# End of Life Care in India: A Model Legal Framework

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V | D H | Centre for Legal Policy

ELICIT
End of Life Care India Task Force

**This report is the product of a collaboration between the End of Life Care in India Taskforce and the Vidhi Centre for Legal Policy, an independent think-tank doing legal research to help make better laws.**

# About the Collaborators

The End of Life Care in India Taskforce (ELICIT) is a joint initiative of the Indian Society of Critical Care Medicine, the Indian Association of Palliative Care and the Indian Academy of Neurology, set up with the objectives of creating a comprehensive law for end of life care, raising public awareness about issues relating to end of life care and facilitating the capacity building of medical and para-medical professionals in providing end of life care.

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# I. Context

In September 2019, a court in the Netherlands acquitted a doctor of violating Dutch laws on euthanasia. The doctor was accused of failing to consult a 74-year-old Alzheimer's patient before administering a lethal drug to her. The court ruled that a written declaration by the woman stating that she would prefer to be euthanised rather than be put in a care home was sufficient to justify the actions of the doctor, even though the woman had to be held down by her family members while the final lethal injection was given.[1]

The 2002 Dutch law legalising euthanasia has come full circle and the legal battleground has now shifted—where courts were once petitioned to allow euthanasia, the first prosecutions for malpractice under the euthanasia law are beginning.[2]

India, however, is at the opposite spectrum of global legal developments on end of life care. In September 2019, the Ministry of Health and Family Welfare introduced a bill to tackle growing violence against healthcare personnel at clinical establishments. Although a comprehensive study of the causes of such violence is not available, news reports suggest that the trigger, in most cases, is the death of a patient.[3] Almost half of such incidents of violence take place in emergency settings or in intensive care units.[4] The process of dying, which should be peaceful for the patient and their loved ones, is instead a source of tension and strife in clinical settings in India. A key reason for this is the absence of a clear legal framework on end of life care.

The Indian Council of Medical Research defines end of life care as a "an approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life."[5] End of life care includes palliative care and usually involves the withholding or withdrawal of life-sustaining treatment. Such treatment includes interventions like cardiopulmonary resuscitation, endotracheal intubation, mechanical ventilation, dialysis, blood products, antibiotics and nutrition that is administered other than through the mouth or alimentary canal. End of life care is not to be confused with euthanasia or physician-assisted suicide. The former is the intentional putting to death of a dying patient by a doctor, usually through the administration of a legal drug. In the latter, the act of killing is committed by the patient, using means provided by the doctor.

## *A. Legal Developments*

Euthanasia and physician-assisted suicide are not legal in India. The Supreme Court has made it clear that their legalisation is a matter for Parliament. This report does not discuss the advisability of either of these interventions. These are issues that should be taken up only when there is clarity regarding the preliminary question of withholding or withdrawal of life-sustaining treatment. There is overwhelming medical consensus worldwide that such withholding or withdrawal is not to be classified as euthanasia, but as a part of the

[1] Daniel Boffey, 'Dutch doctor acquitted in landmark euthanasia case' *The Guardian* (11 September 2019), available at <https://www.theguardian.com/world/2019/sep/11/dutch-court-clears-doctor-in-landmark-euthanasia-trial> (last accessed 16 October 2019).

[2] Christopher de Bellaigue, 'Death on demand: has euthanasia gone too far? *The Guardian* (18 January 2019), available at <https://www.theguardian.com/news/2019/jan/18/death-on-demand-has-euthanasia-gone-too-far-netherlands-assisted-dying> (last accessed 16 October 2019).

[3] 'Resident Doctors at Mumbai's JJ Hospital Call off Their Strike' *The Quint* (22 May 2018), available at < https://www.thequint.com/news/india/doctors-thrashed-by-patient-relatives-at-mumbai-hospital> (last accessed 31 October 2019); 'Safdarjung Hospital Resident Doctors on indefinite strike after colleagues attacked' *India Today* (30 August 2019), available at < https://www.indiatoday.in/india/story/safdarjung-hospital-docter-strike-resident-doctors-1593256-2019-08-30> (last accessed 31 October 2019).

[4] 'Over 75% of doctors faced violence at work, study finds' Times of India (4 May 2015), available at < https://timesofindia.indiatimes.com/india/Over-75-of-doctors-have-faced-violence-at-work-study-finds/articleshow/47143806.cms> (last accessed 31 October 2019).

[5] 'Definitions of Terms used in Limitation of Treatment and Providing Palliative Care at End of Life', Indian Council of Medical Research (2018).

process of allowing natural death. However, this medical consensus was not matched by clear legal sanction until a judgment of a Division Bench of the Supreme Court in *Aruna Shanbaug v Union of India*[6] *(Aruna Shanbaug)* in 2011.

Aruna Shanbaug's case brought the issue of 'passive euthanasia' (as the withholding or withdrawal of life-sustaining treatment was misleadingly named) front and centre in tragic circumstances. Aruna Shanbaug was a nurse at the King Edward Memorial Hospital in Mumbai, who was brutally raped and strangulated in 1973, leaving her significantly brain-damaged. She was lovingly cared for by her former nursing colleagues at her hospital. In 2009, a journalist, Pinki Virani, filed a writ petition in the Supreme Court, pleading for Aruna Shanbaug to die a dignified death and asking specifically for the hospital to stop feeding her i.e. to withdraw a particular kind of life-sustaining treatment.

This was the first time that the Supreme Court grappled with the legal validity of withholding or withdrawing life-sustaining treatment, although there had previously been recognition of the broader right to die with dignity, as an integral component of the right to life under Article 21 of the Indian Constitution. Justice Katju, delivering the judgment for the Court, recognised that life-sustaining treatment could legitimately be withheld or withdrawn from a person who had lost decision-making capacity (which was confusingly characterised as non-voluntary passive euthanasia). Importantly, the Court also discussed who was authorised to take a decision regarding withholding or withdrawal of life-sustaining treatment, a question as important as the legal validity of the action itself.

In Aruna Shanbaug's case, the persons authorised to take this decision, in the absence of any close relatives, were the staff of the hospital where she had worked and was being cared for. Since the staff expressed a desire that Aruna Shanbaug be permitted to continue living, the relief that Pinki Virani asked for was not granted. Nevertheless, the decision was a landmark one because it gave legal sanction to the withholding of withdrawal of life-sustaining treatment in certain cases for the first time. However, the judgment also sowed the seeds of suspicion against healthcare professionals and caregivers, by prescribing a restrictive process to obtain legal sanction for such withholding or withdrawal. The Court held that whenever a decision to withhold or withdraw life-sustaining treatment was taken by near relatives or doctors or the next friend of the patient, it would require the prior approval of the jurisdictional High Court. This suspicious attitude to end of life care decisions permeated the next, and to date, most definitive judgment handed down by the Supreme Court on this issue.

