End of Life Care in India: A Model Legal Framework 2.0

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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 November 2019, the Vidhi Centre for Legal Policy (Vidhi) and the End of Life Care in India Taskforce (ELICIT) (collectively referred to as 'Collaborators') had released a draft model law on end of life care (draft bill) which sought to create a framework to facilitate the withholding and withdrawing of life-sustaining treatment and to give legal validity to advance directives in pursuance of patients' fundamental right to die with dignity.[1] The draft bill adopted a rights-based perspective, while being alive to the realities of health care delivery in India.

In order to seek feedback on the provisions of the draft bill, the Collaborators organised two round-table consultations in Delhi and Mumbai with a number of stakeholders including doctors specialising in critical care and palliative care, patients' rights groups, bioethicists, medical administrators from both public and private healthcare establishments, lawyers, academics and civil society organisations. Since the release of the draft bill, there have additionally been many significant legal and policy developments around end of life care, including initiatives by the Indian Council of Medical Research (ICMR) and the All India Institute of Medical Sciences, New Delhi (AIIMS) which have contributed to thinking around end of life care in India. Finally, at the time of writing, India is in the throes of the Covid-19 pandemic, which has threatened to overwhelm healthcare facilities, especially critical care services, thereby bringing end of life care decision-making into grim focus. Sub-parts A, B and C of this chapter explore these developments in greater detail.

The Collaborators have drafted version 2.0 of the draft model law for end of life care in India in the backdrop of the situation created by the pandemic, to account for the legal and policy developments mentioned above, and to incorporate the feedback received at the consultations on the first version of the law.

A. Consultations

The first consultation was held in Delhi on 17th December 2019 at the India Habitat Centre, where stakeholders provided feedback and discussed the provisions of the draft bill in detail.[2] Some of the key issues raised at the event revolved around the definition of 'near relative' in the context of the power dynamics between those members of patients' families who take financial decisions and those who often end up performing caregiving roles,[3] the need to provide support in decision making to vulnerable communities, the precise circumstances that ought to trigger discussions on end of life care and the role of hospital-based end of life care committees and their composition. The attendees also stressed the importance of a strong rights-based approach which could address access to end of life care including palliative care as well as existing unethical practices such as 'discharge against medical advice' in healthcare establishments.

The second consultation was held in Mumbai on 11th January 2020 at the Bhatia Hospital.[4] Apart from giving their feedback on some of the issues discussed at the Delhi event, attendees at this consultation also provided detailed feedback on the process of end of life care decision making, the usefulness of separate provisions on Do Not Attempt Resuscitation orders, the manner of execution of advance directives, and the scope of applicability of a legal framework on end of life care. During the two consultations, there was emphasis on the need for drafting a law which was accessible to, worked for and was empathetic towards the key stakeholders i.e. patients and their caregivers, persons wishing to execute advance planning instruments, healthcare practitioners and healthcare establishments. Feedback from the consultations with stakeholders has re-shaped the model law in significant ways.

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[1] 'End of Life Care in India: A Model Legal Framework', Vidhi Centre for Legal Policy (2019) <https://vidhilegalpolicy.in/2019/11/15/end-of-life-care-in-india-a-model-legal-framework/> accessed 9 July 2020.
[2] Detailed minutes of the consultation are available on file with the Collaborators.
[3] The current draft of the bill now uses the term 'next friend' instead of 'near relative'.
[4] Detailed minutes of the consultation are available on file with the Collaborators.

B. Legal and Policy Developments

In May 2020, the ICMR released its 'Consensus Guidelines on Do Not Attempt Resuscitation'[5] which creates an algorithm-based format to guide medical practitioners in taking Do Not Attempt Resuscitation Decisions (DNAR) when cardiopulmonary resuscitation is likely to be futile in patients. The guidelines emphasise that medical practitioners who are well-versed with the condition of their patient should take such decisions, after providing the patient or their surrogates with the relevant information. They also clarify that a DNAR does not preclude treatment of the underlying conditions or further medical care. These guidelines are significant because they make end of life decision-making part of the standard of care for critically ill patients, making Indian doctors examine whether continuing life-sustaining treatment in specific cases may result in more harm than benefit.[6] Thus, they underscore the concept of the inherent dignity of patients which was recognised by the Indian Supreme Court in *Common Cause v. Union of India* (*Common Cause).*[7]

Even prior to these guidelines, in March, 2020, AIIMS, New Delhi, which is India's leading medical college and public hospital, released its guidelines on end of life care.[8] These guidelines attempt to make end of life decision making part of the regular protocol in a large public healthcare establishment. They implement concepts such as the initiation of an end of life care discussion upon recognition of futility of further life-sustaining treatment, involving the patient or their surrogate in the decision-making process, developing a hierarchy of surrogate decision makers which moves beyond heteronormative conceptions of family, and also setting up an institutional end of life care committee for resolving potential conflicts.

Both the ICMR and AIIMS guidelines are significant and welcome shifts from the Supreme Court's guidelines in *Common Cause* on the withholding and withdrawing of life-sustaining treatment from terminally ill patients. In addition to these developments, other hospitals across the country, such as the Manipal Group of Hospitals and the Bai Jerbai Wadia Hospital for Children are also initiating internal discussions on end of life decision-making, with a view to implementing workable protocols. The Manipal Group of Hospitals, to the best of our knowledge, is the first healthcare establishment to develop and implement an internal end of life care policy, through its BLUE MAPLE document.[9] In August 2019, an End of Life Care Task Force set up the Federation of Indian Chambers of Commerce and Industry, in collaboration with ELICIT, also released information guides on end of life decision-making, both for patients and their family members, as well as for doctors and hospital administrators.[10]

In fact, the practical difficulties in implementing *Common Cause's* guidelines and the legal uncertainty they created were a key trigger for the Collaborators to argue for a comprehensive law on end of life care.[11] In the second half of 2019, the Indian Society for Critical Care Medicine, one of the three professional medical associations that make up ELICIT, with Vidhi's assistance, also filed an application for clarification before the Supreme Court asking for a modification of the 2018 *Common Cause* guidelines so that they could be

