

End of Life Care, Medicolegal Aspects and Ethics in Intensive Care Unit

ABSTRACT

End of life care is one of the important quality measures of intensive care delivery. Toward the end of life, the focus of care must shift toward comfort and dignity in death. In the care of the dying, medical, ethical, sociocultural, and legal aspects intersect. This chapter begins with a description of a real-life scenario where an end of life decision was made. It briefly touches on the ethical underpinnings of foregoing of life support. It provides definition of terms used around terminal care. It goes on to provide guidance on the clinical pathway to end of life decision-making that includes Withdrawal, Withholding and Do Not Attempt Resuscitation orders. Legal developments in India are summarized and their practical application clarified.

Key words: End of life care, Intensive care, Palliative care, Withdrawal and withholding, Terminal illness, DNAR, Foregoing life support, Living Will in India, Legality of end-of-life care in india

CASE STUDY

Mrs. JG was an 80-year-old mother of a well-loved and celebrated musician. She was admitted to the intensive care unit (ICU) with acute dyspnea and hypoxia that would need artificial ventilation. However, her history pointed to futility of such support. She had metastatic pancreatic cancer for which she had had no hesitation in declining treatment. She had said to her family that having had a full life she only wished for an end without struggle. The Medical team also endorsed her wishes because it was clear that there would be more suffering from interventions with little prospects for cure. It was obvious that hooking her to a ventilator would only briefly postpone but not stop, her imminent death. We opened conversations around the goals of care with her daughters-it was plain to them she did not have long to live. The physician in-charge asked Mrs. JG herself quietly whether it would be right if we used machines to support her life. She indicated to him and her daughters that she would not want that at all. The family and the intensive care team took a collective decision to withhold the ventilator and other interventions such as vasopressors and hemodialysis should the need arise. Her physician in-charge spent time with the family and by the bedside of Mrs JG. Respiratory distress was controlled with non-invasive support and opiates. Hypnotics were used judiciously for sleep. The team refrained from introducing a nasogastric tube for feeding. The family looked for advice and support from physicians and nurses frequently. They, too, needed to be prepared emotionally to face the looming end. To ensure transparency and trust, the critical care team documented the gist of the conversations and the decisions taken together with the family. In the ICU, she was transferred to a single room to ensure privacy and quiet. The family was allowed to be with her all the time. They played music, talking to

Raj Kumar Mani¹, Srinagesh Simha^{2,3,4}, Roop Gursahani⁵

¹Director Clinical Services, Chairman Pulmonology and Critical Care, Yashoda Super Specialty Hospital, Kaushambi, Ghaziabad, Uttar Pradesh, India, ²Medical Director, Karunashraya, Bengaluru, Karnataka, India, ³Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal, Karnataka, India, ⁴Honorary Tutor, School of Medicine, Cardiff University, United Kingdom, ⁵Department of Neurologist and Epileptologist, P.D. Hinduja National Hospital, Office: 2101, Hinduja Clinic, Veer Savarkar Marg, Mahim, Mumbai, Maharashtra, India

Corresponding Author:

Dr. Raj Kumar Mani, Director Clinical Services, Chairman Pulmonology and Critical Care, Yashoda Super Specialty Hospital, Kaushambi, Ghaziabad, Uttar Pradesh, India. Phone: +91-9811131719.
E-mail: raj.rkmjs@gmail.com

her about the life they had shared. The daughters, sons-in-law, and grandchildren all would press her feet, shared hugs, smiles, and tears. All medicines other than analgesics and sedatives were stopped. Monitors were removed and frequent checking of vitals stopped. The team also stopped laboratory tests, bedside imaging and interventions, which had anyway lost any relevance. Nurses and doctors would enter the room only to check if she was in visible pain or distress, to ask if there was thirst and if motion was passed. The physician in-charge would stop by to offer a shoulder to the family who were often overcome with emotion. They asked for nothing but empathy and understanding. She passed away peacefully in a few days. The celebrity daughter we had admired always looked composed, even cheerful. A spiritual presence pervaded the scene. The family expressed gratitude for the support they had received from the team.

INTRODUCTION

The critical care unit, by virtue of its focus on critical illness, is also an area of high mortality that ranges between 10% and 30%, depending on the case mix. Therefore, it has been viewed as an area for resuscitation, rescue, and salvage. The other side of the coin is early recognition of foreseeable death and the appropriate management of the dying process. This area that requires a paradigm shift in the clinical approach and bedside skills has received much attention in the last 2–3 decades. There is increasing refinement of end of life care (EOLC) integrating ethical, medical, legal, and sociocultural dimensions.

