answers can be given to these questions.

For almost any life-threatening condition, modern medical technologies can now delay the moment of death. Death will often not occur until and unless the decision has been made to withhold or withdraw life-sustaining treatment. In other words, when and how a patient dies is often the outcome of a deliberate human decision. But such decisions - whether to resuscitate the terminally ill patient, whether to continue to sustain the life of the permanently comatose patient, or whether to give antibiotics to the blind and deaf octogenarian - all presuppose some kind of answer to the questions raised above: what makes human life valuable and when, if ever, is it permissible to allow, or help, a patient die?

In the following, I shall raise questions - and propose some answers - regarding the treatment of competent or formerly competent patients. I shall say nothing regarding the treatment of severely handicapped newborn infants, for I have covered that topic elsewhere at length.1

THE PROBLEM

To even pose questions about the value of life, or the principles that should inform life and death decisions, raises fundamental ethical and legal problems. Many of us would, before reflecting on the matter, think that all human life, regardless of its quality or kind, has 'sanctity' and should always be sustained by doctors and those charged with its protection. But new developments in the biomedical sciences force us to reflect on the matter.

It was not so long ago that a patient who had suffered massive brain damage would inevitably die. Today, modern medical technology allows us to keep such patients alive - even if they will never again be able to have any conscious experiences. Should we really try to keep such patients alive? And if not, why not? Similar questions are raised when patients are in the grip of a terminal and distressing disease. Should the lives of such patients always be prolonged, or are there times when an early death is the preferable alternative? If we agree that there are some circumstances when life should not, or need not, be prolonged, then we are faced with a difficult set of questions regarding the rights, duties and liabilities of all concerned - patients, relatives and health-care professionals. But we are also faced with a prior, and much more fundamental question - the question whether we really believe that all human life - regardless of its quality or kind - has 'sanctity' and must always be prolonged.

The view that all human life has sanctity has its source in our Judaeo-Christian tradition, according to which life is not our own, but "entirely an ordination, a loan and a stewardship." Today, such views are rarely voiced outside religious circles. The attitudes to which these views gave rise are, however, still part of our pre-reflective beliefs, and they have been incorporated in the law. 3


For medicine this means that:

"... when decisions about life and death and the integrity of life are directly at issue, legal theory appears to consider sanctity of life not just one factor among others in determining prohibitions, responsibilities and sanctions - it is the conclusive and fundamental factor." 4

But if sanctity of life is the conclusive and fundamental factor for determining the prohibitions and responsibilities of health-care professionals, then this raises a troubling question not only for all those cases where a patient is deliberately allowed to die, but also for a very important and fundamental moral and legal principle: a competent person's right to bodily self-determination. For the 'sanctity-of-life' principle would seem to prohibit what the right to bodily self-determination allows: that a person may refuse any treatment, including life-sustaining treatment, and thus opt for an earlier death. Now, it is true, suicide is no longer a criminal offence in Victoria, but what if a person is no longer able to commit suicide - because totally incapacitated and hospitalised, or when she slips into unconsciousness or other disease-induced incompetency? Does the doctor have the duty to uphold the sanctity of human life - irrespective of its quality or kind, and irrespective of the patient's previously expressed wishes?

ALLOWING PATIENTS TO DIE

Most patients, doctors, and moral theologians, do not believe that a patient's life must always be prolonged. Almost everyone agrees that there comes a time when a patient should be allowed to die. 5


Take the following example: In many hospitals it is routine practice to mark some patients' records with the letters NFR (Not For Resuscitation), or a similar coding. If a patient whose records have been marked in this way suffers a cardiac arrest, she will not be resuscitated and the foreseen death will be the result of a deliberate human decision. 6

We often think of modern medical technology in terms of powerful machines and devices, such as resuscitation equipment or heart/lung machines - but even as simple and ordinary as a course of antibiotics can often make the difference between a patient living or dying. Take the following case, discussed as an example of good decision-making by a Catholic Working Party on euthanasia:

**Case 1**

A man in his late 50's had been in hospital for eight years on account of advanced Parkinson's disease. During the last years of his life he lost weight progressively, became generally weaker and spent more time in bed. He was less able to talk clearly and needed increasing help with the basic 'activities of daily living.' During this time he had three attacks of bronchitis. The first two were treated with chest physiotherapy and antibiotics. In anticipation of a further attack it was decided... that the next episode of bronchitis would not be treated with physiotherapy and antibiotics... The outcome of a chest infection in these circumstances was quite likely to be the man's death and it was seen as the natural terminal event of the progressive physical deterioration. 7

But the man's death was, of course, a natural event in only one sense of the term 'natural'. It is true, the patient died of natural causes - a chest infection - but the fact that medicine is normally about preventing people dying from such natural causes should alert us to the human choice that was exercised in this matter. To the extent that it was decided that this patient's life should not be sustained when it could have been sustained, his death was anything but a natural terminal event - it was the result of a deliberate human decision.

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6. See e.g., Andrew L. Evans and Baruch A. Brody: "The Do-Not-Resuscitate Order in Teaching Hospitals", JAMA, April 19, 1985, Vol. 253, No. 15
My point is not that this decision was either right or wrong, but rather that there is widespread agreement (including agreement from the Churches) that patients should sometimes be allowed to die. As one doctor recently put it, when giving evidence to a U.S. court: "These decisions... are made perhaps hundreds of times a day in Massachusetts." They are also made many times a day in Victoria and other Australian states.

But are these life and death decisions based on sound fundamental values and principles? We can't be sure. For simple reference to notion that all human life has sanctity cannot guide our practices and judgements.

As we have seen above though, few people, if any, really believe that all human lives must always be prolonged. And yet, many of these people will also deny that what they are advocating are deliberate life and death decisions. They typically make reference to such traditional distinctions as that between 'ordinary' and 'extraordinary' means of treatment, and between directly intended and merely foreseen deaths - and then go on to argue that it is not contrary to the sanctity of human life to withhold 'extraordinary' means, or to bring about a death that is merely foreseen, rather than directly intended. I have argued elsewhere that these distinctions - to the extent that they can be drawn - are not morally relevant in themselves. The prestigious American President's Commission, in its Report Foregoing Life-Sustaining Treatment, agrees that the distinction between decision-makers "intending" a patient's death and their "merely foreseeing" that death will occur does not help in separating acceptable from unacceptable actions that lead to death. And on the distinction between ordinary and extraordinary means, the Commission comments that the distinction has become "so confused that its

8. See notes 5 and 7.
10. See e.g. Dr. John Cade, Director of the Royal Melbourne Hospital's Intensive Care Unit: "...it is widespread normal medical procedure to disconnect artificial support systems keeping hopeless patients just alive." (Melbourne Herald, November 20, 1973). See also P. Singer, H. Kuhse and C. Singer: "The Treatment of Newborn Infants with Major Handicaps - A Survey of obstetricians and paediatricians in Victoria", Medical Journal of Australia, Sept. 17, 1983.
12. Helga Kuhse: The Sanctity of Life in Medicine, Oxford University Press, forthcoming; and Helga Kuhse and Peter Singer; Should the Baby Live, op. cit.
continued use in the formulation of public policy is no longer desirable." 13 The Canadian Law Reform Commission reached a similar conclusion. 14

Without workable principles for decision-making, however, and without an explication of the underlying values, there is bound to be inconsistency in the approaches taken by individual doctors and by individual hospitals. 15 This is unsatisfactory when the lives - and deaths - of patients are at issue.

PERSONS AND AUTONOMY

What, then, should the values be that guide decision-making for competent, or formerly competent patients? There is wide agreement that it is our ability to choose, or to be self-determining and autonomous, which gives special value to the lives of persons. This fundamental value of autonomy is directly linked to one of the fundamental legal rights - the right to accept or refuse medical treatment - even life-sustaining treatment.

