

## Guidelines



# End-of-life care policy: An integrated care plan for the dying

A Joint Position Statement of the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC)

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### Executive summary

**Purpose:** The purpose was to develop an end-of-life care (EOLC) policy for patients who are dying with an advanced life limiting illness and to develop practical procedural guidelines for limiting inappropriate therapeutic medical interventions and improve the quality of care of the dying within an ethical framework and through a professional and family/patient consensus process. **Evidence:** The Indian Society of Critical Care Medicine (ISCCM) published its first guidelines on EOLC in 2005<sup>[1]</sup> which was later revised in 2012.<sup>[2]</sup> Since these publications, there has been an exponential increase in empirical information and discussion on the subject. The literature reviewed observational studies, surveys, randomized controlled studies, as well as guidelines and recommendations, for education and quality improvement published across the world. The search terms were: EOLC; do not resuscitate directives; withdrawal and withholding; intensive care; terminal care; medical futility; ethical issues; palliative care; EOLC in India; cultural variations. Indian Association of Palliative Care (IAPC) also recently published its consensus position statement on EOLC policy for the dying.<sup>[3]</sup> **Method:** An expert committee of members of the ISCCM and IAPC was formed to make a joint EOLC policy for the dying patients. Proposals from the chair were discussed, debated, and recommendations were formulated through a consensus process. The members extensively reviewed national and international established ethical principles and current procedural practices. This joint EOLC policy has incorporated the sociocultural, ethical, and legal perspectives, while taking into account the needs and situation unique to India.

**Keywords:** Care of the dying, end-of-life care in India, medical futility, position statement, terminal care, withholding and withdrawing

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## Guidelines Summary

### *Physicians objective and subjective assessment of medical futility and the dying process*

Recognizing medical futility and the dying process is the first step in providing end-of-life care (EOLC). A reasonable prediction of mortality is essential to identify the patients in whom EOLC discussions can begin. These should be based on the physician's objective and subjective assessment of medical futility and the dying process.

### ***Consensus among all care givers***

Once medical futility and the dying process have been identified, it should be followed up by discussions and formulation of consensus decisions among all caregivers about the poor prognosis of the patient and the plan to initiate an EOLC discussion.

### ***Honest, accurate, and early disclosure of the prognosis to the family***

The physician should make an honest, accurate, and early disclosure of the poor prognosis of the patient to the family and the patient if capable. He/she should discuss the imminence of death, clearly explaining the futility of any further aggressive medical therapies and the appropriateness of allowing natural death.

### ***Discussion and communication of modalities of end-of-life care with the family***

When the fully informed capable patient/family chooses to opt for the overall treatment goal of "comfort care only" option, the physician should explicitly communicate the standard modalities of limiting life prolonging interventions. These include: (1) Do not resuscitate (DNR); (2) withholding of life support or nonescalation; (3) withdrawal of life support.

### ***Shared decision-making – consensus through open and repeated discussions***

The physician must elicit and respect the choices of the patient expressed directly or through his family and work toward shared decision-making. In the shared decision-making model, the family discussions should include a review of the patient's present status and prognosis, elicitation of the patient's values, physician's recommendations, deliberations, and joint decision-making about ongoing levels of care. Pending consensus decisions or in the event of conflict with the family/patient the physician must continue all existing life supporting interventions and review the situation later.

### ***Transparency and accountability through accurate documentation***

The case notes should clearly reflect, through faithful recording, the entire or gist of all the discussions with the family, the decision-making process and the final decision based on medical appropriateness and patient's/family's preferences.

### ***Ensure consistency among caregivers***

Once a shift is made in the goals of care from cure to comfort, all members of the treating team should

be aware of the plan for cessation of a disease specific therapy. The focus should be on keeping the patient pain-free and comfortable while limiting life-prolonging interventions.

### ***Implementing the process of withholding or withdrawing life support***

Once a shared decision has been made with the family and documented withholding or withdrawing of life support should be initiated. Before proceeding with end-of-life (EOL) measures, it is necessary to prepare staff, family members (patient if, capable), and the patient's environment.

### ***Effective and compassionate palliative care to patient and appropriate support to the family***

Provision of compassionate care at EOL is not mere control of physical symptoms, but involves respecting patient choices on preferred place of care and managing nonphysical issues such as psychological, emotional, spiritual, and existential distress.

### ***After death care***

Culturally appropriate and sensitive after death care should be provided to all the dying patients irrespective of the situation or the setting.

### ***Bereavement care support***

End-of-life care does not culminate at death but continues even after death. Bereavement care helps family/care giver to cope with grief and other issues.

### ***Review of care process***

Review of care process is an important quality assurance activity, which aims to review and reflect on the care provided and in turn improve the process of care.

### ***Purpose***

- To develop an EOLC policy for patients who are dying with an advanced life limiting illness within an ethical framework and through a professional and family/patient consensus process
- To develop practical procedural guidelines for limiting inappropriate therapeutic medical interventions and improving the quality of care of the dying with compassionate palliative care and appropriate support to the family
- To improve awareness about EOLC issues among lay public, medical and paramedical personnel, lawmakers, and others concerned.

## Background

*"Death is not extinguishing the light; it is putting out the lamp because the dawn has come." - Rabindranath Tagore*

*"Despise not death, but welcome it, for nature wills it like all else." - Marcus Aurelius*

*"Dying can be a peaceful event or a great agony when it is inappropriately sustained by life support." - Roger Bone*

Death is an inevitable part of life. Death may be the end-result of relentless progression of a chronic illness, for example, cancer, advanced chronic lung disease, heart failure, AIDS, nervous system disorders. Often death may be imminent in the short course of a severe acute illness, when all medical treatment including life-supporting interventions in an intensive care unit appears to be futile. Where medical treatment including critical care is unlikely to restore patient to a meaningful existence, it is the responsibility of the physician to provide effective palliative care. Indeed, access to palliative and EOLC is a human right. Everyone with a life limiting illness has a right to a life free from pain and distress, psychosocial or spiritual, and also the right to a dignified life that includes the process of death.<sup>[3]</sup>

A significant number of patients die in hospital, and many of these are shifted to critical care units prior to death. It is important to realize that full treatment including all "Diagnostic and Therapeutic Strategies" and "Comfort Care" represents two ends of the continuum of care of a patient with a life-threatening illness. Both are appropriate at different points in the patient's disease process. At the EOL, however, life support interventions will not mitigate their suffering, but rather will add the agony and burden of a prolonged dying process. Death, which we all wish to be peaceful and to occur in the presence of loved ones, may become artificial, away from the family surrounded by the paraphernalia of modern critical care. In addition, most of the health care expenses are borne by patients and families, and inappropriate and aggressive medical interventions at EOL drain the resources of patients and family.<sup>[4]</sup> Prolonged and futile life support has undoubtedly imposed enormous economic strains on patients and families. Nonavailability of EOLC and rising costs have forced up to 78% of patients to leave hospital against medical advice.<sup>[5]</sup> The families unilaterally initiate these discharges resulting in these patients not receiving any symptom relief or EOLC measures.

In today's world, limitation of life-supporting interventions is being increasingly practiced, as

physicians realize that the mission of intensive care includes the avoidance of inappropriate use of aggressive interventions.<sup>[6]</sup> There are a few reports in the literature suggesting that withholding and withdrawal of life support is practiced in Indian intensive care units (ICUs).<sup>[7]</sup> However, there are several impediments to implement EOLC in India. The approach to the patient is generally "paternalistic" as the concept of autonomy is weak in the prevailing cultural ethos. The physician's orientation by his training is only to a curative approach to disease rather than to one of palliation when the patient's prognosis is poor. The physician is generally fearful of being accused of providing sub optimal care or of possible criminal liability of limiting therapies.<sup>[8]</sup> Adding to his dilemma, there is a virtual absence of ethical or legal guidelines relating to deaths in intensive care units in India.<sup>[1]</sup> The recent judgment of the Supreme Court in the Aruna Shanbaug case recognizes the legality of withholding and withdrawal of life support, but unfortunately terms it passive euthanasia. In addition, it prescribes a procedure of securing approval from the High Court,<sup>[9]</sup> which may be appropriate for a patient in a persistent vegetative state, but is totally unsuitable for a patient in whom death is imminent in a week or a couple of days.

