

**STUDY  
ON  
EUTHANASIA – HAPPY END**



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## Introduction

The word 'Euthanasia' literally means 'dying well.' The word used more commonly in medical field is end-of-life. In this document we have used both these words interchangeably. The popular term in Marathi for Euthanasia is इच्छामरण. This subject has been discussed in various forums for past many years. However, we felt that there is a need to look at it afresh as a topic for academic research for two reasons.

On the one hand, we felt that in spite of much interest about the subject, in terms of **action**, it seems to be going nowhere; on the other hand, it was also felt necessary to identify the direction in which the Euthanasia Movement is currently heading.

As academic researchers, this required understanding the subject and tracking its progress over, as it turned out, over a few decades – in fact as we noted, a few centuries. It appears that the discussion about the topic is not related to only the medical dimension. We noted through our research that it has several facets such as religious, sociological, psychological, financial, legal, anthropological, political and of course medical. In fact, one reason why it is difficult to reach a conclusion is because there is no consensus among opinion makers - and decision makers - in each of the areas listed. Even assuming this happens, we noted that this getting translated into a Law of the Parliament, is far from easy – this process even in developed societies, is arduous and very long drawn.

We realized that gathering information first hand, from the patients or their near-ones is not easy; the subject is too sensitive. As a proxy, we investigated cases of Passive Euthanasia – withdrawal of life support equipment or medication – in extreme cases; which is legally permitted in our country. For doing so, we spoke to the doctors who finally had to act on behalf instructions given by the near relatives of the patients. This has provided useful insights about the decision making process leading to Euthanasia.

An important finding however is that the End-of-Life philosophy and practice has been changing course. The Euthanasia activists now think that the issue really is about Dying **with Dignity**. It is about mitigating the physical agony, psychological stress and economic hardship faced by the person during the final days. The reason why active Euthanasia has been pursued by the activists is because it would offer a socially and more importantly, legal way out of the misery. However, that may not be the only way. Recently, Hospice and Palliative Care are considered the preferred ways of offering solace to the patients during their final days. A book on the subject titled 'Being Mortal' by an Indian-American named Dr. Atul Gawande, is currently making waves, which strongly puts forth the case of Palliative care for the terminally ill patients.

We have discussed the issues and the data that led us to the inferences drawn by us, in the pages of this Monograph.

## Literature Review

### **What is Euthanasia?**

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### **What is Euthanasia?**

The word 'Euthanasia' comes from the Greek words 'eu'-meaning good and 'thanatos'-meaning death, which combined means 'dying well.' The dictionary meaning of the word 'Euthanasia' is the practice of intentionally ending human life in order to relieve the person from pain or suffering. The British House of Lords defines it as a 'Deliberate Intervention undertaken with the express intention of ending human life, to relieve intractable suffering.' In the Netherlands, it is understood as 'Termination of life by a doctor at the request of a patient.'

The medical term use for issues related to terminally ill patients is 'end-of-life' issues. It will be useful to define the terms which are used in the context of this subject.

#### **The End-of-life Definitions**

**Suicide** - Impulsive act under severe emotional stress where a person takes his own life.

**Voluntary Death** – Well considered decision by a person if he or she is still able to make medical decisions on how and when they should like to die.

**Physician assisted suicide** – where a doctor knowingly and intentionally provides a person with knowledge or means or both required to commit suicide.

**Passive Euthanasia** – Causing death of a person in a persistent vegetative state with no chance of recovery by withdrawing life support; also a deliberate undoing on the part of the medical professionals of either something necessary to keep the patient alive or stop doing something that is keeping the patient alive, which causes the patient to die.

**Active Euthanasia** –A deliberate act on the part of the medical professionals or another person, that causes the patient to die.

Active Vs Passive Euthanasia further explained.

More often than not, a critical, inevitable but unanswered question crops up as to what is the Moral or Legal distinction between Active Euthanasia and Passive Euthanasia? In simple words, what is the Legal or Moral difference between 'Killing' and 'Letting Die?' - For example, Switching off the Life-support Machines, disconnecting a Feeding Tube, not carrying out a Life-extending Operation or not giving Life-extending Drugs?

As per one of the schools of thought it is acceptable to withhold medical treatment and allow a patient to die, but it is never acceptable to kill a patient by a deliberate human act.

Some medical practitioners agree with the view of the first school of thought as it allows them to provide a patient with the death they want without having to deal with the difficult and critical moral problems they would face if they deliberately killed the patient.

However, as opined by Arthur Hugh Clough, there is no real difference between Active and Passive Euthanasia. In fact, this kind of academic or theoretical distinction is out of the question since stopping treatment is a deliberate human act and most importantly, in both the situations the consequence is the same. For example, switching off a respirator requires a doctor to carry out the actual action of throwing the switch. As a result, if the patient dies, although it is certainly true that the patient dies from lung cancer or any other technical reason, it is equally true that the immediate cause of his death is the switching off of the respirator at the hands of the doctor.

In order to ease the moral dilemma, almost in all situations where Active Euthanasia is legally permitted, the patients are provided the dose of lethal medicine but are required to take it themselves. At least a few decide not to go through with the action.

### Euthanasia – Pro's and Con's

The debate about Euthanasia cuts across complex and dynamic aspects such as, legal, ethical, human rights, health, religious, economic, spiritual, social and cultural aspects of the civilized society.

### Arguments against euthanasia

*Eliminating the invalid:* Euthanasia opponents argue that if we embrace 'the right to death with dignity', people with incurable and debilitating illnesses will be disposed from the society. Right to live of such individuals need to be protected.

*Constitution of India:* 'Right to life' is a natural right embodied in Article 21 but suicide is an unnatural termination or extinction of life and, therefore, incompatible and inconsistent with the concept of 'right to life'. It is the duty of the State to protect life and the physician's duty to provide care and not to harm patients. If euthanasia is legalized, there is a grave apprehension that the State may refuse to invest in palliative care. Hence, a welfare state should not have any role for euthanasia.

*Symptom of mental illness:* Attempts to suicide or completed suicide are commonly seen in patients suffering from depression, schizophrenia and substance usage. It is also documented in patients suffering from obsessive compulsive disorder. Hence, attempted suicide is considered as a sign of mental illness. It is essential to assess the mental state of the individual seeking euthanasia. In classical teaching, attempt to suicide is a psychiatric emergency and it is considered as a desperate call for assistance. Several guidelines have been formulated for management of suicidal patients in psychiatry.

