Dying in an age of technology: an evaluation of terminal care technology and its alternatives

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NOTE

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DYING IN AN AGE OF TECHNOLOGY: 
AN EVALUATION OF TERMINAL CARE 
TECHNOLOGY AND ITS ALTERNATIVES

A thesis submitted in partial fulfilment 
of the requirements for the award of the 
degree of

MASTER OF ARTS (HONOURS)

from

THE UNIVERSITY OF WOLLONGONG

by

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1983
"Those who come after us will wonder why on earth we kept a human being alive against his will, when all dignity, beauty and meaning of life had vanished; when any gain to anyone was clearly impossible and when we would have been punished by the state if we had kept an animal alive in similar conditions."

(Dr. Leslie Weatherhead, C.B.E.)
STATEMENT

This thesis is the result of an original investigation conducted by the author and includes no materials accepted for any other academic award in any university. To the best of my knowledge, it does not contain any material authored by another person, except when duly referenced.

Chloe Leigh
ACKNOWLEDGEMENTS

As with any substantial project, the assistance of many people has greatly aided me in the completion of this thesis.

I would like to thank my Supervisor, Dr. Evelleen Richards, who has carefully and with encouraging patience guided me through the process of completing this research. Her criticism of my work was always given in a positive and constructive manner, which I very much appreciated as I became the mother of twin daughters half way through this project. Professor Charles Kerr, under whom I was able to study during my Masters Degree, also has been instrumental in the clarification and development of ideas that I have had the opportunity to further investigate and evaluate herein.

My husband, James Leigh, has continually encouraged me and without his unflagging enthusiasm in my academic interests and his loving care of our twin daughters, Christina and Maria, my task in completing this thesis would have seemed impossible.

I would like to thank the New South Wales Nurses' Registration Board for awarding me a Scholarship towards the completion of this thesis, without which the task would have been greatly extended.

Finally, I wish to thank Mrs. Enid Sherwin, my typist, whose impeccable secretarial skills and standards have been invaluable in enabling me to present my thesis in this present format.
ABSTRACT

This thesis explores the influences, effects and results of improved life support technologies and of increased medical capabilities on terminal care and the care of the dying. It looks at the results of the application of these death-defying technologies and their effects on the definition of death, as well as the created need for new criteria for the determination of death when such technologies are used. Some legal, moral and ethical issues raised by these developments and their application, and the new medical problems and issues resulting from these 'medical successes' are also looked at.

The reasons behind the increasing tendency towards hospitalizing the dying, and death, are explored. Examination is made of available alternatives to hospital terminal care. The advantages and/or disadvantages of each are explored. Special attention is paid to the alternatives available in Australia.

Due to the ever-increasing powers of life-prolonging technologies, many people have come to dread the thought of prolonged suffering, pain, lingering decline, suspended dying or vegetative existence. This thesis looks at the euthanasia movement, which has articulated these concerns. It also examines the debate over euthanasia, and the legal, moral and ethical issues that it raises. Consideration is also given to some of the positive outcomes of this movement, such as the 'Patients' Bill of Rights', and the 'Living Will'.

It is argued that intensive technological intervention is not appropriate at the terminal stage and that the patient should be able to withhold consent for the use of such technology on him or to request withdrawal of it if already in use. The patient should also
be able to choose where and how he ends his days. In the Australian context the choice, if available, remains mainly between institutions. Community support services require a massive upgrading before home care becomes a viable option.

Finally, on the basis of this analysis, some policy recommendations for terminal care in the Australian context are offered.
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INTRODUCTION

We cannot escape the fact that technology has become an integral part of our social world and an essential element in almost every field of everyday activity. The nature and design of the technology of any society reflects the values of that society or at least the values of those who are in a position to determine the type of technology to be implemented. In other words, the nature of technology is determined by social, economic and political factors. As such, it is related to the distribution of power; sustaining, promoting and reflecting the interests of the dominant social groups of that society, supporting and propagating their ideology. The nature of technology is inseparable from the nature of the social, economic and political structures which incorporate the forces which control the complex interactions between society and technology.

Thus Dickson defines technology:

... as an abstract concept embracing both the tools and machines used by society, and the relations between them implied by their use.

He further defines tools and machines:

... as objects selected or fabricated by man as a means of changing the state of his material environment. 1*

Various models of explanation of technological change have been proposed. Some have singled out one or two variables and attempted through them, to explain such change. Too heavy an

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emphasis on any one variable in the attempt to explain technological change can lead to determinism. Such determinism neglects the interaction of all other variables as they affect change, and limits the explanation of technological change to the factor singled out as the sole means of explanation, e.g.:

- Technological Determinism;
- Economic Determinism;
- Political Determinism, etc.²

On careful examination of each variable, it can be seen that each plays a part in influencing technological change and that it may become dominant at some stage. However, technological change is a complex process with political, social, economic, cultural and other factors interacting with technology and vice versa, to bring about the specific type of change permeating a particular society. This thesis is written with such an 'interactionist' model of technological change in mind.

Medicine has been affected by technological achievements and innovations, and in turn influenced them, as much as any other institution. The visible manifestations of these changes are becoming increasingly obvious. Until very recently, medicine has been used as an exemplar of how technological applications and developments bring only unalloyed good to mankind. The media and the various medical foundations trumpeted one historic victory after another. This inflated view of how technological medicine helps mankind created bias in favour of more and more technology and more costly technology.

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In spite of this increase in technology, little was heard of the adverse effects of the so-called medical 'advances' and 'breakthroughs'. Recently, writings which document the limitations of medical technology have grown. The work of Illich has been of seminal influence in this area.* The lack of objective evaluation of the results of technological interventions, particularly as compared with other less invasive treatments, has led Taylor to call contemporary medicine "science fiction medicine". As he states:

There is a preoccupation of medicine with the newly acquired gadgetry and flashy technology in the face of meagre evidence as to the usefulness of many of these methods in diagnosis and treatment. 3

As Illich and Taylor document, technological medicine has gradually expanded to incorporate all stages of life from birth to death. In the area of terminal care, technological intervention has gradually become the norm, so much so that natural death is no longer feasible where life-support, life-prolonging technologies are employed. Under such circumstances people die while comatosed, monitored, betubed, artificially fed and artificially ventilated. Death in an acute hospital is rarely allowed to occur without the last rites of modern medicine. Thus, where once death was as natural as life, it has now become something to be treated, interfered with, technologically postponed. Death has become a technological event.

Technological intervention at the dying stage has challenged customary definitions of death and has rendered them insufficient and unsatisfactory. This has created the need for a redefinition of death

(*) Illich has been criticised by his contemporaries for his technological determinism. In spite of his criticism of technological medicine, he offers no real viable alternative to it. Reference to his work is made with awareness of this criticism of him and without concurrence with his technological determinism.

(3) Taylor, R. Medicine Out of Control. Melbourne, 1979, p.3.
and has led to the search for new criteria for determining death. Life-support machines can maintain traditional signs of life while the person is 'actually' dead. Advances in organ transplantation capabilities and a shortage of organs for transplants have added to the need for new criteria.

The medical tendency to sustain and prolong life whenever possible has led to increased intervention at the terminal stage. This has resulted in unnecessary investigations and treatments, as well as unnecessary pain and suffering for the dying patient. The tendency is for increased technical care for those patients diagnosed as terminal. Yet the dying patient is in greater need of intensive caring than he is of intensive care.

TERMINAL CARE DEFINED

Terminal care refers to the management of those patients in whom the advent of death is felt to be certain and not too far off, and for whom medical effort has been turned away from active therapy and become concentrated on the relief of symptoms and the support of the patient and his family. Most discussions on terminal care are concerned mainly with malignant disease, but many of the symptoms to be treated and much of the general care and management are relevant to other conditions bringing about death. So terminal care should not be just a facet of oncology, but of geriatric medicine, neurology, general practice and medicine in general. 4

(*) For ease of expression, masculine pronouns refer to both sexes throughout this thesis.

Originally, therapy is directed toward investigation and intervention in order to control and/or cure an illness and alleviate associated symptoms. For dying persons, however, the time comes when cures and remissions are beyond the capacity of current curative treatment. It is then that the emphasis of intervention must shift to palliative care which is designed to control pain in the broader sense and to provide support for patients and their families during this terminal phase of their illness. Today, techniques exist to alleviate almost all of the discomforts and suffering of the dying. This is very rarely a matter of new buildings or expensive equipment and equally rarely is hospitalisation necessary. Palliative care needs extensive personal caring and an ordering of the physical and social environment to be conducive to care. The patient should not at this stage be subjected to aggressive treatments that offer no real hope of being effective and may only cause him further distress and suffering. However, because of the traditional belief that life should be preserved and because of the legal sanctions and moral implications that withdrawal of treatment implies, it is often difficult for doctors to decide to withdraw curative treatments when death approaches; thus many dying end their days in hospital, receiving treatments that are of little value to them and often not of their choice.

The work of Dr. E. Kübler-Ross was a timely criticism of current terminal care practices and has added a new dimension to the care of the terminally ill. Her clinical work has motivated many

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care-givers to work in this field and her writings and lectures have helped make the words 'death' and 'dying' less terrifying. However, Kübler-Ross offers no extended critique of current terminal care technology and its social and economic implications. Her work focuses mainly on the psycho-emotional aspects of terminal care and the failure and inability of the professional carers to meet the needs of the dying patient in this area of care.

This thesis is an attempt to evaluate some of the implications of hospital-based terminal care technology and to assess it against the alternatives offered by hospices and home care. While some of the economic and social dimensions of terminal care technology are explored, a full assessment of these is beyond the scope of this thesis.

The thesis is organised as follows:

Chapter 1 examines the increasing tendency towards the institutionalisation of death and dying and explores the reasons for this trend. It is argued that because of its acute-care nature, the hospital setting of death inevitably leads to the use of acute-care technology on the dying.

Chapter 2 examines the subsequent need for redefining death and the need for formulation of new criteria for the determination of death in the context of modern terminal care technology. It also explores some of the legal, moral and ethical aspects of these developments.

Chapter 3 examines the euthanasia debate which has grown out of the concern over the increased tendency towards technological intervention at the terminal stage and the fear of suspended dying and
lingering decline as well as the fear of unnecessary investigations and treatments and their associated pain and suffering. The issues of 'Informed Consent', 'Patient's Rights' and 'Living Wills' are explored in this Chapter.

Chapter 4 looks at the existing alternatives to institutional care of the dying with some comparisons being made between those alternatives currently available in Britain, the United States and Australia. It is argued that home care is a viable alternative to institutional care, provided that sufficient support services are made available. In the Australian context, these services are still in the embryonic stage and dying at home is not a viable option at present.

The Conclusion sums up these arguments and offers some policy recommendations for terminal care in the Australian context.
CHAPTER 1

THE INSTITUTIONALISATION
OF DEATH AND DYING
1.1 GENERAL INTRODUCTION

Since the beginning of this century, a trend has become established of people dying in institutions. This tendency has shown a constant increase, so that today, the predominant number of deaths occur within the hospital. The hospital was the institution created by society to support the healing services and it is fundamentally committed to the recovery process, to curing and to the restoring of health. In such an environment, the dying are inevitably perceived as out of place and, not infrequently, as failures of modern medical scientific efforts.

Many factors have contributed towards the hospitalisation trend. Popular beliefs and reliance on technological gadgetry and the expectation that, through it, all problems are solvable, has played a major role. Increasingly people have been encouraged by the media, governments, and the medical establishment to believe and expect that all serious illness can only be managed in hospitals. By encouraging the perception of dying from any cause as illness, its hospitalisation became inevitable. Changing social and economic patterns and the constantly increasing urbanisation have also contributed to the trend.¹

Death has changed its shape. The traditional death scene at home has been replaced with a new one located in hospitals and,

more rarely, in nursing homes or hospices. Generally death comes from chronic rather than acute illnesses. In hospitals it arrives in a lonely room, without family or friends around, but with the dying surrounded by and connected to numerous wires and tubes, all aiming at keeping death at bay; what is achieved instead is to keep at a distance any human contact. The loss of personal integrity now often occurs long before biological death. Patients do not meet death any more. Death comes to them while comatosen, betubed, ventilated, narcosed, sedated, intravenously fed; not while conscious, not even human any more. Hence, where once dying was not a matter to be decided upon, but an accepted event, it has gradually become something to be hospitalised, treated, interfered with, avoided, technologically postponed.

1.2 HISTORICAL INTRODUCTION

It is easy to forget that the need for sheer physical survival still prevents the majority of mankind from having a primary concern for the suffering involved in dying. In nations where survival is a constant battle and institutionalised care is of the most basic form and for the most serious of conditions, views on death are markedly different from those in the modern technological world. The people of Europe were in similar circumstances before this century; haunted by famine, epidemics and high levels of infant and child mortality. The average life span rarely exceeded four decades. Under such circumstances, not many could afford the luxury of worrying about the possibility of suffering at the end of their life.
The easing of material circumstances in western societies has brought a decrease in early deaths and in mortality overall, and a reduction in physical suffering. These dramatic improvements have been attributed more to improved nutrition, better living standards, sanitation and water supply, than to medical treatment. Affluence changed life and death considerations. Man could now afford to consider death and suffering. In addition to a new awareness of suffering at the end of life, which is no longer accepted as inevitable, the present concern for the way in which people die has been heightened by the fact that dying has changed so drastically with advancing techniques in modern medical care.

1.3 THE ILLNESSES FROM WHICH PEOPLE DIE

The illnesses from which people die have changed in relative importance since the turn of this century. One of the most significant changes since 1900 has been the decline in major communicable diseases as leading causes of death. There has been a consequent increase in relative importance of (a) the new diseases of civilisation and affluence; and of (b) dying from chronic and degenerative diseases; the latter occurring mainly later in life and thought to be associated with the ageing process. In the early period of life, the advent of the special care nursery has had its impact, with many more children surviving now, no matter how sickly.

The fact that death now not only stems from degenerative
disease, but also comes much later in life\* is of increasing concern
to people. Cardiovascular and cerebrovascular disease, the latter
commonly accompanied by degeneration, are becoming increasingly common
before death. As a result, the fear of dependency and, more so, the
fear of senility, have come to accompany the fear of a long, slow, at
times undignified and possibly painful death.

Coronary heart disease was almost unknown in the early 1900s.
Now it is the main cause of death in middle and older aged men and in
elderly women in most western countries. The expensive technological
attack mounted by the medical establishment against this disease has
little evidence to show that it has had any more than a marginal effect
on mortality.\(^5\) Illich presents evidence to show that there is no
advantage, and argues that:

\[\ldots\ the \ higher \ mortality \ of \ those \ benefited \ by \ mechanical \ care \ in \ the \ hospital \ is \ usually \ ascribed \ to \ fright. \quad 6\]

Yet more resources, human and technological, are invested in this area
of care than are channelled into any other aspect of disease preven-
tion or treatment.

The medical establishment has become progressively accustomed
to asking for and getting the newest available technologies for use,
often prior to any evidence as to their effectiveness or risks, and
more often without any consideration of any possible alternatives.

\(^*\) In America, the average life expectancy was around 40 years at the
turn of this century, and has risen to 70 years along with most
European countries. However, there has been no increase in the
life expectancy of males 30 years and over in OECD countries since
1950 (In Taylor, \textit{op.cit.}, p.18). Accidents and the new diseases
of civilisation seem to have had a stabilising effect (Illich, \textit{op.cit.}, p.89).

\(^5\) Taylor, \textit{op.cit.}, note 3, p.21.
\(^6\) Illich, \textit{op.cit.}, note 4, p.114.
The tendency to treat symptoms rather than to actually prevent the cause has become the common practice. An example of such a recent technological development is the surgical technique of coronary bypass grafting. A lengthy and costly operation, it is presented to those patients considered as suitable candidates, as the solution to their problem, often with no offer or suggestion of alternatives or optional methods of management, which could be equally effective, less costly and less traumatic. At a critical time, of great fear and apprehension, when the patient is in a most vulnerable condition, relying on his doctor for his care, he finds himself in a no-choice situation.

