



# Society To Die With Dignity

Vol. 2, No. 1

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## SOCIETY TO DIE WITH DIGNITY

This edition of news letter brings in the articles on Living Will, dignity of living. The proposed draft of the bill on living will was discussed by a small but eminent group of people last November, 95. The group included retired high court justice, journalists, social workers, scientists, doctors, engineers and, others. Prof. Colabawalla who has drafted the bill could not be present due to sudden illness. His views on the bill were taped and played to the audience. Since then he has recovered from his illness also, has been very active in the working of our society. Mr. Minoo Mansani despite

his advancing age and ill health attended the last executive meeting. He refuted certain incorrect references to his views on dignity of life and, euthanasia as published in Femina. A spade work is being done to publish a book to reflect Indian views on life and, death for Indian and international readership. We hope you will enjoy reading this newsletter. Also, we request an increased participation from the members.

Dr. Nagraj Hullgol.  
Editor

## EDITORIAL CHAIRMAN'S LAMENT :

The Society has been in existence for near 15 years and has 300 or more members. It is sad comment to make the members expect the Society to be more active, without reflecting on the fact of how active they are in furthering the objectives. The burden then rest's on just a few of us practically a handful who are trying their best. But no Society can carry on and further its aims without active participation of more members. Such participation can be in various forms such as (i) gathering groups of people to whom our objectives can be put forth (ii) perhaps arising from that there may be an increase in membership (iii) contributing news items or articles which can be utilised by the Newsletter (iv) submitting articles of their own for publication in Newsletter. (v) offering comments and criticism about the functioning of the Society (vi) obtaining donations for activities of the Society.

I once more appeal to all members to consider the above and keep the Society, if they wish it to carry on with the objects.

### PROJECTS ON HAND

- 1) Draft of the Act to legalize the Living Will.
- 2) A small booklet on various aspects of voluntary euthanasia.

### URGENT APPEAL

Change of Office address. We have shifted to SASSOON BUILDING 1st. Floor, 143, Mahatma Gandhi Road, Fort, Bombay 400 023.

### URGENT NEED

Our Office Executive Mr. R.S.Kasargod, who has rendered splendid service to us, wishes to retire by end of May'95. We have to replace him and an appeal is made to all members to try and secure services of such an individual. The requirements are a) He/She should be a retired person seeking only Part Time employment b) the individual will be required to work at the office three times a week for about 2 to 3 hours only c) He/She should be conversant with basic accounts keeping and preferably be able to do some typing. Remuneration can be discussed with the Chairman, Dr. B.N.Colabawalla, telephone No. 363 0080.

# UNDERSTANDING VOLUNTARY EUTHANASIA : A PERSONAL PERSPECTIVE

## Definition

The phenomenal advances in medical science and technology have not been without a significant impact on society. They have brought into relief issues which are altering the pattern of human living and societal values. Pari passu with these changes is the upsurge of affirmation of human rights, autonomy and freedom of choice. These issues compel us to re-evaluate our concepts of societal and medical ethics and value systems.

Amongst these issues, one which has assumed global dimensions, is the 'right to a dignified death' and the related matter of 'voluntary euthanasia'. The word 'euthanasia' (derived from the Greek - 'eu' meaning 'good' and 'Thanatos' meaning 'death') raises strong emotions and has become controversial as it involves termination of human life which has been unjustifiably equated with 'killing'. Taken singularly the term euthanasia has no practical meaning, and has been qualified by 'voluntary', 'involuntary', 'non-voluntary' and other prefixes. This presentation will concern itself only with some facets of 'voluntary euthanasia'.

The conceptual definition of voluntary euthanasia is based on a philosophy which embraces humanism and compassion, and one which recognises the autonomy of the individual and his freedom of choice, along with recognition of his dignity as much in the process of dying as in that of living.

Voluntary euthanasia can be defined as a means chosen by an individual making a request on the basis of a voluntary decision not to have his life prolonged under specific circumstances of ill-health. The operative principles are voluntarism and self-determination.

