SOCIAL
DEVELOPMENT
COMMITTEE

Inquiry into Options
for Dying with Dignity

Second and Final Report

April 1987
PARLIAMENT OF VICTORIA

SOCIAL DEVELOPMENT COMMITTEE

REPORT

upon the

INQUIRY INTO OPTIONS
FOR DYING WITH DIGNITY

SECOND AND FINAL REPORT

Ordered to be printed

No. 19
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RECOMMENDATIONS

The Committee recommends:

1. That it is neither desirable or practicable for any legislative action to be taken establishing a right to die.

2. That legislative action clarifying and protecting the existing common law right to refuse medical treatment is desirable and practicable and should be brought about by the enactment of legislation to establish an offence of medical trespass.

3. That medical trespass be defined as occurring when a medical practitioner carries out or continues with any procedure or treatment where a competent patient freely and informedly refuses that procedure or treatment.

4. That the legislation also encompasses protection from criminal and civil liability on the part of a medical practitioner who acts in good faith and in accordance with the expressed wishes of the fully informed, competent patient who refuses medical treatment or procedures.

5. That the non-application of medical treatment does not in itself constitute the cause of death, where a medical practitioner is acting in good faith to avoid committing the offence of medical trespass.

6. That the Health Department Victoria as a matter of urgency obtain from all relevant health care institutions 'not-for-resuscitation' (NFR) guidelines in order:

   a. to review current practices in this area, and that such information be referred to the National Health and Medical Research Council (NH & MRC) by the Minister for Health at the next Health Ministers' Conference; and

   b. that the NH&MRC develop a commonly accepted set of standards and practices that can be incorporated into guidelines, and observed.
7. That the Health Department Victoria obtain from all relevant health care institutions 'informed consent' procedures currently in use, and analyse such procedures in terms of their:

- comprehensibility;
- adequacy in terms of a patient's entitlement to information and details of treatment;
- adequacy for non-English speakers; and
- adequacy in terms of appropriate relevant health care personnel involvement.

8. That the analysis of current 'informed consent' procedures be provided to the Victorian Law Reform Commission within a period of three months from the date of tabling of this Report, so that the Commission may evaluate such information in terms of:

- a patient's entitlement to information relating to all types of treatment; and
- the adequacy of communication between patient and doctor,

and that the Commission can formulate guidelines for informed consent procedures.

9. That a uniform set of informed consent procedures be in place within 12 months from the date of tabling of this report.

10. That the statutory definition of death, contained in s.41 of the Human Tissue Act 1982, provides an acceptable definition of death.

11. That the Health Department Victoria ensure that all health care institutions, and institutions involved in the education of medical, nursing and allied professional staff are instructed in, and conversant with:

- the law as it applies to a patient's right to refuse or discontinue any medical treatment; and
- up to date knowledge about palliative care and the right of patients to modern palliative care.

(vi)
12. That a uniform code of practice setting out systematic procedures for the provision of information and adequate explanation of diagnosis, prognosis, the nature and consequences of proposed treatment and consequences of non-treatment, be introduced in all relevant health care institutions.

13. That the Health Department Victoria oversees the development of such a uniform code of practice:

- through an analysis of standard procedures currently in place to inform patients of diagnosis, treatment options, prognosis, and the right of the patient to consent to or refuse treatment; and
- reporting to the Minister for Health within six months of the tabling of this report on an evaluation of current procedures judged against the criteria of universal applicability within the State, capability of comprehension, justice and equity.

14. That the Health Services Commissioner, under the Health Services (Conciliation and Review) legislation, should adopt as principles of and procedures for patient entitlements, the Statement of the Royal Australian Nursing Federation as outlined in paragraph 5.4.3.

15. That at the next Health Ministers' Conference the Minister for Health should recommend that the National Health and Medical Research Council undertake the task of developing guidelines to assist medical staff in the application or non-application of cardiopulmonary resuscitation measures.

16. That the Health Department Victoria work in conjunction with professional health care bodies to promote educational activities and seminars for health care staff on bioethics and, in particular, patient autonomy and principles of the physician-patient relationship in terminal care.

17. That the jurisdiction of the Guardianship and Administration Board in respect of major medical treatment, be extended to include minors who are subject to State guardianship.
18. That the Health Department Victoria inform, on a regular basis, all health care institutions and institutions involved in the education of medical, nursing and allied professional staff regarding:

- the legal rules and equitable doctrines protecting incompetent patients; and

- the current legal position regarding the law of trespass and the rights of incompetent patients particularly relating to unauthorised interference;

and that the Health Department Victoria be responsible for monitoring the effectiveness of this recommendation.

19. That the definition of 'major medical treatment' developed by the Guardianship and Administration Board take into account the flexibility needed in the consideration of terminal conditions.

20. That the Victorian Law Reform Commission in conjunction with its investigation into informed consent be required to consider the question of consent on behalf of an incompetent adult patient where the decision-maker holds no power of attorney on behalf of that patient.

21. That concerned members of the public consider the value of appointing a person to act on their behalf in case of their incompetency by way of an Enduring Power of Attorney.

22. That the Health Department Victoria identify resources currently allocated between preventative, curative and palliative care, and include such a breakdown annually in its Reports to Parliament.

23. That the recommendations made by the Health Department's Palliative Care Policy and Program Discussion Paper, December 1986 (see Appendix F) be implemented by Government.

24. That treating doctors of terminally ill patients provide a brief medical history to be kept in the home.
25. That palliative care education be part of all undergraduate medical curricula and government funding be allocated for the appointment of a coordinator of palliative care education in each Victorian School of Medicine.

26. That palliative care education be a significant and ongoing part of professional development programs for all health care professionals.

27. That the development and implementation of educational programs in palliative care should include:
   - transition from curative to palliative care;
   - emotional support, bereavement and grief counselling skills;
   - symptom control methods;
   - up-to-date means of effective pain control;
   - appropriate drugs and drug dosages; and
   - optimal utilisation of local services and resources.

28. That the Victorian Nursing Council ruling on the provision of intravenous injections by nurses be amended to permit experienced, and specially trained, home care nursing staff members to provide intravenous injections to patients requiring immediate pain relief, on the prior approval of a medical practitioner, without a medical practitioner being required to be present.

29. That the legislation and medical practice governing the supply of analgesics be altered to permit terminally ill patients adequate pain control where failure to supply sufficient analgesics may result in pain and distress for the patient.

30. That care and rehabilitation services for severely brain-injured patients be the subject of further inquiry.

31. That major teaching hospitals be required to establish broadly based bioethics committees to provide guidance on issues relating to ethical and social concerns associated with health care developments.
4E. The functions of the Social Development 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.

Where the Committee is required or permitted so to do by or under this Act.
TERMS OF REFERENCE

The Social Development Committee received the following Order 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 to 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 USA,

   (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 Australian Law Reform Commission,

but not to consider any issue associated with the termination of pregnancy.
CHAIRPERSON'S PREFACE

Throughout its existence, the Social Development Committee has tackled some of the most difficult and complex moral and social issues needing to be addressed by responsible authorities. The present inquiry undoubtedly leads all others so far undertaken, in this regard.

The Committee has addressed the large number of issues raised by the terms of reference from a perspective of genuine concern for the well-being of our society. In the light of an increased technological capacity to sustain life and also concerns about protection of the medical and other health caring professions, the Committee has deliberated at great length upon its overwhelming concern that everything should be done in individual instances to achieve what might be called a 'good death'.

The Committee's deliberations have been undertaken in the light of belief in the sanctity of human life, and also the understanding that human compassion sometimes yearns to end the suffering of those perceived to be in pain and great distress. The Committee has also been aware of the great pressure on doctors and the health care team to perform the miraculous, sometimes by using extraordinary means of resuscitation, even when inappropriate, for fear of criticism or legal action by relatives or the public for not trying hard enough. The Committee makes its recommendations in the full knowledge of the difficulty of making decisions both by or for the individuals involved, and also by the wide range of care-givers attending such individuals. Members of the Committee appreciate the bravery and courage of those in such situations. They affirm their belief in the humanity and good sense of those unfortunate enough to be faced with such fundamental issues.

Throughout the inquiry the Committee has been concerned with the medical expertise and resources for nursing care available in the palliative care field. The Committee believes the compassion it feels for the terminally ill can be expressed in creative measures involving the relief of pain and tender care for the dying. In this, it follows an exhortation of one of the contributors to the Committee's First Report, that it behoves us to 'tend the dying in their living'...rather than to 'end the living of the dying'.

The Committee has spoken to, or heard evidence from, a very wide range of individuals and groups. Discussions have been held with both the providers and recipients of health care. Such recipients include cancer patients, the elderly, quadriplegics, relatives and friends of the head-injured and incompetent, the handicapped, incurably ill people who have spent many years on life-support systems, and children in the terminal stages of illness. The extent of these discussions is indicated in the Appendices of this report.

Such discussions have confirmed the Committee in its belief that it is neither desirable nor practicable for the government to take legislative action establishing a 'right to die'. It also has indicated a number of mechanisms through which an individual may express or have preserved their entitlements at common law concerning medical trespass and the right to refuse medical treatment.

While the Committee has concluded that legislative action is inappropriate as it relates to the 'right to die', the Committee has recommended that legislation is necessary, desirable and practicable as a means of clarifying and protecting existing common law rights. This is particularly so in the area of medical trespass and the right to refuse medical treatment. The Committee was disturbed at the extent of ignorance, misinformation and confusion on these issues at all levels in the community.

The Committee considers that many of the disputes and problems canvassed within the Committee's terms of reference will be resolved by the better understanding of the existing legal framework. In particular, the Committee has emphasised the role of an Enduring Power of Attorney for competent patients, and the role of the Guardianship and Administration Board for incompetent patients. Existing legislation, with minor amendments, contains many of the powers requested by witnesses to the Committee. The Committee recognises, nevertheless, that intractable individual cases may never be resolved. The law may be a marvellously useful instrument for preserving many of our freedoms, it cannot, however, provide for every individual circumstance.

In an inquiry of this nature, very significant demands are made on participants, not only Committee Members and staff, but also witnesses and the general public. As Chairperson of the Committee, I wish to express my appreciation on behalf of
the Committee for the co-operation received from individuals and organisations who assisted the Committee in its inquiry.

I would especially like to pay tribute to the conscientiousness and dedication of Dr Donald Stewart, Director of Research. His professional and meticulous attitude to the most difficult task of managing the investigation and research involved in this inquiry has been of the highest order.

The Committee was also ably assisted by the thorough preparation of materials and information provided by its Research Officers, Ms Necia Burford and Mr Paul Bravender-Coyle. Their hard work and skills contributed in a major way to the report.

The Committee is also indebted to its administrative and secretarial staff, Mr Geoffrey Westcott, Ms Lux Fonseca and Ms Lois Grogan, without whose hard work this report could not have been completed.

The team of Hansard reporters who recorded and transcribed many thousands of pages of evidence were also most appreciated by the Committee.

Finally I wish to express my personal thanks to the Committee members for their dedication and industry during this arduous inquiry. It is no small tribute to their efforts that such a potentially divisive topic should have resulted in an unanimously adopted report.

Judith L. Dixon, MLC
Chairperson
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REPORT

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

INQUIRY INTO OPTIONS FOR
DYING WITH DIGNITY

CHAPTER ONE

BACKGROUND TO THE INQUIRY

1.1 Introduction

This report concludes the first inquiry of its kind to be held in Australia. As anticipated in the Committee's First Report there has been intense public interest and wide community debate on the complex issues raised by the terms of reference.

Throughout the inquiry the Committee has been guided by a number of criteria and principles. For example, the Committee has been fully committed to consultation with patients, health care personnel and the general public. The Committee's investigative methodology, outlined below, indicates measures taken to achieve such consultation.

Secondly, the Committee's deliberations have been guided by its statutory functions, stated on page (x) of this report, particularly considering how the life of individuals, families and communities in the State may be improved. The Committee accepts that, in the absence of exceptional circumstances, a decrease in the physical pain, suffering and mental distress experienced by individuals, families and communities would improve the life of those people.
Finally, the Committee has been guided by the necessity for a balanced and reasoned approach to what is, for many, an emotive issue. In taking this approach the Committee notes the reported statement of the Governor of the State of Victoria, His Excellency The Rev. Dr John Davis McCaughey on bioethical issues:

*The very fact that feeling on such subjects is very passionately held and even sometimes expressed in rather violent language, makes it even more necessary to have a fairly reasoned approach.*

In addition, during the course of its public hearings the Committee became aware of widespread confusion and misunderstanding regarding the current legal situation, particularly with regard to medical ethics and medical practice.

The Committee considers that a clear understanding of the law as it relates to issues raised by the terms of reference is essential. Section 2.4 below provides a descriptive summary of the legal context of the inquiry both in Australia and overseas. It also reviews some major overseas cases, which have provided landmarks in the development of case law in this area. In addition, a brief overview of the current legal situation is provided in Appendix E.

1.2 The Committee's investigative methodology

The Committee has made use of a number of investigatory procedures:

1.2.1 The Committee's First Report

In March 1986 the Committee published its First Report, entitled *First Report on Inquiry into Options for Dying with Dignity, Incorporating a Discussion Paper: A Range of Views on Options for Dying with Dignity*. The purpose in doing so was to assist individuals or groups who wished to participate in the Committee's inquiry, and to provide an insight into some of the highly complex matters raised by the terms of reference.
The Discussion Paper was prepared using the contributions of eminent experts from a variety of backgrounds who were in day to day contact with issues and matters raised by the inquiry. Their contributions provided an illustration of the many perspectives from which individuals and groups could debate the matters raised by the inquiry. It was intended that the views of the panel should form a focus, stimulus and catalyst for the general public.

In setting up the consultant panel, the Committee was aware that it was not possible to represent all shades of opinion, nor all occupational groups caring for patients, in its Discussion Paper. It was considered at that stage that those members of the public who felt that there were significant omissions or an unfair balance in the overall effect would have the opportunity to rectify the matter by making a submission to the Committee. However, at the forefront of the Committee's considerations was the practical problem of putting together a variety of views in a succinct and publicly useful document, while allowing the panel the opportunity to provide a worthwhile and stimulating contribution.

Nevertheless, the Committee made it clear the Discussion Paper was not intended to be exhaustive or conclusive, and the contributions of the panel did not necessarily reflect the opinions or views of the Committee. The Committee did not, by publishing the First Report, signify its endorsement of it or of any of its conclusions. The Discussion Paper was published in accordance with the Committee's policy of assisting the public to participate in its inquiries. The Committee recommended that all those interested in making submissions to the inquiry should first read the Discussion Paper. By this method the Committee hoped that the terms of reference would be fully addressed in an informed manner.

The First Report was tabled in Parliament on 26 March 1986.
1.2.2 Request for submissions

On the same day the Chairperson of the Committee, the Honourable Judith Dixon, issued a media release, and advertisements were placed in both city and country newspapers inviting submissions and comments from the general public. Specific individuals, organisations and institutions, particularly those involved in the care of patients, were invited to make a submission to the inquiry. The Committee set Friday, 30 May 1986 as the deadline for the receipt of submissions, although a brief extension was granted to those individuals and groups who sought one.

In all, a total of 1379 submissions were made to the inquiry. A list of those who made submissions is contained in Appendix A.

1.2.3 Public response to the inquiry

An analysis of public response to the inquiry is contained in Appendix B. Actual case studies from the general public have provided the Committee with an invaluable insight into the experiences, opinions and beliefs of the people of Victoria. Some of these individual cases have been included in Chapter Two.

1.2.4 Public hearings

Public hearings were arranged in the following centres:

- Melbourne - 23, 25 and 30 June; 2, 14, 23 and 30 July; 7 and 11 August; 19 and 24 September 1986; 2 and 4 March and 6 April 1987
- Ballarat - 24 July 1986
- Bendigo - 25 July 1986
- Morwell - 28 July 1986

All public hearings were recorded by Hansard, and a list of witnesses is contained in Appendix C. A total of 152 witnesses gave evidence representing a wide variety of groups and organisations as well as many private individuals who presented their own personal opinions or experiences.
1.2.5 Visits to hospitals and other health care institutions

The Committee and research staff visited 11 hospitals and other health care institutions to investigate conditions and to consult with patients, medical and nursing staff and other health care personnel in these institutions. These visits and consultations formed an essential and invaluable aspect of the Committee's investigations. A list of the visits is contained in Appendix D.

A number of detailed discussions were held with patients including an informal discussion by a Sub-committee with the late Mr John McEwan at Mordialloc on 7 March 1986.

1.3 Outline of the report

Chapter Two of the report describes the context and focus of the inquiry. The implications of technological change on the issues under investigation are noted, and the central role of health care providers established. The wide variety of views which have formed the climate of opinion during the conduct of the inquiry are illustrated, together with recent media commentary. In addition, a number of case studies are quoted. Relevant literature, legislation, judicial decisions and other relevant developments in Australia and overseas are outlined, as required by term of reference (6).

Chapter Three discusses the issue of 'a right to die' as indicated in terms of reference (1) and (2a). The notion of patients being permitted to die peacefully with human dignity is examined. Such a notion is in accordance with the views of both religious and secular commentators. It is also embodied in existing common law entitlements, such as the common law right to refuse medical treatment. A number of key issues are developed, most of which have direct practical connotations. For example, evidence is presented indicating that significant numbers of patients are dying in unnecessary pain and suffering, often exacerbated by developments in medical technology.
Chapter Four examines term of reference (2b) and the current definition of death in s.41 of the Human Tissue Act 1982.

Chapter Five examines term of reference (3) and the circumstances in which competent patients can refuse, or give directions, regarding their medical treatment. The Committee examines, in particular, the issue of decision-making by competent patients in this area.

Chapter Six deals with term of reference (4) and the provision of medical treatment for incompetent patients. Evidence received indicates confusion in the community about the current legal position for such patients. The Committee examines legislation in this area and recommends certain developments in decision-making procedures through existing statutory structures.

Chapter Seven deals with issues arising from the care of the dying and, in particular, the provision of palliative care, hospice care and the need for continuing counselling and after care. Evidence to the Committee indicates a number of problems in the area of palliative and hospice care, which the Committee addresses.

Chapter Eight indicates a number of issues which arose in the course of the inquiry but which extended beyond the Committee's terms of reference.
Footnotes to Chapter 1


CHAPTER TWO

CONTEXT AND FOCUS OF THE INQUIRY

2.1 Implications of developments in medical technology and pharmaceutics

The Committee's terms of reference require it to 'make a final report to Parliament[...], having regard to the greatly increased technological capacity to sustain life[...]. Therefore this factor underlies the establishment of the inquiry. The increasingly common situation occurs where patients, who otherwise would have died as a result of natural causes, can now be sustained indefinitely as a result of the intervention of artificial life support equipment, or other medical and surgical procedures.

In general, moral and ethical problems have accompanied technological advances. This can be seen clearly in the use of advanced medical technology and life saving drugs. On the one hand advances in medical technology have been beneficial and have helped to save many lives. For example, a child who drowns can be given cardiopulmonary resuscitation if he or she is rescued in time, and brought to a hospital. With the aid of artificial life support equipment, the child can be kept alive until he or she has recovered. The same procedures have been used to save the lives of people who have received an electric shock or those who have taken an overdose of drugs. Premature and underweight babies, and severely handicapped babies can also be kept alive artificially.

On the other hand, benefits in medical technology have brought with them less desirable features such as the ability to maintain, almost indefinitely, a person's biological existence, sometimes in a severe comatose and vegetative state. Unfortunately, in some cases there is no possible hope of ultimate recovery. However, the patient may, even though comatose, be sufficiently sentient to experience pain or severe discomfort. The patient, although not suffering from actual physical pain, may experience a sense of severe discomfort similar to the 'terror' or 'fear' or 'pain' experienced in a particularly vivid nightmare - except that this nightmare is not ended by the dawn.
Advanced technology and new procedures are clearly beneficial developments when they sustain patients long enough to assist recovery from a disease or injury and live an otherwise worthwhile and socially useful life. However, when they also result in sustaining patients indefinitely in a comatose, vegetative state, particularly where medical personnel are afraid to terminate such medical procedures or use of life support equipment in case they incur civil and criminal liability, their benefit is substantially reduced.

The widely quoted case of Karen Ann Quinlan\(^1\) brought to world attention the major moral and ethical dilemmas involved in the use of medical technology. In another well-known case (Eichner v. Dillon), mentioned in section 2.5.1 below, some of the problems associated with advances in medical technology were illustrated. In this case, the Court of Appeals of New York stated:

\[
\ldots\text{while technological advances in medicine have achieved what to laymen are no less than miracles, it is equally true that 'the struggle of medical science against death has resulted in its own peculiar horrors'. We speak of a technology that is capable of sustaining an individual in a permanent and irreversible coma for an indefinite period of time.}\]

According to the Court, these advances in medical technology also raise:

\[
\ldots\text{complex questions of appropriate medical 'ethics', and bears moral, religious and philosophical implications. Choices must be made. When should the respirator be withdrawn? How much effort, if any, should be expended to delay the inevitable moment of death for the incurably and terminally ill? The resolution of such questions will affect not only the patient, but his family, the medical community, and our society as a whole.}^2
\]

The implications noted above are receiving increased attention in a variety of forums. This report illustrates an initiative from the Victorian legislature to such complex questions.
The context of this inquiry therefore lies in the social impact of technological developments and medical procedures, that have been introduced with intended patient benefits but have resulted in unintended individual and social consequences.

### 2.2 Health care professionals

Health care professionals are, in most situations, responsible for the implementation of continually developing technological and procedural innovations and improvements. Because of this, they are in a position to be able to assess the beneficial impact to the patient and the unintended consequences or burdens especially for the patient, and also their friends and relatives.

The Committee received evidence indicating that not only were many non-medical individuals and groups concerned about decision-making procedures in these circumstances, but that health care professionals themselves were uneasy at both the role they are sometimes forced to play and also the legal situation attendant upon their decisions. As Dr B. Clarke, Co-ordinator of Critical Care in Victoria, stated:

*I express my unease of the circumstances of the resuscitation of patients. It seems to me that if you look at the spectrum of medical care in hospitals throughout this State there are still difficulties in deciding who might be resuscitated from a cardiac arrest. The guidelines for the provision of resuscitative methods are still vague. That is an area where there is a continuing need for education input and the recording of circumstances and perhaps the enactment of some process.*

Anyway, *I am not sure whether our process works. There are difficulties in deciding who might be resuscitated in the circumstances of cardiac arrest.*

A similar view was put by another witness, Dr. C. Roe:

*I have in mind states of prolonged suffering, unbearable to all concerned, where, when the*
inevitable occurs, it is welcomed as a 'happy release'. On these occasions, members of the caring profession are torn between breaking the law on the one hand and futile inaction on the other. 4

Dr D. Brown, Medical Director of the Spinal Injuries Unit at the Austin Hospital saw these problems, currently experienced by some health professionals, being exacerbated by the present legal situation:

*Present legislation is restrictive in that failure to initiate treatment or withdrawal of treatment can result in a charge of negligence or manslaughter. This is a considerable inhibitory influence on staff trying to give the best and most appropriate care to their patients. It is important to remove the present legislative definitions of these acts as criminal offences.* 5

In a succinct summary the Royal Australian Nursing Federation submission stated:

*Many problems currently exist in our health system regarding the treatment of dying patients. At times, dying patients have their death prolonged against their wishes through the use of medical technology.*

*A difficulty arises when patients are unaware of their rights and the options open to them. Dilemmas in professional practice arise when it is unclear where we cease to prolong life and begin to defer death.*

*Matters are further complicated when health professionals face uncertainty about the possible legal repercussions of their actions or inactions, with respect to the dying patient.*

*Health professionals also lack a suitable education on death and dying, ethics and legalities, to meet the needs of dying patients. The general public is largely ignorant of the ethical questions that have arisen through medical technology.* 6
The Committee received many submissions and letters indicating the difficulties of decisions regarding the most appropriate care for dying patients, particularly when, as Sister J. Fawkes put it:

Within the training of medical and nursing staff the emphasis is predominantly geared toward cure, and the preservation of life. Dying is often overlooked as an aspect of patient care.

A difficult decision that must be made is when to stop active treatment, and tell the patient that any further treatment would be futile.  

2.3 The community context

The Committee received submissions and letters from many hundreds of Victorians, from all walks of life, welcoming the inquiry. In its deliberations the Committee has placed great value on these submissions representing, as they do, the social impact of decision-making in this area. As consumers of health care and potential participants in litigation, the Committee's consultation with the general public is central to this inquiry. This section contains a range of views presented to the Committee by representatives of institutions and organisations and by members of the public. The Committee considers that the opinions and beliefs presented by the community at large must form an overall context to the inquiry.

2.3.1 Views of institutions and organisations

Many senior members of various churches welcomed the inquiry. Speaking on behalf of the Victorian Catholic Bishops, the Right Rev. Dr J.E. D'Arcy, Bishop of Sale, stated:

We, the Roman Catholic Bishops of Victoria, welcome every chance we have to say how grateful we are that legislators seriously consider the moral issues in legislation. This really has developed in comparatively modern times, [. . .]. We genuinely welcome this opportunity and would like to record that. 8
Concerning the need for the inquiry, he stated:

with regard to this inquiry, this is a plight for many Victorians who are old or helpless and we think it is a splendid thing that you should be devoting so much seriousness to their position.9

The Anglican Bishop of Bendigo, The Right Rev. O. Heyward, speaking on behalf of the Synod of the Diocese of Bendigo, also welcomed the inquiry, stating:

our Synod is appreciative of the action of the State Government and, to an extent, encourages the investigation of this important issue.10

Concerning the need for the inquiry, he said:

We believe it is a matter of considerable importance to the community and involves major ethical issues. Therefore, as we believe ethics are relevant for those people with religious beliefs, we value the action of the Government in opening up this question for public discussion. We have noted two points in our resolution concerning that matter. We are glad that the Government is seeking to establish opportunities for achieving greater dignity through the process of human dying and for achieving legal protection for those who have to make hard decisions in the care of those unable to make decisions for themselves.11

The Moderator of the Uniting Church in Melbourne, Mr A. Kilgour, in welcoming the opportunity for discussion and having some input into the problems involved in dying with dignity said:

Where there is an issue troubling society, it is better that it be in the open than to pretend it does not exist. 12

Letters and submissions from groups such as the Humanist Society, and the
Voluntary Euthanasia Society of Victoria and its members also welcomed the
inquiry. For example, the Hon. R.A. Mackenzie, MLC, Patron of the
Voluntary Euthanasia Society of Victoria, welcomed the inquiry because it
enabled an input of a whole range of viewpoints, and stated:

_The subject has been of long-time interest to me. It is a difficult inquiry to undertake and
is considerably different to the normal inquiry in that this is not a tangible subject. I
understand what is involved and the work the Committee is doing, and has still to do to
come to grips with what is an important social question of our time._ 13

Mr C. Duncan, President of the Humanist Society, in evidence presented to
the Committee stated:

_The Society urges Parliament to legislate on a
right to die taking into account the legal,
medical and philosophical issues drawn to its
attention in the course of this inquiry. The
Society is concerned that Parliament should
not protract this endeavour unnecessarily by
attempting to anticipate every such issue nor
be inhibited in formulating legislation because
it cannot encompass every eventuality.

