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“CESSATION OF LIFE IS INEVITABLE “

PROLONGING AT WHAT COST? LIVING WILL "

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ABSTRACT

Introduction

“CESSATION OF LIFE IS INEVITABLE” “PROLONGING AT WHAT COST?”

“LIVING WILL”

Many thousands of patients are kept alive in comatose and permanently vegetative states. Have we ever considered the sufferings and pain of the patient who is not able to speak and the cost burden to their families & government. Nearly 80% of all deaths are unnecessarily prolonged, painful, expensive, and emotionally burdensome to both patients and their families. In underdeveloped countries where health care is not a part of Government system, patients and their families pay from their pocket whereas in countries like USA & Canada its taking a lot on Government & Insurance Companies. In both the situations it is a matter of concern.

From the moral point of view, there are also limits to the obligation on the part of doctors to save or prolong life. There are numerous therapeutic modalities to prolong existence, but it is not just the length of life, but its quality that concerns patients and their families. When this quality can no longer be maintained, it is professionally and socially acceptable to let the dying process take its course.

However “Living Will” can be a document in such situations to deal with life-sustaining medical procedures in the eventuality of the signatory’s sudden debilitation. It allows a person to execute a document that expresses his or her desire not to be kept alive through artificial or extraordinary means in the event of a terminal condition. Any person can make his or her wishes regarding life prolonging medical treatments known through this document which is also referred to as an advance directive, health care directive, or a physician’s directive.

A living will is a document designed to control future health care decisions only when you become unable to make decisions and choices on your own.

The document must be witnessed and notarized. Spouses, potential heirs, attending physician, or employees of health care facilities are usually not allowed to witness Living Will.

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“LIVING WILL”

HISTORICAL EVOLUTION

The living will is the oldest form of advance directive. It was first proposed by an Illinois attorney, Louis Kutner, in a law journal in 1969. Kutner drew from existing estate law, by which an individual can
control property affairs after death (i.e., when no longer available to speak for themselves) and devised a way for an individual to speak to his or her health care desires when no longer able to express current health care wishes. Because this form of “will” was to be used while an individual was still alive (but no longer able to make decisions) it was dubbed the “living will.”

**DISCUSSION**

Adults have the right to control their medical treatment as long as they are mentally able to do so. One should be able to choose which course of treatment you would like from those the doctor offers, be it aggressive, comfort care, or even none. You can refuse any treatment that you do not want. While some may want life extended for as long as possible, even if they may be in pain, unconscious or unable to communicate, others may want otherwise This right is called *Informed consent.* Generally, a living will describes certain life prolonging treatments with the declarant having the option to indicate which treatment he or she does or does not want, in the event of a terminal illness or a permanent vegetative state.

A living will does not become effective unless you are incapacitated; until which time you retain the option to undergo what treatments you do or don’t want. This is based on a certification from the treating doctor and another senior medical consultant that you are suffering from a terminal illness or permanently unconscious condition i.e. brain dead. A living will is only used when your ultimate recovery is hopeless. This right is not absolute, and, if you are unable to take in information or give consent when you need immediate or emergency care, the doctor may go ahead with the treatment.

With a living will, you cannot choose an agent or proxy to make decisions for you or be sure that your wishes are carried out. Key deficits in most living wills is they are limited in scope and often failed to fully address presenting problems and needs. Moreover individuals tend to write out their wishes in ways that are in conflict with quality medical practice.

A living will should not be confused with a living trust, which is a mechanism for holding and distributing a person’s assets to avoid probate. The term *living will* is a misnomer since a will does not by definition take effect until the signatory’s death whereas a *living will* is useless after the signatory’s death. The requirements for a living will vary from one country to another so that you are advised to have a lawyer prepare your living will. Many lawyers who practice in the area of estate planning include a living will and a health care power of attorney in their package of estate planning documents. Hence, if you need to write or update a will or trust, you can take care of your living will at the same time.

**Options**

You may refuse treatment for the following reasons:

- Not worth the pain or risk
- Prolonging life but in an uncomfortable state (i.e. long, burdensome dialysis sessions)
- If there’s a procedure you know that you wouldn’t want under *any* circumstances

In such cases, the health care provider or facility must tell you right away and you may be transferred to another facility that will honor your decision.

**Mental health care directive or psychiatric care directive.**
If you expect problems with mental illness, you can also outline your health care choices in the event that you become seriously mentally ill and unable to make health care decisions. There are many things to think about when drafting a living will such as life-sustaining medical treatment with artificial means that would prolong the dying process for a terminally ill patient such as Ventilators, Cardiac devices, higher antibiotics, costly blood substitutes etc.