But precisely when a person might want to make use of the right to refuse treatment, she might slip into unconsciousness or a state of incompetency and this right is lost. The following case, discussed in the British Medical Journal, will illustrate the point:

Case 2

A 68-year-old English doctor was admitted to hospital with a large and advanced carcinoma of the stomach. Ten days after palliative gastrectomy was performed, the patient collapsed with a massive pulmonary embolism and an emergency embolectomy was done in the ward. When the patient recovered, he asked that

15. See P. Singer, H. Kuhse and C. Singer: "The Treatment of Newborn Infants \dots\", op.cit.
cardiovascular collapse, no steps should be taken to prolong his life, for the pain of his cancer was more than he would needlessly bear. He wrote a note to this effect in his case records and the hospital staff knew of his feelings. However, two weeks after the embolectomy the patient suffered acute myocardial infarction; his heart was restarted five times in one night. He recovered to linger on for three more weeks before he finally died. 16

Whilst most of us might think that it was wrong to resuscitate the patient, it may well be that doctors are legally required to act in this way - for if all human lives are equal before the law and if, as Justice Michael Kirby never tires of pointing out, statutory definitions of 'murder' in Australia typically include reference to omissions as well as positive actions 17 then it may just be a matter of time before doctors in Australia, like their overseas counterparts, will be charged with murder. 18

To safeguard patient autonomy, and to give legal protection to doctors, "Living Will" or "Right to Die" legislation has become a common feature in the United States of America. 19 Such legislation, designed to allow patients to declare in advance what kind of treatment they would wish to undergo when no longer able to make the decision, has also been proclaimed in South Australia in 1985, but was - despite the Victorian Health Advisory Council's recommendation - shelved by the Victorian Government, following alleged opposition from the Catholic Church. 20 I have argued strongly, in my submission to the Council, that a Refusal of Medical Treatment Act be introduced. The reasons I gave then still hold good: without such an Act many patients will continue to have their lives prolonged under circumstances that they regard as worse than death; and doctors will be practicing humane medicine fearing that they might, one day, be charged with homicide. 21

17. M.D. Kirby: "Euthanasia - Old Issue: New Debate", op.cit., p.5
18. See ref.21; and M.D. Kirby, ibid.
19. More than half the U.S.A. states now have "Natural Death Acts" and some states have additionally recognised "durable powers of attorney"; see Society for the Right to Die: Handbook of Living Will Laws 1981-1984, New York 1984
21. Submission by Helga Kuhse to the Health Advisory Council of April 7, 1983.
HELPING A PATIENT TO DIE OR ACTIVE EUTHANASIA

But there is another way in which a patient's autonomy can be overridden in a very serious way. Consider the following case, which closely resembles the sad recent plight of a Melbourne man. 22

Case 3

A woman is dying of terminal cancer of the throat. She is no longer able to take food and fluids by mouth and is suffering considerable distress. She would be able to live for a few more weeks if medical feeding by way of a nasogastric tube were continued. However, the woman does not want the extra two or three weeks of life because life has become a burden which she no longer wishes to bear. She asks the doctor to help her die. The doctor agrees to discontinue medical feeding, removes the nasogastric tube and the woman dies a few days later of dehydration and starvation.

But death by dehydration and starvation is not what the woman had wanted: she had asked for a quick and painless death through the administration of a lethal drug. So whilst the woman was helped to an earlier death through being allowed to die and was given passive euthanasia (like the patient in Case 1), she did not get euthanasia in its literal sense: a good and painless death. She had to die slowly and under distressing circumstances, as well as being denied the choice to die in a manner of her choosing.

As we have seen, passive euthanasia is both widely supported and - despite the legal uncertainties which surround it - widely practiced. But some of the same people who support passive euthanasia are opposed to active euthanasia. This raises the following important question: what is the distinction between active and passive euthanasia and does this distinction, whatever it is, have moral significance?

22. The Melbourne case is described in the press release of the Minister for Health of December 19, 1985
ACTIVE AND PASSIVE EUTHANASIA - WHAT IS THE MORAL DIFFERENCE?

The distinction between active and passive euthanasia is not, as Case 3 illustrates, the distinction between "doing something" and "doing nothing". Rather, it is the distinction between killing and letting die. In passive euthanasia, the doctor withholds or withdraws life support - for example, a respirator, antibiotics (as in Case 1) or a feeding tube (as in Case 2). In active euthanasia, on the other hand, the doctor administers a lethal drug or injection.

The question is whether this distinction between killing and letting die, or active and passive euthanasia, is morally relevant in itself. Would it really make a moral difference if the doctor instead of removing the feeding tube had given the woman a lethal injection? It is true, in this case the doctor would have killed the woman. It is also true that for most people the term "killing" has connotations of being a wrongful act - and so it normally is. Killing is normally wrong because the life taken is a good to the person killed, because the act of killing a person against her wishes overrides her autonomy in the most serious way.

But it is, of course, not only killing which is normally wrong. Deliberate allowing to die can, and sometimes is, just as wrong. Take the following case:

Case 4

Harry wants his aunt dead so that he will inherit her estate. He puts poison in her tea and Aunt Harriet dies of a heart attack. What Harry did was wrong. He killed his aunt.

Now imagine a different scenario:

Case 5

Harry does not want to use poison - there could be an autopsy and he might be found out. Luckily, Aunt Harriet needs a certain medicine, without which she will soon die of a heart attack. Harry refrains from giving Aunt Harriet the medicine and, as a consequence, Aunt Harriet dies.
Now, in the first case Harry killed his aunt. In the second case, he merely allowed her to die. But is what Harry did in the second case any better, or less bad, than what he did in the first case? I think not. The cases are morally equivalent because all the morally relevant factors, such as motivation, intention and outcome are the same. The distinction between killing and letting die is not morally relevant in itself.

The same is true about killing and letting die in the practice of medicine - except that the situation is now reversed: doctors do not generally act from bad motives - rather, they do what they believe to be in their patients' best interests. But if letting die is sometimes a good thing (because life is no longer a good thing, or because the patient has asked to be allowed to die), then - other things being equal - so must be active euthanasia. The mere difference between killing and letting die is not morally relevant in itself.

But things are not always equal. Passive euthanasia may take a long time and may be deeply distressing to the patient. Active euthanasia, on the other hand, is generally a quick and painless process. So while active and passive euthanasia are, in themselves, morally equivalent, a moral difference can arise in the way in which death comes about, and in the way in which passive euthanasia does not allow patients to go in a manner and at a time of their choosing.

Many people - and the growing public support in opinion polls for voluntary euthanasia bears witness to this, are not afraid of death but of the way in which they may one day be dying. They do not want to end their lives in suffering, nor as sedated and be-drugged objects. But as Dr. M. Pabst-Battin recently pointed out, cessation of life-sustaining treatment does often not result in a swift and benign death.

If a patient's kidneys fail and dialysis or transplant is not undertaken, the patient is generally conscious and experiences nausea, vomiting, gastro-intestinal

23. See the 1979 Morgan Gallup Poll reported in The Bulletin, Feb. 20, 1979; Australian Public Opinion Polls, 1979, reported in the Melbourne Sun and Hobart Mercury on December 4, 1979; the 1982 The Age poll, reported in The Age Nov. 13, 1982; and the 1982 Morgan Gallup Poll, reported in The Age on Nov. 26, 1983.

24. See Allan Kellehear in Social Science and Medicine, Vol. 18, No. 9, 1984, pp. 713-723.

haemorrhage (evident in vomiting blood), inability to concentrate, neuromuscular irritability or twitchings, and eventually convulsions. Dying may take from days to weeks, unless high potassium levels intervene.

An untreated respiratory death involves conscious air hunger. This means gasping, an increased breathing rate, a panicked feeling of inability to get air in or out. Respiratory deaths may take only minutes; on the other hand, they may take hours.

Consider next a bowel cancer patient with metastases and a very poor prognosis who refuses surgery to reduce or bypass the tumour. How, exactly, will he die? The likely outcome is: obstruction of the intestinal tract, the abdomen will become distended, there will be intractable vomiting (perhaps with a fecal character to the emesis), and the tumour will erode into adjacent areas, causing increased pain, haemorrhage, and sepsis. Narcotic sedation and companion drugs may be partially effective in controlling pain, nausea and vomiting - but this patient will not experience an easy death. Would it not be better to allow such patients to request active euthanasia from doctors willing to practice it?