Carefully and reasonably framed legislation
will meet the wishes of the ordinary citizen
with opportunities for amending in line with
social change or in the light of experience
with the legislation. The prospect of
continuing without legislation in this
important area constitutes a far greater
problem for dying individuals, those who care
for them and society as a whole than the
introduction of such legislation._ 14

2.3.2 Media commentary

Two recent events in Victoria highlighted to the Committee existing
problems and lack of uniform guiding principles, for all those involved in
decisions arising from a patient's request to be allowed to die.
In July 1985, 23-year-old quadriplegic Cornelius Hus died in an apparent suicide pact with his best friend Wayne McDonald. As *The Sun* reported:

Cornelius had asked friends and relatives to end his sad life many times. Since a motorcycle accident 18 months ago, he had lost the will to live.

"He was putting more pressure on his mate (Wayne) all the time. Finally it happened."

"He said: "You're my best mate. I want to die, you have to do it"."  

Quadriplegic John McEwan, a former waterski champion, died at home in April 1986. Totally dependent on life-support equipment, McEwan previously refused food and some medication and signed a document saying he did not want resuscitation procedures undertaken if he fell into a coma. John McEwan was certified insane after making a plea to die.

In the context of the widespread publicity caused by these cases and the difficulties faced by patients and health professionals, a feature article in *The Sun* newspaper stated:

Each of those cases gave new impetus for a move to review the law or at least to provide clear guidelines for medical workers faced with patients asking them to help end their lives.  

In addition, in the course of the inquiry a number of highly publicised events and cases sharpened the focus of the investigation and promoted widespread community debate. For example, a former Governor of the Reserve Bank, Sir John Phillips, and his wife, entered a suicide pact. Their family subsequently released a statement reported in *The Age*, saying:

We know from them that they, at the age of 75, felt they had reached the culmination of a happy, healthy and fulfilling life and that they preferred to end their lives together whilst
still able and self-reliant. This decision was taken in a spirit of serenity and contentment and we love and respect them for it.\textsuperscript{18}

In another highly publicised case the Supreme Court, dealing with the question of a newborn baby's custody, also became a watchdog over the future of the baby, by simply stating what the current law is. In the course of the case it was alleged that the baby was being denied food and corrective medical treatment after being born with spina bifida. As The Herald reported:

\textit{In a historic judgment, it (the Supreme Court) ordered a hospital to take all necessary measures to preserve the baby's life.}\textsuperscript{19}

It is important to note that this statement was made in the context of, and as a corollary of adjourned proceedings in that baby's contested custody case.

Besides these and other cases which were widely reported throughout Australia, the Committee's hearings in their own right received considerable coverage, undoubtedly due to the very valuable evidence received from many highly respected witnesses, and the intensity of media interest.

2.3.3 Views of members of the public: case histories

The Committee was deeply concerned by the extent of and complexities involved in medical dilemmas and decisions faced daily by parents, relatives, the medical profession and the nursing profession.

As a consequence, the Committee spent a great deal of time throughout the inquiry, both individually and as a group, gaining an understanding of these difficulties, and in particular, the labyrinth of inter-related components involved in each case. The evidence presented to the Committee included medical, legal, ethical, moral, religious and financial components.
CASES

Case studies are outlined here to illustrate the formidable task faced by the Committee. They are quoted exactly as received and read by Committee members. Because of the personal nature of the evidence presented to the Committee, no reference has been made to names except where they appear in the body of submissions.

1. I nursed my mother at home for 8 years until she was 98. She is now 101 and for 3½ years she has been in a nursing home. She is legally blind (no close sight), unhappy, constantly hallucinating and wants to die. In between the hours in bed, she is restrained in a chair. There is no quality of life for her. The Doctor prescribes tablets to help her breathing. Without those tablets, she would be very distressed and it would be a strain on her heart. It is cruel. I spend four hours every day with her in the Nursing Home, when I feed her lunch, afternoon tea and the evening meal. My heart goes out to some of the other patients there, and I wish I had a 'magic wand' I could wave to release them from their 'prison'. Ask any staff member of a nursing home and they will tell you the same thing - they do not wish to be a patient there.

I challenge any member of the Committee, the Government, Department of Health or the medical profession to spend ONE WEEK in a nursing home, restrained in a chair or bed, and then watch and listen. What an experience.

2. I have had the personal experience of three of my family (two brothers and a sister) all dying slow, hopeless deaths. One brother, with a clot of blood on the brain could not speak or communicate in any way with us. The other brother continually having strokes, unable to move or do anything for himself but constantly expressing the wish that he could die. My sister aged 82 years, in a nursing home, then transferred to a Melbourne hospital, first time with a broken hip, next with a broken femur, hopelessly confused mentally. While in hospital she was infected with Golden Staph. The hospital asked my permission (as her nearest relative) to do the femur operation, and I gave permission. I knew afterwards it was cruel to her, as she soon died, and I wished I had been able to save her all her final suffering, as I believe in dying with dignity through euthanasia.

3. I am incurable but as it is not terminal, no help. But what is the difference of incurable and terminal, both very painful and after some time drugs no help.
4. I am a 62-year-old widow sound of mind. Six years ago I transferred my late husband home from hospital to die, as he had terminal cancer, to be precise, melanoma cancer. He had placed his faith in medical science. They had tried a new, thought to be cure for the melanoma, after the usual treatment and two operations - the new treatment consisted of injections into the top part of his body, where the cancer had started. The injections left weeping, inflamed abscesses that needed constant dressings. Also the skin around the area was very inflamed and he was in constant pain. Then at times the blood would pour from these wounds. He was unable to retain any food and had lost control of the bowel and bladder as the cancer spread. His mind and brain were still very alert, he was 54 years of age, had held a very responsible position in a Government department and was in charge of a number of persons. He was six feet tall and a very active family man, prior to the cancer. To see him laying helpless and in so much pain was very heartrending. He expressed to me, also to the family and friends that dying would be far better than the hell he was in, as the new so-called cure was not to be. He had watched his brother at 48 go through the same hell with cancer of the bowel, just a few years prior to he himself being diagnosed with cancer. His brother also expressed the desire to die as he went from 14 stone to 6 stone in weight. I most sincerely hope and pray that the Government passes a bill of rights for a person to be able to have the 'Option of Dying with Dignity'.

5. My mother suffered a stroke in the street, was taken by ambulance to the Alfred Hospital, where she was unconscious for 10 days, but somehow, against all expectation returned to life - but what quality of life! Six years of slow death and agony followed: totally incapacitated, paralysed, loss of sight, and speech, can one call that life? She was 72 at the time of the stroke, 78 years old when she actually died. For us all she really died at 72. We had often discussed such a possibility and she expressed the hope to be helped to die with dignity and little or no suffering. Although conveying these sentiments to the doctors and staff she had to wait six years before she finally died, probably from starvation, as she was all but a skeleton in the end.

6. My father, born in 1902, suffered from extensive emphysema and eventually lung cancer for seven years. He was revived after he collapsed with a burst lung, and allowed to die in terrible suffering and total lack of dignity at 62, his body naked under a thin sheet, lying (in hospital) on layers of newspaper because he was incontinent, unable in the last months to speak or even groan, because his vocal cords were choked. To demand that in law the sufferer should express a desire for euthanasia on the spot is obviously ridiculous in this case.
7. My father tried to take his own life twice at home. He just longed for peace and an end to his suffering. To see him in hospital so thin and clad in a nappie when he was such a modest wonderful man was terrible. How much better to go with dignity!

8. One of my young daughters-in-law was virtually dying for 8 years after two mastectomies and sundry other operations, including those for bowel obstructions. For her last 3 months, with an inoperable bowel obstruction, she was fed by nasal tube and intravenous drip, and had another nasal tube to draw off the stomach reflux about every 15-30 minutes, an unpleasant procedure.

She had nothing by mouth for those 3 months except a little crushed ice. Despite all this she was reasonably cheerful. However during her last week of life she had a very dreadful time and I feel sure that if voluntary euthanasia had been available she would have opted for it before she became so ill.

I know that all her friends, young children and relatives, including her father, a minister of religion, wished that someone could do something, anything, to ease her out more comfortably.

9. My sisters (77 and 85 years) having, after mother's death, continued living together, barely had time to regain their balance, when the younger one fell ill. One affliction followed another, thyroid overactivity, recurring heart attacks, aneurism, kidney malfunction, circulatory difficulties, one medication counteracting the other. Repeated collapses progressively wore out the older sister. The recognition that there was no cure or even a sporadic easing attainable, resulted in increasing despondency and despair. Things being the way they are, no doctor dared complying with their request for help in ending it all. The large number of drugs which had to be taken on a daily basis, were finally, in a mutual pact, swallowed in bulk. One sister, the younger one, did not survive. The other one was 'saved'. Against her will and wish. She had to endure two more years of agonies (as did we, caring, helping but impotent onlookers) before succeeding in starving and mainly willing herself to death. She had not wanted to live any more. She had refused (having seen mother wasting away in an 'old age home') leaving her own four walls. Her misery had been constant. So was ours. CUI BONO?

10. I, myself, as a victim of a slowly progressive cancer, have so far in these early stages been hospitalised three times to undergo surgical excisions of carcinomic tumours. As an atheist having no fear of death as an eventual relief, I would prefer to escape a lingering and torturing finale by practising (if possible) suicide rather than stupidly accepting the present legal limitations which are imposed upon caring and competent physicians.
11. I am the mother of Wayne. Wayne shot his best friend and himself, his best friend being Cornelis Hus a quadriplegic. I am writing in support of euthanasia. When Cornelis was in hospital, my son would spend all his dole money going up to Melbourne to spend time with him. Cornelis once told me that to have an active mind and a body that would not work was sheer hell. If he could end his life he would. He also pleaded with my other son to help him. Wayne used to come home and say he 'could not hack seeing Connie like that'. It took a lot to make my son cry, but he always shed tears when he came home from seeing him. I believe my son would be alive today if a law was passed for euthanasia.

But only in special cases should it be used when there is no hope and that person wants to die. There is so much more to this story that I can't put to you. It is an effort to write this so please excuse writing.

12. I was very fortunate when my dear husband, who I was married to for 44 years, had cancer of the lungs. He received radiotherapy for six months but after two lots of chemotherapy he refused anymore and soon after about two weeks passed on. In any case there was no hope for him.

13. My husband suffered a massive stroke and did not come out of a coma. My family and I pleaded with the hospital authorities and the doctor to allow him to die - but no - he had to be kept alive at all costs. As he had been a fine athlete we knew he would have never wanted to live like this. He slowly wasted away, kept breathing by a wretched machine. After nine months his life came to an end thankfully but left us - his family - devastated. Not by his death which we had prayed for, but the way he was forced to die.

14. My mother in law lived to be 97. In the last two years of her life she was blind, very hard of hearing and in every respect incapacitated. In short, her life became a misery to herself and a heavy burden for those around her. She constantly expressed her wish to be able to finish it all and to be allowed to die. I must add that in the last six months or so of her life, through her misery and unhappiness her character changed, she became noisy, weepy and very demanding. In consequence the hospital staff got fed up and irritated with her and treated her extremely badly, ensuring a vicious circle: she became more and more unhappy and of course irritating to others and the treatment meted out to her got worse and worse.
15. My grandmother, begging and wishing to die in Heidelberg Repat. and being kept alive with feeding tubes to the very end.

My aunt, in a private hospital suffered the same fate. Her granddaughter begged for the machine to be removed - it wasn't.

Just over 12 months ago an aunt was terminally ill with cancer. She attended Peter MacCallum and received radiation treatment and chemotherapy but the cancer spread everywhere in the finish. By the time she could no longer look after herself it was clear to anyone she was dying. She could only be admitted to Peter McCallum if she consented to more treatment - a callous, absurd suggestion, considering her condition. Then after much effort the family had her admitted to Bethlehem Hospital. My aunt's last weeks were peaceful and caring with no 'treatment' (presumably to make you better). She wasn't there long, but she died without tubes in her nose and a machine to keep her breathing, which she was dead against.

16. When I first met Mr. Y he was riddled with cancer but lived on for many months (around 6-9 months after being diagnosed from one of the many lumps he had throughout his body). For all that time he lived on Brompton Hospital cocktail for pain. One night even this wasn't giving relief. I knew he already had a significant level of opiates but that to give him a normal dose would not touch his pain. I think I gave him 1/2 grain of morphia (perhaps more) or its equivalent, not unduly worried if I had miscalculated how much more he could tolerate so long as it blocked his pain, but being careful not to deliberately overdose him. The next day I called early to find him the best he had been for weeks. He thanked me for the good night's sleep. He died about 2 weeks later. If he had died the night of the injection, there would have been no remorse.

17. Mrs. P. was an old (approximately 90 I think) bed-ridden lady who I had come to know and like very much. For the last few years she had been well looked after by her daughter (who was genuinely loving and caring) but there were reasons why Mrs. P's life had become increasingly miserable. When she got bronchitis I agreed with her request not to give her antibiotics as I had done several times before - a decision completely supported by her daughter. She developed pneumonia and quietly died a few days later.

18. I was confronted with the dying experience of my own mother; an 83-year-old who had previously gone through a cancer operation, but later was forced by society's 'rule' to endure months of an existence which simply stated was:

24 hours a day lying in a nursing home bed unable to move even her hands, waiting for the next time a nurse might come in to turn her over to the other side. Though her mind had not left her, her voice had all but;
nevertheless she was still able to muster up a scream on occasions - the only means she had left to let the world know that she'd had all she could take of pain in this life! Previous to these last few months she had made it known to me that she had no desire to go on, and, knowing my mother as I did, I was aware of how she felt about the lack of dignity she was having to endure.

19. My own mother, who died in 1975, aged 96 years 10 months, and who was in complete control of all her faculties until 2 hours before her death at home. On the Saturday night, nine days before her death, requested her physician to let her die. Just prior to this she had had a very animated conversation with him regarding her life and family and his family, and her request came about after he had examined her and asked what he could do for her. This was a routine call because he had been to a conference and was catching up on some work. He was amazed and surprised, but none of her family or her friends were, because the whole process of what she called 'lying up waiting to die' bored her, and she wished to go with dignity and on her terms and not to inflict on the rest of us and her friends the possibility of a dreadful death the like of which she had assisted at many times in her very long life.

20. My own husband who died in 1980, was in and out of hospital during the last 8½ years of his 76. He was suffering from cardiovascular disease, including a cerebro-vascular accident, emphysema, and this was the most horrendous, and a number of other active disease processes. In the last two years of his life he asked both his physicians to help him to die, but of course, they both assured him that they could not do so. In the last fortnight of his life - I nursed him at home to the end - he even asked me to help, and I would have done so had it been legally possible, and I would have considered it the greatest act of love, but with my upbringing (not religious constraint but respect for the law) I could not do so. Incidentally, it had been on both our medical records for many, many years that we were not to be resuscitated in the case of medical or surgical emergency, and that is on my records still, but, of course, one cannot be certain that under certain circumstances one will be under the care of like-minded medical practitioners.

21. My mother died very painfully of gangrene in one foot - she was 92 - too old to operate but she lingered for several weeks in great pain although drugs were given. Surely it would have been better to ease her out of life more quickly - she told them she was happy to die - she had had a good life - she did not want to be kept alive as she was frightened her mind would go, and without a mind what are you?
22. I wish to express my views on this subject because my wife had to die without dignity 12 months ago.

In March 1985 after a half bowel operation for cancer, it was found that she had cancer of the liver and 3 months to live. We were already members of VESV and had agreed to help each other to die with dignity long before we ever dreamed that she would fall a victim to cancer. We also believed when anything like this happened that our doctor would assist.

As it happened, the doctor would not help and I did not know how to obtain my wife's death with success and dignity. So after surviving 12 months, she swiftly went down in the final four weeks.

To see your loved one in serious pain, incontinent, just bones strung together with skin, hollow eyes, no teeth, suffering 24 hours a day, appealing to go on to her Maker - is a most terrible experience - neither of us being able to do anything.

23. I saw my sister who was practically paralysed with arthritis and in constant pain brought back from obvious near death from an infection (her face was grey) by being sent from a nursing home to Fairfield and brought back to a year of pointless suffering and paralysis for another year.

How pointless to protract a life of suffering by artificial means - oxygen and the 'drip'.

My other sister was brought out of a coma of several days - at the age of 91 - to live in a state of almost helplessness - by the same means - artificial means. Why not let nature decide and leave people to go naturally?

24. 'Your husband is a very sick man, he has cancer and nobody could help him' doctor said. It was melanoma. Lump on the hand - amputation - and that didn't help either. Finally the cancer spread on other organs in the body - kidney, head, abdomen, etc. My husband was 65 years old, just retired. His condition took one year. Last 4½ months I've spent with him 6-7 hours a day in hospital. 'I would like to die'; he was refusing to eat. He was skin and bone. He kept falling into coma and coming back to again. Doctors, instead of humanity and common sense - just leave him without pain and in peace - tried on him new tests again and again. He was in coma. 'He will die overnight, you should be with him'. I've held his hand for 19 hours. In the morning he was conscious - coma passed.

It was constant torture, fear, exhaustion for him and me to see and watch how the body and mind are disappearing little by little, day by day and you can't help. One day the Matron looked at me and said, 'I wish it'll finish soon for your sake'.
25. ... the death of my wife - of cancer - in 1980. After several months of severe pain and being passed from doctor to doctor, my wife was admitted to St. Andrews Hospital. A biopsy revealed several tumours metastasised from a primary breast tumour. The first and last diagnosis was 'terminal'. My wife, who was a tough and brave woman, asked an attending physician, 'do you believe in euthanasia?' His answer: 'Yes, I suppose I do'. At another hospital, an oophorectomy was performed by an eminent oncologist. This was, I now feel, at best needless and, at worst, mischievous. In a few weeks she was admitted to Peter MacCallum where she died. I do not question the dedication of any doctor or nurse who attended my wife, but I deplore a system of laws that makes it mandatory for people to suffer as my wife did for no good reason. During a lucid period on the night she died, my wife said to me, 'I'm in bloody agony'. Six years later those words still haunt me.

26. My mother died last year, aged 93 years, suffering dementia. I watched her change from a 5 ft 6 in. tall, outgoing handsome woman, who was in command of her situation, to a sad little bundle of clothes, skin and bone, over the course of 15 years. She had to have a hip replacement operation because of the extreme pain she was enduring some 9 years prior to her death.

The trauma of the operation, coupled with the death of my father at that time, appeared to accelerate her dementia. She never learned to walk without aid on the new hip - she had lost her capacity to learn. From then on she suffered recurring respiratory and urinary tract infections, and after each infection became just a little more confused and weaker.

She was being cared for in a special accommodation house and 1½ years prior to her death was hospitalised and subsequently admitted to a nursing home. By then she was termed incontinent. Because of the chronic urinary tract infections approximately 1 year prior to her death, a urologist decided that the neck of her bladder should be stretched, under anaesthetic, and an X-Ray was required before the operation.

Because my mother couldn't urinate on cue, the X-ray exercise was all for nothing and the specialist intended to do the operation (procedure) regardless of the results. She was therefore subjected to four trips in ambulances - 2 trips for the X-ray from nursing home and return - 2 trips for hospital treatment and return, plus 2 to 3 days in hospital.

The operation proved useless.

Imagine the stress and how frightening the above episode would have been to an already confused person. From that date on, my mother was hardly able to recognise my sister and myself.

The urologist rang me prior to the operation and I said that I didn't approve of my mother having an anaesthetic and suggested acupuncture as an alternative if indeed he felt he had to go on with this useless exercise. He wasn't very amused at my comment!
Mother was ceaselessly calling 'help' day and night regardless of variance of medication.

She had to be tied into her chair or in her high-sided bed because she was capable of extreme physical effort at times and had several falls. After one fall from bed she was again sent off for X-rays by ambulance again, and again for nothing - she was only bruised.

What happened to dying with dignity?

Why couldn't someone, at some stage of the last 18 months of her life, have held back on the antibiotics and let her slip into pneumonia and peaceful endless sleep?

27. She, (my sister) had been racked with pain from osteoarthritis for at least 20 years, inspite of 11 or 12 operations. She was confined to a wheelchair for many years and lost control of her hands, which owing to the neck condition gave false signals of pain, heat, cold, etc. She also became deaf and incontinent. She often longed for death and said to me 'wouldn't it be lovely to go to sleep and wake up dead?'

When at 79 in a nursing home she got influenza, became stuporose and refused to eat, she was continually wrenched awake, and scolded for her refusal. Food was pushed into her mouth, and a kind but stupid nurse said 'if you don't eat, you will die!' She was too tired and ill to answer, and my protests were unavailing. She did die a few weeks later.

My father, a doctor, who died in 1950 told me he had made suicide easy for incurable suffering patients, and I am sure many doctors do. Such compassionate people should not have to fear legal consequences.

28. My own personal experience concerns my mother who last year died at the age of 96 but who in the last 6-10 years knew none of her own children, was totally blind, and for a long time previous to this period while in a relatively stable state of health, had often expressed a wish to be allowed to die.

How many of us, while we are capable of making decisions during our young life, express a desire not to live when are sick and old and not capable or able to make a decision?

29. After seeing my father go from a proud upstanding wonderful man to someone who had to wear a bib because he slobbered over his food - was put into nappies - cowered away from his family - not knowing who they were. After watching my mother linger with a stomach cancer so large - she was cut open and stitched back - to live 5 days - she could not even have intravenous feeding.

26
After seeing a friend sent home from hospital because no more could be done for him and the bed was needed. Sent home to slowly starve to death - he could not eat - stomach cancer again, I plead for the right to 'die with dignity' when I feel I no longer have the physical or mental capacity to lead a worthwhile life.

30. My mother had terminal cancer 4 years ago and because of the law as it is today, the chance of her finding a humane doctor who would assist her to die, was remote.

She was not going to have a death without dignity and so obtained the means and the knowledge to end her own life, at the time of her choosing.

She was courageous and determined in her views and saved her loved ones much heartache, as we did not have to witness nature taking its course, seeing her suffer needless pain and indignity. My family supported my mother and we shared the same views. This was a very great comfort to her and we were all together when she took the fatal dose that ended her life. She was at home and in the arms of her loved ones and that is exactly what she wanted.

31. I submit for your consideration the plight in homes for the aged, and infirm where my wife is a permanent patient. 82 years of age and prior to admission, she was an accomplished pianist.

She has a broken hip beyond repair, arthritis in both knees, a broken left wrist, and broken arm (which terminated her love for the piano). Like everyone at the home, she requires frequent visits to the toilet (sometimes too late).

Her day consists of when she is woken, breakfast, sponged and dressed and wheeled into the lounge room where she sits all day, even her meals where she sits, then later put to bed.

When I visit her she sometimes says 'what have I to live for?' and she has spasms of deep depression and anxiety. The patients around her don't talk or even look at T.V. so are only waiting to die, as they have nothing to live for, some of whom have been there for many years, and no visitors.

I asked one of the doctors if any of his patients was in pain, as my wife is, and others tired of life would he put them down if requested!! He said, 'regardless of their pain and anguish, he would do all in his power to keep them alive'. For what? to live another day as they are doing!
32. I would like to submit the following personal experience in support of the Inquiry into Dying with Dignity.

in 1980, my then 36-year-old daughter was diagnosed as having cancer of the breast. After an exploratory biopsy, she decided against both an operation and radiation treatment, although under enormous pressure from the hospital staff and doctor to do so.

She decided instead to try what is known as wholistic methods of diet control, meditation, exercise, massage and every possible way of building up her mental and physical health and immune system to fight the disease.

For the first two years she seemed to respond to this treatment and her health and vitality was much improved and she then decided to return to Melbourne after 2 years in a warmer climate. However, her condition began to deteriorate and by the end of 1983 she had to resort to painkillers. She contacted a nearby doctor for advice and the necessary prescriptions and from then on was confined to bed due to weakness and pain. This doctor was a woman and unfailingly kind, helpful and considerate of her patient's needs and desires.

By December 1983, my daughter had accepted that she was going to die and extracted a promise - willingly given - from me that she would not be sent to hospital. Up until then, she had had only orally taken pain relief, but as the pain became worse, she discussed the alternatives with the doctor, who explained that once she began morphia injections, she would lapse into a coma until her death, which would be hastened. While still in full possession of her mental faculties and capable of making decisions for herself, she accepted this.

The doctor began 4-hourly treatment but eventually, due to the necessity of continuing around the clock, she showed us how to administer the injections ourselves. After a week or two of around the clock treatment, the police examined the register of the supplying chemist and stopped the supply, presumably on the presumption that the morphia was being procured illegally.