In a recently-published Melbourne study, the cost of a coronary by-pass graft was estimated at $5,000 in 1980 prices. The procedure had a survival rate of eighty-seven percent after five years. An increased return to full-time work was noted and fifty-five percent of the patients were free of angina post-operatively. This was a basic cost and did not take into account capital cost, equipment depreciation, cost of investigation or post-operative follow-up; nor did it include investigation costs of unsuitable candidates. The cost of these was not given, so it is hard to estimate the 'real' cost of each operation. Yet the authors feel that an expensive operation that returns the person to work may be economically preferable to invalidism and social support. Deeply-rooted cultural attitudes and western values become apparent. Physical vitality, independence, success, are valued and sought-after attributes. Dependency, physical or economic, is viewed as undesirable and not cost-effective. The authors agreed, however, that
preventive measures could reduce the cost of all forms of therapy most effectively. 7

The question here is whether society can afford to spend hundreds of thousands of dollars on 'saving' few lives, while other areas are being sadly neglected. The amount of investment society allows could be taken to reflect social attitudes towards this area of care. The dilemma is in choosing who has access and on the basis of what criteria? An equally difficult task is deciding what the cost of a human life is in the area of resource allocations, and whether society is justified in allocating vast resources to preserving few individual lives while denying these resources to more general health objectives. The Federal Minister of Health, Dr. Blewett, feels that politics, power and money have become the central issues in the health care debate, and it is these that determine the outcome. 8, 9

Cancer ranks amongst the commonest causes of death. Though much can be done for many forms of cancer, cancer still remains a dreaded disease because of its often fatal outcome and its progressive pervasive body erosion that leads to loss of control of basic body functions and dependence on others for bodily care. This occurs while the patient is conscious, and thus feeling very humiliated, and always in fear of ending his days in great pain. 10

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(8) Dr. Blewett on A.B.C. Science Programme, 24th April, 1983.

(9) Dr. Blewett, "Technology robbing basic health care", The Australian, April 25, 1983, p.3.

The fear of this destructive disease has been seized upon by the medical establishment. Its propaganda, propagated by the media as 'breakthroughs' and 'medical advances' has led to beliefs that great progress is being made in the treatment for cancer. Taylor cites Greenberg's findings where he examined the National Cancer Institute's statistics and concluded that, in the two decades from 1950 to 1970, there was very little improvement in the survival rates for cancers. Taylor also points out that the review of data of untreated breast cancer patients concluded that survival rates were not markedly different from those patients treated by surgery and with or without drugs and radiotherapy. Because of this, the treatment of breast cancer, the most common cause of cancer deaths in western women, is presently in a state of flux.11

However, in spite of data suggesting little improvement in survival rates, cancer treatment and research is one of the fastest-growing specialties. This led Taylor to state:

*The role of modern therapeutic medicine in coping with this disease has been vastly overemphasised.* 12

Cancer is a very emotive issue and because of it, very successfully manipulated by those with vested interests, be it lobby groups, researchers, the medical establishment, those with financial investments in its technology, or hospital administrators seeking new units or new equipment.

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(11) Taylor, *op.cit.*, note 3, pp.23,30
1.4 THE NEW LOCATION OF DYING

The greatest changes have occurred and are still occurring in the location and circumstances under which death takes place. A variety of reasons are perceived as having contributed to this trend.

At the turn of the century, most Britons and Americans died in their homes. By the late 1950s this had changed to fifty percent of Britons and sixty percent of Americans dying in hospitals and homes for the aged. By 1980, the American figure had risen to eighty percent, while in England, up to sixty percent of the rural deaths and up to seventy percent of urban deaths were institutionalised. These figures give some indication of the increased tendency towards institutionalising death and dying. In Australia, since the beginning of the century, people have felt that death should occur in hospital unless it came too quickly and suddenly to allow transfer there.

1.5 THE REASONS FOR THE INSTITUTIONALISATION TREND

1.5.1 Changed Perceptions of the Hospital Function

This interesting trend has been explained by some as due to a change in the perception of the function of the hospitals. In earlier days, people entered hospital to die, so hospitals were avoided. As medical advances made cures possible, the hospital began to be viewed as primarily an acute-care setting, for short-term care.

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(13) Doyle, op.cit., note 1, p.575.
and cures. People seeking cures began to enter more readily and of course those not cured or curable died there more often. Thus the hospital gradually began to be perceived as the appropriate place for the management of terminal illness and of death.

The situation today is that the majority of people, for various reasons, do not die at home: some because their treatment and care can only be met in hospital; others because home care is not possible or available; and others because they enter for investigation or treatment and never improve enough to leave.

1.5.2 Socio-economic and Cultural Reasons

This constant and great shift in the location of dying has been further encouraged by technological advances in medical care and by a host of social, cultural and economic reasons. With increased urbanisation, a much higher proportion of people live in small homes or units with no extra room for a sick room. A greater number of women are now working, so often there is no-one to care for the sick. The family unit has shrunk; many elderly live alone; if any relatives exist, few are willing to care for their sick and even fewer feel that they could possibly manage.

Because now death comes much later in life, people only witness death or care for the dying at a much later stage in their life. Also, with longer lives and many people dying in institutions, immediate contact with death is less frequent so the would-be carers become more reluctant to undertake the responsibility and are more

(18) Doyle, op.cit., note 1, p.575.
inclined to request institutionalisation of their dying. Very often the dying themselves, not wishing to be a burden to the family, and with little or no community support, seek institutional care as their only choice.

1.5.3 Changing Medical Practices and Public Expectations

Changing public and medical attitudes and expectations have also affected the institutionalisation trend. In our service-oriented society, increasingly people have been seeking outside help to alleviate the difficulties of care of their dying. Of course, the medical establishment, by managing terminal illness and dying under the medical model of disease, has given the impression that death and dying can only be managed in institutional settings with its solutions to be found in the available technology. Hence the institutionalisation - especially the hospitalisation of the dying - has acquired its prime justification. Only under medical care, in an institutional setting, can everything possible be done to sustain life and delay, hopefully avoid, death. So public expectation and pressure demand that death take place in hospital if it can be arranged. The dying are rarely given a choice: "They are in the best place for all they could wish and need, and it is to their benefit".

Death inevitably follows terminal illness. Because a high percentage of deaths from terminal illness occurs in institutional settings, it has been mistakenly assumed by the medical profession that all dying patients are terminally ill. The natural changes of ageing that bring about the end of life have been turned into

pathological events, treatable only with modern medical techniques, but, alas, not curable!! The medicalisation of dying has changing medical practices, and in America fear of litigation, have greatly contributed to the hospitalisation trend. As doctors lose some of their expertise and experience in managing terminal care in the home, they feel insecure in their ability to manage and become reluctant to undertake the responsibility. Also, with their changing perception of what requires investigation and treatment, the hospital choice comes more easily. As community medical and nursing skills in terminal care are either lost or not developed, those choosing to die at home find themselves in the hands of inexperienced carers and are more likely to face difficulties and more suffering, a situation in many ways similar to current obstetric practices and the home birth movement.

The public fascination with high technology is no less entrenched when it comes to health care expectations. Increasingly people have shown a reliance on technology and an overestimated expectation of what it can do. They accept technology, expecting solutions to their problems through it, even when they know that there is no solution. They place high hopes on what they believe the doctors have and can achieve through the application of medical technology. They prefer hospitals, expecting hospitalisation to alleviate their suffering, reduce their pain; in fact, people think that this way they will live longer.

The perception that serious illness can only be managed in hospitals is a belief propagated by the media and encouraged by the

(21) Doyle, op.cit., note 1, p.582.
(22) Illich, op.cit., note 4, p.111.
medical establishment and governments alike. This belief led people to seek hospitalisation for all illness perceived as serious. As more illness becomes hospitalised, and as more conditions of life become medicalised, so the quest for more resources grows, as well as the demand for more and newer technologies to meet newly-created needs. An increasing percentage of health funds is allocated towards life extension technology for terminal patients. This technology, once available, must be used. As more resources are directed into the terminal care technology, more dying people are encouraged to believe in and to seek a technologically-managed death in the institutional setting. For many, the hospital stands as the symbol and guardian of health. As they seek the hospital and the use of its technology, they make themselves dependent on it. Their death ceases to be a normal event, or their own death; it becomes instead a "technological event".23

1.5.4 Terminal Care as an Investment Opportunity

Health care delivery follows the dollar, and that dollar is heavily invested in the institutions where high technology attracts most people. The preoccupation of the people in most western technological countries with health and longer life has given the impetus to pushing ahead in the search for ways and means of prolonging life. The demand is for better and more care and more years to live. Stupendous sums of government and investors' share money are being put into the fight for longer life.*

(23) Ibid.
(*) That much of this is wasted because of inefficiencies and that poor dietary patterns and poor life-styles are more to blame for many health problems does not seem to count in the rush to throw more millions at health care.
Investment opportunities abound in the health sector in America, where investors have been advised to look into this area for investment because of the projected growth. This is based on the trend of a rapidly ageing population and the known expectations of the American people. The private sector of health care investment in Australia is not dissimilar to this.

As more investment is put into terminal care and life extension technology, greater use of it is expected and encouraged. The medical belief that it is the doctor's duty to save lives, irrespective of economic, moral, family, personal or social impact, encourages the use of all available means.

Thus those dying, whether from old age or other causes, become prime candidates for the extensive and expensive care mounted by the medical establishment in order to prolong life. But with such intensive care comes also a lonely death.

1.6 EFFECTS OF INSTITUTIONALISATION ON THE DYING

1.6.1 Isolation - Loneliness - Fear

The shift from dying at home to dying in institutions has greatly increased the loneliness of the patient and his estrangement from his familiar surroundings, his family, friends and relatives. Patients writing or speaking of their experiences, emotions and perceptions of their care in institutional settings, speak of fear, anger and depression, loneliness, helplessness and loss of control of the situation and of their own life. Feelings of anguish and

alienation from family, friends and staff are also mentioned. Doctors and nurses are seen as terribly bad communicators, who avoid talking to the dying.25

A dying patient may fear that he will be subjected to painful and uncomfortable procedures that may prolong existence but not a desirable quality of life. He may fear the unknown or that he may be abandoned once curative measures become useless. The dying need the comfort and reassurance that they will not be left alone and need to be secure in this knowledge. But for the doctors and nurses of the acute care hospital, terminal care is an area they are not interested in, nor one in which they choose to work. For this reason, it is important that these professionals come to grips with the fact that, when they are caring for the dying, they are no longer concerned with saving a life, and that the priority in this case is on providing a good death without needless procedures and suffering. It is, of course, very difficult for them to accept the philosophy of caring and treating with a view to death.26

In a hospital, the dying person is isolated physically and emotionally. He is surrounded by biased systems of communication, in a social setting that gives very low priority to the dying, his individual personality and inner feelings and experiences. His care is delivered in an environment which is seriously deficient emotionally. In hospitals, much effort is directed towards denial and evasion. Many doctors still believe that the dying or terminally ill do not wish to be told, so they do not tell the patient the truth.

This makes it very difficult for nurses, particularly if they feel the patient should be told, so they avoid the patient.

Ours is a death-denying society. Doctors and hospitals are no exception. Death is an event to be camouflaged, hidden from view, denied, evaded and avoided. So, as death approaches, patients are moved into single rooms, preferably closer to the door. From here it is easier to remove the body from the ward. At a time when the patient most needs people around him, he is isolated from them. The fact that he is dying removes from him his attributes and rights as a living person. This, and the evasion of his impending death by the professionals, are the first steps towards isolating him in his own loneliness, fears and anxieties.

1.6.2 The Failures of the Professionals

Care givers constantly fail to understand the needs of the dying patients. The much-publicised work of Elizabeth Kübler-Ross, who has developed a conceptual framework for understanding the process of dying and our ways of dealing with death and dying, has been a major contribution in this area. But her stage theory, when interpreted by well-meaning but inexperienced professionals, predisposes to an approach of putting the dying through these stages, until the ultimate acceptance occurs. They fail to remember, or they do not know, that the emotions of the dying patient ebb and flow and that not all dying people reach the final stage. There is much evidence


(*) Kübler-Ross has described the five stages which may occur when a person is dying: initial shock and numbness, the patient's denial of his impending death, his anger, his willingness to bargain for more time, depression, and preparatory grief and sometimes final peace and acceptance. A common misconception about these stages is that they will occur in the sequence described. Kübler-Ross, E. *On Death and Dying*. New York, 1969.
to show that several other factors influence the behaviour and experiences of the dying. The nature of the disease, the patient's ethnic background, the personality, maturity and life-style of the dying, age, religion, environment and social situation, all have their influence. Patients should not be made to conform to the idealised pattern upon which many professionals seem to have come to rely as part of their own coping mechanism.

Studies show that both doctors and nurses tend to avoid the dying patients. The doctors often, if hard pressed for time and in order to attend other patients more hopeful in terms of recovery, may prescribe life-sustaining techniques, knowing they will not provide a cure, simply because they do not have the time and because "terminal patients tend to be a low priority". Sometimes this onslaught of technology is a façade for denying the truth and facing the inevitable.

Generally nurses experience guilt and embarrassment if caught in conversation with a patient. Nurses tend to avoid dying patients, either because they have become too involved to be supportive, or because they are unable to handle the situation at all. In an environment that emphasises investigation, cure and life maintenance and prolongation, the expertise and outlook of staff are in mismatch with the dying patient's needs. In this type of environment, nurses become caught up with the technical aspects of patient care: monitoring them; taking and recording observations; checking devices; all of which suddenly become all-important and

time-consuming, so that if the patient wishes to talk they appear constantly busy and so avoid personal contact.\(^{32}\) This is mostly due to discomfort and not knowing what to say to a dying person or his relatives, who are under a great deal of stress, which the staff do not seem to notice.\(^{33}\) Yet, when dying is talked about openly, staff become less reluctant to talk to the patient and no longer avoid him.\(^{34}\)

The patient, even though he sees through all this, respects the unwritten rules of the institution and, not wishing to be considered out of line or a trouble-maker, conforms to the non-verbal request that he 'keeps quiet'. At the same time, he bottles up panic, fear, guilt and other emotions arising from this situation. At a time when he should be working towards a peaceful death, he is surrounded by denial and evasion.\(^{35}\)

1.6.3 Mechanisation and Dehumanisation of Dying

All these contribute to the lowered sense of meaningful humanity characterising the end of life in the institutional setting. The dehumanisation is increased by the electrical wiring, the tubes for intravenous fluids, the monitoring machines and electronic devices, all of which aim at delaying death; at least until doctors, nurses and the family have satisfied themselves that they have done all they can and have exhausted all available means of trying to avoid, prevent or postpone death.\(^{36}\) Then the patient can die, and if he is a good patient, he dies without too much lingering on after permission has been given and all have come to expect his death!

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\(^{34}\) Kobrzycki, op.cit., note 20, p.1313.

\(^{35}\) McIver, op.cit., note 26, p.38.

All the mechanisation, the unfamiliar and impersonal surroundings, sleep deprivation from frequent observations and disturbances, coupled in the dying with the fear and prospect of death, can lead to what has been called 'the intensive care syndrome', characterized by acute psychological and behavioural disturbances. Such distress may be worth enduring if cure is in sight, though it could hardly be justified; but for the dying patient these aids create the distance, distress and suffering without providing any cure. In fact, they often become the chosen substitute for the difficult-to-offer, comforting human care.

Medical technology is usually beneficial in the care of the acutely sick or injured persons, sometimes dramatically so. Not everybody agrees, however, on the extent of the measures which should be taken to keep death at bay. Some believe it is a duty to preserve every possible fragment of life. The medical establishment strongly supports this line, but others think that an excessive zeal to delay death can make the possible become senseless.

An increasing number of body functions, vital and otherwise, can be maintained by machines, mechanical respirators, cardiac stimulators, artificial kidneys, and other ingenious devices. No-one doubts their importance when used for the acutely ill, to support them in a crisis, so helping them survive to return to reasonable health. It is these positive outcomes and the human hope of avoiding the inevitable that feed the desire to seek and use all available medical technology. Nevertheless, such technology is often intrusive,

(37) Behnke and Bok, op.cit., note 14, p.11.
(38) Balon, op.cit., note 32, pp.163-164.
(40) Duff, R.S. "Guidelines for deciding care of critically ill or dying patients", Pediatrics, Vol.64, July 1979, p.17.
sometimes cruel and for the terminally or incurably ill, it is of little or no value. Hence its use to prolong a very limited form of life in such persons is increasingly being questioned. There is little justification for its use and it can cause distress to the family.41

In hospitals today there needs to be considerable thought before initiating the use of life-support technology, particularly when there is little hope of future recovery. It is a problem that cannot always be considered at leisure, especially when emergency resuscitation machines are called for, and that if used, can be regretted for a long time afterwards.42 When a state of suspended dying has been achieved, disconnection of support machinery is a disturbing procedure. Yet it has never before been possible to have patients of this type, who are the results of the successes of modern medicine when it is used thoughtlessly.43

Since most of the care of the dying takes place in acute hospitals, where much scientific apparatus is used to aid diagnosis and treatment of remediable conditions, the likelihood of it not being used on terminally ill or dying patients, at least initially, is quite low. Complex diagnostic tests, and distressing and ineffective therapeutic intervention are not what the dying need. Neither do they need intensive care technology, but require more intensive caring, though it is more common for them to receive good quality technical care, while their needs as living persons are neglected, because they are dying.44

(41) Hinton, op.cit., note 19, p.141.
Of course, the commitment to healing and curing and the sense of failure that dying leaves on one, act as strong incentives for the professionals to mobilise all resources and to employ all known diagnostic and therapeutic means "in an all out effort to avoid failure by delaying death". This is an aspect of what Taylor would call "medicine out of control".