EOLC

EOLC aims to provide the patient and family care that focuses primarily on suffering-physical, emotional, psychosocial, and spiritual, around death and dying. Elisabeth Kubler-Ross, a Swiss–American psychiatrist, first described the human response to the sense of loss in anticipated death.^[1] She described five stages of grief – Denial, anger, depression, bargaining, and finally, acceptance. Time, skilled counseling, and empathetic support are needed to take the patient and the family through these stages. In the technology-intensive ICU environment, there is another aspect of the burden of excessive, futile, or non-beneficial care that has, more often than not, come to precede death. In the impersonal environment of the ICU, where heroic medical measures have come to be the norm, the challenge is to facilitate a dignified death with as little of burdens as possible. Delivering a care that respects the patient’s wishes and dignity brings up the questions of prognostic accuracy, ethics of foregoing life support (FLS), the legal requirements for such decisions and the provision of adequate palliative care.

RECOGNITION OF TERMINAL ILLNESS/ SITUATIONS UNLIKELY BENEFIT FROM CURATIVE MEDICAL INTERVENTION

There can be no absolute certainty in prognostication. However, reasonable predictions based on objective and subjective evaluations can be made. To minimize the chances of false positive conclusion of terminal illness, some principles are to be followed:^[2]

1. An iterative and deliberate method of evaluation
2. Collective/collegiate assessment with a low threshold for second or multiple opinions
3. Use of general and disease-specific scoring systems.

With careful evaluation and open discussions over time, the risk of a “self-fulfilling prophesy” can be minimized.

ETHICS OF FLS

The ethical foundations of FLS were enunciated by Beauchamp and Childress in the four well-known principles of Autonomy, Beneficence, Nonmaleficence, and Justice:^[3]

Autonomy

This principle is of respect for the patient as a person with values, wishes, and preferences. The patient must be empowered to exercise his/her free choice which must be respected by caregivers. Open, accurate, and understandable communication of the patient’s condition and prognosis are imperatives to uphold this principle. Furthermore, consistent with this principle, the patient has the unconditional right to consent or to refuse any medical intervention including life-sustaining treatment (LST).

Beneficence and Non-maleficence

These are the physician duties of care, to act for the benefit of the patient without subjecting him/her to unjustifiable or undue risks of harm. In case of tension between the two principles, that is, substantial benefits without some harm appears difficult, potential benefits must always outweigh potential harm.

Justice

The Principle of Justice indicates the duty to act fairly without discrimination on any basis.

With respect to FLS decisions, ethics requires that these decisions are taken on the basis of the patient’s informed refusal coupled with his/her best interests as judged by a team of physicians and caregivers. When a competent and informed patient refuses treatment over the physician’s recommendation, it is an ethical and legal imperative that physicians act in accordance with the patient’s choice. When autonomy cannot be exercised directly, it can be exercised through the agency of (1) Advance Medical Directives (AMD) with or without a legally appointed health-care proxy. (2) Surrogates who may be family/next of kin/significant other.

DEFINITIONS^[4]

Terminal illness: An irreversible or incurable disease condition from which death is expected in the foreseeable future (around 6 months or less).

EOLC: A method of treating a terminally ill patient that moves the focus of care away from treatments intended to cure or extend life and toward symptom control, comfort, dignity, quality of living, and quality of dying.

Palliative care: Palliative care is a holistic approach to treatment that aims to improve the quality of life of patients and their families facing the problems associated with chronic or life-threatening illness, through the prevention and relief of suffering, physical, psychological, emotional, or spiritual.

Withholding of life sustaining treatment (WH): A decision made not to initiate or escalate a life-sustaining treatment in terminal illness in accordance with the expressed wishes of the patient or surrogate.

Withdrawal of life sustaining treatment (WD): A decision made to cease or remove a life-sustaining intervention, without

replacing it with an alternative intervention in terminal illness, in accordance with the expressed wishes of the patient or surrogate.

Euthanasia (or active euthanasia): The deliberate act of ending a terminally sick patient's life on the patient's own volitional request, with a doctor's direct involvement, is known as euthanasia. (Active Euthanasia is illegal in India).

Medical assistance in dying (MAiD): A doctor's deliberate action of giving a patient with a terminal illness the means or techniques to let them terminate their lives on their own volition. (MAiD is illegal in India).

Double Effect: A rule that separates accidental but foreseeable impacts from those that are intended to have a negative impact.