The need for change, however, is of vital importance in India for several reasons. There is an unbearable financial burden to the average patient as healthcare expenses are borne mostly by the individual. Lack of appropriate policies for limiting life support make fair distribution of scarce facilities impossible in this populous country. Finally, a technologically prolonged dying process takes away the serenity and dignity accorded to it by the established cultural traditions and beliefs, and at some stage, it better to let nature take its own course. A report on a study by the Economist Intelligence Unit that was commissioned by Lien Foundation ranked EOLC services in 40 countries (30 OECD countries and 10 select countries), from which data were available. The outcomes of quality of death index showed that India ranked the lowest, 40 out of 40 in EOLC overall score.<sup>[10]</sup> There is thus, an overwhelming need for a national palliative care initiative to bridge these gaps.<sup>[11]</sup>

The Indian Society of Critical Care Medicine (ISCCM) was instrumental in initiating discussions on EOLC in advanced critically ill patients. Initial work, published in 2005, spelt out, for the first time ethical guidelines on limiting life-prolonging interventions and providing palliative care toward the EOL, for Indian ICUs.<sup>[1]</sup> The consensus ethical statement on guidelines for

EOL and palliative care in Indian intensive care were published in 2012<sup>[2]</sup> following the Aruna Shanbaug judgment. Recently, the Indian Association of Palliative Care (IAPC) published its position statement called “An EOLC policy for the dying”. This document recognized that delivery of palliative care at the EOL was suboptimal in India. It aims to address this problem by advocating for patients with EOLC needs, identifying gaps in service provision, and bridging these gaps by improving awareness, persuading the government to formulate a supportive legislation and EOLC policy, promoting EOLC education in health curricula, creating standards and implementation, and monitoring of these standards. While all efforts are being made by the Government to create and roll out a National Strategy for Palliative Care the IAPC is committed to the “Position Statement” and recommends that it is the basis for a palliative and EOLC policy for the dying in all health care set ups in India.

There has been a fresh debate on the legal position of “passive euthanasia.” The discourse is often marred by emotive speech and extreme positions taken by advocates at either end of the spectrum of the debate confined to euthanasia; in the process, the major issues relating to patient care and comfort and the process of a good death have been ignored.

In this setting, two medical professional societies, the ISCCM and the IAPC, that are confronted with these issues on a daily basis, have produced a joint statement on the EOLC policy: An integrated care plan for the dying. This joint statement reviews the medical, ethical, and legal framework on which EOLC decisions can be made, and how the best EOLC may be provided to patients in India. This statement will not only provide guidance to medical practitioners, but will hopefully be widely disseminated to members of the lay public, social workers, patient advocates, public health professionals, Medical Council of India (MCI), lawmakers, Government officials, and policy makers, among others. This document will undoubtedly add a fresh perspective to the current debate and provide a point of view that recognizes the rights and welfare of the dying patient.

## 1.0 End-of-Life Care

End-of-life care is multidisciplinary team approach toward “whole person care” for people with advanced, progressive, incurable or life limiting illness so that they can live as well as possible before they die. The process of care is not just limited to the person who is dying but extends to his/her families and caregivers.<sup>[12]</sup>

### 1.1 Objectives of end-of-life care<sup>[3]</sup>

- To achieve a “good death” for any person who is dying, irrespective of the situation, place, diagnosis, or duration of illness
- Emphasis on quality-of-life and quality of death
- Acknowledge that good EOLC is a human right, and every individual has a right to a good, peaceful, and dignified death.

### 1.2 Principles of good death<sup>[3,13]</sup>

Principles of a good death involve the ability to know when the death is approaching; have physical symptoms well-controlled and nonphysical needs met, right to die in a dignified manner at the place of choice and life not needlessly prolonged with artificial means [Table 1].

### 1.3 Components of good death<sup>[14]</sup>

The components of a good death from patients, families, and providers through focus group discussions and in-depth interviews identified six major components. They were pain and symptom management, clear decision-making, preparation for death, completion, contributing to others, and affirmation of the whole person. Themes identified had biomedical, psychological, social, and spiritual components [Table 2].

### 1.4 Continuum of palliative care

Health care providers often perceive that palliative care referral is appropriate only when patient is dying. This limitation excludes majority of patients who are not dying but has poorly controlled symptoms and distress that could lead to abrupt transition of care from curative to palliative phase. Hence, it is important to consider the continuum of palliative care proposed by World Health Organization. Palliative care referral is best initiated early, often at the time of diagnosis. Ongoing palliative

**Table 1: Principles of a good death<sup>[3]</sup>**

To know when death is coming and to understand what can be expected
To be able to retain control of what happens
To be afforded dignity and privacy
To have control over pain relief and other symptom control
To have choice and control over where death occurs
To have access to information and expertise of whatever kind is necessary
To have access to any spiritual or emotional support required
To have access to hospice care in any location
To have control over who is present and who shares the end
To be able to issue advance directives, ensuring that one's wishes are respected*
To have time to say goodbye and control the timing
To be able to leave when it is time to go and not to have life prolonged pointlessly

\*Unfortunately, such provision does not exist in India. At present, there is an appeal admitted to the Supreme Court on the issue of allowing advance directive

care input can be provided according to the needs and a smooth transition from curative to palliative phase is facilitated. Continuum of palliative care supports the patient and family during EOL phase, process of dying and supports the family during the after death phase and bereavement period [Figure 1].

**1.5 Steps of end-of-life care process<sup>[15]</sup>**

The process of providing a good EOLC follows a sequential series of steps which involves recognizing the dying, EOLC decision-making and communication and initiation and provision of EOLC [Table 3].

**1.6 Infrastructural requirements for good end-of-life care**

The presence of EOLC infrastructure is essential

in all hospital/health care settings across India. Infrastructural requirements for good EOLC primarily require the presence of an overarching hospital policy that supports and guides the healthcare providers in good EOLC process. There is a need for dedicated healthcare providers trained in palliative and EOLC, dedicated space in the hospital for EOLC provision, standardized forms/patient information leaflet and on call special support staff such as clergy, clinical psychologists<sup>[8]</sup> [Table 4].

**2.0 The Legal Position in India**

In India, legal guidelines and provisions clarifying moral/ethical dilemmas around EOLD do not exist at present. Much debate has centered on the issues of euthanasia, suicide, and right to life. Clear

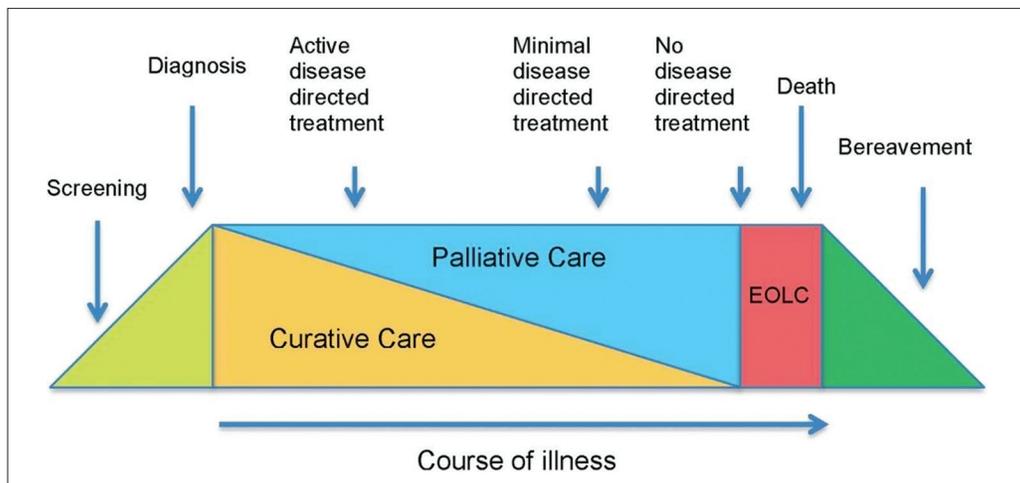
**Table 2: Components of good death**

Themes	Description
Pain and symptom management	Control of current pain and physical symptoms and reassurance that future symptoms like severe pain, extreme shortness of breath, delirium etc., will be promptly managed
Clear decision-making	Reducing the fear of pain and inadequate symptom management through communication and clear decision-making with physicians and empowering the families in decision-making
Preparation for death	Helping patients know what they could expect during the course of their illness and helping them to plan for the events that would follow after their deaths
Completion	Knowing the importance of spirituality or meaningfulness at the end-of-life and dealing with faith issues, life review, resolving conflicts, spending time with family and friends, and saying good-bye
Contributing to others	It involves acknowledging and making provisions for a terminally ill patient to contribute for the well-being of the others. This contribution can be in the form of donations, sharing knowledge and experience etc.
Affirmation of the whole person	It involves affirming the patient as a unique and whole person and not understanding the patient from disease perspective, but understands in the context of their lives, values, and preferences

**Table 3: Six-step approach in EOLC process**

Steps	Description
Identify	“When to initiate” “Whom to initiate”
Assess	Assessment of physical symptoms and distress Assessment of nonphysical issues Assessment of communication needs
Plan	Site of care Review existing care protocol/medication chart and stop all unnecessary interventions/medications/investigations Anticipatory prescription writing
Provide	Communication, consensus, consent Access to essential medication for EOLC symptom control Dedicated space and round the clock staff Special care needs of the patient and family
Reassess	After death care and bereavement support Ensure adequate control of pain and other symptoms through on- going assessment
Reflect	Document any variance and initiate prompt action Review the care process and identify if there were any gaps Improving the EOLC process by constant reflection and mindful practice

EOLC: End-of-life care



**Figure 1:** Representing the continuum of palliative care and end-of-life care in an illness trajectory (Modified from <http://depts.washington.edu/pallcare/training/ppt.shtml>)

separation of euthanasia from foregoing of life support treatments (FLSTs) that is well-settled in the developed world has not yet been acknowledged.<sup>[16]</sup> Case laws and precedents are few and have been none in the context of life sustaining interventions.<sup>[17-19]</sup> However, the amicus curiae in the Aruna Shaunbag case pointed to the fact that in some countries stopping (or not starting) a medically useless (futile) treatment, and stopping or not starting a treatment at the patient's request is considered normal medical practice.<sup>[9]</sup> The issues of patient's self-determination, futility, brain death, FLST, safeguarding of rights during incapacity, death in dignity, right to palliative care, and withdrawal of nutrition/hydration have not been addressed and clarified. The Indian physician, therefore, finds himself in an ambiguous position with respect to civil, criminal, or consumer protection laws.