1.6.4 The New Look for Meeting Death

The burning question is: What extent of technological intervention does the medical establishment consider justified when death is inevitable? People no longer depart in dignity, but in a welter of failed measures, betubed, monitored, artificially fed and artificially ventilated, excreting via tubes and catheters and looking anything but human beings. Our death-denying culture further adds to the impetus of this massive effort to face death in such an unrecognisable face. Whether it really is necessary to do all this to a dying human being so that the survivors will not feel guilty is something that every professional that can exercise power over decisions in this line of action, should ask himself every time he finds himself considering more treatment and more tubes.


CHAPTER 2

REDEFINING DEATH
2.1 INTRODUCTION

In modern medicine, the focus of attention has been on the postponement of death, originally through prevention and eradication of disease, but more recently through the development of impressive life-saving techniques and technology. The growing powers of medicine in prolonging life brought with them new and difficult problems. Advances in sophisticated life-support machines have reached the point where the patient can die only if the life-support machines are turned off. This has opened up a whole new area of problems in relation to the dying process, the dying person, the meaning of life and death, the criteria used in determining that death has occurred, medical initiatives in living and dying, and the extent to which life-maintenance efforts should be pursued. These problems are not only medical but also fundamentally moral and ethical, economic, political, legal and social in nature.

Life-maintenance technology created the macabre situation in which the body lives while the brain is dead. This, and the widespread use of procedures in organ transplanting, being two areas of major developments in medical technology, have led directly to concerns about defining death. As a direct result of new medical capabilities which can sustain the traditional signs of life in the severely ill and injured, death has become difficult to determine as the following definitions from various sources indicate:
Permanent cessation of the integrated functioning of the organism as a whole. 1

Irreversible cessation of spontaneous respiratory and/or circulatory functions. 2

Irreversible loss of spontaneous brain functions ... Irreversible loss of the ability to respond or communicate. 3

The cessation of life; the ceasing to exist; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereupon. 4

2.2 DISCUSSION

Death is not what it used to be. It is not as identifiable as it has been assumed to be in the past. Death was a phenomenon known to the ordinary observer through the visible and palpable manifestations of the cessation of respiration and heartbeat. The development and use of sophisticated machinery to artificially maintain both circulation and respiration has rendered doubtful the significance of these traditional 'vital signs' of pulse, heartbeat and respiration as indicators of continuing life. Death can and does occur in persons whose hearts are beating and whose blood is circulating. It is thus no longer possible to assume that the determining of whether and when a person has died is a relatively simple matter.

The issue of prolonging life creates the awesome responsibility of deciding the moment of death and of letting people die. 5 Even more awesome is the decision not to resuscitate. Such decisions need

(3) Ibid.
to be taken in advance if they are to be of any value. They also need to be made on an individual basis. Where the law recognises the wishes of the individual, this is made easier. The actual resuscitation situation requires speed, leaving no time for deliberations. Without previously-made decisions, reactions of the moment can be regretted for a long time later, in view of the severe brain damage and the suspended dying imposed on the patient. This is usually the case if resuscitation is attempted or continued after 'heart death', when the normally following period of a few minutes before brain death is prolonged into hours or even months. In such cases, by allowing the continuation of intensive medical attention upon a corpse, great injustice is being done to the patient, his family, the professional carers, other sick patients and the community footing the bill. The controversy that arose with the Karen Ann Quinlan case in America focused attention on the issues involved and their implications.

Switching off the machine to allow the process of dying to continue can, under the circumstances, be regarded as abandonment of heroic attempts to restore life. In Britain, as the law stands at present, failure to institute life-saving measures might, depending on the circumstances, constitute culpable negligence. In the Australian State of Victoria, proposed legislation aims to give terminally ill or fatally injured persons a choice and a say as to whether their life should be maintained by life-sustaining procedures and to the medical practitioners, immunity from liability for any act done in pursuance of this declaration, without negligence and in good

faith. In South Australia, it is now legal. Persons over eighteen can direct removal of life supports if the illness is terminal and would result in death had no life-support machines been used.10 *

Most doctors, faced with the problems of suspended dying of doomed patients kept alive by mechanical devices, almost hope for an infection that will put an end to their dilemma. The intertwining of the ethical problem of letting-die with that of defining death and the connection of both with the technology of artificial ventilation, is concisely expressed in a 1974 Lancet Editorial:

The doctor's dilemma about brain death arises only when patients are put on ventilators, and it is therefore of his own making. When a patient who already has severe brain damage develops respiratory insufficiency or cardiorespiratory arrest, careful thought should be taken before artificial respiration is extended beyond the immediate resuscitation period. Prolongation of such a patient's life ... reflects no credit on his doctors, particularly if this is done only so as to postpone the decision to let events take their natural course. It would be unfortunate if the time came when no patient in hospital could die without the last rites of modern medicine - a statutory period on the ventilator. 11

Traditionally, doctors, nurses, and the public believed that when a life could be saved there were never any trade-offs. However, while technological achievements have helped solve many problems of how to save lives, they have also created the problem of when to stop. In recent years, improvement in resuscitation procedures and developments in life-support technologies have resulted in an increasing number of patients accumulating in hospitals who can be kept alive

(10) A.B.C. Nationwide, November 28, 1983.
(*) See Appendix 1A for the 'Living Will' issued by the Voluntary Euthanasia Society of Victoria.
only by extra-ordinary means and for whom there is no hope of recovery. These are problems directly attributable to medical success. They are becoming widespread, affecting all of us. They are practical problems with financial implications and must begin to be seen as such. Where the so-called 'human vegetable' was once an infrequent problem in terminal wards of hospitals, it is now becoming a common problem.

The problem of suspended dying can create confusion and uncertainties that can have far-reaching and distressing consequences. Many social institutions, arrangements and practices depend upon a clear notion of whether a person is still alive or not. At stake are matters pertaining to homicide, burial, family relations, inheritance and, above all, the legal and moral rights possessed by, and the duties owed to, a living human being.

Increasingly the longstanding legal definition of death has been questioned as to its adequacy. Black's Law Dictionary defines death as:

*The cessation of life; the ceasing to exist; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereupon such as respiration, pulsation, etc.* (4th Ed., 1951)

This assumes that the criteria for determining death are settled and not in doubt among physicians. This is no longer the case, particularly since modern resuscitative and supportive measures are used.

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In an effort to clear up the confusion and to provide the necessary guidelines, alternatives have been proposed. These offer specific procedures, criteria and tests to aid the doctor in determining whether the patient has died. These proposals have been widely discussed, by doctors and the public, and while they have gained acceptance in some quarters, they have also stimulated considerable controversy and criticism and at times, public disquiet. The greatest concerns are the prolongation of life and suffering; that the medical profession, via the control of life technology, controls the time of death; and that patients die only when allowed to under these circumstances. Above all is the concern that death may be pronounced more readily if the dying person is a potential transplant donor.

The most widely accepted criteria for determining death are those formulated by the Ad Hoc Committee of the Harvard Medical School, under the chairmanship of Dr. H.K. Beecher. The Committee's primary purpose was to define irreversible coma as a new criterion for death. The Committee gave two reasons as to why there was a need for it:

(1) Improvements in resuscitative and supportive measures have led to increased efforts to save those desperately ill, with sometimes only partial success. This results in individuals whose heart continues to beat, but whose brain is irreversibly damaged. The burden is then great for the family, the hospital and those in need of the already-occupied beds.

(2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.17

(17) Ibid., p.55.
These new criteria go beyond the traditional standards of permanent cessation of heart and lung functions, without discounting them. They are set to deal with cases where life-support machinery is in use. They are essentially the following:

1. Unreceptivity and unresponsivity: Total unawareness to externally applied stimuli and complete unresponsiveness.

2. No spontaneous muscular movements or spontaneous respiration. After the patient is on the respirator, the total absence of spontaneous breathing may be established by turning the respirator off for three (3) minutes.

3. No reflexes, including brain and spinal reflexes.

4. Flat electroencephalogram (EEG).

5. All of the above to be reverified after 24 hours.

6. The patient must not be hypothermic (temperature below 32.2°C) or under the influence of central nervous system depressants. 18,19

The condition is to be determined only by a physician. Death is to be declared and then the respirator turned off. This latter point allows for the obtaining of organs for transplantation.

The Harvard criteria called for detailed verification of all the criteria, including EEG. If all the tests showed negative responses, this would confirm irreversible loss of brain function and the patient's death. 20 As a result of the debate that followed the publication of the report in the Journal of the American Medical

(18) Ibid., pp.56-58.
(20) Scott, op.cit., note 7, p.159.
Association (JAMA) in August 1968, the EEG criterion dropped from favour. Other sets of criteria were formulated, such as those of the University of Minnesota Health Science Center, which place more emphasis on clinical judgement and do not require EEG reading. But the Harvard criteria prevailed.

Soon after the Harvard Report appeared in JAMA, the 22nd World Medical Assembly in Sydney, Australia, proclaimed the Declaration of Sydney. The Declaration drew attention to the changes in diagnosing death brought about by artificial life-support machinery and advances in organ transplantation. It also emphasised that death is a gradual process with different tissues and cells dying at different times:

But clinical interest lies ... in the fate of a person... Determination of the point of death of the person makes it ethically permissible to cease attempts at resuscitation and in countries where the law permits, to remove organs from the cadaver.

The need of transplant teams to obtain organs in good condition from cadavers has stimulated the search for tests that would permit the death of the organism as a whole to be declared before the constituent organs have suffered extensive deterioration. This has given rise to public disquiet, with many people expressing concern that their organs are not removed while comatosed from treatable conditions. It has also prompted comments from ethicists, theologians, lawyers and others, many of whom feel that for a redefinition of death to be acceptable to the majority and morally justifiable, it must have the dying person's interests at heart and as a primary

(21) Walton, op.cit., note 6, p.31.
(22) Scott, op.cit., note 7, p.159.
concern, and not those of another sick person. For example, Ramsey argues that the focus on a new definition should be so that:

... those who have died need not have life sustaining measures inflicted upon their unburied corpses needlessly and at great expense to their families. 23

These reasons should be sufficient in themselves. Any benefit that may accrue to other patients must be an independent by-product. The issue should be resolved as though transplantation did not exist. Unless the two are treated apart, Ramsey feels that the medical profession could be accused of the desire to pass from the spectacular treatment of the dying and indeed of the dead, to the spectacular use of borrowed organs. 24 Cadaveric organ use is an issue that Fletcher does not perceive as unsavoury when he argues against the waste of human tissues and organs from the dead that could be used to restore health to the living, if only man could overcome his cultural-religious resistance to the idea. 25

Both the acceptability of brain death as a standard of death and the criteria to be used (usually the Harvard criteria or something very much like them) have found their way into statutory laws in some countries, such as Italy and Switzerland, and State statutes in the United States of America, with the Kansas Statute being the first in 1971. In America, a general acceptance followed which led to the Uniform Brain Death Act in 1978. 26 It states:

This Act expresses community approval of withdrawing extraordinary life support systems when the whole brain has irreversibly ceased to work.

and the definition is:

(24) Ibid.
For legal and medical purposes, an individual with irreversible cessation of all functioning of the brain, including the brain stem, is dead. 27

This allows the traditional criteria of cessation of blood circulation, breathing and heartbeat to be used if required.

Acceptance by means of legislation has taken place in Canada where the laws are brief, recognising brain death and eliminating liability for those doctors involved. In Britain, it has received support by the Medical Royal Colleges, which have made the criteria very strict, but legislation is not forthcoming. 28 In Australia, the Australian Royal College of Physicians and Surgeons has adopted the British method and criteria of determining brain death. In New South Wales, legislation is before Parliament at present. This will recognise death as the "irreversible cessation of brain function". It also aims at simplifying the procedures for obtaining human tissues after death, particularly when a person had not specifically expressed a wish to that effect. 29

In Victoria, legislation has been introduced giving doctors wide powers, allowing the removal of body tissues for transplant, through the Human Tissue Bill. 30 Donor cards are also being sent out with drivers' licences in an effort to enhance this. 31

(27) Ibid.
(28) Ibid., pp.160-162.
(*) See Appendix 2 for a sample donor card, circulated by the Australian Kidney Foundation.
Scott feels that harder decisions lie ahead. As it becomes easier to maintain circulation and nutrition by mechanical means, people who are brain dead could be used in their vegetative existence for a variety of experimental and research purposes, such as immunological research and drug testing. Their medical training contribution would be invaluable and they would provide a continuous source of hard-to-come-by human body components and by-products. Blood and organs are already being used. \(^{32}\) Fletcher, however, believes that technological advances will make these, or at least some of them, unnecessary. \(^{33}\)

2.3 IN CONCLUSION

Modern medicine, in its desperate attempts to save human life through modern technology, has generated a self-inflicted crisis, that of not knowing when to pronounce someone dead, and when to cease providing medical attentions to a corpse. This has forced the need to produce the entity of brain death: first, to aid doctors in deciding when to stop treatment, and to protect them from litigation and, secondly, to make legally possible the removal of organs for transplantation. In spite of widespread acceptance, people are still concerned that their organs may be removed while comatosed from treatable conditions, or that they may be pronounced dead earlier if they are potential organ donors. Hence the definition of the concept of brain death was seen as necessary to facilitate transplantation work, but also to assure the public that:

\(^{32}\) Scott, op.cit., note 7, pp.163-165.

\(^{33}\) Fletcher, op.cit., note 25, pp.22-23.
... no organ transplants will be performed, unless the clinical, ethical, human and moral requirements have been satisfied. 34

In New South Wales, proposed legislation for tissue transplantation established a new definition of death, that of "total cessation of all brain function", and permits doctors to remove organs without risking the possibility of legal action. 35 By this definition, Karen Ann Quinlan would be declared alive, having not lost all brain function.

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(35) Hospital and Health Care Australia, op.cit., note 9, p.7.
CHAPTER 3

THE EUTHANASIA DEBATE
CHAPTER 3
THE EUTHANASIA DEBATE

3.1 INTRODUCTION

Technological capabilities in the health care field have made it possible for the health professionals to offer cures or alternatives but in terminal care such alternatives are between dying now or dying later.

Prolonging life and the infliction of unnecessary suffering when the prognosis is hopeless and death is known to be unavoidable, is a costly practice for the patient, the family, the health care givers and society at large. The value of it has been increasingly questioned, since the costs are not just economic. Critics have raised many questions and many people are searching for their answers. Questions such as: How far should doctors go in delaying death? Which of the many techniques on prolonging life can they, in good conscience, omit in caring for terminally ill patients? When is it justifiable to withhold or withdraw treatment in order that a patient may be allowed to die? What can patients and doctors do in cases where a conflict exists between prolonging life and easing suffering? Is there anything a person can do before becoming a patient, to decrease the chances of being reduced to intolerable levels of investigation and suffering, loneliness and dehumanization? The answers are not easy for the doctors, and for the patients they are even more difficult. The sanctions against failing to treat are still greater than those for over-aggressiveness. The doctors find themselves drawn in more than one way. Their self-perception as healers encourages use of all available
technology to sustain life; as scientists, they invoke investigation in the search for cures; but as carers and comforters of the dying, when curing is no longer possible, they are at a loss. The dying patient is perceived as a failure of healing and medical science, and doctors find it difficult, if not impossible, to confront their failures.

The constitutional right of privacy includes the right to refuse treatment, but on the issue of euthanasia and of hastening death, that right has been questioned. Should human beings have the right to seek their own death? If so, under what conditions? Should others assist them in dying, and if so, who? Or should such death be prevented by religion, by law, or by anyone capable of intervening?

The arguments for and against are many. Active euthanasia is seen as killing, in contrast to passive euthanasia, which involves letting die by 'omission to save'. A marked division of opinion exists concerning the issue, which is of special significance in medicine. Many doctors acknowledge engaging in passive euthanasia, a practice supported by the Church and society and acceptable legally. However, the question of when a patient may be permitted to die must be distinguished from the question of what a doctor may intervene directly to terminate the life of a patient. The difference is sufficient to lead some ethicists to conclude that euthanasia is never justifiable.

The distinction between voluntary and involuntary euthanasia raises the central issue of informed consent and the question of who should take the responsibility for such consent in cases of (i) infants who now survive since the advent of modern special-care nurseries, and (ii) of comatose patients who cannot speak for themselves? The answer is increasingly taken out of the doctor-patient-family triad and sought in the courtrooms and legislative chambers.
The thought of involuntary euthanasia is associated with compulsory euthanasia programmes and is used as an argument by those objecting to active voluntary euthanasia. However, even if euthanasia is justified on moral grounds, the legalisation of it is a separate matter. So far, attempts to legalise it have met with failure, in contrast to attempts to pass legislative Bills, which would grant adults the legal right to have life-saving treatment stopped, which met with more success.

