

COMMITTEE II  
The Value of Human Life

THE APPROPRIATE MEDICAL CARE OF THE TERMINALLY ILL

by

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The human condition, of its very nature, is a terminal condition. Thus it was contemplated in poignant imagery by an unknown companion of the seventh century Anglo Saxon king, Edwin.

This is how the present life of man on earth, King, appears to me in comparison with that time which is unknown to us. You are sitting feasting with your ealdormen and thegns in winter time; the fire is burning on the hearth in the middle of the hall and all inside is warm, while outside the wintry storms of rain and snow are raging; and a sparrow flies swiftly through the hall. It enters in at one door and quickly flies out through the other. For the few moments it is inside, the storm and wintry tempest cannot touch it, but after the briefest moment of calm, it flits from your sight, out of the wintry storm and into it again. So this life of man appears but for a moment.

In the twentieth century such a view, though real enough to those who stand at death's door: the elderly and the terminally ill, is no longer publicly acceptable.

Indeed, it is well known that in twentieth century Western society death has replaced sex as the great taboo. While more than a million human beings die on this planet each week, mostly from age and terminal illness of one sort or another, and while in the private lives of ordinary people where death occurs there are countless painful explosions of grief and

deep human response, in public we do not die.<sup>2</sup> No longer are we supported by the social customs of millenia, which placed death in perspective as part of the collective cycle of human life.<sup>3</sup> Because the ethos of our culture is so deeply pervaded by materialism, by the priority of material well-being, we experience a collective need to preserve the appearance of happiness. Real death, real grief, the terminal condition of all of us, is no longer acknowledged in the collective public awareness.

Historically speaking, this denial of our terminal condition is a very recent phenomenon. In the world of our ancestors life was short. The average age of the population of England in the early 19th century was less than 30 (comparable to that of modern day Sri Lanka). A mere 7% of men and women lived beyond the age of 60; as compared with around 20% in present day England.<sup>4</sup> That world, now lost to us, was a world full of children; crowds of little children, playing in the village streets and farmyards, crowding around the cottage fires. In Stuart England, for example, 45% of all the people alive were children.<sup>5</sup> And (paradoxically to us) that world of the young was a world where death was ever present. People were used to bereavement. They had to be because it happened all the time. What we consider to be 'natural death', that is, death as a gradual fading away in old age, was the exception rather than the rule. Death by accident, drowning, pleurisy or the plague, pointed out the

philosopher Montaigne in 1580, was far more 'natural' because general, common and universal.

Modern medicine has succeeded in all but abolishing death. For most people premature death no longer lies just around the corner. Life expectancy has increased. The death of infants, children and young adults is now so unlikely as to be virtually unthinkable. Those who die are mostly old (over 80% of us). And the nature of terminal illness has changed. Bubonic plague, smallpox, tuberculosis and other communicable diseases have given way to chronic degenerative diseases--cardiovascular disorders, cancer, arthritis and respiratory diseases (including bronchitis and emphysema). We all die sooner or later. Most of us nowadays expect that it will be later. Most of us live into old age in a state of chronic dis-ease, our natural forces slowly running down, with an indeterminate amount of time ahead of us: the senescent ill. But for some of us, who succumb to severe life-threatening illness, the time ahead is more or less limited and determined: the terminally ill. (The two categories are of course by no means altogether separate). The circumstances which have brought about the prolongation of life and the existence of the senescent ill as a significant part of the population in twentieth century Western society advances in medical science and technology--have brought about also a subtle transformation in our perception of an allotted time, and hence in an idea of death. Death, it is commonly held, need

not occur in the foreseeable future. It is a postponable event. Thus the reality of our basic human condition--our terminal condition--is obscured. This failure simply and appropriately to acknowledge our terminal condition is the source of our deepest problem in caring for the terminally ill.

The classic statement of the aim and scope of medicine: 'to cure sometimes, to relieve often, to comfort always', reflects the balance and sanity of a more tranquil age than our own, an age in which men and women lived in full awareness of their terminal condition. Health, in our culture, tends to be perceived as 'a struggle against death by escalating application of industrial power'.<sup>6</sup> And thus the modern hospital with its advanced technology and specialist expertise is geared towards investigation, diagnosis, cure and prolonging of life. In such a cure-oriented, death defying environment the dying patient is, inevitably, perceived as a failure of the health care system. 'The skills of the institution and the needs of these patients and their families are mismatched, resulting in isolation and compounded suffering'.<sup>7</sup> While every effort is made to block the sparrow's passage, there is certainly no time to contemplate the mystery of its existence.