We then held a meeting with the domiciliary nurses and the doctor to discuss the situation and it was obvious that the nurses, not being used to dealing with death outside a hospital, wanted to transfer the patient to die elsewhere and the doctor was then left to take all responsibility, but because of my promise I was adamant that my daughter had the right to die at home and stated my intention of contacting the Minister for Health or some other responsible authority to obtain the necessary drugs, if she felt unable to do so. Finally, the doctor did whatever was necessary and from then on, enough morphia to keep the patient free of pain was freely available. She died quietly in January 1984.

From this experience I would like to make the following points:

1. The importance of taking from the doctor the unbearable responsibility of making the sole decision about another human life, so that he or she has support at all times.
2. The importance of the doctor discussing with the patient, while he/she is still lucid, the various alternatives and their result in easing pain and to ascertain the patient's true desires regarding prolonging life to a needless extent when there is no hope of recovery. This should be the patient's absolute and unquestioned right.

3. The doctor's right to prescribe - without legal red tape - such drugs as he/she thinks necessary for the comfort of a dying patient when that patient has expressed a wish to die at home in familiar surroundings.

4. The importance of training domiciliary nurses to help them cope personally, emotionally and physically with death outside a professional hospital support system.

In closing, I would like to point out that the alternative desired by the nurses in this case, would, if carried out, have resulted in my daughter dying in a strange institution, where those closest to her would lose all control and her body eventually be whisked away out of sight in order not to disturb staff and patients. She would, with whatever consciousness she may have retained, (and who knows just how much a dying person is aware of, although unable to express) have been deprived of loving, familiar faces, perhaps terror-stricken by her surroundings and helplessness. This, despite her own wish, while fully lucid, to die in her own way.

33. My mother was 48 years old when cancer was first diagnosed and of course felt anger, shock, disbelief, grief, etc. However, she also questioned the validity of medical treatments offered and feared that the final stages would be extremely painful and frightening.

The time between diagnosis and death was 2 years and 10 months. During this time, she underwent chemotherapy for 12 months, radiation therapy for 1 month and finally 3 months of painkillers and other drugs to control every bodily function in order to keep her comfortable while she waited to die.

Her main concern during this time was to 'die with dignity' and prepare herself and her children for a 'happy' death. This concern she had to deal with, in between bouts of vomiting, diarrhoea, constipation, pain and worse, hallucinations resulting from a constant diet of pethidine and morphine.

Compared with 'dying times' of other patients, we were told that 3 months was a relatively short period and that we were lucky for that. I certainly do not regret one moment of that 'nursing' time but as a highly intelligent woman she had discussed this and had wished that the humiliation and suffering was not a 'legal necessity' in the last month of her life.
34. Over a four-year period my husband's cancer spread from bowel to lungs, liver, main intestine and brain in 1978. He was only in hospital for 11 or 12 days after the brain tumour had been diagnosed, and while there, told our minister that he was not afraid to die, but did not want his family to watch him suffering, and hoped that he would not finish up like his mother. Fifteen years before she had also died with cancer all over her body, including the brain, and it was something we would never forget. She was moved to the rear of the private hospital because her cries of distress could be heard all over the hospital.

On the Sunday before his death, if my husband lay on his back he felt dizzy, and if he lay on one side, the pain in his head was terrible. That night I think, they started morphia injections, and the resultant vomiting distressed him more than anything. Even the smell of food made him vomit. He could now only lie on one side, and had to be washed and have the bed changed in that position.

The following day my husband begged the specialist to allow him to go home. I had been learning to give injections so that he could be nursed at home. The specialist agreed to send him on trial the following day, between injections. Whether it was through willpower or the effect of the morphia, he was sitting upright in a wheelchair when I arrived to collect him. After a distressing drive and a long rest in bed, he went to his Hiace van, protesting that he was so weak he needed exercise, and that I must not fuss. Again he rested, and then returned to the truck. He was gone so long that I became worried and went to check up. He was sitting in the back of the van and had shot himself through the temple.

An injection or tablets allowed by law would have been a lot easier for him and us to cope with."

35. Three years ago my father died after living with me for 18 months. He suffered the most terrible pain, which he shared with me, just to help him bear it. He had gangrene in both feet, and at 82 or 83, with arthritis, he knew that amputation would have caused him to be bedridden, necessitating hospitalisation. The thought of that was unbearable to him, so he remained at home with his pain, with a chair by the window, looking out onto the trees. Morphia in any form made my father sick too, and medication like Codral Forte had only a limited effect on the pain. He longed to die for about the last two years of his life, although he put on an amazingly cheerful front most of the time. As he deteriorated he begged the doctor to tell him how many of his tablets would be too many, but she was obliged to refuse. Instead, she managed fairly soon to get my father into Caritas Christi, where the care was very loving, and the pain under better control. But the dignity was gone. My very gentlemanly father apologised as I helped him onto the commode, for the shame of sitting on a nappy without pyjama trousers because he couldn't control his bowels. The drugs caused distressing hallucinations too, that left him in a state of great anxiety, without any peace of mind in his last days. I wish so much that he could have decided when he had suffered enough to put a stop to it.
36. Last year my sister was hospitalised - she was 79 years old. Without any consultation with the family she was operated on and found to be cancerous all through her intestines - so into intensive care. Her surgeon said that she would have died at once without the operation. As it was she spent a week in intensive care - not sedated and peaceful but suffering mentally. My family and I (her fond sisters) begged them to take her off this life support and at last they did. But what she and her family suffered was quite unnecessary.

She had taken her euthanasia cards into hospital with her but they were ignored. Now I am faced with a similar operation (I am 78) but will not have one till I feel its quite final.

I hope this incident will be of some use. I still have nightmares about my sister but am thankful that it didn't go on longer.

37. My sister died last October a very sick lady. We watched her gradually die day by day for 18 months choking for breath, not being able to eat. Therefore, when the end did come it was a terrible sight to see her wanting to die and having to go to her peace. It would have been much better for her and ourselves were she able to go long before that terrible end. She weighed 4½ stone before she died.

38. My first-hand experience in this matter was when I watched my mother waiting to die.

Although she was not subjected to unnecessary operations (such as one hears about) her physical condition had deteriorated so much that all she wanted was to die. She lost control of her bodily functions but her mental capacity was unimpaired. She used to say that she longed to go to sleep and not wake up. She was only too aware of everything about her and hated the pointless degrading existence: unable to stand or to sit in a chair without being tied into it, unable to feed herself and incontinent. She could no longer see. She was able to speak only a few words and these were always to say that she wanted to die.

The nursing home/hospital where she was being cared for did their best, I am not criticising them, but I am critical of the law which denies the right of an individual in her condition to end her life.
39. I should like to submit my experience during the years my daughter was dying of Multiple Sclerosis, knowing all the time that there was no known cure, and seeing her health deteriorating all the time. At first she was catered for at home, her husband and two daughters seeing to her each morning and leaving her seated on the settee. Three days per week my wife and I picked her up with the aid of a folding wheelchair getting her in my car and taking her to Fairfield Hospital for exercises, then home again, a journey of 50 miles as we lived at Templestowe and she at Glen Waverley, and she was a heavy woman. This we carried on for 12 months, seeing her getting worse all the time. Finally she had to go into a private nursing home as all MS hospitals were full.

At first she could pass the time reading, but gradually her sight failed and then she spent many hours weeping. I said to the Matron of the home, 'If some morning you are not able to wake her we shall be pleased', but it was five years before that happened. At her funeral service her minister, who had been a frequent visitor to her in the home said 'This is not a funeral service, but a memorial service to a very brave woman', but what suffering and misery she could have been saved if her doctor could have given her something to die, and what more sensible and humane treatment.

We are a practising Christian family and believe there is hope in death not gloom.

I am aged 90 and carry a card in my pocket to say I do not wish to be kept alive by a machine if I have an accident or a serious illness.

40. My personal experience with my late husband: eight years after a bad stroke, struggling to walk and use his hands, then a ruptured aneurism, a five-hour operation - 40 pints of blood, and in intensive care for 11 days, in hospital, then home, where he and I had a very bad 10 years of illness.

41. I have experienced the long and painful death of my father, who died of cancer two years previously. We nursed him here at our home until 2 days prior to his death. He was sent home to die from hospital, he was in constant agony, and he began by asking me to help end his life, then towards the end, he pleaded with me to end it for him.
42. Many years ago I suffered the agonising experience of watching my mother (aged 54) slowly die over five months, in constant distress unless eased with drugs. Eventually I broached this with my elderly doctor, who quietly told me that under his 'compassionate care' she would not linger for more than 7 days. She died in peace. More recently I watched a close friend with advanced cancer, given no hope of recovery, suffer mental anguish which was shared by her husband and family - over 6 months. She is now mercifully dead. She confided that it was only her religious principles which prevented her asking for 'dignified release'.

43. A 13-year-old boy with leukaemia and severe anaemia (Hgb. less than 1, normal = 13) was discharged from an acute hospital to die at home at the request of the boy and his parents. He was on oxygen support to relieve his difficulties in breathing and to lessen the distress of death. He was in and out of consciousness and his hearing and eye sight failing. He was the only child of this family. During a period of consciousness in his final night, the boy appeared angry and asked his parents to remove the oxygen as he had no strength to remove this himself. The mother rang the nurse 'on call' at 3 a.m. and was hysterical at not being able to accede to her son's request. She asked the nurse to come and do the task for her as they were aware that the oxygen was prolonging the boy's suffering.

The nurse suggested that the mother decrease the oxygen flow which would provide less irritation but not assist in prolonging life. The mother was happy to do this. When the nurse arrived at the home she turned off the oxygen and the boy peacefully died within half an hour. The nurse stayed back with the family as requested, until after the departure of the funeral parlour attendant.

44. I called on someone in hospital recently and she was told that she needed to have her leg amputated or she would die. She refused to have her leg amputated. I spent time with her. Some people who refuse, change their mind. However, that woman refused and no one questioned her competency.

45. I shall give you an example of a lady I shall call Rose. She spoke to me one day when I visited her. She had been receiving chemotherapy on a monthly basis.

She said, 'Graham, they are debating me downstairs; I want to get into the debate'. I said, 'Yes, Rose, you want to get into the debate'. She said, 'Yes, I do, but the trouble is that when the doctor comes to see me he talks over me, not to me; it is like a tennis match conversation'. I said, 'If you are going to get into the debate you have to stop the match'. The next day she said that the doctor would probably suggest more chemotherapy. She
said that she hated chemotherapy and said, 'What good will it do me now? I want to be home with my family'. I said that was very clear and that it sounded as though that is what she wanted to say to the doctor.

She said, 'I could not say that; I am just a simple woman'. I had known her for some years, looked at her and said, 'Nonsense, Rose, you are an extraordinary person and you are powerful. It is up to you whether you want to use your power when the doctor comes'. She looked stunned and said, 'Do you think so?' I said, 'Yes, I do, Rose'. I took her hand and we had a short prayer and I left her.

Later in the day her sister came to me to tell me that Rose had decided to go home to live. I also heard that the doctors had been amazed by the change in her. After questioning her consultant she told him she would have no more chemotherapy and that she would be going home to live. Two months later she died.

She made some choices and she was eventually able to refuse treatment, but she also received much care at home through hospice and the district nursing service.

46. I remember a 52-year-old woman suffering from a serious heart disease saying one day that she had been told by a young resident doctor that perhaps she would be a good candidate for a heart transplant. She said 'little he knows, for I know I couldn't have one, and even if I could I wouldn't put my family through all that'.

47. At one point in our unit we had a woman of 62 years and a man of 40 years, both of whom I had known from another ward. Both had life threatening diseases. They both came into intensive care with respiratory problems. As days went on, hope diminished. Days turned into weeks, with little happening.

The nursing staff began to question what was happening. The woman's daughter accepted that it was enough and the man's wife virtually began to cry, 'Lord, this is enough; I cannot put my husband through any more'. Soon afterwards the medical staff agreed that both situations were hopeless and they told the relatives treatment was now being ceased because there was nothing more they could do.
At the age of 69 my mother developed emphysema. She lived alone and it became apparent that she needed family care. Rather to the surprise of the local doctor, who said that, even in the country, many families did not want elderly relatives, we made ready a flat at my sister's home and brought our mother to Melbourne. Old friends and family were attentive, and many days were happy, but naturally her condition deteriorated.

By the time she was 73, my mother (a woman of 5'6") weighed between 5½ and 6 stone, vomited up many meals and was racked by coughing and asthma. Her circulation was so bad that one day a toenail fell out. I observed her tell the local Melbourne doctor that she should be 'knocked on the head'. His response was to laugh at this appeal for understanding.

At the beginning of January 1976, my mother developed alarming symptoms as the result of a complete blockage somewhere in her digestive system and was sent to a large teaching hospital. A young resident doctor from the hospital telephoned me and said aggressively, 'I believe you are opposed to an operation. It will restore her to the quality of life she previously enjoyed'. He thus demonstrated his complete ignorance of the circumstances.

My mother consented to the operation because, in her condition, she hoped it would kill her. (I now realise that whatever the outcome, surgery in such circumstances is probably necessary to prevent pain.) At this time she was calm and completely lucid.

I would have preferred that we had not reached such a situation, but I consider that the following consequences of the operation were inhumane:

(a) my mother was put in Intensive Care;
(b) my mother was X-rayed because of her chest trouble, and I understand that if another test had shown a bacterial infection of the lungs, appropriate antibiotics would have been administered;
(c) anti-cancer drugs were administered without our consent although she was overwhelmingly invaded by the disease.

Visiting every day, on occasion I found my mother both in pain and in restraint because she had been annoying other patients. She was by then extremely confused by the drugs. I do not recall ever seeing a doctor although my sister may have spoken to one. My sister and I told my mother she was dying and my sister asked that she be given a sedative.

This situation lasted for one month. My sister and I decided to bring our mother home and for two days the only medical treatment prescribed was pain relief. She died, peaceful at last, in her own bed.

Months later one of my mother's closest friends told me of her intense wish to die. This highlighted one of my greatest difficulties. As a family member, I could not have pursued this subject with my mother, who dreaded becoming a burden, for fear that she might feel rejected in some way. It seemed to me then that promises made, half laughingly, years earlier, to 'never let me get like that' cannot be acted upon. It still seems to me that the onus is on the person who is suffering to express his or her wishes quite clearly. This may not be possible during an illness.
49. My husband's sister suffered a massive stroke as a result of which she lost all ability to use any physical attributes. Only an eye movement suggested a mind alive in a dead body. After two weeks of intensive tests, the doctors concerned stated that this state would remain to the end. Yet she was permitted to exist for another seven weeks, probably enduring massive mental anguish and what physical pain we have no way of knowing. Why did we not have a compassionate law which ended her life at the time the doctors ended her hopes? (Age 79).

50. At present I know of a case whereby a man went into a local hospital to have a simple operation, he caught an infection and his life was in serious danger. The nurse was informed that he was not likely to make a full recovery and therefore not to resuscitate him in the case of a heart attack. At present such action is not legal and yet this is happening in our midst. By the way, this family nor his family were warned about the decision which had been made.

51. I pose this question on behalf of my mother, a question she would ask if her mind and body were not broken down by illness. For whose glory, for whose benefit is an 86 year old, incontinent, paralysed on one side woman kept alive? Every time I come to her to ask if she wants anything, the answer is, 'Yes, let me die'.

She was once a dignified, energetic and independent human being. Now she is a shell, an empty shell without dignity and without hope.

52. I would like to tell your Committee of the experience I had in January this year when my 73-year-old husband was admitted to hospital on Dec. 29th with a sudden pneumonia.

After 4 weeks of careful and caring nursing (he was diabetic, had angina, and had had a stroke 2 years previously), his condition suddenly deteriorated and every breath became painful and exhausting. He was of course hardly conscious. His family and I were unanimous that he should not be allowed to continue this struggle for each breath. The doctor was obviously relieved to hear our views and suggested that 4-hourly morphine injections should be given the following day. To which we readily agreed. The following day he was as before, semi-conscious; but peaceful, and he died in the evening.
53. Apropos an article which appeared in Preston's 'Post Times', 13.5.86, 'Govt to say if you have right to die', I have almost given up hope on that issue. Would it be flogging an already dead horse?

In June 1979 Preston Council made a statement, in that same paper - 'The aged in this area far outnumber the young'. I answered through the paper. The old were being kept alive(?) against their will. A journalist interviewed me, then another from The Age, The Herald, Caroline Jones, Sydney Radio, and the resulting publicity amazed me. I was assured, by mail and phone, by the families of the old who were confined to nursing or geriatric homes, that their old parents would rather have died quietly at home than live out their remaining time as vegetables.

At that time, wide publicity was given to what was dubbed my Living Will. I have carried it with me for 20 years - 'In the event of prolonged unconsciousness due to stroke or heart attack, or brain damage through accident, no life-prolonging drugs or intensive care will be administered. I will be given pain-killing drugs only. To act otherwise will be an invasion of my privacy. I donate all or any part of my body for research or teaching...'. My next-of-kin has a copy.

For more than a year I pestered various Government administrations, but came up against a blank wall every time. On 2.10.80 the Hon. R.A. Mackenzie brought in a Bill, to enable persons to refuse medical treatment in certain circumstances. It was read for the second time 10.12.80 (Hansard No.12, 1980).

In 1951 my husband suffered an illness which became bi-lateral and widespread. He was terminally ill in 1955. One day he asked me, so casually, where was the rifle. I sent that rifle to a neighbour, and forced that man to live for another pain-filled year. He was 45. I have to live with guilt of not having put that rifle where he could find it, and leaving the house. I cannot look at that as a 'coward's way out', it would have taken enormous courage and sheer desperation to take his own life. He lived on drugs.

Obviously, the priorities of pet animals and valuable racehorses take precedence over those of human beings, they are not forced to live on into helpless old age, when there is no hope of recovery. The geriatric branch of medicine did us no favours.

In Holland, while the right to die is not legal, it is not frowned on. Mr Mackenzie promised me that he would carry his Bill through, January 1981. But it went into the limbo of forgotten Bills. I am just too old to fight as hard as I did 7 years ago.

In the 'Herald' 13.8.79 a spokesman for the AMA is quoted as having said that 'if a doctor is legally satisfied that the instructions on a card relate to the person then the doctor would probably be obliged to follow them...etc.'

My daughter, my only child and next-of-kin, has my Enduring Power of Attorney.
In that same paper, the Victorian Law Institute said that 'there have been no known such cases in Australia . . .', if a doctor operates without the consent of the patient etc. But if a card (my living will) specifically says 'I do not consent to this action', a doctor may be leaving himself open to a civil suit etc.

But, during the past 6 years, we have 'grown up' more than at any other time in history. It was not my intention to have a Bill relating to any person over the age of 18. I was thinking only of the old, but in recent years, all that has changed. So many brain-damaged victims of accidents, who should never have been given intensive care in the first place. Correction - the families, not they, are the victims (the late John McEwan should have taught us something). The brain-damaged or deformed new-born also count.

Obviously, a lot of opposition will come from Church dignitaries, and perhaps some politicians. Before they voice their opposition, I would like one question answered. How many of them owned a much loved dog or cat. When it became too old to walk, suffered from painful rheumatics, did they allow it to crawl under the house to die in agony, or did they have it put painlessly to sleep? Do they think people are lower down the scale than their pets?

54. Dedicated to our precious granddaughter

'Rebecca Kate'

Like falling blossoms in the Spring
She gently touched our lives
With love
For a very short while

I have always been a rather decisive person with clear cut opinions, not easily swayed; one of those opinions has always been 'severely handicapped newborns should not be allowed to survive'. Very easy to say, only words if it didn't affect you - but I completely changed my opinion when it happened to us and our family.
Our two sons' first babies were expected within days of each other. A healthy, beautiful girl was born on the 2nd and Rebecca on the 6th, a phone call from the other grandmother in the country alerted us that 'something was very wrong'. I'll never forget ringing the hospital and hearing the nursery sister say that most dreaded word 'ABNORMAL'. Flashing through my mind was perhaps it's a finger or toe missing or hairlip. I didn't understand what she was saying so she repeated it in layman's terms 'spina bifida' - severe deformity of the spine and hydrocephalus, fluid on the brain. How could this happen to us?, My daughter in law had a wonderful pregnancy, she had a scan and they knew it would be a breech but these parents were each from a family of five healthy children, it was just unbelievable?

Rebecca was brought to the Children's, and while our son drove down he worked out that the doorways of the house they were building could be widened to take a wheelchair and they would trade their car on a van also to take a wheelchair, this was his daughter and he was prepared to take care of her forever - no matter what.

My first thought was - with all these problems I hope she doesn't live too long - but all that changed the moment I saw this beautiful little rosebud, to the untrained eye there was very little head swelling and her spinal injury was covered by clothes and blankets, but she became so special, she was ours, a member of our family, because of her short life expectancy she was very precious to us even though she was the sixth grandchild, no one except the first had been so important and so loved.

Some of the Bowls ladies put it in perspective for me when they said 'At least you've got something, twice I went through hell spending months in bed and I ended up with nothing'.

I was stunned that I, a reasonably intelligent person in my mid-fifties could live so long and learn so little, as two of my close friends had still-born children around a similar time I had my own and I felt great sympathy, sorrow and compassion for them - but I never began to appreciate the traumatic consequences of the loss of a child on parents, grandparents and family until it happened to us.

Rebecca spent a week at the Children's, (she was given 2 days - 3 weeks to live, her bowels and kidneys were severely affected) then sent back to the country where she spent another week in hospital, but as there was nothing they could do for her we brought her home, to be amongst those who could give her the very best thing 'lots of love'. She thrived, put on 1 lb in 2 weeks, knew her Mum's and Dad's voices, surprised the specialist on her Thursday visit but on the next day was admitted to hospital with meningitis and not expected to live the weekend. My son when he rang was devastated,
he and his wife made the very difficult and painful decision not to have the meningitis treated. (What of the next time and the one after that if the meningitis were treated?) It was the following week that Becky was to come back to the Children's for a shunt but that wasn't to be.

I was surprised on arriving at the hospital what good colour Becky had and how strong her grip on our fingers, she was going to fight and she did. I was her constant companion for the next few days until she died on the Tuesday. I nursed her, fed her, talked with her, along with her Mum and Dad we took it in turns to be with her, two of us together, even though she was obviously failing and became very pale, no way could we have stopped feeding her or wanting her to be fed. As long as she was comfortable and without pain, I didn't want anyone to hasten her death, nor did I want her to stay too long and prolong the agony for her parents if the end result were to be the same. The nurses and sisters were terribly upset 'It isn't fair, she's had more love in her short 5 weeks than some kids will have in a lifetime. Why did it happen to them?'

I did advise our children, Becky's parents, 'Some painful decisions will have to be made, I think the sooner the better'. So while I stayed with Becky they talked with the minister, undertakers and discussing what they would do 'when the time came'. We were with her when it did, her Mum and Dad nursing her, whispering words of love, and we continued to do so when she died and we put on her 'new best dress'. I was amazed that sisters of years' training, the 25-year-service mothercraft nurse and even the female doctor were in tears, it was 'something you never got used to' they said.

Even though I'd lost many close friends in their forties and early fifties, some of our friends' sons died in their teens and early twenties tragically and I'd lost my parents within a few months of each other, no grief I'd ever suffered prepared me for the traumatic and devastating effect the death of our very small granddaughter had on us, her parents and our family and friends.

I've been grateful ever since that Becky didn't die soon after she was born. We knew she was on 'borrowed time' but we were able to have our baby at home, she was able to use a lot of her babies' things - clothes, basket, bath and pram - they have added meaning because she used them, but she wasn't around long enough (like a toddler) to have toys, furniture and room of her own, that would have been even more difficult to cope with; then she went to hospital for the few days before she died, which helped prepare us for her not coming home again and most important my daughter-in-law was almost recovered from Becky's birth and she and my son were able to help and comfort each other after Becky's funeral, something that would not have been possible had Becky died early whilst her mother was in hospital.
What have I said after all this? That unless newborns were so deformed as to be repulsive, handicapped babies should be allowed to survive even a few weeks to give their parents 'time and breathing space' and a feeling that even for a little while they were able to love and receive love from their own special creation - their baby.

Looking back I'm selfish enough to have wanted Becky to have lived longer, until she didn't crawl, sit or walk and her handicaps were obvious. Would it have been more of a relief when she died and easier to let her go? As it was she was just like all other little babies who needed feeding, changing and lots of love and tender care.

I've tried to tell myself since that: 'IT WAS EXPECTED, IT WAS INEVITABLE AND POSSIBLY IN THE LONG TERM IT WAS BEST' but it was oh, so very traumatic and painful and the pain never quite goes away.

Since then my heart aches and bleeds for parents of babies who need heart and liver transplants, who have to raise thousands of dollars for operations, go overseas in a strange country without the comfort and moral support of friends and family, amongst strangers, specially if they still lose their baby. At least they know they did everything they possibly could, but how can they cope with the loss?

Or how do parents ever come to terms with putting a healthy child into its cot and picking up one who's no longer breathing? One such broken hearted parent said to us 'At least you know what your baby died of - no one can tell us why our baby died' (I've since become involved with the cot death organisation).

After the initial shock of having a deformed, handicapped or very ill baby, parents and family need that most precious of all commodities 'time' to come to or try to come to terms with what they have to face, time to give love and treasure their baby, time to get used to the idea their babies are only on loan and time to be able to let go and not to be too selfish as to prolong life at the price of the sufferings of a small baby.

Perhaps if given time, they too can be grateful for the short life their babies might have, however undesirable at first it may appear; at least they will have 'something to look back on, remember and treasure', most important for grieving parents. Perhaps too at some later time they can even feel relief, as I do, when they see a severely handicapped child and be grateful that their loved baby didn't live to suffer so much.
55. Ailing old people are not afraid of dying, but we are afraid of not being allowed to die. I am 76, and in excellent health. But that is something over which I have no control. I just do not know what is round the corner. I live among 300 old people, and I know many more. Too many of them hoard sleeping pills. That in itself is an indictment against the powers-that-be. I fully condone that hoarding. Too many of them have children who are either too old to care for ailing old parents, or have families of their own to consider, so, the geriatric home! Pills to quieten them, more pills to put them to sleep every night, days spent tied to a commode, because of their incontinence. I saw so much of it. I was horrified. I hope those barbaric conditions no longer prevail.