Best Interests: A principle that calls for doctors to confirm that potential benefits outweigh potential harms before performing medical interventions.

Shared decision-making (SDM): A dynamic process when the health-care team, the patient, or surrogates share responsibility for decisions regarding the medical treatment of a patient.

Advance Directives (ADM): A written declaration made by a person with decision-making capacity outlining how they would like to be treated or not treated once they lost that capacity.

Do not attempt resuscitation (DNAR): A considered decision by the patient or by the medical team in her best interests, not to have cardiopulmonary resuscitation (CPR) performed in the event of an anticipated cardiorespiratory arrest.

MEDICAL PROCEDURE OF FLS

Principles and procedures for FLS decisions have evolved over the last 2–3 decades.^[5,6] Several guidelines have been published by professional bodies at both national and international levels. Longitudinal surveys have estimated that in the US and Europe 70–90% of deaths in the ICUs are preceded by an FLS decision.^[7] There is a wide variability of the rates of FLS decisions preceding ICU deaths. The factors may be socioeconomic, cultural, religious, or legal variations. It also depends on physician characteristics such as years of professional experience, training in ethics and EOLC, and personal beliefs.^[5]

The guidelines by the ISCCM-IAPC joint statement comprise the following steps:^[8]

1. Identifying terminal illness to consider transition from curative to palliative care: Table 1 lists the contexts/triggers when the goals of care need to be reviewed.
2. Consensus among the treating team: FLS decisions are to be initiated by a group of clinicians, rather than by an individual physician as per the current standards of end of life decision-making. When there is uncertainty in prognosis, curative treatments must continue.
3. Opening up conversations with the patient/surrogates on prognosis and the unlikelihood of benefit from therapeutic

Table 1: Triggers to identify patients in need of end-of-life care

1. Catastrophic brain injury with coma (other than brain death) with poor prospects for meaningful neurological recovery
2. Critical illness on a background of irreversible severe neurological disability such as a highly dependent state due to quadriplegia or end stage muscular dystrophies
3. Critical illness on a background of chronic irreversible disorders of consciousness such as advanced dementia or Permanent Vegetative State
4. Post-cardiac arrest Glasgow Motor Score $M \leq 2$ with neurophysiological markers of poor prognosis > 3 days after return of spontaneous circulation (ROSC)
5. Advanced or metastatic malignancy where prognosis for survival is poor or treatment options are exhausted or declined by the patient
6. Advanced age and frailty with organ failure or co morbidities where interventions have a low probability of success or are declined by the patient.
7. Acute decompensation of chronic end stage organ failure such as pulmonary, cardiac, renal, or hepatic with life expectancy < 6 months where curative options are exhausted or transplantation is unfeasible or declined by the patient
8. Worsening critical illness due to acute conditions refractory to a reasonable trial of organ support
9. Any patient who expresses a desire against aggressive care or a patient who has lost decision-making capacity had previously executed a valid AMD declining such care.
10. Any other clinical scenario where the answer to the question "would you be surprised if the patient is not alive at the end of 6 months–1 year" is in the negative.

Adapted from: Mani et al. Guidelines for end-of-life and palliative care in Indian ICUs: ISCCM consensus ethical position statement. *Indian J Crit Care Med.* 2012;16 (3):166–81. doi: 10.4103/0972-5229.102112

interventions: In case of an incapacitated patient, the existence of an AMD should be asked for.

Early, open, and complete disclosure of information is the key to fulfilling ethical principles. In the case of an incompetent patient in the absence of an AMD, conversations with surrogates are the means to identify patient's values and wishes. Quality communication requires time, skill, experience, and sensitivity.^[9,10] Structured training programs are found to be useful. A shared decision-making is the favored standard of care. This model combines and balances the principles of autonomy, beneficence, and non-maleficence. An FLS decision is made through the above steps [Figures 1 and 2] and duly documented. Transparency is not only a legal requirement but also essential to keep public trust and to minimize the possibilities of misjudgment and misuse.

