



THE SOCIETY FOR THE RIGHT TO DIE WITH DIGNITY

(AFFILIATED TO THE WORLD FEDERATION OF RIGHT TO DIE SOCIETIES)

NEWS LETTER

VOL. X, AUGUST 2000

EDITORIAL

The concept of 'Living Will' is now accepted in many countries. There have been problems in executing living will especially when the 'living will' documents the circumstances under which treatment should be avoided in great detail. The argument may look quixotic, yet it is true that the circumstances under which one may have to live towards the end of life can't be envisaged in all the details. We have no crystal ball to gaze into the future. The limitations of living will was apparent in a simulated arguments in one of the meetings organized by our society a sometime ago. The list of situations under which the life could be terminated or a person should not be plugged to life sustaining device kept growing with each passing hour. Thus Docker's proposition to add to living will is a welcome suggestion. This newsletter includes correspondence on important issues like withholding the treatment as well as withdrawal of the treatment. Withdrawal of treatment in ICU is done even in India with the full consent of close relatives, even in the absence of power of attorney. The relatives however take the responsibility of consequences. Generally, "discharged against medical advise" is the common phrase below which the relatives even without power of attorney sign. The legal status of this procedure hasn't been contested so far. However, it has helped a large number of patients in our country. May be we should evolve guidelines and an appropriate law to execute withdrawal or withholding treatment without the fear of reprisal by the law. Till that time "discharged against medical advise" should help to transcend vegetative existence due to an incurable disease.

"Life", always evokes awe and a sense of mystery. Hence, it is so inconceivable for many to think of ending life no matter the state of mental or physical distress. What is living will? What is good dying? Pain is dreaded by all, but when someone enters a state of coma, where the person is incommunicado, when he is no more in pain, should we really terminate the life? Is it in the best interest of the patient or those living around him? Life at some stage loses all its relevance. It raises a fundamental question – what is life after all? Why does one exist? What is the purpose of life? There may be a purpose for life. It could be something like realizing God. Life is not worth living once body or mind lose their ability to procreate, sustain and satiate our desires. It is not a hedonistic definition – as desires could be a quest for truth or to next coital fix. Will a man on a respirator with an incurable disease and blunted mind can aspire to satiate any desire? Can he sustain himself? What use is life which has no desire nor a capacity to fulfill the desire. Such a life has no reason to continue. An active or passive euthanasia may be an appropriate solution. There is a need for responsible human

intervention. One wished God could do it. Well, sometimes one of us has to do it as we are all the instruments of God.

Dr. Nagraj G. Huilgol

ORCHESTRATING THE "GOOD DEATH"

Physicians have an obligation to their patients to aid in the process of dying. Effectively to fulfil this responsibility, physicians need to discuss frankly issues vital to facilitating a dignified death with their patients. These issues include (1) durable power of attorney for health care, (2) advance directives, (3) do-not-resuscitate orders, (4) hospice care, and (5) aid in dying.

1. Durable power of attorney for health care (DPOA).

Perhaps no directive is more important in the process of dying than the execution of a DPOA. By designating a person intimately familiar with the patient's own wishes for care at the end of life, the patient ensures that his or her desires are followed. In the absence of this document, the decision-making responsibility goes to the nearest relative, who may not share the patient's attitudes toward end-of-life care.

2. Advance directives. Although carrying less legal weight in most states compared with the DPOA, advance directives convey to caregivers and support systems the patient's desires for specific care at the end of life. This may be particularly important in dealing with withdrawal of life support or nutritional therapy or the patient's desire for the actual location of death.

3. Do-not-resuscitate orders (DNRs). Discussions of heroic measures at the end of life are essential to the provision of a dignified death. In the absence of these discussions, primary-care physicians and housestaff are left to flounder about trying to reconstruct the desire of the patient for aggressive therapy. It must be stated that no physician is required to provide futile therapy; however, a patient's desires generally should hold sway. Patients must understand the components of a DNR order. Chest compression, pressor therapy, cardioversion, intubation and ventilation, invasive lines, and intensive care are all procedures that should be explained when discussing DNR orders. Finally, patient desires need to be clearly and prominently reflected in the medical record.