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[5] Roli Mathur et al, 'ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation' Indian J Med Res 2020;151:303-10.
[6] Dhvani Mehta, 'ICMR Guidelines on "Do Not Attempt Resuscitation" Move the Needle on End of Life Care' Vidhi Centre for Legal Policy Blog (22 May 2020) <https://vidhilegalpolicy.in/2020/05/22/icmr-guidelines-on-do-not-attempt-resuscitation-move-the-needle-on-end-of-life-care/> accessed 9 July 2020.
[7] 2018 5 SCC 1.
[8] Guidelines for End of Life Care, AIIMS, New Delhi, <https://www.aiims.edu/en/notices/notices.html?id=10914> accessed 7 October 2020.
[9] Before Life Ends, Understand and Evaluate the Choice of Medical Treatment Offered Methodised Action Plan for Limitation of Life-Sustaining Treatment and End of Life, Palliative Medicine and Supportive Care Department, Kasturba Hospital, Manipal (2010), < http://vishnudutas.com/wp-content/uploads/2020/03/Blue-Maple-1-End-of-Life-Care-Policy-Document-of-Manipal-Hospitals-1.pdf> accessed 7 October 2020.
[10] Improving End-of-Life Care and Decision-Making, *Information guide to facilitate execution of End-of-Life Decisions* (2019), < http://www.ficci.in/study-page.asp?spid=23114&sectorid=18> accessed 7 October 2020.
[11] For a detailed critique of the guidelines in Common Cause v. Union India, see 'End of Life Care in India: A Model Legal Framework', Vidhi Centre for Legal Policy (2019) <https://vidhilegalpolicy.in/2019/11/15/end-of-life-care-in-india-a-model-legal-framework/> accessed 9 July 2020.

meaningfully implemented.[12] In its order dated 22 January 2020, the Supreme Court directed the Union of India to convene a meeting of stakeholders to reach consensus regarding modifications to its guidelines.[13] However, such a stakeholder consultation is yet to be convened. As we await further developments in Court, the steps taken by ICMR, AIIMS and other institutions are important since they push the envelope on end of life care in India and further open up possibilities for a comprehensive law which version 2.0 of this model bill seeks to achieve.

C. Covid-19 Pandemic

On 11 March 2020, the World Health Organisation ("**WHO**") declared Covid-19 a pandemic. At the time of writing, as India emerges from months of lockdown, it has the second highest number of cases globally, although it also has one of the lowest case fatality rates. Evidence shows that elderly persons and patients with comorbidities are far more vulnerable to the virus and have lower chances of recovery once infected. A significant number of such patients are also likely to require life-sustaining treatment, particularly in the form of ventilation. In other countries, professional medical associations concerned about overwhelming numbers of critically-ill patients in intensive care units, have issued guidelines for the ethical allocation of scarce life-sustaining resources.[14] These guidelines reflect the different ways in which different professional bodies interpret and apply the ethical guidance issued by the WHO for 'priority setting and equitable access to therapeutic and prophylactic measures.'[15] India has not reported a scarcity of ventilators or other life-sustaining treatment (although issues of access to quality care for socio-economically disadvantaged patients persist); consequently professional medical guidelines for critical care for COVID-19 patients are confined to clinical management without any explicit attempt to answer difficult ethical questions about the allocation of scarce life-sustaining resources.[16]

Although such ethical questions may continue to remain hypothetical for the moment, at least in India, decisions about withholding or withdrawing of life-sustaining treatment from some Covid-19 patients will continue to have to be made routinely in critical care settings. This is simply because such treatment is likely to be non-beneficial for certain patients because of a variety of factors such as age and co-morbidities. However, legal uncertainty around the withholding and withdrawing of life-sustaining treatment due to the guidelines in *Common Cause* make it difficult to facilitate end of life decision-making in healthcare establishments. This confusion forces medical practitioners to continue providing such treatment even when it is not in the best interests of the patient, thereby increasing financial costs without any hope of recovery and ultimately increasing the trauma and anguish faced by the patient's caregivers. During Covid-19, when caregivers may not even be physically present at hospitals (given the highly infectious nature of the disease), this anguish is only likely to increase.

It is in light of this that a facilitative framework on end of life decision-making becomes all the more important to ensure that there is certainty around end of life care decisions. Moreover, the decision to withhold or withdraw life-sustaining treatment should not result in the absence of care or compassion towards such patients. In such instances, the focus of treatment has to shift from 'cure' to 'care' ensuring the dignity of the patient.[17] This course of action is not only ethically sound but also a legal imperative considering the Supreme

[12] Miscellaneous Application No. 1699 of 2019 in Writ Petition (Civil) No. 215 of 2005.
[13] Order dated 22 January 2020 in Miscellaneous Application No. 1699 of 2019 in Write Petition (Civil) No. 215/2005 in the Supreme Court of India.
[14] Susanne Jöbges, Rasita Vinay, Valerie A Luyckx and Nikola Biller-Andorno, 'Recommendations on COVID-19 triage: international comparison and ethical analysis' (2020) 34 Bioethics 948-959. This article reviews and compares triage recommendations issued by professional societies in Australia/New Zealand, Belgium, Canada, Germany, Great Britain, Italy, Pakistan, South Africa, Switzerland and the United States.
[15] World Health Organisation, 'Ethical considerations in developing a public health response to pandemic influenza' (2007).
[16] Yatin Mehta et al, 'Critical Care for COVID-19 Affected Patients: Position Statement of the Indian Society of Critical Care Medicine' (2020) 10 Indian Journal of Critical Care Medicine 1-20.
[17] Akshat Agarwal, 'Covid-19 and the Need for a Framework to Support End of Life Decision-Making' Vidhi Centre for Legal Policy Blog (24 March 2020) < https://vidhilegalpolicy.in/2020/03/24/covid-19-and-the-need-for-a-framework-to-support-end-of-life-decision-making/> accessed 9 July 2020.

Court's recognition of the right to die with dignity as a fundamental right. A sound legal framework on end of life care is also required to ensure that healthcare establishments continue to provide supportive and palliative care.

The Covid-19 pandemic has brought into sharp relief the urgency of a comprehensive and facilitative legal framework on end of life decision-making. The Collaborators hope that this this model law will fill this gap.

II. Model End of Life Care Bill, 2020

Bill No. ___ of ___

The End of Life Care Bill, 2020

A

BILL

to create a facilitative legal framework for end of life care by laying down minimum standards and procedures to guide healthcare practitioners and healthcare establishments regarding the withholding and withdrawal of life-sustaining treatment, and by giving legal recognition to advance planning instruments.

The right to die with dignity, which was recognised as an aspect of the right to life under Article 21 of the Indian Constitution 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 medical treatment, including life-sustaining treatment.

This right also extends to the creation of advance planning instruments that give effect to the patient's wishes regarding withholding and withdrawing of life-sustaining treatment when they lack healthcare decision making capacity. For patients who lack this capacity and who have not made advance planning instruments, 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.

Respect for the right to health, which is a also a part of the fundamental right to life, also requires that patients have adequate and affordable access to end of life care services.

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

Enacted by Parliament in the Seventy-First year of the Republic of India as follows:

Explanatory Note

This is intended to be a comprehensive law on end of life care. There has always been legal uncertainty in India regarding the withholding and withdrawal of life-sustaining treatment. While the right to refuse such treatment was definitively recognised by the Supreme Court of India in 2018 in *Common Cause*, this uncertainty remains because of the complicated guidelines laid down by the Court before life-sustaining treatment may be withheld or withdrawn. Medical professionals continue to remain hesitant to withhold or withdraw life-sustaining treatment even when such treatment is not beneficial to patients or against their wishes.