If dying, in passive euthanasia, is often so hard, why do people continue to object to active euthanasia? One common claim is that patients could not rationally and autonomously chose active euthanasia. If opponents of active euthanasia, however, really believed this, then they would also have to hold that no patient could ever autonomously and rationally refuse life-sustaining treatment. But this is not what most opponents of active euthanasia believe. Rather, they suggest - most implicitly - that a patient can rationally choose refusal of treatment or passive euthanasia, but not active euthanasia. This is inconsistent. The question is whether a patient can rationally choose an earlier death to a later one - and that choice is made in either case. Hence, if patients can rationally choose passive euthanasia, then they must also be able to rationally choose active euthanasia.

Other arguments revolve around the claim that active euthanasia, whilst sometimes preferable from an individual patient's point of view, raises so many insurmountable practical problems that it should never become legal. Or, the point is sometimes made, that even though self-determination is a very important value, it must, in this case, be subjugated to the common good; for to allow active euthanasia would arouse concern about the lessening of the law's protection of human life as an absolute value. 26

26. See M.D. Kirby; "Euthanasia - Old Issue...", op.cit., p.1
CAN WE RATIONALLY SANCTION PASSIVE AND PROHIBIT ACTIVE EUTHANASIA?

Before we deal with the above objection, let us recall that both active and passive euthanasia are instances of the intentional termination of life - in other words, that the death of the patient is in either case the consequence of a deliberate human decision. Once the full impact of this is realised, many of the objections that are commonly raised against active euthanasia (but not against passive euthanasia) will lose their force.

Take the recent editorials in the Melbourne Herald and The Age, where the following practical difficulties are raised as objections to active euthanasia:

- Who should decide?
- What if the patient is unconscious or incompetent?
- How could prior consent be proved? What safeguards could ever be strict enough to ensure that the right to take life is not abused?

I do not deny that there are practical difficulties; what is often overlooked, though, is that the same difficulties must be faced with regard to passive euthanasia, or allowing to die. And allowing to die, I have suggested throughout this paper, has become standard practice in the modern hospital setting.

Take the practically very important questions: "Who should decide?" or "How can prior consent be proved?" It takes very little to see that these questions are the same, regardless of whether they are raised in the context of active or passive euthanasia - for a patient who is allowed to die is just as dead as a patient who is helped to die. There is no distinction in the gravity of the decisions which must be, and already are being made.

Finally, it will be said that it will be impossible to frame laws and provide safeguards against abuse. But the opportunity for abuse does, of course, already exist. If doctors wanted to abuse the powers they already have, they could do so by simply allowing their patients to die unjustifiably. What is more, detection - as in the case of Harry who merely allowed his aunt to die (Case 5) - would be less likely than it would be in the case of unjustified killings: there would be no direct evidence, the patient having died "naturally" of whatever life-threatening disease afflicted him or her. Thus, there is an argument that active voluntary euthanasia properly institutionalised, would decrease - not increase - the scope for abuse.

I agree that the framing of laws will be difficult, but I deny that it will be impossible. In the Netherlands, it has proved to be possible to make medical as well as legal provision for active voluntary euthanasia. In August 1984, the Royal Netherlands Medical Association (KNMG) issued a policy statement sanctioning active voluntary euthanasia. This statement also stipulates that the doctor has the duty to discuss with the patient the question of euthanasia and that the patient should be referred to another doctor if the patient's own doctor does not - for religious or other reasons - wish to practice euthanasia. 29 With this the KNMG has given its support to active euthanasia as practised by Dutch doctors in full view of the law since the 1981 Rotterdam Court Ruling on the Barendregt (Alkmar) Case. 30 Support for legalised active voluntary euthanasia was also given by the Dutch Government Commission on Euthanasia in its final report released on August 19, 1985, to the Ministers of Justice and Welfare, Public Health and Culture. 31

What the Netherlands experience indicates is that life is not devalued by a decision to allow or help a consenting patient die; but the value of life is lessened by a failure to allow a competent patient the freedom of choice and to make her suffer more than she is willing or able to bear. I believe it is time for those who continue to oppose active voluntary euthanasia to reflect on the values they are trying to preserve.

29. KNMG: Standpunt inzake euthanasie, Medisch Contact, Jaargang 39, nr. 31 d.d., 3 August 1984
30. Eugene Sutorius, barrister and solicitor: "How Euthanasia was Legalized in Holland", unpublished paper.
Reverence for life is common to all civilized societies, and in Judaeo-Christian cultures, where the rights and responsibilities of individuals are accorded special importance, each human life is seen as infinitely precious. The preservation of life has traditionally been the main duty of the medical profession. It is only in recent decades that the role of doctors in the struggle of life versus death has become controversial. This new concern arises from three related developments:

1. Medical technology has developed greatly, and it is now possible to resuscitate and maintain vital functions such as heart beat and respiration in people who have suffered shocking injuries or other damage;

2. Medical and social advances have caused a lengthening in the average human life-span, with an ever-increasing proportion of people reaching advanced old age and being subject to the frailties and indignities which may accompany the ageing process;

3. New diagnostic technologies have allowed the very early intra-uterine diagnosis of foetal abnormalities and have therefore prompted, more frequently than heretofore, the question of therapeutic termination of pregnancy.

These changes have raised the issue of whether and when there might be a "right to die" as well as a right to live, and whether new legislation is required to help society deal with the complex issues involved. Issues related to early human development and other aspects of reproductive physiology are particularly difficult and emotive. They will not be addressed in this essay, which will focus on the rights of adults and their relatives.
Three Examples of Dilemmas Encountered in Modern Medical Practice

It is convenient to begin with three examples of situations encountered by the medical profession reasonably frequently in Australia today. The first takes us into any one of the many intensive care wards of our large hospitals. A young man has been brought in from the casualty section in a deep coma. He is a motor accident victim, and has multiple fractures, a punctured lung and diffuse brain damage from a head injury. His heartbeat is strong, but his breathing slow and irregular, so he is intubated and put on a respirator. The fractures are set, the lung suitably re-inflated, fluid balance and nutrition are provided intravenously, but a CT scan shows multiple small brain haemorrhages and a great deal of swelling and waterlogging of the brain. After five days, the patient has not moved, does not respond to any painful stimuli, and for the third time in succession an electroencephalogram shows no brain-wave activity. There is a conference involving a neurologist, a neurosurgeon, the head of the intensive care unit, several registrars and residents, and the senior nursing staff. There is unanimous agreement that the brain damage is too severe to sustain independent life. The patient's parents, who have been carefully briefed several times daily, are told that their son is "brain dead" and that there is no point in persisting with the respirator. They are told that their son's still healthy kidneys might save the lives of two other people. They give their informed consent to the transplants. The respirator is turned off. No spontaneous breathing takes place. Very soon the heart stops. The patient is certified dead, and the kidneys are removed.

The second example involves a nursing home for the aged. An old lady of 83 has been admitted because her increasing degree of mental confusion has made it impossible for her to stay in her own home, and there is no one willing and able to look after her. Over three years, her condition deteriorates. She loses the ability to speak, requires to be fed, and becomes incontinent. Finally, she cannot sit in an armchair any longer, and is confined permanently to bed. One day, she contracts pneumonia. The relatives are contacted, and the matron of the nursing home tells them that she and the doctor she uses most frequently have worked out a loose arrangement for cases of this type. With advanced senile dementia, they treat the first three infections with antibiotics, and after that, mindful of the adage that "pneumonia is the old person's friend", they let nature take its course. The matron emphasizes that if the relatives desire, all infections can be vigorously treated. The relatives agree with the rule of thumb. The patient dies of a urinary tract infection six months later.
The third example involves a 75-year-old woman who has strong views favouring euthanasia, and who has made a "living will", the existence of which is well known to her husband and relatives. This says that, in the event of her becoming in any way incapacitated, she wants nothing whatever done by way of resuscitation or treatment. The woman suffers a severe stroke, is entirely paralyzed down the right side, and cannot speak. The husband is in a frenzy because he respects his wife's views. Nevertheless the doctor is called. He prescribes pills against high blood pressure and arranges intensive nursing. After a few weeks, it is obvious that the old lady registers everything that is going on. She clearly enjoys the visits of the grandchildren. She begins to say a few words, and the help of a speech therapist is enlisted, but progress is very slow. The physiotherapist is a little more successful, the patient learns to feed herself with her left hand and to walk a few steps with the help of a walking frame. Daily life is very hard despite the old couple's relative affluence, as looking after her at home absorbs much of the family's energies. Improvement continues for six months, then slows. Two years later, the patient has a second stroke and dies.