Medical advancement may have enhanced the ability to sustain the beating of the heart, or blood circulating through a damaged brain, but is that life, if the person is suffering, and is totally unaware of his surroundings and could not function without a machine attached to him? That is existence, not life!

I sincerely wish you every success. Then I will feel that my lone voice crying in the wilderness will not have been in vain.

2.4 The legal context

The Committee’s terms of reference and evidence from a variety of witnesses indicated clearly to the Committee that the legal perspective relating to the substance of the inquiry was of the greatest importance.

From the beginning of the inquiry, the Committee had lengthy discussions with its legal research officer. As well, discussions were held throughout the inquiry with international legal experts experienced in this complex area. (See Appendix C).

On the basis of evidence presented to the Committee regarding widespread lack of information and knowledge about certain common law rights and diverse interpretations of the major legal principles addressed by the Committee, the legal situation is discussed in the context of:

(a) the law in Victoria;
(b) protection for medical, nursing and other professionals;
(c) Australian developments; and
(d) overseas developments.
2.4.1 The law in Victoria

In the course of its public hearings, the Committee heard evidence indicating widespread confusion and misunderstanding regarding the current medical-legal situation.

Because of this confusion and diverse interpretation, a brief overview of the current legal situation is provided in Appendix E.

An analysis of the evidence received by the Committee showed that the existing common law right to refuse treatment created great concern and legal confusion for a large number of people.

Some witnesses considered legislation establishing a right to die unnecessary because a patient already has the common law right to refuse treatment. Many submissions and letters, however, clearly indicated to the Committee that such a right is not known or understood by many people. Evidence was also given to the Committee that exercising this right in certain situations is not practicable, or for some people, not even possible.

As Section 3.4 below indicates, the common law right to refuse medical treatment is not an absolute right. The Committee is also aware that exercising this right depends on the legal advice obtained by a care-giver, and the legal interpretation of the particular medical situation by the legal adviser or representative giving that advice.

For example, Dr J. Toscano, the medical practitioner who treated Mr John McEwan after his discharge from the Austin Hospital, told the Committee that according to Dr Toscano's legal advice from solicitors representing the Medical Defence Association, Mr McEwan could not take out an injunction (against Dr Toscano) to stop treatment, as was his right. That is, Dr Toscano's legal advice was that if he is doing something to prolong another person's life, he cannot be charged with assault. 20

This contradicts other legal evidence consistently received by the Committee. That evidence indicated every individual has a common law
right to refuse any medical treatment, and a secondary legal measure being the right to take out an injunction against their medical practitioner to have treatment ceased.

The common law right to refuse medical treatment is discussed further in Chapter Three.

2.4.2 Trespass to the person

Associated with the common law right to refuse medical treatment is the centuries old form of action of the common law known as trespass to the person, the principal forms of which are assault, battery and false imprisonment.

A medical practitioner who provided surgery or medical treatment on a competent patient against that patient's wishes would be committing a battery on the patient. Battery consists of the intentional infliction of force upon another person without the consent of that person. The patient could institute legal proceedings against the medical practitioner claiming damages for the battery. Such proceedings are civil proceedings.

However, assault, battery and false imprisonment were also criminal offences at common law. Recent amendments to the Crimes Act 1958, however, have introduced new offences (sections 15-31). Thus, a medical practitioner who intentionally or recklessly subjected the patient to serious bodily injury without the patient's consent could be charged with one of those offences.

2.4.3 Protection for medical, nursing and other professionals

The Committee was required in term of reference (5) to investigate the matter of protection for medical, nursing and other professionals who allow an individual to die, or assist an individual in dying. Evidence to the Committee illustrated divided public understanding and opinions on whether adequate protection is currently provided in Victoria for health professionals.
and carers. St Vincent's Bioethics Centre were very clear on the matter:

The current legal position is that competent patients have a right to refuse medical treatment including life-sustaining treatment, and health care professionals have a legal duty to exercise reasonable care. The pair of principles provides adequate protection for the rights of patients and a health care professional who respects the right to refuse and who exercises reasonable care within the scope of valid therapeutic purposes need not fear legal proceedings.

There is, therefore, no need to provide further protection for health care professionals, although there is a need to educate the media, the public and health care professionals about their existing rights under the law. In recent times a degree of confusion seems to have arisen in that regard. 21

The Royal Australian Nursing Federation, on the other hand, submitted that uncertainty existed for health care professionals regarding legal repercussions:

The fear of litigation causes many inconsistencies. Even when they act in accordance with patients' wishes, health professionals are not necessarily protected.

Dilemmas in professional practice also arise when it is unclear where we cease to prolong life and begin to defer death. 22

Dr H. Kuhse concurs with this concept but goes one step further however, pointing out the difficulties that infiltrate major medical advances:

In earlier times, an informal policy was not so obviously inadequate because many life-sustaining means were simply not available. The physician would decide what treatments were appropriate and when treatment should be stopped. It seemed like a purely technical, medical judgment. Certainly this is not the case today when the question arises whether or not a particular patient is to be resuscitated, or whether or not life-sustaining
respiratory assistance and intravenous feeding are to be discontinued. Quite clearly, in cases such as these, doctors are making life and death decisions; and they are doing so at the risk of being charged with murder. In addition to this, and most importantly as far as the rights and interests of patients are concerned, we need to note that there is great variation among physicians and hospitals as to which treatment is regarded as 'appropriate' under particular circumstances and which is not. Doctors, like the general public, have views ranging from 'treatment at all cost to the very end' to 'let the patient die under such and such circumstances'. 23

Dr D. Brown, the Austin Hospital Spinal Injuries Unit Director, told the Committee his current understanding of the law was that failure to initiate treatment, or withdrawal of treatment, can result in a charge of manslaughter or negligence. The solution to the current dilemma offered by Dr Brown is protective legislation:

Legislation is needed to protect treating staff so that they cannot be charged with manslaughter or negligence if in the course of their professional duty they decide to withhold or terminate treatment in the best interest of their patients. Such legislation should recognise that the treating staff are professional staff trying to do the best thing by their patient and should provide for appropriate peer review to ensure that guidelines... have been followed and that all such reasonable steps have been taken. 24

Justice Kirby, citing the Crimes Act 1900 (NSW), s.18(1)(a), offers one legal interpretation:

Statutory definitions of 'murder', in Australia at least, typically include reference to omissions as well as positive actions:

'Murder shall be taken to have been committed where the act of the accused, or the thing by him omitted to be done, causing the death charged, was done or omitted with reckless indifference to human life, or with intent to kill or inflict grievous bodily harm upon some person'.

46
Although commentators may seek to draw a valid moral distinction between positive acts and passive refusal to act in order that nature might 'take its course' the distinction is not always easy to sustain in practice. Although arguments may turn on whether the omission 'caused' the death, this too is a debatable argument where omissions expand into positive facilitating actions.

Justice Kirby added:


Certainly, it is arguable that the failure to give nourishment, or the failure to provide a routine operation or the failure to give 'a shot of penicillin' fall within the legal definition of 'murder', provided the requisite intent exists. It may be unreasonable to doctors to expose them, unguided by society, to accusations of murder. But it is equally unsatisfactory that decisions of this kind made by doctors should be left to the vicissitudes of unstructured moral determinations varying from individual to individual and from hospital to hospital: made without any guidance at all or, at best, with the help only of a closed hospital committee or appeals to the traditional medical way of doing things. 25

On the other hand, the Right to Life submission cited Mr F. Galbally's interpretation of the law:

It has been argued too, that '...the law in Australia provides ample protection to the medical practitioners who are involved in the difficult decision making process of withdrawing life-support systems and allowing the patient to die from the existing condition...(since)...the medical practitioner's action in withdrawing artificial life prolongation machinery is not the real cause of death or even a substantial cause of death. His action merely allows the existing fatal condition to operate naturally'. (F. Galbally, Australian Law Journal, Vol.55, June 1981, p.343). 26
The Committee's experience is that not only is the legal situation ambiguous and capable of a variety of interpretations, and some would argue that such is the nature of common law, but also that many providers of health care are uncertain of their position.

The Committee concludes that legal uncertainties must, as far as possible, be eradicated and the position clarified, in order that appropriate shared decision-making and compassionate care may have priority over undue fears of criminal or civil liability, together with any undue influence these fears may have upon such decision-making. To this end, the Committee finds that adequate protection, particularly for those involved in palliative care, is essential. Such protection should be provided to medical practitioners who act properly and in accordance with the wishes of their patients not to receive medical treatment. This issue is discussed further in the following chapter.

2.4.4 Australian developments

South Australia is the only Australian State to have enacted a law, the *Natural Death Act* 1983, giving legal recognition to an individual's advance declaration directing the withholding of life-sustaining measures in the event of terminal illness or injury.

In summary this Act states that a person of sound mind, 18 years or over, who desires not to be subjected to extraordinary measures in the event of a terminal, irrecoverable illness or injury may make a direction to that end. The direction is to be made before the illness happens, in the prescribed form, witnessed by two people and states that no medical or surgical measures to prolong life be initiated.

Similar legislation, the Refusal of Medical Treatment Bill, was introduced in Victoria in 1980 although it did not become an Act. The proposed legislation was to enable refusal of medical treatment in certain circumstances.

In summary, the 1980 Bill stated that a person, 18 years or over, of sound mind, may declare that if suffering from an illness or injury diagnosed as irreversible and progressing inevitably to death, life is not to be maintained by life-sustaining procedures.
The declaration required two witnesses, remained in force for ten years and could be revoked verbally or in writing by the person making the declaration. The attending medical practitioner was to act in accordance with a conscious patient if another medical practitioner certified in writing that the patient could only be maintained by life-sustaining procedures.

The Committee considers both the South Australian Natural Death Act 1983 and the Refusal of Medical Treatment Bill proposal 1980, useful in their deliberations for a number of reasons.

The first, and most important one, is the provision in s.6(1) of the South Australian Act that, for the purposes of the law of South Australia, the non-application of extraordinary measures to, or the withdrawal of extraordinary measures from a person suffering from a terminal illness does not in itself constitute a cause of death. The effect of this provision is to clarify the common law relating to the provision of necessaries. The Victorian Refusal of Medical Treatment Bill did not contain a provision like this.

Secondly, the South Australian legislation provides a clear indication of the intention of the legislature to respect the decision of a competent patient who has executed a prior written directive in accordance with the Act.

Finally, the legislation plays an important role in educating the public and health care personnel in the legal right of a person to execute a directive in the form, and under the circumstances, permitted by the Act.

There are, however, a number of shortcomings in the South Australian Natural Death Act. There are also shortcomings in similar legislation in the USA (see Section 2.5.5). Several submissions to the Committee, and articles in legal and medical journals have outlined problems brought about by this type of legislation.

The major shortcoming drawn to the attention of the Committee refers to the narrow definition of existing legislations. For example:

(a) There is a lack of clarity in the terminology used, such as 'imminent'
death; temporary or permanent recovery; extraordinary, or life saving equipment; and terminal illness;

(b) Those people who do write directives do not always comply with, or fit within the stated scope of the statutes. For example, not all people die of a terminal illness, and people who are suffering are faced with burdensome treatment at differing stages in their lives;

(c) Cases such as those of Karen Quinlan and John McEwan do not always fit within the existing legislations. Some can be narrowly interpreted whereby they do not cover these real life situations;

(d) Such a declaration may, at some future time, be contrary to the patient's wishes in changed circumstances; and

(e) No allowance is made for the distinctions between directions given by a patient before any knowledge of a terminal illness and directions which may be given after such diagnosis.

The major criticism raised was that 'living will' declarations appear to involve an uninformed refusal of treatment in a wide range of unforeseeable circumstances. Some submissions to the Committee interpret this as a form of suicide in the face of serious illness, using a blanket refusal of appropriate treatment as the instrument.

A further shortcoming was indicated by a comparative analysis of both the Australian natural death legislation and the 23 existing American State Acts, which reveals that very few natural death acts, or living will legislations explicitly provide for the appointment of an agent for medical decision-making if the patient becomes incapacitated or incompetent.

To circumvent this problem, 50 American States have enacted statutes creating a power of attorney that gives an agent authority to act even after the declarant is incapacitated or incompetent, (when normal power of attorney ceases) called Durable Power of Attorney Acts. Australia has similar legislation, i.e. Instruments (Enduring Powers of Attorney) Act 1981
(Vic.), (New South Wales [1983]), and (South Australia [1984]). The Victorian Instruments (Enduring Power of Attorney) Act 1981 is discussed further in Chapter Six.

These durable power of attorney acts are meant to offer a simple, flexible and powerful device for making health care decisions on behalf of incompetent patients; even though they are intended primarily to provide for decisions affecting the individual's property.

This application of the durable power has not been widely used in America because uncertainty exists (except in California only) as to whether they authorise the person appointed to refuse life-sustaining treatment for a declarant in a terminal condition. In Victoria however, once the Enduring Power of Attorney is made the person appointed as attorney is authorised to carry out anything the represented person can lawfully authorise an attorney to do.

2.5 Overseas developments

On the basis of its review of evidence from previous judicial decisions and overseas legislation, the Committee examined the following major principles established in case law and these are:

(i) refusal of treatment;

(ii) withdrawal of treatment for both competent and incompetent patients;

(iii) an individual's request to be allowed to die;

(iv) informed consent; and

(v) 'living will' legislation.

All legal cases described in this chapter are based on American and English circumstances. In addition, the list is not an all-inclusive listing of every
Such is not the purpose of this section, rather, these cases are an illustration of the legal complexities raised by the terms of reference. In extensive legal consultations, the Committee was advised that very few situations in the Australian legal, ethical, medical, and hospital areas have led to Court cases and judicial decision-making.

In the course of the inquiry, however, several relevant legal, medical and ethical dilemmas occurred in Australia including cases such as: Mr Cornelius Hus; Mr John McEwan; (in Melbourne), and Sir John and Lady Phillips (a Sydney suicide pact), discussed above in Section 2.3.2. In South Australia Mr James Johnstone was given a token non-parole period of ten days in prison, after having been convicted of electrocuting his dying wife - indicating the judge's reluctance to impose a heavy penalty on a so-called 'mercy-killer'.

The purpose of this section is, therefore, to provide relevant judicial decisions and legislation as a background to understanding the recommendations made by the Committee in other chapters.

2.5.1 Right to refuse treatment

The Karen Quinlan case was the first of many cases about patients' rights in treatment decisions. Such cases rested on the Courts' interpretation of several issues, namely:

(a) patient autonomy;

(b) right to refuse treatment even though the person would die without it;

(c) the condition being burdensome and incurable; and

(d) the expressed wishes of a patient.
Karen Quinlan case

Medical condition

Karen Ann Quinlan became the symbol of the dilemmas created by the new technology. Rendered permanently comatose in 1975, apparently by an injudicious combination of alcohol and drugs, the young woman was declared by her physicians to be unlikely to regain consciousness or ever to breathe on her own. Nonetheless, she was considered indefinitely supportable with the assistance of a respirator.

The artificial prolongation of her non-sentient life seemed wrong to:

(a) Karen's father, who unsuccessfully requested the attending physician to cease treatment;
(b) Catholic Church representatives consulted by Mr Quinlan; and
(c) ultimately to the justices of the New Jersey Supreme Court.

Court deliberation

By the time the case reached New Jersey's highest Court in early 1976, it had attracted national attention.

In espousing her right to choose, the Chief Justice concluded - based on testimony from the woman's parents as well as his own suppositions - that if Karen were herself miraculously lucid for an interval, she would decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death. Having assumed the unknowable, the Court next tackled the task of overcoming 'competing' interests that appeared to counsel against shutting off the respirator.

The Court concluded that whatever interests the State had in the preservation and sanctity of human life they were diminished by Karen's poor prognosis (here the Court focused on her prognosis to resume cognitive life, rather than the likelihood that death would supervene) and the degree of bodily invasion necessary to support her:
Ultimately, there comes a point at which the individual's rights overcome the State interest. It is for that reason that we believe Karen's choice [to stop the respirator], if she were competent to make it, would be vindicated by the law. 28

Karen's attending physicians, supported by several qualified experts who testified in the case, had contended that removing the respirator would not conform with medical practices, standards, and traditions. The Court brushed this concern aside, concluding that

the interests of the patient...must be evaluated by the Court as predominant, even in the face of an opinion contra by the present attending physicians. 29

Elsewhere in the decision the Court suggested that the physicians might have been influenced in their opinions by their fear of malpractice liability if they had agreed to remove respiratory support, a factor portrayed as contaminating their decisions with less than worthy motivations.

In as simple a manner as that, the New Jersey Supreme Court disposed of two major impediments to the termination of life support, which in this case rested on the Court's interpretation of the value of autonomy.

Court's conclusion

The right of autonomy was held to be paramount: patients would or should choose to have their respirators turned off or similar life support withheld and decisions rendered in favour of withholding care. The Supreme Court held, inter alia, that the decision to permit Karen to die of natural causes was an important part of her constitutional right to privacy.

In a now established line of cases, it had been held that incompetent and unconscious patients have a right to refuse medical treatments that could restore their competence or sustain their lives.
Outcome

The supreme irony in the Quinlan case is that contrary to the expectation of her physicians, Karen Ann Quinlan began to breathe on her own after her respirator was turned off. Although she never regained consciousness, she lived until June 1985, more than nine years after the New Jersey Court ruled that her autonomous choice would have been to die.

Satz v. Perlmutter

This was a decision by the District Court of Appeal of Florida (subsequently approved by the Supreme Court of Florida), that allowed Mr Perlmutter to refuse life support treatment.

Medical condition

Mr Abe Perlmutter, 73 years old, was suffering from amyotrophic lateral sclerosis (Leo Gehrig's disease). There was no cure and he was expected to live two years.

The disease had progressed to almost total paralysis, speech was an extreme effort and he was totally dependent on a mechanical respirator for breathing. Even with this life support system assistance, the medical prognosis was death in a short time. The patient was, however, in command of his mental faculties and legally competent. He wished to have the life support treatment discontinued.

Criminal and civil liability

Under the Florida Murder Statute s.782.04 or manslaughter under s.782.089, the hospital and the physicians feared criminal prosecution and civil liability.

The State of Florida maintained that:

(1) the physician had an overriding duty to preserve life; and
(2) termination of supportive care, (whether by the patient himself, his family or medical personnel), was an unlawful killing of a human being.

The Court took into account relevant points made in a similar case (Superintendent of Belchertown State School v. Saikewicz)³³ whereby an individual's right to refuse treatment was tempered by the State's public policy interests, i.e.:

(1) interest in the preservation of life;
(2) need to protect innocent third parties;
(3) a duty to prevent suicide;³⁴ and
(4) a requirement that it (the State) help maintain the ethical integrity of medical practice.

The Court's decision

The Court stated there was no doubt that the State did have an interest in preserving life, but agreed with the decision in Superintendent of Belchertown State School v. Saikewicz that what was of paramount importance was the condition being incurable, and burdensome treatment:

...there is a substantial distinction in the State's insistence that human life be saved where the affliction is curable, as opposed to the State interest where, as here, the issue is not whether, but when, for how long and at what cost to the individual [his] life may be briefly extended.³⁵

Observing that in the present case, the patient's condition was terminal, his situation wretched, and the continuation of his life temporary and totally artificial, the Court could see no compelling State interest to interfere with the patient's expressed wishes.³⁶
The Court observed that there was no requirement in law that a competent, but otherwise terminally ill, patient undergo the surgery or treatment which constituted the only hope for temporary prolongation of his life. This being so, it could see little difference between a cancer-ridden patient who declines surgery, or chemotherapy, necessary for his temporary survival and the predicament of Abe Perlmutter.

**Erickson v. Dilgard**

This was a decision before Meyer J. of the Supreme Court of New York.

**Medical condition**

The patient, Mr Jacob Dilgard, Sr, was voluntarily admitted to the County Hospital where a diagnosis of upper gastro-intestinal bleeding was made. It was suggested to the patient that he submit to an operation, including a blood transfusion to replace lost blood. 37

The patient declined to submit to a blood transfusion, but did indicate a willingness to submit to the operation without a blood transfusion. The patient's son also refused to give permission for a blood transfusion, but he was willing to authorise the operation without a blood transfusion.

Dr Erickson, the hospital superintendent, gave evidence that an operation was necessary to tie off the bleeding site, a blood transfusion being necessary to assure the best chance of recovery. He also testified that there was a very great chance that the patient would have little opportunity to recover without the blood. 37

**Competency**

Dr Erickson also testified that the patient was completely competent and capable of making decisions on his own behalf, and that he had explained to the patient the increased risk of having the operation without the transfusion, and that the patient's refusal to consent to a blood transfusion represented the patient's 'calculated decision'. 38
Court decision

The Court held that the patient did have the right to refuse a blood transfusion even though he would most likely die without it.

Superintendent of Belchertown School v. Saikewicz

Medical condition

This case in 1977 in Massachusetts involved a 67 year old, profoundly retarded resident of a State institution for mentally retarded persons. Mr Saikewicz had incurable leukaemia that was treatable with chemotherapy to gain symptomatic remission. This made a brief extension of his life possible, for a period of months or years.

Court deliberations

Evidence was received by the Court clearly indicating the majority of competent persons in similar situations elected to undergo treatment. Treatment involved uncomfortable and even painful side effects, sufficiently serious to cause many reasonable persons to forgo the treatment.

Because treatment was available a choice existed.

Court decision

The Court held that Saikewicz was not to be deprived of the right to decline chemotherapy simply because of his incompetence to make the choice himself.

It was decided that such a choice could be made by a probate judge placing himself, as best he could, in the position of Saikewicz, attempting to approximate, subjectively, the decision Saikewicz would make himself.

In so ruling, the Court vindicated the right of an incompetent person to decline treatment in a situation where treatment was available which presented a substantial question of choice. \(^{39}\)
2.5.2 Requests for withdrawal of life-support treatment and nutrition

*Barber & Nedji v. California* 40

Central issue

The central issue in this 1982 Californian case was whether the doctors had a legal duty to continue life-sustaining treatment for a patient legally pronounced as being in a comatose state; and for whom any meaningful recovery of cognitive brain function was exceedingly unlikely.

Medical condition

Mr C. Herbert, aged 54, suffered a cardiopulmonary arrest in the recovery room shortly after the successful closure of an ileostomy, (a permanent opening of the small intestine through the abdominal wall). He was revived by a team of physicians and nurses and immediately placed on life-support equipment. Tests over the next three days determined the patient was in a deep coma from which he was not likely to recover. As the Court found, Mr Herbert had suffered severe brain damage, leaving him in a vegetative state likely to be permanent.

The family, having been informed of this prognosis, convened, and subsequently forwarded a written request to the hospital, stating they wanted all the machines taken off that are sustaining life. The two accused (the surgeon and the internist) thereupon ordered that the patient be taken off the respirator and other life-support equipment. The patient continued to breathe without the equipment, but showed no signs of improvement. After two more days, the accused, having consulted with the family, ordered the removal of the intravenous tubes providing hydration and nourishment. From that point until his death, Mr Herbert received only nursing care which preserved his dignity and provided a clean and hygienic environment.

Court deliberations

The case before the Californian Court of Appeal (Compton, Roth and Beach J.J.), by way of a writ of prohibition on a point of law was:
Is it murder to withdraw all food and fluids, leaving a permanently comatose patient with 'nursing care' only?

The Court began its deliberations with the observation that

... a murder prosecution is a poor way to design an ethical and moral code for doctors who are faced with decisions concerning the use of costly and extraordinary life-support equipment.

To complicate the issue before the Court, California had recently adopted the Natural Death Act, which permits an adult to execute, in advance, a directive for the withholding or the withdrawing of life-support equipment in the event of sustaining a terminal condition. (See section 2.4.4 regarding natural death legislation). It was argued that, since the deceased had not issued such a directive in his lifetime, the family's request was therefore a legal nullity. The Court of Appeal was not persuaded. It concluded that since a competent adult patient always had the right to refuse medical treatment, it followed that:

... when the patient, however, is incapable of deciding this issue for himself, because of his medical condition or for other reasons, there is not clear authority on the issue of who is to make the final decision, and under what procedure. It seems clear, in the instant case, that if the family had insisted on continued treatment, the accused would have acceded to that request.

In the alternative, the prosecution argued that the family's decision was a legal nullity, because only the duly appointed legal guardian has the authority to act on behalf of another. The Judges held that, while guardianship proceedings might be used in this context, they were not aware of any authority requiring this procedure.

The importance of the case lies in the fact that the Court saw no distinction between withholding life-support equipment and withholding nourishment and fluid, a 'distinction' based more on:

the emotional symbolism of providing food and water to those incapable of providing for
themselves rather than any rational difference in cases such as the one at bench. 43

Court decision

The Court held that a physician was under no duty to continue treatment once it was proven to be ineffective. In summing up, the judge concluded that an appropriate rational approach involved the determination of whether the proposed treatment is proportionate or disproportionate in terms of the benefits gained versus the burden caused.

Judge Crahan saw no important legal distinction between turning off respiration, and discontinuing hydration.

In the Matter of Conroy, Supreme Court New Jersey 44

Central issue

This case deals with the request by the patient's family to withdraw nutrition. As opposed to the outcome of the previous case, the New Jersey Appeals Court viewed this case, not as one of refusing medical treatment, but one in which the patient was to be purposefully killed by starvation.

Medical condition

The patient was 83 years old, incompetent but not comatosed. There was no cognitive or volitional functioning and communication was carried out on a very primitive level. Her nephew - her only relative and Court-appointed guardian - asked that naso-gastric feeding and hydration be discontinued and that his aunt be permitted to die. Her physician would not remove the feeding tube. 45

Court deliberation and decision

Ms Conroy's nephew petitioned the Court for authority to have the feeding tube removed. In February 1983, a Superior Court judge ruled in his favour stating that to prolong the patient's life 'would not help her, it would be wrong to her'. 46
Before this ruling could be implemented, a stay of proceedings was obtained and the case was referred to the Appellate Division of the Superior Court.