However, the Supreme Court guidelines are to remain in force only until Parliament passes a law to replace them. This bill is intended to be that law. It has the following objectives:

- to create procedures for the withholding or withdrawal of life-sustaining treatment that conform to the most up-to-date medical professional guidelines and ethical standards
- to ensure that the rights of patients to refuse life-sustaining medical treatment as well as to receive palliative and supportive care are respected by healthcare practitioners and establishments
- to codify the legal recognition of advance planning instruments that allow patients' prior wishes regarding life-sustaining treatment to be respected even when they are no longer able to exercise decision-making capacity
- to create certainty regarding persons who are able to take healthcare decisions on behalf of those who are no longer able to exercise decision-making capacity
- to ensure that the right to refuse life-sustaining medical treatment is exercised only after making an informed decision, and not because of lack of access to medical care
- to impose an obligation on the appropriate government to provide access to palliative and supportive care

CHAPTER I
PRELIMINARY

Short title, extent and commencement

1. (1) This is the End of Life Care Act, 2020.

(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, 2020;

(b) "adult" mean a person who is 18 years of age or above;

(c) "advance planning instruments" mean statements comprising advance directives or medical powers of attorney made in accordance with the provisions of this Act;

Explanatory Note to Clause 2(c)

Two types of instruments are included in this definition. The first are advance directives, where a person may simply have expressed their wishes regarding life-sustaining treatment. The second are medical powers of attorney through which a person delegates decision-making regarding life-sustaining treatment to another person named in the instrument. A reference in this bill to advance planning instruments will refer to either one of these. As long as the effect of an instrument is either to express such wishes or to delegate end-of-life decision-making, and as long as they comply with Chapter IV of this bill, they will be treated as advance planning instruments.

(d) "advance directive" means a statement made by a person with healthcare decision-making capacity regarding refusal of life-sustaining treatment, including their wishes regarding the withholding or withdrawing of life-sustaining treatment;

Explanatory Note to Clause 2(d)

The advance directive must be made at a time at which the person executing the directive possesses healthcare decision-making capacity. Through this instrument, a person might express their wishes regarding the withholding or withdrawing of life-sustaining treatment in different ways. For instance, a person might make a blanket refusal to be ventilated, irrespective of the nature of their illness. Someone might also state that they do not wish to be administered antibiotics if they are suffering from Alzheimer's disease and happen to fall ill with a pulmonary infection. Yet another person might make an advance directive refusing cardio-pulmonary resuscitation in the event of a cardiac arrest above the age of 75. A format for such advance directives is available at <https://vidhilegalpolicy.in/research/end-of-life-care-in-india-a-model-legal-framework/>.

Please note that an advance directive cannot demand that the patient definitively be provided life-sustaining treatment in every circumstance.

(e) "appropriate government" means, —

(i) in relation to any healthcare establishment and health-related program or policy wholly or substantially financed by the Central Government or the Administration of a Union Territory having no legislature, the Central Government;

(ii) in relation to any healthcare establishment and health-related program or policy wholly or substantially financed by:

(A) the State Government, the State Government; or

(B) the Government of a Union Territory having a legislature, the Government of the Union Territory.

(f) "best interests" means a course of action for the patient in accordance with recognised professional standards, such that the benefits to the patient are maximised and the risks of harm are minimised;

Explanatory Note to Clause 2(f)

The meaning of the term 'best interests' varies widely in writings on philosophy and ethics. Naturally, it is impossible to capture all of these varied meanings in the definitions section of a bill. The term has been used in the bill as the standard that ought to guide treating healthcare practitioners through their shared decision-making process on end-of-life decision-making for patients who do not have healthcare decision-making capacity and who have not executed an advance planning instrument. Together with the next friend or surrogate of such a patient, healthcare practitioners must rely on the most up to date treatment guidelines and ethical practices to determine which course of treatment will ensure that, on balance, benefits to the patient are maximised, and risks of harm are minimised. Next friends or surrogates will contribute to this decision-making process by making the values and preferences of the patient known to the treating healthcare practitioners. While this definition of 'best interests', read with the shared decision-making process in Clause 17 of this bill means that different healthcare practitioners might reach different conclusions regarding the ultimate course of action for a particular patient, it will still be possible to assess some portion of this conclusion objectively against what is commonly accepted within the medical professional field as the appropriate course of treatment.

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

(h) "end of life care" means the provision of care to a patient suffering terminal illness that shifts the focus of care to symptom control, comfort, dignity, palliative care, 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;

Explanatory Note to Clause 2(h)

This definition emphasises that care does not stop after the withholding or withdrawal of life-sustaining treatment and includes care that is not restricted to a medical intervention.

(i) "end of life care committee" means a committee constituted under section 30 or 31 of this Act;

(j) "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, whether or not such care, service, procedure or treatment is curative;

Explanatory Note to Clause 2(j)

End of life care is to be recognised as an integral part of healthcare. This is the intention of the qualifier to this definition-'whether or not such care, service….is *curative.*'

(k) "healthcare establishment" means a hospital, healthcare centre, 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; or

(ii) a trust, whether public or private; or

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

(iv) a local authority.

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

(m) "life sustaining treatment" means any medical treatment that artificially supports or replaces a body function essential to the life of the person and includes but is not limited to cardiopulmonary resuscitation, endotracheal intubation, extra-corporeal membrane oxygenation, mechanical ventilation, vasopressor therapy, left ventricular assist devices, parenteral or artificial enteral nutrition, dialysis, blood products, antibiotics, intravenous fluids;

(n) "medical orders for life sustaining treatment" means a document recording the wishes and preferences of a patient, with healthcare decision-making capacity, regarding refusal of life sustaining treatment including the withholding and withdrawing of life-sustaining treatment;

Explanatory Note to Clause 2(n)

Medical orders for life-sustaining treatment are different from advance directives. Medical orders for life-sustaining treatment are made when the treating team ascertains the wishes of the patient regarding the withholding and withdrawing of life-sustaining treatment and records them accordingly. Medical orders for life-sustaining treatment are necessarily recorded in a formal healthcare setting. Advance directives, on the other hand, may be executed at any time and place, provided the procedure that is followed is in accordance with the provisions of this bill. They may be executed by a person at any time after they attain the age of 18 years, whether or not they are ill.

However, the effect of advance directives and medical orders for life-sustaining treatment is the same—both express the wishes of the patient regarding life-sustaining treatment and must be respected. Medical orders have the advantage of recording the most recent expression of the patient's wishes in response to an actual medical condition, rather than a hypothetical one, as is the case with advance directives.