### 2.1 Existing legal provisions

Common law confers the right to informed consent or refusal, which applies, to all medical interventions. This alone would suffice for an FLST decision. The case of Rathinam<sup>[17]</sup> allowed the right to die when faced with intolerable suffering thereby invalidating the suicide laws. This opinion was superseded by the Kaur judgment<sup>[18]</sup> wherein, the Supreme Court ruled that the constitutional right to life enshrined in Article 21 cannot be interpreted as a right to take one's life. This law has been inappropriately invoked to interpret all FLST decisions as attempts at suicide. It should be noted that the case was in relation to suicide and abetment to suicide, not to critical illness requiring life support interventions. Significantly, in the latter case, the judges made an exception in the situation of the dying patient allowing a "dignified process of death," but did not expand further on the issue.

### 2.2 Law Commission report

The Law Commission of India in their 196<sup>th</sup> report clearly separated euthanasia from EOLD.<sup>[19]</sup> Euthanasia is defined as the administration of a lethal drug by a physician as an act of mercy at the patient's request. FLST decisions differ fundamentally as it is only "letting die" - a decision not to intervene in a dying process already started. It pronounced FLST as lawful when a capable patient refuses treatment. Refusal to accept medical treatment does not amount to "attempt to commit suicide" and endorsement of FLST by the physician does not constitute "abetment of suicide".

The Law Commission, however, did not empower the family with the right to act on the patient's behalf

**Table 4: Infrastructural requirements for good end-of-life care<sup>[3]</sup>**

Policy	Presence of a guiding hospital policy Awareness and implementation of policy
Space and staff	Specially allocated area in the hospital A suitable room that ensures necessary privacy Round - the - clock staff
Education/training	Education to doctors, nurses, social workers and all involved health care professionals, on end-of-life care Hands on training and mentorship to junior staff
Documentation	End-of-life care pathway (structured and tailor made to suit individual health care setup) Standardized forms on withholding and withdrawing life support Patient information leaflet on end-of-life care
Special support	Contact details of religious leaders to meet end-of-life religious needs Clinical psychologists to meet extreme grief reactions Contact details of funeral directors/undertakers to facilitate after death care Contact information of embalmers/body transfer ambulances etc.

when he/she is incapacitated. This would render EOLD difficult in the ICU setting when 95% of the patients are known to lose the capacity to take their own decisions.<sup>[20]</sup> Advanced will was also disallowed for fear of "misuse" which means that advance care planning, preparing patient for anticipated death, allowing patients the opportunity for life closure and eliciting their preferences would not be possible.

A second report of the Law Commission in 2012 in the wake of the Aruna Shaunbag judgment, endorsed the reforms suggested in the first report. It said "passive euthanasia" should be allowed on humanitarian grounds and for protecting doctors who genuinely act in the best interests of patients.<sup>[21]</sup> It endorsed safeguards suggested in the Aruna Shanbaug, but for procedure they concurred with the previous report of the Law Commission.

### 2.3 The Aruna Shaunbag case

In the Aruna Shaunbag case, the judges pronounced "involuntary passive euthanasia" to be lawful under certain strict safeguards.<sup>[9]</sup> The term of reference was the not the rights of a vegetative patient but whether euthanasia was constitutionally allowed. It did not, therefore, touch upon several of the grey areas mentioned above. The definition of passive euthanasia was not in consonance with current medico legal literature and is thus subject to misinterpretation.<sup>[22]</sup> The Court did rule that withholding or withdrawal of life support was not illegal, and should be allowed in certain circumstances. A court procedure was

recommended for all EOLD on incapacitated patients that would be practically impossible to implement in emergency and critical care situations. The procedure, thus is applicable only for chronic vegetative states where life support institution/withdrawal was not in question.

#### **2.4 Possible misuse/inappropriate use of end-of-life care provisions**

As with any medical decision, EOLD could be applied inappropriately through an error of judgment or deliberately for a vested interest. Patient may be deemed to be facing death without the usual exploration of diagnostic and prognostic pitfalls, thus foreclosing treatment options prematurely. Such decisions may also be resorted to in order to find easy solutions to dilemmas like inability of the family to meet mounting expenses. Finally, it may be possible (but there exist no case examples) to use such decisions to deny appropriate care to a critically ill patient with a criminal intent. EOLD should always be evaluated against “acceptable standards of care” and the tests of “professional negligence.” On the other hand, motivations for instituting disproportionate interventions are even more as revenue from healthcare is linked to instituting treatments and procedures. For this reason, in many countries, standards of care and legal requirements include discussion of EOLC in chronic debilitating diseases.<sup>[23]</sup> Errors of judgment are an inherent risk with every medical decision and are not peculiar to EOLD. Therefore, the potential for misuse of FLST should be balanced against that of inappropriate interventional decisions.

#### **2.5 Professional safeguards against misuse**

Professional guidelines and standardized decision tools are designed to improve physician skills and minimize errors of judgment. The guidelines of the ISCCM clearly spell out the deliberate and careful steps to be followed. These decisions should be made by the senior most physician of the care-giving team. As a “responsible body of medical persons” is required for EOLD on incapacitated patients, more than one physician should be involved. Documentation should be explicit, complete, and mandatory for such decisions to prevent poorly judged decisions or foul play. Finally, as with other medical decisions, EOLD should be subject to audit for compliance with quality standards. A local oversight committee could be made mandatory as for the approval of an organ donor. Professional training should include skills in EOLC as clearly defined by European training modules for intensive care specialists (CoBaTRICE).<sup>[24]</sup>

#### **2.6 Current legal proceedings**

A petition was filed by an NGO named “Common Cause” for declaring “the right to die in dignity” as a fundamental right and thereby also permitting Living Will and attorney authorization. In response, the Chief Justice of India has appointed a five-judge Constitution bench to look into the issues around euthanasia and death in dignity as in his opinion the Aruna Shanbaug judgment appeared ambiguous. The ISCCM has filed an “impleadment petition” as a party respondent in the above writ petition.

### **3.0 The Ethical Principles of End-of-Life Decisions**

Compliance with an established code of ethics is essential in medical practice. Ethical requirements for EOLD are more complex but the essentials remain much the same. The four fundamental principles of autonomy, beneficence, nonmaleficence, and social justice have to be carefully interpreted and translated in practice.

#### **3.1 Autonomy**

Autonomy means respecting patient’s choices and preferences.<sup>[25]</sup> This translates in practice as the right of informed consent or refusal. For any medical intervention except in special circumstances, a consent form needs to be signed by the patient or surrogate. This should equally apply to life prolonging interventions. Physicians are by common law bound to respect patient’s refusal who has received complete information even if this would lead to his or her death. The physician’s approach should, thus be to address the patient as a whole person than merely as a disease entity. Open and complete disclosure of information is, thus an essential part of empowering the patient in taking an autonomous decision. To be able to exercise his/her autonomy directly the patient should be mentally competent to identify and express his/her choices. If the patient has lost capacity, the right of autonomy is maintained through other means. His/her preferences are to be elicited from the next of kin or a duly appointed legal representative and are termed as “substituted judgment”.<sup>[26]</sup> An advance Will as permitted in US law documents patient’s preferences in times of full mental capacity and is to be taken into account in EOLD by caregivers. In case patient’s wishes and preferences are unknown the patient surrogate and the physician is expected to act in his/her “best interests”.

#### **3.2 Beneficence**

Beneficence flows from the fiduciary obligation to act always in patient’s best interests. While the disease can

still be cured or controlled, this obligation translates as the need to carefully weigh the risks and benefits of any intervention. In terminal illness, since benefits of a curative intervention are negligible, FLST is often in patient's best interest. This is even more so when patients' values and preferences suggest that such interventions are unwanted. Best interests also include protecting him/her and the family from economic or social difficulties when these are clearly expressed. Physician's insisting on continuation of futile therapies is, therefore, to be regarded as violation of this principle.