The Advantages of a Pluralistic Approach and Collective Decision-Making

These three examples can be annotated to show the advantages of a pluralistic approach to life and death decisions and the value of collective decision-making. Take patient 1. He was shockingly injured and perhaps should not have been resuscitated in Casualty, but who was to know? He had to be given a chance. Had there been a law making it illegal to turn off the respirator, he could have gone on for weeks, and the end result of such a law could (in the long run) easily have been that the casualty resident would not have resuscitated him, for what society could afford dozens of brain-dead people on respirators for weeks or months on end? In the event, he was given the best that medical science could offer, and when this failed, a decision was taken which tapped the collective wisdom and experience of all involved. Things could have been slightly different. He could, after three days, have begun a feeble attempt to breathe himself, allowing the respirator to be removed a few days later. He might eventually have recovered, though then the probability of residual brain damage would have raised agonising dilemmas. Right until the final, fateful decision, there were shades of grey, requiring discussion, evaluation, sifting in the light, above all, of individual and institutional experience. Who could codify all the contingencies into laws?
There will doubtless be a wide spectrum of views about Patient 2. A few intrepid souls within society are beginning to talk about euthanasiia for advanced senile dementia, but they would be in such a small minority at the moment that no legislature would even dare or wish to begin that debate.

There would be many who believe that vigorous treatment of all illnesses should be instituted, short of heroic measures such as open heart surgery or organ transplants (but even this involves a subjective judgement). There would also be considerable sympathy for our matron's view that one "should not strive officiously to keep alive" a person whose life has lost value and meaning. Surely a decent and compassionate society must accommodate such pluralism! Note that our matron did not reveal her little rule of thumb until the contingency arose, nor did she or the doctor write it down anywhere. Nor, most importantly, did she try to impose her views on the relatives. Again, the detailed decision on each particular case depended on collective wisdom and judgement.

Patient 3 is perhaps the most illustrative of all. The key element here is that the well person cannot possibly know how he or she would feel at the particular time and in the particular circumstance of some future contingency. The husband could have failed to call the doctor; the doctor could have failed to control the blood pressure. In either event, the patient would have died sooner. But who is to know what joy those visits from the grandchildren brought one human life under the new circumstances now prevailing? Suppose that legislation were in place giving effect to her wish for no medical treatment. The patient could not speak. Suppose, following the stroke, an intense desire arose within her to live at least until the eldest grandchild's forthcoming marriage - a desire unknown and unexpected when well? Or suppose that the recovery had been just a little more complete? Again the range of possibilities is so great that the most equitable solution demands decisions taken at the time and not on hypothetical cases infused with the mores of the society that are themselves constantly changing, and with the good faith of a number of people involved in the particulars

A Mature Election to Die

A more difficult area concerns very painful terminal illnesses, such as some advanced metastatic cancers. I have intentionally not put this in the format of a case study, but rather left it to last for special consideration. In most instances
pain can be controlled at least to a degree. Such control has inherent clinical risks, for example, high doses of morphine depress respiration, but these are negligible in the equation. Should a terminal patient have the right to ask to be killed outright by the doctor? I would not sit in judgement of either party to such a contract, but would myself not feel justified in participating in it. I do believe that patients should be given free and easy access to narcotics and hypnotics, and if it is necessary to push the dosage to levels which could be fatal in order to control pain, I have no ethical difficulties with that. To me, the difference between this approach and a formally lethal injection are quite real in moral terms. At present, many doctors in the real life situation, ensure a great deal of discretion in self-medication for terminal cases. Fortunately, in most instances such agonizing situations are usually of short duration. A positive legislative act to permit mercy killing would outrage large sections of the community. In the absence of a consensus or even of a reasonably broadly held and clearly articulated view in favour of mercy killing, I believe the harm that would be done to the social fabric would outweigh any good that might accrue to the very few individuals who would wish the free choice. In the event, many cancer patients cling to the last rays of hope and threads of life, and, when all the stops are pulled out, medical science can do much to make the end more bearable. In my experience, the issue is more of a straw man than the three examples analysed above, although distressing exceptions certainly occur.

But a mature election to die, and the rights of a person making such an election, constitutes an issue on which people of goodwill may differ. Each individual's position will reflect his or her background, training, experience and subjective assessment. My position is to warn against a change to the status quo.

Conclusions

Under our system of governance, we have the rich twin heritage of statute law and case law. Each can contribute notably to societal progress. Case law is a kind of societal safety valve. If something appears to someone to be wrong, but no statute clearly prohibits it, case law and the appellate system will sooner or later shine a light on the issues, and, if necessary, new legislation through the political system will be triggered. In Australia, the paucity of landmark cases on the "right to die" issue seems to reflect that fact that the untidy, polyvalent, inchoate and unwritten methods of a diversified, free and humane society are working reasonably well.
Laws, once enacted, are difficult to change. Medical technology and society's reactions to it, on the other hand, change constantly and with surprising speed. There are so many checks and balances already at work, as illustrated by our three examples. Laws or no laws, the question of how hard to try to prolong life will always be a medical decision, subtly different in each particular case. In an imperfect world, it is sometimes better to permit the shades of grey.
OPTIONS FOR DYING WITH DIGNITY

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To begin a discussion of the intensely practical subject of dying with dignity, it is pertinent to remind oneself of some of the fundamental realities of life. The process of life is a consequence of the influence of probably a small number of physical laws on the matter of life. The difference between life and death is ultimately to do with organisation and therefore, in an entropic world, energy. Life is about the constant provision of energy to maintain and increase organisational integrity. Physicochemical phenomena continually operate to increase system randomness moving ultimately and inevitably towards death. Death marks a (usually) catastrophic decline in organisational energy levels to a point of critical instability, that is, natural irreversibility.

Such realisation touches upon our present understanding of life and death. What might appear to be a sterile approach to the subject may quickly be seen to have practical application. Until recently death was defined in terms of cessation of the circulation, a point from which total randomness of all system organisation could be certainly predicted. We have retreated from that stance with a more modern definition of death, a definition based upon death of the brain. Whilst unsupported existence following death of the brain and brain stem is impossible, the insertion of control inputs to breathing may ensure the indefinite integrity of a large number of body systems.

Nevertheless we have taken the view that vegetative existence in the absence of cerebral function forms no useful basis for life. Such new definition of death serves a very useful purpose for the therapist involved in decisions about life support. Notice that what has occurred here is a re-definition of death in energy or organisational terms. In a sense then death is part of a continuum of energy change that occurs throughout life. It is intriguing that a contemporary medical controversy surrounds a similar process at the other end of life - the insertion of positive control inputs to the conceptive process, invitro-fertilisation.
Sanctions exist against many processes that increase the organisational randomness of life. This could be seen as a corporate intellectual extension of those individual biological developments which favour survival - the legalisation of the evolutionary process. In deference to the rights of the individual, these sanctions usually relate to the influence of one individual upon another; each individual is legally, if not morally or ethically free to do with him or herself exactly as they please. We even steadfastly, perhaps irrationally, protect the right to terminal life support for the individual after a lifetime of unrestrained self destructive behaviour. What is being said. What is being said here is that death is a very personal thing, it is acceptable to choose it for yourself quickly or slowly, but one cannot expect another to be involved.

If everybody has the fundamental legal, if not moral or ethical right to die, we need only talk about Government intervention when the dying process involves another person. Thus, if a change to the legislation is required, it logically would deal with the legal dilemma of the second party to be involved in the process, not necessarily the rights of the dying. This confusion is perpetuated in attempts to legislate for the dying individual.

The difficulties of the South Australian Natural Death Act - 1983, make this point clearly. This act gives legal effect to directions against artificial prolongation of the dying process. First it requires each individual who seeks to become the subject of the Act to make an appropriate written direction. This may be very inconvenient for the majority who have not. Second to meet the requirements of the Act, the death of the individual must be imminent if extraordinary measures are not undertaken, and result from a disease from which there is no prospect of even temporary recovery.