(o) "medical power of attorney" means a statement by a person with healthcare decision-making capacity appointing a surrogate to take decisions regarding the withholding and withdrawing of life-sustaining treatment on behalf of the person executing the medical power of attorney when such person loses healthcare decision-making capacity;

Explanatory Note to Clause 2(o)

A medical power of attorney can vary depending upon the extent of guidance that it provides to the surrogate. It may contain no instructions at all for a surrogate. i.e. it may delegate all authority to take decisions regarding the withholding or withdrawal of life-sustaining treatment to the surrogate. Or it may instruct the surrogate to keep certain factors in mind, but to reach their own conclusion regarding the withholding or withdrawing of life-sustaining treatment. A medical power of attorney may also require the surrogate to take a decision as if they were the person executing the instrument. To the extent that a medical power of attorney provides some degree of guidance to the surrogate, it also contains elements of an advance directive.

(p) "mental health review board" means the mental health review board established under section 73 of the Mental Healthcare Act 2017 (Act 10 of 2017);

(q) "next friend", in relation to a patient, means a person in the following order of preference:

(i) Spouse or *de facto* spouse or a partner with whom the patient has a relationship in the nature of marriage or a

friend of long standing who regularly attends to the patient in the healthcare establishment;

(ii) Adult children;

(iii) Parents;

(iv) Siblings;

(v) Any other lineal ascendant or descendant of the patient who is present at the healthcare establishment.

Explanatory Note to Clause 2(q)

A treating team and the administration of a healthcare establishment frequently need to be in contact with someone other than the patient, but known to, or attending to them. If the patient dies, there must be someone to take possession of their body and to receive their medical records. If the patient loses healthcare decision-making capacity, there must be someone whom the treating team can consult in order to arrive a decision about the best course of action.

However, there is no definitive legal answer that can point the treating team or the administration of the healthcare establishment to the person who should be provided information or consulted in the above scenarios. Most healthcare practitioners usually communicate with such family members as are available. However, this practice privileges relations of kinship over those of caregiving and does not take into account the fact that there may be patients who belong to non-heteronormative families or who have strained relationships with their family members. Healthcare practitioners are also unclear about the precedence that ought to be given to different family members. Such uncertainty can impede end-of-life decision-making.

Therefore, the term 'next friend' has been defined in this bill to guide healthcare practitioners and administrations regarding the persons they should approach in order to provide information and to consult with in the context of end of life care. The definition has been expressed in the form of a hierarchy i.e. precedence is given to the spouse or de facto partner, or if neither of these exist, then to someone who is the primary caregiver of the patient, in so far as they regularly attend to the patient at the healthcare establishment. If no person of this description is available, then the treating team or administration may move down in the list in the order of preference listed in the definition.

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

(s) "palliative care" means a holistic approach to treatment that improves the quality of life of patients and their

families at the end of the patients' life, through the prevention of pain and the relief of suffering;

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

(u) "potentially non-beneficial" in relation to healthcare interventions means treatment that carries a greater possibility of harm than benefit;

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

(w) "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;

Explanatory Note to Clause 2(w)

This essentially refers to 'standard treatment guidelines', which are also guidelines issued by health authorities or professional medical associations setting out the best, most up-to-date practices associated with the diagnosis, treatment and management of medical conditions. In effect, 'recognised professional standards' would constitute a 'responsible body of medical opinion', which is the standard used by courts in India to make a determination of medical negligence. i.e. a course of action will not be negligent if a responsible body of medical opinion would also have acted similarly.

There is no single authoritative body in India that is *exclusively* authorised to issue such standards or guidelines. Therefore, the definition makes a reference to any well-established body of medical professionals, such as the Indian Society of Critical Care Medicine as well as any other body that is legally authorised to issue such guidelines, such as the National Medical Commission.

(x) "registered medical practitioner" means a person registered under the State Register or National Register under section 2(m) and 2(v), respectively, of the National Medical Commission Act, 2019;

(y) "shared decision-making" means a dynamic process where decisions regarding the healthcare of a patient are jointly made by the healthcare practitioners attending to the patient and the surrogate or the patient's next friend, as the case may be, through a process of consultation;

Explanatory Note to Clause 2(y)

The bill, in Chapter III, sets out the instances in which shared decision-making must be undertaken. Shared decision-making is not required where a patient retains their decision-making capacity, nor is it usually relied upon if there is a valid advance directive or medical power of attorney.

(z) "surrogate" means a person who has been authorised, through a medical power of attorney, to take decisions under the provisions of this Act on behalf of the person executing the medical power of attorney when such person loses healthcare decision-making capacity;

Explanatory Note to Clause 2(z)

A surrogate is not necessarily the same as the next friend. A surrogate is someone who was specifically named in advance by the patient, and may or may not be the same as the various categories of persons listed in the definition of 'next friend'. Where a surrogate has been validly named in a medical power of attorney, such person shall have precedence over a next friend in making end of life decisions on behalf of the patient. This is explained in greater in detail in Chapter III of this bill.

(aa) "withdrawing life sustaining treatment" means the cessation or removal of life sustaining treatment presently being provided to a patient and the term 'withdraw life sustaining treatment' shall be construed accordingly;

(bb) "withholding life sustaining treatment" means not initiating or escalating life-sustaining treatment and the term 'withhold life sustaining treatment' shall be construed accordingly.

CHAPTER II
RIGHTS OF PATIENTS TO END OF LIFE CARE

Right to access end of life care

3. (1) All patients shall have the right to access end of life care at healthcare establishments.

(2) The right to access end of life care shall mean the right to access end of life care that is:

(a) of good quality, in accordance with recognised professional standards, and provided in a manner consistent with the autonomy and dignity of the patient;

(b) affordable;

(c) sufficiently available;

(d) geographically accessible; and

(e) culturally appropriate.

Provided that the rate at which services related to end of life care shall be provided shall be such as may be prescribed.

(3) All patients who are below the poverty line, whether or not they are in possession of a below poverty line card, or who are destitute or homeless shall be entitled to end of life care free of charge at healthcare establishments run or funded by the appropriate government.

Provided that till such time end of life care is made adequately available at healthcare establishments run or funded by the appropriate government, the costs of provision of end of life care incurred by other healthcare establishments in respect of patients referred to in sub-section (3) shall be reimbursed by the appropriate government in such manner as may be prescribed.

Explanatory Note to Clause 3

This clause guarantees a positive right to persons to access end of life care which includes palliative care. This provision, which imposes an obligation on both public and private healthcare establishments, ensures that no one who is receiving treatment at the establishment can be denied end of life care even if a decision to withhold or withdraw life-sustaining treatment has been taken. Such care is to be provided free of charge at public healthcare establishments, and at prescribed rates at private establishments. This right also has to be understood in the context of the general obligations of the State to improve access to end of life care including palliative care in clause 5.

This should also allay concerns that the legalisation of withholding or withdrawal of life-sustaining treatment will exclude persons, especially those from economically weaker sections, from receiving appropriate end of life care. These concerns should also be allayed by other provisions in the bill that require end of life decision-making, including withholding or withdrawal of life-sustaining treatment to meet professional standards. Any lapse in this regard will be open to legal challenge.