In 2018, a Constitution Bench of the Supreme Court, hearing a petition filed by the non-governmental organisation, Common Cause (and intervention applications by the two collaborators of this report), reconsidered the legal permissibility of withholding or withdrawal of life-sustaining treatment discussed in *Aruna Shanbaug*. It also considered whether to grant legal validity to advance medical directives, instruments through which a person could express the treatment they did or did not desire to receive at the end of life, when they might not be in a position to exercise decision-making capacity. The Court unanimously held that the right to refuse life-sustaining medical treatment is an exercise of the rights to autonomy, dignity and privacy that make up the right to life under Article 21. It reaffirmed the legal validity of withholding or withdrawing life-sustaining treatment and also granted legal recognition to advance medical directives, but followed Justice Katju's lead in prescribing a restrictive process for putting either of these into operation.

## *B. Practical Challenges*

As the law currently stands, life-sustaining treatment may be withheld or withdrawn from a terminally ill person or one who has 'no hope of recovery and cure.' Medical practitioners may also give effect to advance medical directives authorising the withholding or withdrawal of life-sustaining treatment. However, this must take place according to the guidelines laid down by the Supreme Court [See Table 1], until these guidelines are replaced by a law. It is these guidelines that are the source of confusion among healthcare practitioners

[6] Aruna Shanbaug v. Union of India, (2011) 4 SCC 454.

today, and it is in response to them that the collaborators of this report have developed a draft Bill to remove uncertainty regarding end of life care decisions.

*Table 1. Supreme Court Guidelines for the withholding or withdrawal of life-sustaining treatment*

These guidelines are laid down in Paragraphs 191 and 192 of Chief Justice Dipak Misra's judgment. They govern the withholding or withdrawal of life-sustaining treatment in two cases: one, where a valid advance medical directive exists, and second, where no such directive exists and the patient in question has lost the capacity to exercise judgment and make a decision. However, the procedure laid down for both these scenarios is virtually identical.

*Application of the Court's Guidelines*

To terminally ill patients, undergoing prolonged treatment in respect of ailments that are incurable or where there is no hope of being cured.

*Step I*

Ascertain whether the patient meets the eligibility criteria above.

*Step II*

Ascertain the genuineness and authenticity of an advance medical directive from the jurisdictional Judicial Magistrate of the First Class, where such a directive exists. Discuss the nature of the illness, alternative options and the effects of refusing treatment with the guardian or close relatives of the patient. If no such directive exists, proceed to Step III.

*Step III*

Set up a Hospital Medical Board, comprising the Head of the treating Department and at least three experts from general medicine, cardiology, neurology, nephrology, psychiatry or oncology, with experience in critical care and overall standing of at least twenty years.

*Step IV*

Hospital Medical Board to visit patient in the presence of the guardian or close relative and certify whether or not to carry out the instructions in the advance medical directive regarding the withholding or withdrawal of life-sustaining treatment.

Where an advance medical directive does not exist, the Hospital Medical Board to discuss the pros and cons of refusal of the withholding or withdrawal of life-sustaining treatment with the family members of the patient. If consent in writing is provided by the family members, Board to certify whether or not to withhold or withdraw the treatment.

*Step V*

If the Hospital Medical Board gives a preliminary opinion that life-sustaining treatment should be withheld of withdrawn, the jurisdictional Collector to be informed of this opinion. The Collector to constitute a Medical Board, chaired by the Chief District Medical Officer and comprising three experts with the same qualifications as the experts on the Hospital Medical Board, but who were not members of that Board.

*Step V*

Second Board to jointly visit the hospital where the patient is admitted and to determine whether or not to endorse the opinion of the Hospital Medical Board.

If an advance medical directive exists that nominates a person to take decisions on the patient's behalf, the consent of such person to be obtained for the withholding or withdrawal of life-sustaining treatment.

*Step VII*

If the Second Board endorses the opinion of the Hospital Medical Board, the decision to be conveyed to the jurisdictional Magistrate of the First Class.

Judicial Magistrate to visit the patient, examine all aspects of the case and authorise the decision of the Board.

Where the withholding or withdrawal of life-sustaining treatment is not authorised by the second Board constituted by the Collector, the nominee of the patient or a family member or the treating doctor or the hospital staff may obtain permission from the High Court to withhold or withdraw life-sustaining treatment through a writ petition under Article 226 of the Constitution.

The guidelines prescribed by the Supreme Court are simply not implementable in real life critical care settings. The Court's process, founded on an inherent suspicion of unethical doctors and grasping family members, is designed to require approval at three different stages from three different authorities. It is a lengthy process that is not mindful of the short timelines (from a few hours to a few days) within which decisions must be taken in intensive care units. The multi-tiered process required by the Court will take much longer to implement, especially given that the Court contemplates a personal visit by an already overburdened Judicial Magistrate to a hospital before permitting the withholding or withdrawal of life-sustaining treatment. Although this procedure aims to be more accessible than the one laid down in *Aruna Shanbaug* (which would have required every doctor exercising a decision about the withholding or withdrawal of life-sustaining treatment to approach their jurisdictional High Court), it is still unworkable in an Indian setting, keeping in mind the large numbers of patients, overstretched doctors (especially in the public health system), and decades of knowledge of the slowness of any Indian bureaucratic machinery (which the Court replicates through its Boards).

It is no wonder then that doctors, although welcoming of the broad principles of the Court's decision, are critical of its nuts and bolts. Nearly 20 months have passed since the Court's decision, but the process that it has laid down is yet to be implemented. To the best of our knowledge, no Medical Boards have been constituted by jurisdictional Collectors to endorse the opinion of Hospital Medical Boards, and Judicial Magistrates remain unaware of their duties under this judgment. With these components of the Court's process missing, doctors remain fearful of withholding or withdrawing life-sustaining treatment, and ironically, unethical practices abound in order to avoid legal action.