Totally out of step with the common attitude down the ages, Western medicine's practical denial of the human condition has resulted in the last ten years, in a reactionary

phenomenon of astonishing vigour and vitality--the hospice movement, oriented toward comfort rather than cure, with its humane goal of symptom control aimed at providing optimum quality of life for the dying. In North America alone hospices now number in the hundreds, and the literature is vast.<sup>8</sup> 'Hospice' was originally a medieval name for a stopping place on the way, where pilgrims and travellers could be replenished and cared for. And the hospice ideal is, clearly, an attempt to recover the traditional, age-old awareness of death--death as part of life itself, a mystery to be contemplated rather than a problem to be attacked by medical intervention. It may be, however, that there is still more of value in the care of the terminally ill to be learned from the past.

Currently, in the English speaking world, there would appear to be four 'cardinal principles' in use in medical ethics: Patient autonomy, Beneficence, Non-maleficence and Justice.<sup>9</sup> How such principles are applied to the care of the terminally ill has recently been demonstrated by Dr. Edmund Pellegrino, Director of the Kennedy Institute of Ethics in Washington at the Sixth World Congress on Care of the Terminally Ill (Montreal, Sept-Oct 1986). In a compelling paper, Dr. Pellegrino outlined a comprehensive scheme for deciding what is in the best interests of the terminally ill patient. The guiding principle of his scheme was Beneficence: how do we help and heal this particular patient, recognising that helping and healing do not stop even though we have made a diagnosis of terminal illness, and a hopeless future? The

distinction between what is legal and what is ethical (a distinction nowadays often blurred) must always be kept in mind. An ethical, morally defensible treatment of the terminally ill patient must proceed with due deference to the personhood and humanity of the patient and of all involved in the decision-making process. (In a pluralistic society, neither the patient nor any member of the health care team may impose his or her values on one another.) Thus Pellegrino's starting point was the concept of patient autonomy--the competent patient can and should decide for himself how his treatment should proceed. In the U.S. since the Quinlan case (1976) the courts have upheld the principle of autonomy--the legal and moral right to decide how one will live one's life and/or end it. For the incompetent patient Pellegrino outlined a framework of alternatives for substitute judgement: by anticipatory declaration, living will, durable power of attorney, or other verifiable statement by the patient of what he would have wanted had he been able to speak for himself. For the never competent patient (newborn or retarded) he outlined a surrogate or proxy arrangement (via family, friend, legal guardian, durable power of attorney, or, in the last resort, physician) and the conditions for a morally valid act by such a proxy or surrogate (he or she must be competent, must know the patient and his values, and there should be no conflict of interest or serious emotional conflict).

Within a pluralistic society and a system of medical care

ethics based on the principles of Autonomy and Beneficence, conflicts are bound to arise--between patient/surrogate, doctor, family and health care team members--as to what is in the best interests of the patient. Hence, various mechanisms must be available for negotiation, consultation and resolution of conflicts--including ethics committees and, in the last resort, courts of law.

At the bedside the principle of Beneficence is called into play in the face of a host of dilemmas. Beneficence dictates that the effectiveness of an available treatment be weighed against its benefit to the patient. Many treatments may not be beneficial--e.g. an effective treatment for pneumonia in a case of advanced malignant disease--and may violate the patient's autonomy if he/she does not wish to be so treated. Conversely, some treatments may put the patient in danger--e.g. treatment for pain in malignant disease--yet be beneficial. On the question of whether and when to discontinue life-sustaining measures, Beneficence is again the guiding principle. For the patient in a state of total brain death or in a permanent vegetative state, many if not most, would feel that life support measures could be discontinued. But the weakest part of medicine since Hippocrates, Pellegrino argues, has always been prognosis. Patients in coma have been known to recover. Beneficence, in Pellegrino's view (others we might add, may invoke the same principle to argue the opposite) sees the danger of ceasing life-support measures. And Beneficence draws attention to the slippery slope of the progressive



de-valuation of life, as witnessed by the past ten year history of court decisions in the U.S. - Quinlan (1976), Conroy (1983-84), Bouvier (1986): the respirator may be stopped/ the naso-gastric tube may be removed from a non-comatose patient/ it is tantamount to duty for the health professional to assist the competent patient who so wishes, to die.

In the care of terminal care ethios the most hotly debated issue in the U.S. is that of the withholding of food and fluids. Court decisions have, for the most part, favoured the withdrawal of food and fluids when the benefit of the patient (as interpreted by the medical attendants) is not served. Two extremes are the following: In March 1986 the American Medical Association stated that food and fluids should be regarded as treatment, and could be withdrawn as long as one did not deliberately or willfully aim for the death of the patient. At the other extreme, a group under the auspices of the Pontifical Academy of Sciences, on Oct. 1985, drew a distinction between treatment and care; treatment being intervention that is medically indicated, care being ordinary help due to bedridden patients, as well as compassion and the effective and spiritual support due to every human being in danger. For the terminally ill patient in a brain damaged or vegetative state, treatment could be discontinued, but care (including food and fluids) could not. Indeed, 'care' must be lavished upon such a patient. In practice, argued

Dr. Pellegrino, the principle of Beneficence must guide the physician. In cases where food and fluids are excessively burdensome, merely prolonging life (thereby becoming a mode of injury to the patient and a violation of natural law) they may properly be withdrawn.

