

THE END OF LIFE CARE ACT OF 2016

An Act for the recognition and establishment of End of Life Care standards and procedures including:

- i. The legal validation of Advance Care Planning Instruments, including Living Wills and Medical Power of Attorney;
- ii. Establishment of due process for resolving issues related to medically inappropriate treatment and withdrawal and withholding of Life-Sustaining Treatment; and
- iii. Uniform determination of death including by neurologic criteria.

The primary purpose of this Act is to create a legal framework to ensure that patients are provided with care that is respectful of their dignity and autonomy. This Act establishes the rights of patients as well as that of the Health Care Professionals and providers, and puts in place a framework for End of Life Care, in order to ensure that everyone has access throughout the continuum of care, to quality End of Life Care which is appropriate to their respective needs, including prevention and relief from suffering and avoidance of disproportionate treatment.

In addition, this Act recognizes the primacy of freely, informed and clearly expressed wishes with respect to End of Life Care, in particular, by executing an Advance Care Planning Instrument.

CHAPTER I

PRELIMINARY

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| Short title, 1
application and
commencement | (1) | This Act shall be called the End of Life Care Act, 2016. |
| | (2) | It extends to the whole of India, except for the state of Jammu and Kashmir. |
| | (3) | It shall come into force on such date as the central Government may, by notification, appoint and different dates maybe appointed for different states and for different provisions of this Act. |
| | (4) | Save as otherwise expressly provided by the Central Government, this Act shall apply to all Medical Care Facilities. |

DEFINITIONS

In this Act, unless
the context
otherwise
requires,—

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- (a) "Advanced Care Planning" shall mean the process by which an individual may decide on his future medical care in the event of his Terminal Illness or otherwise.
- (b) "Advanced Care Planning Instrument" shall mean a Living Will and/or any other written instrument which:
 - i. Records treatment preference of a person in the event of his future incapacity; and
 - ii. appoint an individual(s) as a Surrogate(s), to make decisions on behalf of the maker of the Advance Care Planning Instrument by creating a Medical Power of Attorney which shall become operative only in the event of the person's future incapacity.
- (c) "Health Care Provider" shall include Registered Medical Practitioners, nurses and such other medical/para medical professional attending to the patient.
- (d) "Expert Committee" shall mean a committee constituted in accordance with Chapter VI of this Act.
- (e) "Terminal Illness" shall in relation to a patient, means an illness which in reasonable medical judgment will, in the ensuing period of 6 months, without the application of extraordinary measures result in the death of the patient.
- (f) "Life-Sustaining Treatment" shall include any medical treatment that supports or replaces a body function essential to the life of the patient and shall include CPR, endotracheal intubation, mechanical ventilation, vasopressor therapy, total parenteral nutrition, dialysis, blood products, antibiotics, and intravenous fluids.
- (g) "Medical Care Facility" shall include all hospitals, private clinics, nursing homes and medical facilities, where patients can be subjected to Life-Sustaining Treatments.
- (h) "Medical Power of Attorney" shall mean a written Power of Attorney issued by any person in favour of Surrogate(s) in order to give effect to the health care choices of such person to make medical decisions in the event of future incapacity of the grantor.

- (i) "Palliative care" shall mean specialized medical care for people with serious incurable illnesses, which specialized medical care shall include an approach that improves the quality of life of patients and their families through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical and psychosocial.
- (j) "Surrogate" shall mean any person nominated under the Advance Care Planning Instrument or a Medical Power of Attorney to implement the wishes of the person and in the event of absence of any Advance Care Planning Instrument or a Medical Power of Attorney, the family members or close friends / relatives of the person, who are attending to him during the illness.
- (k) "Withholding of treatment" shall mean a conscious decision by a patient or a Surrogate(s) on behalf of a patient not to initiate or escalate any of the Life-Sustaining Treatments, in order to defend themselves from possibly unwanted negative consequences of life-prolonging medical technology, especially when the patient's quality of life lowers dramatically;
- (l) "Withdrawal of treatment" shall mean a conscious decision by a patient or a Surrogate(s) on behalf of a patient to stop or remove any Life-Sustaining Treatment after it has begun with the decision not to reinstate it, in order to relieve the patient from unwanted negative consequences of life-prolonging medical technology, especially when the patient's quality of life lowers dramatically.

CHAPTER II

RIGHTS OF THE PATIENT WITH RESPECT TO END OF LIFE CARE

Guidelines for a 3
Medical care facility

- (1) The Healthcare Provider shall give utmost respect to the patient's autonomy and recognise his rights and freedom while performing every act under this Act.
- (2) The Healthcare Provider shall treat all patients with understanding, compassion, courtesy, fairness and respect his dignity, autonomy, needs and safety.
- (3) The Healthcare Provider must establish and maintain comprehensive communication and transparent disclosure of prognosis with the patients and/or his Surrogate(s) as and when applicable. The Patients and/or his Surrogate (s) shall have a right to chose or refuse such communication and such choice or refusal shall be

recorded in writing by the Medical Care Facility and the same shall form part of the the Patient's medical records.