The most pernicious amongst these is the practice of having family members sign a 'Leave Against Medical Advice' form, often when they are unable to continue to bear the mounting expenses of treatment in intensive care. Having washed their hands off such patients, hospitals fail to make appropriate arrangements for the withdrawal of life-sustaining treatment that inevitably follows, although Indian Medical Association guidelines require patients for whom a LAMA form has been signed to be transferred from life support to life support, including making arrangements for a suitably equipped ambulance.[7] As a result, life-sustaining treatment may be withdrawn in the absence of a trained medical practitioner and the patient may be denied the comfort care that they are entitled to at the end of life, notwithstanding the LAMA form. One of the most egregious examples of this in the recent past is 8-year-old Adya Singh's case. Adya's parents signed a LAMA form, agreeing to take her home from Fortis hospital in Gurugram fourteen days after she was admitted with symptoms of dengue. The hospital, however, has been accused of failing to provide the family with an ambulance appropriately equipped for the withdrawal of life support, confirmed by a committee appointed by the Haryana government to investigate the hospital. Although the committee has categorically stated that "withdrawal of life support by the hospital staff in the ambulance amounts to negligence and is against the law of the land"[8], our experience interacting with doctors at intensive care units across the country suggests that there is not enough awareness about the unacceptability of this practice and that this is compounded by confusion surrounding the procedure for the withdrawal of life support that the Supreme Court guidelines now require.

Practices like this, apart from violating the right of patients to a dignified death, contribute to growing mistrust of the medical profession. Ultimately, this has adverse consequences for doctors and other healthcare practitioners through increased incidences of violence. A country that already ranks very poorly

[7] 'It's murder, not death': Haryana Govt. to probe into 7-year-old's death in Gurgaon Fortis' *Hindustan Times* (7 December 2017), available at < https://www.hindustantimes.com/india-news/gurgaon-fortis-overbilling-haryana-govt-says-hospital-guilty-of-negligence/story-fbbDCCd5GQYdxb6aCWbjqM.html> (last accessed 31 October 2019).
[8] 'One year after 7-year-old girl's death created a furore, Fortis hospital escapes the police net' *The Scroll* (11 January 2019), available at <https://scroll.in/pulse/908824/one-year-after-seven-year-old-girls-death-created-a-furore-fortis-hospital-escapes-the-police-net> (last accessed 31 October 2019).

on the Quality of Death Index[9] cannot afford to compromise its end of life care further because of an unclear legal framework. This draft Bill attempts to address this gap by protecting the autonomy and dignity of patients and creating clear legal obligations for healthcare practitioners and clinical establishments that are mindful of the constraints of delivering intensive care in the Indian context.

## *C. Overview of the draft Bill*

The Bill is divided into seven chapters. The first chapter defines key terms that are commonly used in end of life care settings, drawing on work already done by the Indian Council of Medical Research. This is an important component of the Bill because the use of inappropriate terms to characterise actions in end of life settings may have created negative perceptions about the removal of life-support. In particular, the use of "passive euthanasia" to describe the withholding or withdrawal of life-sustaining treatment creates the impression that the latter is analogous to the intentional causing of death. This in turn is likely to have prompted the Supreme Court to err on the side of excessive caution in prescribing a three-step process to permit the withholding or withdrawal of life-sustaining treatment.

Through its definition of 'near relative' as any relatives or friends of long standing regularly attending or accompanying a patient to a healthcare establishment, the Bill marks a shift in thinking about surrogate healthcare decision-makers. Such surrogates are no longer restricted to relations by blood or marriage and no hierarchy among such relatives is prescribed. The purpose is to give primacy to the principal caregiver and to recognise relationships outside of traditional, hetero-normative family structures.

The second chapter of the Bill enshrines the rights that form the bedrock of the Bill: the right to end of life care in a manner consistent with autonomy and dignity, the right to refuse any medical treatment, including life-sustaining treatment and its corollary, the right to execute advance medical directives. These rights will form the standard against which the actions of healthcare practitioners and establishments in end of life care settings will be judged.

The third chapter of the Bill sets out the procedure for the withholding or withdrawal of life-sustaining treatment which is intended to replace the Supreme Court guidelines. Currently, the withholding or withdrawal of life-sustaining treatment is contemplated only for terminally ill persons or those in a persistent vegetative state or those in whom the initiation, continuation or escalation of life-sustaining treatment would be potentially inappropriate. The Bill does not specify what conditions might fall within this last category, leaving it instead to the professional judgment of medical practitioners, and allowing flexibility for the Bill to cover situations that were not explicitly contemplated in the judgment of the Supreme Court.

This procedure in this chapter contemplates three situations: where the patient possesses healthcare decision-making capacity, where the patient lacks such capacity and has made a valid advance medical directive, and where the patient has neither capacity nor a valid directive. The procedure in the Bill gives primacy to the autonomy of the patient, requiring their best interests to be taken into account in the third scenario. Even then, best interests must be determined keeping in mind the values and preferences of the patient. Rather than create a hierarchical relationship between the healthcare practitioners attending to the patient and their 'near relatives', the Bill requires a shared decision-making process to be followed, involving multiple rounds, if necessary, to resolve any disagreements. This is in keeping with guidelines recommended by professional medical associations worldwide.[10] It is intended not to perpetuate the paternalistic role that

[9] India ranked 67th amongst 80 countries, see 'The 2015 Quality of Death Index: Ranking Palliative Care across the World', The Economist Intelligence Unit (2015).

[10] See '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', Vol. 8, Issue 9, Indian Journal of Critical Care Medicine (2014); 'End of Life Care Policy for the Dying : Consensus Position State of Indian Association of Indian Association of Palliative Care', Vol. 20, Issues 3, Indian Journal of Palliative Care (2014); Challenges in the end-of-life care in the ICU: Statement of the 5th international Consensus Conference in Critical Care: Brussels, Belgium (2003),

doctors have traditionally played in India, while also compelling near relatives to take the best interests of the patient into account, using 'substituted judgment'[11] instead of giving primacy to their own feelings.

The Bill does not require prior approval from a Board or magistrate before permitting the withholding or withdrawal of life-sustaining treatment. Instead, a safeguard is provided in the form of a subsequent audit of such decisions by an end of life care committee. The sixth chapter of the Bill deals with the constitution of such committees. Healthcare establishments of a certain size must constitute their own committees, while others may rely on a district end of life care committee to be set up by the Chief Medical Officer of that district. The committee draws experts from a diverse range of backgrounds-apart from medical experts, lawyers (with a knowledge of bioethics) and social workers experienced in issues related to end of life care. An external medical practitioner will serve as the chairperson of the committee, to ensure independence and effectiveness in its functioning. The committee will have both the power and the obligation to recommend appropriate action under relevant laws against healthcare practitioners and establishments found to be making end of life care decisions in bad faith. The Bill also requires members of end of life care committees to undergo training, the specifics of which will be set out in the rules to be framed under the Bill.