### 3.3 Nonmaleficance

Nonmaleficance comes from the doctrine of "first of all do no harm." However, this needs to be interpreted appropriately in terminal illness. Harm confined only to the physiological standpoint would be too narrow an interpretation. A dying patient and family should be given the opportunity to prepare for death.<sup>[27]</sup> An appropriate environment for ensuring good death should be made available. All the while whole person interests should be safeguarded. The family too must be protected from harm that may accrue from incomplete information, financial pressure of disproportionate treatments, and posttraumatic stress disorder from inadequate attention to counseling during the dying process and bereavement.

Freedom from pain and distress is a fundamental right and withholding adequate palliative therapy would violate this principle. The doctrine of "double effect"<sup>[28]</sup> addresses the situation when adequate analgesia and sedation may have the unintended side effect of shortening the dying process. This principle clearly sets the obligation to provide freedom from pain and distress above the principle to do no harm provided the harm is unintended.<sup>[20]</sup> Intention is revealed in the care taken to titrate the drug dosing which would mean that protocols for palliative therapy should be in place and documentation should be meticulous. Of course, doses beyond usual recommendations should be adequately justified.

### 3.4 Social justice

Social justice means allocating resources appropriate to the medical condition of the patient in order to maximize their benefits and minimize wastage. Futile application of therapies would clearly violate this social obligation. Situations may arise when patient or family may insist on therapies physicians would consider inappropriate, when the principles of autonomy and justice may appear to be in conflict. In such an event, repeated communication and negotiating a middle path may be the best course. It would

also be worth remembering that the physician is bound to act only according to professional standards of care and not obliged to follow blindly the dictates of the patient.<sup>[20]</sup>

## 4.0 Communication during End-of-Life Discussions

The purpose of doctor-patient communication is to establish the therapeutic doctor-patient relationship. The firm establishment of this relationship is vital to a good therapeutic outcome irrespective of whether the patient survives or not. A good therapeutic outcome in EOLD may be characterized as one in which the patient and/or the family understand the disease process in question, the likely prognosis, the time that is available to the patient and family and the comfort care options that are available.

### 4.1 Goals of communication during end-of-life discussions

- Establishing consensus about the disease process among care givers
- Providing accurate and appropriate information about the disease process to the family
- Eliciting and resolving the concerns prompted by the EOLD.

#### 4.1.1 Establishing consensus about the disease process among caregivers

Many health care professionals are usually involved in the care of acutely ill patients including the intensivist, the primary care team and the specialists to whom the patient may have been referred. The doctor under whose care the patient is admitted assumes primary care for the patient. In closed units, this doctor is the intensivist but more often than not units in India are semi-open, semi-closed, or open in which case the primary physician is from the respective specialty. Each specialist is likely to have differing opinion about futility and about when to start EOLD. The intensivist often has to assume the role of coordinator and communicate with all stakeholders in order to arrive at a consensus. This is a painstaking and arduous process. It is a good plan to schedule a meeting among all significant caregivers and establish a consensus before starting EOLD with the family.

#### 4.1.2 Providing accurate and appropriate information about the disease process to the family

Once consensus is established among the caregivers, the intensivist schedules a meeting with all significant family members including friends.

#### 4.1.3 Eliciting and resolving the concerns that are prompted by the end-of-life discussion

The communication skills<sup>[29]</sup> required by a physician for eliciting and resolving concerns prompted by EOLD are:

- The ability to distinguish between intellectual and emotional components of what the patient or family says during the EOLD and to respond to this sympathetically
- The ability to clarify uncertainties and doubts. This includes being able to talk to the patient or the family about what the physician has understood about the patient's or family's perspective and also about the physician's perspective itself
- The ability to listen more and talk less. Typically, the physician should spend more than 75% of the interview in listening empathically.<sup>[29]</sup>

In case one is left with lingering doubts or uncertainties more meetings could be offered for sorting these out before an actual EOL decision is taken.

Nonverbal communication may be as important as verbal communication during EOLD. The acronym SOLER stands for a method that the physician can use for nonverbal communication.<sup>[30]</sup>

- S Face the patient/family Squarely at eye level to indicate your interest and involvement
- O Adopt an Open body posture (do not cross your arms, do not sit across the table)
- L Lean toward the patient/family
- E Use Eye contact to show that you are paying careful attention (do not look at your watch or be distracted by your mobile phone)
- R Maintain a Relaxed body posture.

#### 4.2 Physician style of communication<sup>[31]</sup>

Certain physician characteristics may help or hinder communication during EOLD. These have been described as physician styles during communication.

##### *The inexperienced messenger*

Information is delivered fast with no warning and with no understanding of the specific medical, psychosocial, spiritual, or emotional issues involved in EOLD. Patients or family will perceive this as a junior inexperienced doctor without empathy.

##### *Emotionally burdened expert*

Communication is careful and good but doctor comes across as someone who is too involved and under emotional strain.

##### *Rough and ready expert*

Delivery of information is quick, clear, and delivered

in terse sentences with closed body language. Listening is minimal and patient/family emotions are not acknowledged. Doctor is perceived by the patient/family as unemotional, uncaring, and lacking respect.

##### *Benevolent but tactless expert*

Information is conveyed competently with a sympathetic attitude but there is a lack of ability to pick up emotional verbal and nonverbal cues from the family. The doctor comes across as someone who is well-meaning but without an understanding of the family or patient situation.

##### *Distanced expert*

Information given is to the point, precise, and is delivered calmly in an objective manner. There is a lack of emotional involvement and the expert tends to avoid emotional and psychosocial issues. Patient/family perceives the expert as someone who was disinterested and did not really care about the patient as a person with hopes and feelings.

##### *Empathic professional*

Information delivered with the right mix of empathy and medical competence. This physician is able to read both verbal and nonverbal cues from patient/family and is able to address practical and potentially distressing concerns well family perceives the physician as one of their own and someone who is able to put himself in their own shoes and yet able to offer an unbiased and correct opinion.

#### 4.3 Patient/family-centered communication

The empathic professional is able to provide the most appropriate information, is able to elicit patient's/family's expectations and concerns, their preferences for therapy and is able to provide support and guidance through the entire EOLD. In short he is collaborative, concerned with the patient as a person, and is able to think from the patient/family perspective. The communication skills described before can help the empathic professional achieve this goal of patient/family-centered communication.

These skills include active communication skills such as being attentive and focusing on the here and now, listening to both verbal and nonverbal cues, showing interest through appropriate speech and body language, having ability to restate and clarify patient/family position. One should be careful not to interpose one's personal opinions/biases to influence the family. Communication should empower the family to

implement what they perceive to be the patient's wishes and finally be able to lead the EOLD to a fruitful mutually acceptable plan. More often than not it is the family that participates in EOLD and a useful mnemonic for valuing and understanding the family<sup>[32]</sup> is presented below.

The VALUE Mnemonic<sup>[32]</sup>

- V Value statements by family members
- A Acknowledge family member emotions
- L Listen to family members
- U Understand who the patient is as a person and how decisions are made in the family
- E Elicit questions from family members.

#### **4.4 The SPIKES approach to patient/family centered communication<sup>[33]</sup>**

A useful mnemonic for this whole process of empathic reflective communication is "SPIKES".

##### **Setting up**

Setting up the environment is important. Having a quiet room with comfortable seating that provides privacy is very important. Adequate time must be set aside for the meeting and there should be no disturbances during the meeting.

##### **Perception**

Patient's/family's perceptions regarding the progress so far and their understanding of the illness must be assessed before proceeding to the EOLD. One may also ask regarding their discussions with other physicians including their primary care physician. This gives us an idea of how prepared the family is likely to be during EOLD. It also allows us to confirm the consensus among caregivers through the family.

##### **Invitation**

One must confirm that the patient wishes to receive information about the diagnosis and prognosis. Sometimes, patients are not ready and this must be kept in mind.

##### **Knowledge**

Regarding the illness and the likely prognosis are given in a language that is understandable to the family.

##### **Emotional support**

It is provided by identifying the emotion that the patient/family expresses and by responding to it appropriately.

##### **Strategy and summary**

At the end of the meeting, one summarizes the current

situation, explains the future plan for comfort care, and documents the EOLD accurately.

#### **4.5 Conflict during end-of-life discussions**

Conflict at a personal level arises when there is a gap between "what is" and what the person/s feel/s "should be." Conflict during EOLD is not only at a personal level for all involved individuals but also at an interpersonal level within family, within healthcare team and may lead to conflict between family and health care team.