*Mala fide intention:* In the era of declining morality and justice, there is a possibility of misusing euthanasia by family members or relatives for inheriting the property of the patient. 'Mercy killing'

should not lead to 'killing mercy' in the hands of the noble medical professionals. Hence, to keep control over the medical professionals, the Indian Medical Council (Professional Conduct, Etiquette and Ethics Regulations, 2002) discusses euthanasia briefly in Chapter 6, Section 6.7 and it is in accordance with the provisions of the Transplantation of Human Organ Act, 1994. There is an urgent need to protect patients, and also the medical practitioners caring for the terminally ill patients from unnecessary lawsuits.

*Emphasis on care:* Whenever, there is no cure, the society and medical professionals become frustrated and the fellow citizens think of (extreme) measures such as suicide, euthanasia or substance use. What the dying probably need at that stage is palliative and rehabilitative care which would provide relief from distressing symptoms and pain, and support to the patient as well as to the care giver. Palliative care is an active, and compassionate alternative to Euthanasia. The societal and the medical professionals' perception needs to be altered to focus on care in addition to cure.

*Commercialization of health care:* Passive euthanasia occurs in majority of the hospitals across the country, where poor patients and their family members refuse or withdraw treatment because of the huge cost involved in keeping the patients alive. If euthanasia is legalized, then commercial section of the health sector may serve death sentence on many disabled and elderly citizens of India for lack of money. This has been highlighted in a Supreme Court Judgement.

Arguments in favor of euthanasia

*Caregiver's burden:* 'Right-to-die' supporters argue that people who have an incurable, degenerative, disabling or debilitating condition should be allowed to die with dignity. Majority of such petitions are filed by the sufferers or family members or their caretakers. The caregiver's burden is huge and cuts across various domains such as financial, emotional, time-related, physical, mental and social. Adequate and affordable palliative care is not available. Coupled with state's inefficiency, apathy and meagre investment in health-care, 'Right to life' is a mockery.

*Refusing care:* Right to refuse medical treatment is well recognized in law, including medical treatment that sustains or prolongs life. For example, a patient suffering from blood cancer can refuse treatment or deny feeds through nasogastric tube.

*Right to die:* Many patients in a persistent vegetative state or else in chronic, terminal illness, do not want to be a burden on their family members. Euthanasia can be considered as a way to uphold the 'Right to life' by honouring 'Right to die' with dignity.

*Encouraging the organ transplantation:* Euthanasia in terminally ill patients provides an opportunity to advocate for organ donation. This in turn will help many patients with organ failure waiting for transplantation. Not only euthanasia gives 'Right to die' for the terminally ill, but also 'Right to life' for the organ needy patients.

Euthanasia Administration -

Euthanasia can be accomplished either through an oral, intravenous, or intramuscular administration of drugs, or by oxygen deprivation (Anoxia). In individuals who are incapable of swallowing lethal doses of medication, an intravenous route is, in general, preferred. Dr Jack Kevorkian, an American pathologist and a Euthanasia activist, had created a device which delivered the euthanizing drugs intravenously. Kevorkian called the device "Thantron" ("Death machine", from the Greek Thanatos, meaning "death").

### **Historical Perspective**

On 22 Nov. 1998, Dr. Jack Kevorkian, mentioned earlier, actually killed a patient with poison at the patient's request to stop his heart. Dr. Kevorkian, in order to defy the authorities, videotaped the patient's death and circulated the tape. In 1999, Dr. Kevorkian had to go to jail for 'a term of 10 to 25' years for the offence of second degree murder. He actually served the jail sentence for 9 years, before being released.

This was one of the long series of events stretching back to the 19<sup>th</sup> century, that represents attempts by numerous individuals to change the society's attitude and laws towards Euthanasia. Since the 19th century, Euthanasia has sparked intermittent debates and activism in North America and Europe. According to Medical Historian Ezekiel Emanuel, it was the availability of Anesthesia that ushered in the modern era of Euthanasia. In the year 1828, the first well recognized Anti-Euthanasia Law in the United States was passed in the state of New York, with many other localities and states following suit over a period of several years. They were united by their commitment to fighting for the right not to suffer because of unwanted pregnancy and lingering, painful death.

In 1915, a Chicago surgeon refused to operate on a deformed baby thereby allowing it to die. The extensive press coverage of this case sparked off a debate, creating a support for Euthanasia among a small minority of educated individuals. Euthanasia was then considered mainly to let defective babies die curtailing the number of unfit individuals in the society.

The Euthanasia movement suffered a setback because of reports about Nazi medical killings between 1939-1945 which in the name of Euthanasia killed more than 100,000 handicapped adults and children.

Some of the developments that have influenced Euthanasia are

1. The decline of doctor-patient relationship
2. The rise of the 'rights' culture
3. Medicine's inept handling of end-of-life care
4. Aids epidemic

The Euthanasia movement started essentially to provide medically assisted end-of-life to terminally ill individuals. Various proponents of Euthanasia have expressed willingness to cover persons with disabilities, handicapped newborn and unconscious geriatric patients or to justify the

right to die for social and economic reasons. The opponents fear that this will lead to lack of respect for human life, ultimately affecting the disabled and other vulnerable persons in the society. "Right to die" can too easily become "duty to die".

There is little historical evidence however that the right to die movement in the developed world has resulted into misuse, or in the worst case genocide as the alarmists believe. The social and cultural atmosphere in the countries adopting legalized Euthanasia is extremely important in this context. It is necessary to look beyond 'good guys' vs "bad guys" mentality and focus on ethical, social, cultural and economic issues related to death and the dying.

Euthanasia Society of America was formed in 1938 in New York. There is also a Federation of Right to Die Societies in the world having member societies in several countries, though predominantly in the developed world - North America, Europe, Australia and Japan. (web-site, [www.worldrtd.net](http://www.worldrtd.net)). Society for Right to Die with Dignity also exists in India, having its office at 143, 1<sup>st</sup> Floor, Sassoon Building, Mumbai 400001.