It also imposes a progressive obligation on the appropriate government to ensure that adequate provision for end of life care is made at public healthcare establishments. Till such time as the appropriate government is not able to provide such care at public healthcare establishments, it must reimburse costs incurred by private healthcare establishments in providing free end of life care to those who are eligible.

Obligation of Healthcare Establishments to make provisions

4. (1) All healthcare establishments shall implement such internal processes and provide facilities and provide services of such quality as are necessary under this Act and rules framed thereunder to protect the right to access end of life care under section 3.

for end of life care services

(2) Without prejudice to the generality of the obligation under sub-section (1), healthcare establishments shall —

(a) provide end of life care, including care after a decision regarding withholding or withdrawing life-sustaining treatment has been made;

(b) establish protocols and internal algorithms to facilitate the withholding and withdrawing of life-sustaining treatment in accordance with the provisions of this Act;

(c) ensure the availability of adequately trained healthcare practitioners to provide end of life care to patients in accordance with the provisions of this Act;

(d) provide services aimed at supporting the next friend, caregivers and other members of the patient's family, including ensuring the availability of support-persons, bereavement counsellors and social workers.

Provided that the appropriate government may prescribe that these obligations may be met in different ways by different kinds of healthcare establishments.

(3) Healthcare establishments shall ensure that all end of life care, including the withholding and withdrawing of life sustaining treatment, is provided in accordance with recognised professional standards.

Explanatory Note to Clause 4

This clause sets out the specific steps that healthcare establishments, both public and private, must take in order to give effect to the right guaranteed in Clause 3. This requires the positive provision of end of life care in a manner that is consistent with recognised professional standards. It also requires trained professionals to administer these services. This includes palliative care physicians, nurses, as well as counsellors and social workers. The bill does not contain any prescriptions regarding the number of trained professionals that each healthcare establishment must maintain—the appropriate government may frame rules to prescribe different requirements for different healthcare establishments. Finally, the healthcare establishment must set up internal standard operating procedures that allow it to take decisions regarding the withholding or withdrawal of life-sustaining treatment in an ethically sound manner in accordance with recognised professional standards and the provisions of this bill. National professional associations such as the Indian Society of Critical Care Medicine and the Indian Association of Palliative Care have already issued professional guidelines on end of life care in India. Further, hospitals like the Manipal Group and the All India Institute of Medical Sciences, New Delhi, have also put in place such standard operating procedures.

Chapter III of the bill now puts in place a general framework for these procedures.

Obligation of appropriate government to make provision of end of life care services

5. (1) The appropriate government shall ensure the availability of adequate end of life care, having regard to the needs of its population and the burden of disease.

(2) Without prejudice to the generality of the obligation under sub-section (1), the appropriate government shall —

(a) integrate end of life care including palliative care services in general healthcare services at all level of healthcare including primary, secondary and tertiary care and in all healthcare programs run by the appropriate government, where relevant;

(b) formulate and implement policies in states in accordance with recognized professional standards and international and national best practices to give effect to their obligation to provide adequate end of life care including palliative care at the district level;

(c) formulate and implement training policies for healthcare practitioners.

Prohibition of discrimination

6. There shall be no discrimination in the provision of end of life care services to any patient on any basis including on grounds of gender identity, sex, sexual orientation, religion, cultural or ethnic identity, caste, social or political beliefs, class or disability.

Explanatory Note to Clause 6

This is an obligation that applies both to public and private healthcare establishments. It ensures that no person can be denied treatment at a healthcare establishment on any of these prohibited grounds, nor can there be a difference in the quality of end of life care provided to patients on the basis of any of these grounds. This provision specifically restates the constitutional vision of equality and non-discrimination in accordance with Articles 14 and 15 of the Constitution in the context of end of life care.

Right to dignified transfer from healthcare establishments

7. (1) All patients shall have the right to a dignified transfer between healthcare establishments and shall be entitled to the use of ambulance services to be transported to another healthcare establishment or any other place of their choosing, upon their discharge from the healthcare establishment, irrespective of whether a decision regarding withholding or withdrawing of life sustaining treatment has been made in accordance with the provisions of this Act.

(2) All healthcare establishments have the obligation to ensure that they provide a dignified transfer at such reasonable cost as may be prescribed.

Explanation: For the purposes of this section, a "dignified transfer" implies discharge and subsequent transfer of the patient in a manner that is in consonance with the patient's dignity and autonomy while ensuring continued care, including end of life care.

Explanatory Note to Clause 7

This provision has specifically been included because of the prevailing practice of 'leave against medical advice' or 'discharge against medical advice' adopted by healthcare establishments. Economically vulnerable sections of society often find it difficult to bear the prohibitive cost of critical care at healthcare establishments and are therefore unable to continue life-sustaining treatment. In such instances, in order to exempt themselves from any legal liability, healthcare establishments discharge such patients 'against medical advice', leaving them to fend for themselves once life-sustaining treatment has been withdrawn. By foregoing life-sustaining treatment, such patients are also compelled to forego appropriate end of life care. This clause is intended to prohibit healthcare establishments from washing their hands off patients who have decided not to continue with life-sustaining treatment at such establishments for economic reasons or otherwise. Even when the decision regarding such withholding or withdrawal of life-sustaining treatment is not made in accordance with the procedure set out in this bill, the healthcare establishment must ensure that all continuing care is provided to the patient, whether this is to ensure that they are transferred to another healthcare establishment or taken home.

Obligation to release the body of the deceased patient

8. All healthcare establishments shall be obliged to release the body of the patient upon their death to the next friend or the heirs of the deceased patient, as the case may be, as expeditiously as possible, in accordance with any laws for the time being in force.

Provided that the non-payment of the costs of treatment at the healthcare establishment or any dispute regarding the same shall not be a valid reason to deny the release of the body of the deceased patient.

Explanatory Note to Clause 8

This is already recognised by the Charter of Patient Rights adopted by the Ministry of Health and Family Welfare. This clause gives this right statutory backing and legal enforceability.

Obligation to ensure access to opioid analgesics and other pain relief substances

9. The appropriate government shall be under an obligation to ensure availability of and access to opioids, analgesics and other pain relief substances to ensure access to end of life care in accordance with recognized professional standards.

Explanatory Note to Clause 9

Access to pain relief in India has often been hindered because of stringent regulations governing opioids, analgesics and other pain relief substances. This provision imposes an obligation on the appropriate government to ensure availability and access. Governments may have to revise their procurement practices or include such substances on essential medicines lists in order to fulfil this obligation.

Right to information and access to patient records

10. (1) All patients, their next friend and surrogate, if any, as the case may be, shall have the right to receive complete information regarding the patient's medical condition from the healthcare establishment in a language and form in which they can understand.

(2) On the death of the patient, the next friend and the heirs of the deceased patient shall have the right to access and procure a copy of the patient records upon verification of identity in such manner as may be prescribed.