It is clear that no reasonable therapist would embark upon the extraordinary support of such a person unless there was some secondary purpose such as organ donation. To do so would be obscene. To be fair the Act does give protection from perverse therapists. It is true that many people are supported, in many people's view, beyond what is reasonable or dignified. This is because even with properly constructed and widely consultative care the outcome is uncertain. This truly is the doctor's dilemma. Ultimately the patient has placed themself in the medical practitioner's care, it is he or she who must finally be responsible for their wise management. The South Australian Act does nothing to relieve such a practitioner of responsibility for a negligent decision as to whether or not the patient is
suffering from a terminal illness. The Act sidesteps the very issues which it presumably is designed to address. No amount of legislation will prevent bad medicine.

It is interesting to contemplate why such acts are promulgated. One answer may be that this is the next logical, legal evolution in a world of high technology medicine, following the re-definition of death. Another may be an increasing public perception that the medical profession is performing less than satisfactorily in this area. It is notable in the latter regard that an often quoted reason for nursing devolvement from the care of the critically ill is anxiety about the appropriateness to the patient of the care being provided. Such anxiety is not limited to questions of mere survival but touches broadly upon the likely quality of life.

In this regard I would like to address my remarks essentially to the care of the seriously ill, elderly patient.

Doctors of course are making decisions about the provision or non-provision of therapy all of the time. When a doctor/patient relationship is formed it is tacitly accepted that the patient is placing themself in the care of the doctor and a number of special rights and responsibilities attach to that relationship. Sometimes certain aspects of the relationship are formalised, for instance the gaining of consent in writing, but in the main they are assumed. Notice that it is the care of the best interests of the patient that is in question and not necessarily the blind pursuit of survival.

The wise doctor, in a thousand different settings, will make kind decisions which compared to what might be technically possible will shorten the patient's life. These are decisions made usually privately, sometimes sub-consciously, often in consultation with relatives or friends. They are part of the essence of good medicine. The overwhelming majority of these decisions, be they to treat or withdraw, are seen as appropriate, and are not subject to public or legal criticism or scrutiny. They are accepted as the proper substance of the contractual relationship between patient and healer.

The patient has their legal redress but the American experience has too often shown the folly of conducting a patient's affairs in a strongly litigious framework.
Not only is the trust between patient and doctor generally eroded but an atmosphere of protective over-investigation is engendered. This may be hazardous to the patient and compete unnecessarily for scarce medical resources. In a worst situation, the Court is called upon to make very public and none-too-occasionally unhappy decisions. Except where complex questions of basic human rights are involved, such cases risk becoming a parody of the medical process. They are generally a sign that it has failed.

Exactly the same principles would apply to the care of the critically ill, but there are many reasons why balance may be lost. Such care has to a large degree become institutionalised and thus the decisions involved are very public and are shared.

Those caring for the patient may be quite remote from the private contractual relationship that was initially established between the doctor of first contact and the patient. The patient or their relatives in crisis may cling to unreasonable expectations of what may be provided in technical or resource terms. These expectations may be re-inforced by the practitioner referring the patient for care, sometimes in the charged atmosphere of failed first line treatment. Medical providers of extraordinary care have a "survival ethos" based on a rigorous training, a very proper place as the patient's last advocate and a "no expense spared" philosophy, powerfully encouraged by a supporting industry. Such a caring doctor may weary of forever bringing referring colleagues to the extremely difficult realisation that here is a life that should not be so vigorously supported, even if such action enjoyed legal sanction. He may be accused of defeatism or abrogation of the responsibility placed upon him; may he never be wrong in his judgements. It is far easier to retreat to the technical world in which the therapist feels most comfortable, realising of course that the better he is at the hard data, the more difficult the soft decisions may become.

Such a practitioner may have little knowledge of, or time for, resource questions as to how his contribution relates to, or limits, the total health resource. In an environment unforgiving of poor standards his perceptions are more likely to relate to the obvious limitations that surround him.

Against this background, maintenance of a holistic approach to care and perspective about the downstream limitations of illness requires constant vigilance,
exceptional knowledge and uncommon wisdom. We live at a time where the technological provision has outrun the human and humane answers.

It must be made clear that some of the emotive questions that arise in high technology medicine, those that relate to the provision for scarce or very expensive resources to a small number of patients and find their way on to the front pages, truly represent the tip of the iceberg. It is far more likely that difficult management questions will arise in the patient suffering the vicissitudes of a debilitating common disease.

Though the unusual situation where special organisational structures are brought to bear may teach us about wise decision making, it is this largely silent population that must be addressed if "dying with dignity" is to have any meaning in numerical terms.

Firstly any assault on the problem must begin with good training. As a general statement the student therapist in Australia receives scant instruction in the management of the dying process. Training tends to be survival oriented and the focus technical. It would be almost unknown for such a student to be exposed to simulation exercises in the conduct of the very natural processes leading towards death; to discuss the options, the ethics, to know the wording of the legal restraints or the resource channels available. This is a serious deficit that must be addressed.

Thus unarmed, the novice practitioner finds himself in the front line of hospital practice where coping with his patients and his own survival may leave little thought for the appropriate care of the dying. His attitudes may be reinforced by zealous, performance-oriented seniors. Dying never was popular.

With time and particularly confidence about decision-making for the living comes the realisation that the support of a patient and family during dying is for the carer, one of the most rewarding of therapeutic experiences. This probably first happens in a private way; there later evolves the ability to successfully handle dying in an institutional environment. It is a long evolution. It is axiomatic that such training should keep in step with the advancing technological edge of medicine. In general it has not.

The training solution would appear to be theoretically simple and would be a good point for government input.
Second, it needs to be seen that the normal decisional rights of a doctor to care for his patient, in so far that caring may involve both treating or withdrawing, extends to those highly visible areas in which extraordinary means of support are provided. We have already established that this is the substance of everyday medicine, the principle is no different for those under intensive care. Implicit in a decision to provide a particular means of support must be the contralateral right to take it away if it is inappropriate. The fact that there is closer temporal and therefore perhaps causal relationship between decision and outcome doesn't change the principle when compared to a decision made for example twelve months previously. It is intolerable to ask for a reversible decision to be implemented uni-directionally if, having made it, no useful patient interest is served.

It undoubtedly happens that decisions to withdraw life support of those whose survival is uncertain occur every day in the Australian environment. Very probably acts of both commission and omission which shorten the duration of life are made after proper consultation and due regard to the known wishes of patients and their families. A widespread criticism of such terminations of support is that they are unnecessarily delayed and occur only after every possible treatment avenue has been explored. Even then if the letter of the law is strictly applied the course of therapy may lie outside what is legally correct, to say nothing of ethical and moral restraints.

Many of the carers for the patient have a deep sense of frustration and anguish that they are implicated in the inappropriate prolongation of life, sometimes not truly believing in it and feeling that they have no voice. The beleaguered doctor who is ultimately responsible may feel trapped between what is legally acceptable, what he or she finds personally ethical, the soft questions surrounding the best interests of the patient and the emotional well being and continuing involvement of the carers themselves.

The guiding principles here ought to be simple and a wise carer will heed them. The best interests of the patient are paramount. That is the nature of the medical contract. They are arrived at by the widest possible consultation and the best available information about the patient, his life, his ethos and the medical restraints. This is a process of consensus. It relates to an individual and is judged by individuals with all the limitations that that entails. There are no all-embracing formulae. Ultimately it cannot be otherwise. It may not necessarily be formal or
structured. When a decision is reached it is communicated to all of the involved parties to the limit of that possibility. This is a most important step and allows comment and review in that it may touch individual sensitivities. Communication is a two way process. Only when these matters are completed may the medical process run its course.

Before contemplating a change in the law it is important to recognise that in the overwhelming majority of cases, particularly where "extraordinary measures" and a team approach are involved, it is much more likely that medical advocacy rather than legal restraint protect the sanctity of life. There are inbuilt safeguards where a number of therapists are involved and there is corporate implication in the design and institution of therapy. As a corollary the law should recognise the special position of those who are attendant upon the dying process where unnatural processes may alter its course.

It would be the writer's view that the wisest practical change to the law would affect not the rights of the patient, be he or she capable of giving direction or not, but that much more limited group, the medical, nursing and other professionals who care for the dying. The legislation would recognise the potential legal vulnerability of those whose thoughtful and caring actions may be construed by others to have intentionally caused death rather than merely allowing the dying process. Without particularising, such enabling legislation needs to be brief and easily understood and would require evidence of adherence to the above principles. It should be widely promulgated. It is not immediately clear why special legal restraints for the users of life sustaining equipment or techniques would be required.