The foregoing has been presented as an example of a reasoned, cogent approach to some of the problems of terminal care from the point of view of medical ethics. Though such discussion is a phenomenon of recent origin, it is now commonplace and widespread. In 1970 there were a mere half dozen articles written in English on health care law and ethics. By 1980 there were 14 specialty journals devoted to the field. 'Medical ethics' as we now know it, has come into existence in large part as a result of the advent of new life-sustaining treatments and technologies, and of the spectacular developments of modern medical science in the last two decades--organ transplants, the artificial heart, test-tube babies and genetic engineering. While William Schroeder and his artificial heart, and the plight of 4 year old Gabriel Bruce, desperately awaiting a new liver, capture and hold the attention of the public as part of our daily entertainment, medical ethicists and their works multiply ever more rapidly.

Medical ethics, then, is part and parcel of the expanding Western medical-industrial complex. As such it belongs to a social milieu in which public dependence on medical care has reached unprecedented heights, while public trust in the

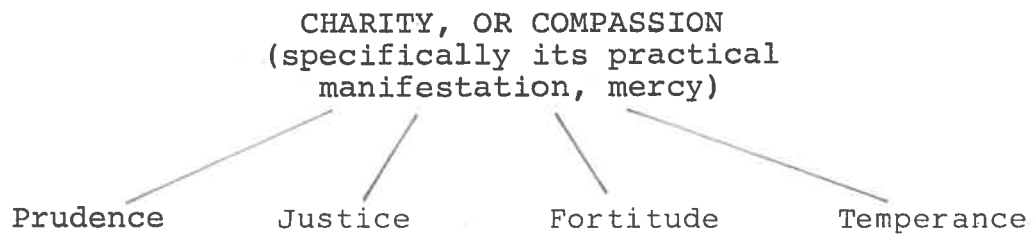
medical profession is close to a breakdown. Health care litigation in the U.S. has reached an all-time high, due to a crisis of communication. "The doctor of old had fewer surgical successes, but no suits because he had an ongoing relationship with his patients." Analysis of recent malpractice suits in North America reveals not medical incompetence, but simple failure to sit down and simply talk.<sup>10</sup> In such an environment medical ethics attempts to humanize the practice of medicine. The irony is that many of the questions raised by medical ethics (witness the aforementioned food and fluid controversy) serve only to obscure the real issue at stake--the relation between doctor and patient.

In this paper we shall argue that the basic issue at stake in the appropriate care of the terminally ill is the doctor-patient relationship. Further, we shall argue that if four 'cardinal principles' are to be invoked, they might just as well be the traditional four cardinal virtues. This ethical scheme, in use for many centuries, has in our day fallen into general disuse. Its practical application to the care of the terminally ill has, to our knowledge, never been considered. Yet its usefulness may readily be seen.

In the Middle Ages this approach was so commonplace that it was apparently not considered necessary to enunciate it with regard to the care of the sick. However, a fifteenth century French treatise, Livre de la vie active, written by

the overseer of the Hotel-Dieu, a large hospital in Paris, is an exception.<sup>11</sup> The work is a treatise on the active, as distinct from the contemplative, life, which used the service and administration of the Hotel-Dieu by way of illustration. It provides a vivid glimpse of the practical ethics of the health care system of that long lost world. In a striking illumination, seven patients, naked but for their nightcaps, in various states of malaise, lie tucked up in four beds. At the foot of each bed stands a nun in dark habit, accompanied by two or three small assistant novices in white. Each nun bears on her habit the name of the virtue which she represents, and holds in her hand the symbol by which she ministers to the suffering human beings in her care: prudence (the rod), temperance (the bit), fortitude (the tower), justice (the scales).

In the classical scholastic order of things the four cardinal virtues, prudence, fortitude, temperance and justice, took their place after the three theological virtues, faith, hope and charity. Charity was regarded as the foundation and root of every other virtue. And thus, in the care of the sick the necessary virtues might be depicted as follows:



In an age when life was 'nasty, brutish and short', when human beings lived in full and open awareness of their terminal

condition, such was considered fundamental to the appropriate medical care of the terminally ill. If for no other reason it is deserving of our respect and consideration.