Ms Conroy died shortly after, with her naso-gastric tube still in place. The case continued. Five months after her death, a panel of three judges reversed the lower Court's ruling and found that withdrawal of a naso-gastric feeding tube, required for nourishment, would constitute homicide. 47

**Hydration and nourishment withdrawal**

The two previous cases, Barber & Nedjl v. California, and re Conroy in New Jersey, clearly show that Courts in California and New Jersey reached dramatically conflicting conclusions on the legality of withdrawing nutrition from incompetent patients.

The California Court decided that removal of intravenous tubes providing hydration and nourishment, by a physician with the family's consent is an omission, which, even though done intentionally to end the life of the patient, is not unlawful killing so long as the intravenous feeding offers no reasonable benefit to the patient. On the other hand, the New Jersey Court concluded that withdrawal of a naso-gastric feeding tube, required for nourishment of the patient, would constitute homicide. The cause of death in this case would be dehydration and starvation. 48

Because of these conflicting decisions about hydration and nourishment withdrawal, stipulations have been added to five recent American State Living Will statutes:

> ... in five of the new laws, the administration of nourishment/sustenance has been listed along with the other procedures that are not included in the definition of life sustaining procedures that can be withheld or withdrawn from a qualified (dying) patient. 49

A ruling released in March 1986 by the American Medical Association Council on Ethical and Judicial Affairs, 50 states it is ethical to discontinue all means of life prolonging medical treatment, including nutrition and
hydration:

Even if death is not imminent but a patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis and with the concurrence of those who have responsibility for the care of the patient, it is not unethical to discontinue all means of life prolonging medical treatment.

Life prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. In treating a terminally ill or irreversibly comatose patient, the physician should determine whether the benefits of treatment outweigh its burdens. At all times, the dignity of the patient should be maintained.  

Brother Fox (Eichner v. Dillon) (Substituted Judgment)

Medical condition

Brother Joseph Charles Fox, aged 83, underwent surgery for an inguinal hernia on 2 October 1979. During surgery, he suffered a cardiac arrest and consequent brain damage. He remained in a coma from which, according to medical evidence, he would never recover. Father Eichner, the president of the school at which Brother Fox taught, sought an appointment as guardian with authority to direct the termination of Brother Fox's life support system.  

Court deliberation

The Appellant Division of the New York Supreme Court (the second last appeal level in the State) said that not to exercise its power to decide the issue would be an abdication of a fundamental judicial responsibility. As in the case of Saikewicz, the Court recognised the right, supported by common law and the United States Constitution, of a competent patient to refuse
life saving medical treatment. It also recognised that the right may be over-ridden by countervailing public or State interests of the kind listed in Saikewicz. If competent patients have that right, then logic, morality and medicine required the same right to be accorded to incompetent patients.

The Court held that the medical criteria for the exercise of this right were:

(a) a terminal illness;
(b) a vegetative coma that is permanent, chronic and/or irreversible;
(c) a lack of cognitive brain function; and
(d) an extremely remote probability of recovery.

Satisfied that these were fulfilled, the Court stated that its task was to ascertain and to implement the patient's wishes. This would be simplest if the patient had expressed unequivocally a desire not to have his life prolonged beyond a certain point by artificial means and especially if that desire had been expressed at a time when the patient had contemplated the medical catastrophe that had ultimately befallen him. When the patient had not done so, the Court, through the process of substituted judgment, must attempt to fulfill the patient's 'dying wishes'.

In the Court's opinion, the implementation of those wishes must involve the neutral presence of the law because, although the opinions of the medical profession will have priority on the medical aspects, the patient's wishes, any relevant religious views, the views of the family and the concerns of society are also significant considerations. The Court's intervention should be the last in a succession of decisions by doctors, hospital ethics committees and families.

**Court decision**

Because there was clear evidence of Brother Fox's wishes (he had twice expressed a desire not to be maintained if ever in a coma), there was no need to follow the full pre-Court succession of decisions. Confident that it was implementing the patient's wishes, the Court permitted the guardian to authorise termination of treatment. 53
2.5.3 Patient's request to be allowed to die

**Bouvia case**

**Central issue**

In December 1983, Mrs Elizabeth Bouvia, 26 years old, competent, educated and a non-terminally ill patient in a Californian hospital applied to the Court for permission to starve herself to death.\(^{54}\)

**Medical condition and viewpoints**

Mrs Bouvia, paralysed from birth by cerebral palsy, had been confined to a wheelchair with only slight control of one hand. She was either cared for by her parents, or by State-subsidised home care assistance. She sought an order to prevent the staff of the hospital from force-feeding her or from giving her anything more than maintenance care and relief of pain.

She could not kill herself without the knowledge or aid of others, thereby putting them at risk of prosecution for aiding a suicide. It was only by refusing anything but pain relievers and hygienic care, Mrs Bouvia said, could she terminate her own life - a life which she contended was not worth living because of constant pain and not being able to survive unaided.

The hospital's chief of psychiatry refused to discontinue feeding because he considered her mentally competent but clinically depressed.

The hospital argued that to rule in favour of Mrs Bouvia would infringe the rights of the staff and patients, damage the interests of other disabled people and threaten the integrity of medical ethics.

Her estranged husband said he would sue under civil statutes if the hospital let her die.\(^{55}\)
Court deliberations

Judge J.H. Hews stated that if Mrs Bouvia chose to remain in hospital, she had to continue to accept nourishment or he would permit the hospital to force feed her. There was, he declared, no other option.

Recognising that it was impossible to fully appreciate what her life had been, he upheld her right to terminate her own life but not 'with the assistance of society'. Mrs Bouvia appealed. 56

Outcome

In April 1986, attorneys for Mrs Bouvia won Court approval from a Californian State Appellate Court to starve herself to death.

At that time she filed suit to prevent a Los Angeles county hospital from weaning her from morphia (her pain-killing narcotic). The hearing is pending and Mrs Bouvia is still waiting. 57

2.5.4 Informed consent

In discussions concerning a patient's right to be fully informed about treatment contemplated by medical practitioners, and the corresponding right to refuse such treatment, informed consent means something different to different people.

Informed consent is also interpreted differently world-wide. Diverse meanings range from:

(a) a requirement that all risks, forms of alternative treatment and possible outcomes are explained to the patient; to

(b) an obligation that medical persons merely indicate the general procedure of treatment to be undertaken.
The doctrine of informed consent is accepted in some overseas jurisdictions as a legal right of patients. Nearly half the States of America have statutes that seek to specify the legal requirements of informed consent. 58

This does not, however, generally apply to Australia. The Law Reform Commission of Victoria completed at the end of 1986 an extensive review of the legal definition of informed consent, to be finalised and forwarded to the Attorney-General's Department by April 1987.

This section now describes significant American and English cases.

**An American case**

*Salgo v. Leland Stanford Jr. University of Trustees*

**Central issue**

In this 1957 Californian case, a doctor failed to warn his patient of the risk of paralysis inherent in the performance of translumbar aortography.

After subsequently suffering severe paralysis of the lower limbs, the patient claimed for damages based on the doctor's failure to warn of the risk of paralysis.

**Court's decision**

During judgment in the Court it was stated:

\[\ldots a \text{ physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.}\]

A lack of informed consent, therefore, nullified any consent given to initiate the procedure, rendering the doctor liable in damages for trespass.

* Under the American doctrine, the Court decides informed consent on an objective patient basis, concentrating solely on the attitude of the patient. 60
English cases

Hills v. Potter and Others (1983)

In this case, the Court ruled in favour of the doctor.

Medical condition

A woman suffering from a neck deformity known as spasmodic torticollis, was left paralysed from the neck down, in 1974, after undergoing an elective operation to effect a cure. Consent was given for this operation. There was an inherent risk that paralysis would result from the operation even if it was competently performed.

Action taken

In 1980, she sued the surgeon and the health authorities for damages for personal injury claiming he was in breach of the duty of care by failing to provide her with all information about the operation enabling her to make a truly informed choice regarding the operation.

Court decision

The Court ruled in favour of the doctor whereby prior to an operation a doctor or surgeon did not have to inform the patient of every risk inherent in the operation. The doctor was not guilty of negligence because he had acted in accordance with the practice accepted as proper by a responsible body of medical men skilled in the relevant area of practice. 61

** The English Courts have rejected the American doctrine with its sole concentration on the attitude of the patient. The English position as stated is, a doctor is not required to disclose all possible risks, but only a warning that there may be some small risk of untoward results. The doctor then, is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in the relevant area of practice. 62
Sidaway v. Bethlehem Royal Hospital Governors and Others (1985)

Medical condition

Mrs Sidaway, 63 years old, suffered from persistent pain in her neck and shoulders and on the advice of a neurosurgeon, proceeded with a laminectomy to relieve the pain.

She was warned of the possible damage to the spinal cord, estimated to be less than one per cent. The possible resultant injury could have ranged from mild to very severe. After the operation she was severely disabled and unable to walk alone.

Court decision

The Court held that a medical practitioner need only provide the patient with a minimum of information relating to a general description of the operation and a warning of some small risk of untoward results. Damages were agreed, but they were subject to liability. Basing the claim, not on negligence but on the ground the plaintiff had not been warned of the specific risks associated with the operation, it was held she would not have undergone the operation. 63, 64

2.5.5 'Living will' legislation

'Living will' is a generic term applied to legislation identified by a variety of currently used phrases - natural death, death with dignity and right to die.

These 'living will' laws are a new form of legislation. The earliest - the Californian Natural Death Act - was signed into law in 1976. Laws were passed in seven additional American States in 1977.

Since then nearly half of the American States have enacted similar legislation.
This form of legislation in America was prompted by a number of right-to-die cases being decided in Court, beginning with the Karen Ann Quinlan case in 1975.

The Yale Legislative Services Model Bill was drafted in 1978. It provided an easily administered system of implementing patients' wishes secured by means of a document which could be executed at any time. It did not include the appointment of a proxy empowered to make treatment decisions on behalf of the 'living will' declarant if the latter was incapable of doing so. 65

Analysis of all 'living will' legislation enacted to date

Overall, legislation attempts to focus on:

(a) acknowledging the right of adults to control decisions concerning their medical treatment;

(b) clarification of the rights of terminally ill patients to refuse treatment;

(c) setting out guidelines for physicians regarding the termination of life support systems;

(d) appropriate and inappropriate application of medical technology;

(e) providing immunity from criminal or civil liability to physicians and other health care providers who comply with a patient's advance directive; and

(f) defining terms as used in the laws, e.g. stating the meaning of 'life-sustaining procedures' and defining 'terminal condition'. 66
The appointment of a proxy decision-maker

Aside from these typical provisions, some of the more recent legislation expressly provides the option of a proxy appointment or establishes procedures for decision-making on behalf of comatose patients who have not executed a declaration. (It will be recalled that this situation has been central to some of the cases that have been before the Courts, outlined earlier in this Chapter). 67

2.5.6 Summary

Discussion with both Australian and overseas legal experts in this complex area have identified the wide variety of issues raised by the terms of reference. In the course of its deliberations it has become clear to the Committee that the judicial development of the common law lags to a significant degree behind medical and pharmaceutical advances. This situation was commented on by the presiding judge in the Eichner v. Dillon case, (concerning Brother Fox, who was 86 years old, life support dependent and irreversibly comatose after a cardiac arrest), who clearly stated that medical technology and the law do not advance in a parallel manner:

Technological advances in medicine have generally outpaced the ability of the judicial system to deal comprehensively with them in a manner consistent with the fulfilment of social policy objectives. Subjects that only 15 years ago were within the exclusive domain of such visionaries as Ray Bradbury, Arthur C. Clarke and Isaac Asimov - genetic combinations, microsurgery, transplantation of organs and tissues - are now very real, straining the traditional boundaries of the law. 68

This case law study indicates that decision-making is virtually a lottery with widely different outcomes and often confusing and indeed contradictory results.

The Committee considers that such issues as the refusal of medical
treatment must, in the light of rapid technological advances, be squarely faced by the legislature, and not be left solely to judicial decision.

2.5.7 Recent developments in the Netherlands

Introduction

Because of public knowledge, interest, and submissions to the Committee, the Committee's attention has been drawn to recent developments in the Netherlands.

Legal situation in the Netherlands

Voluntary euthanasia and assisted suicide are illegal in the Netherlands. Punishment for the former still carries a prison sentence of 12 years maximum, and the latter a sentence of three years.

In 1985, a government commission in The Hague recommended the Dutch Law be amended to allow euthanasia in cases where patients in acute distress make a voluntary, well considered request to doctors to be assisted to die. 69

Team discussion appears to be a prerequisite for avoiding legal prosecution. Those who practise it openly, at the patient's request and in consultation with nurses and priests, are not prosecuted.

Since 1973 the Courts have been actively involved in the euthanasia debate in The Netherlands, but only in 1984 was a euthanasia case brought before the Dutch Supreme Court. 70

Current practice

Voluntary euthanasia is currently practised in the Netherlands. The extent to which it is practised is not known. The Royal Dutch Medical Association (KNMG) states that 5-6 000 cases occur annually in Holland. (These figures include both active and passive euthanasia and assisted suicide). 71
It is viewed by those doctors practising it as an act of respect to an incurable patient. When it is in that patient's interest and at his/her request, they regard voluntary euthanasia as a dignified last act of medical care for a patient in the terminal phase of an illness.

**KNMG definitions and medical decisions**

The KNMG states clearly that euthanasia is the application of means or actions at a person's request to shorten life.

The KNMG details a number of medical actions taken that are not considered by them to be euthanasia in any form. These actions are considered to be appropriate medical decisions to terminate valueless treatment.

These 'appropriate medical decisions', defined by the KNMG, are:

(a) The termination, or as the case may be, the non-application of a treatment, which, in a medical sense is valueless. The physician is not guilty of negligence or maltreatment because he has no right to prolong life unnecessarily unless the patient requests it.

(b) Giving medical aid to relieve pain and suffering in the dying state, despite a secondary effect of accelerating death.

(c) The abstention from medical action at the request of a patient. The patient has the right to refuse treatment and the right to have treatment withdrawn on request. If death results, Article 293 of the Dutch Criminal Code of Law and imprisonment does not apply.

The question of action or non-action does not apply here because the physician is under no obligation to act in this situation, and does not have the right to act against the patient's wishes. 72
KNMG medical guidelines

Principles and requirements of the KNMG outlined as guidelines to be followed when any request for active assistance is being considered are:

(a) the physician is required to ascertain whether the decision is totally voluntary on the part of the patient without any pressure applied by family members,

(b) the request is to be considered very carefully by the physician only after every conceivable treatment option and the prognosis have been outlined clearly to the patient,

(c) further efforts are to be made to alleviate pain, fear or loneliness that may have formed the basis of the request. Impulse requests or temporary depression are not grounds for an agreement to euthanasia,

(d) every physician confronted with a request for euthanasia must consult with a colleague,

(e) upon declining a request, a physician is obliged to refer the patient to another colleague.

A practising doctor's views 73

Dr Admiraal from the Delft General Hospital in Holland believes every patient has the right to the truth regarding their prognosis and full information about all treatment options. In certain cases, euthanasia is discussed quite freely between himself, his patient and all staff members.

Many cases in which Dr Admiraal is involved are patients suffering from malignant diseases that can and do result in pain, suffering and distress. In addition, some experience less painful but very distressing complications such as respiratory difficulties, vomiting, oedema and gangrene.
The intensity of this pain, suffering and distress can vary from mild to agonising. Not all patients, therefore, are offered or request euthanasia. Dr Admiraal stresses that extensive experience with terminal patients is required by the physician as well as a very strong doctor/patient relationship:

On the one hand medical science gives us more and more possibilities of keeping the patient alive. But on the other hand one can well ask whether that is always in the best interest of the patient. Today a growing number of patients request a say in that matter. 74

All options need to be evaluated for every individual patient. Pain, real pain, is seldom the reason for requesting assistance to die. According to Dr Admiraal pain can and should be controlled:

'Pain' related to depression, fear and sorrow should be recognised as an alarm signal, indicating shortcomings in meeting the patient's needs. One can even say that a lot of this kind of 'pain' is the result of poor interhuman contact and of misunderstanding of the patient's situation. If this kind of patient would ask for euthanasia it would be medically unjustified to comply with this request. What the patient really asks for is maximum human and emotional support during the last phase of his life, as was already recognised decades ago in the United Kingdom by Dr Saunders at the St Christopher Hospice. 75

It is the suffering for 'a multitude of reasons' that prompts either the patient or Dr Admiraal to discuss the possibility of euthanasia. Dr Admiraal adds further:

(a) every patient has the right to ask for euthanasia,

(b) every doctor has the right to perform euthanasia,

(c) every doctor has the right to refuse,
the patient is the only one who can decide, the doctor and the family cannot make the decision for that patient. 76

Committee's comment

From the evidence available to the Committee, the legal situation in the Netherlands would seem to be as uncertain as anywhere else. That is, the practice is very different from the statute law. There has been no change in the law but decisions have been made not to invoke it.

2.6 Additional features of the inquiry context

2.6.1 Care of the dying

The Committee noted the concern expressed by some that the terms of reference of the inquiry do not appear to permit the investigation of provision of care for the dying and the development of hospice care.

The Committee's interpretation of the terms of reference is, however, that the Order of the Governor in Council invests the Committee with power to investigate and make recommendations to Parliament on these matters. Throughout the inquiry, the Committee stated in public on many occasions that the matter had 'been taken on board very strongly by the Committee'. 77,78 The Committee has visited several hospices and has made a number of recommendations in this area. (See Chapter Seven).

2.6.2 Resource allocation

The economic context in which this inquiry has been held, was an important consideration mentioned by many witnesses. A major consideration has been the efficient and effective distribution of health care resources between preventative, curative and palliative care areas within the health care system as a whole.
In connection with this issue, the Committee noted Director of the Walter and Eliza Hall Institute of Medical Research, Professor Sir Gustav Nossal's perspective concerning the necessary hard choices that must be made at an economic level:

... at least 70 per cent of the national health system's total $20 billion was spent on people who would never be cured.

Instead, emphasis should be switched from crisis treatment at the tail-end of disease to preventive and curative research, public health and education.

The saving would be billions of dollars ultimately. 79

Dr J. Epstein representing the Australian Medical Association indicated to the Committee that health care professionals responsible for the implementation of technological and procedural developments and making judgments about distribution of resources do not receive guidelines regarding community wishes about resource allocation.

Dr Epstein stated:

Billions of dollars are being spent and decisions are being made about where that money is being spent and the profession has hardly any guidance from the community about issues of social justice. If we are to get into questions of ethics, it is the ethics of social justice with which we are particularly concerned.

He added further:

We do not hear from the community whether it would prefer us to concentrate on the young or the old. We do not hear whether it would prefer us to spend more money on providing custodial or residential facilities for the elderly or on neonatal care facilities for premature infants. 80
On the other hand, the Committee received a considerable number of letters and submissions from members of the general public advocating a change in resource allocation from curative, invasive treatment to palliative care with a greater emphasis on treatment choices and family discussion. These submissions can be typified by Dr J. Buchanan, who told the Committee:

'Treatment' is assumed to be always aimed at cure, and assumed to be 'ethically mandatory'. Death is assumed to be the enemy. In fact, treatment of cancer, for example, is deliberately aimed at the goals of cure, or palliation, or symptom-control, whichever is appropriate for the stage of disease and patient wishes. What is required is Government promotion of more extensive palliative care services, and teaching of health professionals in the area of selection of the most appropriate goal for a particular patient. 81

2.7 Conclusion

The Committee has examined certain salient features relating to the context of the inquiry. Its investigations have revealed that there is clear public concern about the issues under investigation and, in addition, a large number of submissions welcomed the inquiry.

The inquiry has been conducted within a context of intense public discussion. This has been brought to the attention of the Committee by means of submissions from members of the general public; statements, evidence and submissions from interested groups, both religious and secular; and widespread comment within both electronic and press media.

The Committee's terms of reference require it to examine overseas developments and certain relevant features of experience overseas have been discussed. This chapter also examines relevant literature, legislation and judicial decisions relating to the major principles addressed by the inquiry.
Recent medical and pharmaceutical developments have, the Committee concludes, produced important implications due to the greatly increased technological capacity to sustain life. Health care professionals, the key players involved in the development of medical technology and procedures, are concerned about the legal, ethical and social dilemmas posed by such developments.

The Committee is deeply concerned about the efficient and effective distribution of health care resources, particularly in relation to the broad area of palliative care. It recognises that the increasingly scarce health dollar will be the subject of fiercely competing demands over the next decade. This issue is addressed further in Chapter Seven.

The Committee concludes that because the legislation surrounding these medical problems does not reflect modern technology and patient needs then, inevitably, too many decisions will devolve upon the judiciary, causing undue delay and suffering. The Committee addresses this problem in its recommendations in the ensuing chapters.
Footnotes to Chapter 2

5. Submission by Dr D. Brown, p.3.
9. Ibid.
11. Ibid.
12. Discussions with Mr Kilgour, 3.10.86.
15. The Sun, Tuesday, July 30, 1985, p.8.
17. The Sun, Friday, January 3, 1986, p.11.
18. The Age, Thursday, October 9, 1986.
20. Minutes of Evidence 2.3.87, pp. 1043-1044.
22. Submission by Royal Australian Nursing Federation, p.4.
23. Submission by Dr. H. Kuhse, p.7.
24. Ibid., p.3.
29. Ibid., p.24.
32. The appellant was the State Attorney for Broward County, Florida.
34. This duty might not exist in jurisdictions where suicide, and attempted suicide, are no longer crimes. It might be replaced by the duty to prevent the aiding and abetting of suicide.
37. 44 Misc. 2d. 27, 252 N.Y.S. 2d 705 (1962).
38. Ibid., 706.
41. Ibid., p.536.
42. Ibid., p.536.
43. Ibid., p.537.
47. Ibid.
48. Professor Annas, p.19.
51. Statement of the American Medical Association Council on Ethical and Judicial Affairs, March 15, 1986, Withholding or Withdrawing Life Prolonging Medical Treatment.
52. Eichner v. Dillon 73 A.D. 2d 431, 426 N.Y.S. 2d 517, 531 (Supreme Court, Appellate Division, 1980).
56. Glanville Williams, The right to die, New Law Journal, January 27, 1984, pp.73-76.
57. The Age, 23 April 1986.
61. Ibid., p.13.
63. Ibid., p.14.
67. Ibid., p.3.
71. Institute of Medical Ethics, Number II, February 1986, p.10.
74. Ibid., p.24.
75. Ibid., p.23.
76. Ibid., p.24.
78. See, for example, Minutes of Evidence, 28 July 1986, pp.796, 830.
81. Submission by Victorian Association of Hospice Care Programs, pp.2-3, prepared by Dr J. Buchanan.
CHAPTER THREE

TERMS OF REFERENCE (1) AND (2a)
'A RIGHT TO DIE'

3.0 Terms of reference (1) and (2a)

Terms of reference (1) and (2a) require the Committee: 'having regard to the greatly increased technological capacity to sustain life', to investigate:

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

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

3.1 Introduction

Both of the above terms of reference are addressed together in this chapter because the key issues outlined below are incorporated in, and relate to, both of them. Evidence received concerning such key issues is also presented below. The issues addressed include:

(a) the notion of a right - together with some discussion of the moral perspective, positive and negative rights, and rights and duties;

(b) the development of the notion of a 'right to die' to the notion of 'a right to die with dignity' - together with some discussion of the moral permissibility of forgoing disproportionate, extraordinary or burdensome treatment, the moral permissibility of the administration of analgesics which may incidentally shorten life, and the interpretation of the 'right to die' as 'euthanasia'; and
the common law right to refuse medical treatment - together with a discussion of the meaning of this right and certain problems arising from common law rights.

While witnesses were generally in agreement on the existence of this right there is little consensus on the practical consequences and implementation of such a right.

A number of practical issues raised by witnesses influencing an individual's entitlement to die peacefully with human dignity are then explored, including 'not for resuscitation' notices, the management of pain, and the role of advance declarations.

Evidence received regarding the distinction or otherwise between 'acts' and 'omissions' at the terminal stage of life is then presented.

The chapter continues with a report of a survey of public opinion in Victoria on the issues under investigation.

Finally evidence is presented from witnesses concerning the desirability or otherwise of legislation in the 'right to die' area.

3.2 \textbf{The notion of a 'right'}

The 'right to die' has proven to be one of the most contentious and difficult issues for the Committee to deal with in this inquiry, and has promoted extensive discussion of the notion of a 'right'. This dilemma is typified by Baroness Warnock, Mistress of Girton College, Cambridge, who chaired a British committee of inquiry into human fertilisation and embryos. In evidence to this Committee and commenting on the Committee's First Report, Baroness Warnock stated:

\begin{quote}
that it made me very much aware of the need in this area for public education, and, if one is going to try to introduce a new way of looking at it, how careful one has to be about vocabulary - the words one uses in decisions.
\end{quote}
That seems to be a great responsibility of yours, to use the words with great care, because as we all know people get extremely over-excited by words like 'kill' and so on.  