Finally one should be attendant upon the emotional care in addition to the legal protection of the carers for the terminally ill. Prevention as always is better than cure. It is the author's experience that anticipation of the anxieties of the therapist, the encouragement of early involvement in management strategies and communication about the directions of care is a better approach than formal counselling. With appropriate support the principle of "therapist heal thyself" should apply.
"Dying with Dignity" is the right of all patients and indeed exists for most patients. In Catholic health care facilities regard to this is paramount in the delivery of medical services that are rendered to assist patients to enjoy their lives.

The term "right to die" is a misleading term and our principles seek to bring about a right to die with dignity. Our Christian belief is that God is the one who has ultimate control over life and death. We are stewards of our lives but we do not have the right to determine when to die; we do not have the right to actually take our lives.

There is a right not to prolong dying and this decision to withdraw or withhold life support procedures is legally and ethically recognised. Rather than legislation which cannot adequately encompass many distinctions needed preference is given to internal guidelines.

We contend that carefully prepared guidelines within our health care facilities provide a satisfactory basis for handling the more difficult instances, for example, seriously defective newborns. Use should be made, in these circumstances of ethics committees, chaplains, ethicists. We believe that good communication between treating medical officers, the patient where that is possible, and relations, does result in the adoption of appropriate arrangements for continuing health care management.

We strongly oppose legislation in this area as it will divide the community. There is a right to die. Death is the normal natural end to the life on earth process. Legislation bestowing on individuals the "right to die" purports to give to another something which does not belong to the State - the power over life and death. That power belongs to God alone.

Instead of introducing unnecessary new legislation it would be preferable if increased provision were made to expand the hospice program, the staffing of critical care areas and the provision of greater support services to the handicapped and the dying, enabling them to die with dignity.
This paper seeks to approach the questions raised from a Catholic point of view. From the time of Christ to the present, those involved in Catholic health care ministry, religious and lay, have cared for people according to Christian values - love, compassion, understanding, commitment and, most importantly, hope.

The teaching of the Catholic Church condemns the killing of the unborn by abortion, of the disabled newborn by infanticide, of the terminally ill or injured or of the aged by euthanasia. This is clearly set out in the Vatican document "A Declaration on Euthanasia" issued by the Sacred Congregation for the Doctrine of the Faith with the approval of Pope John Paul II. It is also affirmed that while Christians have a definite duty to preserve life, there is no duty to prolong the process of dying. Every human being has a right to life, and every effort should be made to protect that right.

In his address to a group of Disabled Persons in November, 1985, Pope John Paul II stated:

"In certain nations, the abrogation of the right to life of the unborn of even of the newborn has been 'legalised' when it is a question of disabled human beings. At this moment, I would like to remind the legislators, statesmen and rulers of such nations and of all the nations of the earth of the powerful word of God: 'Thou shalt not kill' (Ex 20:13, Deut 5:17), which is intended to protect, safeguard and defend human beings, every human being, from the moment of conception." 2

In the document "Declaration on Euthanasia", the Sacred Congregation for the Doctrine of the Faith commented:

"It is necessary above all to recall the respect for the life and for the dignity of the dying when, in spite of the treatment offered, death seems no longer avoidable. The presence of suffering even in the terminal phase, while it should stimulate every effort to lessen the pain and to sustain the spirit of the dying, should never allow actions or omissions as their goal to shorten the life so as to spare the patient or his relatives suffering".  

In his address to the Conference on Human "Pre-Leukemia" in November 1985, Pope John Paul II stated:

"Practices of euthanasia, more or less manifestly proclaimed, signal a moment of regression and of abduction on the part of science, and an offence to the dignity of the dying and also to his person."  

Human relations achieve their highest peak when we take on our neighbour's burden or when we seek to benefit the less fortunate by the best means at our disposal. While we have no obligation to use every possible medical technology to maintain a patient's life when it is burdensome, we have no right to take life, under any euphemism. Active, intended euthanasia, is a direct rejection of the Creator's gift of life.

In the following sections reference will be made to the specific items set down for the Committee of Inquiry. However, the above principles form the basis for the views expressed.

"Greatly increased technological capacity to sustain life"

This report was requested because of the difficulties which now arise due to the many advances made in medical technology particularly in life support systems.
is acknowledged that these developments have improved health care. However, it
is realised that in providing such new technologies to prolong life artificially, there
arises the necessity to make decisions, not previously required, as to the use and
the cessation of such procedures. From a Catholic viewpoint, these vital decisions
are deemed to be made best after careful discussion between doctors, patients and
other relevant parties whose combined considerations should review all factors
with the ethical aspects being paramount.

Dr. John Cade at the 1984 St. Vincent's Bioethics Conference set out the
indications and procedures used in critical care wards. This is an example of
guidelines which we can support. 5

1. "Whether it is desirable and practicable for the Government to take
legislative or other action establishing a right to die."

To this first term of reference, a negative response is given in the paper.
The chain of life, through birth to death is a normal human expectation and
in the vast majority of instances moral or ethical difficulties do not arise.
Moreover for Christians, death is seen as the beginning of a new life when a
person made to the image and likeness of God goes to his or her maker. In
its health care ministry and in other activities the Church prepares its
members for death, provides sacramental assistance and other pastoral care,
in addition to the various hospital and hospice services normally provided for
the sick and dying.

If the "right to die" reference really means the ability of an individual to
choose his or her time and method of dying then the purpose of such
legislation is quite clear. What is actually proposed is euthanasia whether it
be voluntary (or assisted suicide) or involuntary which is really homicide,
both of which are currently illegal. Any change in legislation along these
lines opens the door for disputation, misuse and even exploitation. Those
with utilitarian motives would see that many of our community declared to
have futures which were "meaningless", "devoid of value", those having "no
morally relevant characteristics", are not persons, have no entitlements, and
should be given a "quick, good, painless or happy death". This is totally
unacceptable to those professing Judaeo-Christian principles.

5. Proceedings of the 1984 Conference on Bioethics, St. Vincent's Bioethics
Centre.
This term of reference requires consideration of other methods of setting down principles of management. Health care institutions should have ethical and practical guidelines established concerning the right to life and right to die with principles set out to deal with the difficulties which arise during the lifetime of individuals (newborn through to the aged) and to the particular conditions surrounding each person's treatment. There are examples of such guidelines for making critical life decisions, which allow for various circumstances and within which the patient, the treating doctor and other relevant persons can address these issues. However, in certain situations time may not allow much consultation. The doctor involved may need to make an immediate decision. In such cases it is safe to adhere to certain well established principles. Review of difficult decisions is desirable and should be undertaken with other competent people. Such a review by an ethics or medico/legal committee may lead to, at times, some modification in that hospital's guidelines.

The use of guidelines in this way is far more preferable to legislation which would lead to more litigation and this would profoundly influence the decisions made by doctors and members of the treatment team.

2(a) "The fundamental question as to whether, and under what circumstances, if any, a person should have a right to die."

A competent patient may decline customary or non-extraordinary treatment because of deteriorating health, pain or other perceived justifications. Provided no excessive burden for the patient in treatment is involved, deteriorating health alone for example, is not a sufficient ground for withholding ordinary treatment. Every effort should be made to persuade the patient and the family of the full ramifications of the decisions while reassuring the patient of comfort, support, of self-worth and the inherent value of their life.

There are circumstances however, where prolongation of life maybe deemed to be inappropriate and "heroic", extraordinary, or burdensome efforts are not demanded.

Such decisions not to prolong dying unduly are made and must be properly

6. Ibid.
recorded in the patient's medical record. There may be "do not resuscitate" orders, and in hospitals, medical procedure manuals or guidelines are recommended to ensure that proper decisions are made concerning the future management and care of such a patient. Efforts to revive a patient suffering an acute respiratory or circulatory arrest would be applied in normal instances as an immediate response. The "do not resuscitate" order is a specific instruction, considered ethically appropriate in the extreme cases, well known to the treatment team. A competent patient must be fully informed of the consequences of such decisions and must give consent. Normally the stage of curing an illness would have been passed and resuscitation would be unnecessarily burdensome. Such considerations would apply to all age groups, from newly born to the aged.