Explanatory Note to Clause 10

This is another statutory recognition of the right in the Patient Rights Charter to receive access to patient records and other medical information. This provision imposes an obligation on both healthcare practitioners and the administration of healthcare establishments. Healthcare practitioners must impart information in a manner that is easily comprehensible and that allows persons to take healthcare decisions. This clause sets out a more expanded version of this obligation.

Ordinarily, it is the patient who has the primary right to access their information and records. However, even when the patient retains healthcare decision-making capacity, they may consent to their information also being shared with their next friend or surrogate. Of course, when the patient no longer retains healthcare decision-making capacity, the right to such information and records, by virtue of this clause, will automatically extend to their next friend or surrogate.

The administration of the healthcare establishment must also ensure that all patient records are appropriately transferred on the death of a patient. Records must be provided both to the next friend as well as the heirs of the patient.

Right to exercise healthcare decision-making capacity

11. (1) All patients who are adults shall have a right to exercise healthcare decision-making capacity and shall be presumed to possess healthcare decision making capacity until a contrary conclusion is arrived at by a registered medical practitioner in accordance with recognised professional standards and the provisions of this Act.

(2) Healthcare decision-making capacity, in the context of a healthcare intervention, is the capacity of a person to make and communicate, whether verbally or otherwise, an informed decision regarding such intervention.

Explanation: For the purposes of this section, an informed decision, in the context of a healthcare intervention, means a decision arrived at by a patient after fully understanding the nature of the intervention and its benefits and risks of harm as well as the benefits and risks of harm of not carrying out the intervention and of alternative interventions;

(3) Healthcare establishments shall be under an obligation to provide all manner of support to patients to enable them to realise their right to exercise healthcare decision-making capacity under sub-section (1).

Explanation: For the purpose of this section, "support" means a range of arrangements, whether formal or informal, which help patients in realizing their rights, will and preferences, including the provision of a trusted support person or next friend who assists the patient in exercising their capacity and aids in communication.

(4) In pursuance of the right under sub-section (1), all patients possessing healthcare decision-making capacity in the context of a healthcare intervention, shall have the right to refuse such intervention including life-sustaining treatment, as the case may be, and upon such refusal, the treatment shall be withheld or withdrawn in accordance with the provisions of this Act.

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

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

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

(6) The provisions of section 17 of this Act shall not apply to the withholding or withdrawing of life-sustaining treatment from patients possessing healthcare decision-making capacity.

Explanatory Note to Clause 11

This provision is at the heart of the right to autonomy that the bill is intended to protect. In the first instance, it ensures that all patients are given the necessary tools in order to be able to take a decision regarding a healthcare intervention. There is a presumption of healthcare decision-making capacity unless proved otherwise. The mere fact that a patient might need assistance in exercising healthcare decision-making capacity should not mean that they lack such capacity. The inability to express one's will or preferences verbally should also not be assumed to be on account of a lack of healthcare decision-making capacity. There is a positive obligation on healthcare practitioners as well as establishments to enable patients to exercise such capacity.

Once such capacity is recognised, decisions taken by a patient in exercise of such capacity are to be respected, even if such decision will eventually result in the death of the patient or is one that the healthcare practitioner, their next friend or surrogate may not agree with. This provision gives effect to the Supreme Court decision in Common Cause i.e. that there exists a right to refuse all medical treatment, including life-sustaining treatment, and that this right exists as an integral part of the right to autonomy, dignity and privacy under Article 21 of the Constitution.

Further, the healthcare decision making capacity of a person has been defined keeping the healthcare context in mind and is not necessarily synonymous with their decision making capacity in other spheres. For instance, a person may not have the decision making capacity to make investment decisions, but may still be able to exercise and express their wishes regarding the refusal of treatment. It is also possible that a patient may be able to exercise healthcare decision-making capacity in the context of a particular healthcare intervention but not another.

Advance planning instruments

12. All adults possessing healthcare decision making capacity shall have the right to execute advance planning instruments in accordance with the provisions of this Act and rules framed under it.

CHAPTER III
END OF LIFE DECISION-MAKING

Initiation of end of life care discussion

13. (1) If, in the opinion of the treating registered medical practitioner, the initiation, continuation or escalation of life-sustaining treatment in the patient is potentially non-beneficial or the patient is in a persistent vegetative state, then the treating registered medical practitioner shall initiate a discussion on withholding and withdrawing of life-sustaining treatment and provision of end of life care in accordance with the provisions of this chapter.

(2) The treating registered medical practitioner shall determine whether the patient meets the conditions specified in sub-section (1) in accordance with recognised professional standards.

Provided that at least two registered medical practitioners who are not directly involved in the care of the patient should concur with the determination of the treating registered medical practitioner.

Explanatory Note to Clause 13

This chapter is intended to apply only to end of life decision-making in healthcare establishments. This is evident from the definition of 'patient', which refers to those receiving care at healthcare establishments. The procedure set out in this chapter is not intended to apply to persons at home who

may be suffering from a terminal illness, although any medical practitioner attending to such patient should always act in accordance with recognised professional standards.

This clause is intended to guide the treating team at a healthcare establishment regarding the initiation of a discussion on the withholding or withdrawal of life-sustaining treatment as well as the provision of end of life care. As the provision indicates, determining whether to initiate, continue or escalate life-sustaining treatment is a medical decision that must be taken in accordance with recognised professional standards and which must be independently verified by medical practitioners who are not directly attending to the patient, in order to check abuse by the treating team. Such practitioners may, however, be from the same healthcare establishment as the treating medical practitioner.

Please note that this determination need not be restricted only to terminally ill persons—it may apply to anyone for whom life-sustaining treatment may be non-beneficial.

Implementing the patient's wishes and preferences

14. (1) Upon determining that the initiation, continuation or escalation of life-sustaining treatment is potentially non-beneficial, in accordance with section 13, if the patient possesses healthcare decision-making capacity within the meaning of section 11, the treating registered medical practitioner shall initiate an end of life care discussion with the patient which shall include a discussion about their wishes and preferences regarding further treatment.

(2) In the course of the end of life care discussion with the patient, the patient may exercise their right under sub-section (3) of section 11 to refuse a healthcare intervention, including life-sustaining treatment and request the withholding or withdrawing of such life-sustaining treatment.

Explanation: For the removal of doubts it is clarified that the withholding and withdrawing of life-sustaining treatment shall include the non-initiation of cardio-pulmonary resuscitation in the event of cardio-respiratory arrest.

(3) The wishes and preferences regarding life-sustaining treatment expressed under sub-section (2) shall be recorded as medical orders for life-sustaining treatment in such format as may be prescribed.

(4) The medical orders for life-sustaining treatment recorded under sub-section (3) shall be signed by the treating medical practitioner and the patient and shall form part of the patient's medical record. and will thereafter be implemented in accordance with recognised professional standards.