It is also important to know that there is a difference between “Refusing all medical care “ & not to have “aggressive medical treatment” wherein goal of treatment becomes comfort rather than cure. There are situations when a health care provider may reject a medical decision made by you or your proxy based on your advance directive. This may happen in the following situations:

- when the decision is against the individual health care provider’s conscience
- when the decision is against the health care institution’s policy
- if the decision violates accepted health care standards

You can revoke (end or take back) a living will at any time. If possible, the changes should be signed, dated and witnessed. You should inform your proxy or agent, loved ones, and doctor if you change or cancel your advance directive. You must also destroy all copies of the old advance directive so there is no confusion on the part of your proxy or family.

Terminal illness
A terminal illness is an irreversible condition that in the near future will result in death or a state of permanent unconsciousness from which you are unlikely to recover. In most states, a terminal illness is defined as one in which the patient will die “shortly” whether or not medical treatment is given. Terminal implies a debilitating condition which is medically incurable or not treatable in terms of available technology and which can be expected to cause death and includes conditions where death is imminent and with no reasonable hope of recovery.

Permanent unconsciousness
A persistent vegetative state results from a partial death of the brain from which a person cannot recover. It is different from a coma, because sometimes people wake up from comas. The diagnosis of persistent vegetative state takes time to make. A person in a persistent vegetative state may survive for years, so a few states do not permit life-sustaining treatment to be stopped in these cases. On the other hand, all states have legally adopted a standard definition of brain death as an “irreversible cessation of all functions of the entire brain, including the brain stem.” Brain death is when all parts of the brain have stopped working. It is determined by a flat electroencephalogram (EEG) and certain medical signs checked and endorsed by the treating physician, a neurophysician and hospital director. When brain death happens, the person is considered dead. Life support can be turned off and organs harvested for donation.

“Do Not Resuscitate” orders
The success of intensive care is not just measured by the statistics of survival, as though each death were a medical failure. It has to be measured by the quality of the lives preserved or restored, but by the quality of death and human relationships involved. If you are in the hospital, you can ask your doctor to add a “Do Not Resuscitate” or DNR order to your medical record. You would ask for this if you didn’t want the hospital staff to try to revive you if your heart or breathing stopped. The DNR order allows the natural process of dying to take its course without any interference. It is not a disguised version of euthanasia or a cryptic terminology for abandoning treatment.

Life sustaining treatment means medical care, procedures or interventions that applied to a patient with terminal illness would have little effect on the underlying disease, injury or condition and would only serve to delay the timing of death. This includes resuscitation, artificial nutrition, hydration, mechanical...
ventilation and dialysis but does no include medical procedures deemed necessary for providing comfort like oxygen for breathlessness, analgesics for pain etc. Where the central principles of beneficence, non-malfeasance and medical ethics prompt disagreements, cases are best referred to a multidisciplinary hospital ethics advisory committee. The patient’s choice must be preeminent over the physician’s moral stance, when the latter can hand over the patient to another colleague who is not so constrained. If no written instructions are available, the patient’s family must be considered as the guardian unless they make unreasonable judgment when judicial review can be requested. Remember that an in-patient DNR order is only good while you are in the hospital. Also the DNR status needs to be reviewed regularly, as 38% of patients with DNR orders do not suffer a major event while in hospital and are discharged.

Outside the hospital, it’s a little more difficult.

Home-bound patients who want their advance directives honored have a special DNAR form or wear a special bracelet labeled “do not resuscitate.” Some countries and states have an advance directive that is called a Do Not Attempt Resuscitation (DNAR) or special Do Not Resuscitate (DNR) order for use outside the hospital. The non-hospital DNR or DNAR is intended for Emergency Medical Service (EMS) teams, who answer 108 calls and are usually required to try to revive and prolong life in every way they can. Even though families expecting a death are advised to call other sources for help when the patient worsens, a moment of uncertainty sometimes results in a 108 call. This can mean unwanted measures that prolong death. The non-hospital DNR or DNAR order offers a way for patients to refuse the full resuscitation effort in advance, even if EMS is called. It must be signed by both the patient and the doctor.

Organ donation
Organ and tissue donation instructions can be included in your advance health care directive document. Many states also provide organ donor cards or add notations to your driver’s license.

Body Donation
You may write a will to donate your body for Scientific studies to Medical Colleges when you do not want your family to cremate your body after death.