The fourth chapter sets out the conditions in which healthcare practitioners may issue do not resuscitate orders, independently of the execution of advance medical directives covered in the previous chapter. Such orders are only to be issued in consultation with patients possessing healthcare decision-making capacity or their near relatives. The fifth chapter governs the execution of advance medical directives. Only adults of the age of 18 years and above may execute such directives in the presence of two witnesses. Unlike the Supreme Court judgment, which requires directives to be executed in the presence of a Judicial Magistrate, the Bill only requires directives to be notarised, in keeping with requirements in other jurisdictions. Healthcare practitioners treating the patient are disqualified from acting as witnesses because of a conflict of interest. Advance directives are valid for a period of ten years but may be altered or revoked at any time in the same manner as they are to be executed.

The Bill also puts to rest a debate that has vexed transplant doctors and intensivists since the enactment of the Transplantation of Human Organs and Tissues Act in 1994 i.e. whether brain-stem death constitutes death outside of the context of organ transplantation. This debate has arisen because death under the Registration of Births and Deaths Act, 1969 has traditionally been understood only as cardio-respiratory death, while brain-stem death has been defined as death only under the Transplantation of Human Organs and Tissues Act. This Act prescribes a process for the certification of brain-stem death when there is authorisation for the removal of organs from the body for the purpose of transplant. As a result, several doctors have labored under the belief that brain-stem death may be certified only when there is consent for organ donation, not otherwise. If there is no such consent, brain-stem death may not be ascertained and correspondingly, life support may not be removed. This interpretation of the law creates a logical absurdity: a person is considered brain-stem dead if there is consent for organ donation, but not otherwise. This cannot be the case since brain-stem death is an objective fact to be medically determined, independent of the consent of any person. Although it is possible to argue that neither the Registration of Births and Deaths Act, 1969 nor the Transplantation of Human Organs and Tissues Act should be interpreted in this manner, this Bill unambiguously clarifies that there is a uniform definition of death which means the irreversible cessation of the heart and circulatory function, or neurological function of the brain including the brain stem. This definition is intended to have an overriding effect over any other law in force.

This model end of life care Bill is an important step towards improving the quality of death in India. It recognises the autonomy of patients, removes legal uncertainty surrounding the withholding or withdrawal of life-sustaining treatment, and provides safeguards against bad faith end of life care decisions. Changes to the legal framework cannot, in isolation, ensure a dignified death. Greater awareness about end of life decision-making is needed, both among lay persons and healthcare practitioners. Capacity-building measures are also needed to ensure that practitioners have the right expertise and training in delivering end of life care, especially as regards communication skills. Finally, it is important to recognise that millions of Indians face

[11] *Id.*

very high financial barriers to critical and intensive care and that the public health system is not well equipped to deliver high quality care, leave aside end of life care. The model Bill must also be accompanied by a renewed commitment to meeting the goal of universal public healthcare. The Bill must not be used as a convenient tool to force end of life decisions because of financial constraints, especially when patients might benefit from life-sustaining treatment. Its objective is to facilitate better care at the end of life, to allow a dignified death, to reassure patients that their decisions will be respected, and to give healthcare professionals the confidence to deliver care that is both ethical and in accordance with the law.

# II. Model End of Life Care Bill, 2019

**Bill No. of**

**The End of Life Care Bill, 2019**

**A**

**BILL**

*to create a legal framework for end of life care by laying down minimum standards and procedures governing healthcare practitioners and healthcare establishments and by giving legal recognition to advance directives.*

*The right to die with dignity, which was recognised as an aspect of the right to life by the Supreme Court of India in Common Cause v. Union of India, is a fundamental right. Therefore, it is essential to give legal recognition to the autonomy and dignity of patients by respecting their right to refuse treatment, including life-sustaining treatment.*

*This right also extends to the creation of advance directives, to give effect to the patient's wishes regarding withholding and withdrawing life-sustaining treatment when they lack healthcare decision-making capacity. For patients who lack this capacity and who have not made advance directives, their right to dignity must be protected by recognising the legal validity of withholding and withdrawing life-sustaining treatment when this is in their best interests.*

*Respect for the dignity of patients necessitates focusing on end of life care, which is an approach that shifts the focus of care to upholding patient dignity through symptom control, comfort, quality of life and quality of dying rather than on cure and the prolongation of life.*

*It is necessary to lay down standards and procedures for end of life care and to create a legal framework for the recognition of advance directives. It is also necessary to lay down the rights and obligations of patients, healthcare practitioners and healthcare establishments in this regard.*

Enacted by Parliament as follows:

## CHAPTER I

## PRELIMINARY

Short title, extent and commencement

1. (1) This is the End of Life Care Act, 2019.

(2) It extends to the whole of India.

(3) It shall come into force on such date as the Central Government may, by notification in the Official Gazette, appoint.

Definitions

2. In this Act, unless the context otherwise requires,—

(a) "Act" means the End of Life Care Act, 2019;

(b) "advance directive" means a statement made by a person with healthcare decision-making capacity regarding how they wish to be treated or not to be treated at a stage when they lose such capacity, including their wishes regarding the withholding and withdrawing of life sustaining treatment, and includes a medical power of attorney made by a person in favour of a surrogate;

(c) "child" means a person below the age of 18 years;

(d) "end of life care" means the provision of care to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life and includes care provided after the withholding or withdrawing of life sustaining treatment;

(e) "end of life care committee" means a committee constituted under section 17 or 18 of this Act;

(f) "healthcare" means any care, service, procedure or treatment provided by a healthcare practitioner for the purpose of diagnosing, maintaining or treating an injury, illness or other medical condition of a person;

(g) "healthcare decision-making capacity" means the capacity of a person to make and communicate, whether verbally or otherwise, an informed decision regarding the provision of healthcare;

(h) "healthcare establishment" means a hospital, maternity home, nursing home, dispensary, clinic, sanatorium, hospice or an institution by whatever name called that provides healthcare and includes an establishment owned, controlled or managed by-

(i) the Government or a department of the Government;

(ii) a trust, whether public or private;

(iii) a corporation (including a society) registered under a Central, Provincial or State Act, whether or not owned by the Government;

(iv) a local authority; or

(v) a single doctor;

(i) "healthcare practitioner" means any person qualified under any law in force to provide healthcare and includes medical practitioners, paramedical and emergency medical care technicians, nurses, occupational therapists and physical therapists but does not include social workers or counsellors;

(j) "informed decision", in the context of a healthcare intervention, means a decision arrived at after fully understanding the nature of the intervention and its risks and benefits, as well as the risks and benefits of not carrying out the intervention and of alternative interventions;