It should be stated at the outset that the ideal of care that we are proposing here goes against current moral trends--those of a society which is daily moving deeper and deeper into a value system based on a philosophy of relativism and individual functionalism. The problem is this. The physician is largely a reflection of society. Basic human character traits are well developed before a student enters medical school. And no amount of medical training can convert a fundamentally self-centred and egotistic person into a humanitarian. 'The crisis of humane medicine, it has been said, is the result of the failure of secular democratic societies to inculcate moral and ethical values into their educational systems'.<sup>12</sup> In such a milieu, while there is much talk of moral values and of medical ethics, genuine morality and ethical conduct may remain curiously elusive. For the hallmark of genuine morality is more than a legalistic and impersonal exercise--'justice' or 'beneficence' put into action stage by stage. Genuine morality requires personal commitment between human beings, and spontaneous compassion. Persons who live life in this way--the doctor or nurse who acts in this way--do so at risk to themselves. Yet the result may well be a more liberating personal autonomy and authenticity than that which is commonly taken for granted.<sup>13</sup>

In this sense 'doctor autonomy' is as much an issue at stake as 'patient autonomy'.

Jay Katz, (Professor of Law and Psychoanalysis at Yale) in his outstanding study of the doctor-patient relationship, The Silent World of Doctor and Patient (New York Free Press, 1986), shows how the legal doctrine of informed consent works to augment the therapeutic alliance. Katz, examining the psychological complexities of the doctor-patient interaction, advocates a change from paternalism to an egalitarian relationship, from blind trust to earned trust, one-sided to shared decision-making. Trust is not possible without intimacy. Intimacy is not possible where there is deception. Deception is present when we refuse to share our uncertainty with the other person. But when both sides feel free to share their uncertainty intimacy is possible, and trust is earned. At the very least, the railroading of patients--seeing scores of them in a day in conveyor belt fashion--would be affected, for the kind of conversation and communication envisaged here demands time.) Yet, if doctors could learn, and in turn teach their patients, that it is possible to sit down and reason together about the most important personal anxieties and fears that illness and its treatment engenders, then they could also point the way to living life not by submission but by mutual respect, with careful attentiveness to one's own and the other's rationalities and irrationalities'.<sup>14</sup> Such cannot be achieved without cost.

'Mutual respect' and 'careful attentiveness', we shall argue, are synonymous with compassion, in action (i.e. mercy). What we propose then, is not a set of moral rules, but rather a relationship--an authentic sharing of the self--in the context of which the four cardinal virtues may be taken as guides to appropriate action.

The kind of doctor-patient relationship that we are proposing here, based on compassion in action ('mutual respect' and 'careful attentiveness') is becoming imperative for many reasons. It is increasingly recognised that twentieth century medicine is experiencing a metaphysical crisis. The distinction between mind/body which came into being at the end of the Middle Ages, was fully articulated by Descartes in the eighteenth century, and which has dominated modern science until the twentieth century, lies at the root of this crisis.<sup>15</sup> While the Cartesian view has been drastically undermined by the discoveries of modern physics (that energy and consciousness, mind and matter, are interdependent, that the world cannot be understood apart from the mind of the observer--that we ourselves are part of the field of energies which we observe, and hence that science can never be objective), nevertheless it remains the basis of the current biomedical model. In the Cartesian paradigm the patient is viewed as a passive, physiological mechanism, an 'object-body'. Hence, he or she must rely on outside forces for cure--on a doctor who knows how to fix the mechanism, and on technological

intervention of one sort or another--physical (surgery or radiation) or chemical (drugs). Such a paradigm directs attention toward curing the body rather than healing the person, treating the disease rather than the patient. Its dehumanizing effects are only too well known, yet its principles are thoroughly ingrained in our culture. Increasingly, however, as the narrow conceptual basis of this biomedical model is recognised, so it becomes evident that many subtle, less tangible factors--the emotional state of the patient, the patient's attitude toward his illness, the quality of the therapeutic alliance of doctor and patient--are fundamental both in diagnosis and prognosis.

#### CHARITY, OR COMPASSION

(mutual respect and careful attentiveness)

In the face of immanent death the Cartesian 'object-body' biomedical model is unhelpful. When all has been done to ease the dying patient's passage, the care-giver has nothing to offer but himself. For this reason, over the past decade or so, the medical specialty of palliative care has moved ahead of other specialties in articulating (in a growing body of literature) a new kind of approach--one in which the therapeutic alliance of patient-caregiver has been intimately explored, often with great subtlety and sensitivity. The spirit of this new literature is typified by Charles A. Garfield's opening sentence in Psychosocial Care of the Dying



Patient: 'A recurrent theme of this book is the importance of emotional accessibility, the art of being fully present to another human being. Present not only as an expert in the physiologic nuances of life-threatening illness and treatment, but as a willing companion'.<sup>16</sup> In the brief space available to us here we shall indicate, drawing on the work of some of the most skilled clinicians (those who have attempted to be fully present to the dying patient and to enter into and share his reality) what, in our and their experience, are most commonly perceived to be the deepest needs of the dying patient.