(5) Medical orders for life-sustaining treatment under sub-section (4) shall be implemented in accordance with recognised professional standards, irrespective of any

advance planning instruments that the patient may have executed in the past and shall override all such instruments.

(6) Medical orders for life-sustaining treatment will be reviewed by the treating registered medical practitioner at regular intervals and will accordingly be updated, if required, in accordance with recognised professional standards.

Provided that the patient shall be continue to be consulted about their wishes and preferences so long as they retain healthcare decision making-capacity and a medical order for life-sustaining treatment shall not be implemented if the patient subsequently changes their wishes and preferences regarding the course of treatment.

Explanatory Note to Clause 14

This provision kicks in once the treating medical practitioner has determined that the initiation, continuation or escalation of life-sustaining treatment may be non-beneficial. The next step is to determine whether the patient has healthcare decision-making capacity regarding the withholding or withdrawing of life-sustaining treatment and the provision of end of life care. If the patient is found to possess such capacity, the step that follows is for the treating medical practitioner to have a detailed discussion with the patient about their wishes and preferences regarding the withholding and withdrawing of life-sustaining treatment, such that the patient is able to make an informed decision.

Once the patient has made such a decision, the discussion, as well as the decision ought to be recorded in such a manner that it forms part of the patient's medical records and can be consulted by other members of the treating team. These medical orders constitute the most up-to-date and authentic expression of the patient's wishes regarding the withholding and withdrawing of life-sustaining treatment and the provision of end of life care. Should the patient lose healthcare decision-making capacity subsequently, it is these medical orders that ought to guide the treating team, over and above any advance planning instrument that the patient may have executed in the past.

This is because an advance planning instrument executed in the past may be difficult to verify, despite having been executed in accordance with the provisions of this bill. Circumstances might also have changed since the execution of the instrument, making it invalid. Verifying the authenticity and validity of such instruments is a heavy burden to impose on a treating team, although it will be required under Clause 15 if the patient no longer retains healthcare decision-making capacity.

Therefore, even if a patient has executed such instruments, so long as they retain healthcare decision-making capacity, the treating medical practitioner should nevertheless ascertain their wishes and preferences regarding the withholding and withdrawal of life-sustaining treatment

and the provision of end of life care, and then record these in the medical orders for life-sustaining treatment. It might often be the case that these orders mirror what has already been documented in the advance planning instrument. However, it is these orders that must be consulted by the treating team because they represent the most recent wishes and preferences of the patient. Such orders serve the same purpose as an advance planning instrument, with the added benefit that they are recorded in consultation with the treating team.

To ensure that these medical orders continue to represent the most recent expression of the patient's wishes, they must be regularly updated by the treating medical practitioner.

When the patient cannot exercise healthcare decision making capacity and a valid advance directive exists

15. (1) Upon determining that the initiation, continuation or escalation of life-sustaining treatment is potentially non-beneficial, in accordance with section 13, if a patient cannot exercise healthcare decision making capacity, the treating registered medical practitioner shall make reasonable efforts to ascertain whether there exists a valid advance directive made by such patient, and for this purpose, may consult a next friend.

(2) Where a valid advance directive exists, the registered medical practitioner shall give effect to such an advance directive.

(3) If there is a reasonable doubt regarding the applicability or validity of the advance directive in the mind of the registered medical practitioner then the healthcare establishment shall make an application to the Mental Health Review Board under section 24 to review the directive.

Explanatory Note to Clause 15

Clause 15 kicks in only if the patient cannot exercise healthcare decision-making capacity. Once this determination regarding lack of capacity has been made, the treating registered medical practitioner must make all reasonable efforts to determine whether a valid advance directive exists, usually by relying on the next friend of the patient. If it does, the directive represents the most authentic wishes of the patient regarding the withholding or withdrawing of life-sustaining treatment and the provision of end of life care, and it should be implemented. However, if there is doubt regarding the validity of the directive, the healthcare establishment can utilise the procedure under the Mental Health Care Act, 2017, for reviewing the directive.

Advance directive not to be applicable in certain cases

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

(a) if conditions for the validity of an advance planning instrument under section 21 are not satisfied;

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

(c) 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.

Explanatory Note to Clause 16

This provision sets out the instances in which treating medical practitioners should not be guided by the advance directive in making decisions about the withholding or withdrawal of life-sustaining treatment and the provision of end of life care. Examples of such instances are:

- the instrument is unsigned
- the person executing the instrument had requested the withholding of cardio-pulmonary resuscitation should they be suffering from Alzheimer's disease and also suffer a cardiac arrest. However, this wish was expressed on the assumption that Alzheimer's disease was incurable. If a new treatment has been discovered that has the potential to reverse the disease, then the instructions in the advance directive should not be implemented
- the person executing the instrument had refused ventilation in all instances because they were concerned about the pain and discomfort that the procedure might cause. A new method of ventilation has now been developed that entirely eliminates such pain and discomfort. In such an instance, it is reasonable to assume that the patient may have altered their instructions, and therefore, the advance directive should not be implemented.

When the patient cannot exercise healthcare decision making capacity and valid advance directive does not exist.

17. (1) Upon determining that the initiation, continuation or escalation of life-sustaining treatment is potentially non-beneficial, in accordance with section 13, if the patient cannot exercise healthcare decision-making capacity and a valid advance directive does not exist, then the treating registered medical practitioner shall follow the procedure outlined in this section.

(2) The treating registered medical practitioner shall ascertain if a surrogate has been appointed by the patient through a valid medical power of attorney and shall provide the surrogate with all the information regarding the condition of the patient and brief them about their role in the end of life decision-making process.

(3) If the patient has not appointed a surrogate or the surrogate who has been appointed is not available or not willing to participate in the end of life decision-making process, then the treating registered medical practitioner shall make all reasonable efforts to ascertain if a next friend is available, and shall provide such next friend with all the information regarding the condition of the patient and brief them about their role in the end of life decision-making process.

Provided that if no next friend is available, the healthcare establishment shall approach the Chief Medical Officer of the district for the appointment of a social worker of repute from the district who shall act in the capacity of a next friend and participate in the end of life decision-making process.

(4) End of life decision making, including decisions regarding the withholding and withdrawing of life sustaining treatment shall be undertaken through a process of shared decision-making among the healthcare practitioners attending to the patient and the surrogate or next friend, as the case may be, available at the healthcare establishment.

(5) For decisions under sub-section (4), the healthcare practitioners and next friend or surrogate, as the case may be, shall make a decision in the best interests of the patients and will be guided by the known values and preferences of the patient.

Provided that a social worker who is acting as a next friend shall participate in the decision-making process keeping the dignity of the patient in mind.

(6) Where the patient is a child, the provisions of this section with regard to end of life decision-making shall apply 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 treating medical practitioner;

(b) the next friend 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.

Provided that if the guardian of the child is not available, then the nearest kin of the child may participate in the decision-making process.