ESA – Euthanasia Society of America – tried mightily to nudge popular opinion toward acceptance of Active Euthanasia. The right to die with dignity societies even today plead for active Euthanasia. However, they ran into opposition on two counts. Opposition from religious minded, Roman Catholic Church, in the Western World was one. The other was lack of support from general public, concerned with Nazi-like misuse of Euthanasia. The Euthanasia movement therefore was in a state of stalemate until 1960's. The ESA shifted their focus from active to passive Euthanasia post 1960 i.e. the right to refuse unwanted medical treatment in the case of terminally ill patients rather than a medically administered speedy death. Euthanasia ceased being defined as active mercy killing with its disturbing overtones of coercion and social usefulness and increasingly became viewed as personal freedom against unwanted interference in one's own life. The feminist movement which started taking roots around the same time, also advocated personal freedom in several walks of life; it provided nurturing environment for the Euthanasia movement as well.

The redefined Euthanasia, favoring the passive approach, has been gaining increasing support since the 1970's. Several states in the USA have legalized living wills, wherein among other things, an individual can indicate his/her choice to refuse unwanted medical treatment while dying. The Supreme Court in India is also considering a Bill related to living will being legalized. Euthanasia activists continue to press for Active Euthanasia. However several people believe that issues surrounding death and dying are far more complex than earlier envisaged and warranted further study and discussion.

Post 1990's, as interest in palliative care, pain management and hospice treatment spread. Consequently, other organizations were formed, dedicated to care for the people at the end-of-life but highly skeptical of the need for legalizing active Euthanasia or physician assisted suicide. A state task force on Life and Law, in 1994, has supported a long standing argument that a legal right to die would diminish respect for life. At least some states in the USA (Michigan and Maine, in 1998 and 2000 resp.) voted against legalizing physician assisted suicide.

The summary is that though its history since the 19<sup>th</sup> century suggests that it has come a long way, major shift toward active Euthanasia still eludes the Euthanasia movement. The future of the movement will depend on how the debate over self vs society unfolds in the present century, how the search for boundless individualism and the quest for a meaningful community is resolved.

Stages in the Euthanasia movement can be summarized as below.

Breakthrough	1920-1940
Stalemate	1940-1960
Riding a great wave	1960-1975
Not that simple!	1975-1990
1990's and beyond	

## **Euthanasia under World Cultures**

The issues related to death, are a part of anthropological heritage of the mankind. Several cultures and religious systems, which emerged over millennia have their own interpretation of death; of which dying with dignity has always been an integral part.

### **Euthanasia under Indian Culture**

An argument is that Indian laws are based on the Anglo-Saxon judicial system and Western jurisprudence. They don't take into account the influence of Indian customs and cultural practices on society and people's thinking. In many ancient civilizations, including India, voluntary death was accepted. The Mahabharata refers to the Pandavas and Draupadi giving up their kingdom and embarking on mahaprasthan (the great departure) to meet death. The Manusmriti says: "When a householder sees he's wrinkled and grey, and when he sees the children of his children, he should take himself to the wilderness. The householder should set out in a north-easterly direction and walk straight ahead, diligently engaged in consuming nothing but water and air, until the body collapses."

Suicide is generally prohibited in Hinduism, on the basis that it disrupts the timing of the cycle of death and rebirth and therefore yields bad 'karma'. An exception to the Hindu prohibition of suicide is the practice of prayopaveshan - प्रायोपवेशन, or fasting to death. Prayopaveshan is not regarded as suicide because it is natural and non-violent, and is acceptable only for spiritually advanced people under specified circumstances.

### **Santhara (संथारा) in Jainism**



Santhara (also Sallekhana, Samadhi-marana, Samnyasa-marana सल्लेखना, समाधि-मरण, संन्यासमरण), is the Jain practice of voluntary and systematic fasting to death. Jain texts say it is the ultimate route to attaining moksha and breaking free from the whirlpool of life and death. The vow of Santhara is taken when one feels that one's life has served its purpose. The objective is to purge old karmas and prevent the creation of new ones. Jains claim that Santhara or Sallekhana is the most ideal, peaceful, and satisfying form of death. The young are not allowed to undertake Santhara. Like most Dharmic religious traditions, Jainism considers suicide as wrong since that only retains the karma from the current life and does not allow escape from the cycle of births and rebirths. Santhara has been declared illegal by a ruling of the Rajasthan High court; a decision which is being strongly resisted by the Jain community and contested in the higher court.

### Suicide under Buddhism

The Pali Canon, or Tripitaka, is the primary sacred text in Buddhism, especially the Theravada tradition. According to it suicide is permissible if the person concerned is seriously and painfully ill. However he/she must be at an advanced spiritual level. The action ought to seem virtuous.

### Other religions on Euthanasia

Christianity - Christians are generally opposed to euthanasia and physician-assisted suicide, on the grounds that it invades God's territory of life and death and has other ethical problems. Comment by a practitioner of the religion is as follows - "theologically speaking, perhaps suffering may provide an atonement for moral wrongs done by people in this life to correct the wrongs done previously so they won't have to suffer in the hereafter. Euthanasia deprives them of this atonement and consigns them to the harsher process of cleansing the soul in purgatory".

Islam - Euthanasia is Islamically forbidden since it requires a positive role on the part of the physician to end the life of the patient and to hasten his death via lethal injection, electric shock, a sharp weapon or any other way. This is an act of killing, and, killing is a major sin and thus forbidden in Islam.

### **Euthanasia under Indian Law**

In India abetment of suicide and attempt to suicide are both criminal offences. In 1994, constitutional validity of Indian Penal Code Section 309 was challenged in the Supreme Court. The Supreme Court declared that IPC Sec 309 is unconstitutional, under Article 21 (Right to Life) of the constitution in a landmark judgement. In 1996, an interesting case of abetment of commission of suicide (IPC Sec 306) came to Supreme Court. The accused were convicted in the trial court and later the conviction was upheld by the High Court. They appealed to the Supreme Court and contended that 'right to die' be included in Article 21 of the Constitution. Any person abetting the commission of suicide is merely assisting in the enforcement of the

fundamental right under Article 21; hence their punishment is violation of Article 21. This made the Supreme Court to rethink and to reconsider the decision of right to die. The matter was referred to a Constitution Bench of the Indian Supreme Court. However, the Court held that the right to life under Article 21 of the Constitution does not include the right to die.