3.2 THE MEANINGS OF EUTHANASIA

The term 'euthanasia' originates from the Greek Eu, meaning good and Thonatos: death. Its definition encompasses the following meanings: a good death; a painless putting to death of persons having an incurable disease; an easy death; also, mercy killing.\(^1\)

The term originally meant a good death, a painless and happy death, with no reference to whether such a death was induced. Eventually a second meaning began to prevail, so that euthanasia now generally means "an act or method of causing death painlessly so as to end suffering".\(^2\) Thus euthanasia has come to be synonymous with a painless and deliberately foreshortened process of dying, and increasingly it has come to be equated with mercy killing.

In active euthanasia, an agent - usually a doctor - administers a death-dealing agent that kills the patient.

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Terms commonly used are:

(i) Active vs. Passive Euthanasia;
(ii) Voluntary vs. Involuntary Euthanasia; and
(iii) Killing vs. Letting Die, denoting the legal terminology for Active vs. Passive Euthanasia.

3.3 A "RIGHT TO DIE" vs. "QUANTITY OF LIFE"

The decision to end life is the final expression of the moral right to be free, a right that Illich feels that the patient has lost through the medicalisation of life. "The patient's unwillingness to die on his own" has made him pathetically dependent on the doctor and made the "right to be professionally killed into a major issue". Euthanasia is thus an issue that became important only since terminal care has been medicalised. Its contemporary contentious status is thus the direct outcome of the growing technological dependency of terminal care.

More and more frequently, doctors and nurses have been expected to make difficult decisions concerning the choice between life and death, or between life which is worth living and life which is hardly preferable to death; choices about which there are deep disagreements and uncertainties, but choices that increasingly have been expected of them because of the complexities of modern medicine.

For many people, personal integrity is more important than biological survival. Yet in the realm of medical care, the sanctity of life has had priority at all costs. When one is asking: What is preferable - quantity or quality of life? one is also asking: Can we any longer morally accept the principle that in medical care we are

(3) Bertram & Bandman, E., "Rights, justice and euthanasia", in M. Kohl (Ed.) Beneficent Euthanasia, New York, 1975, p.94.
always obliged to prolong life as much as the available means make possible? To say 'yes' is to assert that quantity is more important, but to say 'no' is to accept that quality comes first. Fletcher believes the latter, and states: "We should drop the classical sanctity of life ethic and embrace a quality of life ethic instead".\(^5\)

Thus, in considering prolongation of life, a major point to focus upon should be whether this can add to quality or simply quantity, and at what costs: physical and mental suffering of the patient and family; social, economic and other concerns of society must also be taken into account.\(^6\)

A great number of people dread the thought of prolonged suffering and pain, a lingering decline, or a vegetative existence. Their fears could be much reduced if they knew that they were in the care of a doctor who shares their views and would not needlessly strive to keep them alive. However, these days most people die in hospitals,\(^7\) in the care of doctors that they very rarely know well, and thus they are very unlikely to have that sort of understanding.\(^8\) Patients know that doctors differ in their attitudes to active vs. passive euthanasia and more and more people feel that the best way of securing a dignified death is to make their own arrangements, not relying on the doctor, their luck, or even upon nature.

With the institutionalization of death, the dying became dependent on the professionals. After several decades of full dependence, people are beginning to re-assert the right for self-determination

\(^{(5)}\) Fletcher, J. "The right to live and the right to die", In M. Kohl (Ed.), Beneficent Euthanasia. New York, 1975, p.46.


in death, even to the extent of removing death from the hospitals. This is a move that is hardly surprising at a time when more people are demanding greater say in their medical treatment and care. The suicide guide, entitled *A Guide to Self Deliverance*, and distributed by the British Voluntary Euthanasia Society (now EXIT) has been seen by some as an intermediate stage in the campaign for self-determination on death.\(^9\)

3.4 THE EUTHANASIA DEBATE

As indicated above, euthanasia is a very controversial issue, signifying to some, literally, a 'good death', while to others it signifies a morally outrageous death. To some it means any steps to hasten the dying process, whether actively doing something, or simply by the decision not to start, or to stop a medical treatment, so that the dying process can continue. To some, certain omissions are considered the same as euthanasia, while to others certain actions are.\(^10\)

The issue of actively hastening the death of a dying patient as against passively letting the patient die has been widely debated. The former point designates acts in which one does something directly to end life when it would otherwise go on, while the latter designates acts in which one refrains from doing something so that death will come more quickly. The question of whether a difference exists between actively aiding a person's death and letting him die through omitting a remedy, when his death is intended in both cases and comes about in both, has become a major issue in the euthanasia debate. What is


central to the issue is whether there is a difference between an act of commission and an act of omission. Those who use the outcome as the criterion would argue that there is no difference between them. Thus Fletcher argues:

This seems a cloudy and tenuous distinction; either way the intention is the same, the same end is willed and sought and the means used do not justify the ends in one case if not the other. 11

However, Ramsey takes the view that:

... the difference between only caring for the dying and acts of euthanasia is the important choice between doing something and doing nothing. In omission, no human agent causes the patient's death directly or indirectly. He dies his own death. 12

Passive euthanasia involves refraining from doing something that could prolong or save a human life, for reasons of compassion. In letting die, the agent's motivation is to refrain from doing something, thus letting the dying process continue. This is a legally acceptable act, fostered by religion and public attitudes.

What is legal, however, is not always ethical and similarly, what is morally justifiable may not be sanctioned by law. Therefore, whether it is moral or not to actively kill the dying patient for mercy, there is a clear legal distinction between active killing and simply letting die. Since active euthanasia involves actively and intentionally killing the person, it is clearly illegal. Being active and having the distinct element of intention for a specific outcome, that of death, under the present laws it is murder. The ethical reason of compassion does not enter into this legal definition. But in spite of it, only rarely have doctors been prosecuted for committing euthanasia

and even then they have been acquitted, usually on the grounds of discontinuing 'extra-ordinary' measures or omitting the same. 13, 14

This shows the clear-cut reliance by the courts on the medical community and the general tendency to place such moral decisions in the doctors' hands. It might be argued that this reflects the powerful position of the medical profession in our society and the control they have over definitions of health and illness, not to mention life and death definitions and their ethical and moral implications.

For the person who is inevitably dying, refusal of treatment seems much easier to justify, when there is simply nothing more that medical science can do to serve the interests of that person, but for a person who could go on living if treated, the judgement involved is much more qualitative. In the case of the dying person, to continue treatment is to impose a useless burden on the patient, while not serving that person's interests in any significant way. The questions are how far a doctor should go in his efforts to prolong life and whether all that medical science can offer should be done prior to doctors ceasing treatment, and withdrawing life-sustaining measures. In the latter case, the decision could be either to treat or not to treat, depending on which principle of medical ethics one uses.

Barton 15 lists four different principles and shows how each would influence the decision to treat or not to treat. Briefly, these are:


(14) "Bond for suicide assistance", Sydney Morning Herald, April 15, 1983, p.2. This article refers to the Larkin case in Melbourne which appears to have followed similar lines, acquitting Larkin on the grounds of enormous stress, and placing her on a good behaviour bond. Larkin, a nurse, had administered insulin to assist Mr. Pick to a dignified death.

(15) Barton, op.cit., note 10, pp.159-161.
(1) The Hippocratic principle: The emphasis here would be on doing what is thought to serve the interests of the patient.

(2) The quality of life principle: This makes decisions harder, since the judgement could be arrived at that some lives are not worth living - a conclusion not in accord with the fourth principle, and strongly opposed socially, by law, and by religion.

(3) The social benefitting principle: A dangerous and troublesome principle that allows the interests of one person to be traded against the interests of another.

(4) The right to life principle: This supports a right to life for all. What seems not to have been resolved here are the lengths to which one goes in ensuring that right.

From the Roman Catholic point of view, since the use of modern techniques on patients with hopeless outlook is a treatment that goes beyond the ordinary means to which one is bound, it cannot be held that there is an obligation to use them. But the professional view is that it is better to err on the side of active treatment since it can be at times difficult to determine what 'extra-ordinary measures' are. Yesterday's extra-ordinary techniques are today's routine.

However, at some point doctors have to stop staving off death; but the crucial question is, at what point? When a doctor thinks that the expected benefits do not justify the amount of suffering inflicted on a patient, particularly when treatment prolongs life but does not

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cure or ameliorate the condition, then the doctor may refrain from continuing or initiating a treatment. But he may also not do so, if uncertain of the prognosis. It is then that the dying person endures unnecessary suffering and the burden of suspended dying, because treatment is not curtailed. It is over this point that the euthanasia lobby has campaigned to introduce the right of the patient to exercise a choice, and to direct withdrawal of 'extra-ordinary' means of life maintenance.

3.4.1 Arguments in Support of Euthanasia

Those who believe in euthanasia insist that it is morally obligatory to respect the patient's wishes and withdraw life-sustaining measures, particularly when such people have expressed the fear of being kept alive by machines and requested termination of life under such circumstances, in which case there is no obligation to save such life. The legal acceptance of 'The Living Will' accepts this principle, and allows for withdrawal of extra-ordinary means if the person requests it.*

The supporters of this view argue that, as more and more people are being kept alive by life-support machines, there will be more and more patients maintained in a vegetative existence. The use of modern technologies becomes problematic on many accounts. Does one use them on all, and if so, are there enough for all? If not, who comes off a machine and who goes on? Who decides what happens to those that come off? Are they to be left to die? The active euthanasia proponents would argue that letting die can be worse than intentional killing, since it intentionally condemns someone to suffering and to a long,

(*) See Appendix 1A and 1B.
lingering, painful death, as compared to a good death by euthanatic means.

There are, of course, those who would argue that active euthanasia is kindness and since society and its members have an obligation to treat each other kindly, in certain circumstances there is a moral obligation to induce death; it is in fact seen as a duty to do so.\(^{(19)}\)

The critics of this idea would ask: If it is permissible to allow mortally ill people to die, why should it be necessary to wait for the disease to bring them close to the end? Why should not euthanasia be made available earlier?\(^{(20)}\) Or even to others with continuous suffering, but who are not terminally but perhaps chronically ill?

3.4.2 Arguments Against Euthanasia

Those opposing euthanasia would insist that it is important to society's ethical code that we do not end human life. A dogmatic prohibition is necessary to act as a bulwark against erosion of our value of others' lives. They argue that euthanasia is a reversal from culture to barbarism; it is against the traditional Christian teaching of the value of human life and against the great western Christian tradition that has never sanctioned the killing of the innocent.\(^{(21)}\) Welty goes on to defend this absolute opposition to euthanasia with the argument that:

\[\text{It is not God's will, and it is neither permitted to us mortals nor indeed possible for us to strip death}\]

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(20) Hinton, \textit{op. cit.}, note 14, p.146.
of all its terror and pain; death is meant to be the last and greatest test we have to undergo here on earth. 22

The possibilities of abusing euthanasia have also been used as arguments against it. But the greatest abuse of all, as seen by those opposing euthanasia, is that of the 'wedge principle', that legalisation makes possible. The wedge principle refers to an act that would injure humanity if raised to a general line of conduct and as such it is wrong, even in an individual case. Hence Sullivan states:

Euthanasia must not be administered, for to permit in a single instance the direct killing of an innocent person would be to admit a most dangerous wedge that might eventually put all life in a precarious condition. 23

The argument continues and makes the point that, once permitted, there is no way of stopping the advancement of that wedge. If voluntary euthanasia were legalised, there is good reason to believe that, at a later date, another Bill would legalise compulsory euthanasia. This would lead to killing off all incurable patients, charity patients, the aged, the deformed, the mentally afflicted. The Nazi holocaust is inevitably evoked by those using this argument.

Therefore, according to this view, euthanasia is never kindness and is misapplied when used to justify killing. 24 This is in spite of the fact that many have pointed out that the Nazis never engaged in mercy killing, but in merciless genocide. 25

(25) Fletcher, J., op.cit., note 5, p.137.
3.5 THE POSITION OF THE MEDICAL ESTABLISHMENT

Members of the medical profession generally reject the idea of euthanasia, seeing their role as that of healing and prolonging life rather than ending it. However, as more and more critics are alleging, doctors cannot always cure and there are times when prolonging life is of questionable value and can be seen as prolonging dying. It would therefore appear that the medical rejection of euthanasia is based less on logic or sound professional reasons and more on economic and utilitarian reasons, such as the maintenance of their traditional role and position of power, the maintenance of their image and of public confidence. The traditional conception of the doctor's role is that of 'loving care' and 'doing everything possible' in the final stages of life. From the medical point of view, a change in that conception could have adverse effects on the doctor-patient relationship and the doctor's image. *

Thus, the main objection of doctors to legalisation of active euthanasia appears to be the fear that they, by admitting to it even in the most justifiable cases, may be branded as killers and suffer loss of public confidence. This is a fear that Williams, a doctor himself, sees as ill-founded. He believes that patients would feel more secure with the doctor in the knowledge that they would not be forced to remain alive "in some horrid parody of life".  

Barton goes further, to say that active euthanasia would change the doctor's role, but maybe it should, so that doctors could

(*) This is not to say that doctors at all times ensure that nothing they do or say reflects badly on their image. For example, doctors have shown little concern regarding the effects on their image of deliberately deceiving their patients in front of relatives who may be patients themselves one day.

actively kill for mercy. 27

The American Medical Association (AMA) clearly rejects the intentional termination of life, while allowing under certain conditions, passive euthanasia. The Association states:

The intentional termination of the life of one human being by another - mercy killing - is contrary to that for which the medical profession stands and is contrary to the policy of the A.M.A. The cessation of the employment of extra-ordinary means to prolong the life of the body, when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family. The advice and judgement of the physician should be freely available to the patient and/or his immediate family. 28

Generally, members of the medical profession acknowledge engaging in and supporting the idea of passive euthanasia, while rejecting that of active euthanasia. The public seems to be also of the same opinion. In one study, 80 percent of the doctors and lay persons favoured passive euthanasia. Twice as many medical students favoured active euthanasia as did doctors. 29 In a 1973 poll, 37 percent of lay persons thought that the terminally ill patient with no cure in sight had the right to tell the doctor to put him out of his misery, while 53 percent thought it was wrong. 30 The doctors' self-perception as healers and the legal status of euthanasia were major factors affecting their attitudes. In a study, 59 percent of the doctors said that they would act upon request to withdraw treatment if they were sure it was legal, but only 27 percent said that they would positively hasten death if it were legal. 31

(28) Quoted in Steinbock, op.cit., note 15, p.70, by Steinbock.
(29) Williams, R.H. "Propagation, modification and termination of life", in R.H. Williams (Ed.), op.cit., note 6, p.94.
Traditionally, the doctor-patient relationship has been one where the doctor is in the position of power as the holder of information and of the means of treatment, while the patient is at the powerless receiving end. To accept situations where the patient is in a position to choose and dictate the terms of treatment or lack of it, would be to accept a reversal of this traditional doctor-patient power relationship, which could pose a threat to and create uncertainty and insecurity in the doctor who is not likely to have been prepared for such a situation. It could be a strong enough reason for the profession as a whole to object to such a change.

Thus, in responding to the Karen Ann Quinlan case, McCormick wrote in an Editorial in JAMA:

The medical profession should be terrified at the possibilities hidden... The Quinlan case should never have gotten to the courts. The real moral issue is not merely a narrowly considered one about the limits of our duty to sustain life... It is the very moral matrix of the healing profession... that roots in the conviction that decision making within health care, if it is to remain truly human and an expression of the cardinal rule of the physician, must be controlled primarily within the patient-doctor-family relationship... If technology and law were largely to usurp these prerogatives... we would all be worse off... That is always the root of oppression and depersonalisation.

Recently in the United Kingdom and America, several mechanisms which bring the patient more directly into the decision making process have been proposed. The 'Living Will' is a model letter, authorising the withholding of heroic measures and artificial means of sustaining life in the event of a terminal condition. It does not authorise active killing, but it eliminates heroic measures.

Its critics object to it because they argue it is not known whether the patient could have changed his mind since the Will was signed.*

In order to facilitate the 'right to die' and 'death with dignity', some States have introduced pieces of legislation to that effect. This excludes active euthanasia, but allows terminally ill patients to order their doctors to put an end to artificial life-sustaining efforts. 35 The first State to introduce such legislation in Australia is South Australia, where persons over eighteen can direct removal of life supports if the illness is terminal and would result in death had no life support technology been used. 36

3.6 CONSENT

A central question in the euthanasia debate is whether or not consent is necessary and/or a sufficient condition.