(k) "life sustaining treatment" means any medical treatment that artificially supports or replaces a body function essential to the life of the person and includes cardiopulmonary resuscitation, endotracheal intubation, mechanical ventilation, vasopressor therapy, parenteral or artificial enteral nutrition, dialysis, blood products, antibiotics, intravenous fluids;

(l) "best interests" means a course of action for the patient that accounts for the patient's values and preferences and is in accordance with recognised professional standards, such that the benefits to the patient are maximised and the risks minimised;

(m) "near relative" means any relative or friend of long standing regularly attending or accompanying a patient to a healthcare establishment;

(n) "notified" means a notification published in the Official Gazette and the term "notify" shall be construed accordingly;

(o) "patient" means a person receiving healthcare at a healthcare establishment;

(p) "potentially inappropriate" in relation to healthcare interventions means interventions aimed at cure that reasonably carry a greater possibility of harm than benefit;

(q) "prescribed" means prescribed by rules made by the Central Government under this Act;

(r) "recognised professional standards" mean evidence-based clinical guidelines for the diagnosis, treatment and management of injuries, illnesses or other medical conditions that are adopted or recommended by a reputed body of medical

professionals or any other body authorised under any law in force to issue such guidelines;

(s) "shared decision-making" means a dynamic process where decisions regarding the healthcare of a patient are jointly made by the healthcare providers and the patient's near relative through a process of consultation;

(t) "surrogate" means a person or persons who have been authorised, through an advance directive, to take decisions regarding healthcare on behalf of the person executing the directive when such person loses healthcare decision-making capacity;

(u) "terminal illness" means an incurable and irreversible condition caused by injury, disease or illness that would cause death in the foreseeable future, and the term 'terminally ill' shall be construed accordingly;

(v) "withdrawing life sustaining treatment" means the cessation or removal of life sustaining treatment presently being provided to a patient when the patient's chances of survival with continued life sustaining treatment are poor, with the burden outweighing the possible benefit, and the term 'withdraw life sustaining treatment' shall be construed accordingly;

(w) "withholding life sustaining treatment" means not initiating or escalating life-sustaining treatment where the patient's chances of survival after initiation or escalation of life sustaining treatment are poor, with the burden outweighing the possible benefit, and the term 'withhold life sustaining treatment' shall be construed accordingly.

## CHAPTER II
## RIGHTS AND OBLIGATIONS

Right to End of Life Care

3. (1) All patients have the right to end of life care and all actions under this Act shall give utmost respect to and be in furtherance of their autonomy and dignity.

(2) Healthcare establishments shall implement such internal processes and provide such facilities as are necessary under this Act and rules framed under it to protect the rights in sub-section (1).

(3) Healthcare practitioners shall ensure that the provision of end of life care including the withholding and withdrawing of life-sustaining treatment is in accordance with recognised professional standards.

Right to Refuse Treatment

4. (1) All terminally ill patients not being children and possessing healthcare decision-making capacity shall have the right to refuse any medical treatment, including life-sustaining treatment, and on such refusal, the treatment shall be withheld or withdrawn in accordance with this section.

(2) Healthcare practitioners and healthcare establishments shall ensure that:

(a) all patients are made aware of, and are provided every opportunity to exercise their right under sub-section (1), including when they are unable to communicate verbally, by facilitating the expression of their wishes;

(b) all patients are provided with, and understand the information necessary to make an informed decision;

(c) all patients refusing treatment are making an informed decision freely and voluntarily.

(3) The provisions of section 10 of this Act shall not apply to the withholding or withdrawing of life-sustaining treatment from patients possessing healthcare decision-making capacity.

Advance Directives

5. (1) All persons possessing healthcare decision making capacity shall have the right to execute advance directives in accordance with the provisions of this Act and rules framed under it.

(2) All terminally ill persons, except children, in a healthcare establishment, who have not executed advance directives, shall be informed of their right to execute advance directives.

## CHAPTER III
## PROCEDURE FOR WITHDRAWING AND WITHOLDING LIFE SUSTAINING TREATMENT

Applicability of Procedure

6. (1) This Part shall apply to a patient who is terminally ill or in a persistent vegetative state or to any other patient for whom the initiation, continuation or escalation of life-sustaining treatment would be potentially inappropriate.

(2) Medical practitioners shall determine whether patients meet the conditions specified in sub-section (1) in accordance with recognised professional standards, with at least three senior medical practitioners at the healthcare establishment agreeing on such determination.

Determination of Healthcare Decision-making Capacity

7. (1) Once it has been determined that a patient meets the conditions specified in sub-section (1) of section 6, healthcare practitioners attending to the patient shall determine whether such patient possesses healthcare decision-making capacity.

(2) If the patient possesses healthcare decision-making capacity, then such patient may exercise their right to refuse medical treatment, including life-sustaining treatment, in accordance with section 4 of this Act.

Procedure where there is

8. (1) If a patient does not possess healthcare decision-making capacity, the healthcare establishment shall

no Healthcare Decision-making Capacity and Valid Advance Medical Directive Exists

determine whether there exists a valid advance directive made by such patient, and for this purpose, may consult a near relative of the patient or request access to the online registry set up under section 16 of this Act.

(2) If the healthcare establishment is reasonably satisfied that a valid advance directive exists through which the patient has appointed a surrogate, such surrogate shall be made aware of their right to refuse medical treatment, including life-sustaining treatment, on behalf of the patient in accordance with section 4 of this Act.

(3) The surrogate shall take a decision in accordance with the advance directive and by accounting for the values and preferences of the patient.

(4) A decision by the surrogate under this section, including a decision to withhold or withdraw life-sustaining treatment, shall be implemented notwithstanding any disagreement with this decision by a near relative, unless there is reason to believe that the surrogate is acting on extraneous considerations unrelated to the best interests of the patient.

(5) Where a valid advance directive exists, but the patient has not appointed a surrogate, healthcare practitioners shall give effect to the advance directive including instructions to withhold or withdraw life-sustaining treatment.

(6) Healthcare practitioners shall not give effect to the instructions in an advance directive if there is reasonable doubt regarding the validity of the advance directive.

Advance directives not to be valid in certain cases

9. (1) Notwithstanding anything contained in this Act, an advance directive shall not be considered valid in the following instances:

(a) if circumstances have arisen which were beyond the anticipation of the person who executed the advance directive;

(b) if a situation has arisen or an event has occurred that would cause a reasonable person in the position of the person who executed the advance directive to alter the instructions in their directive.

(2) While determining whether the circumstances or situations specified in sub-section (1) have arisen, the following factors may be taken into account:

(a) the age of the person at the time of execution of the advance directive; and

(b) the time that has passed since the execution of the directive.