These procedures, such as "do not resuscitate" refer to a consideration of not prolonging life as it would be too burdensome in proportion to the benefits of treatment. They are not decisions to terminate life. Ordinary nursing care, warmth, nourishment, pain control, etc. would be continued. Efforts to control pain by drugs are ethically lawful for doctors to apply even if a possible reduction in the length of life is an unavoidable consequence.

2(b) "What is an acceptable definition of 'death'."

The Victorian Legislation already includes an acceptable definition in the Human Tissue Act 1982, S41, and is based upon brain related criteria, as well as cessation of blood circulation. It is medically, morally and legally appropriate to diagnose death on the basis of total and irreversible cessation of all brain function. Death is a medical diagnosis and if criteria agreed upon in standard medical practice are used it will lead to acceptable, accurate and reliable decisions. In most instances, the decision is not at issue. However, since the transplantation of organs from the "dead" has become acceptable ethical practice, a careful determination of death is required, in addition to the existence of standard consents to use those organs or tissues. Certain medical conditions can often simulate cessation of brain function and at those times extreme caution should be used to determine the irreversibility of brain function. Those diagnosing death in cases of transplantation of organs should have no part in the procedures and indications for transplantations.
3. "The right of an individual to direct that in certain circumstances he or she be allowed to die, or assisted in dying and the form which such a direction should take"

In addition to what has been noted already in relation to this term of reference, some comment needs to be made regarding the form which a direction to be allowed to die might take. The ethics of the right to life has been enunciated and this rules out immoral and at present illegal acts to "assist persons to die", ordinarily interpreted as active, or involuntary euthanasia. The Catholic position, as already stated, is that actions or omissions which by their nature or in the intention of the agent, have as their goal to shorten life, are never permissible. One form of such a direction to refuse treatment is known as a "living will." Generally the frank exchange of information between treating doctor and patient - relatives where appropriate, may facilitate correct and ethical decisions to be made.

There are so many known practical difficulties relating to "living wills", involving such factors as informed decision making, loss of will, witnesses, reversibility and inflexibility. Support cannot be behind something which complicates important basic relationships and sound currently accepted practices. The standard expected of the medical profession is that decisions in this area must be written clearly in the record, so that all staff especially nurses and chaplains are fully aware of the position being taken and of any change to orders previously written or discussed.

4. "The right of an individual who has not and is incapable of giving such a direction to be allowed to die, or assisted in dying."

The matter of most importance in this reference relates to the decisions not to continue burdensome treatment made in situations where the individual is incapable of being involved. These are the areas of great difficulty. In these circumstances the incapable person needs to be protected by appropriate guidelines. Again good communication procedures, involving the family, treating doctor, chaplain, ethicist and any other close person, will minimise the difficulties which can arise. The incapable group of individuals are discussed in the following sections:
Newborns: Assuming a newborn has a serious defect, paediatricians and families become involved in decisions not to provide extraordinary or burdensome treatment. There is a wide range of conditions which provide reasons for considering this action. The position of the Catholic Church on this point may be summed up by saying firstly that it aims to protect life and does not accept the killing of the newborn. It accepts that proper and ethical decisions need to be made after careful discussion with an ethics committee where time permits and/or between doctors, nurses, chaplains and parents. Always there will be the need to provide normal nursing, pain relief and ordinary nourishment for the newborn and then to allow the dying process to take its course. There are situations when a neonate is "born dying." Difficult decisions made without involvement of an ethics committee, should be subject to a confidential review by competent people. From time to time the guidelines may need to be amended to cover previously unknown circumstances, or new techniques. The patient's right to life must be always the prime consideration.

Decisions to cease active life support of the newborn resulting in death, like the killing of defective newborns, are and must be seen to be irreversible. They may never be taken lightly.

It must be a serious matter of conscience for all those who are directly involved. It cannot be adequately covered by legislation. There is no uniformity of circumstances which can be properly worded in legislative form. Opportunities for litigation would increase as lawyers made their legal distinctions and argued the "value" of a particular life. The answer to the anticipated suffering and disadvantages for the surviving newborn and his or her family, must be for our society, governments, the Churches and support services - to provide appropriate help. This is one hallmark of a good civilised society. A selfish community removes its difficulties by unacceptable actions and sets up a state of inequality between human beings.
(ii) **Irreversibly Comatose Patients:** This is a most complex area for decisions about the prolongation of life. Here all possible treatment methods do not have to be applied when palliative care may be the appropriate decision. However, normal care due to the sick must be applied, especially pain control, warmth, attention to skin, bodily functions, nutrition and hydration. The decision which requires, as stated above, wide consultation particularly between the treating doctor and next of kin and/or ethics committee, chaplain, etc. must be proceeded by a careful assessment of the benefits of continued treatment. As in other circumstances the best interests of the patient must be the principal consideration.

(iii) **The Elderly Incompetent Patient:** These patients represent a large number of circumstances involving prolongation of life decisions. It may be difficult to assess the burden of treatment and the resulting benefits. Decisions have to be made very carefully. Wide consultation will minimise errors. Clearly actions which are designed to dispose of a "problem" person are unacceptable. Age and handicap alone are not suitable criteria. Where there is a fine balance between alternatives, the decision should be made in favour of allowing a human being to run a natural course to death. In this group, the adoption of a proper "do not resuscitate" order procedure referred to earlier is essential once the decision has been made that an individual's life should not be prolonged.

5. "Protection for medical, nursing and other professionals who allow an individual to die, or assist an individual in dying, including the need for guidelines for carers in the use of life sustaining equipment and procedures and need for continuing counselling and after care."

The care of medical, nursing and other professionals in health services is of the utmost importance. Continuing the position noted earlier, this support cannot cover illegal or unethical acts. However, in the matter of "prolongation of life" decisions, careful support and facilitation of the decision making process should be all pre-arranged. These need to provide a framework in which critical decisions are made by all involved, including
medical and nursing staff. If the staff are not involved in illegal acts, no new legislation is required. These staff however, do need carefully prepared guidelines for reference and properly constituted ethics committees to consult on the really difficult instances.

Both staff and management will find critical care areas (neonatal or adult) extremely strenuous. Due consideration should be given to adequate hours of staffing in order that the health of the carer is protected otherwise, they cannot be expected to cope with the stress involved and with the contact with emotionally-charged persons interacting with their department. The choice of staff for critical care is vital. It is important that placement decisions are made skillfully and in-service or external education be made available and access to counsellors, chaplains and other helpers facilitated.

6. "Relevant literature and judicial decisions."

This term of reference provides information on literature, judicial cases and more recent developments here or overseas. Some of these were covered as this paper was in preparation.

The Quinlan case set the precedent in law for withdrawal of life support systems in the United States of America. Other references include terminology which is now being queried or is limited to application in terminal illnesses. The South Australian Act refers to "extraordinary" measures and this term needs to be further refined as medical science develops.

In general, the literature emphasises disproportionately the most difficult circumstances involving multi-handicapped persons or other complications. Hard cases make bad law. It is contended that legislation which tends to be broad in application and has problems in definitions, is a greater danger than the existing position where use of internal guidelines and good communication between the appropriate parties involved will satisfy the vast majority of instances.
CONCLUSION

Accepted professional standards still provide a sound basis for the satisfactory solutions of most cases in an admittedly difficult area. The number of extremely contentious decisions is minimal. Therefore the need for new legislation is rejected. However, there is the need for hospitals, nursing homes, hospices, etc., to have carefully drawn up ethical guidelines as to when it is not necessary to prolong life by the use of every possible life support system.

Catholic health care facilities continue to provide a whole range of services to assist those who are suffering through handicap, trauma, terminal illness or who are facing death as part of the normal unavoidable life process. The care of the dying has been enhanced by the development of a high level of expertise in such areas as hospice, pain control in the provision for the wider care of relatives and families with pre- and post-bereavement counselling and with the general support of community services.

Instead of introducing unnecessary new legislation it would be preferable if increased provision were made to expand the hospice program, the staffing of critical care and the provision of greater support services to the handicapped and the dying enabling them to die with dignity. By all means let people die with dignity and to die at home if requested.