Amongst those who believe that acts of euthanasia are permissible and morally justifiable, some see fully informed and freely given consent as a necessary condition and that the consent must be given by the individual concerned, and it is not transferable. 37 Others believe that consent or request by the person concerned should be a sufficient condition for making euthanasia morally and legally permissible if the person is competent and voluntarily consents.** 38 The above does not allow for those who cannot express consent. Must a person suffer simply because he cannot express consent? There are

(*) See Appendix 1A and 1B for the 'Living Will', Australian and American.
(36) A.B.C. Nationwide, November 28, 1983.
(37) Bertram and Bandman, op.cit., note 3, p.84.
(**) The law at the moment does not incorporate such aspects.
those who feel that, if what is known of the person's wishes and preferences is to the effect of terminating life, then there exists a *prima facie* case to do so. 39*

3.6.1 Necessary Elements of Consent

In order for consent to be valid, the following elements are necessary:

1. Consent must be informed.
2. Consent must be voluntarily given.
3. The person giving it must be competent to do so.
4. The consent must cover the act that it is given for. 40

3.6.1.1 Fully informed consent:

This is an essential safeguard and one of the best defences against injustice. As applied to euthanasia, the patient should have the right to consent to his treatment or to his own death and to participate in those decisions that determine when death will occur and how life will continue.

The doctor has the obligation to determine the patient's wishes and to inform him of the prognosis, of various forms of treatment and how each may affect or alter the prognosis. The risks, discomforts and how much these can be alleviated, what functional life can be restored, must also be explained. Whether a cure or a remission is anticipated should also be pointed out. In countries where the patient bears the cost of treatment and hospitalisation, this may

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39) Brandt, *op.cit.*, note 17, pp.112-113.

(*) As it has already been pointed out, however, in our modern medical care systems, the patient's wishes are very unlikely to be known, since doctors in large institutions are not likely to know the patient before admission.

be a significant factor in any decision taken, and the patient should be informed of such costs.

The process of relaying the above information for fully informing a patient can be very complex. With modern technology, treatments have become highly technical and their details understood by few specialists. The question of who should give the information, the expert specialist or the patient's doctor, becomes important. How much of it is to be told? Is hope to be removed? Must all questions be answered truthfully? The patient's perception of life quality could help if known.

It has not been uncommon for doctors to withhold information and present an unduly optimistic picture, as well as attempting to prolong life as long as possible, making use of all facilities, artificial and otherwise, even when delaying death prolongs the agonies of the patient and his family. Williams believes that, when the prognosis is hopeless and there is much suffering, discussions to inform those concerned and to ascertain their wishes are crucial. If euthanasia is considered, the opinions of any special committees should also be sought.41

The time of relaying the information is also crucial, but choosing the appropriate moment can be very hard. Legally it should be given when the person is alert and can appreciate the complexities so that a sound and steady judgement may be made. But is it humane to speak of death when death is the last thing in the person's mind? But then, when one is too ill, or too affected by treatment, to consider what is involved, is the consent obtained valid? If the risk and/or

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(41) Williams, op.cit., note 6, p.148.
benefits cannot be assessed, is the person's wish to discontinue treatment to be obeyed?

This point, carried to its extreme, can be taken to mean that when someone is ill and distressed and wants death, he is in no mental condition to have his request for euthanasia taken seriously. Cases have been known where this has actually happened for the above reason, and because the resident doctor did not know the patient.

The other extreme is that, when one is well and happy and one's requests would be respected, one is unlikely to ask for death. That some of those that have requested euthanasia often change their mind when their suffering is relieved, even if they are fatally ill, further complicates matters.

What is of concern to patients is that, if the decisions are made, will they be respected or brushed aside as invalid? Not all doctors are inclined to consider euthanasia; their calling prevents them from destroying life. Their tendency to label patients as irrational or too sick to be taken seriously, or worse still, as incompetent, and thus brush their requests aside, stems not only from their self-perception as healers but also from their increased fear of litigation. Thus many patients may suffer and be subjected to unwished-for heroic treatments and measures, since doctors, for one or all of the above reasons, refuse to withhold treatment or to issue "no resuscitation orders".

(44) Cawley, op.cit., note 42, p.860.
3.6.1.2 The consent must be voluntarily given:

In what sense can a person exercise free will under duress of a failing body, possibly increasing insurmountable pain and potent drugs, in a hospital environment, while dependent for care on the hospital staff? "Illness makes one dependent and eager to please".46

Much has been written about the constraints of institutionalisation on free consent. The patient who is ill, particularly if seriously ill, is undoubtedly in some measure intimidated by the hospital setting, aware of his dependency on its staff and technology for curative or palliative care. Separation from his family, in a foreign environment, with rigid rules on visiting, possibly in a unit a great distance from home, all add to the sense of loneliness, separation and increased intimidation. But the most important factor of all is pain. Pain is associated with general discomfort and malaise, fatigue, sickness. It is tiring and emotionally draining. The patient in prolonged pain might agree to virtually anything for relief.

All these factors constitute a potent force of subtle coercion, hence: "to discuss a patient's wishes about extra-ordinary care under pain is to expect a decision under duress",47 a decision that would be more the staff's than the patient's and which, given under duress, is therefore invalid.

3.6.1.3 Competence:

The patient's competence at the time consent is sought is a crucial factor in achieving informed, valid consent. Often it is

(47) Ibid., p.201.
assumed that, if the person appears to be incompetent, confused or 'not himself', then one need not bother with consent, or if the patient expresses an opinion under such circumstances, it is legitimate to disregard that opinion.

Enforced treatments are justified on the grounds that the patient is not competent to decide. Aggressive efforts can go on and on because of the doctor's fear of being caught in a legal trap.48 There have been cases where psychiatric assessment became necessary prior to the patient being declared competent to decide whether he wished to continue or discontinue treatment.49

The cases of the incompetent and of terminally ill patients, and children who cannot speak for themselves, present the toughest of all ethical dilemmas. Increasingly, the answers have been sought in courts, in spite of the strong feelings held by many physicians that courts are far less qualified than they to make life-and-death decisions.50

The case of Karen Quinlan was only the first of a series that has concerned and confused lawyers and doctors alike. In subsequent cases, the courts' decisions have varied. In the Joseph Saikewicz case,* the court ruled that the courts should make such decisions. The court acknowledged that all persons have a right to

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(50) McCormick, op. cit., note 33.
(*) Joseph Saikewicz was 67 years old, had an IQ of 10, a mental age of 2 years, 8 months, and was suffering from acute myeloblastic monocytic leukaemia. The institution in which he lived sought court approval to withhold chemotherapy (therapy with cytotoxic drugs). In July 1976, approval was given. Joseph died 2 months later. In November 1977, the court published its reasons.
refuse life-prolonging treatment. It also acknowledged that there are public or state interests in preserving life, protecting the innocent and maintaining the integrity of the medical profession, and that in some cases the weight given to these interests may not permit the exercise of the private right to refuse treatment. That indicates that the public good is above that of individual interests, and that individuals' lives may be prolonged for the purpose of social benefit.

In the case of children and minors, the questions are numerous - ethical, moral, economic and social. Should babies doomed to a blighted life be enabled to survive? Who should decide: the doctors, the courts, the parents? If the parents have the right to give informed consent, does this mean they also have the right to deny consent, even when such denial means death for their child?

When parents decide to withhold consent, a number of questions on the rights and obligations of doctors, nurses, other staff and society arise. Should doctors go ahead regardless? Should they seek court interference? Should nurses go against parental and medical advice and feed malformed babies? Does society have the right to take the case to the courts and to impose the burden of care onto parents?

Some would say 'yes' and some would say 'no'. The question is, if one says 'yes', which infants should be allowed to die? On what grounds? By whose criteria?

In most cases so far taken to courts, in spite of medical intervention against the parents' wish, the babies have died. Some

have not and the parents say, of the burden of care imposed on them, "It is not fair". In a study at Yale University School of Medicine, Department of Pediatrics, of the 299 deaths in the special-care nursery over a period of three years, 14 percent were associated with discontinuance of treatment because of poor prognosis for "meaningful life". An awesome and agonising choice for staff and parents, because of its finality and the potential for error in prognosis, but one which made many of the doctors involved admit that this was not a new event; it had been an implicit practice that is now becoming more explicit. It is happening in Australia too. Paediatricians are seeking guidelines because they are faced with more frequent decisions as to whether to "save or let die".

In spite of publicity, we are no closer to setting any guidelines and the parents, the doctors, and those close to the deformed child or incompetent patient will still be faced with making increasingly controversial decisions in the context of growing ambiguity.

There are, of course, those that do not believe in euthanasia as currently understood, but support the 'good death' idea. This group of people believes that the aim should be to provide care for the imminently dying by providing:

(a) relief of pain;
(b) relief of suffering (physical and emotional);
(c) respect for the patient's right to refuse treatment; and
(d) universal provision of total health care.

(53) Clark et al., op.cit., note 49, p.44.
That is, no family alone should have to carry the burden of extensive care and costs. In this form, mercy can be extended to patients without inducing death.

Some supporters of this line are E. Kübler-Ross and Dr. Saunders, the founder of hospice in the United Kingdom. Most of the above principles are being implemented by hospices. Hinton, on speaking of euthanasia, says: "If euthanasia were accepted, would there be just as great an impetus to improve further the care of the dying?"\(^{56}\) It is a worrying thought that deficiencies in providing care for the incurable could find a latent counter-balance in increased requests for euthanasia. But there is also the concern that many people's request for letting die could go unanswered in the hope and the quest for a better way to die than that which is currently common in busy hospitals and nursing homes.

\(^{56}\) Hinton, \textit{op.cit.}, note 14, p.147.
CHAPTER 4

TERMINAL CARE IN SETTINGS OTHER THAN THE ACUTE CARE HOSPITAL
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TERMINAL CARE IN SETTINGS OTHER THAN THE ACUTE CARE HOSPITAL

4.1 INTRODUCTION

Once, a person died at home, surrounded by family, neighbours and clergy. With the gradual shift to the hospital and its sophisticated technology, family care and support were taken out of the hands of the family and so was death. They were placed in the hands of strangers who were professionals. Control over personal fate shifted from the patient to the institution and its staff. In an environment where the emphasis was more on cure than care, pathology became central and people peripheral. The dying found themselves isolated from their support systems and their familiar environment. They were cared for in an atmosphere of technical efficiency but also of depersonalisation. In such an environment, impersonal attitudes towards death and dying inevitably developed.

Medical and nursing staff became increasingly engrossed in the advancements of medical technologies, concentrating their efforts into providing better technical care, particularly for those who would get better. As these professionals learned to rely more and more on technological instruments and tools, they became more and more distant from the patient as a person. The sick person was seen more as a condition to be investigated, a diseased organ to be treated and cured, than as a sick person in need of care as well as cure.¹ It has been erroneously assumed that technical care, because of its effectiveness

in many cases, will also be effective for terminally ill patients; the basic assumption being that technical care is better and that it can replace human care. In such an environment the dying received efficient technical care but their total care as dying individuals has been grossly neglected.  

Once the care of the dying was moved into hospitals, the dying were left with little choice but to either enter and die in hospital or stay at home. Since quality care of the dying requires very little or no technology, the financing of the home health services has always been limited. The dying patients' families have thus been faced with the dilemma of either managing the round-the-clock care with little or no help, employing trained nursing personnel for after hours and weekends* if they could afford it, or institutionalising their sick - usually hospitalising them. This marked absence of choice is greater in Australia than it is in England or in America. In England, home health and help services are quite widespread and well developed, and in America terminal care teams are enhancing the home nursing services. The financing differs in each country.

The hospital, with its isolation and depersonalisation, its technological intrusion, the unnecessary investigations and treatments and the associated suffering, has remained and still is, the only choice for most dying persons. Those wishing to die in an environment different from that of the hospital, but still not being cared for by their family, had, and mostly still have, not much choice as to where they go.


(*) Most home health services, particularly in Australia, are on a Monday to Friday, 9 am to 5 pm basis, if they are offered at all.

Gradually the subtle yet marked dissatisfaction with prevailing treatments and ways of dying surfaced. Open discussions of how death touches all, of the treatment and care of the terminally ill, and of how the dying and their families can be helped, became more common. The increasing dissatisfaction with so much technological intervention and yet so little concern for the human beings with life-terminating illnesses, has led to the search for alternatives. The recognition of the inadequacy of care of the dying in the acute care setting, where death is at odds with the goals of care and control of disease, has led to the hospice movement. Hospices came into being in an attempt to fill the hiatus between home and hospital as a place to die. Now, at least some of those not wishing extraordinary measures to be used to prolong their lives, but not wishing to die at home, have a choice. As hospices proliferate, more people will be able to make this choice between hospital, hospice or home as a place to die.

4.2 THE HOSPITAL CARE OF THE DYING

4.2.1 Some Criticisms

The hospital care of the dying has been criticised for its isolation and its loneliness and its emphasis on technical care, while neglecting the care of the total person as a human being. The standard of nursing care of the dying in hospitals is also poor. Lamerton feels that "... did this not arise from ignorance one would call it hospital neglect". Criticism has also been levelled at the medical staff for their failure to relieve distress from physical

(4) Buckingham, R.W. "Primary care of the terminally ill", Geriatrics, Vol.34, December 1979, p.73.
symptoms, fear and panic and for not calling in other professionals who can be of help to the dying. This is further aggravated by the fact that many doctors fail to recognise that there is a problem. They feel that the dying receive good care and that nothing further is required. Yet evidence suggests that physical symptoms are inadequately treated. In one study of patients in the last week of their life, 16 percent were in almost continuous physical distress, while 27 percent suffered substantial distress less continuously. In another survey, 54 percent had pain, 18 percent were always in some pain and 26 percent had severe or very severe pain. Depression and anxiety were also often left untreated.

There are, of course, those who believe that hospital is the best place for the dying. Many patients, relatives and doctors fall within this group. Little evidence exists indicating where best to treat and care for those who are mortally ill. What evidence there is shows no consistent difference in ratings overall, though there are differences on specific aspects. The findings of a 1979 survey, comparing places and policies for terminal care, led Hinton to conclude that it is not necessarily unkind to keep the dying in acute hospitals that are more concerned with investigations and cures. The hospital scores came between the hospice and the foundation home* used in the

(*) These are outdated public assistance institutions taken over as hospitals under the National Health Service in 1948, and now used as hospitals for the chronically ill, most of them terminally ill. In spite of renovations, however, some foundation homes are so inappropriate and deficient that they have been called 'human warehouses'. Such a poor reputation makes many dying determined to stay at home, even if they have to suffer excessively.
study, showing that patients felt that there were neither overwhelming advantages or disadvantages in being cared for in such a setting. The trend favouring the hospital over the home reached statistical significance in data from the spouses.\(^9\) In Australia, particularly in rural areas, hospital care is the only choice and some feel that because of the community aspect, it can be a home away from home.\(^10\) The opposite can be argued, of course. That is, since for many the familiar hospital environment can be a reminder of past hopes and expectations of cure, it can be very upsetting and distressing as the end approaches.

4.3 PAIN MANAGEMENT

It is the pain of dying of which most people are in fear. Pain is the most notorious discomfort and often the thought of pain concerns people more than the fact that they are going to die. Being free of pain greatly assists the patient in dealing with death realistically. For many, death is a welcome relief from a prolonged and painful dying. Medical practice should not concern itself exclusively with the prolongation of life by administering technically possible treatments. The practice should be equally concerned with the relief of suffering. Pleas for the legalisation of euthanasia are based on too many cases of unrelieved pain and other forms of distress. The strength of the euthanasia appeal is to remedy cruelty and dehumanisation. "The continued evidence of suffering will gradually make it more plausible", Dame Cicely Saunders believes.\(^11\)

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The easing of pain and suffering should be the primary concern of professional carers, even at the risk of addiction, if the patient approves; for if death is near, addiction should not be an issue. Narcotics should therefore be given freely and regularly when needed. Opiates, being drugs of addiction, make the original decision to use them difficult, especially in chronic illness when death is a long way off. Doctors and nurses may need to revise their opinion on this when the patient is dying and medication should aim at relieving pain, anxiety and the fear of pain that can occupy the dying person's uppermost thoughts to the exclusion of all else.\(^{(12)}\)

It was mainly the unsatisfactory relief of pain of the dying in hospitals and the reluctance of doctors to prescribe regular analgesia that prompted Dr. Saunders\(^*\) to start the first hospice in London. She has effectively demonstrated that regularly administered narcotics control pain and render untenable the arguments of addiction and overdosage as justification for not medicating patients in pain on a round-the-clock basis.\(^{(13)}\)

Pain relief, using oral medication for as long as possible, should be the aim, leaving more invasive methods as a last resort.\(^{(14)}\) Even the comatosed patient should be assumed to experience pain, some feel, and analgesia should therefore continue.\(^{(15)}\) Evidence regarding pain management is contradictory when comparing hospital pain relief with home care pain control. Some studies show that pain was controlled as successfully at home as in hospitalised patients, and that in

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\(^{(12)}\) Buckingham, *op.cit.*, note 4, pp.74-75.
\(^{(13)}\) Now Dame Cicely Saunders.
fact, because of the decreased level of anxiety and stress which contribute to pain, home patients were able to participate in family routines until shortly preceding death.16,17

In those studies in which unsatisfactory relief of pain was found, this was most often due to the doctor's failure to prescribe and titrate medication levels for optimal relief, or to the patient's reluctance to accept medication out of fear that it would be detrimental to his recovery.18 The fact that some surveys are retrospective and rely on views expressed by surviving carers who tend to perceive more suffering than the professionals, may also affect the results presented. This was found to be the case by Reilly and Patten, whose study showed that the perception of the intensity of the patient's physical suffering and psychological distress differed considerably between relative carers and professionals.19,20 More recently it has been demonstrated that, in spite of good management, teaching and experience, 25 percent of home-managed patients suffered continuous pain, as compared to 20 percent in hospital, and below 10 percent in hospice.21 The latter appears to be the most successful in pain relief and management. This could be due to the fact that only dying patients in their last three months of life are accepted in hospices.