“Euthanasia”
The word euthanasia comes from a Greek phrase meaning “a gentle, happy and easy death.” Euthanasia is defined as any action or omission that causes death with the purpose of ending suffering due to illness. Euthanasia is an intervention that anticipates a terminal path physiologic process and purposefully speeds up that process to minimize suffering. There are 2 major types of euthanasia: active and passive. Active euthanasia involves someone other than the patient taking active measures to end a patient’s life, such as personally giving a deadly dose of a drug. Active euthanasia is illegal in many countries even if the patient requests it. Active drug euthanasia may be of following types:

(1) Voluntary active euthanasia: Intentionally administering medications or other interventions to cause the patient’s death with the patient’s informed consent.
(2) Involuntary active euthanasia i.e. without the competent patient’s consent.
(3) Non voluntary active euthanasia where the patient is incompetent and mentally incapable of giving consent.

Passive euthanasia is defined as stopping, termination or withholding of life-sustaining treatment, such as breathing machines or feeding tubes. This allows a terminally ill patient to die naturally, without further prolonging death.
Indirect euthanasia is the process of administering narcotics or other medications to relieve pain with the incidental consequence of causing sufficient respiratory depression to result in the patient’s death. Active euthanasia is defined in the Belgium and Netherlands as an intentional act to terminate life by a person other than the person involved on request of the latter. Active euthanasia accounts for 1.8% of deaths in the Netherlands. If left alone, 87% of patients subjected to active euthanasia would have lived for a month at most while another 12% would have survived for a maximum of 6 months. Netherlands has a committee to check whether doctors have adhered to legal requirements in voluntary euthanasia. They apply 4 criteria to determine the legitimacy of euthanasia:

(a) The patient must be under severe mental and/or physical anguish with no prospect of relief
(b) The patient must make the request freely, frequently, consistently and without coercion and the Treating physician must not, in any way, solicit the patient
(c) Assisted death may not be an answer to pain, fear, failing care or loneliness. Alternatives to euthanasia must be offered by the physician in such cases.
(d) The primary physician must consult another colleague to confirm the diagnosis and prognosis and the lack of further treatment options to ensure that all the legal requirements for euthanasia are met.

Even though Alzheimer’s disease is not a terminal condition, a patient’s request is considered appropriate on the basis of “suffering hopelessly and unbearably” In spite of the possible benefits of euthanasia, it is indeed a slippery slope that may be perilous as a public policy especially around the issue of involuntary euthanasia for marginalized and disempowered persons, and corrosive to medical practice, by detraction from issues such as better pain control and terminal care strategies. Assisted suicide is different from active or passive euthanasia. Assisted suicide is giving a patient the means to take his or her life, such as by writing a prescription for deadly dose of barbiturates that the patient may choose to take. The states of Oregon and Washington allow doctors to write a prescription for a lethal dose of medicine for terminally ill patients who wish to end their lives. Those states honoring ‘Death with Dignity Acts’ prohibit active euthanasia; that is to say, no one else can administer the lethal dose of medicine. The patient must do that for him or herself. The person must be aged 18 or older, within 6 months of death, informed of possible alternatives, and must make several requests over time for help in hastening death. Not all doctors can be expected to write such prescriptions even for people who meet all the requirements. Doctors can refuse to prescribe these drugs based on conscience. Decisions to commit suicide are usually based on the loss of autonomy and control of bodily functions and less concerned with the fear of uncontrollable pain or financial burdens. This may be in part due to the progress medicine has made in dealing with pain.

**GLOBAL OVERVIEW**

*The Netherlands*

Patients and potential patients can specify the circumstances under which they would want euthanasia for themselves. They do this by providing a written *euthanasia directive*. This helps establish the previously expressed wish of the patient even if the patient is no longer able to communicate. However, it is only one of the factors that is taken into account. Apart from the will in writing of the patients, at least two physicians, the second being totally unrelated to the first physician in a professional matter (e.g. working in another hospital, no prior knowledge of the medical case at hand), have to agree that the patient is terminally ill and that no hope for recovery exists. The 4 criteria used to determine legitimacy are:-

(a) The patient must be under severe mental and/or physical anguish, with no prospect of relief
(b) The patient must make the request freely, frequently, consistently and without coercion. The physician may not solicit the patient
Assisted death may not be an answer to pain, fear, failing care or loneliness and alternatives to euthanasia must be offered by the physician

A colleague must be consulted by the primary physician to confirm the diagnosis and prognosis and the lack of other treatment options and to ensure that all legal requirements for euthanasia have been met.