"Conflict during EOLD" is broadly defined as failure to achieve consensus on the goals of care and related treatment at the EOL despite allowing time (usually 48 h) and holding repeated discussions between involved parties (conflict resolution in EOL settings - a report NSW Department of Health).<sup>[34]</sup>

Many patient/family factors, physician/healthcare team-related factors and the environmental factors that may be responsible for conflict during EOLD [Table 5].

##### **How to resolve conflict at end-of-life discussions?**

Empathy, trust, and hope are the three pillars on which an effective patient-family-doctor relationship rests. Empathy not only requires a deep understanding of the patient/family perspective but also a deep self-awareness on the part of the physician. Trust is built on honesty and understanding and is vital for taking the EOLD to a fruitful conclusion. Hope on the part of the patient/family needs to be understood and valued by the physician.

Conflict usually arises when the patient/family requests the physician/healthcare team that everything be done and the physician/healthcare team face medical or physiological futility in treating the patient. This can usually be resolved by frequent and repeated family conferences held by empathic professionals who are able to convey in simple terms the consensus in the healthcare team about the disease process and the likely prognosis. A second opinion may be requested either by the family or by the empathic professional if a consensus is elusive. It is only very rarely that legal recourse would be needed for resolving conflict at the EOL.

#### **4.6 Conclusion**

End-of-life discussions are difficult for all the people involved. Patients and family are very sensitive to verbal and nonverbal cues during these discussions. It is incumbent on the physician/healthcare team to train

**Table 5: Various factors that may be causative for conflict at EOLD**

Patient/family factor	Physician factors	Environmental factors
Patient experiencing an end-of-life situation	Level of medical education	Society's expectation from medicine
Sentient and afraid of what is happening unless the illness has affected the ability to perceive and think	Grounding in medical ethics	Type of hospital (fee for service/free healthcare facility)
Wishing to continue living but at the same time not wanting to suffer	Communication skills	Risk management approach of institution
Depth of understanding of one's situation (religious/spiritual/educational background)	ICU culture	Developed/developing country
Family/spouse/parents/siblings/friends (anybody intimately related to the patient) who experience depersonalization, loneliness, emotional stress	Depth of understanding of the patient's situation	Accepted ethical standards and legal guidelines of the country
Quality of relationship with the patient	Patient's medical condition and prognosis (failure to recognize dying)	
Depth of understanding of patient's situation and values	Patient's ability to pay	
Socioeconomic status	The consensus within health care team	
Ethnicity and religion	Lack of clarity of who takes responsibility for looking after the patient and decision-making (intensivist/physician/surgeon/oncologist)	

EOLD: End-of-life discussion; ICU: Intensive care unit

themselves in active listening skills, correct body language, and appropriate empathic responses in order to convey information in a clear, concise, and empathic manner. This will allow creation of a therapeutic plan that is appropriate and results in a good outcome for all concerned.

### 5.0 Prevention of Intensive Care Unit Admissions in Palliative Patients

Guidelines for ICU admission, discharge, and triage have prioritized ICU admission criteria under prioritization model as priority 1-4. The 4b priority includes all palliative patients who are not candidate for ICU admission. Under 4b priority are patients with terminal and irreversible illness facing imminent death (i.e. too sick to benefit from ICU care)<sup>[35]</sup> [Table 6].

Prompt identification of this subset of population is essential to prevent any malfeasance. Patients, families, and health care providers should be educated about appropriateness of ICU admission, nature of ICU interventions including resuscitation, outcomes and futility of these interventions, and detailed information on alternatives to ICU admission. Good palliative and EOLC are not just the alternative, but also a superior and most appropriate mode of treatment when compared to inappropriate ICU admission.<sup>[36]</sup>

### 6.0 Guidelines for End-of-Life Care Process [Figure 2]

#### 6.1 Guideline 1

#### *Physician's objective and subjective assessment of medical futility and the dying process*

Recognizing medical futility and identifying the dying process is the first step toward planning and delivering effective EOLC.

**Table 6: 4b priority patients**

Severe irreversible brain damage
Irreversible multi-organ system failure
Metastatic cancer unresponsive to chemotherapy and/or radiation therapy
Patients with decision-making capacity who decline intensive care and/or invasive monitoring and who wish to receive comfort care only
Brain dead nonorgan donors
Patients in a persistent vegetative state, patients who are permanently unconscious

#### **Rationale**

It is not always easy to recognize "medical futility" and whether the patient is going through the dying process. Identifying these situations often needs experience and expertise. Sometimes, the clinician's judgment may be influenced by his own biases and attitudes toward death. A reasonably good prediction of mortality is essential to identify the patients for whom EOLC discussions can begin. These should be based on the physician's objective and subjective assessment of medical futility and the dying process.

#### 6.1.1 The dying patient

Clinicians should be able to diagnose the dying patient with a fair amount of accuracy in order to ensure that good quality of EOLC is provided for all those who need it and also to identify when restorative treatment aims are appropriate.<sup>[37,38]</sup> Recent reviews of the Liverpool Care Pathway<sup>[37]</sup> have highlighted the complexity of diagnosing dying and recommend the need for development of clear guidance for professionals and further research in diagnosing dying.<sup>[39,40]</sup> A recent review<sup>[41]</sup> examined evidence available on how clinicians judge patients as being in the last hours or days of life concluded that there is uncertainty in diagnosing dying and the need to work with and within this concept. As it is not always easy to predict impending death, and the

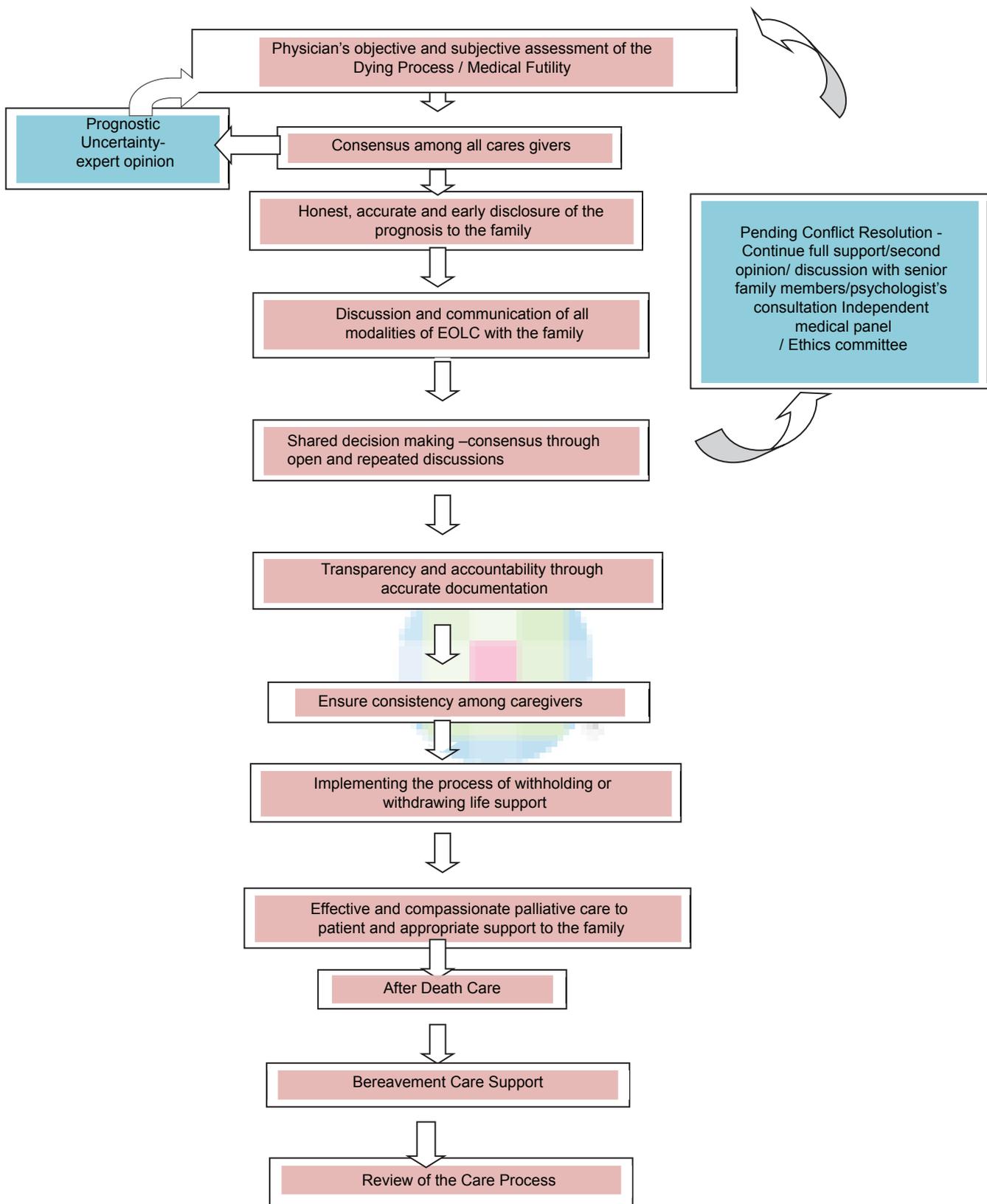


Figure 2: End-of-life care process pathway<sup>(1)</sup> modified with permission

best approach is to correct the correctable while accepting that the patient might be dying.