4. Hospice care. Most patients do not have an adequate understanding of hospice care. Oftentimes, it is "just a place you go to die". The ability of hospice care to offer psychosocial support as well as palliative therapy should be discussed with the terminally ill patient considering hospice admission. Moreover, attitudes toward continuing

medication and the provision of nutrition or hydration should be thoroughly examined.

5. **Aid-in-dying.** It is not unreasonable to want some control over how one dies. Patients do not cede responsibility for themselves to others when diagnosed with a terminal illness. Unfortunately, we cannot always make death a tolerable process. Despite our best efforts, some incurably ill patient's wish for deliverance from suffering and a quiet, pain-free death. However, public attitudes towards aid-in-dying are at odds with professional positions on the issue. This conflict recently has been increased with judicial rulings that will likely increase the availability of aid-in-dying. (as in the USA & Netherlands)

A. It is important to understand **why some patients request aid-in dying**. First, it is a need to maintain control over their lives. Most patients who request aid-in-dying do not kill themselves! Second, it is often a fear of the process of dying –dementia, incontinence, immobility etc. These people are not invariably depressed or psychiatrically disordered. The request is, however, a signal to the caregiver and family that the patient's needs and fears have not been adequately addressed. When confronted with a request for aid-in-dying the caregiver's first responsibility is to elicit these fears and needs and attempt to alleviate them.

B. Aid-in-dying may be appropriate for some terminally ill patients and ethics committees are struggling to offer guidelines for use. In the absence of institutional guidelines, some **general recommendations** are offered.

i. The patient should have **advanced illness associated with severe, unrelieved suffering – both physically & mentally or progressively fatal disease**

ii. **The patient must be able to understand all therapeutic alternatives and initiate the request** for aid-in-dying. The decision to use aid-in-dying and when to implement the plan must reside solely with the dying patient. Adequate comfort measures, sometimes including psychiatric evaluation, should be exhausted. The decision should be made within the context of a long-term patient-physician relationship, and the best time to discuss aid-in-dying is early in the course of an incurable disease like AIDS or Cancer.

iii. All physicians must adhere to their personal codes of ethics. If caregiver believes aid-in-dying is morally incompatible with personal ethical standards, then the caregiver should refer the patients to another physician for aid-in-dying while continuing to offer supportive care to the patient.

iv. The methods of deliverance should be reliable and not add to the patient's suffering. Commonly, the combination of opiates, barbiturates, and alcohol is used.

v. Provision of a lethal prescription does not end a caregiver's responsibility for **care**. There must be a clear understanding of the caregiver's role in aid-in-dying beyond the provision of medications. What is the physician's availability and involvement if the attempt is unsuccessful? What further measures should be used? Should the support group call an ambulance? Further, the physician must familiarize the patient support group with the process of death-gasping incontinence, seizures, etc.

C. These are weighty issues and responsibilities, and those who question their involvement would do well to consult with **senior staff or ethics committees**.

Quotes

Ode to a Nightingale

Darkling I listen; and, for many a time
I have been half in love with easeful Death;
Call'st him soft names in many a mused rhyme,
To take in to air my quiet breath;
Now more than ever seems it rich to die,
To cease upon the midnight with no pain,
While thou art poring forth thy soul abroad
In such an ecstasy

---Keats

"Pain is unavoidable so long as there is form"

---Ramakrishna Paramahansa

DISADVANTAGES OF PLASTIC BAGS

over reliance on plastic bags as a principle mechanism for achieving death, failure to obtain a suitable bag and possible premature removal of the plastic are all seen as disadvantages. The successful deployment of a plastic bag in suicide needs either luck or careful planning.

Development of physician assisted suicide with appropriate safeguards will hopefully, in the longer term, make such deliberations and dilemmas redundant.