Four major areas of need identified by psychiatrist Colin Murray Parkes,<sup>17</sup> are: 1) Physical (need for pain relief) 2) Cognitive (need for information) 3) Affective (need for human closeness) 4) Spiritual (need for God). All terminally ill patients have in common the fact of being forced to undergo major changes in their lives. Their world will never be the same again. Countless assumptions, structures of meaning built up over years, suddenly collapse. At a time when security is most needed, the terminally ill patient is beset by interior chaos. Parkes has articulated a theory of Psychosocial transitions, which embraces all four of these dimensions. Psycho-social transitions, life changes whose magnitude we are unable in a short time to take in or cope with, are characterized by: 1) Pain (physical and mental)

2) Cognitive confusion 3) Intense emotions (pining, anger, bewilderment) 4) Spiritual perplexity, as the meanings of life are shattered. Each must be articulated and shared if patient and family are to pass through the transition, re-learn their world, and discover new reasons for living and for dying.

When the terminally ill person's internal model of the world, built up from all his previous life experiences, is suddenly shattered, the sense of loss may be overwhelming.<sup>18</sup>

1) Loss of control: of his body, his emotions, of life itself. Paradoxically, this sense of loss of control is usually worsened in the hospital situation, where individual autonomy is given very low priority. (As we shall see, there is much that can be done to support the patient's sense of control.)

2) Loss of identity. 'Who am I?' 'What is left of me now?' With an altered body image, the patient fears the reactions of others in the face of changes in his appearance. Changes in sexuality, at a hidden level, may be devastating. His fear is of being defined exclusively in terms of his illness. (When the patient's sense of identity falters, ongoing support and affection from the family and caregiver are crucial.)

3) Loss of relationships. An aspect of human behaviour frequently observed when a person is known to be dying is avoidance, or emotional withdrawal on the part of those around.

The phenomenon has been repeatedly observed among health care professionals, family and friends.<sup>19</sup> It has been called a 'bereavement of the dying'.<sup>20</sup> Struggling with his own disorientation and anticipatory grief in the face of multiple losses - of self, of loved ones, of all that has been important in his life, the patient, with a heightened sense of being alone in the face of the unknown, reaches out for assurance that he will not be abandoned, for love and companionship. In the hospital situation loneliness is generally intensified.

In those with malignant disease suddenly confronted with approaching death, powerful and painfully disorienting emotions are the natural response. The stages of realization (though by no means clear-cut or inevitable) have been described by such experienced clinicians as Elizabeth Kübler-Ross and Cicely Saunders. 'Most human beings', writes Saunders, 'have the capacity for coming to terms with their circumstances which they retain even as death approaches, though for some it is a struggle that is deeply painful to watch'.<sup>21</sup>

From our starting point of compassion, or 'careful attentiveness' to the dying person's needs, we move now to ask what can be done to assist the dying patient in coming to terms with such circumstances? What are the appropriate modes of conduct and treatment under such circumstances?

1. PRUDENCE is a steady disposition of practical reason to right action. It has two aspects - one concerned with gathering knowledge, with establishing a yardstick, the other concerned with evaluation, decision and command. It is the readiness to judge soundly and to act rightly, and as such is the mother of the other virtues.<sup>22</sup>

In the care of the terminally ill it is imperative from the outset. In the question of truth telling the ethical maxim, primum non nocere is part and parcel of prudence. Over the past 20 years doctors appear to have become more inclined to tell cancer patients the truth of their diagnosis, though in some places (e.g. South American countries) the conspiracy of silence is still the rule rather than the exception. Telling the truth of a fatal diagnosis may be regarded as a moral dilemma by the ethicists - to tell or not to tell? In practice, the basic principle of charity (the underlying relationship of mutual respect with careful attentiveness) will guide the physician toward the most prudent course of action.

The patient has a right to know, and a right not to know. In fact only 80-90% of patients want to know. The current trend towards open awareness has caused many doctors to see it as their duty to tell all. But total candour may be devastating to the patient who is not ready to hear. It is important therefore, that the patient be given the opportunity to control the information he is given. Careful

attentiveness is needed to the amount of information imparted and the patient's ability to receive it. In this way, the patient has time to accommodate himself in various ways - one of which is by worrying. (Worry, Parkes points out,<sup>23</sup> is a way of preparing a possible world that enables us, if our fears are realized, to cope more effectively with the reality which we must now enter.) In situations where information needs to be communicated, it is prudent to begin by finding out how much the recipient knows, or thinks he knows, about his condition. The patient can be encouraged to control the input of information by inviting questions: 'Have you got any questions?' In this area doctors often do not invite questions. The patient then senses that the doctor must be frightened, which causes the patient to become more frightened. Conversely, the doctor who invites questions indicates that he is not frightened of giving answers, which can be reassuring for the patient. The questions which follow will reveal quite precisely how much the patient is ready to be told. In sensing what the patient wants to reveal of his thoughts and attempting to meet him where he is, we cement the therapeutic alliance.