Regarding suicide, the Supreme Court reconsidered its decision on the subject. Abetment of suicide (IPC Sec 306) and attempt to suicide (IPC Sec 309) are two distinct offences, hence Section 306 can survive independent of Section 309. It has also clearly stated that a person attempting suicide is in a depression, and hence needs help, rather than punishment. Therefore, the Supreme Court recommended to Parliament to consider the feasibility of deleting Section 309 from the Indian Penal Code.

Passive Euthanasia is legal in India. On 7 March 2011 the Supreme Court of India legalized passive euthanasia by means of the withdrawal of life support to patients in a permanent vegetative state. The decision was made as part of the verdict in a case involving Aruna Shanbaug, who had been in a Persistent Vegetative State (PVS) until her death in 2015.

In March 2011, the Supreme Court of India, passed a historic judgement - law related to Passive Euthanasia in the country. This judgment was passed in wake of Pinki Virani's plea to the highest court in December 2009 under the Constitutional provision of "Next Friend". It is a landmark law which places the power of choice in the hands of the individual, over government, medical or religious control which sees all suffering as "destiny". The Supreme Court specified two irreversible conditions to permit Passive Euthanasia Law in its 2011 Law: (I) The brain-dead for whom the ventilator can be switched off (II) Those in a Persistent Vegetative State (PVS) for whom the feed can be tapered out and pain-managing palliatives be added, according to laid-down international specifications.

The same judgement-law also asked for the scrapping of Section 309, the provision which penalizes those who survive suicide-attempts. In December 2014, government of India declared its intention to do so. On 25 February 2014, a three-judge bench of Supreme Court of India had termed the judgment in *Aruna Shanubauge* case to be 'inconsistent in itself' and has referred the issue of euthanasia to its five-judge Constitution bench. On December 23, 2014, Government of India endorsed and re-validated the Passive Euthanasia judgement-law in a Press Release.

The high court rejected active euthanasia by means of lethal injection. In the absence of a law regulating euthanasia in India, the court stated that its decision becomes the law of the land until the Indian Parliament enacts a suitable law. Active Euthanasia, including the administration of lethal compounds for the purpose of ending life, is still illegal in India, and in most countries.

On Dec 10, 2014 The government has decided to decriminalize "attempt to suicide" by deleting Section 309 of the Indian Penal Code from the statute book. Under the said Section, a suicide bid has been punishable with imprisonment up to one year, or with fine, or both.

## **Hospice and Palliative Care as alternatives for Euthanasia**

Recently Hospice and Palliative care have emerged as strong alternatives to Euthanasia. It is felt that Euthanasia whether active or passive, appears to treat the dying as a clinical problem. At a human level, it is about people who want to live, fulfill their priorities, focus on what matters most to them during those last few days/ months of their life. This is the objective of hospice and palliative care.

The critics of treating end-of-life as a clinical problem are especially severe on medical professionals who make the patients undergo complex medical procedures which quite often makes their life miserable – these procedures may prolong the life marginally but considerably worsen the quality of life. The concerned patients can be spared of this misery (and cost) by allowing them to live a near-normal life with minimum of medication, related to, by and large pain management.

Hospice and Palliative Care are evolving in a small way in India as well. The comments below will outline the general nature of these services and the way in which these may make a difference. Though the information about Hospice and Palliative Care is based on information obtained from western sources; the purpose is to outline shape of things to come.

What is Hospice?

Hospice is a service, for end-of-life care. Hospice is based on the idea that if someone has an incurable illness, and treatment to prolong life and keep the illness under control no longer works, there is still something that medical science can do. Even if life cannot be prolonged, comfort can always be provided, and it should be provided effectively.

- Although hospice is an idea not dependent on a particular place or facility, hospice is delivered to the patient and the family at a place.
  - The place is most often the patient's home because that's where most people would like to be in their final months.
  - Sometimes a patient may need a specific type of care that cannot be provided at home or the patient is too frail or ill to provide care. Then hospice may be delivered somewhere other than the home of the patient. Some health care centers have hospice facilities. These could be separate buildings or designated rooms in a hospital or nursing home.
  - When hospice care is provided outside the home, every effort is made to make the place as homelike as possible. Making a hospital or a nursing home room homelike takes imagination and effort. That's why many health care centers, if they can get sufficient funding, build freestanding "hospice houses".
  - Wherever hospice care is provided for the patient, the family should expect to have 24-hour-a-day access to the patient. Children should be allowed to visit, and within limits, pets may have an access to the patient.
- Hospice care is directed at the entire family, so wherever it's provided, it consists of more than just nursing care and medications for comfort.

- Spiritual guidance is offered. Spiritual guidance can be independent of religious background.
- Social work help is available when needed.
- Volunteers might be with the patient at least for several hours and at least twice a week. The volunteers provide company for the patient while the family caregivers take time to do whatever they need to, in order to keep up with their other responsibilities and interests. One of the problems with being a primary caregiver for a person who has a terminal illness is that there's a temptation to get so totally involved that, when the person dies, you have nothing to look forward to except grief. Hospice staff do all they can to prevent this from happening.

## Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and precise assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- accepts and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- **offers a support system to help patients live as actively as possible until death;**
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- aims at enhancing the quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

### Who gives palliative care?

Any health care provider can give palliative care. But some providers specialize in it. Palliative care may be given by:

- A team of doctors
- Nurses
- Registered dietitians
- Social workers
- Psychologists
- Massage therapists

Palliative care may be offered by hospitals, home care agencies, cancer centers, and long term care facilities.

The differences between hospice and palliative care.

Hospice care and palliative care are very similar when it comes to the most important issue for dying people: care. Hospice can be considered a method of providing palliative care. Palliative care is both a method of administering “comfort” care and increasingly, an administered system offered most prevalently by hospitals. As a supplement to some of the more “traditional” care options, both hospice and palliative care protocols call for patients to receive a combined approach where medications, day-to-day care, equipment, bereavement counseling, and symptom treatment are administered through a single program. Palliative care programs and hospice care programs differ in the care location, timing, payment, and eligibility for services.