Rights with respect to end of life care 4

Every person, has the right to receive end of life care at any premises including a Medical Care Facility subject to the specific requirements established by this Act.

No denial of end of life care 5

A person shall not be denied end of life care for previously having refused to receive end of life care or having withdrawn consent to end of life care earlier.

Determination of Death 6

An individual who has sustained either (a) irreversible cessation of circulatory and respiratory functions, or (b) irreversible cessation of all functions of the entire brain, including brain stem, is dead. A determination of death must be made by the Health Care Provider in accordance with accepted medical standards.

Validity of an Advance Care Planning Instrument 7

- (1) Every Advance Care Planning Instrument shall be in writing.
- (2) Every person of sound mind, having capacity to contract and above the age of 18 years may execute an Advance Care Planning Instrument.
- (3) An Advance Care Planning Instrument or any part thereof, the making of which has been caused by fraud, undue influence or coercion, or by such importunity as takes away the free will of the person, is void.
- (4) The Advance Care Planning Instrument shall be attested by atleast two witnesses, each of whom has seen the person sign or affix his mark to the Advance Care Planning Instrument, in the presence of the person, and each of the witnesses shall sign the Advance Care Planning Instrument in the presence of the person.
- (5) If the person opting for Advance Care Planning cannot date and sign the Advance Care Planning Instrument because the patient cannot write or is physically incapable of doing so, a third person may do so in the patient's presence and in the presence of a Medical Practitioner.

**CHAPTER III
ADVANCE CARE DIRECTIVE**

Validity of an 8

- (1) Every Advance Care Directive shall be executed by an

Advance
Directive

Care

individual in a language which he can read and be recorded in writing

- (2) Every person of sound mind above the age of 18 years may execute an Advance Care Directive .
- (3) An Advance Care Directive or any part thereof, the making of which has been caused by fraud, undue influence or coercion, or by such importunity as takes away the free will of the person, is void.
- (4) The Advance Care Directive shall be attested by atleast two witnesses, each of whom has seen the person sign or affix his mark to the Advance Care Directive , in the presence of the person, and each of the witnesses shall sign the Advance Care Directive in the presence of the person.
- (5) If the person opting for Advance Care Planning cannot date and sign the Advance Care Directive because the patient cannot write or is physically incapable of doing so, she/he may affix a thumb impression or a third person may do so in the patient's presence and in the presence of a Medical Practitioner.

CHAPTER IV

DUTIES OF MEDICAL CARE FACILITIES

Duties of Medical
Care Facilities

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- (1) When a patient arrives at a Medical Care Facility, with an existing Advance Care Planning Instrument, such facility shall;
 - a. verify that such an Advance Care Planning Instrument has been executed in accordance with the Act; and
 - b. act in a manner to facilitate the implementation of an Advance Care Planning Instrument as a standard operating procedure.

- (2) In the event a patient arrives at a Medical Care Facility without having any Advance Care Plan Instrument, then such Medical Care Facility shall inform the individual of his rights under this Act and the patient's option to formulate an Advance Care Planning Instrument or to undergo Palliative Care as recognized under this Act and facilitate the execution of the same in consonance with the Medical Care Facility's Standard Operating Procedure.
- (3) In case a patient arrives at a Medical Care Facility in a condition where he is not in a medical condition to inform the Health Care Provider about having executed an Advance Care Planning Instrument, then;
 - a. the Health Care Provider treating such a patient, shall ascertain if the said patient has executed an Advance Care Planning Instrument. If so, the Advance Care Planning Instrument shall be consulted about the wishes of the patient and the wishes of the patient shall implemented in accordance with the Advance Care Planning Instrument.
 - b. In the event no Advance Care Planning Instrument has been excuted, the Health Care Provider shall inform the family members / friends of the patient about the—condition of the patient and make an attempt to determine if the patient had expressed his choices about end of life care. In the event of lack of clearly expressed preferences on the part of the patient, the treating physician and the patient's family must arrive at a consensus decision based in the best interests of the patient.
 - c. If the Health Care Provider and the patient's Surrogate(s) arrive at a consensus decision to move over to Palliative Care, the decision shall be documented and implemented under the oversight of the Expert Committee of the Medical Care Facility.
- (4) In the event the Health Care Provider of the patient advises the family members or friends of the patient to opt for Palliative Care and to withhold/withdraw Life-Sustaining Treatment, and the family members or friends of the patient do not agree with the recommendation of the Health Care Provider, then the case shall be forthwith referred to the Expert Committee which shall decide the reference expeditiously.

		(5)	In the event the family members or friends of the patient do not concur with the findings of the Expert Committee, then either the family members or friends of the patient or the Medical Care Facility shall approach the courts of competent jurisdiction for further directions with regard to the course of action to be adopted for the patient.
Every Medical Care Facility must offer end of life care	10		Every Medical Care Facility shall offer end of life care to their patients and ensure that it is provided to the persons requiring it in continuity and complementarity with any other care that is or has been provided to them.
Patient Records	11	(1)	All information and documents in connection with a request for Advance Care Planning, regardless of whether the Health Care Provider administers it or not, including the form used to request such Advance Care Planning, the reasons for the Health Care Provider 's decision and, where applicable, the opinion of the physician consulted, must be recorded or filed in the patient's record.
		(2)	A decision to withdraw a request for implementing the wish of the patient set out in an Advance Care Planning Instrument or to put off the Life-Sustaining Treatment must also be recorded in the patient's record.