3.2.1 The moral perspective

The Committee has been aware throughout the inquiry of the moral perspective which underlies any discussion of the right to die. In the Committee's First Report Professor Max Charlesworth made this fundamental issue abundantly clear. While recognising the relevance of medical and scientific evidence to the issue, he writes:

*it can never be decisive in determining what is finally a question about the value of human life.*

He comments that:

*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.*

The issue of moral autonomy or self-determination is one that is taken up by a wide variety of witnesses. In their submission entitled "Protecting the Rights of the Seriously Ill in an Acute Care Hospital", the St Vincent's Bioethics Centre equated the right to refuse treatment with being able to control one's own integrity:

*The right to refuse treatment is a right in the sense of a freedom to control one's own integrity. It is not a right which makes a demand or places an obligation on others, but a right to be left alone, a right against interference. Thus it places a limitation on the activity of others, rather than an obligation on them to provide a service.*
In her submission to the inquiry, Dr H. Kuhse states:

Competent patients have interests, or rights, that go beyond well-being. They have, as many of the paper writers for the Committee's First Report agree, a right to bodily self-determination. This means that competent patients have interests not only in, say, being free from pain, but also - and more importantly - in self-determination [...] It is self-determination, I believe, which is central to the notion of what it is to be a moral agent or a person; to deprive a person of control over her own life - in an area where this does not cause harm to others - is therefore quite unjustifiable because it shows a most serious disrespect for that person. 4

Professor P. Singer argues that:

It would be absurd to suggest that... we should always do everything possible to prolong life, irrespective of the wishes of the patient, or the patient's closest relatives, or of the patient's prospects of leading a life which anyone could consider worthwhile. Quite apart from the cruelty and denial of autonomy which such a course would involve, the burden on our already strained health care resources would require substantial cuts in other areas which would be very difficult to defend. 5

He goes on to say that:

Where serious interests are at stake... the autonomy of the individual is a principle which must be respected unless there is clear evidence that the person is not fully competent to judge her or his own interests.

So who should decide on the life or death of a patient? If the patient is competent, there can be no doubt. It must be the patient.

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Of course there must be consultation. The doctor should discuss the matter with the patient and the patient's family. Nursing staff must be brought into the discussion, since they will often be more closely in touch with the patient's views, and they may - for instance in the case of a 'not-for-resuscitation' order - be the ones who actually carry out the decision.

3.2.2 Positive and negative rights

Fundamental differences about positive and negative rights were evident in the Committee's First Report. These are also evident in many of the letters received by the Committee.

The Voluntary Euthanasia Society of Victoria (VESV) submitted that the 'right to die' must, 'if it is to make any sense, refer to an individual's being able to choose when and how he or she will die'. VESV noted, as did other witnesses, such as the Right to Life Victoria and the submission by the Victorian Catholic Bishops, that there is an ambiguity that is initially present in all talk about rights. This is spoken of as positive or negative rights, or involving the interference or non-interference on the part of others. Disagreement stemming from this ambiguity was clearly evident in submissions to the Committee. The submission of the Catholic Bishops stated:

In any serious study of Rights, one must distinguish between Positive Rights and Negative Rights. When a person has a Positive Right to X, then someone else has a duty to provide him/her with X. When a person has a Negative Right to X, there is no corresponding duty on someone else to provide him/her with X, but only a duty not to prevent him/her obtaining or enjoying it; and in many cases, the Government has a duty to prevent others from interfering with the person's so doing.

For instance, the right of a child to school education is a Positive Right: it entails that the appropriate authority has a duty to provide such schooling. The right to free speech, on the other hand, is a Negative Right: it does not entail that the Government has the duty to
provide every citizen with a public address system, or time on radio and television: it entails only the duty not to prevent the person speaking freely.

A Positive Right to Die would therefore entail that someone else had a Duty to Kill. The Victorian Catholic Bishops reject this unequivocally. 7

On the other hand the Voluntary Euthanasia Society of Victoria comments that:

Many rights require more than non-interference on the part of others, but as well the positive facilitation by others of whatever it is to which the right-holder is entitled. It is a poor joke to say that individuals who are dying of starvation or thirst (not because of any choice of their own) have a right to life but to do nothing to enable them to exercise their rights - merely to leave them to their own devices is decidedly not a suitable way to acknowledge their rights. It is quite crucial to the concerns of the Inquiry that the right to die be understood as going beyond merely leaving people to their own devices, because those most likely to want to exercise such a right (to determine when and how they will die) will frequently be incapable of exercising it without the positive assistance or facilitation of others. 8

Concurring with the Bishops' interpretation that a person's positive right would necessarily impose on another individual a duty to kill, Drs J. and J. Santamaria elaborated this duty and the meaning for those involved:

If the principle that a person has the right to be killed is accepted in our society, it will be necessary to impose a DUTY on other members to comply with these provisions. It is obvious that this duty is to be placed on the medical and nursing professions, the majority of whom will not comply on conscientious grounds. It would be a travesty of their commitment to care for patients and it would destroy the basis of trust that should be nurtured between the professions and those who seek the skills and training of doctors and nurses. 9
3.3 The 'right to die' and 'the right to die with dignity'

The Committee found that, while opinions were divided on definitions of a 'right to die', there appeared to be considerable common ground as to what a 'right to die peacefully with human dignity' means, in a practical, everyday sense among the major religious and philosophical traditions in our community.

In essence, there appears to be common ground among these traditions that a dying person has a basic right to die with dignity. From a moral perspective such a basic right is comprised of two elements:

(a) that it is morally acceptable to forgo medical treatment which is 'disproportionate' or 'extraordinary' or 'burdensome'; and

(b) that it is morally acceptable to administer pain-killing medication with the intention of relieving pain and suffering, even though the medication may shorten life.

The following sections now examine some of the evidence presented supporting these two elements. The Committee notes that such support is offered from those with widely differing philosophical and religious perspectives.

3.3.1 Extraordinary, disproportionate or burdensome treatment

On 24 November 1957, in an address, entitled 'The Prolongation of Life', to the International Congress of Anesthesiologists, Pope Pius XII made the following statement about the use of extraordinary and burdensome treatment.

Natural reason and Christian morals say that man [and whoever is entrusted with the task of taking care of his fellow man] has the right and the duty in case of serious illness to take the necessary treatment for the preservation of life and health. This duty that one has
toward himself, toward God, toward the human community, and in most cases toward certain determined persons, derives from well-ordered charity, from submission to the Creator, from social justice and even from strict justice, as well as from devotion toward one's family.

But normally one is held to use only ordinary means - according to circumstances of persons, places, times, and culture - that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends. On the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more serious duty. 10

Commenting on the distinction drawn between ordinary and extraordinary treatment, the Dietrich Bonhoeffer Ecumenical International Institute for Bioethical Studies, Adelaide, in a submission to the inquiry stated:

The notions of ordinary and extraordinary treatment were originally introduced for the guidance of Catholic doctors by Pope Pius XII. As they were seen to be useful ethical considerations at the time, they were incorporated into general medical ethics. However, with time and the technological advances of recent decades, they have lost much of their value to ethical decision-making. This relates to the fact that the definition of what is ordinary and what is extraordinary varies considerably from time to time, place to place and from patient to patient. 11
Despite the passage of time and changing circumstances the Committee notes that many witnesses still preserve the distinction between 'extraordinary' and 'ordinary' treatment.

The Declaration on Euthanasia by the Sacred Congregation for the Doctrine of the Faith (5 May, 1980), approved by Pope John Paul II substituted the concepts of 'proportionate' and 'disproportionate means'. The Declaration states:

"It is also permitted, with the patient's consent, to interrupt these means, where the results fall short of expectations. But for such a decision to be made, account will have to be taken of the reasonable wishes of the patient and the patient's family, as also of the advice of the doctors who are specially competent in the matter. The latter may in particular judge that the investment in instruments and personnel is disproportionate to the results foreseen; they may also judge that the techniques applied impose on the patient strain or suffering out of proportion with the benefits which he or she may gain from such techniques.

It is also permissible to make do with the normal means that medicine can offer. Therefore one cannot impose on anyone the obligation to have recourse to a technique which is already in use but which carries a risk or is burdensome."

The Committee notes the continued use of the notion of 'burdensome' treatment.

In general, the Committee considers that the comment of the Honourable Bruce Chamberlain, MLC, in his submission to the inquiry fairly represents the broad view of witnesses who commented on this issue:

"Clearly there are circumstances which are widely recognised where prolongation of life may be deemed inappropriate and"
extraordinary. Decisions may be made not to prolong life as the means of prolonging life would be too burdensome in proportion to the benefits of treatment. 19

Submissions received from Christian Churches commenting on this issue, made a distinction between euthanasia, (generally condemned as morally wrong), and the morally acceptable decision to forgo useless medical treatment where the prognosis for the patient is hopeless.

The Committee has been advised of a number of religious perspectives on this issue held by non-Christian members of the community. Due to the multi-cultural nature of Victorian society the Committee made strenuous efforts to obtain and consider such views, and invited a number of non-Christian community representatives to provide evidence at public hearings.

In general, evidence indicated that the perspective outlined above was agreed to by traditional orthodox Judaism, conservative Judaism, liberal Judaism, liberal Islam, Buddhism, Taoism and Confucianism. However, evidence received by the Committee indicated a very different perspective on the part of orthodox Islam.

According to orthodox Islam, any act (other than capital punishment) which shortens the earthly and material existence of a person, by even one second, is contrary to its religious laws. It does not matter how burdensome or useless the procedure is, if it preserves the earthly and material existence of the human body, then the procedure must be maintained. The suffering and pain involved is not a justification, for, as Sheikh Fehmi el-Imam, an Imam representing the Islamic Society of Victoria, explained in giving evidence before the Committee:

... there is a purpose to every suffering which takes place around us in the world. Even in pain, there is a purpose that comes out of the suffering. 14

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Thus, orthodox Islam apparently does not allow any of the faithful to exercise their enforceable common law entitlement to refuse medical treatment. As Sheikh el-Imam explained to the Committee:

No person has any right to refuse medicine. He has to take the ways and means to cure himself. If he does not, he is falling into sin and subjecting himself to unnecessary consequences. He has to take medicine so he has to take ways and means. Maybe it will cure him, or not; but that is the condition on him. 14

3.3.2 Use of pain-killing medication

In the address to the Congress of Anaesthesiologists referred to in 3.3.1, Pope Pius XII also made his position clear on pain-killing medication used with the intention of relieving pain even though such use might incidentally shorten life. In response to the following question:

Is the suppression of pain and consciousness by the use of narcotics [...] permitted by religion and morality to the doctor and the patient (even at the approach of death and if one foresees that the use of narcotics will shorten life)?

Pope Pius XII declared:

If no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties: Yes. 15

The Declaration on Euthanasia of 1980, quoted in Section 3.3.1, takes a similar approach. Concerning the administration of analgesics to terminally ill patients to relieve pain and promote comfort even though they may incidentally be the clinical cause of death, the Declaration states that although:
... some Christians prefer to moderate their use of painkillers, in order to accept voluntarily at least a part of their sufferings and thus associate themselves in a conscious way with the sufferings of Christ crucified (cf. Mt 27:34). Nevertheless it would be imprudent to impose a heroic way of acting as a general rule. On the contrary, human and Christian prudence suggest for the majority of sick people the use of medicines capable of alleviating or suppressing pain, even though these may cause as a secondary effect semiconsciousness and reduced lucidity. As for those who are not in a state to express themselves, one can reasonably presume that they wish to take these painkillers, and have them administered according to the doctor's advice. 16

The 1983 statement by the Church of England takes a similar stance, stating that it is morally permissible for medical practitioners to provide analgesics to terminally ill patients even though the provision of such medication may incidentally shorten life:

> There is in all medical treatment a degree of risk to the patient which has to be assessed in relation to the good which it is hoped to achieve. When the patient is in the terminal stage of a fatal illness and there is no longer any hope of a cure or of a worthwhile alleviation of the disease, the good to be achieved is his comfort and peace of mind. The appropriate treatment is therefore good nursing care and the use of pain-killing drugs where necessary. 17

The Rev. Dr John Henley argues that:

> By clearly making human intention paramount, this formula [sc. 'only caring for the dying'] 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. 18

Such a position is in accord with that put before the Committee in submissions received from other Christian Churches. They were all clearly concerned about patients dying in unnecessary pain, and strongly support the use of painkillers. They believe that many demands for euthanasia arise because a significant number of patients die in unnecessary pain, and if that pain was relieved totally, the demands for euthanasia would not arise. (See Section 3.5.2 and Chapter Seven).

The Catholic Archbishop of Melbourne, The Most Rev. Dr Sir Francis Little, in a comment on the Declaration on Euthanasia issued by the Sacred Congregation for the Doctrine of the Faith, states:

With admirable clarity and deep sensitivity, the document speaks both of the meaning of suffering for Christians and the use of painkillers. It recognises that if no other means exist, and if, in the given circumstances, the action does not prevent the carrying out of other religious and moral duties, the use of narcotics for the suppression of pain and consciousness is permitted by religion and morality to the doctor and the patient (even at the approach of death and if one foresees that the use of narcotics will shorten life). 19

In their submission to this Committee, the Victorian Catholic Bishops state that in such a situation the administration of analgesics to patients is
morally permissible because:

the doctor or nurse is administering pain-killing drugs with the intention precisely of killing pain, but foresees that the level of drugs necessary for this may very well cause death. The intention is to kill the pain, not to kill the person. Death is a foreseen but unintended consequence. The doctor or nurse would have achieved the objective if the pain was stopped and death did not ensue. If very bad pain could be assuaged only by that level of drug, the person who administers it should not be held guilty of wrong-doing. Where however the intention is to bring about death, or intentionally and importantly collaborate in bringing about death, one should be held guilty under the law for violating the inalienable right to Life.

3.3.3 The 'right to die' and euthanasia

Submissions to the inquiry and witnesses at public hearings provided a wide variety of interpretations and definitions of the notion of a 'right to die'.

Sometimes the notion was equated with suicide; on other occasions it was employed as a synonym for the right of patients to refuse medical treatment where their condition is diagnosed as terminal, and where they wish to die naturally (i.e. without the use of intrusive life support equipment) and in comfort. Some claimed that the phrase was a euphemism for euthanasia and mercy killing.

Louisell in the Catholic University Law Review defines 'euthanasia' as follows:

In its precise meaning, 'euthanasia' is the desideratum of religion as well as any morally or ethically based social policy that has to do with death. Coming from the Greek words meaning 'good' and 'death', it specifies the kind of a death that must be as much the ideal of the moral theologian as it is of the philosopher and secular humanist—a happy death. Yet
its corruption seems pervasive in popular usage. It has come to mean the deliberate, intended painless putting to death of one human person by another, the willed termination of human life, which is a euphemism for murder as defined by our law. It would have been better to adhere to the original meaning of 'euthanasia' and use another word, perhaps 'biathanasia' for deliberate, affirmative killing in the mercy-death context.21

The Oxford English Dictionary provides a number of definitions of the word 'euthanasia':

1. A gentle and easy death.
2. The means of bringing about a gentle and easy death.
3. In recent use: The action of inducing a gentle and easy death.

Used esp. with reference to a proposal that the law should sanction the putting to death of those suffering from incurable and extremely painful diseases.

As Louisell points out, the word 'euthanasia' in its modern usage, is now used in the sense of the third definition in the Oxford English Dictionary.

The Committee concludes that the meaning of 'euthanasia' is quite distinct from the notion of a religious or moral right to die with dignity. This is further discussed in section 3.6 below.

3.4 Common law right to refuse medical treatment

3.4.1 Introduction

The Committee received legal evidence that every person has an enforceable legal right at common law to refuse medical treatment. It derives from the right which every person has not to be unlawfully subjected to assault or battery (see section 2.4.2).

The common law right of a person to refuse medical treatment is not, however, an absolute right. In this respect it is like most other rights, since
there are few, if any, rights which are recognised by the law as absolute. Even the 'right to life' is not absolute, since the Parliament could, at any time, enact legislation providing for the lawful killing of human beings where they have been convicted of certain offences (e.g. murder). An exception to the right to refuse medical treatment may occur when the public interest is adversely affected, for example, if a criminal offence will be committed, or an innocent third party, or the public generally will suffer if the right is upheld.

However, in general, a medical practitioner, or other health care provider, who treats a patient against the express wishes of the patient may be liable in a number of ways:

(a) **Civil proceedings**

1. The patient could sue the medical practitioner or nurse for assault.

2. If the medical practitioner or nurse intentionally or negligently applied any physical force to the patient (clearly, surgery could come within this), then the patient could also sue them in a civil action for battery.

(b) **Criminal proceedings**

3. The patient could also report the matter to the police, in which case the medical practitioner or nurse could be charged under the criminal code with, and possibly convicted of, the offence of assault.

4. Finally, where actual physical force had been applied to the patient, the medical practitioner or nurse could also be charged with, and convicted of, the offence of battery.

Advice was received indicating that it is always open for a patient to discharge himself or herself from the care of the medical practitioner and then go to a medical practitioner who would respect the patient's wishes.
The Committee remains well aware, however, that the above analysis of an important legal concept is divorced from the realities of a person in extremis. The Committee rejects as cynical and unrealistic, proposals which suggest that persons in the final stages of unendurable pain can discharge themselves from the care of a practitioner and engage in a hunt through whatever means may be available, for an alternative practitioner who will respect their wishes. Evidence in Chapter Two illustrates the lack of practicality involved in such suggestions.

Upholding the status quo and interpreting the existing common law right to refuse treatment as being synonymous with moral autonomy or self-determination, Mr Kevin Andrews, LLB, in The Knights of the Southern Cross submission states:

*Patients do have a right to control their own treatment. The common law always has held that a person has a right not to be touched without his or her consent. For a doctor to ignore this right is an assault. Unfortunately, the passive attitude and possible ignorance of many patients may have led this principle to have been obscured.*

Eight of the major submissions received from those opposed to any legislative change agreed with this. It was, however, very clear to the Committee that an overwhelming proportion of all witnesses and submitters were either unaware the common law right to refuse treatment existed, or were confused about what it meant, or its purpose, or the context in which the common law right to refuse treatment could be exercised.

The Committee is particularly concerned about a general lack of knowledge or information in the community about their rights in this area, especially at a time when they are most likely to be vulnerable, i.e. towards the end of their life, especially at the end of their life. In specific circumstances, particularly those related to dying, many people feel powerless to refuse treatment or even to disagree with their medical practitioner. Evidence indicates that some people are intimidated, not only by the system, but also by their own circumstances.
The Committee strongly endorses the entitlement of all patients to refuse any treatment. It is a central issue in the inquiry and provides the driving force behind many of the Committee's recommendations.

3.4.2 Witnesses' views on the right to refuse treatment

In their evidence to the Committee, some witnesses equated the 'right to refuse' treatment with a 'right to die', hence negating the need for right to die legislation.

For example, in their submission to the inquiry, St Vincent's Bioethics Centre stated:

In legal theory and in hospital practice, as we have outlined it, patients have a right to refuse treatment and hence have a 'right to die' in the sense that they can refuse life-prolonging treatment. 23

These comments were endorsed by Rev. Father Daniel, Lecturer in Moral Theology:

The basic right at stake in this area is the right to refuse medical treatment. In law the competent patient has a complete liberty in this respect. In morality this right knows only the limit of reasonableness: it is reasonable to refuse a treatment that is futile or one that is unduly burdensome for oneself or others. A 'right to die' in this sense says no more than the right to be left alone. This right is there in our law already, and so any talk of a 'right to die' is unnecessary.

I would regard legislation embodying a 'right to die', even in a morally acceptable sense, as misleading and futile. It would be misleading inasmuch as it would suggest that doctors need somehow to be authorised to do what is their professional duty already, namely to respect the wishes of patients, and not to institute or persevere with treatments that are useless or excessively burdensome. It would be futile inasmuch as the law is a clumsy instrument for regulating such finely judged decisions, and it would be incapable of preventing the occasional episode of therapeutic officiousness. 24
The Royal Australian Nursing Federation also agreed with this principle:

*Modern medicine has too often aimed at keeping people alive at all costs without considering the quality of life or dignity of the individual as he or she determines.*

*It logically follows that if the dying patient has the right to refuse treatment, such as artificial measures to prolong life, he/she has the right to die.*

### 3.4.3 Right to refuse treatment in practice

Outlining a major confusion regarding this common law right in current medical practice, St Vincent's Bioethics Centre submitted that in a well publicised case, the late Mr John McEwan's right to refuse treatment appeared not to have been respected:

*Mr McEwan had a legal and ethical right to refuse medical intervention.*

*Secondly, his decision to refuse treatment in the circumstances was morally justifiable. The treatment, particularly the catheterisation of his lungs, was particularly burdensome for him and intrusive; no-one should be obliged to go to such lengths to prolong his life.*

*The apparent difficulty for the treating personnel was that to simply withhold treatment would have caused him great suffering. To then apply pain-relief measures might have contributed to his death.*

*We see no moral problem with such a course provided that the intention was to relieve his suffering rather than to bring about death. It is often the case that medical treatments have undesirable side-effects, but there is no moral or legal culpability for applying them provided that the harmful side-effects are not disproportionate to the benefits.*

*Nevertheless, we can understand the reluctance of a doctor to pursue such a course of action when it could be readily misunderstood as a deliberate attempt to bring about death.*
The Committee sought to obtain further information to clarify the situation
in this particular case regarding refusal of life-support treatment.
(Appendix I).

Once home, John McEwan was found to be fully cognisant of his condition,
his treatment and prognosis. Dr J. Toscano, the treating home visiting
physician told the Committee his legal advice from the Medical Defence
Fund was that by not reconnecting John to the ventilator, he would be guilty
of a major charge, i.e. assisting John to die.

Dr Toscano outlined his position further to the Committee:

MRS RAY: Could I clarify the situation of the
difference between John McEwan and people
who are terminally ill? I think you said that
because he was not suffering from a condition
that would lead to his death, your legal
position was different?

DR TOSCANO: That is right. If I had a
patient with a terminal illness who, say,
needed dialysis, I would explain the situation
to them and say that if they have a carcinoma,
society respects that person’s right to receive
treatment or not to receive treatment such as
chemotherapy but in John’s situation where he
has a reasonable life expectancy, maybe
another 20 or 30 years with technology, it is a
different matter. There is no fixed end point.
If we intervene, there would be a fixed end
point.

MRS HIRSH: You are saying that the law
differentiates between types of technology
that can be refused by a patient?

DR TOSCANO: I do not know if it is in law
but...

MRS HIRSH: But you believe the law
differentiates? You appear to have that
belief.

DR TOSCANO: I do appear to have that belief
because if the area was clear, the Austin
Hospital spinal injuries unit would be in a
position of terminating John’s treatment in the
Austin Hospital. He was an in-patient there
for over ten months and on a number of
crances he expressed his desire for the right
to die. They felt they could not do that
because they were in a legal grey area and eventually he was discharged home and I was lumbered with the problem. 27

Dr H. Kuhse has pointed out that we need to ensure that inevitable life and death decisions have a sound ethical basis:

_We need to ensure that medical decision-making is properly centered around the rights and interests of those who are most affected by the decisions: the patients. At the moment, much depends on the often idiosyncratic views of individual doctors or institutions. This is quite clearly most unsatisfactory when decisions of such magnitude are at issue._

_The fundamental question, then, becomes: on what ethical principle or principles should life and death decisions in the practice of medicine be based? Who should make the decisions and how are they to be implemented? But these questions, I suggest, cannot properly be discussed until and unless we give public recognition to the fact that these life and death decisions are already being made and that they must always be made._ 28

A number of witnesses to the Committee confirmed that, sometimes as a result of human intervention, but more often as a result of a lack of human intervention, decisions are being made regarding a patient's death. The Committee acknowledges that such decisions are already being made, and inevitably must be made in the modern medical setting.

As the above quotation indicates, many witnesses referred to a fundamental question inherent in the modern hospital context. The question is not whether to allow people to die, but rather who makes these decisions.

Such decisions may be made on important medical grounds, but many witnesses and members of the general public who wrote to the Committee question whether that is the correct, or most appropriate focus for those decisions.
Commenting on some of the contributions to the Committee's *First Report* about the crucial question of *who* makes these decisions, the Humanist Society of Victoria stated:

*Physicians seem to agree amongst themselves that the decision on the matter of passive or active euthanasia should be left for the physician to decide.* Professor Max Charlesworth suggests that these matters must remain problems of ethics and morals and the individual patient must make such decisions. Jenny Gibbs also argues for the right of the individual and advocates for the patient's right to decide although disagreeing with active euthanasia. Sir Gustav Nossal throws the ball back to the judiciary and declares his adherence to the case law. The Hon. Justice Kirby, whilst stating that if pressed the common law system can find an answer to this problem, but he himself would like to hear this problem addressed by theologians, scientists and philosophers. So we are going round and round, all the spokespeople of these disciplines are afraid to commit themselves, to this - no doubt - immensely difficult problem. 29

The Committee has been left in no doubt that decisions about the termination of people's lives are being made daily in a variety of situations throughout Victoria. The Committee has observed intensive care wards, terminal cancer wards and geriatric centres, also it has held extensive formal and informal discussions with a wide range of care-givers and patients including the late John McEwan. It is also well aware of procedures sometimes called 'not-for-resuscitation' (see Section 3.5.1) in place in some health care institutions. The lack of public discussion of such procedures, and the indications of confusion among many medical practitioners concerning the right to refuse treatment is of particular concern to the Committee. The Committee emphasises that such confusion is, to a considerable degree inevitable when dealing with common law rights.
3.4.4 Incompetent patients and their right to refuse treatment

Incompetent adult patients and incompetent minors have the same rights as competent persons. Problems arise in exercising these rights. Because of their incompetency:

(a) they may be subject to the provisions of certain statutes such as the Mental Health Act 1986 (when it is proclaimed; until then the operative Act is still the Mental Health Act 1959), the Guardianship and Administration Board Act 1986, or the Community Welfare Services Act 1970; and

(b) the decision to institute civil proceedings is usually made by the parents or guardian of the minor or by the guardian or next of kin of the incompetent adult. Proceedings in the Supreme Court would be instituted by the person appointed as the incompetent's litigation guardian.

The exercising of the rights of incompetent patients is dealt with in Chapter Six.

3.4.5 Parents and children

Where a child is incompetent (i.e. the child is not capable of understanding the nature, consequences and risks of the proposed medical treatment or non-treatment, and who is therefore, incapable of consenting to, or of refusing, medical treatment) the duty devolves upon the parents or guardian to authorise or refuse medical treatment for their children. The exceptions are that a blood transfusion can be given to a child without the parents' consent under s.24 of the Human Tissue Act 1982, and, at common law, a medical practitioner can provide medical treatment to a child without the parents' consent in an emergency situation.