### 6.1.2 Medically futile/inappropriate

The idea of futility is not new. The famous Hippocratic corpus included a promise not to treat patients who were “overmastered by their disease.”<sup>[42]</sup>

#### Various definitions and subtypes of futility

- Physiological futility - Treatment that cannot achieve its physiological aim<sup>[43]</sup>
- Quantitative futility - Treatment that has < 1% chance of being successful<sup>[44]</sup>
- Qualitative futility - Treatment that cannot achieve an acceptable quality-of-life, treatment that merely preserves unconsciousness or fails to relieve total dependence on intensive care<sup>[44]</sup>
- Lethal condition futility - The patient has an underlying condition that will not be affected by the intervention and which will lead to death within weeks to months<sup>[45]</sup>
- Imminent demise futility - An intervention that will not change the fact that the patient will die in future.<sup>[45]</sup>

Since the term “futile” has been difficult to define, and has negative overtones, some have suggested that this term should not be used at all when talking with families.<sup>[46]</sup> “Medically inappropriate” may be a more suitable term, since it makes it clear that these are judgments made by doctors and avoids the pseudo-objectivity sometimes implied with the term “futile.” Furthermore, referring to the inappropriateness of treatment highlights the importance of clarity on what treatment is appropriate.<sup>[47,48]</sup>

Perceived futility remains the most common justification for withdrawal of treatment in critically ill patients.<sup>[49,50]</sup> A study<sup>[51]</sup> that looked at intensivists’ ability to predict outcome in a neurosurgical patients who were ventilated for longer than 72 h, showed that they had a high level of accuracy at predicting poor outcome (moderate or greater disability, or death). About 94% of those patients in whom a poor outcome was predicted either died or were significantly impaired at 6-month follow-up. A recent review<sup>[52]</sup> systematically looked evidence used to support or refute claims of medical futility. Less than 1/3 of studies, which showed that treatment was futile, actually met the common standard for quantitative futility. Many studies lacked the criteria for determining whether or not the treatment was futile.

However, sufficient and conclusive data from evidence-based medicine on futility are to some extent still lacking. Until this is available, physicians may have to rely on their professional judgment and consider patient autonomy to make an informed shared decision.<sup>[53]</sup> The limits of futility will also change with the available facilities and with the evolution of medical science. Futility usually focuses on the principles of improving the rate of survival and the quality of prolonged life.<sup>[52]</sup> Physicians should consider whether further treatment will abide by these two principles, and if not, futility ensues. It is ethical for physicians to decline to provide treatment, which is judged to be medically inappropriate, either where such treatment is not in the interests of the patient, or where there are insufficient resources to provide treatment of this level of benefit.

#### Practice points

Recognizing medical futility:<sup>[2]</sup>

- The following table can serve as a guide to recognize medical futility. However, these points should not be used in isolation, but in the context of the clinical status and condition of the patient. Whenever there is doubt about the prognosis, the physician should not take any hasty decisions, but wait for the disease process to unfold [Table 7]
- Recognizing the dying patient:<sup>[38]</sup> [Table 8] These following physiological changes are mere pointers to

**Table 7: Recognizing medical futility<sup>[1]</sup>**

Advanced age coupled with poor functional state due to one or more chronic debilitating organ dysfunction. For example, end stage pulmonary, cardiac, renal or hepatic disease for which the patient has received/declined standard medical/surgical options
Severe refractory illnesses with organ dysfunctions unresponsive to a reasonable period of aggressive treatment
Coma (in the absence of brain death) due to acute catastrophic causes with nonreversible consequences such as traumatic brain injury, intracranial bleeding, or extensive infarction
Chronic severe neurological conditions with advanced cognitive and/or functional impairment with little or no prospects for improvement - For example, advanced dementia, quadriplegia, or chronic vegetative state
Progressive metastatic cancer where treatment options have failed
Postcardio respiratory arrest with prolonged poor neurological status
Any other comparable clinical situations coupled with a physician prediction of low probability of survival

**Table 8: Recognizing that the patient is dying<sup>[3]</sup>**

Progressively falling blood pressure
Progressively falling body temperature - cooler hands and feet compared to rest of the body
Altered breathing pattern (Cheynes - Stokes)
Skin color - duller/greyish blue/mottling - nails bluish
Bedridden patient with decreasing spontaneous movement
Ceases to respond to questions; no spontaneous verbalization
Total detachment from surroundings/nil interest in food/water
Bedridden patient with diminishing spontaneous movement
Comatose state
Unable to take oral medications, disinterested to feed orally
Severe cachexia

suggest poor prognosis and very limited life expectancy and may not always suggest that the patient is dying.

In the intensive care unit, patients who are sedated and on a ventilator may not show many of these signs and symptoms.

### 6.2 Guideline 2

#### Consensus among caregivers

Once medical futility and the dying process have been identified by a member of treating team, it should be followed up by discussions and formulation of consensus decisions among all caregivers about the poor prognosis of the patient and the plan to initiate an EOLC discussion. The overall responsibility for the decision to initiate an EOLC discussion rests with the attending physician of the patient, who must ensure that all caregivers including the medical, nursing staff, and other paramedical staff are in agreement.

#### Rationale

There should be consensus among all caregivers. It is essential that all members of the team are fully aware and in agreement of the patient's prognosis and the plan to initiate an EOLC discussion. This will help prevent any conflicting or inconsistent messages about the patient's prognosis going out to the patient's family. One of the well-known sources of family dissatisfaction is inconsistency of information given by caregivers.<sup>[54]</sup>

#### Practice points

- A consensus should be reached among the treating teams about the patients poor prognosis and plan to initiate an EOLC discussion
- If there is any difference of opinion among the members of the treating team regarding the prognosis of the patient, the decision to initiate an EOLC discussion should be deferred and the situation should be reviewed again later as the clinical state unfolds. Inputs from experts should be taken if required
- The senior treating physician responsible for the patient, should take the lead in addressing all caregivers about the prognosis and plan to initiate an EOLC discussion
- No member of the team should address the family individually regarding the patient's prognosis until a consensus is reached among all caregivers.

### 6.3 Guideline 3

*Honest, accurate and early disclosure of the prognosis to the family*

The physician should make an honest, accurate, and early disclosure of the poor prognosis of the patient to the family and the patient if he is capable. Clear, candid communication is a determinant of family satisfaction during EOLC.<sup>[55]</sup> The physician should discuss the imminence of death, clearly explain the futility of any further aggressive medical therapies and the appropriateness of allowing natural death. Clinicians should recognize that the family members of the patient are often "living with dying" as they are maintaining hope though faced with uncertainty.<sup>[56]</sup> Though "hope" should be respected during prognostic disclosure a realistic view should be maintained<sup>[57]</sup> (refer to communication during EOLD).

#### Rationale

Respect for the patient's autonomy and to act in his best interest are the basis for providing accurate information. The physician has a moral and legal obligation to disclose to the family, with honesty and clarity, the dismal prognostic status of the patient, the imminence of death, and that further aggressive support may be futile. Waiting, watching, and postponing discussions on prognosis of the patient will only increase the stress to the family and the caregivers.

#### Practice points

- It is helpful to identify early a responsible family member as a surrogate decision-maker for the patient for regular communication, who will in turn communicate your discussion with the rest of the family (if the patient is not capable)
- The "family" means spouse, parents, children, siblings, the next of kin who is available or even a trusted friend. A hierarchy of surrogates does not exist in Indian law for making EOLD
- If feasible as many members of the treating team along with the primary physician should jointly address the family
- Avoid addressing different family members at different times to avoid any inconsistencies in communication
- Give as accurate a prognosis as is possible in a language and in terms that the family can understand
- Inform the family the diagnosis, prognosis, the range of therapeutic interventions available as well as the option of no therapy, including their risks, benefits, costs, and consequences.

### 6.4 Guideline 4

*Discussion and communication of modalities of end-of-life care with the family*

When the fully informed capable patient/family chooses

to opt for the overall treatment goal of “comfort care only” option, the physician should explicitly communicate the standard modalities of limiting life prolonging interventions.