CHAPTER V

GUIDELINES TO PROMOTE AND IMPLEMENT END OF LIFE CARE

Implementation of End of Life Care by Medical Care Facilities	12		Every Medical Care Facility shall, at all times; <ul style="list-style-type: none"> a. maintain end of life care policies and standard operating procedures in accordance with standard professional guidelines subject to the provisions of this Act b. provide appropriate educational programs for staff, individuals receiving medical care by or through the Medical Care Facility, and the medical community on ethical issues concerning end of life care and Advance Care Planning Instruments.
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CHAPTER VI

EXPERT COMMITTEE

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| Functions of the End of Life Care Committee | 13 | (1) | Every Medical Care Facility shall constitute an Expert Committee to oversee and resolve disputes concerning end of life decisions. In the event the Medical Care Facility does not have an Expert Committee, then they shall use the services of an Expert Committee at the nearest Medical Care Facility having an Expert Committee. |
| Referenece to the Expert Committee | 14 | (1) | <p>In case of a reference to the Expert Committee, the Expert Committee shall:</p> <ul style="list-style-type: none">a. examine the medical condition of a patient in order to ascertain whether the patient's illness is terminal or not;b. in case patient's illness is terminal, then authorize the end of life care as decided between the Health Care Providers and the patient's family, integrating patient's wishes in case an Advance Care Instrument is available or otherwise; andc. facilitate the execution of the same as a standard operating procedure. |
| Constitution of the End of Life Care Committee | 15 | (1) | <p>The End of Life Care Committee shall comprise:</p> <ul style="list-style-type: none">a. The director or his nominee of the Intensive Care Unit at a Medical Care Facility but not part of the team treating the patient;b. the Chief Administrator or his nominee of a Medicial Care Facility who is not part of the team treating the patient;c. an invited senior physician preferably a neurologist not appointed by the Medical Facility;d. a legal expert appointed by the Medical Facility; ande. a lay perperson preferabaly involved in social service. |

**CHAPTER VII
MISCELLANEOUS**

Effect of Advance Care Planning Instruments on insurance policy 16 (1) Execution of an Advance Care Planning Instrument does not, in any manner, restrict or inhibit or impair or modify the procurement or issuance or continuation of a life insurance policy of the person creating the Advance Care Planning Instrument.

Notwithstanding anything contained in the terms of the life insurance policy, the withdrawal of Life-Sustaining Treatment does not, in any manner whatsoever, affect or impair or invalidate the patient's life insurance policy and/or the right of the family of the patient to receive the death benefits and proceeds under the life insurance policy in the event of the death of the patient and the family members of the patient would be entitled to receive all the benefits under the life insurance policy of the patient as they would have been otherwise entitled to.

Refusal to administer an Advance Care Planning Instrument 17 A Health Care Provider may refuse to administer an Advance Care Planning Instrument on the grounds of personal preferences and/or religious beliefs , and a health professional may refuse to take part in administering it for the same reason. In such a case, the Medical Care Facility must nevertheless ensure continuity of care is provided to the patient at the same Medical Care Facility or another Medical Care Facility.

Filing of Advance Care Planning Instrument 18 (1) When Advance Care Planning Instruments are given to a Health Care Provider, they must file the instrument in the medical record of the person concerned.

(2) If the Advance Care Planning Instrument is given to the Health Care Provider by the person concerned and the person is capable of giving consent to care, the Health Care Provider must first inquire whether they still correspond to the person's wishes.

Revocation and alteration of an Advance Care Planning Instrument	19	<p>(1) Advance Care Planning Instruments may be revoked or altered at any time by the person concerned by means of oral or written communication.</p> <p>(2) Such directives may only be changed by writing new ones. The new directives replace any previous ones.</p> <p>(3) In emergency cases, if a person capable of giving consent to the Care Giver verbally expresses wishes different from those set out in their Advance Care Planning Instrument, the would be construed revocation of the Advance Care Planning Instrument..</p>
		<p>The Health Care Provider shall cause such oral revocation or alteration of an Advance Care Planning Instrument to be recorded in writiting and the same shall form part of the patient’s medical record.</p>
Protection of action taken in good faith.	20	<p>No prosecution, civil or criminal shall be instituted against any Health Care Provider or Medical Facility performing or intending to perform an act in good faith under this Act. No organization or association or health care provider shall be subject to discipline, suspension, loss of licence, loss of privellage, loss of membership or any other penalty for any act performed in compliance with this Act. Any act performed in compliance with this Act shall not constitute an act of negligence.</p>
Confidentiality	21	<p>A person engaged or formerly engaged in the administration of this Act shall not divulge or communicate personal information obtained in the course of adminsterating this Act except in connection with the administration of this Act.</p>
Advance Care Directives from other jurisdictions	22	<p>The Central Government, may, by notification in the official gazette, notify such territories, whereAdvance Care Directives executed are recognized in India.</p>