### Place

#### Hospice

Hospice programs far outnumber palliative care programs. Generally, once enrolled through a referral from the primary care physician, a patient’s hospice care program, which is overseen by a team of hospice professionals, is administered in the home. Hospice often relies upon the family caregiver, as well as a visiting hospice nurse. While hospice can provide round-the-clock care in a nursing home, at a specially equipped hospice facility, or, on occasion, in a hospital, this is not the norm.

#### Palliative Care

Palliative care teams are made up of doctors, nurses, and other professional medical caregivers, often at the facility where a patient will first receive treatment. These individuals will administer or oversee most of the ongoing comfort-care patients receive. While palliative care can be administered in the home, it is most common to receive palliative care in an institution such as a hospital, extended care facility, or nursing home that is associated with a palliative care team.

### Timing

#### Hospice

A patient must generally be considered to be terminal or within six months of death to be eligible for most hospice programs.

#### Palliative Care

There are no time restrictions. Palliative care can be received by patients at any time, at any stage of illness whether it be terminal or not.

### Treatment

#### Hospice

Most programs concentrate on comfort rather than aggressive disease abatement. By electing to forego extensive life-prolonging treatment, hospice patients can concentrate on getting the most out of the time they have left, without some of the negative side-effects that life prolonging

treatments can have. Most hospice patients can achieve a level of comfort that allows them to concentrate on the emotional and practical issues of dying.

#### Palliative Care

Since there are no time limits on when a patient can receive palliative care, it acts to fill the gap for patients who want and need comfort at any stage of any disease, whether terminal or chronic. In a palliative care program, there is no expectation that life-prolonging therapies will be avoided.

**Hospice and Palliative end-of-life-care, together, is one of the fastest growing branches of Health Care profession.**

#### Hospice and Palliative end-of-life-care in India

Despite its limited coverage, palliative care has been present in India for about 20 years. There are many obstacles in the growth of palliative care in India. These include factors like population density, poverty, geographical diversity, restrictive policies regarding opioid (sedative) prescription, workforce development at base level, as well as limited national palliative care policy support and lack of institutional interest in palliative care. However, there have been visible changes in the mindset of health care providers and policy makers with respect to need of palliative care in India in the last two decades. For a major break-through to happen, systematic and continuous education for medical staff should be mandatory; for achieving this purpose, it would be necessary to increase the number of courses and faculties in palliative medicine at most universities.

McDermott *et al.* identified 138 organizations currently providing hospice and palliative care services in 16 states or union territories. These services are usually concentrated in large cities and regional cancer centers, with the exception of Kerala, where services are more widespread. The Kerala network has more than 60 units covering a population of greater than 12 million and is one of the largest networks in the world. In April 2008, Kerala became the first state in India to announce a palliative care policy. The Calicut model has also become a WHO demonstration project as an example of high quality, flexible, and low cost palliative care delivery in the developing world and illustrating sound principles of cooperation between government and NGOs. CanSupport (for Cancer Support) India, Delhi has 11 home care teams, each consisting of doctors, nurses, and counselors trained in palliative care, to cover the different parts of Delhi and National Capital Region.

Cipla Palliative Care and Training Center in Pune is one of the finest palliative care centers. Started in 1997 it has a 50 bedded unit comprising of 4 wards. The treatment, stay & medicine for patients is FREE OF COST. One relative stays with the patient. Cipla follows the family care model, where the relatives are trained to take care of the patient after their discharge from the hospital.

Palliative Care is an emerging career in Medical Practice. Many jobs are available. There is also a national level organization named National Hospice and Palliative Care Organization, which coordinates work in this field.

### **Euthanasia Movement, the status in 2015**

There have been instances of Euthanasia being legalized and implemented. Five states in the USA, Oregon, Montana, Vermont, Washington and California have assisted dying laws (California has been the latest addition. New Mexico has also been trying). A survey by 'Economist' in 15 countries shows growing support for Euthanasia. Except Poland and Russia, a majority of respondents in other countries felt that there should be laws to assist terminally ill adults to die. In general, there has a tilt in public opinion toward legalization of Euthanasia. As stated earlier suicide has been decriminalized in India.

Passive Euthanasia has already been practiced to a limited extent i.e. under strict medical supervision. The doctors have to be careful not to violate the law. 'Economist' reports a case in the USA where a doctor admitted to having supplied sleeping pills to a patient dying of Leukemia but was let off by the jury.

Arguments against Euthanasia center around the following:

1. Is it used as a cheap alternative to palliative care?
2. Will tight rules get relaxed at the stage of implementation?
3. Will it weaken Doctor-Patient relationship?
4. Will it pressurize the dying to finish themselves off rather than be a burden on the relatives?
5. Is ending a human life always wrong?
6. Whether ending life of a person, especially the disabled, devalue life of others suffering from similar ailments?

Lawmakers all over the world need to consider these issues before legalizing Euthanasia.

The countries, and states in USA, which have laws in favour of Euthanasia have been reporting smooth progression. In Switzerland a hospital named 'Dignitas' (or Dignity), permits even the foreigners to use the facilities. Since 1998, about 1700 people from 40 countries, ended their lives at 'Dignitas'. The hospital does not just handle cases of patients who are terminally ill. Patients who show 'consistent wish to die' are also considered. The hospital spends considerable time in counseling, which they say is their most important job. Very few who contact the clinic, go through with killing themselves. All patients are interviewed to ensure that the decision is theirs; they must take the final dose themselves. That final step takes much courage and determination, say the Doctors attending the patients. Assisted suicides are recorded as unnatural deaths and investigated by the authorities. No malpractice case has ever been brought.

Switzerland's practice of allowing the patients from outside the country has resulted into this practice being labelled as "suicide tourism".

The state of Oregon, USA, has more restrictive rules compared to Switzerland. The rules exclude people with serious but non-fatal afflictions. For this reason Oregon's rules are more likely to be

copied elsewhere. Though the number helped to die has risen over years, as the awareness about the law spread, it remains quite low. Since 1997, 1327 people have received prescriptions about lethal medication of whom only two-thirds have taken it. Doctors must brief the patients about pain medication and hospice care. A second doctor must review each case. No case of professional misconduct has been reported. Contrary to belief that the law will be used by poor people who lacked resources and are desperate for release from untreated agony, almost all who have used it are well educated and have been in hospice care – considered gold standard of palliative care. Lawmakers in Oregon are confident that this law works.