Procedure where there is no Healthcare Decision-Making Capacity and Valid Advance Medical Directive does not exist.

10. (1) The procedure in this section for the withholding or withdrawing of life-sustaining treatment shall apply to a patient who:

(a) meets the conditions specified in sub-section (1) of section 6;

(b) does not possess healthcare decision-making capacity; and

(c) in respect of whom a valid advance directive does not exist or has not been given effect to under sub-section (6) of section 8.

(2) The healthcare establishment shall make reasonable efforts to ascertain whether a near relative of a patient to whom this section applies, is available, and shall provide information to such relative regarding the condition of the patient.

(3) Withholding or withdrawing of life sustaining treatment shall be undertaken through shared decision-making among the healthcare practitioners attending to the patient and the near relative of the patient available at the healthcare establishment.

(4) A decision in sub-section (3) shall be made in the best interests of the patient.

(5) Where the patient is a child, the provisions of this section shall apply to the withholding or withdrawing of life-sustaining treatment, with the following modifications:

(a) the views of the child shall be taken into account, to the extent possible, if the child is capable of exercising healthcare decision-making capacity, in the opinion of the healthcare practitioner;

(b) the near relatives of the child participating in the shared decision-making process shall be the parents of the child, or in their absence, the guardian of the child.

(6) Any differences among the healthcare practitioners and the patient's near relative regarding the withholding and withdrawing of life-sustaining treatment that cannot be resolved through multiple rounds of shared decision-making shall be referred to the end of life care committee, which shall attempt to resolve the differences as expeditiously as possible in accordance with the provisions of the Act and rules framed under it.

(7) If the end of life care committee is unable to resolve differences among the healthcare practitioners and the patient's near relative, then the withholding and withdrawing of life-sustaining treatment shall occur only with the approval of the High Court within the

local limits of whose jurisdiction the healthcare establishment is situated, upon an application to it by the healthcare establishment or the near relative, as the case may be, and such High Court shall decide such proceedings as expeditiously as possible.

(8) Any further appeal from the orders of the High Court, not being interlocutory orders, shall lie with the Supreme Court of India which shall decide such appeal as expeditiously as possible.

Provided that the Supreme Court of India shall only hear appeals on any substantial question of law arising out of the orders of the High Court.

Maintenance of Patient Records

11. (1) Any information, reports, opinions, decisions and details of the procedure relating to end of life care, including withholding and withdrawing life-sustaining treatment under this Part shall be documented by the healthcare practitioners and the healthcare establishment and maintained in the records of the patient.

(2) It shall be the obligation of the healthcare establishment to ensure that the privacy and security of the patient is protected in accordance with any applicable law in force.

Subsequent Audit by the End of Life Care Committee

12. (1) All withholding or withdrawing of life-sustaining treatment under this Part shall subsequently be audited by the relevant end of life care committee on a monthly basis.

(2) Healthcare establishments that do not have their own end of life care committee shall report all instances of the withholding or withdrawing of life-sustaining treatment to the district end of life care committee.

(3) The end of life care committee shall have the power to call for patient records during an audit under sub-section (1).

(4) The end of life care committee shall record the findings of its audit in writing and such findings shall form part of the patient's record maintained by the healthcare establishment and a copy of these findings shall be reported to the Chief Medical Officer of the district at the earliest.

(5) If the end of life care committee concludes that the withholding or withdrawing of life-sustaining treatment was not carried out in good faith or demonstrated disregard for recognised professional standards on part of the healthcare practitioners or the healthcare establishment or in any other way violated the provisions of this Act and rules framed under it, then the committee may recommend appropriate action against the healthcare practitioner or the healthcare establishment, including make complaints against registered

medical practitioners under the National Medical Commission Act, 2019 (30 of 2019), as the case may be, in accordance with any law for the time being in force and the rules prescribed under this Act.

## CHAPTER IV
## DO NOT ATTEMPT RESUSCITATION ORDER

Do not attempt resuscitation order

13. (1) Notwithstanding anything contained in the provisions of this Act, if a medical practitioner is of the opinion that:

(a) a patient meets the conditions specified in sub-section (1) of section 6; and

(b) the likelihood of such patient surviving cardiopulmonary resuscitation is extremely low;

then they may issue a do not attempt resuscitation order in accordance with recognised professional standards.

(2) An order under sub-section (1) will only be issued:

(a) if the patient possesses healthcare decision-making capacity, in consultation with the patient; or

(b) if the patient does not possess healthcare decision-making capacity, in consultation with the near relative of the patient.

(3) The treating healthcare practitioner shall periodically review an order issued under sub-section (1).

## CHAPTER V
## EXECUTION OF ADVANCE DIRECTIVES

Conditions of Validity of an Advance Directive

14. (1) Any person of sound mind not being a child may execute an advance directive.

(2) Every advance directive shall be made in clear and unambiguous terms and shall be in writing.

(3) An advance directive must be voluntarily executed by a person possessing healthcare decision making capacity.

(4) An advance directive or any part thereof, the making of which has been caused by fraud, coercion, inducement or under importunity that takes away the free agency of the person shall be void.

(5) A person executing an advance directive shall date and sign or affix their mark on the advance directive and where they are physically incapable of doing so, the directive shall be dated and signed by some other person in their presence and under their direction.

(6) Every advance directive shall be executed in the presence of at least two witnesses, whose qualifications will be such as may be prescribed, each

of whom has witnessed the execution of the advance directive in accordance with sub-section (5); and each of the witnesses shall sign or affix their mark to the advance directive in the presence of the person executing the advance directive.

Provided, that the healthcare practitioners attending to the patient shall not be witnesses to the execution of the advance directive.

(7) The execution of every advance directive shall be verified by a notary appointed under the Notaries Act, 1952 (53 of 1952).

Alteration, Renewal and Revocation of Advance Directives

15. (1) An advance directive may be altered at any time after its execution by the person who executed it, and the alteration must comply with the conditions for execution under section 14 of this Act.

Provided that an advance directive may be revoked orally in instances when the person who executed the advance directive is incapable of revoking it in writing.

Provided further that such oral revocation must take place in the presence of a healthcare practitioner and two witnesses.

(2) An advance directive shall be valid for a period of ten years from the date of its execution, after which it must be explicitly renewed by the person who executed the advance directive to retain its validity and such renewal must comply with the conditions of execution under section 14 of this Act.

Online Registry

16. (1) The Central Government may establish an online registry where advance directives may be filed after execution, for purposes of record keeping.

(2) Upon a request by healthcare establishments, advance directives may be made available to them through such registry.