**Germany**

On 18 June 2009 the Bundestag passed a law on advanced directive, applicable since 1st September 2009. Such law, based on the principle of the right of self-determination, provides for the assistance of a fiduciary and of the physician.

**Switzerland**

There are several organizations which take care of registering patient decrees, forms which are signed by the patients declaring that in case of permanent loss of judgment (e.g., inability to communicate or severe brain damage) all means of prolonging life shall be stopped. Family members and these organizations also keep proxies which entitle its holder to enforce such patient decrees. Establishing such decrees is relatively uncomplicated. However, in Switzerland, a patient decree has, as of November 2008, no legally binding effects, whether concerning civil nor criminal aspects. Such a decree is today merely viewed as representing the supposed will of the person with the incapability. There is, however, a revision of the Swiss Civil Code under way that aims to change this situation (intended to be article 360 of the Swiss Civil Code) by making the patient decree a legally binding document.

**England & Wales**

People may make an advance directive or appoint a proxy under the Mental Capacity Act 2005. This is only for an advanced refusal of treatment for when the person lacks mental capacity and must be considered to be valid and applicable by the medical staff concerned.

**United States of America**

In the United States, most states recognize living wills or the designation of a health care proxy. For example California does not recognize a living will but instead uses an Advanced Health Care Directive. However, a “report card” issued by the Robert Wood Johnson Foundation in 2002 concluded that only seven states deserved an “A” for meeting the standards of the model Uniform Rights of the Terminally Ill Act. Surveys show that one-third of Americans say they’ve had to make decisions about end-of-life care for a loved one. In Pennsylvania on Nov. 30, 2006, Governor Edward Rendell signed into law Act 169, which provides a comprehensive statutory framework governing advance health care directives and health care decision-making for incompetent patients. As a result, health care organizations make available a “Combined Living Will & Health Care Power of Attorney Example Form from Pennsylvania Act 169 of 2006.”. In 1997, Oregon enacted the Death with Dignity Act. This law allows—but does not require—doctors to prescribe medication to competent, terminally ill patients, knowing that the medication is going to be used by the patient to end his life. In 1997, three terminally ill patients, four doctors, and a nonprofit group that counsels patients considering physician-assisted suicide filed suit in federal court, claiming that Washington State’s ban on physician-assisted suicide is unconstitutional. They asserted that the “right” to receive assistance in committing suicide is a liberty protected by the Due Process Clause of the Fourteenth Amendment. They prevailed at the district court and appellate court levels, but ultimately lost in the U.S. Supreme Court which stated that Washington’s ban on physician-assisted suicide did not infringe on a fundamental liberty under the Due Process Clause. The Court held, the ban was rationally related to legitimate government interests, such as prohibiting intentional killing and preserving human life, protecting the medical profession’s integrity and ethics and maintaining physicians’ role as their patients’ healers, and preventing harm to those people who are the most vulnerable, including the poor, the elderly, disabled people, and the terminally ill. In a companion case decided the same day, the Court also held that New York State’s ban on assisted suicide did not
violate the Equal Protection Clause of the Fourteenth Amendment. The Supreme Court held that the distinction between letting a patient die and making a patient die is important, logical, rational, and well established: The two acts are different. The Court’s rulings leave states free to decide to enact laws allowing physicians to assist patients who wish to end their lives. The Court’s rulings simply mean that the states are not required by the Constitution to do so.

India

Ichhmaran’ The important law aspect in living will is sui juris. That means “of his own rights”. A person who can validly contract and bind himself by legal obligation, uncontrolled by any other person, is said to be sui juris, in other words a person not subject to any incapacity, such as non-age or insanity, possessing full social and civil rights, not under any legal disability or the power of another guardianship. The Ichhmaran would be 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). The Living Will is not yet a legally valid document in India. The Society for the Right to Die with Dignity, the Freedom First Foundation and the Leslie Sawhney Program joined hands to organize the Mr Minoo Masani Memorial Program on May 29, 1999 when noted urologist Dr. B. N. Colabawala has prepared a draft bill on ‘Living Will’. He has proposed 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 emphasized. 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 and penalties clauses for abuse, have been included. The bill is still under scrutiny.