There are nonetheless some qualifying clauses to the definition:

- \* The decision has to be made by a mature adult.
- \* He (or she) should be in full possession of his (her) decision making capacity.
- \* The decision should be made after careful consideration and due deliberation.
- \* There should be no element of duress or coercion.
- \* The conditions of ill-health must be such as to qualify as irreversible illness which is causing undue pain and suffering and where the terminal event of death is probable in a relatively short period of time.

## Complexity of Issues

The apparent simplicity of this definition does not however mean that the issues are simple. Albert Einstein once stated that 'everything should be made simple, but not simpler'.

Let us consider autonomy and freedom of choice. These are cardinal concepts in any society which professes to embrace liberalism and freedom. Amongst the rights evolved by such a society is the 'right to live and die with dignity'. Any right of the individual is however subject to the fact that they should not trample upon the rights of other or vitiate societal ethics and values. It is difficult to accept that an individual's decision affecting nobody else except himself, either violates anybody's rights or has an impact on societal values.

The freedom of choice though raises one issue- and that is the 'reasonableness' or 'unreasonableness' of the decision and request. In the context of voluntary

euthanasia, the 'reasonableness' of the request may be questioned when an individual wishes to have his life terminated in the early stages of even an incurable disease when the quality of life and functional usefulness to the family and society are not severely compromised. One may have to draw a line between the decision made after considerable deliberation and that made on the spur of the moment under stress of acutely distressing circumstances.

## Objectives

The primary objectives of voluntary euthanasia is the relief of suffering, of which unmitigated pain is probably the most significant component. Pain is a subjective perception and is, at times, very difficult to assess objectively by any scale of measurement. Can we then make a moral judgment of the issue? It may become necessary to accept the patient's assessment, because it is only he who can make a judgment on acceptability or otherwise of his pain.

Pain is not the only factor in suffering. One has to take into account mental distress caused by other manifestations of the disease, such as loss of control over bodily functions or loss of cognitive existence, causing a sense of loss of dignity of life. The respect for life and duty to preserve it are concepts of value but they have to be taken in conjunction with the quality of life preserved. We have to differentiate between existence and living. When an individual is no longer able to contribute to his own physical, intellectual and spiritual well being, sustaining such a state is a perversion of the concept of respect for life. Tagore has stated - though in a different context - that we must be made 'conscious not of volume but the value of existence.' It is a negation of respect for life if mere physical life is maintained at the cost of unmitigated pain and suffering for the individual and the family.

The concept of voluntary euthanasia presupposes that death is inevitable in a relatively short period of time. This period of the process of dying can, now be extended by technology almost to the point of absurdity. The question then will be how to judge the end point and who should make such judgments.

The above issues have been posed not to detract in any way from the primacy of the individual's autonomy. They pose some issues of philosophy and moral judgments. A discussion on them is necessary if the procedure of voluntary euthanasia is to be made transparent for general acceptance by society.

## Reasons why people opt for voluntary euthanasia

- \* Most individuals fear the process of dying rather than the terminal event of death which they realise is an inevitable end of life.
- \* They fear the indignity of being hooked on to life support machines and other forms of treatment when all such treatment is futile and death is inevitable.
- \* Under such circumstances they wish to exercise their right to die with dignity. When pain, mental anguish and suffering are only prolonged by such measures and all sensuous existence may have ceased with a loss of personhood.
- \* The desire not to subject the family to emotional and

financial distress when all treatment may be futile.

### **The Living Will and voluntary euthanasia**

In the context of voluntary euthanasia a document variously called the 'Living Will' or 'Advance Health Directive' assumes significance.

Some considerations pertaining to the document are mentioned below :

- \* The directive establishes the individual's legal rights to refusal of any form of treatment offered to him.

The declaration outlines certain conditions under which he would not like life - or rather the process of dying - prolonged, when all treatment is deemed futile.

\* The directive is applicable even when at the critical time, the individual may not have a decision-making capacity. It specifies that under such circumstances the directive may be taken as the final expression of his wishes.

\* The living will should preferably be made out when the individual is in fit state of health for future consumption.

\* The family and personal physician should be made aware of the existence of the declaration.

\* The individual has the right to withdraw the declaration at any time.