(3) The manner in which advance directives may be filed, renewed, altered or revoked with the registry and the fees that may be payable by persons filing such directives or by healthcare establishments to access these directives shall be such as may be prescribed.

## CHAPTER VI
## END OF LIFE CARE COMMITTEE

End of Life Care Committee

17. (1) All healthcare establishments with more than 75 beds or an intensive care unit shall constitute a committee to be known as the "end of life care" committee to resolve differences and conduct an audit of the withholding or withdrawing of life-sustaining treatment under this Act.

(2) An end of life care committee shall comprise:

(a) the Director or equivalent, or his nominee, of the healthcare establishment;

(b) the Chief Administrator or equivalent, or his nominee, of the healthcare establishment;

(c) a senior medical practitioner of the healthcare establishment, with relevant expertise in end of life care, to be nominated by the healthcare establishment;

(d) two senior medical practitioners, with relevant expertise in end of life care, to be nominated from outside the healthcare establishment, one of whom shall serve as the chairperson of the committee;

(e) an expert with relevant experience in both law and bioethics, to be nominated by the healthcare establishment;

(f) a person with experience in social work and familiar with issues relating to end of life care, to be nominated by the healthcare establishment.

District End of Life Care Committee

18. (1) The Chief Medical Officer of every district shall constitute a "District end of life care committee".

(2) The district end of life care committee shall comprise the following persons, to be nominated by the Chief Medical Officer:

(a) three senior medical practitioners from the district with relevant expertise in end of life care,

Provided that one of the doctors will also be appointed as Chairperson by the Chief Medical Officer

(b) an expert with relevant experience in both law and bioethics,

(c) a person with experience in social work or familiar with issues relating to the end of life care.

(3) In the event a healthcare establishment does not have an end of life care committee, it shall use the services of the district end of life care committee to perform the functions of end of life care committees under this Act.

(4) The procedure for meetings, allowances and terms and conditions of service of members of the district end of life care committee shall be such as may be prescribed.

(5) Without prejudice to sub-section (2), the Chief Medical Officer shall also maintain a register of eminent medical practitioners from the district, with relevant experience in and knowledge of end of life care.

Qualifications and Training of Members of End of Life Care Committees

19. (1) The senior medical practitioners nominated to end of life care committees may be anaesthetists, intensivists, neurologists, palliative care physicians or oncologists.

(2) All members of end of life care committees shall undergo such training in end of life care as may be prescribed.

## CHAPTER VII
## MISCELLANEOUS

Uniform definition of death

20. Notwithstanding anything contained in the provisions of any other law for the time being in force, death shall mean the irreversible cessation of the heart and circulatory function, or neurological function of the brain including the brain stem.

Medical practitioners not to be compelled to provide treatment not in the best interests of the patient

21. Nothing in this Act shall be construed as requiring a medical practitioner to provide a specific treatment or intervention on the request of a patient or near relative, where such practitioner is of the opinion that the treatment or interest would not be in the best interests of the patient.

Provided that the opinion of the medical practitioner shall be in accordance with recognised professional standards.

Use of services of counsellors and social workers

22. Healthcare establishments may use the services of counsellors and social workers to assist in the performance of their functions under this Act.

Effect of Advance Directives on Life Insurance

23. (1) The execution of advance directives shall not in any manner restrict, inhibit, impair or modify the procurement, issuance or continuation of a life insurance policy of the person executing the advance directive.

(2) The withdrawing and withholding of life-sustaining treatment in accordance with the provisions of this Act, shall not affect or invalidate the patient's life insurance policy and shall not affect payment of any death benefits and proceeds under the life insurance policy, and any terms and conditions in the life insurance policy to the contrary shall be void.

Civil Court to have no Jurisdiction

24. No civil court shall have jurisdiction to entertain any suit or proceeding in relation to the withholding and withdrawing of life-sustaining treatment in respect of which approval is to be sought from the High Court under the provisions of this Act and no injunction shall be granted by any court or authority in respect of any action taken or to be taken in pursuance of any power conferred by this Act.

Power of Central Government to make rules

25. (1) The Central Government may, by notification, make rules to carry out the provisions of this Act.

(2) In particular, and without prejudice to the generality of the foregoing power, such rules may provide for all or any of the following matters, namely:-

(a) the manner in which and the authorities to whom end of life care committees may recommend appropriate action against the healthcare practitioner and healthcare establishment under sub-section (5) of section 12;

(b) the qualifications of witnesses under sub-section (6) of section 14;

(c) the manner in which advance directives may be filed, renewed, altered or revoked with the registry and the fees that may be payable for filing or accessing such directives under sub-section (3) of section 16;

(d) the procedure for meeting, allowances and terms and conditions of service of members of the district end of life care committee under sub-section (4) of section 18;

(e) the training in issues relating to end of life care to be undergone by members of end of life care committees under sub-section (2) of section 19;

(f) any other matter which is required to be, or may be, prescribed, or in respect of which provision is to be or may be made by rules.

Laying of rules before Parliament

26. Every rule made under this Act shall be laid, as soon as may be after it is made, before each House of Parliament, while it is in session, for a total period of thirty days which may be comprised in one session or in two or more successive sessions, and if, before the expiry of the session immediately following the session or the successive sessions aforesaid, both Houses agree in making any modification in the rule or the Houses agree that the rule should not be made, the rule shall thereafter have effect only in such modified form or be of no effect, as the case may be; so, however, that any such modification or annulment shall be without prejudice to the validity of anything previously done under that rule.

Overriding effect of the Act.

27. Save as otherwise expressly provided under this Act, the provisions of this Act shall have an overriding effect to the extent that such provisions are inconsistent with any other law for the time being in force or any instrument having effect by virtue of any such law.

Power to remove difficulties

28. (1) If any difficulty arises in giving effect to the provisions of this Act, the Central Government may, by order, published in the Official Gazette, make such provisions not inconsistent with the provisions of this Act as may appear to be necessary or expedient for removing the difficulty.

(2) No such order shall be made under this section after the expiry of two years from the commencement of this Act.

(3) Every order made under this section shall be laid, as soon as may be after it is made, before each House of Parliament.

# III. Questions for Consultation

While preparing the draft Bill the Collaborators identified a number of complex questions which require wide stakeholder consultations to be resolved in a satisfactory manner. This part details these specific questions for consultation and also provides context for the positions that have currently been taken in the bill and highlights some of the considerations which need to be accounted for.