The ‘death with dignity’ bill was passed in Oregon in 1994; after legal challenge, it came into effect in 1997. It requires two doctors to agree that the person requesting help to die has less than 6 months to live and is of sound mind.

Netherlands and Belgium allow doctor assisted dying in many more circumstances than Oregon. They permit doctors to administer the lethal dose intravenously rather than requiring the patients to take it themselves. It is available to people experiencing “unbearable suffering with no prospect of improvement” and for terminally ill children over the age of 12 with parental consent. Around 3% deaths in Netherlands are doctor assisted. It needs to be stated that Netherlands has had a long history of doctor assisted dying even before the law came in – the cases of passive Euthanasia, where doctors allowed terminally ill patients to die by refusing to treat them through aggressive medication. The social acceptance of these practices has made passing of the law and its use by affected patients easier than in other parts of the world. In 2002 the Netherlands which for years had turned a blind eye to doctors prescribing lethal medicine to terminally ill, legalized this practice and extended it to those who, though not close to death, found their suffering unbearable.

Almost in all countries/ states, which have Euthanasia legislation, administering life-ending medication to patients who are either in dementia or coma is difficult. These cases fall outside the country’s assisted dying laws which require that patients are competent and request help to die.

In most places, the medical establishment is opposed to laws on doctor-assisted dying, though both in Netherlands and Belgium, the National Medical Association shifted from opposition to neutrality while framing the law. The opposition by doctors has deep roots. “Nor shall any man’s entreaty prevail upon me to administer poison to anyone; neither shall I counsel any man to do so” runs the Hippocratic oath written nearly 2500 years ago.

The so-called passive Euthanasia also requires legislation. Many doctors help their terminally ill patients to die by withdrawing treatment. Usually, the doctors act after talking to patients or their relatives. Occasionally, when doctors overstep the mark, they are investigated (but rarely charged).

It needs to be realized that despite its use, principally Passive Euthanasia is unethical and unworkable. It is unethical because the explicit choice that should lie with the patient, gets transferred to the doctor. It is unworkable because doctors work within a legal and professional framework; they will not accept the patients’ or the relatives’ request unless there is a legal sanction. It is therefore necessary that there exists a legislation which will place both the patients and the doctors on a firmer ground.



## **Toward Mortality Management**

Good palliative care supported by Hospice has emerged as an option which the terminally ill patients have been needing. Euthanasia, whether active or passive, appears to treat the dying as a clinical problem. At a human level, it is about people who want to live, fulfill their priorities, focus on what matters most to them during those last few months of their life. Euthanasia may be an alternative but good palliative care is an aspect which the society needs to give more attention to. Euthanasia assists patients to die with dignity; however assisting them to live with dignity even in those final days should be a more laudable objective.

This also presupposes an attitudinal change towards the phenomenon of death itself. Spending the final days in a state of relative calm requires acceptance of mortality as an inevitable yet normal outcome. Though obvious, this is break-through thinking for the medical profession. Dr. Atul Gawande, mentions in his book (Being Mortal, 2014) that death has never been a subject of study in a medical school. He mentions that as the profession saw it, “the purpose of medical schooling was to teach how to save lives, not how to tend to their demise”. From here, to acceptance of death as a part of medical practice is a fundamental change. Once accepted, it will lead to a new discipline – which may be called, ‘Mortality Management’. The essential ecosystem for managing the discipline should emerge as a logical outcome. This will mean psychological counseling, palliative care clinics, health-care strategies, specialist doctors and paramedical professionals, applied research etc. Over a period of time, this should develop into a full-fledged branch of the medical profession.

Being an integral part of the post-liberalization global society, India will also adopt the same approach to the extent permitted by the availability of resources. We should expect more palliative care centers emerging, facilities being extended to poorer sections of the society, more NGO’s getting into the act. Like other walks of life, we may not match the developed world in terms of reach as well as the quality of service, but the direction will nearly be the same.

It will be useful to make a conjecture about the future of the original Euthanasia movement. Considerable effort has gone into attaining societal acceptance to the principle of Active Euthanasia; and one can expect that it will make slow, yet steady progress. Some more countries and states may legislate in its favour. It however appears that eventually it will exist only as a part of a broader field of Mortality Management.

We will end our remarks on the note that Euthanasia Movement which started with a simple idea of assisting terminally ill people to die with dignity has been moving towards something which is broader and more profound.

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## Research Methodology

In order to understand the end-of-life decision, which is an essential part of Euthanasia, we carried out a survey about cases related to Passive Euthanasia in Pune. Considering sensitive nature of the subject, we spoke with medical care givers (the doctors) rather than the decision makers themselves.

### **Objectives of the Survey**

The primary objectives were to understand:

- a. under what conditions 'End of life decisions' are made
- b. Who are involved in arriving at the decision

### **Tool for data collection:**

A Structured Questionnaire was designed to solicit the responses. The questionnaire consisted of 7 questions of which all, except the last were close-ended. The data sought was in line with the objectives of the survey. The last question was intentionally kept as open ended. If the respondents had to contribute additional information which is relevant to the study based on their experience, observation, and/or based on their expertise it allowed them to contribute.

### **Sampling Technique:**

In Research Methodology, probability sampling technique is used to generalize the findings of the study. By way of probability sampling, researcher biases are aimed to be eliminated. Most probability sampling require a sampling frame, from which the samples are drawn. For the present project the medical practitioner was decided to be a sampling unit. As all the medical practitioners need to be registered with Medical Council of India and those who wish to practice within the state of Maharashtra are also registered with Maharashtra Medical Council, it was decided to explore the possibility of using the list of registered medical practitioners so that scientific probability sampling technique could be implemented. The list consisted of diverse range of medical practitioners such as Oncologists, Gynecologists, Pediatricians, Ophthalmologists, Radiologists, Dermatologists, physicians and surgeons. We felt that end-of- life decision situations are not faced by all the specialists, therefore a random sample might lead to an inappropriate respondent or might even lead to a null sample. Preliminary survey was carried out with the experts who had shown interest to contribute towards the study to understand who would be the most appropriate medical practitioners from whom the data could be obtained. We also used snow-ball sampling. Although it is reported in literature that by employing snowball sampling, the finding of the study cannot be generalized, the subject matter being sensitive, and for the purpose of removal of non sampling biases and skewed data, a compromise in sampling techniques was thought to be

acceptable. The medical practitioners, who had shown interest to contribute to the study, were the starting referral points. Finally, the total number of respondents was 36.