Two other points of significance may be noted. One is that it is always preferable to make out a durable Power of Attorney to two individuals who can then act in case of the individual not being in a competent state of mind. The other is that, unlike in many other countries, the Living Will has no legal sanction in India today. This does not detract from its value of establishing the individual's wishes and has a moral force when the decisions have to be made at critical time. In the absence of such a declaration, futile treatment may be continued by the family out of misplaced sense of duty and by the physician out of misplaced sense of ethics.

### **Medical profession vis-a-vis voluntary euthanasia**

Medical practice today is oriented on the culture which considers that the prime function is to sustain life at whatsoever cost and irrespective of the quality of life. The physician treats death as an enemy and feels a sense of personal defeat when he fails to avert it. This 'monoculture' of the mind of fighting death, coupled with adherence to outmoded concepts of ethics has led to a mental and emotional block in most physicians towards voluntary euthanasia which is irrationally equated with 'killing' and hence with death. Perhaps the fear of the law and opportunism in society may be contributing to this attitude of mind.

Historically, societal and medical ethics have never been static they always been evolving to suit the needs of the time.

Medical science and technology have produced an impact which calls for re-evaluation of societal and medical ethics and value systems. The prime duty of the medical professional is to relieve suffering and voluntary euthanasia should be viewed in the context. Indeed it is the duty of the physician to treat, heal and offer an acceptable quality of life to a patient. But above all is the relief of suffering by all means available to him. An end point is often reached when death via the medium of voluntary euthanasia is the only 'good medicine'. The physician cannot and should not deny the patient this final wish for relief. The era where physicians knew what is best for patients has long passed. When dealing with irremedial diseases, the choice of the patient - even through it may be for euthanasia - has to be respected.

Some facets of medical ethics in the context of voluntary euthanasia.

\* A physician respecting the patient's right to refuse any treatment offered to him; or withholding or withdrawing any treatment considered as futile; or using pain killing drugs even in doses which may shorten life - is not transgressing any ethical bounds as it is not euthanasia.

\* The patient's voluntary and informed consent to accept treatment forms the legal and ethical basis for offering any form of treatment to him.

\* Contrariwise any treatment connected with euthanasia against his desires and consent is unequivocally unethical and immoral.

\* As much as the patient has the right to refuse treatment, the physician has a right to refuse participation in the procedure of euthanasia if he has strong conscientious objection.

\* A quote from the report of the Institute of Medical

Ethics Working Party outlines the ethics of euthanasia. 'A doctor, acting in good conscience, is ethically justified in assisting death if the need to relieve intense and unnecessary pain or distress caused by an incurable illness greatly outweighs the benefit to the patient of further prolonging life. This conclusion applies to patients whose wishes on this matter are known to the doctor and should thus be respected as outweighing any contrary opinions expressed by others.'

\* No immutable guidelines can be suggested as each individual case must be addressed on its own merits. Nonetheless the requirements as laid out in a ruling of the Nagoya High Court in Japan may be of some aid.

They indicate what might be ethically acceptable.

- The patient is suffering from unbearable pain.
- The patient's condition must be terminal with no hope of recovery.

- Euthanasia must be undertaken to relieve suffering.

- It can only be undertaken at the expressed request of the patient.

- A doctor must carry out the procedure.

- The method must be ethically acceptable.

### **Role of the physician**

The role of the physician in voluntary euthanasia is not only desirable but almost imperative as several vital decisions can only be made by him. This has been summarised by Muller and Hetcher :

'... involvement of physician at the request of a competent patient is desirable in order to ensure voluntariness of request, the incurability of the condition from which the patient is suffering, caring presence at the time of death and a swift painless death.'

Besides the above there is a very controversial area where the physician may be called upon to exercise some philosophical and moral judgment. This area is the one concerning 'means' used to terminate life. The ongoing debate is between the negative means of 'allowing death to occur' by withholding treatment and the positive means of 'causing death to occur.' The question posed is whether there is a moral difference between the two means. The borderline is certainly blurred when the patient has made a firm request for euthanasia and the terminal event is not far away. It is difficult to see the moral difference between the two when in both means the doctor has accepted moral responsibility for actions taken. As Preston puts it '... it is a delusion to believe we are not terminating life when we withdraw life supports.' Would it not be more

humane and compassionate to bring about a rapid and forceful end by positive means such as suitable doses of narcotics, rather than prolong the process of dying? The above also brings into relief the issue of 'double effect principle' which often provides a shield for physicians. Once again it is a delusion to believe that we administer drugs, perhaps in increasing doses to relieve pain and if death occurs thereby it was unintentional! The medical profession should forsake such hypocritical arguments they must surely know that from times immemorial to our day, physicians have used narcotics with a view not only to relieve suffering but also to terminate life.