4. Implementation of WD/WH/DNAR decisions: Shift from cure to care implies focus on the patient's comfort. Palliative care involves impeccable symptom assessment and control. It includes physical, emotional, and spiritual well-being of the patient. Palliative care is inclusive of support to the family in preparing them for the impending death of a loved one that extends to the bereavement period. Ensuring adequacy of symptom control may

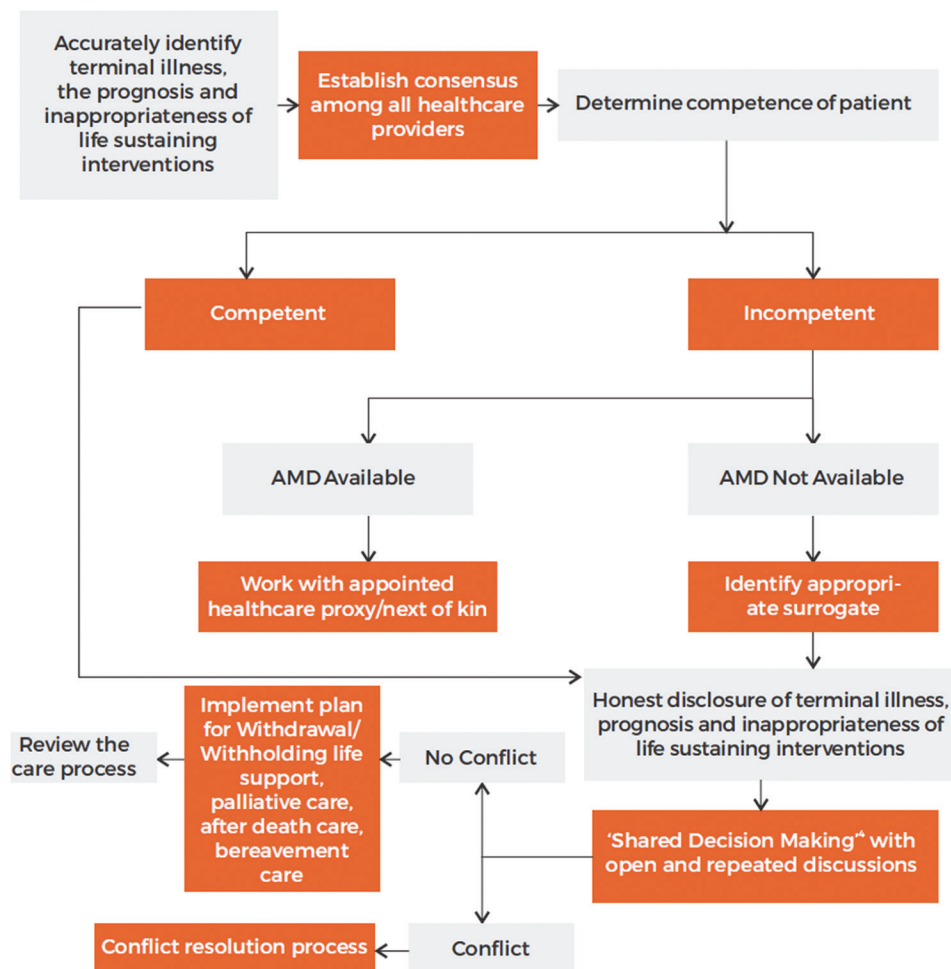


Figure 1: End of life care decision-making algorithm.

Adapted From: FICCI-ELICIT Guide to improving End of Life Care and Decision-making <http://ficci.in/spdocument/23114/FICCI-ELICIT-Guide-for-Doctors-and-Administrators.p>

impose a foreseen but unintended effect of hastening the patient's death. However, this risk is widely regarded as ethically justifiable by the doctrine of "double effect."^[3] An unintended adverse effect during the course of treatment aimed at providing comfort is not culpable, although largely foreseeable. In the US, under this concept, if due care is taken to identify terminal illness and palliation is applied according to standards of care, it is legally acceptable.

1. Location of death and access to family: The option of dying at home should be discussed. Since in the Indian culture as in others sanctity is attached to dying in one's home, such a request should be honored and enabled. If the location is the hospital, steps should be taken to ensure privacy and access to the family. Family presence around the dying hours should be facilitated. As far as possible requests for simple spiritual rites/rituals or the presence of priests should be allowed. A professional psychologist should be available if needed.

2. Family support: The emotional stress of a loved one in the hospital, the uncertainties, stressful end of life decision-making, and financial burdens all take their toll. anxiety, depression, and post-traumatic stress disorder (PTSD) are frequent among the family caregivers that can be mitigated by appropriate support. Support to the family should be provided in the immediate period after death and extended to bereavement, if required. Psychologist/psychiatric support may also be required
3. Oversight, assistance, dispute resolution, and quality control by a hospital EOLC committee.