(19) Ibid.
(21) Doyle, D., op.cit., note 6, pp.577.
4.4 DYING AT HOME

When patients and their families wish it, home can be the best place to die, but it can also be the worst place if family willingness is lacking. Of course, home care is not for everyone and not all patients are suitable for it. Even when physical facilities are adequate, the emotional adjustments needed must not be minimised. Caring for the sick and dying has been so completely removed from everyday experiences that the stress of caring may cause tensions so that the sick are barely tolerated. For many people, dependence on family or friends can be difficult to endure.

4.4.1 Criteria for Successful Home Care

The first and most essential requirement for successful home care is willing relatives and friends who are prepared to undertake the responsibility. It must be remembered that they may be reluctant to do so because they feel inadequate and lacking in nursing skills. It is most important that adequate relief is organised for the relatives, especially if much attention is required outside waking hours. The inevitable desire to attend to all the patient's wants can soon turn into deep regret and even resentment when the lack of much-needed rest and sleep wears one down. To achieve this, the carers must know what available help there is, if any, and how to get it.

Help may not always be available but even when it is, limited use is often made of it, either because carers and patients are largely unaware of such help except for nursing, as found by Reilly and Patten, or because families wish to avoid intruders or are even reluctant to

(22) Gates, op.cit., note 10, p.342.
(23) Reilly and Patten, op.cit., note 20, p.534.
admit they need help. Doyle, in a 1982 survey, found that only 52 percent of seriously ill patients had a District Nurse and the seriousness of their condition or of their symptoms did not seem to make any difference.* In England, home help and home nursing services are well developed. Night sitter are available to patients at least three times a week; yet only 10 to 15 percent of patients made use of them. Over 41 percent of the patients in this study died at home and it was felt that nearer to 50 percent would do so if more night help was available.24

4.4.2 Advantages of Dying at Home

4.4.2.1 For the patient:

The potential benefits of home care for the terminally ill have long been established. Studies have determined that most dying patients prefer spending their final days at home rather than in hospital.25 The dying person can feel accepted, with no fear of isolation and loneliness or inappropriate handling. The patient is in control of the situation and not in an intimidating system. The professionals are no longer threatening or part of a power system over which the dying have no control. Home care nullifies the risks of unnecessary treatments and interference, of intubation-resuscitation and heroic measures, thus allowing a peaceful end with no prolongation of existence and suffering. 

(*) This, Doyle felt, was due to the possible reluctance of patients or families to report symptoms or, if they did, whether these were brought to the attention of the nurse. The latter points to unsatisfactory monitoring of the patient's needs and places the doctor's central position in this case in question.


(25) Sampson, op.cit., note 17, p.2405.
Many patients and their families view discharge from hospital to the home as a mixed blessing. Yet the home environment, with its familiar faces and things, can ease the trauma of adjustment that terminal illness imposes. At home the person retains his dignity and a degree of independence and control over his life, his affairs and his destiny, even when bodily functions begin to fail. He is not subjected to hospital routines and discipline, often designed to fulfil the wishes of the professionals rather than those of the patient. Home allows more choices which are more likely to be honoured. It provides continuity and reinforces the person's identity. Habits can be observed as long as possible. Familiar surroundings help maintain stability and a sense of security. Disorientation is less likely. Murray Parkes found that people dying at home were much more likely to remain mobile, out of bed and in clear consciousness than patients dying in hospital.

4.4.2.2 For the family:

Family involvement in most cases is good for the family. It gives them the opportunity to do something concrete that helps them face dying and eases acceptance. Home care mitigates feelings of guilt and assists in the process and resolution of grief. Above all, family and patient are not robbed of the privilege of making the most of the valuable time left. Relationships previously fragmented can be cemented and the opportunity to nurse a relative expiates guilt and results in warm memories. Having done all one feels one could have done leaves a positive feeling.

(29) Buckingham, op.cit., note 4, p.75.
Home care has a major impact upon adaptation following death. Studies have shown that grief and guilt are resolved more quickly and effectively when the family participates in the care. In a programme for dying children, many parents reported that their feelings of guilt and grief were eased by the knowledge that they had successfully completed a difficult and demanding task. The same group displayed better adjustment patterns and relatively rapid attainment of the family's previous lifestyle. Communication between the home carers and the patient has been found to be much more open than between institutional carers and the patient; more home carers than doctors spoke openly with the patients about their impending death. Also, spouses of hospital-centred patients suffer more psycho-physical distress, as determined by anorexia, weight loss, insomnia, tiredness and forgetfulness, than spouses of home-centred patients.

4.4.3 Disadvantages of Dying at Home

When someone dying is managed at home, his presence dominates family life and disrupts normal routines. For working adults, this means additional pressure and workload, or even loss of a job and of economic independence. Fears and anxieties about the patient's well-being, the family's ability to provide adequate care, and the anticipation of emotional stress can all deter people from attempting this transition. If demand is constant and pressure is great and not relieved, relations grow weary and then the patient may perceive his care as a burden. Guilt feelings can then arise for all.

(32) Reilly and Patten, *op.cit.*, note 20, p.536.
(33) Murray Parkes, *op.cit.*, note 18, p.15.
(34) Lichter, *op.cit.*, note 7, p.15.
The lack of home care facilities and of round-the-clock medical coverage can make the home carer's task very heavy and apprehension greater. The social isolation of the dying and their families by relatives, friends and neighbours reduces the chances of outside help even further. Our death-denying culture is so strong and attitudes so deeply embedded that people feel uncomfortable in the presence of a dying person. They begin to avoid them at a time when their help and support is most needed, particularly so where home care support is lacking, which is often the case in Australia.\(^{35}\)

Unfamiliarity with methods of caring for the sick, practices that the professionals, particularly nurses, take for granted, can be of great concern to the family. Caring has been so removed from daily life that even simple tasks need to be taught. The perceived professional efficiency adds to the family's sense of insecurity and inadequacy. A source of great stress to the family and the patient is the progression of terminal disease. As the end approaches, misapprehension of how to handle it increases tension and anxiety. As the family grows weary, these are magnified, so that even the effects of drugs administered are a cause for concern, even of mistrust of the doctor near the deathbed. Lamerton attributes this situation to the damaging propaganda of the euthanasia lobby.\(^{36}\)

Home care is quite often not all that it could be. The hardship and squalor met at times has shocked some people\(^{37}\) yet Reilly and Patten found that home unsuitability was rarely mentioned as a


However, dying at home can be just as lonely as dying in an institution and the chance of enduring more pain is often greater.

4.4.4 Support for the Family

Relatives determined to care for their dying at home will and do find a way. Such families are few. Fewer still are those who are well prepared to deal with the various problems that home care entails.

If home care is to succeed, the professional health care team support is crucial for both actual care and moral support. This must be available twenty-four hours a day, seven days a week, and needs to be supported by a network of resources that will permit needs to be met as they become evident. A list of numbers to call, on a twenty-four hour telephone basis is a much-needed comfort and gives the carers a sense of security. That someone can respond to their call for help allays fears and possible panic. Assurance that emergency measures can be obtained if needed to manage a crisis at home has been reported by families as the most important service.

Forewarning the family of what to expect next helps them cope. Doctor's visits, even if nothing can be done, are supportive. Advice on what to do and what not to do as death approaches is crucial. The family needs support and help so that they do not panic and, in an attempt to fight back against death, transfer the patient to hospital where unnecessary procedures, even resuscitation, may be carried out. Many families experience a sense of urgency as death approaches. The

(38) Reilly and Patten, *op.cit.*, note 20, p.536.
(41) Putnam et al., *op.cit.*, note 27, p.1452.
need to do something can undercut their original determination to let their patient die in peace. 42

Above all, the hospitalisation option must remain open. The burden of care may sometimes become too great to manage at home, even when considerable help is made available through the various domiciliary services. 43 Care must be exercised for hospitalisation not to be seen as a failure if it becomes necessary. Timely hospitalisation is important, before the family is exhausted and before it is too late for the patient to benefit from the move. 44

At times the relatives may need a short break from the stress of caring for their dying. A temporary admission to an in-patient facility may be all that is needed to provide relief. More often, temporary admissions are necessary to achieve symptom control and re-adjustment of treatment and care. This is because of the changing pattern of symptoms as the disease advances or the end approaches. Of course, some people feel more secure as in-patients and others seek admission so as not to burden the family. The limited home care support services could weigh heavily towards the patient's decision for institutional care. 45 Doyle found that this accounted for 90 percent of cases. 46 Sadly, some patients who would rather die at home and who could be managed there, are unable to do so, because the families insist that hospitalisation is better for them since there they have all the necessary services right at hand. This is not infrequently encouraged by the doctors, who either give in to family pressure, or feel insecure

(42) Lamerton, op.cit., note 15, p.816.  
(43) Lichter, op.cit., note 7, p.15.  
(44) Murray Parkes, op.cit., note 18, p.27.  
(45) Lichter, op.cit., note 7, p.15.  
(46) Doyle, op.cit., note 6, p.582.
in their ability to manage the dying at home. It seems that it is not only the relatives who need to be re-educated and encouraged to manage their dying at home, but doctors also need to regain their confidence.47

With the move towards home care, there is also more consideration given to the family, both during the terminal care period and afterwards. Practical help, professional help and the availability of contact persons during the period of care and afterwards, are all part of family care. The latter is achieved by putting the family in touch with support groups such as 'Make Today Count' during the period of care, and afterwards in touch with groups dealing with loss and bereavement, such as 'The Society of Compassionate Friends', an organisation of bereaved parents, or 'Widow to Widow', all of which can offer great help and emotional support.†

4.5 THE HOSPICE MOVEMENT

The recognition that the physical and social environment were as important a therapeutic tool for the dying as expert medical management, led Dr. Cicely Saunders to seek alternatives and to eventually establish the first hospice, that of St. Christopher's in London, in 1967. Her work has provided a powerful impetus to the hospice movement. Since then there has been increasing concern with the physical and emotional needs of the dying patients and their families.

(47) Sampson, op.cit., note 17, p.2405.
(†) Details of how these groups work can be found in:

4.5.1 Hospice Goals

The strength of the hospice lies in the ability of its staff to concentrate on the problems of the dying and their families. Hospice aims to make the final period before death as comfortable and productive as possible for the dying and his family, and at home if at all possible. Goals of care can be clearly defined in a hospice and a therapeutic pattern established. In hospice there is no high medical technology, but intensive personal caring.

Symptom management and control are seen as necessary for the patient's comfort and peace of mind. In hospice there is a variety of solutions to be used by staff, patient and family when trying to resolve the problem. The approach takes into account the needs of the patient and the concerns of the family. The most common problems requiring management are: pain, anorexia, nausea, vomiting, bowel problems such as diarrhoea and constipation, skin problems, confusion, restlessness, anxiety, depression, general weakness, incontinence. Geltman and Paige offer a detailed account of how these symptoms are managed under hospice care.\(^{(48)}\)

The relief of pain, both physical and psychological, is a hospice goal, seen as a prerequisite to attempts to alleviate emotional and spiritual suffering. Some of the approaches developed as part of hospice care have revolutionised care for all patients. Such an example is that of controlling pain without excessive drowsiness or addiction. Its feasibility was not appreciated until Dr. Saunders and her staff had effectively demonstrated that regularly given narcotics could be adjusted to the patient's level of pain without fear of overdosage or addiction, the arguments often used for not medicating

\(^{(48)}\) Geltman and Paige, \textit{op.cit.}, note 13, pp.79-85.
patients on a round-the-clock schedule and which have been rendered untenable since.49

Comfort, symptom management and frankness are hospice hallmarks. Hospice staff are prepared to talk frankly with the dying if they wish it. Lack of information can increase fear and anxiety. Fear, like any other form of suffering, needs to be relieved. Good communication can do this better than drugs. Communication must be both efficient and kind, with the main objective of maintaining morale and helping the patient achieve equanimity and peace of mind. There are, of course, the few who do not wish to know,50 but for the majority, knowing makes their remaining life less troubled by the lack of knowledge, and Wilkes, in a survey, found that two-thirds of those who knew their diagnosis were classed as having excellent quality of life at the end.51

Hospice uses a psychosocial model of care that provides good physical care and comfort but also, because of its holistic approach, views the patient's spiritual and psychosocial needs as being equally important. McIver believes that this is the type of care needed, not only by the dying, but also by those who are chronically ill.52 For the patient in distress, feeling rejected and neglected once all curative efforts have been exhausted, or who chooses no more curative efforts, the warm competence of hospice staff and their aim to improve the quality of the remaining life can be the only ray of hope at a time of despair.53

(49) Ibid.
4.5.2 Types of Hospices

In America there are presently about eight hundred hospices and in Britain, around forty were open by 1981. Three hospice categories can now be distinguished:

(1) Free-standing hospices - the original and most commonly known type;

(2) Hospital-based units - a more recent development; and

(3) Community-based specialist teams on terminal care, which are reversing the traditional practice of taking the patient to the care facility, by taking health care personnel to the patient.

4.5.2.1 Free-standing hospices:

Free-standing hospices attempt to fill the gap between home care and acute hospital care. Their goals and practices set them apart from other forms of institutional care and make them the choice for a patient wishing not to die at home, but also not wishing the type of life prolongation and curative efforts that acute hospitals offer. With increasing costs and the continued expectation of the public for care by professionals, the need for hospice care in institutions or at home has begun to be carefully looked at. Health policy-makers are beginning to look at ways of how to encourage the integration of hospice care into the existing health care system. The risk here is loss of, and inhibition of, innovation and diversity that have characterised hospice practices so far.

4.5.2.2 Hospital-based units:

The hospital-based terminal care units, or palliative care units, offer the significant advantage of economy of scale, but their

(54) Geltman and Paige, op. cit., note 13, p.78.
(55) Morris, op.cit., note 2, p.287.
(56) "Experts probe issues around hospice care", In Hospitals, Vol.54, June 1, 1980, pp.63-67.
staff need to gain the necessary autonomy so as to handle competing claims placed upon them by the large institution. Their presence in these institutions can do much to influence and modify attitudes and practices relating to death and dying. These units are also considered desirable because they offer symptom control for the patient and support for the family, while allowing access to specialists' services should they be necessary.57

4.5.2.3 Community-based specialist teams:

Hospice principles can be applied anywhere, but not without the expertise of a supporting team, and medical back-up. The terminal care community-based team is a new concept and has the advantage that it can work within the existing system of care. It can start immediately, using existing facilities and resources. It brings hospice skills and care to the patient at an earlier stage, without competing with hospice institutions and it is relatively inexpensive. It has teaching potential and it appeals to General Practitioners who wish to continue caring for their dying patients. These were some of the advantages reported by the St. Thomas' Hospital Terminal Care Support Team. 58

The goals of such a team are: (a) rapid, informed clinical evaluation of the terminally ill, with emphasis on effective symptom control; (b) attention for the patient but also for the family; (c) planning future care, whether at home or in another care facility; (d) reducing inappropriate procedures and providing up-to-date information on available resources; (e) providing continuity of care; and

(f) researching into problems and dealing with them as they arise.\textsuperscript{59}

The terminal care teams support the relatives and enable patients to die at home if they so wish. They consist of nurses, social workers, physiotherapists, chaplains, and a doctor specialising in terminal care.

4.5.3 The Hospice as a Challenge

The hospice movement has caused concern for some doctors who saw it as the development of yet another specialty that would further erode the family physician's practice. The movement has been viewed by many as a movement for reform that has challenged customary attitudes and ways of care of the dying and has achieved the bringing about of changes in these attitudes. The rights and roles of patients, the responsibility and accountability of care givers, have been discussed and reformulated by individuals, institutions and professional societies. The physician's right to withhold an unfavourable or poor prognosis from the patient, or to prescribe treatment without discussing alternatives with the patient has been challenged by the powerful American Hospital Association in its Patients' Bill of Rights.\textsuperscript{60} In Australia, the Medical Consumers' Association has responded by adopting, modifying and publicising this Bill of Rights.*

The hospice movement has spread and is now at a critical point. In America, where efforts are being made to eventually integrate it into the health care system, the way in which it is integrated will determine its scope, quality and longevity. Though an institution

\textsuperscript{(59)} Erle, \textit{op. cit.}, note 53, p.1164.