#### Attitudes of doctors towards voluntary euthanasia

##### In India

This has not been analysed on a significant scale involving a large cross section of the profession. Extracts from a sample survey of 200 doctors carried out by the Society for the Right to Die with Dignity in

Bombay, do offer some indications:

- \* 90% stated they had the topic in mind and were concerned.
- \* 78% argued that patients should have the right to choose in case of terminal illness.
- \* 74% believed that artificial life supports should not be extended when death is imminent; but only 65% stated

that they would withdraw life supports.

\* 41% argued that Living Will should be respected. 31% had reservations.

\* Considerations involved ethics, morality, law and religion in that order of importance.

\* More than 70% were apprehensive of the abuse of the law if one was enacted to legalise voluntary euthanasia.

#### Voluntary euthanasia and society

The issues of right to a dignified death and voluntary euthanasia are not the concern of the medical profession alone, and it should not be so if society has to keep a watch over abuse of the concepts. All sections of society must be vitally involved as the issues transcend any philosophical, moral, legal or theological considerations. It is an issue of humanism and compassion. Society will need to change its value systems in the context of the changing medical scenario, of socio-economic environment, of increasing cost of medical services and their cost-effectiveness.

As Spring has stated: 'Will we use our knowledge and new power intelligently or will we just adhere to dogmas and beliefs that have no relevance for this age of biological revolution and spectacular medical skills? If we have to call ourselves a civilised society, we must understand death, respect it and civilise it, as much as we respect life.'

**B. N. Colabawalla**

## ON DEPARTING WITH GRACE

Life is never asked for; it is thrust upon one, and passively received. Along with this unsolicited gift comes an in-built fuel for its propulsion: the instinct to survive. This instinct, as strong in other animals as in humans, bids us live, independent of circumstance: savouring joy or enduring despair, in state of dignity or through humiliation, it is by far the strongest instinct in humans, so powerful in fact as to frequently override reason and judgment. Responsible for some of the most spectacular acts of struggle and survival, it is lauded for being the source of tremendous courage and resilience which can sometimes be summoned in situations of despair. Indisputable as that may be, what is much less often mentioned is that the will to survive results also - and perhaps more often than in the classical kind of heroism in the loss of grace. For when the time comes to die, there are but a few amongst us who graciously let go. We cling desperately to whatever moments of existence may be left of us, and try pitifully to extend them as far as we can. This despair provoke to be our undoing. At the very end of a life which in substantial part may have been spent in seeking the greatest possible degree of dignity for oneself, one slides paradoxically into the indignity of despair, the clutching after straws. And it is this that brings us, in the final reckoning, humbly close to the rest of the animal kingdom, no matter how assiduously we set ourselves apart from them.

Any domineering human instinct, because a large majority will inevitably subscribe to it without questioning, stands a good chance of canonization. For example, the instinct that persuades the human mind of the existence of a divine control of destiny results in the notion of God and religion; likewise, the instinct to survive persuades us of the sanctity of the struggle for life. Because of this canonization, the final despair for the smallest of leases of life is considered as being not

undignified but, on the contrary, honorable, even ennobling. Indeed if you regard the final struggle to be debasing you are likely to be considered inhumanely insensitive.

Of course it is morally dubious to pass judgment on whether or not somebody else's life is seen to be fit to continue. However when the question is of one's own existence, then one should surely have the right to opine on its quality and act appropriately. Life does have its sanctity and its allure, irrespective of the fouling of circumstance. But there are conditions, such as those associated with terminal illnesses which may already have eaten deep into the flesh and mind - malignant cancer being one such, and irreversible coma another - in which the prolongation of life makes but little biological or intellectual sense. Life under these conditions can be made to continue, manufactured anew each instant by the astonishing medical technology of the day. But is not the kind of life that nature had intended, or given. It is contrived and forced, and it cannot reasonably be argued that it must be accorded the same level of sanctity as the natural mechanisms that keep us, going. When nature's mechanisms go horribly wrong, when the body and mind become repositories of degeneration and decay, then one should have the liberty to decide whether one can escape with dignity the ensuing vortex of despair.