#### 6.4.1 Standard modalities:

The following three standard available options for limiting the supports (also called FLST should be discussed with the family:<sup>[58]</sup>

- Do not intubate (DNI)/DNR: Aggressive ICU management up to, but not including endotracheal intubation (DNI) or attempts at CPR (DNR)
- Withholding of life support/no escalation order: The considered decision not to institute new treatment or escalate existing life support modalities (intubation, mechanical ventilation, vasoactive drugs, dialysis, antibiotics, intravenous fluids, nutrition, etc.) with the understanding that the patient will probably die from the underlying condition
- Withdrawal of life support: Withdrawal of life support is the cessation and removal of an ongoing medical therapy, with the explicit intent not to substitute an equivalent or alternative treatment. It is fully anticipated that the patient will die following the change in therapy primarily due to the underlying disease conditions.

#### Rationale

The capable patient/family should be informed and made to understand the various standard modalities of EOLC available to him/her and their implications. This will help in the process of reaching a consensus through shared decision-making.

#### 6.4.2 Other modalities

##### Active shortening of the dying process

Deliberate administration of large doses of drugs (barbiturates and morphine) until death ensues.

##### Physician assisted suicide

A medical doctor provides patients with means to kill themselves.

Analgesics and sedatives are used during EOLC to ensure that no patient dies in pain or distress. However, in high doses these may produce side effects that may hasten the dying process. Physician-assisted suicide should to be distinguished from these, since the primary goal of the therapy is to relieve pain and discomfort and hastening of death is not intended. Quill and associates termed it “the double effect” to distinguish the intended and unforeseen effects.<sup>[28]</sup> Suicide and abetment to suicide are declared punishable by the Indian Penal Code.<sup>[5]</sup>

#### Euthanasia

Euthanasia is intentional killing of a patient by the direct intervention of a doctor, ostensibly for the good of the patient or others.

The recent Supreme Court judgment of the Aruna Shanbaug case recognizes the legality of withholding and withdrawal of life support, but unfortunately terms it passive euthanasia and prescribes a procedure of securing approval from the court. This may be appropriate for a patient in a persistent vegetative state, but is not feasible in a patient in whom death is imminent in a week or a couple of days (see section on legal position in India).

#### 6.4.3 Discharge/left against medical advice (DAMA/LAMA)

This refers to a unilateral withdrawal decision by the family mainly due to unbearable financial and other burdens.<sup>[5,59]</sup> Physicians may at times endorse this practice as the only way to prevent perceived social and legal complications of making an EOLC decision. This practice should be discouraged as the patient has a miserable death without any palliation.

#### 6.4.4 Brain death

Brain death is an irreversible cessation of all functions of the brain including the brainstem. This category does not include patients who maintain brainstem function, such as patients with persistent vegetative state. In the US, brain death is death. In India, brain death was initially defined only for the purpose of beating heart organ retrieval in the Transplantation of Human Organ Act 1994. Outside of this context, in the Aruna Shanbaug case, the judges have ruled that brain death is equivalent to death (p. 52, Art 103). In the opinion of the committee, there should no longer be any ambiguity in this regard in physicians’ communication to the patient’s family.

#### 6.5 Guideline 5

##### Shared decision-making – consensus through open and repeated discussions

The physician must elicit and respect the choices of the patient expressed directly or through his family and work toward shared decision-making. Surrogates need to be free from anxiety and depression and be well informed in order to function effectively as decision-makers for the patients. In the shared decision-making model, the family discussions should include a review of the patient’s present status and prognosis, elicitation of the patient’s values, physician’s recommendations, deliberations, and joint decision-making about the level of limiting therapy.

## Rationale

Through a shared decision-making process the physician would ensure respect to the patient's autonomy in making an informed choice, while fulfilling his obligation of providing beneficent care.

Decision-making models vary across the world, however, the trend is toward a shared decision model.<sup>[20,26,60]</sup> One extreme is the traditional parental approach, where physician shares information but takes the primary responsibility for decision-making. The other extreme is when the patient makes the decisions, and the physician has an advisory role. In North America and in some parts of Europe,<sup>[20]</sup> the shared decision-making model is used where the physicians and patients or their surrogates share information and participate jointly in decision-making.<sup>[61]</sup> In a multicenter survey in North India<sup>[62]</sup> which was a customized version of the modified Molter's questionnaire,<sup>[63]</sup> interestingly, of the five domains in the instrument (information, comfort, support, assurance, and proximity), the priority for the Indian family appeared to be information needs (e.g., details of patient's condition and discussion on prognosis) as opposed to assurance needs (e.g., that patient is well-cared for, having hope) for the American family.

Family members may lack confidence in their role as decision maker, if they have had no previous experience as a surrogate or no prior dialogue with the patient about treatment preferences.<sup>[64]</sup> The burden of decision-making is a silent source of strain among family members of dying patients in the ICU. Anxiety and depression are also prevalent in half the patients' families.<sup>[54,65]</sup>

Pending consensus decisions or in the event of conflict with the family/patient the physician must continue all existing life supporting interventions. The physician, however, is not morally or legally obliged to institute new therapies against his better clinical judgment in keeping with accepted standards of care. The physician may not subject a patient to a particular therapy, even if the family may demand it, if it is against his professional judgment. Conflicts may be resolved through improved communications, seeking second opinions, and psychologist's consultation, seeking the help of other senior physicians of the hospital or the hospital's Ethics Committee, if in existence.

## Practice points

- The discussions should be between the family and treating team. The presence of a nurse and a junior doctor will ensure consistency in subsequent discussions

- There should be multiple conferencing of adequate duration. Family must be given adequate time and opportunity to ask questions and to express their views and emotions so that they do not feel "rushed" into a decision. This should also be done in a manner that ensures privacy, in a waiting room or similar area
- The family members may express feelings of guilt or remorse that should be resolved with patience. It might be useful to remind the family that death is inevitable and medical science cannot offer cure in all situations; that during the dying process the patient needs a humanistic approach rather than a purely technical one. In case the family has difficulties in accepting the possibility of death, counseling by a professional psychologist may be considered
- The family should receive assurances that due care will be taken to alleviate patient's pain and distress
- Pending consensus decisions or in the event of conflict with the family/patient the physician must continue all existing life supporting interventions.

## 6.6 Guideline 6

### *Transparency and accountability through accurate documentation*

The case notes should clearly reflect, through faithful recording, the entire or gist of all the discussions with the family, the decision-making process and the final decision based on medical appropriateness and patient's/family's preferences.

## Rationale

Documentation implies transparency, clarity, and evidence of an evolving decision-making process that indicates appropriate care on the part of the physician. It would also ensure that the patient is informed of all the available options and that overall care plan has been explained to him. It would provide security for the patient in case of malafide intentions on the part of caregivers or his own family. This would also be helpful to the physician to demonstrate his bonafide intentions in the event of litigation.

## Practice points

- Details of the communications between the medical team and the family should be documented accurately and completely
- Documentation should include details of the discussion and the final decision. The specific modalities withheld or withdrawn should be documented and the comfort strategies planned
- Though signature of a family representative is not mandatory, it is preferable to have a life support limitation form duly filled and signed by two or more

members of the family and treating team.

### 6.7 Guideline 7

#### *Ensure consistency among caregivers*

If a shift is made in the goals of care from cure to comfort, all members of the treating team should be aware of the plan for cessation of a disease specific therapy. The focus should be on keeping the patient pain-free and comfortable while limiting life-prolonging interventions.

#### **Rationale**

It is important that all caregivers are aware of EOLC plan has been made for the patient. This will avoid any unnecessary therapeutic interventions and make the team focus on comfort measure and family support and have consistency in communication with the family.

#### **Practice points**

- The primary physician should address all the members of the team about the discussion; modality of EOLC planned for the patient and shared decision made with the family
- Clear documentation of the plan will help in communicating with other members of the team who are not present during this discussion
- The bedside nurse can play an important role in ensuring that there is consistency among all caregivers in following the care plan.

### 6.8 Guideline 8

#### *Implementing the process of withholding or withdrawing life support*

Once a shared decision has been made with the family and documented withholding or withdrawing of life support should be initiated. Before proceeding with EOL measures, it is important to prepare the staff, the family members, the patient if capable and the patient's environment. The common modalities involve not initiating new therapies aimed at cure, withholding, weaning/withdrawing from mechanical ventilation, vasopressors, renal replacement therapy, therapeutic medications, nutrition, and extubation.

#### **Rationale**

To give a patient with life limiting illness a right to a life free from pain, and distress and avoid the agony and burden of a prolonged dying process through life support interventions.

Whatever approach is used, appropriate use of pharmacologic therapy, depending on prevailing levels of analgesia and sedation at the time of EOLC decisions,

should be individualized and used to ensure that the patient is pain-free and comfortable at all times.