(*) See Appendix 3.
aiming at change needs freedom to carry out its ideas, it must also engage in negotiations to secure the approval of regulatory agencies trying to strike a balance between the ideals of reform and the political and economic realities. Reformers and their goals represent change and thus challenge the status quo. Hospices' emphasis on palliative care for symptom control is a challenge to curative treatment. Intensive personal care is a challenge to intensive technology. Family involvement challenges the perception of the family as visitors only. Interdisciplinary teams are a challenge to specialisation and departmentalisation. A system that provides continuous care in a variety of settings is a challenge to many health agencies operating separately. The question that the movement must now ask itself is: If compromise is necessary for the survival of the movement, will the ideal survive with the compromise?\textsuperscript{61} McIver feels very strongly about this, when she states:

\begin{quote}
Hospices should function independently from other institutions to prevent the carry over of traditional attitudes, policies and practices. \textsuperscript{62}
\end{quote}

4.6 COST OF TERMINAL CARE

Resources are, by definition, limited. There is an increasing awareness that this economic truism applies to terminal care resources too. The cost differential of caring for the dying at home, in a hospice or hospital has implications for total medical care cost. It also has health care policy implications, present and future. It affects government cost containment initiatives and intensive care provision plans for the dying.

\begin{itemize}
\item[(61)] \textit{Ibid.}
\item[(62)] McIver, \textit{op.cit.}, note 52, p.41.
\end{itemize}
The cost of dying in institutional settings is commensurate with the institution's level of function and technological equipment. Heroic measures and medical interventions to postpone death require costly high technology and medical expertise. These are being increasingly perceived by patients and their relatives as undesirable intrusions, causing unnecessary suffering. This suffering and the rising costs prompt many people to remove themselves from the acute hospital environment to that of a hospice, the home or, in Australia, into a nursing home, where the cost to the patient is less, intervention is avoided and death can occur in a more dignified and peaceful manner.

As home care becomes established, terminal care shifts from hospital-based medical management to home-based nursing management and support. Dying at home reduces the financial burden of being an in-patient. In-patient expenses can amount to 25 percent of the family's weekly income. In America, insurance companies are just beginning to provide coverage for dying at home or in a hospice. Most individual policies also provide for some home care benefits, but money is hard to get and it often entails undesirable obligations.63

Hospice care has shown that, by reducing the appropriate tests and procedures, it can deliver care at a cost below that of acute hospital care, even when more time is given to the patient. Yet third-party reimbursement for hospice services has been a major issue in America. After the initial enthusiasm, the potential for excessive cost and commercial abuse enjoined caution. In a period of rapidly

(*) This will be elaborated upon later in this Chapter.
rising health care costs, the general unavailability of reimbursement has slowed developments in this area. 64

Home, hospice or institutional hospice care supports the family and the dying in meeting their objective, while keeping a number of hospital beds free. This has a double effect when utilisation of these beds by acute cases is taken into account. Amado et al. found, in a study of fifty-five patients, that home/hospice intervention saved $93,549 at 1979 health care value, or 943 hospital bed days. Hence they recommend that, if third-party financing could be made available, hospice care be fused onto existing health care services. 65 That home or hospice care is a less expensive form of care for the dying, and that excessive technology does not necessarily improve a person's quality of life at this stage but only adds to cost, were the major findings of a pilot study conducted by Bloom and Kissick. 66 In this study, they measured the billed charges of the last two weeks of life for terminally ill patients dying at home versus those dying in hospital. It was found that the hospital terminal care was 10.5 times greater, exceeding home care costs by $106,000 for nineteen patients. This was found to be due to the greater range and larger quantity of diagnostic and therapeutic services provided for the hospitalised dying. The 10.5 fold difference bought for them more intensive technological measures - diagnostic, therapeutic and palliative - with diagnostic and therapeutic services given to nearly all patients until the day of death. (*)

(64) Erle, op. cit., note 53, p.1163.
(65) Amado et al., op. cit., note 3, p.526.
(*)) For cost details, see Appendix 4.
The great cost differences found in the Bloom and Kissick study suggest that home care is an important economic alternative to hospital care in terminal illness.\(^{(67)}\) The extraordinary disparity found in this study raises the question of utilisation of scarce resources and the necessity of such an extensive provision of these services to terminally ill patients. However, though the cost-effectiveness of home care is obvious, the fact that issues of monetary costs bear a complex relationship to other hidden costs to the family and society, must not be disregarded. The quality of care must remain a primary consideration. The fact that dying people may choose to avail themselves of the more costly but more intensive technological measures of hospital care must also be taken into account. That our society has traditionally tended to provide the terminally ill with sophisticated technological treatment, and to sustain life as long as possible as a way of dealing with death and dying, must not be forgotten. This tendency has encouraged certain cultural attitudes and social expectations that can not be easily altered because of economic considerations.

Economic considerations could, in fact, further encourage the seeking of hospitalisation. All but one hospitalized patient in the Bloom and Kissick study\(^{(68)}\) would have qualified for benefits under the proposed Catastrophic Health Insurance Legislation, as their bills exceeded the $2,500 limit (mean cost was $2,986). Cost coverage could act as a strong incentive and stimulus to categorise dying and/or terminal illness as catastrophic and therefore a technological problem. As such it could and should be managed in hospitals and be reimbursed by health insurance funds.

\(^{(67)}\) Ibid.  
\(^{(68)}\) Ibid.
While, in the American system, services are on a fee-for-service basis, in the British system the cost of terminal care is borne by the Government who provides most health care services. Thus the incentive for seeking more viable economic alternatives in hospital care remains with the Government. The problems faced under the British system are those of cost for the Government and those of quality and standards of care for the patients. Many dying choose home as a better alternative to that of institutional care, even if it entails more hardship and often more suffering. 69,70

4.7 THE AUSTRALIAN SCENE

The Australian system of care is somewhere in between the British and the American system, except that neither system has an exact equivalent to the Australian nursing home. Survey findings suggest that the cost of providing home care services is less than the cost of hospital care, except in cases of extremely intensive levels of home care. In the same survey, the quality of home care was found to be at least as good as hospital care when and if it could be provided. Ten to 33 percent of hospital, and 25 percent of nursing home patients could be managed at home if adequate community-based care facilities were available. These findings were also borne out by studies both in Britain and in Canada. 71 In the former, it was found that only a small improvement in domiciliary care would keep 25 percent of hospitalised dying out of hospital. 72

(69) Hinton, op.cit., note 37, p.152.
(71) Relative Cost of Home Care and Nursing Home and Hospital Care in Australia. Commonwealth Department of Health, Monograph Series No.10, Canberra, 1980, pp.27, 85, 90, 93.
(72) Hinton, op.cit., note 37, p.156.
In Australia, home care services are greatly lacking and, if present, they are still at a very rudimentary level. As a result most people die in hospitals or nursing homes, often in circumstances that are far from ideal or desired by the dying.  

4.7.1 Nursing Homes

In Australia, 'good care' is still seen as institutional care. Nursing homes have developed into the institutions that fulfill the roles of:

(a) providing respite care;
(b) providing care for the chronically ill and those incapable of self-care;
(c) homes for the aged, providing long-term residential care; and
(d) often providing terminal care for those patients unable to be managed at home and for whom the acute hospital can offer no further treatment or care.

Admission is on medical or hospital social worker's recommendation. Nursing homes are required to be licensed. However, some fail to maintain Health Department standards and thus lose their licence. Conditions and services also vary in the licensed homes. Further, standards of care and staff training and expertise vary widely from home to home. It is important to note that 58 percent of all the nursing workforce in nursing homes is comprised of Assistants in Nursing* and 79.4 percent of these are in private nursing homes.  

Australia has a higher number of nursing home beds per capita than any other country. This number was 4 beds per 1,000 population in 1976 and rose to 4.5 beds per 1,000 population in 1980. In bed numbers

(*) Untrained staff.
this means 55,578 nursing home beds in 1976 rose to 65,289 beds in 1980. Of these, 35,850 are beds run for private profit. The State of New South Wales has 26,529 beds, or 5.2 beds per 1,000 population, of which 17,539 are private profit beds.  

This may be partially due to the social demand for this type of institutional care.

There has developed within the community, according to the Department of Health, the attitude that to have your aged relative admitted to a Nursing Home is the normal thing to do when that person ceases to be able to look after himself ... by placement there will be the feeling that the family's obligation has been discharged.  

This attitude has been perpetuated and encouraged and has become part of the cultural attitudes and expectations of Australian society. So nursing homes have waiting lists and there is a public outcry for improvements in the shortage of these beds. Ironically, however, thousands are living in them needlessly.

The present funding arrangements have also contributed to this trend. Approved nursing homes have Commonwealth subsidies. Some health funds also subsidise nursing home care. So it is easier for one to receive cost coverage for institutional care than for home care.

General hospitals which are well equipped in terms of staff, expertise and facilities to meet the dying patient's needs are being criticised for their poor record of caring for the terminally ill. At the same time, 30 to 40 percent of the dying end their days in nursing homes, in an environment of inadequacy of care and in a place totally ill-equipped to manage the needs of the dying.


(76) In a home or at a home: Accommodation and home care for the aged. A report from the House of Representatives, October 1982, as quoted by Dorgan, D. and Myers, K., Who cares? About caring for the ill at home. Surry Hill, N.S.W., 1983, p.73.
As Professor Balfour Mount put it:

*More is needed than tender loving care and this is frequently complex enough that it has to be done by a team.*

The nursing home is hardly likely to provide this.

4.7.2 Hospital Care

Hospital costs have been escalating, with teaching hospital bed day costs being the highest. Yet surveys conducted at different hospitals at various times show that an average of 10 percent of all occupied beds are occupied by terminally ill patients, whose life-expectancy is less than three months and for whom the acute care setting can offer no better care than other, less expensive, facilities, or even the home. Most of these patients (40 percent) once they are deemed terminal with no more curative treatment possible, are often discharged into the hands of frantic, helpless, unprepared relatives, who do not know how to cope and have no back-up services for support, and nobody to turn to. It comes as no surprise that the dying are rushed back to hospital as death approaches. At a time when the dying need peace and comfort, they are faced with the trauma of transfer and of possible technological intervention and needless suffering.

In spite of escalating costs and repeated Government calls for cost containment, the financial incentive is towards maintaining institutional care rather than expanding domiciliary services. The fundamental problem is believed to be the Commonwealth funding policy, particularly for nursing homes, which gives State and Local Governments

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the financial incentive to maintain nursing homes, rather than to expand domiciliary care. The 1982/83 Commonwealth spending on institutional care, used by 3 percent of the aged, was eleven times as much as that of home care used by 10 percent of the aged. This uniquely Australian institution of care seems to have gained enough support to attract high funding.

Health insurance benefits only apply to the institutional care. Payments are made for repeated hospitalisation or for care in other long-term institutional facilities, but not for home care or home services. Thus many patients can not afford to go home, even when the relatives are willing to take them, and professional care can be arranged. This is because home nursing is very expensive and hospital and medical funds refund far more towards the cost of institutional care than towards home care. Benefits for home care are limited to only two, both of which are means tested, one of them twice - the only benefit in Australia to be doubly means tested.

Home nursing services are mainly available to residents of major cities on a Monday to Friday, 9 am to 5 pm basis. After hours and weekend care remains totally unsupported. If private nurses are engaged, the family usually bears the costs.

Home care, if it is to become a viable alternative to institutional care, needs professional back-up support on a twenty-four hour basis, seven days a week. Presently this is not available, and neither is there any specialist terminal care team available. Most care of the dying is done by relatives and generalist community nurses. The only

(79) Dorgan and Myers, op.cit., note 76, pp.73-74.
(80) Ibid., pp.35, 54.
specialist oncology sisters in New South Wales are seven sisters in the North Shore area of Sydney, one in Wollongong, and one attached to the Royal Alexandra Hospital for Children, Sydney, all on a Monday to Friday basis. The Seven Hills area has the only private palliative care unit in New South Wales, that of Mount Carmel, which extends its services to the local community. Yet a little more community support would help many more stay at home longer, or even die at home.

There are, of course, many people who still believe that only hospitals can offer quality care. This, coupled with the widespread traditional attitudes and expectations that death should occur in hospital, encourages many to hospitalise their dying. Many doctors hold similar views and, as the end approaches, they recommend or even insist at times, that the dying be admitted to an institution. Dorgan and Myers suggest that this may be the medical profession's way of guarding against legal action against them after death. It could also be that they lack experience and confidence, or simply that they do not wish to be disturbed by housecalls.

4.7.3 Alternatives

Some large city hospitals have recognised the need of special expertise in terminal care and the special needs of the dying. As a response to it, they have established their own palliative care units and some have even been able to form palliative care teams, manned by those interested and/or experienced in the care of the dying. Their services, however, can only be offered on a limited scale, mainly to cancer patients and usually their own patients. Without specially

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(82) Dorgan and Myers, op.cit., note 79, p.78.
allocated funds, such efforts can only be limited, in spite of the awareness of the need. Continuing public pressure and media publicity is beginning to give results, the first such success being an oncology sister to follow-up paediatric cancer cases at home, from the Royal Alexandra Hospital for Children.

Another alternative, but very limited, is the choice for hospice care. Hospices are very few and the choice is only available to a small number of people in capital cities. There are presently six hospices in New South Wales, all within the Sydney Metropolitan area, and they will only accept people who are in their last three months of life. Some offer day-care facilities at $90 a day, which is lower than in-patient cost and which keeps the family at work while allowing them involvement in the care of their dying. The desired home care hospice service remains a theoretical concept, since attempts to launch it have failed because of lack of approval for funds.84,85 Of course, hospices do not exist in rural areas or in smaller cities, where the hospital remains the primary choice, and often the only choice, if home care can not be arranged or managed.

The most commonly chosen alternative remains the nursing home. Within the Australian community, the prevailing attitude is that the family's sense of obligation is discharged with placement. This also solves the problem of constant worry of what will happen to, and who will look after the person needing care. For many aged, however, nursing home placement is viewed as a time to die, so that they cease to be a constant problem and burden to the family, and of course many

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terminally ill do die very soon after admission. Hinton quotes the figure of 56 percent dying within a week of admission to homes for terminal care, in Britain.

4.8 CONCLUDING REMARKS

In a death-denying society, the more intensive caring needed by the dying may not be at its best in hospitals catering for acute cases, with the emphasis towards cure rather than care. In hospitals, family support suffers, communications systems are misleading and the dying are isolated at a time when they are most in need of human presence. Hospital carers deliver quite high technical care, but neglect the patient's total needs. These needs can be met equally well in a hospice environment or at home, the patient having the final choice.

The patient and relative carers need advice about the services available and encouragement to use them. They need to discuss alternatives available to them regarding place of death. Choices must be discussed early to allow for planning and preparation. To meet this, health professionals must be aware of the available alternatives to hospital death, and must be willing to discuss these with the patient and family.

Home can provide a very secure, familiar and acceptable environment for the terminally ill patient and his family. Decisions for choosing home care impinge on many factors: on the willingness of the family; the existence of and relationship with other available family members; the available domiciliary support services; and any other

(86) Hinton, op.cit., note 9, pp.67-68.
resources that the family can call upon or use for help. The patient's condition, its treatment and side-effects and how these impinge on family routine; the means of pain relief and how they can be obtained; all these and many more factors will determine the outcome.

Cost containment considerations are another impinging factor on the care of the terminally ill. Home care presents a very viable economic alternative to institutional care, but it must remain as an open alternative with the final choice resting with the patient and/or his family. Cost is only one criterion that may affect the final choice. Of course, unless Governments redistribute their money allocations, to bring home support services on a twenty-four hour basis, and to remove financial reimbursement incentives towards institutionalised care, then the tendency for and choice of expensive terminal care will continue, whether it is to the benefit of the dying or not.
CHAPTER 5

CONCLUSION AND RECOMMENDATIONS
5.1 CONCLUSION

The search for cures has been rewarded with a phenomenal technological revolution in health care. This expansion in medical capabilities has added greatly to the possibilities for intervention against disease, disability and even death. The complexity of many of these interventions, and their implications for the welfare of individuals and of society as a whole have greatly complicated medical decision making.

The task of providing care for the dying has been largely left to the medical profession, at least in industrial countries. Medicine has been given the final authority in dealing with health, illness and life. Yet the medical profession as a whole has hardly started to consider the question of the type of care which should be provided for the dying. That many doctors believe that the presently-available care is good and all that is needed, does not help matters.

The doctors are faced with a conflicting mandate between curing and the use of scientific and technological developments for prolonging life and that of caring and alleviating suffering in the dying stage. In the ever-increasing dimensions of intervention, the tendency has been to uphold the former against the latter where the two conflict.
These days, the predominant number of deaths occur within the hospital, the institution fundamentally committed to healing and curing. In the midst of the current technological emphasis on healing, and because of the commitment to curing and the recovery process, the incurable patient is perceived as a failure. The commitment to curing and the sense of failure act as the incentives and impetus for the professional in mobilising all resources and employing all known diagnostic and therapeutic means in an all-out effort to avoid failure by delaying death. Intervention at the terminal stage becomes the norm. Death has become something to be treated, interfered with, technologically postponed. It has become a technological event.