When the message is emotionally disturbing and loaded with information which necessitates a major psycho-social transition, it is not surprising that there may be communication problems. The simple statement, 'The biopsy was positive', may be so overwhelming that the patient may not

be able to take it in. For this reason it takes time and emotional support to break bad news. In all of this our role is simply to help the patient to tackle each problem on his own terms, in his own time. The question of control is fundamental here. As Parkes points out, most people are able to monitor their input of information in order to control the rate at which to restructure their internal world and to avoid overload. Thus what appears to be denial may simply be a form of postponement of one psycho-social transition in favour of another. In such a situation considerable understanding and prudence in the face of ambiguity is called for in the care-giver. At all events, those who wish to use denial should not be assaulted by truths that they may not be able to handle.

In the care of the terminally ill patient within the setting of the family unit, prudence is indispensable. In times of trouble most families will rally around to provide care, concern and security for their members. In times of psycho-social transition, however, when the members of the family are often at the end of their tether, the reverse may happen. Members of the family may back away, or negative energies may be released between family members. Anger, clinging, avoidance of closeness, lack of communication, are all signs that the family may be in trouble. The concerned care-giver has a role to play in expressing that concern and facilitating the family in talking about their underlying difficulties.

One of the worst fears of cancer patients and their families is reflected fear - fear in the eyes of those around. Grief and fear need to be distinguished. Grief arises when people come face to face with losses. It is the intense pain that results when we are confronted with major discrepancies between the world that is, and the world which must be. We pine for that which we must lose before we can let go of it and rebuild our assumptive world. Fear changed to grief must be worked through and resolved. Grief may thus be seen as a creative energy, the attuning of the self to a new reality. The reduction of anxiety and fear in the patient, family and care-givers must be given high priority.

Home may be the place where most people would like to die. But it may also be the place where people are vulnerable to reflected fear, for full responsibility rests on the family, and home care is often associated with high levels of stress in family and patients. A balance between home care and good in-patient care is needed.

The reduction of fear is basic to control of pain in the patient. Here the human presence of the care-giver is of the utmost importance. Physical suffering responds to human presence as much as to pharmacologic agents for the relief of pain. We shall deal first with the latter. In the past there has been much misunderstanding around the use of narcotic analgesics. Fear of addiction or the rapid escalation of the effective dose has led to under-prescribing. Due

largely to the hospice movement, such is now widely recognised as inappropriate in the terminal care situation. Pain due to advancing cancer is usually continuous. Therefore its treatment should be continuous - prophylactic or preventive rather than pro re nata. Pain itself is perhaps the most powerful anti-analgesic. And therefore, allowing pain to re-emerge before administering the next dose both causes unnecessary suffering and encourages clinical tolerance. The problem of the terminally ill patient in pain has always presented a dilemma which requires careful judgement on the part of the physician - that of providing a degree of analgesia, while not hastening death by depressing vital functions, thus maintaining optimum awareness and communication with family and friends.<sup>24</sup>

In terminal illness the issue of confidentiality is now becoming problematic. In the physician-patient relationship a basic obligation is that all information regarding the patient be kept confidential, though of necessity, when the harm done by a legal wrong is less than the harm that is avoided, the legal wrong may be done in order to avoid the greater harm. In most cases there is no risk that the sharing of that information will have any adverse effects for the patient. With the AIDS situation, however, this is no longer the case. Considerable prudence is needed in discerning when confidentiality may be breached by reason of a moral duty to warn a third party of potential or actual



danger - as, for example, in the hypothetical case recently cited by Margaret Somerville, of 'Dr. Webster' and his patient 'John', with AIDS, about to undergo minor surgery, also scheduled for dental treatment, with a pregnant wife. Who should Dr. Webster tell - the surgeon? the dentist? the wife?<sup>25</sup>

2. JUSTICE: the strong and firm will to give to each his due.<sup>26</sup>

Health care law and ethics are concerned with the relief of suffering. Hence a possible conflict exists. Medicine focuses on needs (treatment to relieve suffering), while law focuses on rights (the patient has the right to refuse treatment). In a situation where a person refuses treatment which the physician considers necessary for his good, it should be remembered that there is no more dangerous situation, in terms of infliction suffering and harm on another human being. For such would be a breach of human rights. As Somerville has pointed out, the law's definition of suffering may be closer to reality than that of medicine. For medicine may reduce physical suffering but increases psychological suffering. Unconsented to interference makes the person feel as though he has lost control over what happens to him.