Apart from the legal context, there is clear evidence that many terminally ill children have clear views regarding their treatment. The committee understands good medical practice involves the treating medical practitioner to give effect, as far as is practical, to the child's wishes.
The Committee endorses this practice. (Refer to the 'Webster Report' below in Section 7.5).

3.4.6 Suicide and the right to refuse medical treatment

The Committee received evidence of uncertainty on the part of some, as to whether a patient who refuses medical treatment in certain circumstances is, in fact, committing suicide. Some people, including medical practitioners who testified before the Committee, believe that to refuse certain treatments would be to commit suicide. The Committee finds this view is inconsistent with the legal definition of suicide. Essentially, the elements of suicide are similar to those of murder, except that the killer is also the victim. The common law elements of suicide state that four elements of suicide must be satisfied before an act can be deemed to constitute suicide at common law.

The principles are:

(a) the person who intends to commit suicide must actually die;

(b) the killer must deliberately intend to kill himself or herself;

(c) the person must have caused his or her own death; and

(d) the first and second elements must happen at the same time.

Taking these principles into account, a competent adult Jehovah's Witness, for example, who refuses a blood transfusion which will save his or her life, is not committing suicide.

Similarly, a competent adult person who refuses artificial life support equipment which cannot cure, and which causes the person to experience strain and suffering, is not committing suicide. Indeed, that person may very much desire to be made healthy again. But they may wish to let nature take its course when medicine no longer has anything to offer except to prolong the strain and suffering which that person is experiencing. The
Committee notes that to die of a pre-existing illness or condition which cannot be cured does not constitute suicide. Rather, a person is merely exercising their common law entitlement to refuse medical treatment.

Thus, the Committee concludes that there is a clear distinction between suicide and an individual's enforceable right at common law to refuse medical treatment.

3.5 Practical issues

3.5.1 'Not For Resuscitation'

Evidence was presented to the Committee of the existence of a procedure within hospitals which was variously labelled, but which may be broadly described as an attempt to prevent pointless suffering. Such a procedure has been called 'NFR' or a 'Not For Resuscitation' notation.

In the Committee's First Report Dr Kuhse comments that:

> 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. 30

Mr Joseph Pavone adds further information:

> There are circumstances however, where prolongation of life may be 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 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. 31

'Not for resuscitation' (NFR) or 'no-code-decision', 'code blue', or whatever the heading used, is an increasing dilemma. The Committee finds it most disturbing that no guidelines, uniform or otherwise, appear to exist in Victoria in this area. It appears that in many cases covert procedural mechanisms are currently used to allow hopelessly ill people to die. Evidence provided through extensive discussions with health care professionals, indicated clearly to the Committee that most medical practitioners at present are loathe to indicate in written notes in patient records that a patient is not for resuscitation. Coloured dots, slow codes or verbal communication between staff members are procedures often used.

The Royal Australian Nursing Federation expressed deep concern to the Committee about this issue:
MRS HAMILTON: I am not sure whether the NFR issue - not for resuscitation - is one which you could actually bring to public notice. In any hospital there is a system, an informal system, as one of the inhibitions that exist, that this cannot be more formal, where patients are coded NFR in an informal way. It cannot be done formally because doctors fear litigation if it is done in the histories, and they will not put down a statement of fact, or an opinion, about the state of the patient. This leads to a situation where, in the event of a sudden episode, people will be resuscitated against their wishes, or inappropriately it may be an elderly ill patient and there is this sudden event, and the policy of resuscitation is strong in every acute setting that I know of. Junior or inexperienced people may call a Code Zero, and before you know where you are, you have got 80-year-olds being resuscitated, or terminally ill patients being resuscitated.

MISS MILLERSHIP: Can I just interrupt there. It is not even a sudden occurrence. If somebody has been deteriorating over days, there appears to be an obligation for people to resuscitate that patient when they stop breathing or their heart has seemed to have stopped. This causes nurses, in particular, a great deal of concern for two reasons. One, because they know from the knowledge of the history that resuscitation measures are not going to assist this patient's quality of life, or prolong their life more than a few hours in some instances. Secondly, one of the beliefs that nurses hold, and we believe that the patients and their relatives have the right, is that if relatives want to they can be with a patient who is dying. That is a very difficult situation if in the midst of this somebody is going to say a patient needs to be resuscitated at the end of their life because relatives have to be removed from the scene. You cannot have them there. It is an unpleasant process, that of resuscitation, it removes relatives. We believe from some patients that have been resuscitated that it is not the best experience to go through, some of them would not want to go through it, but there is uncertainty within the hospital system about resuscitation.
measures. If you go around hospitals and you know what to look for, one may find little stars or little crosses, or whatever the ward sister determines is an appropriate thing to communicate to her staff that this patient is not for resuscitation. But, in fact, if you said to the doctor, 'Could you indicate to me that this patient is not for resuscitation', he will not do that because the doctors believe they are open for litigation. I believe this is an untenable situation in our hospitals because if you forget to put the sticker there, or it falls off...

MRS HAMILTON: You would have nurses running slowly to push the button which is ridiculous.

MISS MILLERSHIP: Yes.

Dr R.P. Evans, Medical Director of Dandenong and District Hospital, approached the Committee to discuss Cardio-Pulmonary Resuscitation (CPR), a 'long-term problem area' currently being addressed at the hospital.

The medical and nursing staff at the hospital have expressed concern about the performance of CPR, an extremely traumatic procedure for all parties, in some instances where it appears to be inappropriate for a particular patient. The Committee was informed that on a certain recorded signal CPR-trained nurses and doctors resuscitate a collapsed patient - often without full knowledge of that patient's clinical details. As a consequence, people who should not be resuscitated because of their clinical condition, are resuscitated.

Because of such difficulties, and having taken advice, the hospital Medical Advisory Committee is considering draft instructions outlining CPR guidelines and instructions. A copy of the draft instructions is included in Appendix G.

The Committee investigated this issue in depth since both the extent of this practice and also the procedures involved were unclear. The Committee
concurs with the submission of the Humanist Society of Victoria (HSV) that community discussion and involvement is necessary for the application of appropriate guidelines:

While it is recognised that assisting people to die is an accepted practice in certain circumstances in medical care, the guidelines that apply, most obviously in Not For Resuscitation cases, have not been subject to community view, and it appears that there may be considerable variations from one institution to another, or even from one practitioner to another. 34

The Committee considers that while some may describe such notes on the patient's record as 'humane medicine' or an aspect of 'good medical practice' such procedures should be the subject of community discussion and scrutiny. The Committee notes the position of the HSV:

As part of public debate, the HSV seeks the release of all such [NFR] guidelines and sees the review and recognition of current practice as an important contribution to the development of legislation. Current practice should provide a useful basis for reaching a commonly accepted set of standards and practices that could be incorporated in legislation. 35

To illustrate the dilemmas currently experienced, an actual case study, submitted by the Austin Hospital, is outlined below:

Mr X was a 78 year old gentleman who was admitted to our ward area, as an emergency admission via casualty. This was to be his third admission to the Unit, presenting with a provisional diagnosis of Transitional Cell Carcinoma of the Bladder, with metastatic spread to the lungs, liver and spinal cord and brain. His presenting problem for this admission was urinary retention. In casualty he had been examined by the unit's Resident Medical Officer, who ordered that a long-term urinary catheter be inserted into Mr X's bladder in order to alleviate his problem of urinary retention.
Upon admission to our ward area, I observed Mr X to be a lethargic, frail gentleman who had lost a good deal of weight from the time of his second admission. He appeared to be suffering from a greater degree of pain and was somewhat disorientated as to place and time. He stated that he had long lost his appetite for food and occasionally suffered from bouts of nausea and vomiting. From this observation, it was apparent to me that Mr X's disease process had insidiously created a decline in his overall well-being, to a point where it had now affected his quality of life.

Upon consultation with the Unit Resident Medical Officer on Friday morning, it was stated that Mr X had now reached the terminal stage of his illness and short of keeping his pain under control, maintaining a viable catheter (urinary), attending to his physical needs, thereby keeping him comfortable until his impending death, there was not a great deal more that we could medically do for him. At this time a decision had not been reached by the Unit that if Mr X's condition was to deteriorate further and he should arrest, as to whether or not we should instigate an emergency resuscitation procedure.

On Friday evening, the nurse in charge of the shift had been discussing with Mr X's relatives, with regard to the decline in Mr X's condition. His relatives were distressed over the deterioration they had observed over the past few weeks in Mr X's condition and well-being. At this time they emphatically expressed their wish that should Mr X arrest while in hospital, they in no way wanted an emergency procedure of resuscitation performed on him, and wished for him to be allowed to die peacefully with a degree of dignity assured.

Over the period of Friday evening, Mr X's condition continued to deteriorate. His pain had increased to the extent whereby he was being administered 10 mg of intramuscular morphine every four hours, along with a 30 mg proladone suppository on a TDS regime, in order to keep his pain under control. By ensuring ongoing quality nursing care, he was kept as comfortable as possible.
Late Friday evening Mr X requested to speak to a Hospital Chaplain. This opportunity was made available by paging the on-call Chaplain. After talking to the Chaplain, Mr X requested that should he die that evening he had no wish to be actively resuscitated and would prefer to die peacefully. The Chaplain relayed this request to the nursing staff.

On Saturday morning, when I was in charge of the ward, I observed that Mr X's condition had deteriorated significantly overnight. I then contacted the covering Resident Medical Officer, requesting that in view of Mr X's decline in condition and his wish not to be resuscitated should he arrest, I would like him to come and medically examine Mr X, in order that we could formally establish that Mr X would not be for resuscitation. The doctor examined Mr X, and agreed that he should not be for cardio-pulmonary resuscitation. However, he also stated that he could not instigate that decision until Monday morning, until he had consulted the Registrar and Consultants of the Unit, thereby allowing his decision to be reached as a team decision. On this note, Mr X was still for resuscitation should he arrest, in spite of his and his relatives' wish to allow him to die with peace and dignity.

Over the next 24 hours, Mr X exhibited a further dramatic decline in his condition. All nursing measures were maintained to ensure that his physical needs were catered for. Unfortunately at 5 p.m. on Sunday afternoon, at the time when his relatives were visiting him, he sustained a cardiac arrest. In view of the fact that the covering Resident Medical Officer had requested that he should be resuscitated until discussed with the unit on Monday, an immediate CODE ZERO, full-blown resuscitation procedure was instigated, much to the distress of his relatives who were ushered to our interview room. After 20 minutes of active resuscitation, with no positive outcome, Mr X was declared to be clinically dead. His relatives who had been informed of Mr X's death, were distraught about this and even more so about the fact that Mr X had been resuscitated both against his and their wishes. They expressed their anxiety that Mr X had not died with a degree
of dignity as a consequence of this resuscitative action instigated. The Chaplain was notified in order to console these distressed relatives.

In my opinion this case study demonstrates the dilemmas encountered in attempting to allow a patient to die with dignity. I feel that if a patient's life is in the balance as a result of a terminal condition, close consultation with the patient concerned, his relatives, nursing and medical staff should take place, in order that we can establish whether or not the patient has a wish to be actively resuscitated. By doing this we enable patients the opportunity to determine THEIR destiny. We therefore, respect THEIR RIGHT as to what DEGREE OF DIGNITY they wish to die with.

In the instance of this case study, I believe that both Mr X and his relatives' decision of not wanting him actively resuscitated, should have been respected. The covering resident medical officer should not have allowed this decision to 'RIDE' until Monday, when it could have and more than likely would have been instigated after consultation with the treating unit. As a direct consequence of this indecision Mr X's relatives are left wondering as to the injustice of actively resuscitating Mr X - thereby negating an elementary human right of wanting to die with a degree of dignity. The Committee is in agreement with the views of witnesses that decisions to allow hopelessly ill, suffering human beings die naturally is a profound act of compassion. Such decisions are morally appropriate with the deepest respect for life. The Committee finds that good medical practice not only encompasses a duty of care, but also requires ongoing discussions with the patient and/or the family in the formulation and implementation of clear not-for-resuscitation policies and guidelines, whenever possible.

Evidence to the Committee indicates a lack of clarity as to the legality of NFR codes. It concludes that more or less covert procedures such as not-for-resuscitation notices must be subject to public discussion and scrutiny.
3.5.2 Pain management

Many letters to the Committee indicated that fear of pain and lack of pain control is an area of considerable concern for many people. Frequently such fears were fuelled by uncontrolled pain experienced by a member of the family when dying.

As letters indicated, people watched their family members die painfully, suffering a great deal:

To see your loved one in serious pain, incontinent, just bones strung together with skin, hollow eyes, no teeth, suffering 24 hours a day, appealing to go on to her Maker - is a most terrible experience - neither of us being able to do anything. 37

The issue of pain management was, therefore, of great concern to the Committee. However, throughout the inquiry, the Committee continually received contradictory evidence about and experiences of pain management.

On the one hand, witnesses told the Committee that not only do a vast majority die without pain but those who request assistance to die because of the pain and suffering experienced, are really asking for love and support.

Letters received by the Committee, typified by the letters in Chapter Two, indicate people do experience pain and/or suffering when they die - pain that was apparently uncontrolled, or uncontrollable.

Others gave evidence to the Committee that because of advances in techniques, methods of pain control and the availability of a range of drugs, pain can and should be controlled.

For example, Dr R. Redpath, who has cared for hundreds of cancer patients in both the UK and Australia, clearly outlined the situation to the Committee:
I believe it has already been said by the previous witness that severe pain in the vast majority of cases can be controlled in situations in which the medical profession have informed themselves on this and those methods are used by the nursing staff and the junior medical staff who have training in that area also.

I have just come from the Dandenong Hospital having seen a patient to whom that was not happening. I called the junior doctor to my side and told him how the situation should be handled and I expect tomorrow the pain will be adequately controlled but it was not controlled this morning. This is the kind of palliative care that physicians can use but in the vast majority of cases in this city patients are not cared for in this way. 38

Dr Redpath added:

For whatever reason, it is inbuilt in the hospital system that the dangerous drug cupboard, that was present long before the worry about drug addiction, is locked at all times and the key placed in the hands of a particular responsible person. That was the situation when I did my training and has been inculcated into everybody in the medical profession, that morphine is dangerous.

Morphine is not dangerous to patients who have pain. Cancer patients who are in chronic pain need chronic pain control and the most often drug available is morphine.

The inhibitions that have been built up about the danger of morphine have been present for a long time. It is something we must come to grips with. I have been fortunate in that I have learnt about this and I hope to share that knowledge with other people. I see education as one of my main roles in this area. I cannot get on the phone and tell a general practitioner that he must do this but I can, by my example, show him how it can be done so that he has the confidence to do it and is not so frightened about it with the next patient that comes to him.
Patients who have pain do not become addicted. If the pain disappears and the morphine is stopped, the patient may have some physical withdrawal in the initial stages but the patient does not get hooked on morphine. That is the message we must get across to doctors. That education must start in medical student and nursing training days. 39

On the other hand, the Committee received alarming evidence of chronic pain being allowed to remain uncontrolled because of a reluctance to prescribe narcotics that would control the pain, but created anxiety for the treating medical practitioner who was concerned about drug dependency:

DR. HEMINGWAY: I know of one 80-year-old lady who has had a wretched disease for many years and has had multiple complications on top of that. We have run out of pain-killers because they no longer have any effect and we cannot give narcotics, which is a real problem.

MS SIBREE: Why can you not give narcotics?

DR. HEMINGWAY: Because she will be hooked on them. I have been caring for the lady for five years and it would be horrific if she were on doses of narcotics. I had one patient for three or four months who was on a significant amount of morphine every day. For every 20-odd injections I had to write for an authority from Melbourne. Just because of the paperwork, it can be difficult satisfying people from the drug dependence unit who were worried about having these large doses of narcotics. If patients are to die, it does not matter that they have them for a short time, but it is different for people with arthritis or crook backs who go on and on.

I had another luckless fellow who had cancer of the tongue which was irradiated. He also had radiation necrosis in the back of the mouth. He swallowed palfium which was prescribed by the Peter MacCallum Hospital over a long period and took up to 100 tablets every two or three weeks.

A private practitioner can get only 20 palfium tablets on a prescription and must write to the Health Department Victoria to get more. This
fellow would go through more than 20 tablets in a week and he would come back knocking on my door. I know people from the drug dependence unit were aware of the situation but mostly he got them from the Peter MacCallum Hospital, sometimes in the hundreds.

That is a serious problem because on the one hand we have a dependent patient who comes back looking for more of the same thing and the drug dependence unit is upset, on the other hand, because we are overprescribing these things. That is another good reason why one would not put chronically-ill patients on narcotics, apart from the fact that, as I stated in my submission, drug dependence is another problem that they can do without.

It is very clear to the Committee from this evidence, that whether the patient is crying out for love, support and comfort or asking for active assistance, pain is not being adequately and consistently controlled. A need exists for more uniform effective pain management to be an integral part of generally available health care and not just provided by specialty institutions such as hospices.

Education about, and an understanding of methods and techniques of adequate, effective pain management, and relief of suffering, should be a necessary part of ongoing education processes, for all healthcare professionals.

Because of the importance of pain management, this issue is dealt with in more detail in Chapter Seven, especially aspects of palliative care.

3.5.3 Advance declarations

A number of witnesses referred to the practice, legally recognised in the majority of American states, a number of European countries and in South Australia, of having properly attested advance declarations made by individuals. This type of legislation is viewed by those who support it as an extension of a patient's common-law right to refuse treatment (see Chapter Two).
The President's Commission for the Study of Ethical Problems in Medicine in America released a comprehensive report on the ethical, medical and legal issues in treatment decisions, which concluded that:

the authority of competent, informed patients to decide about their health care encompasses the decision to forgo treatment and allow death to occur. We note, however, that all patients, including those who reject various forms of life-support, should receive other appropriate medical care to preserve their dignity and minimise suffering to the greatest extent possible.

When patients are incompetent to make their own decisions, others must act on their behalf. The Commission found that existing legal procedures can be adapted for the purpose of allowing people while competent to designate someone to act in their stead and to express their wishes about treatment.

The enactments of the American jurisdictions and the Natural Death Act of South Australia all give legal effect to a written document, in a prescribed form, in which a person states that in the event of terminal illness, life-prolonging treatment is not to be initiated, and if so, it is not to be maintained. Such advance declarations provide a means of preserving some self-determination for patients who may lose their decision-making capacity.

The Public Questions Committee of the Baptist Union of Victoria, arguing in favour of some form of advance directives, states:

The task of the medical profession is to sustain life.

However, a person should be allowed to indicate that if he or she becomes senile or contracts a terminal illness with no hope of cure or remission, he or she should not have life unnaturally prolonged by the use of a life-support apparatus, naso-gastric or intravenous feeding, or repeated resuscitation after cardiac arrest.
Such indication should be entirely voluntary and be in writing, witnessed by at least two people, one of whom should be the person's doctor.

If such written indication has not been made, then the decision on treatment should be left, as at present, with the medical profession. 42

Professor P. Singer makes the additional point that:

We must consider, too, the good effect there will be on the peace of mind of the competent if they can expect that their wishes will be followed in the event of their losing their competence. 43

Based on the principles of autonomy and well-being Dr H. Kuhse argues that in the case of formerly competent patients who are no longer competent:

Whenever possible, decision-making for patients who are no longer competent should be based on the previously expressed wishes of the patient. In other words, the surrogate decisionmaker should attempt to reach the decision that the incapacitated person would make if she or he were able to choose. The consequence is that not only the patient's own understanding of 'well-being' is respected but also her interest in 'self-determination'. 44

On the other hand, many letters, submissions and witnesses were opposed to advance declarations in any form, for a variety of reasons.

Some stated that a person may change their mind at the time a terminal illness presented. Others, such as Drs J and J Santamaria, argued that advance declarations would place a great burden on the treating doctor, forcing him into premature judgments based on inadequate data, creating more confusion and uncertainty rather than clear direction:

In this dilemma, the doctor is likely to act in a way more motivated by fears of litigation than in the best interests of the patient. 45
The Knights of the Southern Cross legal representative, Mr K. Andrews, states:

A 'living will' must be exercised in writing but can be revoked verbally. How is a doctor to know the final wishes of his patient? Uncertainty abounds. In the place of good medical judgment, the legislation would leave doctors liable for damages arising out of the uncertain application of the general principle in individual cases. 46

The Right to Life Victoria submitted that a major difficulty with advance declarations was that they do not constitute informed consent. Sufficient information regarding the nature, consequences, alternative treatments and prognoses is not available when the declaration is signed.

The Royal Australian Nursing Federation believes that directions of this nature are best made only when the person is diagnosed as terminally ill or injured:

We believe that directions to be allowed to die are best made only when the person is dying. It is only at that point that the patient, or patient’s family, can make informed decisions about available options. 47

Despite a number of unresolved issues about how advance directives should be drafted, given legal effect and used in clinical practice, the American President’s Commission believes:

that advance directives are, in general, useful as a means of appropriate decisionmaking about life-sustaining treatment for incapacitated patients. The education of the general public and of health care professionals should be a concern to legislators, as the statutes are ineffective if unknown or misunderstood. 48

The Commission concluded by commending the use of advance declarations:
Institutions concerned with patient and practitioner education have an important role to play in encouraging patients to become familiar with and use advance directives, and in familiarising practitioners with the ethical and practical desirability of their patients using these mechanisms. Finally, legislators should be encouraged to draft flexible and clear statutes that give appropriate legal authority to those who write and rely upon advance directives. Such legislation needs to balance the provisions aimed at restricting likely abuses and those intended to allow flexibility and individuality for patients and proxies. 48

The Committee has investigated the issue of advance declarations, or 'living will' legislation, (the American generic term applied to legislation known synonymously as advance declaration, living will and natural death.) It concurs with principles outlined earlier, that:

(i) whenever possible, decision-making for patients who are no longer competent should be based on the previously expressed wishes of the patient; and

(ii) attempts should always be made to ascertain the patient's wishes, whether competent or incompetent.

The Committee does not consider the introduction of similar legislation in Victoria to be appropriate or necessary. Some of the most frequently mentioned criticisms of such legislation have been outlined in Section 2.4.4 above. The Committee has been persuaded by such criticisms and finds that the interests of most Victorians would be better considered and more effectively addressed by the adoption of currently available mechanisms and further recommendations made in Chapter Six.
Informed consent is a key issue in this inquiry. It has been interpreted as a principle of law embodied within a patient's autonomy or their right of self-determination. That is, decisions about health care ultimately rest with competent fully informed patients. Consent must be given before any treatment is carried out.

From discussions with witnesses, consultants and health care professionals regarding health care decisions and decision-making, it became abundantly clear to the Committee that the principles of decision-making and fully informed patients run parallel. Fully informed consent or dissent is a fundamental principle inherent in all aspects of decision-making, whether those decisions made about health care and or treatment are made by competent people or guardians representing incompetent people.

The efficacy of any consent is fully dependent on

(a) the medical practitioner undertaking reasonable disclosure to the patient about the treatment and any associated risks; and

(b) the patient or representative/guardian voluntarily consenting and being competent to consent.

Informed consent constitutes a defence to an action in battery (that is medical trespass).

From a number of articles, journals, and Law Reform Commission seminars attended by the Committee, it was evident, however, that 'informed consent' is interpreted differently both internationally and nationally. (See Paragraph 2.5.4).

The Committee concurs with the American President's Commission's interpretation of 'informed consent':

123
A principle of law embodied within the patient's autonomy or right of self-determination. It requires that the patient must be informed of all proposed medical procedures, the material risks of those procedures, alternative courses of action and the material risks attendant to the alternatives.  

While the doctrine of informed consent is accepted as a legal right of patients in many overseas jurisdictions, this is not yet the case in Australia. Some Australian states have investigated their informed consent procedures and attempted to specify the legal requirements of informed consent and the ethical principles of autonomy or self-determination as is the rationale for informed consent.

The Victorian Law Reform Commission is currently carrying out an extensive review of the legal definition of informed consent and existing consent procedures and forms pertaining to Victoria. At one of the many regular seminars held throughout 1986 and attended by Committee members, Dr. Neville Hicks, lecturer at the Department of Community Medicine, University of Adelaide, indicated difficulties in achieving the above goals because of the existing variations in the amount of information provided to the patients. As well, consent forms used are either too complex, do not clearly outline the notion of the risks involved in treatments offered, and create problems due to the medical vocabulary used.  

Evidence was received by the Committee that such problems exist with consent forms used in Victorian hospitals. Professor Robert Eagleson of the University of Sydney wrote that sample consent forms currently in use illustrate clearly that:

(a) legalistic and difficult language is used;
(b) the patient is asked only whether they understand the authorisation itself and not whether any information about the treatment has been conveyed;
(c) patients are often not given any guidance on what information they are entitled to;
(d) broad vague statements are used with no specific relevant detail used to guide the patient;

(e) many use a system that relies on nurses to obtain the consent, in particular to get the consent form signed without any personal discussions or negotiation by the doctor involved; and

(f) non-English speakers are not always catered for and patients' relatives, or cleaners or orderlies are sometimes asked to deal with these situations. 52

The Committee considers that the above existing areas of concern must be addressed as patients are entitled to information in broader areas relating to all types of treatment and not just for an operation needed. The emphasis should be on the medical profession improving their quality of communication as a part of sound medical treatment.

The Committee concurs with Professor Eagleson that the focus needs to be on more information communicated in order to help patients be involved in not only determining their own health but being able to fully understand what it all really means. This will be achieved by moving away from a litigious atmosphere of law and conflict, to an environment of comprehensive communication and shared decision-making.

On evidence, the Committee concludes that guidelines for informed consent procedures are a necessary component of all doctor/patient relationships throughout the health care setting. Whether formulated at an individual hospital level, or by a broader more uniform method, the Committee considers any guidelines proposed must be formulated in a way that ensures patients will as a matter of routine receive the following information in an easily comprehensible manner:
(a) the nature and extent of their condition;

(b) the nature and extent of the proposed treatment or procedures and any risks involved;

(c) treatment options including non-treatment and the risks involved; and

(d) the outcome, success or failure of all treatments and procedures.