**Data Analysis:**

Data was edited and coded for the analysis. Editing of data was carried to ensure that the data was consistent and free of errors. The data was represented in tabular or graphical form.

**Data Analysis:**

- 1) **The approximate number of end of life situations encountered by the respondents during the period 2011-2013 is represented below.**

**Table 1**

Approximate Numbers of End Life Situations Encountered			
Frequencies	2011	2012	2013
0	8	8	7
1 - 50	23	23	24
151 - 200	2	2	2
351+	1	1	1
Total	34	34	34

Apparently there seems to be no noticeable difference in the number of end of life situations encountered by the respondents for the period 2011-2103.

2) The reasons for request for end of life situation:

Table 2

Importance of Reasons	Cannot afford the medical expenses	No close relatives, others find it difficult to spare time look after the patient.	There is remote possibility of recovery of the patient within the scope of Medical Science.	Even if the patient recovers, may not be able to live normal life on his/her own.	The productivity /usefulness of the patient to the family is insignificant.	Patient had signed a living will expressing his wish, not to keep him alive by use of life support system.
Not important	12	13	4	5	18	13
Important	4	4	2	6	3	1
Just Important	5	6	5	7	4	6
Very important	2	6	9	9	1	2
Very much important	8	2	14	7	6	5
Total	31	31	34	34	32	27

In the opinion of the respondents the most important reasons for request for end life of was 'There is remote possibility of recovery of the patient within the scope of Medical Science'.(14+9 = 23 respondents). This was followed by 'Even if the patient recovers, may not be able to live normal life on his/her own.'. (9+7=16 respondents). The next is 'Cannot afford the medical expenses'. (8+2=10 respondents).

- 3) The relation of the person and the importance of reason for decision of end of life is tabulated and shown in table 3. When the treating doctors inform the spouse of the patient, that there is remote possibility of recovery of the patient within the scope of Medical Science, the importance of end life of decision attains 'most important' status (7+4=11). The next influential group of persons is Close Relatives (4+2=6)

**Table 3**

**The relation of the person and the importance of reason 'remote possibility of recovery of the patient within the scope of Medical Science' for decision of end of life**

The relation of person who has been informed about the status of the patient.	Not at all important	Not Important	Important	Very important	Very much important	Total
Other	1	0	0	0	0	1
Spouse	1	1	1	4	7	14
Son's/Daughter/s	2	1	2	0	3	8
Close Relative	0	0	0	2	4	6
Other	0	0	1	1	0	2
Total	4	2	4	7	14	31

- 4) The relation of the person and the importance of reason 'the productivity/usefulness of the patient to the family is insignificant' for decision of end of life appears in Table 4-A. The spouse of the patient have ranked the reason 'the productivity/usefulness of the patient to the family is insignificant' as least important factor.

**Table 4 - A**

**The relation of the person and the importance of reason 'the productivity/usefulness of the patient to the family is insignificant' for decision of end of life**

The relation of person who has informed about the status of the patient.	Not at all important	Not Important	Important	Very important	Very much important	Total
Other	0	0	0	0	1	1

Spouse	7	2	2	0	2	13
Son/s, Daughter/s	4	0	0	1	2	7
Close Relative	4	0	1	0	1	6
Other	2	0	0	0	0	2
Total	17	2	3	1	6	29

The relation of the person and the importance of reason “Cannot afford the expenses of medical treatment’ for decision of end of life. The spouse of the patient have ranked the reason “Cannot afford the expenses of medical treatment’ as least important factor as seen in table 4-B below (3+3=6).

**Table 4 - B**

**The relation of the person and the importance of reason ‘Cannot afford the expenses of medical’ for decision of end of life**

The relation of person who has informed about the status of the patient.	Not at all important	Not Important	Important	Very important	Very much important	Total
Other	1	0	0	0	0	1
Spouse	3	3	2	2	2	12
Son/s, Daughter/s	4	0	1	0	3	8
Close Relative	4	0	1	0	1	6
Other	0	1	0	0	1	2
Total	12	4	4	2	7	29

It is observed that although the cost of medical expenses have increased, the reason had highest frequency in ‘not at all important reason’. 16(12+4) out of 29 respondents have sited it as either ‘not at all important’ or ‘not important’.

**5) The area of specialization of the respondents (doctors) is tabulated below.**

**Table 5****The Area of Specialisation of the Medical Practitioner and the number of Years in Practice**

Specialty	No. of years in practice					Total
	Between 1-5	Between 6-20	Between 21-30	Between 31-50	More than 50	
Physician	2	0	3	2	1	8
ICU	2	1	1	3	1	8
Orthopaedic	0	2	0	0	0	2
Ophthalmology	1	0	0	0	0	1
Neurology	0	1	0	0	0	1
Radiology	1	0	0	0	0	1
Surgeon	0	0	0	1	0	1
M D Chest	1	0	0	0	1	2
ENT	2	3	0	1	0	6
General Practitioner	2	1	0	0	0	3
Oncologist	0	0	0	0	1	1
Total	11	8	4	7	4	34

**6) Views of Medical Practitioners**

As mentioned earlier the questionnaire prepared to solicit the responses of the medical Practitioners, had one open ended question where the respondents were free to express their opinion about 'End of Life Decision' . 16 respondents had commented on the topic. The common opinions expressed were:

- a) Laws in India about Euthanasia are not clear.
- b) It is a very important issue from social angle.
- c) Difficult to apply in India, but needs to apply.



- d) It needs to be regularised legally.
- e) Relatives are helpless due to the economic condition of their own.
- f) Age of the seriously ill person should be taken into account before any such decision. However, everyone has a right to live.
- g) Although point of having 'living will' is important, no standard 'living will' is available. Moreover, its legal validity is not tested.

The opinions expressed have thrown important points such as

- i) Euthanasia has social aspect
- ii) There is a need to have specific legal frame work to deal with end of life situations and if required laws related to Euthanasia be enacted
- iii) There is strong feeling expressed that everyone has a right to live

These points have given rise for need for further study of Euthanasia, End of life situations.