Here patient autonomy is the issue at stake. But patient autonomy raises a fundamental problem. If the competent patient is truly informed, we may assume that he will make a right choice. The difficulty arises when the patient does not have all the information necessary to make a truly in-

formed decision. The real issue at stake therefore is one of trust in the doctor, and of the nature and depth of the therapeutic alliance. Justice, then, can only be seen in the context of that relation of mutual respect and careful attentiveness.

Refusal of Treatment - When treatment is refused the resulting situation may be increased pain, but because that refusal was respected, decreased suffering. Refusal of treatment is more common in AIDS patients (where the patient has a fair idea of the outcome) than in other forms of terminal illness. Such refusal may be difficult for the health care professional to accept, particularly if the patient is a young man in his twenties. The law states that no treatment can be inflicted upon a competent patient without his consent (the patient must be treated as a person, not an object). The patient is not obliged to accept medical treatment, even if his refusal may result in his earlier death. The refusal situation in itself may be therapeutic opportunity. For by accepting the patient's refusal of treatment, the health care professional, despite the fact that he thinks the patient is making a mistake, augments the therapeutic alliance, which is of vital importance in a debilitating disease like AIDS. In the words of one AIDS patient: 'I hope physicians everywhere will remember they are dealing with real people and not with plastic dolls they can manipulate at whim. I am frightened, but not of death, rather, I am frightened of being helpless'.

Acceptance of Treatment - An accumulating body of evidence indicates that patients who do not have information about their treatment experience a sense of helplessness and high anxiety levels, and that, further, a direct relationship exists between the anxiety state and pain. Studies have shown that patients psychologically prepared for major surgery, who were given full information about the bodily effects of the procedure, warned how they should expect to feel afterwards, and advised how they could control pain and symptoms, and encouraged to express their feelings about what was happening to them, coped better than those given bland reassurance and minimal information. The prepared group required less in the way of narcotics and ran less risk of post-operative psychoses than those not prepared in this way. The patient not warned to experience pain in a phantom limb is alarmed to wake up after surgery and discover it. By contrast, is the case of the patient cited by Parkes, who when asked, 'Did you have any pain in your foot after it was taken off?' replied, 'Yes, I was so pleased. The doctor had told me to expect it to hurt, so I knew that everything was going according to plan'.<sup>27</sup>

The implications for care of the terminally ill are clear. Feelings of helplessness and hopelessness have been shown to have an adverse effect on a patient's prognosis. Mutual respect on the part of doctor-patient can be shown to have measurable effects on body physiology, which equal those of powerful pharmacological agents. In an experiment of several weeks' duration,<sup>28</sup> following surgery a 'special

medicine', 'far more powerful as a pain killer than morphine', but without any of the toxic or side effects of morphine, was prescribed. The patients were able to call for injections whenever they wanted. The special medicine was simply saline solution and the patients who received it did much better and experienced less pain than those receiving morphine. When told what had been done these patients generally replied that what had helped them was to be able to ring the buzzer and get the medication right away, rather than waiting for the nurse and being told they had another hour and 15 minutes before their shot was due. Further study has shown that morphine relieved 75% of severe post operative pain, while the placebo effect was effective in 35% of cases.

By being given control many patients may be helped not only to responsible and effective behaviour, but also to considerable fortitude in the face of great suffering. Feifel<sup>29</sup> points out that most dying patients do not expect miracles, that when recognition of their decision input and appreciation of their integrity are major features of the treatment process, the results are reduced depression, less projection of blame onto others, and diminished feelings of guilt in patient and health care professionals.

3. FORTITUDE: courage of soul that strengthens and enables one to adopt and adhere to a reasonable course of action when faced with the danger of death or other grave peril.<sup>30</sup>

For those who deal with the terminally ill, fortitude is

called for at every turn. This is particularly true for the health care professional who is in most immediate contact with the patient and gives 80% or more of all care - the nurse. Terminal care is one of the most demanding and stressful situations encountered by nurses. 'Keeping the patient clean, fed, and comfortable until he dies is not always easy or pleasant, nor is working with families living under the stress of impending death'. Added to these difficulties is the responsibility for making decisions that could have a life-or-death outcome.<sup>31</sup>

What enables the care-giver to sustain continued involvement with people confronting life-threatening illness? The ability called for here - to take emotional risks, to experience deep feelings, to share the reality of patient and family in distress can lead to what is commonly termed 'emotional burn-out'. Thus the care-giver must engage in on-going honest appraisal of her capacity for repeated cycles of attachment-loss.