1. In Section 2(m) the model bill defines "near relative" as meaning any relative or friend of long-standing regularly attending or accompanying a patient to a healthcare establishment. The definition is intentionally not based on a hierarchy of relatives. Any hierarchy privileges one set of relatives over others, with the hierarchy corresponding to an assumed degree of closeness to the patient. Further, any such hierarchy may exclude non-heteronormative family structures or instances where patients may be estranged from their natal families. Therefore, the definition in the bill is based on the assumption that near relatives will be persons, whether related or not, who are the primary caregivers of the patient and attend to them regularly. Such a definition has the added advantage of freeing healthcare practitioners from the obligation to ascertain and contact certain specific relatives, allowing them instead to rely on primary caregivers who may be more easily available.

**Is this approach that focuses on caregiving instead of the degree of closeness in relationships by blood or marriage the most inclusive while also accounting for the concerns of healthcare practitioners?**

2. Section 3 of the model bill recognises the right of all patients to end of life care. It also casts an obligation on all healthcare establishments to implement internal processes to protect this right. Although these are not mentioned explicitly in the Bill, they would include processes like protocols for healthcare practitioners to ascertain the existence and validity of an advance medical directive, implementing shared decision-making, issuing do not resuscitate orders etc. Ultimately, however, the Bill confers a right to end of life care on all patients. Since end of life care has been defined as an approach which shifts the approach of care to symptom control, comfort, dignity, quality of life and quality of dying, this may be interpreted to mean that all patients have the right to access end of life care, including palliative care. Further, although the Bill does not specify whether this includes a right to access such care free of charge, the broad manner in which the provision is phrased might support such an interpretation. However, given the wide variation in the various kinds of healthcare establishments in the country, and in their capacity and the expertise of their professionals to provide such care, imposing a blanket obligation of this nature may not be feasible. At the same time the recognition of such a right may be a useful tool in the hands of patients and patient rights groups to ensure meaningful implementation of the right to receive high-quality care at the end of life and to have a dignified death.

**Is it meaningful to guarantee a broad right to end of life care in the Bill? Should the Bill explicitly mention specific components of the right to end of life care and corresponding obligations on healthcare establishments and practitioners? What remedies should the Bill provide for violations of this right?**

3. Section 5 of the model bill requires the healthcare establishments to inform patients in such establishments of their right to execute advance directives. However, the provision does not impose any further obligation to facilitate the execution of such advance directives. The execution of advance directives requires a notary and witnesses, of which at least the former may not easily be accessible in a hospital setting. On the one hand, imposing an obligation on healthcare establishments to assist patients with the supporting machinery of execution of advance directives may promote the use of these instruments. On the other hand, it could be argued that this may impose a significant administrative burden on the establishment, being out of the scope of its traditional functions.

**Should the Bill impose an obligation on healthcare establishments to facilitate the execution of advance directives? If yes, how should this be facilitated?**

4. Section 6 of the model bill makes provisions relating to the withdrawing and withholding of treatment applicable to patients who are terminally ill or in a persistent vegetative state or for whom the initiation, continuation, or escalation of life-sustaining treatment would be potentially inappropriate.

**Are these eligibility criteria comprehensive? If not, which other criteria should be included? Should the Bill specify the medical conditions in which the initiation, continuation or escalation of life-sustaining treatment would be potentially inappropriate?**

5. Section 12 of the model bill provides for the subsequent audit of all instances of withholding and withdrawing of life-sustaining treatment by the end of life care committee. The findings of this audit are required to be recorded in writing, a copy of which shall be reported to the Chief Medical Officer of the district. If the end of life care committee concludes that the withholding and withdrawing of life-sustaining treatment was not carried out in good faith or demonstrated disregard for recognised professional standards or violated any provisions of the law, then the committee can recommend appropriate action, including complaints under the National Medical Commission Act, 2019.

**Are the requirements of subsequent audit by the end of life care committee and reporting to the Chief Medical Officer a sufficient safeguard against the possible misuse of a legal framework that permits the withholding or withdrawal of life-sustaining treatment? Is there an adequate forum to report wrong doing by the healthcare establishment, in addition to individual healthcare practitioners? Should the Bill explicitly mention such a forum?**

6. Section 13 of the model bill provides for a specific provision regarding do not attempt resuscitation orders. It states such orders should be issued upon the satisfaction of certain specific conditions and only after consultations with the patient and near relatives, as the case may be. While advance medical directives are patient-initiated, DNR orders are doctor-initiated and are intended as a guide for healthcare practitioners who might be attending to patients in the event of a cardio-respiratory arrest. However, both directives and DNR orders ultimately deal with decisions about the withholding or withdrawal of life-sustaining treatment and it could be argued that section 13 of the Bill overlaps with sections 6-10 of the Bill, leaving room for uncertainty regarding which of these processes to follow-the issuing of DNR orders or the implementation of advance directives (where a valid directive exists) or the withholding or withdrawal of life-sustaining treatment from patients without a valid advance directive and lacking decision-making capacity. The Bill does not, at the moment, specify that issuing DNR orders may be a step precedent to those contemplated in sections 6-10. The Bill also distinguishes between DNR orders and advance directives, although there is room to argue that a DNR order is a specific form of advance directive, and therefore does not require an independent provision.

**Are there distinct differences between DNR orders and advance directives? If yes, how should the Bill capture this distinction? Should the issuing of DNR orders form part of one of the steps in the withholding or withdrawal of life-sustaining treatment in sections 6-10 of the Act?**

7. Section 14(6) provides that every advance directive should be executed in the presence of at least two witnesses who shall sign or affix their mark on the directive. Healthcare practitioners attending to the patient have been disqualified from becoming witnesses, however, other qualifications for witnesses have been left to delegated legislation.

**Should specific qualifications for witnesses be specified in the law? If yes, the what should such qualifications be?**

8. Section 16 of the model bill envisages the creation of an online registry by the Central Government for easy access to advance directives by healthcare establishments and to provide a technology-based solution to avoid doubts regarding the validity of advance directives.

**Is an online registry the best way to help healthcare practitioners and establishments ascertain the existence of valid advance medical directives? Are there any concerns regarding misuse of such registries? If yes, what other options can the Bill provide to facilitate access to advance directives by healthcare establishments?**

9. Section 17 stipulates the constitution of end of life care committee at healthcare establishments. The composition of such committees envisages a majority of external members with one of the external senior medical practitioners acting as the chairperson of the committee. This is intended to ensure independent functioning and effective accountability against any instances of professional misconduct.

**Are the end of life care committees at healthcare establishments committee sufficiently independent to conduct an impartial audit and to report instances of wrong doing to the relevant authorities? Is there any alternative composition that could also be explored?**

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