3.5.5 Quality of care

The Committee received disturbing evidence regarding the quality of life and quality of care of patients, particularly elderly patients, in a significant number of private nursing homes and special accommodation houses. The Committee has a long-standing interest in the conditions of such institutions, and accepts that such conditions are, in many cases, a major criterion affecting either dying with dignity, or being treated in the final stages of life in conditions labelled by one witness as 'worse than animals'.

Mrs Judith Taylor of Moorabbin Aged Action Group indicated that the Action Group:

...completely rejects the frequently publicised statement that most nursing homes are good. The true picture is that most nursing homes are mediocre. The very good are few and a significant percentage are poor. 53

Cases were presented to the Committee indicating that the quality of care in many nursing homes is appallingly inadequate. Such cases support the need for the introduction of a well publicised grievance, or complaints mechanism, such as that recommended in an earlier report by this Committee.

Mrs Taylor's evidence was supported by that of the Regional Accommodation Team Services representatives, who also expressed their
concern over the quality of care offered in some nursing homes and special accommodation houses. Mrs Annette Madden made the point:

Most old people would choose to live at home and to die at home. The loneliness of living alone is not necessarily alleviated by living with other people, who are usually complete strangers with little in common. 54

Such comments, and others relating to the inadequate management of grief and lack of understanding about loss of longstanding companions in an institutional setting are of concern to the Committee. Such a concern is increased by reports, such as that which appeared in Melbourne newspapers on 5 September 1986, which detailed how a nursing home helped to hasten the deaths of two elderly women patients. 55,56 As The Sun reported:

One patient's leg was so ulcerated and gangrenous it had to be amputated.

Other patients, including one with a broken leg, were in chairs for long periods, Prahran Court heard.

Patients at the Maroona Private Nursing Hospital, in Maroona Road, Glenhuntly, received inadequate care and treatment, the Court was told.

Mr Graeme Golden, SM said it was the worst case of patient neglect he had heard.

The Court heard Mrs Fay fell and fractured her femur in April and was not treated for several days. Infection set in and her leg was amputated.

Other particulars noted by the Health Department included patients being given meals while on commode chairs and being washed with a communal washer from a communal bowl.

Linen was 'grey in appearance' and washed in cold water, the Department said.
The Committee notes the supportive evidence provided by the Ministerial Review of Special Accommodation Houses, chaired by the Honourable Mal Sandon, MLC, in its Interim Report to the Minister.

The Committee discusses the issue of high quality palliative care and care for the terminally ill in further detail in Chapter Seven.

3.6 Acts and omissions: active and passive euthanasia

Several witnesses argue that there is no morally significant distinction between what has been called 'passive' euthanasia, i.e. the withdrawing of medical treatment to bring about death, and 'active' euthanasia, i.e. the taking of active steps to bring about death, such as administering a lethal injection. For example, Professor P. Singer states:

In my view a clear-minded analysis of the distinction between acts and omissions reveals that the distinction is not itself morally significant. There may well be circumstances in which we would be more inclined to blame someone who took active steps than someone who merely allowed a person to die, but the difference always turns out to depend on motivation or some other factor, not simply on the difference between an act and an omission. In recent years many philosophers have come to this conclusion.

In the case of euthanasia, often the major difference between active and passive euthanasia is that passive euthanasia takes longer, and the patient suffers more in the process. Sometimes - as in the case of 'not for resuscitation' orders - the result is that an outcome agreed upon by all as desirable is left up to chance events, such as whether a cardiac arrest occurs. 57

In the submission of the Voluntary Euthanasia Society of Victoria this distinction is linked to the right to autonomy:

The exercise of this right of autonomy will for some who are e.g. terminally ill, suffering pain
and no longer able to do the things in and with their lives that give those lives their particular significance, lead to them asking others to help make the choice to die effective. To deny such help is to deny these people the right to live and die as they choose. Some, of course, will want no such assistance to help them die - that is their right as autonomous beings.

In general, those who see rights as spheres of non-interference are willing only that no strenuous efforts be required to prolong the dying process. They oppose the very autonomy which others believe is their right, namely the autonomy to choose to die on their own terms which will only sometimes be realizable through others agreeing not to interfere. 58

In proposing that no distinction between acts and omissions can be made, Dr H. Kuhse states:

... the argument is sometimes put, that there is a difference between performing an action that results in a patient's death and merely doing nothing', thereby allowing the patient to die. But the real question is not, in my view, whether a doctor performs an action, or merely 'does nothing', when she deliberately chooses to act in a way that results in a patient's death, but rather whether that action or omission serves the rights and interests of particular patients. Similarly, regarding the distinction between killing and letting die. It does not, in itself, matter morally whether a patient's death is the result of a deliberate killing or a deliberate letting die. 59

Right to Life Victoria submitted:

We have no quarrel with Dr Kuhse's proposition that passive euthanasia and active euthanasia are morally alike. Whether by act or omission, seeking to cause or hasten death is wrong. 60
Such a position is rejected by other witnesses. For example, Mr Nicholas Tonti-Filippini, Director of St Vincent's Bioethics Centre, Melbourne, writes that:

*letting die does not necessarily involve seeking the death of the patient. For instance, if the only way of preventing death was by means of removing life support from another patient then the doctor might choose to let the patient die rather than to deprive another of life. This is not to say that the doctor would be seeking the death of the former, it would not be euthanasia [. . .].*

*In not providing the extremely painful and burdensome treatment the doctor would be letting die but because death is not the object (he or she would not be concerned or disappointed if the patient survived), it would not be euthanasia. Euthanasia is characterised by the seeking of death, whether by active or passive means. Letting die need not be passive euthanasia.*

The Committee's observations are in accord with the statement of the VESV that 'passive euthanasia is rarely, if ever, a matter of non-interference'. As the VESV submission states:

*Where, for example, a patient has his or her life support system disconnected, or where a patient is designated as 'not to be resuscitated', it is false to say a policy of non-interference is in place. To turn off machines, or to intentionally not take resuscitative action, is to act decisively. There can, then, be no ready identification of non-interference with passive euthanasia.*

Dr H. Kuhse argues that the distinction between a doctor intending a patient's death and a doctor merely foreseeing that a patient will die as a consequence of what she does, involves the following points:

*Firstly, resuscitation is no more 'burdensome' for a terminally ill patient than for a patient who is not terminally ill. What is more*
burdensome for a terminally ill patient is the life that awaits her after she has been resuscitated. So what is generally behind the distinction between intending and foreseeing death in the present context is something like the 'best interests principle': that a patient should be resuscitated if life is, everything considered, in her best interest; she should not be resuscitated if life, after resuscitation, would be excessively burdensome. But if that is what those defending the distinction have in mind, then it would avoid much confusion if they were to speak directly about the rights and interests of individual patients, rather than about what the doctor intends and what she merely foresees.

And this brings me to my second point: there are sound reasons as to why the law has traditionally regarded foresight as sufficient for intention. It is not only that it is sometimes difficult to draw the distinction between what an agent intends and what she foresees (one reason is that only the agent will be able to tell you what she had on her mind), but also - and this is the point I made at the beginning of my submission - that health care professionals in deliberately choosing one course of action rather than another are also deliberately choosing all the consequences of their actions: in other words, they are sometimes choosing a patient's death.

So if the law is intended to protect patients against doctors unjustifiably bringing about their deaths, or unjustifiably allowing their deaths to occur, the question is not what a doctor has on her mind when she does what she does, but rather whether a doctor in deliberately bringing about one consequence rather than another is acting in accordance with the patient's rights and interests. (emphasis added). The distinction between a doctor intending a patient's death and merely foreseeing that death will occur cannot provide the answer to that question. 63

The Voluntary Euthanasia Society of Victoria, as well as numbers of individuals, many of them members of the VESV, argues in favour of active euthanasia:
Given that the intention in carrying out passive voluntary euthanasia will be the same as in a situation where a medical professional actively intervenes to administer euthanasia at the patient's request (viz, to relieve unnecessary suffering or the prolongation of a meaningless existence), and given that the outcome will be the same, there can be no ground for morally permitting the passive method over the active. The VESV takes the view that where there is any moral difference between the passive and the active approaches the advantage will lie with the active. There is a simple reason for this, namely that the passive approach is apt to allow the patient to linger and so, if there is any pain and suffering being undergone, to result in more pain and suffering with no good purpose. We will not labour the point here that it is not morally preferable to let die once a competent individual has expressed his or her desire to die. Dr Kuhse's contribution is convincing on this count. [In the Committee's First Report] 64

Representatives of the medical profession argue against legislation to introduce active euthanasia:

The Board is strongly opposed to any legislative action which could lead to the medical profession being asked to practise active euthanasia. In simple terms, this is opposed for the reasons

1. That it is against every principle for which the medical practitioner stands.

2. That depression (or despair) is a common accompaniment of severe illness; a depressed individual may seek termination of his life when either (a) the condition is not terminal or (b) his mental state is such that he is not competent to make the request.

3. There are no absolute certainties in medicine, no doctor can ever be absolutely sure as to when an illness has entered a terminal phase. 65
3.7 Public opinion

The Committee has emphasised above (Section 3.2.1) the moral perspective underlying this inquiry. It concurs with Professor Charlesworth in his comment that 'you cannot proceed in an ethical inquiry as you might proceed in a scientific or medical inquiry'. However, at the risk of being labelled '"plain blunt man" pragmatists' tending 'to rely surreptitiously upon a half-baked utilitarianism (whatever brings about the greatest amount of human happiness is good)', the Committee believes it important to report on certain results of a recent Victorian opinion poll, presented to it as evidence. In reporting such data the Committee preserves its position regarding the ethical nature of its inquiry, however it uses a feature of its customary methodology to assess the views of members of the Victorian public.

The Morgan Research Centre conducted an opinion poll into options for dying with dignity which consisted of a sample of 815 men and women interviewed in Victoria on the weekends of May 10-11; 17-18, and 24-25, 1986. 66

The questions were as follows:

1. Next, about whether a person who is terminally ill or injured, with no chance of recovery, should have the right to choose to die?

2. If a person is terminally ill or injured with no chance of recovery asks for a lethal dose so as not to wake again or asks for some other help to die, should that person be helped to die or not?

3. Looking at the card which lists some illnesses and injuries, under which of these circumstances if any should a person incapable of asking be allowed to die?

4. It has been suggested that the government should legislate to establish a person's right to die. In your opinion should the government legislate to establish a person's right to die?
The answers to these questions were analysed by area (city/country); sex; age; marital status/with or without children; education; occupation; income; religion; country of birth; and Federal voting intention.

The total figures for each of these questions were as follows:

1. 'Terminally ill or injured allowed to die'

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<tbody>
<tr>
<td>Yes allowed to die</td>
<td>86.6%</td>
</tr>
<tr>
<td>No not allowed</td>
<td>8.9%</td>
</tr>
<tr>
<td>Can't say</td>
<td>4.5%</td>
</tr>
</tbody>
</table>

2. 'Should a lethal dose be given to a terminally ill or injured person'

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes helped</td>
<td>74.2%</td>
</tr>
<tr>
<td>Not not helped</td>
<td>18.4%</td>
</tr>
<tr>
<td>Can't say</td>
<td>7.5%</td>
</tr>
</tbody>
</table>

3. 'Illnesses and injuries for which a person be allowed to die'

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terminally ill</td>
<td>48.2%</td>
</tr>
<tr>
<td>Seriously injured</td>
<td>54.2%</td>
</tr>
<tr>
<td>Coma/brain death</td>
<td>65.1%</td>
</tr>
<tr>
<td>Pain due to terminal illness</td>
<td>41.0%</td>
</tr>
<tr>
<td>Pain due to accident injury</td>
<td>43.1%</td>
</tr>
<tr>
<td>Senile dementia</td>
<td>19.3%</td>
</tr>
<tr>
<td>Others</td>
<td>2.2%</td>
</tr>
<tr>
<td>Total in favour of giving dose</td>
<td>83.9%</td>
</tr>
<tr>
<td>Under no circumstances</td>
<td>14.0%</td>
</tr>
<tr>
<td>Don't know</td>
<td>2.1%</td>
</tr>
</tbody>
</table>

4. 'Legislate to establish person's right to die'

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes legislate</td>
<td>73.0%</td>
</tr>
<tr>
<td>No should not</td>
<td>22.3%</td>
</tr>
<tr>
<td>Can't say</td>
<td>4.7%</td>
</tr>
</tbody>
</table>
On this last question the breakdown by 'Federal voting intention' of 'Yes legislate' was:

ALP = 76%  Aust. Democrats = 67%  Liberal = 72%  NP = 72%

On question 2 (broadly speaking the 'active voluntary euthanasia' issue) the breakdown by religion of those who responded 'Yes, helped' was:

Catholic = 66.3%  Anglican = 80.3%  Presbyterian/Uniting = 71.1%
Other Christian = 68.5%  No religion = 82.9%

Mr Robert Young, President of the Voluntary Euthanasia Society of Victoria, in a brief evaluative summary stated:

_The survey of public opinion in Victoria that was presented to the Committee shows overwhelming support for people wanting to see improvement in the situation of individuals in the State. It showed that 86.6 per cent are willing to support passive voluntary euthanasia and more than 90 per cent in those cases where patients were terminally ill, suffering pain and so on. The figures are enormous._

_Even the 74 per cent who were for active voluntary euthanasia included 66 per cent of Catholics who were surveyed and showed people are much more aware these days of the need to protect the rights, autonomy and needs of the patient._

Many submissions and letters to the Committee requested that euthanasia be made accessible. Some in fact were requests related to other issues. For example, many people who saw euthanasia as the most appropriate treatment were asking for the right to refuse treatment. Another area of major concern was uncontrolled and unrelieved pain that can and should be addressed effectively and compassionately by up to date palliative care.
3.8 Desirability of legislation establishing a right to die

Submissions to the Committee were divided upon this point. Some argued that legislative or similar reform is necessary because, as Dr H. Kuhse says:

1. Without such legislation, the rights and interests of patients may be overridden by laws which place emphasis on mere 'life', rather than on the rights and interests of those whose life it is.

2. Without such legislation, medical professionals are practising humane medicine, fearing that they may one day be charged with murder.

The point I wish to make is this: Leaving open for the moment, the question as to what particular policies the Victorian government should develop, I believe it is no longer possible to take the view that there should be no policy at all.

Another reason put forward as indicating the need for legislation was the question of uniformity. This was stated as a particularly important issue as far as the rights and interests of patients are concerned. As Dr H. Kuhse commented:

... we need to note that there is great variation among physicians and hospitals as to which treatment is regarded as 'appropriate' under particular circumstances and which is not. Doctors, like the general public, have views ranging from 'treatment at all cost to the very end' to 'let the patient die under such and such circumstances'. What is important is that these inevitable life and death decisions are based on the rights and interests of the patients.

The Knights of the Southern Cross believe that there is no need for legislation of any sort because a common law right to refuse treatment already exists:
Patients do have a right to control their own treatment. The common law always has held that a person has a right not to be touched without his or her consent. For a doctor to ignore this right is an assault. Unfortunately, the passive attitude and possible ignorance of many patients may have led this principle to have been obscured.

The proposed legislation overlooks the fact that the law already gives the competent person the responsibility to consent to treatment, hence the right to refuse that treatment.

The situation of the incompetent person is made difficult, not by the obscurity of the law, but by the need to ensure that appointed guardians are acting in the patient's best interests.

What is required is further education of medical students, doctors and the public alike to ensure that informed decisions can be made by individual patients.

Those who support legislative change, however, see it as an extension of an individual's right of informed consent coupled with their right to refuse treatment. The dying patient is frequently unable to exercise that right. Further, it is considered to be a means to establish and protect the individual's right to a dignified death without recourse to unnecessary, unwanted medical treatment which serves only to prolong dying and cause needless suffering. An additional argument is that it frees physicians and other health care professionals from liability for honouring the patient's wishes made clear in a written directive.

3.9 Summary and conclusions

This chapter has addressed many of the fundamental issues presented to the Committee in the course of its inquiry. In a number of ways the first two of the Committee's terms of reference encapsulate issues and notions which are reflected throughout the discussion of the remaining terms of reference. This is to be expected in an inquiry of this nature, which has an underpinning ethical dimension.
The Committee first presents the evidence regarding the notion of a right and noted the centrality of the right to moral autonomy or self-determination. Certain disagreements involving the interference or non-interference of others in accomplishing an individual's 'right' were then presented.

An area of agreement appeared, however, to lie in the general goal of achieving an individual right to die peacefully with human dignity. Certain elements of such an entitlement, for example the moral permissibility of forgoing disproportionate treatment and of administering analgesics with the intention of relieving pain - such medication incidentally shortening life, were broadly supported. The Committee considered that an individual's moral entitlement to die with human dignity was not synonymous with, or a euphemism for, euthanasia.

Distinctions between passive and active euthanasia are considered by the Committee to be semantic and unhelpful.

The Committee then addressed an additional element comprising the right to die with dignity, which encompasses the common law right to refuse medical treatment. There appeared to be broad support for this element. However, while there was general agreement regarding the existence of such a right there was little consensus as to what this right means in practice. Not only does it appear that there is little understanding and, indeed, information available regarding a patient's entitlements, but it also appears that the medical and other health care professions need greater legal protection in the area of dying with dignity.

Having discussed the elements of an individual entitlement to die peacefully with human dignity, the Committee examined a number of practical issues which arose in conjunction with earlier considerations. The Committee considers that such more or less covert procedures such as 'not for resuscitation' be more subject to community discussion and scrutiny. Other issues included the management of pain and the role of advance declarations. The Committee is concerned that pain is not being adequately controlled and discusses the issue of symptom control as a major ingredient.
of palliative care in Chapter Seven. It is very clear that the issue of pain control is one which must be taken extremely seriously by the medical profession. Various positions presented by witnesses regarding advance declarations (or 'living wills') are detailed which, with the description of some of the merits and criticisms of such a system set out in Chapter Two, have led the Committee to reject this as a legislative option.

The chapter then continues with evidence presented regarding the distinction between 'acts' and 'omissions'. A number of positions were put to the Committee regarding this distinction. The Committee notes the significance of 'intention' in this area, but is also cognisant of everyday medical decision-making in an unclear legal context which may blur such a distinction.

The Committee next reports on evidence presented to it regarding public opinion in Victoria.

Finally the chapter presents evidence regarding the desirability or otherwise of legislative or similar reform in this area. A variety of perspectives are presented together with arguments for and against such action.

3.9.1 Conclusions

The Committee has examined a number of key issues which are central to terms of reference (1) and (2a) and has noted the variety of interpretations of the notion of a 'right to die'. Despite evidence of extensive debate by moral philosophers, theologians and others the Committee found no universal agreement in definition of this term. Due to both conceptual and practical difficulties relating to the notion, the Committee has concluded that it is neither desirable nor practicable to legislate or take other action to establish a 'right to die'.

The Committee has, however, found extensive evidence of reference to a moral right, or entitlement, to die with dignity. Such an entitlement, the Committee concludes, should be the fundamental principle upon which all codes of practice established for those involved in terminal care, should be based.
The Committee therefore concludes that despite public opinion polls which indicate the contrary, legislation to cover 'euthanasia' is not appropriate in Victoria.

The Committee in its later recommendations has indeed addressed many issues raised in the public opinion polls by pursuing the notion of dying with dignity and by reinforcing and indeed supporting the right of the patient to refuse medical treatment.

The Committee recognises that there are inherent difficulties morally, philosophically and legally, in covering all the areas raised by the advocates of euthanasia and believes that the total recommendations in the Committee's report will reduce the call for such an interventionist solution to complex personal questions.

One of the key issues influencing the Committee has been the existing common law right to refuse medical treatment. Every person, both competent and incompetent has an enforceable legal right at common law to refuse unwanted medical treatment. This right is, however, qualified in practice and in law by the fact that it is not an absolute right. Incompetent persons may be subject to certain statutes and have their rights enforced by 'significant others'. The refusal of medical treatment by competent adults and minors, the medical treatment of incompetent adults and minors, and the legal liability of medical practitioners, nurses and other health care professionals for the withdrawal of life support systems need to be made certain, and must therefore be clarified in such a way that the legal position is clear.

**Legislative action**

The Committee concludes that the primary mechanism for clarification of the common law right to refuse medical treatment is by means of legislation. Such legislation should verify the right of a competent adult to refuse medical treatment or life support systems, thereby protecting the individual concerned, their relatives or care-givers, and the medical team caring for the individual.
The Committee concludes that the best way of ensuring these rights are protected is to establish in the same legislation an offence of medical trespass. Medical trespass occurs where a medical practitioner carries out or continues with any procedure or treatment where a competent patient, freely and informedly refuses that procedure or treatment. At the same time, the Committee concludes that medical practitioners must be given legal protection in the same legislation where they act in good faith in accordance with such freely given and informed instructions from competent patients.

Such legislation should allow for guidelines which protect all parties and preserve patients' entitlements.

Other action

Further clarification of an individual's right to die with dignity can be achieved by the establishment of acceptable practices and procedures, for the guidance of health care workers. These should include:

(a) standards of acceptable medical practice for the care of special categories of patients, in particular the terminally ill and seriously ill, neonates and the elderly;

(b) procedures for the use by medical practitioners, nurses and other health care personnel of life support equipment and other forms of intrusive medical technology;

(c) standards for the provision of adequate pain relief for terminally ill patients;

(d) standards for the provision of information for terminally ill patients;

(e) procedures in respect of useless or burdensome treatment, such treatment being disproportionate to the condition of the patient; and

(f) written instructions for 'not for resuscitation' procedures together
with indications of all patients' wishes, whether competent or incompetent.

Acceptable practices and procedures, once developed, should be:

(a) adopted as a part of the curriculum undertaken in all tertiary institutions training health carers; and

(b) promoted by specialised colleges, and other medical and nursing societies and associations.

3.10 Recommendations

The Committee recommends:

1. That it is neither desirable or practicable for any legislative action to be taken establishing a right to die.

2. That legislative action clarifying and protecting the existing common law right to refuse medical treatment is desirable and practicable and should be brought about by the enactment of legislation to establish an offence of medical trespass.

3. That medical trespass be defined as occurring when a medical practitioner carries out or continues with any procedure or treatment where a competent patient freely and informedly refuses that procedure or treatment.

4. That the legislation also encompasses protection from criminal and civil liability on the part of a medical practitioner who acts in good faith and in accordance with the expressed wishes of the fully informed, competent patient who refuses medical treatment or procedures.
5. That the non-application of medical treatment does not in itself constitute the cause of death, where a medical practitioner is acting in good faith to avoid committing the offence of medical trespass.

6. That the Health Department Victoria as a matter of urgency obtain from all relevant health care institutions 'not-for-resuscitation' (NFR) guidelines in order:

. to review current practices in this area, and that such information be referred to the National Health and Medical Research Council (NH & MRC) by the Minister for Health at the next Health Ministers' Conference; and

. that the NH&MRC develop a commonly accepted set of standards and practices that can be incorporated into guidelines, and observed.

7. That the Health Department Victoria obtain from all relevant health care institutions 'informed consent' procedures currently in use, and analyse such procedures in terms of their:

. comprehensibility;
. adequacy in terms of a patient's entitlement to information and details of treatment;
. adequacy for non-English speakers; and
. adequacy in terms of appropriate relevant health care personnel involvement.

8. That the analysis of current 'informed consent' procedures be provided to the Victorian Law Reform Commission within a period of three months from the date of tabling of this Report, so that the Commission may evaluate such information in terms of

. a patient's entitlement to information relating to all types of treatment; and
. the adequacy of communication between patient and doctor, and that the Commission can formulate guidelines for informed consent procedures.
9. That a uniform set of informed consent procedures be in place within 12 months from the date of tabling of this Report.
Footnotes to Chapter 3

1. Notes on Discussion, 30.7.86, p.2.
2. Social Development Committee First Report on Inquiry into Options for Dying with Dignity, March 1986, p.44.
3. Submission by St Vincent's Hospital Bioethics Centre, p.9.
4. Submission by Dr H. Kuhse, p.8.
5. Submission by Professor P. Singer, p.2.
6. Ibid., p.3.
7. Submission by the Catholic Bishops of Victoria, p.4.
9. Submission by Dr Joseph and Dr John Santamaria, p.12.
13. Submission by The Hon. B.A. Chamberlain, MLC, p.3.
15. Ibid., p. 393.
20. Ibid., pp.6-7.
22. Submission by Knights of the Southern Cross, Appendix 1, p.6.
23. Ibid., p.5.
25. Submission by Royal Australian Nurses Federation, p.11.
26. Ibid., p.6.
27. Minutes of Evidence, 2.3.87, p.1040.
28. Ibid., p.4.
29. Submission by Humanist Society of Victoria, p.2.
31. Ibid., pp.121-122.
34. Ibid., p.1.
35. Ibid., p.1.
36. Submission by Helen Hamilton, Nurse Researcher, and David Douglas, Deputy Medical Director of the Austin Hospital, pp.22-23.
37. See Chapter 2, letter 22.
39. Ibid., p.224.
41. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Deciding to Forego Life-Sustaining Treatment, Washington, March 1983.
42. Submission by Public Questions Committee of the Baptist Union of Victoria.
43. Ibid., p.5.
44. Ibid., p.10.
45. Ibid., p.7.
46. Ibid., Appendix 1.3, p.9.
47. Ibid., p.6.
48. Ibid., pp. 149 and 153.
50. Dr N. Hicks, Informed? Australian Society, June 1986, p.44.
56. The Age, Friday 5 September 1986, p.3.
57. Ibid., p.6.
58. Ibid., pp.2-3.
59. Ibid., p.15.
60. Ibid., p.15.
62. Ibid., pp.3-4.
63. Ibid., p.14.
64. Ibid., p.4.
65. Submission by Medical Board of Victoria, p.3.
67. Minutes of Evidence, 2.7.86, p.399A.
68. Ibid., p.7.
69. Ibid., Appendix 1.3, p.5.