Components of a Living Will
1. The Living Will document itself
2. Power of Attorney for Health Care
3. Optional documents:
   (a) Personal Values Statement
   (b) An Organ Donation Statement

Advance Directive

Early powers of attorney allowed an individual to name someone to act in their stead in legal or business matters. Later on these statutes were expanded to allow “durable” powers of attorney (also known as a lasting or enduring powers of attorney) meaning that the legal appointment could continue even if the individual who originally executed the document later lost capacity to make his or her wishes. Depending upon these laws, “durable powers of attorney for health care” and “health care proxy appointment” documents were created and codified in law, allowing an individual to appoint someone to make health care decisions on their behalf if they should ever be rendered incapable of making their wishes known. Substituted judgment means a decision made by a surrogate decision maker on behalf of a patient who lacks decision making capacity.

The living will was incapable of doing any good if no one knew about them. For situations where you are incapacitated and therefore unable to speak for yourself, but your health situation is not so dire to make your living effective, you should have a health care power of attorney or health care proxy- substitute person, also called an agent or surrogate (5 wishes option). The durable power of attorney for health care is a legal document that gives someone else the authority to make health care decisions on your behalf in the event that you are incapacitated. The primary benefit of second-generation advance
directives is that the appointed representative can make real-time decisions in actual circumstances, as opposed to advance decisions framed in hypothetical situations, as recorded in a living will.

The person you designate to make health care decisions on your behalf is supposed to consider what you would want. Hence, you have to make sure that all aspects are discussed threadbare. It may be a difficult conversation, but it is asking someone to take on a great burden on your behalf. It becomes important to discuss your living will with your family, religious service providers and lawyers. You must also make sure that you discuss with your doctor what kinds of end of life medical treatments you want. He or she can help you by answering any questions you may have about certain treatment protocols. Once you have decided what it is you do or do not want, you can make your wishes known to your doctor and family. Some countries have laws that say which family members (in a listed order of priority) may act on behalf of a person who cannot communicate. You must ensure that copies of your advance directive are handed over to your proxy or agent, family members, and friends who may be contacted if you becomes seriously ill.

Do not keep the advance directive locked up where no one can find it or access it. It is up to your proxy, or a family member to give a copy of your advance directive to your doctor and hospital when it is needed.

In advanced countries, federal law requires that hospitals, nursing homes, and other health care agencies ask at the time of admission whether or not a patient has an advance directive. If the advance directive is not available, it may not be included in your medical record. If unavailable, you may get medical care that you never wanted. No one, including health insurance companies, can mandate you to have or prevent you from having an advance directive, as it does not affect any terms of your life insurance.

Limitations & Improvements

Studies found most of what appointed proxies are told was too vague for meaningful interpretation. In the absence of meaningful information, family and physician “guesswork” was found to be inaccurate as much as 76% of the time.

Third generation advance directives were designed to contain enriched content to assist individuals and their appointed agents, families, and physicians to better understand and honor their wishes. The goal of this advance directive is to move away from a focus on specific treatments and medical procedures to a focus on patient values and personal goals. Six case scenarios for advance medical decision-making are detailed. The scenarios are each associated with a roster of commonly considered medical procedures and interventions, allowing the individual to decide in advance which treatments are wanted or not wanted under the circumstances.

Several criticisms regarding this advance directive have been expressed as it prompts individuals to make medical treatment decisions, which they are typically not equipped to make. Five Wishes directive was developed in collaboration with multiple experts with funding from the Robert Wood Johnson foundation, and is distributed by the ‘Aging with Dignity’ organization. The document records “wishes” or preferences rather than “directives,” and addresses only five key areas and may be too limited for comprehensive planning.

The most recent third generation advance directive is the ‘Life care Advance Directive’. It has reviewed more than 6,700 medical, legal, academic, and other literature sources in seeking essential inclusion material, and scrutinized by scores of medical and legal professionals. This document best relays treatment choices from the individual to an appointed representative, inspires greater confidence that the directives would be honored, and leads to the lowest use of burdensome medical treatments in poor outcome situations. The document is very long and detailed.

Timing

The best time to make an advance directive is before you need one! In other words, before you become too sick to make your own choices and decisions about what medical care you want or refuse. Young
people as well as older people should think about making an advance directive when in a reasonably good state of health and in a sound and calm frame of mind. Advance directives can be changed or revoked at any time. They should be reviewed and updated if you are diagnosed with a serious illness.

Recommendations
You can have a living will and a durable power of attorney for health care at the same time. In most cases, you can provide extra instructions in your advance health care directive for situations not covered by the living will. It is important living will. It is important to be sure that these documents are consistent with each other so that there will be no confusion about your wishes if you are rendered unable to make them known. Some countries also allow you to have a single, combined advance directive/living will document. The living will should not direct doctors to engage in anything illegal (euthanasia or assisted suicide that may still be considered illegal).