### **General**

#### **Scope of the Study**

- 1) The geographical area of the survey was limited to the limits of Pune Municipal Corporation.
- 2) The Responses were collected from Medical practitioners of Allopathic system of Medical Science.
- 3) The Responses were collected from the medical practitioners who showed willingness to provide the information.

#### **Limitations**

- 1) The survey was conducted which was limited to the medical practitioners. It did not include the patients or their relatives / friends.
- 2) The data pertains to the opinion and responses based on the experience of the respondents. The responses may be based on the experiences, and the memory of the respondent.

## Findings and Conclusion

The purpose of undertaking the research has been three-fold.

- (1) To study the current state of acceptance of the concept in our part of the world and also in the western society (the so-called 'developed world').
- (2) To study, through a survey, of cases involving passive end-of-life i.e. withdrawal of life support care, which is legally permissible under certain circumstances.
- (3) Based on above, make suggestions about what can be done to advance the practice of Euthanasia in our society and to study available alternatives.

The research topic of Euthanasia is not new. Medically, a term more common is 'end-of-life'. It has been called इच्छामरण in our society. These ideas have been discussed in our as well as other societies for decades. If one considers practices such as 'Santhara' in Jainism or 'Prayopveshan' in Hinduism, or the Hippocratic Oath, which prevents a doctor from administering 'poison' to a patient, even at his request, Euthanasia can be said to have a history as old as the civilization itself.

The two terms which are most common in the context of Euthanasia are Active Euthanasia and Passive Euthanasia, defined as below.

Active Euthanasia is a deliberate act on the part of the medical professionals or another person, that causes the patient to die.

Passive Euthanasia is a deliberate undoing on the part of the medical professionals of either something necessary to keep the patient alive or stop doing something that is keeping the patient alive, which causes the patient to die. This usually concerns a person in a persistent vegetative state with no chance of recovery.

The modern Euthanasia movement started in the western world around 1920. The Euthanasia activists have been following the path of creating favorable public opinion, so that appropriate laws can be passed permitting Active Euthanasia. There have been extreme cases of Euthanasia activism. On 22 Nov. 1998, Dr. Jack Kevorkian, an American pathologist and Euthanasia activist, actually killed a patient with poison at the patient's request to stop his heart. He had to go to jail for a term of 9 years for the offence of second degree murder.

The Euthanasia movement suffered a setback because of reports about Nazi medical killings between 1939-1945 (which, in the name of Euthanasia killed more than 100,000 handicapped adults and children), and has in fact never fully recovered. While passive Euthanasia is permitted in several countries of the world, including India, its more sought after counterpart, Active Euthanasia, in a regulated format, is legalized in only 5 states of USA (Oregon, Washington, Montana, Vermont and California) and 3 countries of Europe (Switzerland, Netherlands and Belgium). While the educated elite in many parts of the world are in favour of passing the law, the legislators in general are not ready to run the risk of possible abuse of the law to terminate life. This is the inference to be drawn from a comprehensive survey carried out by 'Economist' magazine in 15 countries of Europe.

Pursuing this course of action in India, is therefore unlikely to yield results in the absence of adequate precedents.

We carried out a survey of medical practitioners in Pune who had an important role in administering Passive Euthanasia to terminally ill patients, in vegetative state. The purpose was to analyze end-of-life decisions taken by the persons close to the patients. 34 Doctors, from various specialties participated in the survey. In the opinion of the doctors, the important factors in end-of-life decision in these cases were (1) There is remote possibility of the recovery of the patient (2) the patient, if recovered, will not be able to live normal life and (3) Cannot afford the expenses, **in that order**. The decision makers have been mainly the spouse and close relatives.

The progress towards legislating in favour of Active Euthanasia has been, and will be slow. The current thinking among health care professionals however has been in a different direction. It is felt that Euthanasia whether active or passive, appears to treat the dying as a clinical problem. At a human level, it is about people who want to live, fulfill their priorities, focus on what matters most to them during those last few days/ months of their life. This is the objective of hospice and palliative care, which have evolved in the last two decades to take care of the terminally ill. Euthanasia may be an alternative but good palliative care is an aspect which the society needs to give more attention. Euthanasia assists patients to die with dignity; assisting them to live with dignity even in those final days could be a more important objective.

The critics of treating end-of-life as a clinical problem are especially severe on medical professionals who make the patients undergo complex medical procedures, at an unaffordable cost, which quite often makes their life miserable – these procedures may prolong the life marginally but considerably worsen the quality of life. The concerned patients can be spared of this misery and cost by allowing them to live a near-normal life to the extent possible, with by-and-large pain management. Most important issue is their living among their close relatives and friends, fulfilling their final priorities and wishes.

Palliative care is thus emerging as one of the fastest growing discipline in the health care profession. Despite its limited coverage, palliative care has been present in India for about 20 years. There have been obstacles such as population density, poverty, geographical diversity, restrictive policies regarding opioid (sedative) prescription, workforce development, national palliative care policy deficit and lack of institutional interest in palliative care. However, there have been visible changes in the mindset of health care providers and policy makers with respect to need for palliative care in India in the last two decades. For a major break-through to happen, systematic and continuous education for medical staff should be mandatory; as well as increase in the number of courses and faculties in palliative medicine at most universities. Incidentally, Cipla Palliative Care and Training Center in Pune is one of the finest palliative care centers in the country.

#### Towards Mortality Management

Emphasis on Good palliative care supported by hospice presupposes an attitudinal change towards the phenomenon of death itself. Spending the final days in a state of relative calm requires acceptance of mortality as an inevitable yet normal outcome. Though obvious, this is

break-through thinking for the medical profession. Until now, “the purpose of medical schooling was to teach how to save lives, not how to tend to their demise”. From here, to acceptance of death as a part of medical practice is a fundamental change. Once accepted, it will lead to a new discipline – which may be called say, ‘Mortality Management’. The essential ecosystem for managing the discipline should emerge as a logical outcome. Over a period of time, this should develop into a full-fledged branch of the medical profession.

India may not match the developed world in terms of reach as well as the quality of palliative care, but the direction will nearly be the same.

It will be useful to make a conjecture about the future of the original Euthanasia movement. It appears that eventually it will exist only a part of a broader field of Mortality Management.