LEGAL STATUS OF FLS (WD, WH, AND DNAR) IN INDIA

Law by judicial precedence or Common Law has always existed even before the Constitution of India came into force, for the right to protect bodily integrity and individual

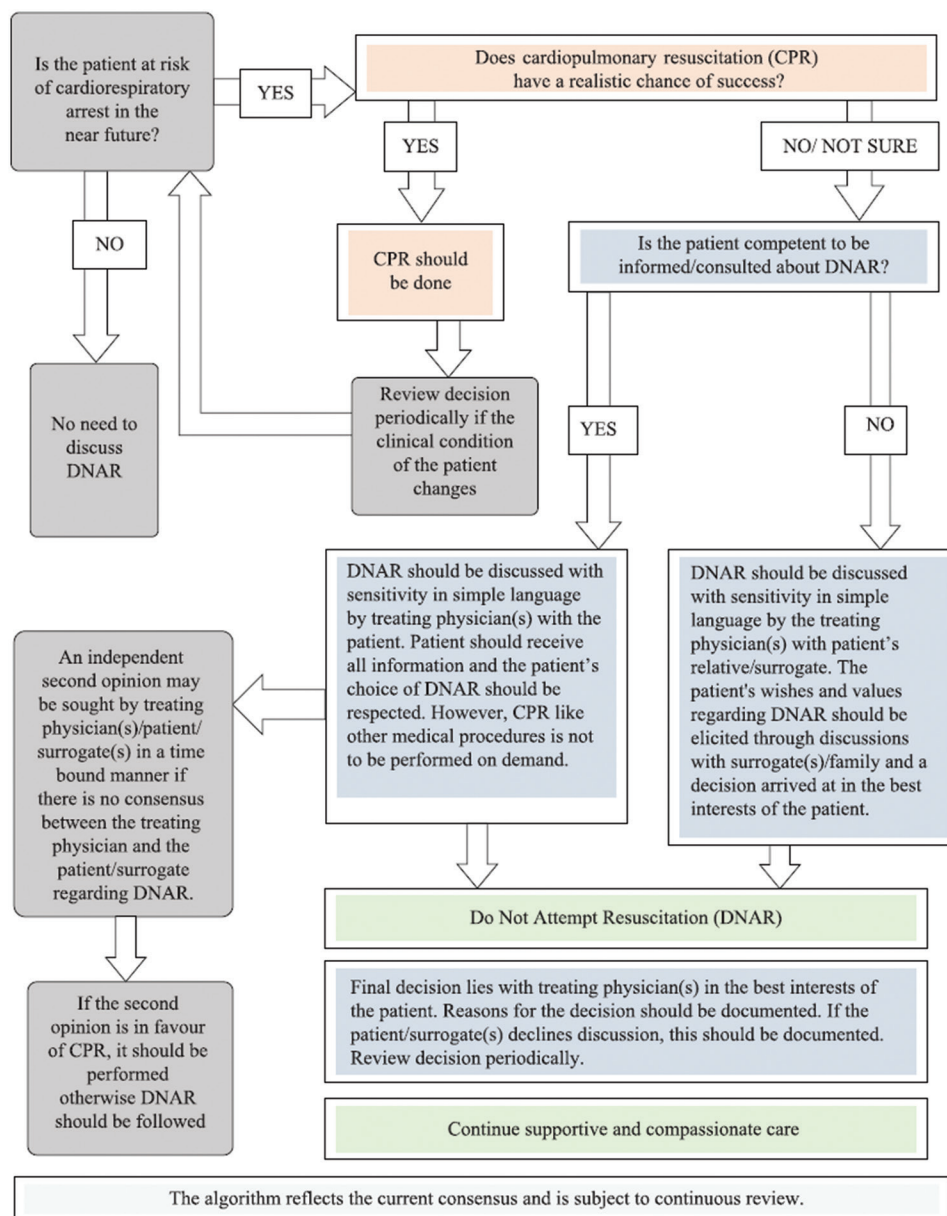


Figure 2: Do not attempt resuscitation decision pathway.