The United Nations in its 1948 Universal Declaration of Human Rights proclaimed - "Everyone has the right to life, liberty and security of person" (Article 3); and "All are equal before the law and are entitled without discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination" (Article 7).

In its 1966 International Covenant on Civil and Political Rights, the States Parties, in accordance with the principles proclaimed in the Charter of the United Nations agreed that - "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of life" (Article 6).

7. United Nations Universal Declaration of Human Rights
The most basic of all human rights is the right to life. Everyone has the right to life. No one has, and nowhere has it been proclaimed by the United Nations that a person has a "right to die." The term "right to die" is itself confusing and ambiguous. If "right to die" is interpreted to mean the right to procure death either by one's own hand or by means of someone else, as one pleases, then it is not only not a right but it is an abrogation, a violation of the most fundamental "right to life". However, if "right to die" be understood to mean simply the desire to die peacefully with human and Christian dignity, then some more apt and less confusing term should be used as there is a continuing need for society to provide for the sick and the dying not only appropriate medical and nursing care and treatment but also all the signs of human kindness and love by those close to him or her.

The position of the Catholic Church on these questions has been made abundantly clear time and time again. In its Charter on the Rights of the Family, issued by the Holy See on 22 October 1983, it has been stated once more - "Human life must be respected and protected absolutely from the moment of conception" (Article 4); "Children, both before and after birth, have the right to special protection and assistance" (Article 4(d), which is based on the 1959 United Nations Declaration on the Rights of the Child, Preamble and Principle 4); "The elderly have the right to find within their own family or, when this is not possible, in suitable institutions, an environment which will enable them to live their later years of life in serenity while pursuing their activities which are compatible with their age ... [Article 9(c)]. 9

There can be no ambiguity about the position of the Catholic Church on Euthanasia or "right to die" if understood to mean an action or an omission which of itself or by intention causes death. It states that "nothing and no one can in any way permit the killing of an innocent human being, whether a foetus or an embryo, an infant or an adult, an old person, or one suffering from an incurable disease or a person who is dying. Furthermore, no one is permitted to ask for this act of killing, either for himself or herself or for another person entrusted to his or her care, nor can he or she consent to it, either explicitly or implicitly. Nor can any authority legitimately recommend or permit such an action" (Declaration on Euthanasia, 1980).

The answers given to the questions raised by this inquiry will depend on the answers one would give to much more fundamental questions like - what is the purpose of life?, what is the meaning of death? Upon such basic questions community opinions will be divided. Legislation purporting to grant people the right to die or to end another's life in certain circumstances would deepen such division in the community. This is not the time to introduce such legislation. Recognising that death is inevitable and unavoidable, and will end the life of every human it would be much preferable for the Legislature to concentrate now on measures enabling people simply to die with dignity.

General References

(a) To Treat or Not to Treat - The Catholic Health Association of the United States - 1984.


(c) Determination of Death - Theological, Moral, Ethical and Legal Issues - The Catholic Health Association of the United States - 1982.

(d) Seminar on Euthanasia; Papers presented at Seminar organised by the Newman Graduates Association of Canberra, November 1985.


(f) Ethics & Medics - Various editions, prepared by Pope John XXIII Medical - Moral Research and Education Center, Massachusetts.

(g) Hospital Progress - Various editions, published by the Catholic Health Association of the United States.

(h) Deciding to Forego Life Sustaining Treatment - Ethical, Medical and Legal Issues in Treatment Decisions. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, March 1983.


NOTES ON CONTRIBUTORS

REV. HOWARD AINSWORTH is an Anglican priest and a clinically trained chaplain. He has been Interdenominational Chaplain at Preston and Northcote Community Hospital since 1973.

DR. NEIL CAMPBELL graduated M.B.B.S. from the University of Melbourne 1966, and received his Fellowship of the Royal Australian College of Physicians in 1971. He trained in perinatal medicine at Queen Charlotte's Maternity Hospital (University of London) 1972-74. He has been engaged in the practice of newborn medicine at the Royal Children's Hospital, Melbourne, since 1974. Since 1978 he has been Director of the Department of Neonatology, Royal Children's Hospital, Melbourne.

PROF. MAX CHARLESWORTH is Professor of Philosophy at Deakin University, Victoria. He is a member of the Monash University Centre for Human Bioethics and also a member of the Standing Review and Advisory Committee set up under the Victorian 'Infertility (Medical Procedures) Act 1984. He is the author of 'Biotechnology and Bioethics: New Ways of Life and Death', Current Affairs Bulletin, University of Sydney, vol. 61, no. 5, October, 1984.

MISS JENNY GIBBS, M.Sc. (Nursing), RN, RM, Director of Nursing Services at the Cancer Institute/Peter MacCallum Hospital, Melbourne. She has had more than 25 years experience in the nursing profession both in Australia and the United Kingdom.

REV. DR. JOHN HENLEY has been Dean of the Melbourne College of Divinity since 1976. He has lectured in theological ethics since 1969 at what is now one of the College's associated teaching institutions, the United Faculty of Theology in Parkville. He was a consultant to the Australian Law Reform Commission on the matter of human tissue transplants and a member of the Committee to consider the Social, Ethical and Legal Issues Arising from In vitro Fertilization (the so-called 'Waller Committee') established by the Government of Victoria. He is currently a member of the Standing Review and Advisory Committee established by the same Government in accordance with its Infertility (Medical Procedures) Act 1984.

HON. JUSTICE MICHAEL D. KIRBY, C.M.G. has been President, Court of Appeal, Supreme Court of N.S.W. since 1984. Between 1975-1983 he was Chairman of the Law Reform Commission of Australia, and he was Deputy President of the Australian Conciliation and Arbitration Commission between 1975-1983.

DR. HELGA KUHSE is a research fellow at the Monash University's Centre for Human Bioethics. Appointed in 1981, she has been instrumental in setting up the Centre and in organising its first conferences and seminars. She has published several articles on medical ethics and is co-author, with Prof. Peter Singer, of a recently published book titled "Should the Baby Live?"
SIR GUSTAV NOSSAL has been Director of the Walter and Eliza Hall Institute of Medical Research and Professor of Medical Biology at The University of Melbourne since 1965. Nossal's research is in fundamental immunology but of necessity also extends to other areas of medical science of interest to the Institute and to the difficult area of communication between the scientist and the lay community. He has been an active spokesman for Australian science both through the media and in his work on various Government committees.

DR. GEOFFREY PARKIN has been Director of the Intensive Care Unit, Prince Henry's Hospital since 1974. He graduated from Monash University in 1966 and did his medical training at the Royal Melbourne Hospital and Prince Henry's Hospital.

MR. JOSEPH PAVONE is currently the Executive Director of the Australian Catholic Health Care Association, and the Victorian Delegate to the Australian Private Hospitals Association. He has been President of the Victorian Private Hospitals Association since 1983. He is also a member of the Provisional Committee of the International Federation of Catholic Hospitals. Prior to his current position he was Executive Director of the Sacred Heart Hospital, Coburg, and he has worked in the area of health service administration for many years.
Wednesday, 3 April 1985


Question--put and resolved in the affirmative.

Wednesday, 25 September 1985

6. SOCIAL DEVELOPMENT COMMITTEE--The Honourable Evan Walker moved, by leave, That the Honourables J.L. Dixon, R.M. Hallam and R.I. Knowles be members of the Social Development Committee from 1 October 1985.

Question--put and resolved in the affirmative.

Wednesday, 3 April 1985

35. SOCIAL DEVELOPMENT COMMITTEE--Motion made, by leave, and question--

That Mr. Ernst, Mrs. Hirsh, Mr. Micallef, Mrs. Ray, Mr. Richardson, Mrs. Sibree, Dr. Vaughan, Mr. Wallace and Mr. Williams be appointed members of the Social Development Committee until 1 October 1985 (Mr. Fordham)--put and agreed to.

Wednesday, 25 September 1985

9. SOCIAL DEVELOPMENT COMMITTEE--Motion made, by leave, and question--That Mr. Ernst, Mrs. Hirsh, Mr. Micallef, Mrs. Ray, Mr. Richardson, Ms Sibree, Dr. Vaughan, Mr. Wallace and Mr. Williams be appointed members of the Social Development Committee from 2 October 1985 (Mr. Fordham)--put and agreed to.