The care-giver it would appear, must possess a high tolerance for ambiguity, in order to step into the lives of those whose existence is founded on such uncertainty, and an inner freedom to flow with the experience, without needing to impose a rigid structure.<sup>32</sup> It has been pointed out that the caregiver's own history of loss is relevant here. In such encounters unresolved losses loom large. The terminally ill person has an acute sense of vision by which the care-giver's difficulties become transparent. Feifel and others have stressed the

care-giver's need to come to terms with her own fears of personal death. In nursing literature over the past decade much emphasis has been placed on recognising and meeting the 'Needs of the Dying Patient'. An increasing amount of evidence indicates that emphasis needs to be placed on the 'Needs of the Nurse who is Nursing the Dying Patient'. Experienced nurses have attested to the fact that irrespective of the patient's medical problems, it is only as the nurse is able to come to terms with herself, her own conflicts, her negative and 'unprofessional' feelings, that she is able truly to enter into the stressful world of another.<sup>33</sup> Recognition of personal mortality, - that to die is the human condition - long regarded as one of the foremost entry ways to self-knowledge, would appear to be fundamental in the active day-to-day care of the terminally ill. And yet, counters Parkes, how do any of us know that we have faced the reality of our own death until we are dead? What matters, in the end, is the kind of commitment that enables the care-giver to 'hang in' with those in deep distress - a commitment facilitated by compassion. The fact is that those who care for the dying in the most effective and compassionate way more often than not have a religious commitment of one sort or another. And thus, we are led back to our starting point - to charity - a concept with theological dimensions which lie beyond the scope of this paper - of participation in the divine love.

4. TEMPERANCE is the virtue by which we are able to achieve a certain moderation with respect to objects which attract us. Tranquility of soul is said to belong, par excellence, to temperance.<sup>34</sup>

In terminal care the issue of quantity vs quality of life is raised. It is often said that palliative care is concerned with increasing quality of life. In fact, most patients and their families want both quality and quantity. Some patients opt for increased quality, some for quantity with diminished quality. It must be remembered that the patient does not always do as the doctor would, that quality of life can only be assessed by the individual whose life is in question. In this regard, the patient undergoing chemotherapy may have much reduced expectations and demands. Good quality of life, argues Dr. Twycross, is attained when hopes are matched by circumstances.<sup>35</sup>

Temperance comes into focus most sharply in the vexed question of the prolongation of life. Here, we would argue, the key principle is to avoid futile treatments. As Twycross has pointed out, the question 'to treat or not to treat?' is inappropriately formulated. The question should rather be, 'what is the appropriate treatment, given this patient's prospects?' Resuscitative measures such as intravenous infusions, blood transfusions, C.P.R., the use of antibiotics, respirators and coronary care units, were introduced to help the patient through an acute crisis, on the basis of his

previous biological prospects. The moribund or semi-moribund patient may be offered such a treatment. If it prolongs the distress of dying rather than prolonging of sustaining useful life, we would consider such treatment inappropriate under the circumstances.

Thus stated, and seen always in the context of compassion and continuing communication with patient and family, what may be turned into a big ethical question - to treat or not to treat - takes on a less momentous dimension. The doctor does not have a duty, legally or ethically, to prolong life at all costs. In certain circumstances we have to give death a chance, which is not the same as killing the patient. The 'two day rule' is suggested by Twycross as a practical guide. If the terminally ill patient develops a chest infection and the care-giver is not certain how close he is to death, do not prescribe antibiotics. Review the situation tomorrow and the next day. If the patient is much worse, the answer is clear. If the patient is holding his own but troubled by a problem or expectoration, then antibiotics would appear to be indicated.

In the hospital setting the availability of new technology (e.g. respirators), hospital regulations, external pressures from hospital bureaucracies and a certain human dynamic among the staff, set into motion a certain momentum making it difficult for the individual care-giver to refrain from using such technology even against his better judgement. And over



any decisions not to use life-prolonging technology, there hovers what has been called 'the brooding presence of medical liability'.<sup>36</sup> Fifty years ago, pneumonia was known as 'the old man's friend'. Hospital regulations require that any patient in an intensive care unit, in coma or otherwise, who contracts pneumonia automatically be treated for it. Under such conditions, temperance is far from easily maintained.

Temperance, the virtue of moderation or right proportion, brings us back to the starting point of this paper - the ultimate mystery of life and the realization of its brevity and fragility, symbolized by the poignant image of the sparrow's flight, the recognition of which is the basis for the truly appropriate care of the terminally ill.

SUMMARY

The appropriate medical care of the terminally ill is predicated upon a relationship - that of patient and caregiver - which must at all times be one of mutual respect and careful attentiveness. Such a relationship of compassion manifests itself in practical terms by way of the four traditional virtues: prudence, justice, fortitude and temperance. We have put forward these rubrics not as a rigid dogmatic structure, but as four common-sense headings, appropriate in a pluralistic milieu, which fully encompass the practicalities of terminal care, keeping it, at the same time, within the parameters of a human relationship. (And we have briefly indicated how they may be applied.) We believe that this approach will prove useful, for it is a breakdown of relationship, that of doctor-patient, which lies at the heart of the present crisis in medicine.

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