Adapted From: Mathur R. ICMR Consensus Guidelines on “Do Not Attempt Resuscitation”. Indian J Med Res 2020;151:303-10

autonomy. Implicit in it, there exists a Common Law right to refuse medical treatment, including the right to demand that a treatment ongoing be withdrawn. Not respecting refusal amounts to battery by the Indian Penal Code.^[11]

As per the Constitution of India, the right to refuse treatment is further validated by three landmark judgments in the last decade. In the *Aruna Shanbaug vs The Union of India* (2012), withdrawal of life support for an incompetent person was allowed under certain conditions that included a court procedure. The Amicus Curiae (a legal expert appointed by the Court) had notably observed “....several

situations that are not subject to the restrictions of the law at all, because they are considered normal medical practice. These are: Stopping or not starting a medically useless (futile) treatment; stopping or not starting a treatment at the patient’s request.”^[12]

According to the judgment in *Justice (Retd). Puttaswamy v Union of India* (2017) the right to privacy includes the right to refuse life-sustaining treatment.^[13]

In the landmark judgment, *Common Cause vs. The Union of India*, (2018) AMD and WD/WH were clearly held to be legal. It unambiguously decriminalizes/allows all forms of

FLS under certain conditions and safeguards.^[14] The prescribed procedure is as follows:

For AMD, two attesting witnesses are required and countersigned by Jurisdictional Magistrate of the First Class (JMFC). Copies are to be sent to Registry of the District Judge, a competent officer of a local authority and the family physician. The document will be valid only after the executor loses competency.

Implementation of FLS, with or without a valid AMD, involves a three-level system of oversight: An Internal Medical Board for a preliminary opinion, followed by a Board constituted by the District Collector, before final physical verification by the JMFC. The rules do not take into account the fact that most decisions in the ICU are required to be made under time pressure. More than half the FLS decisions are reported to be made within the 1st week of admission, as most situations are in the acute refractory or terminally acute stages of chronic incurable conditions. Recently, the Indian Society of Critical Care Medicine (ISCCM), along with the Vidhi Center for Legal Policy has filed an Application for Clarification and Modification of the procedure laid out in *Common Cause*.

TRANSLATION OF ESTABLISHED LEGAL PRINCIPLES IN EVERY DAY PRACTICE^[15]

1. Following the “spirit” of the Law rather than the “letter”: The Supreme Court (SC) judgment *Common Cause* establishes the fundamental right of Autonomous choice to the patient. As an important safeguard against errors of judgment or misuse, the SC recommends a collegiate as opposed to an individual physician decision making. At least three physicians take part and sign off. As per the SC directives, all decisions should follow the principle of “shared decision” making with the patient, or with surrogates if the patient is incapacitated. Every hospital must have a standard EOLC policy with a standard operating procedure. A hospital EOLC committee should be set up and be available for review, consultation, verification of adherence to protocol, and dispute resolution. Typical constituents of the committee are as per Table 2. Direct involvement of the committee is not required in most situations. This is because FLS decisions involve the building up of trust over time between treating teams and the family. Documentation and transparency should be reflected in the case records.
2. The refusal of consent for life sustaining treatment as basis for FLS decisions: FLS decisions are viewed as exercising the right of informed refusal to continue an ongoing life support intervention once the treating team has conveyed its futility/non-beneficial effects of medical interventions. By Law, no treatment can be initiated or continued when consent is refused.
3. Precedence/practices around the world prescribe a process similar to that recommended by professional bodies/ Statutory organizations/institutions in India.

Table 2: Constituents of the Hospital EOLC committee

1. The Director or his nominee of the ICU at a Medical Care Facility who is not part of the team treating the patient
2. The Chief Administrator or his nominee of a Medical Care Facility who is not part of the team treating the patient
3. An invited senior physician with relevant experience not on the staff or otherwise employed by the Medical Facility
4. A legal expert appointed by the Medical Facility
5. A lay person preferably involved in social service

Adapted From: Vidhi Centre for Legal Policy and End of Life Care in India Task Force, *End of Life Care in India: A Model Legal Framework* (2019) https://vidhilegalpolicy.in/wp-content/uploads/2019/11/191031_End-of-Life-Care-in-India-A-Model-Legal-Framework.pdf

4. The duty of care to respect autonomy and privacy includes dignity in death. Continuing with unwanted and unjustifiable burdens would violate these basic tenets of physician duties.

Documentation: Model forms for DNAR directives and for FLS are available by expert consensus.^[16] If forms are unavailable, the case records must document the disease diagnosis, prognosis in terms of life expectancy and quality of life, details of family meetings, individuals present in the meetings, and the final consensus decision taken along with signatures.

CONCLUSIONS

EOLC is integral to intensive care delivery. For quality EOLC, the ethical, medical, and legal aspects of patient care need to be addressed together. Formal training in Ethics and EOLC for caregivers in intensive care is crucial. The last decade has seen significant legal reform relating to withdrawal and withholding of life support. It has also seen the emergence of advocacy groups for improving EOLC in India.

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