Chris Doch

Exit Vol.20 NO.2, April 2000

Humour Me

St. Peter becomes aware of a man standing outside the Pearly Gates pacing up and down. "Excuse me, can I help you?" he asks. "No, it's alright. Won't be long." And he distractedly looks at his watch, shrugs and paces on. St. Peter gives it another 5 minutes and asks again. The man stops and says, "Look, you know I'm dead. I know I'm dead. Will someone please tell the cardiac arrest team?"

A Special Stillness

In the space between each thought and act is a special stillness that carries from stillness to stillness giving balance to thought and act.

Everything arises from and returns to stillness. Stillness is the ease in which non-thinking and non-doing happen of themselves.

Even in union is stillness....so no effort at all; just bodies non-doing their bodies and minds in stillness playing awareness.

Live Well – Leave Well

Is a society with objectives similar to ours. It is based in Bangalore. Chairman Dr. M.C.Modi, has been actively guiding the society. The address of the society is as follows: Live Well – Leave Well Society, No.6.RBI Colony Anand Nagar, Bangalore 560 024.

Tel.No.: 080-333 1175

DECISIONS TO WITHDRAW TREATMENT

Values histories are more useful than advance directives

Winter and Cohen recognize one of the problems with advance directives when they correctly state: "The advance refusal of treatment is legally binding provided certain conditions are met... A problem still exists unless they are precisely worded"

Traditional advance directives are becoming less and less useful, partly as a result of lack of data on when treatment becomes futile in different clinical scenarios. When advance directives were first introduced, the application of standard "heroic measures," often without reasonable expectation of result, was far more common than it is today. In that situation, a general advance directive about refusing, say, cardiopulmonary resuscitation, was an appropriate statement of common sense. The situations facing modern intensive care towards precise wording in advance directives to make them legally binding has made it difficult for them to keep up with the pace of medical technology."

An alternative approach that is finding increasing favour, either as an adjunct to the advance directive or as a stand alone instrument, is the "values history". Values histories relate to the declarant's values rather than instructions. Patients' values are recorded as a basis for decisions on medical treatment (rather than including explicit instructions on specific treatments). They identify core values and beliefs in the context of terminal care that are important to the patient.

Values histories take a goal based rather than prescriptive approach, giving guidance on a policy to be implemented rather than the medical means to the end. The legal persuasiveness of them is less strong, but they may be useful adjuncts when a person is seeking to have an advance refusal respected or they may provide valuable guidance in their own right. In general, the trend towards greater use of values in advance statements is more useful to patients and intensive care doctors than is the trend towards increasingly specific wording of treatments to be refused. Use of values histories should therefore be encouraged.

Further details on values histories may be obtained from the Living Will and Values History Project, BM 718, London WC1N 3XX.

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TREATMENT CAN SOMETIMES BE WITHDRAWN AT HOME

The intensive care unit can be noisy and stressful for grieving relatives. It may be difficult to provide a comfortable and private environment for families and patients who are terminally ill.

In appropriate circumstances it is possible to take patients to their home and withdraw treatment there. Since 1996 we have taken six patients from our unit home to die.

In all cases the relatives found this approach helpful. Relatives often state that, given the choice, the patient would prefer to die at home rather than in hospital. Moreover, relatives seemed better able to cope with their grief in the familiar surroundings of their homes.

There are several conditions that should be satisfied before a patient in intensive care can be taken home to die. There has to be medical consensus that continued intensive therapy is futile and withdrawal of ventilation or cessation of inotropes should preferably lead quickly to death. Organ donation should not be an option, and the patient's death should not require referral to the coroner. Ideally, the patient should live locally. An intensive care nurse and doctor need to be available to accompany the patient and to manage the process of withdrawal of treatment once at the patient's home. Transport needs to be booked in advance.

A clear drug palliation plan should be formulated that uses opiates and benzodiazepines to ensure that the patient is sedated and absolutely comfortable. It is essential to discuss the plan with the patient's general practitioner so that ongoing care for the family can be instigated. Under certain circumstances the general practitioner may issue a death certificate.