#### **Practice points**

- Prepare the patient's room - Patient may be kept in a special room or even taken home to die if feasible and palliative care support is available. Comfort of the patient and family is paramount (e.g., Noise levels, lighting, and temperature). Remove unnecessary equipment and bring additional chairs into the room, if required
- Prepare the patient
  - Position the patient comfortably
  - Stop unnecessary monitoring (e.g., Oximetry), unnecessary devices (e.g., feeding tubes), unnecessary tests (e.g., blood investigations), and discontinue medications that do not provide comfort and provide those that do
- Ensure that the patient is calm and distress-free before while withholding or withdrawing support.
- Family - Make visiting restrictions liberal (e.g., number of visitors, timing, and duration). Honor requests for cultural and religious rituals. Caregivers could mitigate the stress of the family by discussing what is likely to happen during the dying process.

### 6.9 Guideline 9

#### *Effective and compassionate palliative care to patient and appropriate support to the family*

Provision of compassionate care at EOL is not mere control of physical symptoms, but involves respecting patient choices on preferred place of care and managing nonphysical issues such as psychological, emotional, spiritual, and existential distress.

#### **Rationale**

Provision of EOLC is strongly founded on certain guiding principles such as (A) Good control of pain and physical symptoms. (B) Preferred place of care should be respected. (C) Preferred place of care should be safe and secure with few crises. (D) Care givers should feel involved, supported, empowered and satisfied. (E) Health care providers feel comfortable, confident and foster a sense of teamwork. It is important for the family to be prepared, educated, and feel supported about EOLC provision and health care providers to be accepting and anticipating that patient is dying and willing to provide EOLC.<sup>[15,66]</sup>

Scope of palliative care in EOLC involves:

- Relief of EOL symptoms such as pain, dyspnea, delirium, and respiratory secretions
- Review of existing care protocols (medical/nursing)

- Review of medication chart and stopping unnecessary medication
- Stopping routine and unnecessary investigations that may not contribute to the process of care
- Continued communication throughout the process
- Counseling regarding optimal hydration and food intake
- Psychosocial support to patient, family, and caregivers
- Meeting special family requests (religious/spiritual/cultural).<sup>[67]</sup>

Principles of EOLC Symptom management and physical care [Table 9].<sup>[68,69]</sup>

### 6.10 Guideline 10

#### After death care [Table 10]

Culturally appropriate and sensitive after death care should be provided to all the dying patients irrespective of the situation or the setting.

#### Rationale

After death care begins with communicating the news of the death to the family and caregivers, early and in a sensitive manner. The news should be communicated in a calm and private environment. It is essential to take inputs from the family regarding after death rituals. Verification and certification of the death should be done at the earliest and every effort should be directed at smooth and dignified exit of the patient from the hospital.<sup>[70]</sup>

### 6.11 Guideline 11

#### Bereavement care support [Table 11]

End-of-life care does not culminate at death but continues even after death. Bereavement care helps family/care giver to cope with grief and other issues.

#### Rationale

Bereavement support to the family should begin before patient's death. Families and caregivers who are at high risk for bereavement are identified and are prepared for patient's death. In bereavement phase care givers with bereavement symptomatology are promptly identified and managed with the help of medical social workers, clinical psychologists, and psychiatrists.<sup>[71]</sup>

### 6.12 Guideline 12

#### Review of care process [Table 12]

Review of care process is an important quality assurance activity, which aims to review and reflect the care provided and in turn improve the process of care.

**Table 9: EOLC symptom management**

Symptom	Management
Pain	Change of route of administration Increase in background PRN (SOS) liberally used Remember - unconscious people also experience pain SC morphine at home, or SC/IV morphine as intermittent/continuous infusion are most preferred in hospital and intensive care unit
Nausea and vomiting	SC or IV metoclopramide, treat the cause if possible Consider SC/IV haloperidol/IV cyclizine for refractory cases
Dyspnea	Fan (air blowing on the face), oxygen ± Opioids (SC/IV morphine) + benzodiazepines (SC/IV midazolam) Noninvasive ventilation Use of bronchodilators if required Muscle relaxants may be used if patient is fighting the ventilator in ICU patients
Delirium	Optimal dose of anti-psychotics (SC/IV haloperidol) Adjunct benzodiazepines (SC/IV midazolam) Environmental changes + correcting correctable
Respiratory Secretions	Optimizing hydration Nursing interventions SC or IV glycopyrrolate
Care of skin and mucosa	Skin care: Positioning, comfort beds, pressure point care Mouth care: Hydrate with unflavored sponge tipped swab every 2-4 h Avoid commercial mouthwash, lemon glycerin, artificial saliva Eye care: Methylcellulose eye drops

EOLC: End-of-life care; SC: Subcutaneous; IV: Intravenous

**Table 10: After death care<sup>[3]</sup>**

Information about the death is communicated early and sensitively to the family
The primary team is informed
Body laid out in the culturally appropriate manner (take inputs from family as needed)
Provide presence and support to the family
Privacy and space to the family
Timely and correct verification and certification of death
Timely and dignified transfer of the deceased from the hospital

**Table 11: Bereavement support<sup>[3]</sup>**

Identifying families/caregivers who are very likely to need bereavement support
All bereaved families to be part of bereavement support groups run by medical social workers and volunteers
All bereaved patients with bereavement symptomatology (anxiety, depression, emotional distress, somatic symptoms) should undergo counseling and psychotherapy-based treatments
Prompt psychiatry referral and pharmacotherapy interventions to those with complex bereavement symptomatology refractory to counseling and psychotherapy-based treatment

**Table 12: Review of care process<sup>[3]</sup>**

To know and understand if the care process was complete and if there were any gaps
To know whether the family received adequate health related communication
To know whether the family fully understood and accepted the care process
To know if the family had any concerns regarding the care process, was it freely expressed and whether these concerns were addressed
To know if the family felt supported and appreciated the care process
To assess the satisfaction of healthcare providers
Initiate any improvement needed in the EOL care process

EOL: End-of-life

## Rationale

Quality of EOLC provided should be reviewed on a case-by-case basis by the multidisciplinary team that provided the care and the series should be audited periodically with the help of external auditors. Review will help to bridge gaps in care process, understand the family's perception of the care provided, and satisfaction of the healthcare providers such that there is a continued improvement of the EOLC process.<sup>[72]</sup>

## 7.0 Conclusion

Setting goals appropriate to clinical situations of poor prognosis are an integral part of patient care. At the EOL, the goal of treatment should shift from cure to comfort. The Joint Policy of the ISCCM and the IAPC provides the basis on which doctors can practice good medicine, and provide optimal care to their patients when death is imminent. This document contains the major practice points for EOLC. Individual practitioners must adapt these to the appropriate sociocultural context for their patients and areas of practice. The ambiguous legal position on withholding and withdrawing life-sustaining treatments at the EOL should not deter physicians from providing the best and ethical care to their patients. Honest, transparent, and compassionate communication and meticulous documentation together with effective palliative care aiming at ensuring a good death for the patient are well-grounded in the cardinal principles of medical ethics. A consensus regarding the practices relating to end-of-life care in India should eventually lead to the evolution of appropriate legislation in keeping with the changing needs of medical practice.

## 8.0 Future Directions

### Education

This policy recognizes that EOLC in India is poorly developed. The ISCCM and IAPC, through this document, have signaled a determination to improve the quality of EOLC in this country. This will require significant churning not only in the practice and thinking of medical practitioners, but also in the society and all those that represent its various sections.

The only way to bring about an awakening in the society is through education, advocacy, and debate. The ISCCM and IAPC must act as catalysts in this process, through providing leadership and direction. They must engage with opinion leaders, politicians, press, lay public, jurists, and patient groups, to encourage a rational, healthy debate based on science and ethics.

The term euthanasia must be clearly separated from withholding and withdrawal of life support at the EOL. It is only when lawmakers respond to societal needs will an enabling law be enacted. Even today, misunderstanding of the terminology and fear of misuse stand in the way of a law facilitating EOLC.

The concepts of medical futility, recognition of the dying patient, palliative care, and providing a good death must form an integral part of the curriculum in undergraduate and postgraduate medical courses. Every doctor should be aware of EOLC practices, not just palliative care and critical care experts. The IAPC and ISCCM and other like-minded organizations and experts must develop educational modules and disseminate them widely to practicing physicians throughout the country.

### Practice

In order to help doctors practice EOLC better, the following educational material could be developed for use across the country:

- Algorithms for EOL decision-making
- Algorithms for management of EOL symptoms
- Framework for application of standard principles of ethics in EOLC
- Framework for surrogate decision-making in EOLC
- Framework for documentation of EOLC
- Standard formats for documenting FLST.

### 9.0 Research

Research in India in this expanding field of healthcare has been negligible. Empirical data on EOL and palliative care need to be generated for India. The unique barriers to EOLC in its sociocultural and political context should be better understood through research. Measures to overcome these barriers should be defined through appropriate interventional studies. Quality of EOLC should be assessed by audit through predefined parameters. The vast cultural and ethnic diversity of the country provide a unique opportunity for research on factors influencing EOL and palliative care practices.

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