The problem is that under such conditions one is quite likely to become incapable of taking a rational decision. However the human mind is blessed with the ability to foresee and to anticipate; and if one is sufficiently persuaded while still in full possession of one's life should be brought to a graceful end. It is here that the right to die differs from suicide; unlike suicide, it is not the termination of a life that is considered subjectively, and transiently, to be unfit for continuation, but which in fact may still prove to be fruitful. On the contrary, it is

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The problem is that under such conditions one is quite likely to become incapable of taking a rational decision. However the human mind is blessed with the ability to foresee and to anticipate; and if one is sufficiently persuaded while still in full possession of one's life should be brought to a graceful end. It is here that the right to die differs from suicide; unlike suicide, it is not the termination of a life that is considered subjectively, and transiently, to be unfit for continuation, but which in fact may still prove to be fruitful. On the contrary, it is

the termination of a life that has from all rational points of view ceased to be a natural phenomenon, whose continuation cannot possibly be associated with any betterment in its quality, and whose present quality is abhorrent. It is in view of the possibility of entering this mode of existence tomorrow that one should be able to say today: "I wish never to continue to live, or be forced to live, in this way", and issue a legally valid direction for its termination.

It is to be emphasized that the decision to end one's life under such circumstances stems from a deep respect

for the quality of life, not from a contempt for life itself. It is to prevent, in the final moments, instinct from prevailing over good reason. For many other facets of existence humankind has devised laws and tenets which ensure that reason triumphs over instinct, and god judgment over impulse; it would be inconsistent not to extent this philosophy to be forced continuation of existence. If one wishes to depart with grace in situations where one has been robbed forever of the last vestiges of dignified and fruitful existence, should be allowed to do so.

Rohit Manchanda

## A REFLECTION ON DYING

I learned to look on death as something inevitable as life itself. Waiting for death is much worse than dying right away.

Profile in courage - Wei before his rearrest-China's dissident.

The simple is overlooked by complexity. The easy is missed by cleverness. It is with difficulty that we make a fool of ourselves: This Zen wisdom is extremely apt when one discusses the need to legalize living will and other issues related to die with dignity. There are scores of systems to assess the quality of life in the attempt to define life with dignity in medical lexicon. Yet we all understand what it means to live with dignity at different planes of existence.

The grandeur of human existence is marked by the ability of the mind for abstract and logical thinking. It is this faculty which has paid to rich dividend. The march of civilisation is the quantum leap of the human mind. Infect, the Indian philosophers always enunciated that the reason for human existence is to seek truth. Death does not end this human spirit but allows newer

elements to grow. That is why God of Death is also called God of Immortality. The onslaught of western thinking has obscured this profound thinking which seeks immortality in death.

The grandeur of life may suddenly sometimes come to an abrupt halt when an incurable, chronic, and painful disease befalls a man. Does he have an escape route under such circumstances? Should he be condemned to wallow in pain?

Should he be asked to spiritualise the incredible ennui and goad him to live inspite of insufferable pain. Should state and the health care system deny him the right of self determination?

'Living Will', tries to answer all these practical and ethical questions. Finally, the question of legalizing 'Living Will' boils down to the question of the fundamental right for self determination.

This right of self determination should never be abrogated by any of the state judiciary or executive.

Dr. Nagraj G. Huilgol

## LEGAL AND ETHICAL CONSIDERATIONS OF 'LIVING WILL'

### Death and dying

Immortality is neither possible nor necessary. Death and dying are inevitable accompaniments of life. Dying, a natural process for many, becomes a nightmare for some.

In recent times the autonomy of the individual (in all its aspects) is gaining importance in the health care system. The natural consequence of this autonomy is the express need and desire of patients to monitor their last days, particularly in the face of incurable disease. In brief, the right to fix the last supper rests with the patient. Advanced directives, assisted suicide and euthanasia are the outcome of these perceived individual rights in life and death.