Once all the conditions are satisfied the possibility of taking the patient home can be offered to the family. The process should be discussed in detail and they should be told of the risk of death during transfer. It is essential that all family members agree before the patient is transferred.

We believe that when intensive care is deemed futile, consideration should be given to withdrawing treatment in the patient's home.

Paul Frost consultant in intensive care

On behalf of medical and nursing staff from the Department of intensive care medicine.

Middlemore Hospital, Auckland, New Zealand

Quote unquote——

Dying is the most hellishly boresome experience in the world! Particularly when it entails dying of "natural causes".

Somerset Maugham (1874-1965)

There is no medicine against death, and against error no rule has been found

Sigmund Freud

MOST DECISIONS ARE BASED ON SUBJECTIVE APPRAISAL

The death in intensive care often follows a process of withholding or withdrawal of treatment and that these issues are becoming increasingly common as well as complex.

In a prospective audit of deaths over nine months in a paediatric intensive care unit in the United Kingdom, we found that 44(84%) of the 52 deaths resulted from a process of withholding or withdrawal of treatment. Withdrawal of active treatment, such as inotropes or renal replacement therapy or extubation from mechanical ventilation, was by far the commonest process. These decisions were often made on the basis that death was imminent or that prolonging treatment was futile. A combination of worsening severity of illness, minimal response to aggressive treatment, and poor future quality of life were often the stated reasons for withdrawal. However, our objective analysis of these deaths using severity of illness measurements with the paediatric risk of mortality (PRISM II) score, showed that 22 (50%) and only 10 (23%) had mortality risks >80%. Twenty (45%) had conditions that were associated with extremely poor long term treatment were based on subjective appraisal of the child's deteriorating condition. A study in a paediatric intensive care unit in Malaysia has shown that personal bias of the intensive care doctor and the patient's socio-cultural background may influence these decisions. The concept of futility may differ quite substantially among intensive care doctors and also among patients.

We disagree with an argument that it is easier to withhold a treatment than to withdraw it once it has been instituted. We often find ourselves in situations where the inappropriateness of intensive care and limitations of treatment have not been discussed with the family before referral to the intensive care team. In the current audit all the patients had received mechanical ventilation and a variable period of aggressive intensive care before treatment was withdrawn.

With advances in critical care these ethical dilemmas are expected to intensify. Until such a time that objective criteria for futility become sufficiently accurate for individual patient prognostication, we agree with the authors that the principles that guide intensivists on end

of life decision making should be based on beneficence and non-maleficence to our patients.

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SOCIETY NEWS

There is a loud cacophony all around. Sound bytes are in abundance. There are competing ideas. Audience is small. Hence, Dr. B.N.Colabawalla, Chairman and the members of the executive have decided to appoint an advertising agency to help us reach the discerning and influential audience. 'Living will', is assuming greater importance with more and more ICU's going high tech and market face driven. A meaningless life will be prolonged in those ICU's, which, have sprung even in small urban centers. Our society will soon come up with a campaign to popularize 'Living Will'. A budget of 6 lakhs has been envisaged. Your donations will be highly appreciated. Your donations will be acknowledged in newsletters. You may send the donations to Dr. Colabawalla. The cheque may be drawn in favour of 'The Society for the Right to Die with Dignity'.

THE PERMANENT VEGETATIVE STATE: PRACTICAL GUIDANCE ON DIAGNOSIS AND MANAGEMENT

- The diagnosis of the vegetative state can be made only in a patient shown to be unaware of self and environment.
- Published research varies in relation to prognosis and permanence-currently, the vegetative state is considered permanent by 12 months at the latest.
- In England and Wales, stopping artificial nutrition and hydration requires the approval of the High Court.
- The patient is represented legally by the official solicitor.
- The question for the court is whether continued treatment will be in the patient's best interest.

Derick T Wade, Claire Johnston

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