Life-sustaining technologies, when used, challenge customary definitions of death and render them insufficient. As well, they test many moral, social, legal and ethical issues and create conflict between the individual's rights and desires and society's best interests.

Medical and legal bodies at the national and international level have been forced to re-examine the definitions and criteria which determine death and to search for new ones in an attempt to reduce legal complications. Developments in organ transplantation and the increasing number of patients now in hospital maintained by machines but with no hope of recovery, have acted as strong incentives for this re-examination process.

People's concern about the way they may end their lives and the fear of needless prolongation of dying and suffering has led to these concerns being articulated through the euthanasia movement. This movement is concerned with issues of voluntary euthanasia,
patients' rights and the patient's ability to choose and direct what technologies, if any, are to be used upon himself through his 'Living Will'. The movement works towards legislative changes to incorporate all of these.

The acute hospital, with its emphasis on curing and on delaying death, with its isolation, depersonalisation, technological intrusion, unnecessary investigation and treatments, and the suffering associated with all of these, is at odds with the needs of the dying and can be counter-productive. The dying need more intensive caring than intensive technical care, yet the hospital remains the only choice for many.

In the health service, the dying (possibly because they do not survive to talk about their experiences and needs) and their care have, to date, been given very low priority, both in terms of resources allocated by health authorities and large hospitals for facilities in this area of care, and in the importance accorded to this care by health professionals.

The increasing dissatisfaction with so much technological intervention and technical care and yet so little concern for the human being who is dying, and the failure of acute care institutions to meet the needs of the dying, have led to the search for alternatives in the care of the dying. Recently, escalating health care costs are reinforcing this search for alternatives.

Hospices and their holistic model of care, offer a viable alternative for many patients, particularly those not wishing to die at home, but also wishing to avoid hospitalised death. The home hospice teams make this form of care available to those cared for and dying
at home. Hospice, as a new institution and form of care, has been seen by existing professionals as a threat, since it challenges customary methods of care.

Home care is increasingly gaining prominence and acceptance and is seen as a feasible, desired and equally effective alternative to institutionalisation of the dying. However, medicine has not been geared towards home care so doctors need to re-orient themselves and to regain the knowledge and expertise and confidence necessary for supporting their patients at home. Good knowledge of the available community support services for home care is also essential.

While there is no conclusive evidence to suggest which is the best place for the dying, the best place is the one which the dying themselves choose, assuming that there is a choice possible and that it is made among existing, real and viable alternatives. In Australia, such options and choices can only be made if the Government gives serious consideration to the development of positive long-term plans with specified objectives with a view to the general upgrading of terminal care facilities and services. Only then, with the development of the present rudimentary services, could it be claimed that the dying have any real options from which to choose.

5.2 SOME RECOMMENDATIONS FOR AUSTRALIA

(1) Consideration should be given by Government, health bodies and health care professionals to the allocation of a greater proportion of health resources towards increasing and improving terminal care facilities and domiciliary health services, particularly those support services necessary for the home care of the dying.
(2) Greater priority should be given to improving and expanding home support and home management of the dying by all health care personnel.

(3) Hospices, as alternatives to acute hospital care, should become more prolific if a choice is to be made available for the dying.

(4) Palliative care units in hospitals should be supported to expand their services so that not only patients in the unit benefit, but also home-managed patients who may be given the advantage of their expertise. Palliative care teams, based on a concept similar to that of the St. Thomas Hospital in London, can greatly support the terminally ill at home, as well as relieve expensive services.

(5) Existing units for palliative care should be upgraded and new ones created so as to meet the existing need for an alternative.

(6) Teams servicing the community should be increased to ensure provision of care and support on a 24 hours a day, 7 days a week basis. Priority should be given to improving the availability, supply and maintenance of equipment and appliances necessary for managing home care and the dying at home.

(7) Evaluation of services by quality control and data collection is also necessary if the care and the needs of the dying, so far badly neglected, are to be met.
APPENDICES
APPENDIX 1A

THE ADVANCE DECLARATION OR 'LIVING WILL'

The advance declaration, or 'living will' as it is known widely in the United States, is designed to enable any citizen to state clearly to his family and medical advisers that in the event of his suffering any incurable and intolerable medical condition he forbids the use of life-support that would in effect merely prolong the act of dying, and requests, instead, adequate distress control until natural death ensues.

The declaration can be helpful to a doctor who, faced with a difficult decision regarding life-prolongation in the circumstances specified, is thereby made aware of the considered conviction of his patient expressed when in full possession of his faculties.

The declaration does not ask the doctor to do anything contrary to existing law; indeed, what it asks of him is already required of him by medical ethics, and under common law it is an offence for a doctor to treat a patient against the latter's will. Nevertheless the rights of patients are not adequately protected in law, and the advance declaration is not yet backed by statute. It is, therefore, of persuasive force only and is not legally binding on the doctor, even though one would hope he would consider it morally binding.

When the declaration is backed by statute the declarant may direct, not merely request, his desired treatment. Statutory backing for similar declarations has been enacted in a dozen American states and, at the time of writing, similar statutes are before the South Australian and Victorian parliaments awaiting approval. Enquiries about the current state of the law in Australian states should be directed to the address below.

**********

- The declaration form should be witnessed by two persons who should not be relatives or have any expectation of material gain from the estate of the declarant.
- One copy should be given to the doctor to be kept with the declarant's medical records.
- Another copy should be kept with the declarant's personal papers, or given to his solicitor or other personal agent to act in his interest in time of need.
- The yellow card should be kept by the declarant on his person, or, if he is hospitalized, affixed to the bedhead where it can be seen by all medical staff.
- Extra copies of the declaration and card are available on request.

**********
If you would like to know more about V.E.S.V.'s work for patients' rights and for good and responsible dying, or if you would like to become a member and participate in that work, please contact:

THE VOLUNTARY EUTHANASIA SOCIETY OF VICTORIA
P.O. Box 71, Mooroolbark, 3138. Phone: 818 1245
THE 'LIVING WILL'

TO MY FAMILY AND MY PHYSICIAN

This statement is made by me \( \text{[full name and address]} \)

\[ \text{at a time when I am of sound mind and after careful consideration.} \]

If the time comes when I can no longer take part in decisions for my own future, let this Statement stand as the testament to my wishes:

If there is no reasonable prospect of my recovery from physical or mental illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I request that I be allowed to die and not be kept alive by artificial means and that I receive whatever quantity of drugs may be required to keep me free from pain or distress even if the moment of death is hastened.

Signed \( \text{[signature]} \)

Dated \( \text{[date]} \)

Witnessed by:

1. \( \text{[name]} \)

   of \( \text{[relationship]} \)

2. \( \text{[name]} \)

   of \( \text{[relationship]} \)

\[ \text{NOTE: Witnesses should not be members of the family.} \]
THE 'LIVING WILL' IN CARD FORM

(Side 1)

Name ________________________________________________
Address _____________________________________________
Phone No. _______________________________
My Doctor is __________________________________________

(P.T.O.)

(Side 2)

TO WHOM IT MAY CONCERN

Should I be unable to communicate, please note that I have signed, in the presence of two witnesses, the following Declaration:

If the time comes when I can no longer take part in decisions for my own future, let this Declaration stand as the testament to my wishes.

If there is no reasonable prospect of my recovery from physical or mental illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I request that I be allowed to die and not be kept alive by artificial means and that I receive whatever quantity of drugs may be required to keep me FREE from pain or distress even if the moment of death is hastened.

Date _______________  Signed _______________________

P.T.O.

Issued by: The Voluntary Euthanasia Society of Victoria
EUTHANASIA EDUCATIONAL COUNCIL

TO MAKE BEST USE OF YOUR LIVING WILL

1. Sign and date before two witnesses.
   (This is to insure that you signed of your own free will and not under any pressure.)

2. If you have a doctor, give him a copy for your medical file and discuss it with him to make sure he is in agreement.

   Give copies to those most likely to be concerned "if the time comes when you can no longer take part in decisions for your own future". Enter their names on bottom line of the Living Will. Keep the original nearby, easily and readily available.

3. Above all discuss your intentions with those closest to you, NOW.

4. It is a good idea to look over your Living Will once a year and redate it and initial the new date to make it clear that your wishes are unchanged.

18th printing
Revised April 1974
TO MY FAMILY, MY PHYSICIAN, MY LAWYER, MY CLERGYMAN
TO ANY MEDICAL FACILITY IN WHOSE CARE I HAPPEN TO BE
TO ANY INDIVIDUAL WHO MAY BECOME RESPONSIBLE FOR MY HEALTH,
WELFARE OR AFFAIRS

Death is as much a reality as birth, growth, maturity and old age - it is the one certainty of life. If the time comes when I,

---------------------------------------------
can no longer take part in decisions for my own future, let this statement stand as an expression of my wishes, while I am still of sound mind.

If the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or "heroic measures". I do not fear death itself as much as the indignities of deterioration, dependence and hopeless pain. I, therefore, ask that medication be mercifully administered to me to alleviate suffering even though this may hasten the moment of death.

This request is made after careful consideration. I hope you who care for me will feel morally bound to follow its mandate. I recognize that this appears to place a heavy responsibility upon you, but it is with the intention of relieving you of such responsibility and of placing it upon myself in accordance with my strong convictions, that this statement is made.

Date ______________________ Signed ______________________
Witness ____________________ Witness ____________________
Copies of this request have been given to

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APPENDIX 2

UNIFORM DONOR CARD
AUSTRALIAN KIDNEY FOUNDATION

UNIFORM DONOR CARD

OF ________________________________

PRINT OR TYPE NAME OF DONOR

In the hope that I may help others, I hereby make this anatomical
gift, if medically acceptable, to take effect upon my death. The
words and marks below indicate my desire:

I wish to give:
(a) my kidneys
(b) my eyes
(c) any needed organs

For further information consult your
Doctor or:
The Australian Kidney Foundation
Hutton Street, Canberra City, A.C.T. 2601
(Branch Offices in all Capital Cities)

SIGNED by the donor and witness in the presence of each other.

SIGNATURE OF DONOR DATE OF BIRTH DATE SIGNED

ADDRESS POSTCODE

ADDRESS NEXT OF KIN TELEPHONE

ADDRESS POSTCODE
APPENDIX 3

PATIENTS' RIGHTS AND RESPONSIBILITIES

The Medical Consumers' Association of NSW appreciates the opportunity of making this document available to you.

As the consumer YOU are the person who is really responsible for making decisions about your own health care. The Charter below is designed to help you obtain the relevant information to enable you to make informed decisions.

A. These are already your Legal rights:

1. Right to a clear, concise explanation in lay person's terms of your condition, problems or disease.

2. Right to a clear, concise explanation in lay person's terms of all proposed procedures and possible alternatives. The explanation should include information about the risk of any side- or after-effects, problems relating to recuperation and possibility of success, risk of death and whether such procedures or treatments are of an experimental nature.

3. Right to seek 'alternative health care' and to receive such care from any person competent to provide it. 'Alternative health care' includes acupuncture, chiropractice, herbalism, homeopathic, hypnotherapy, naturopathy, osteopathy and the like.

4. Right to obtain the professional opinions of anyone of your choice at any stage of the health care programme. You also have the right to know the identity and professional status and qualification of those providing health services.

5. Right to refuse any specific treatment, drug, examination or other health care procedure, and you must not be subjected to procedures or treatments without your competent and understanding, voluntary consent.

6. Right to change your mind and refuse treatments even if you have previously agreed to them. But you should think carefully before you change your mind.

7. Right, even without asking, to be informed about, and to refuse to participate in, any research and/or experimental procedures which use you.

8. Right to have your case-history kept confidential, except where you consent to have such information divulged or where it is required by law to be divulged.

9. Right to receive itemised details of the total, final account for services rendered, regardless of the source of payment.
10. Right to leave the health care facility regardless of your physical condition or financial status. You may be requested to sign a release, stating that you are leaving against the medical judgement of your doctor or hospital, but there is no legal compulsion to sign it. Exceptions to the right to discharge yourself may occur if an infectious disease has been diagnosed, or if you have been certified as mentally ill.

11. Right to compensation for injuries or illness incurred in hospital care facilities or aggravated by the health therapist.

12. Right to expect adequate instructions about how to look after yourself when you are discharged from hospital.

13. Right to refuse examination, treatment or observation by or in the presence of, medical students. You may also refuse to see an outsider who wishes to visit you. Exceptions may occur when police are investigating criminal cases. In this instance, permission to interview should have to be obtained from the resident medical officer.

THE MEDICAL CONSUMERS' ASSOCIATION BELIEVES YOU SHOULD ALSO HAVE THE RIGHT TO:

14. Be treated in a humane manner, with considerate and respectful care.

15. Prompt and appropriate treatment, according to health needs.

16. The highest standard of health care, regardless of source of payment, social status, age, sex, race, religion or political beliefs.

17. Be informed about the facilities available for your own specific requirements.

18. Nominate a medical practitioner of your own choice to obtain access to all medical records about your own care and to inform you of what they contain.

19. Access to people outside the health care facility (by means of visitors and telephone). Parents should be able to stay with their children and relatives should be able to stay with terminally ill patients 24 hours a day.

20. A qualified interpreter if you cannot speak or understand English.

21. Nominate a friend, advocate or representative to join you and your health therapist in making decisions.

22. Be consulted before decisions are made to transfer you to any other health facility.

23. You should have the right to die with dignity.
B. Patients' courtesies and responsibilities.

If you are in need of health care you should, in your own interest:

1. Seek information as to your rights and see that your rights are satisfactorily applied.

2. Ensure that you have understood the purpose of all tests, treatments or other procedures, the reasons for them and possible alternatives before agreeing to them.

3. Take responsibility for postponing, terminating or continuing part or all of the proposed healthcare programme, including operations. You should insist upon explanations until you feel suitably informed and should consult with all relevant persons before reaching a decision.

4. Know your own and your family's medical history.

5. Keep appointments, or inform those concerned of your intention not to do so.

6. Comply with treatment, or inform the therapist of your intention not to do so.

7. Accept the consequences of your own informed decisions, and not change your mind about treatment without good reason.

Compiled and published by the Medical Consumers' Association of New South Wales, March 1978.

## APPENDIX 4

### TABLE A4.1

<table>
<thead>
<tr>
<th></th>
<th>Home</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Room</td>
<td>$2711</td>
<td>$</td>
</tr>
<tr>
<td>Physician</td>
<td>$17</td>
<td>$280</td>
</tr>
<tr>
<td>Nurse</td>
<td>$192</td>
<td></td>
</tr>
<tr>
<td>Home Aide</td>
<td>$138</td>
<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td>$38</td>
<td>$876</td>
</tr>
<tr>
<td>Laboratory</td>
<td>$5</td>
<td>$811</td>
</tr>
<tr>
<td>Diagnostic X-Ray</td>
<td></td>
<td>$223</td>
</tr>
<tr>
<td>Therapeutic X-Ray</td>
<td></td>
<td>$30</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td></td>
<td>$120</td>
</tr>
<tr>
<td>Respiratory Therapy</td>
<td></td>
<td>$428</td>
</tr>
<tr>
<td>Blood</td>
<td></td>
<td>$309</td>
</tr>
<tr>
<td>Supplies</td>
<td>$53</td>
<td>$222</td>
</tr>
<tr>
<td>Equipment Rental</td>
<td>$32</td>
<td></td>
</tr>
<tr>
<td>Work Loss</td>
<td>$78</td>
<td></td>
</tr>
<tr>
<td>All Other</td>
<td>$33</td>
<td>$170</td>
</tr>
</tbody>
</table>

Mean Total: Home $586, Hospital $6180

In this study, the mean cost of personal medical care was calculated to be for:

<table>
<thead>
<tr>
<th></th>
<th>Hospitalised Patients</th>
<th>Home Care Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic tests³ accounted for</td>
<td>18.7%*</td>
<td>&lt; 1%*</td>
</tr>
<tr>
<td>Palliative care⁴ costs accounted for</td>
<td>28.6%</td>
<td>11.9%</td>
</tr>
<tr>
<td>Loss of income was only recorded for home care at $78 and was considered an important cost</td>
<td></td>
<td>13.3%</td>
</tr>
<tr>
<td>Nursing care was the highest expense for home care</td>
<td></td>
<td>56.3%</td>
</tr>
<tr>
<td>Doctor's charges were at a low</td>
<td></td>
<td>2.9%</td>
</tr>
</tbody>
</table>

The above are some of the cost comparisons of hospital versus home care.

**Key:**

1. This included physician charges.
2. This included charges for physician, home nurse, home health aide and homemaker.
3. These included laboratory tests, radiology examinations, and other tests.
4. Palliative care costs included radiation therapy, pharmaceuticals and equipment rental.

* Percentages are those of the total cost of care in each category.
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