This article will briefly summarize the definitions, ethical arguments and the law.

### 'Living Will' or 'Ichhamaran'

This is a document executed by a competent person of sound mind, on his/her own volition and without coercion, about the health care decisions to be followed in the event of the person becoming incompetent to make crucial decisions. The 'Living Will' may be in the nature of detailed instructions regarding health care decisions laid out by an individual or it may be a proxy directive whereby a durable power of attorney is delegated to someone else (surrogate decision maker).

**Proposed law : 'Living Will' in India**

'Living Will' is not yet a legally valid document in India. Dr. B. N. Colabawalla has prepared a draft bill on 'Living Will'. It proposes to empower persons above the age of 18 years, in sound possession of mind and not under any duress to execute the will. The bill defines competent person, terminal conditions, attending physician and qualified patient. The bill also defines the conduct of the physician. Voluntarism of both, the physician and the patient is emphasised. The bill seeks legal immunity for physicians acting in accordance with the 'Living Will' act. It also seeks to consider such a death as natural and not suicide. Safety clauses, including penalties for abuse, have been included.

Any person above the age of 18 years can execute 'Living Will'. It is presumed that a major has the capacity of dispassionate thinking about his or her own good. 'Living Will', unlike a suicide note, is addressed specifically to the treating physician or next of kin. It documents the dos and don'ts for the physician in the event of terminal illness so that the suffering soul is not trapped in a tattered body. A 'Living Will' should include detailed guidelines on situations under which the patient should not be resuscitated or the life prolonged endlessly. This helps in clearing any ambiguity and enhances compliance by the treating physician.

### When should life not be supported?

\* The draft of the 'Living Will' lists the following situa-

tions where advanced directives to stop supporting life can become operational :

- \* Stoppage of heart function for a period which can result in irreversible damage.
- \* Severe and lasting brain damage from any cause.
- \* Cessation of brain stem function.
- \* Any irreversible or irremediable disease causing severe physical or mental distress which renders one incapable of rationally purposeful and useful existence or when the vital bodily functions are incapable of independent functioning.
- \* Any form of terminal illness such as malignant cancer, severe immune deficiency disease or advanced degenerative disease of the nervous system leading to vegetative existence.
- \* 'Living Will' is a very personal document. Hence, the proposed law in cognisance of this accepts any directive which is in consonance with the spirit of the above listed indications.

#### **Directives**

The declarant having listed the conditions, also documents the directives. They are to allow the person to die with dignity. The request stems from the correct understanding of human mortality and limitations of existing medical science and technology. To die with dignity is to waltz off the stage without pain, without humiliating sores, without being drenched in smelly secretions, without clutching to a labored breath which in the normal course would have been the last breath. To die with dignity is to pass off with a smile however emaciated the body. The treating physician should, in compassion, understand the tender feeling of the declarant.

The 'Living Will' instructs the physician to desist from indulging in any heroic life-supporting treatment such as artificial ventilation, intravenous infusion or nasogastric feeding tubes. The declarant also directs the physician to administer only those medicines, in appropriate doses, which can relieve the person from pain and suffering, even if the administration of the drug shortens life. These directives are deemed sacrosanct and binding unless the patient in sound mind revokes the will. The right to revoke the will, which the declarant can exercise at any time in his life, rests with the declarant.

#### **Safeguards**

There are adequate safeguards built into the proposed law to prevent any possible abuse of the provision. Here is an example. Two witnesses are required to testify that the declarant has drawn up his will in sound mind and when in the full possession of decision making faculty. The witnesses are required to declare that they have no claim on any portion of the estate of the declarant upon his/her death.

#### **Binding on physician**

The law, when enacted, expects the physician to respect 'Living Will'. The attending physician shall have the right not to comply with the directive if he feels it is against his moral principles. A physician who does not wish to comply is, however, required to make all possible attempts at transferring the care of the declarant to another physician who will respect the 'Living Will'.

**Dr. Nagraj G. Hulligol.**

#### **BOOK POST :**

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