(7) Any differences among the healthcare practitioners and the patient's surrogate or next friend, or between the parents of a child, as the case may be, regarding end of life decision-making, including the withholding or withdrawing of life-sustaining treatment that cannot be resolved through multiple rounds of shared decision-making shall be referred to the relevant 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.

(8) If the end of life care committee is unable to resolve the differences in sub-section (7), then the withholding or 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 surrogate or next friend, as the case may be, and such High Court shall decide such proceedings as expeditiously as possible.

(9) 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.

Explanatory Note to Clause 17

This is the third and final scenario that is contemplated—the patient does not have healthcare decision-making capacity, nor have they executed an advance directive, making it difficult to ascertain their wishes and preferences regarding the withholding or withdrawing of life-sustaining treatment. The patient may, however, have executed a medical power of attorney nominating someone as a surrogate. If they have, the treating medical practitioner and the surrogate must reach a decision regarding the withholding or withdrawal of life-sustaining treatment through shared decision-making.

If the surrogate is unavailable or unwilling to act or if there is no medical power of attorney, the treating medical practitioner must undertake the process of shared decision-making with the next friend of the patient. The next friend will be determined in accordance with the order of preference set out in sub-clause (q) of clause 2.

If even a next friend is not available, it is the duty of the healthcare establishment to inform the Chief Medical Officer, who will, in turn, appoint a social worker who can act as a next friend in such circumstances. The Chief Medical Officer should put together a set of social workers who can be called upon in such circumstances.

The persons to be consulted vary if it is a child from whom life-sustaining treatment has to be withheld or withdrawn. In such circumstances, given that children of a certain age are likely to be able to exercise healthcare decision-making capacity, their wishes must be taken into consideration, and their parents

must jointly act as next friends. If the parents are not available, this responsibility falls on the guardian, failing which the nearest kin of such child is to be consulted.

Healthcare practitioners are likely to be able to bring their medical expertise to the shared decision-making process. They must discuss the benefits and risks of initiation, continuing or escalating life-sustaining treatment with the surrogate or next friend, as well as the benefits and risks of alternative interventions. The surrogate or next friend should bring their knowledge of the values or preferences of the patient to the shared decision-making process. In cases where a social worker has been appointed, they must keep in mind the dignity of the patient, given that they are unlikely to know the values or preferences of the patient.

The aim of the shared decision-making process is to reach a consensus regarding the withholding or withdrawing of life-sustaining treatment and the provision of end of life care. Differences may arise between the treating medical practitioner and the surrogate or next friend. In the case of children, differences may also arise between parents inter se. In such instances, multiple rounds of shared decision-making must be undertaken to reach a consensus. However, if this fails, then the case may be referred to the relevant end of life care committee, discussed in detail in later provisions of the bill.

If the end of life care committee also fails to resolve these differences, an application may be made to the High Court in whose jurisdiction the healthcare establishment is situated. It is the person who desires life-sustaining treatment to be withheld or withdrawn who must make the application to the High Court. An appeal from a decision of the High Court lies with the Supreme Court of India, but only on matters of law. This means that the Supreme Court will not re-examine the facts of the case, or hear evidence regarding the advisability or potentially non-beneficial nature of the life-sustaining treatment or the wishes or preferences of the patient.

Maintenance of patient records

18. (1) Any information, reports, opinions, decisions and details of the procedure and decision-making process relating to end of life care, including withholding and withdrawing life-sustaining treatment under this Chapter 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.

(3) The patient's surrogate or next friend, as the case may be, and their legal heirs shall have a right to access the patient's records in accordance with section 10.

Explanatory Note to Clause 18

This provision strikes a balance between transparency and the protection of health information. Given the sensitive nature of the end of life decision-making process, it is important that all the steps required by this Act are appropriately observed and documented. The registered medical practitioner should document their determination regarding the potentially non-beneficial nature of life-sustaining treatment, the confirmation by two independent medical practitioners, as well as the details of end of life care discussions with the surrogate or next friend of social worker, as the case may be, and of course, the final decision regarding withholding or withdrawal of life-sustaining treatment.

All of this is to be documented as part of the patient's official medical records. This is important because the bill also guarantees the patient, their next friend and heirs the right to access these records. Therefore, the obligation to document the end of life decision-making process is directly linked to the protection of the patient's right to access their own information under clause 10 of this bill.

At the same time, given that sensitive personal information is being recorded in detail, whether physically or electronically, every legal obligation in force regarding the privacy and protection of such health information must be respected.

Subsequent audit by the end of life care committee

19. (1) All withholding or withdrawing of life-sustaining treatment under this Chapter 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 in such manner as may be prescribed.

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

(4) The end of life care committee shall record the findings of its audit in writing in an audit report which shall be in such form as may be prescribed.

(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 the 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 record such a finding in its audit report and may recommend appropriate action, if applicable.

(6) The audit report shall be submitted to the healthcare establishment and shall form part of the patient's record and a copy of it shall be forwarded to the District Magistrate and the Chief Medical Officer of the district within fifteen days of the completion of the audit.

(7) Based on the findings and recommendations of the audit report, the healthcare establishment or the District Magistrate or the Chief Medical Officer shall take appropriate action, if required, including initiating civil or criminal proceedings, in accordance with any law for the time being in force and the rules prescribed under this Act.

Explanatory Note to Clause 19

The intention of this clause is to act as a check on the unethical withholding or withdrawal of life-sustaining treatment. Given the nature of critical care and the time-sensitive nature of end of life decision-making, it is not possible to require approval in advance from an external body before taking a decision to withhold or withdraw life-sustaining treatment. This has been the biggest hurdle with the Supreme Court's guidelines for the withholding and withdrawal of life-sustaining treatment in *Common Cause*.

Therefore, this provision creates an external audit in the form of an end of life care committee that reviews all instances in which the withholding or withdrawal of life-sustaining treatment has taken place and ensures quality control going forward. This is in accordance with guidelines jointly issued by the Indian Society of Critical Care Medicine and the Indian Association of Palliative Care. The primary obligation is on the healthcare establishment to report all such cases to the end of life care committee (larger healthcare establishments are required to constitute their own committee, others must report to a district end of life care committee).

The committees have the power to inspect and review patient records and then record their findings in the form of an audit report. The findings might throw up negligence-for example, the treating medical practitioner may not have acted in accordance with recognised professional standards. They might also throw up procedural irregularities—the treating medical practitioner may not have documented all discussions and decisions. Most seriously of all, they might uncover decisions taken in bad faith, a product of collusion between the treating medical practitioner and the surrogate or next friend.

In all such instances, the end of life care committee, while it does not have the power to take action itself, must send a copy of its audit report to authorities like the District Magistrate and the Chief Medical Officer, who can in turn, recommend appropriate civil or criminal action. Since the audit report forms part of the patient's record, their next

friend and heirs will also have access to it, by virtue of their rights under clauses 10 and 18 of this bill.

CHAPTER IV
ADVANCE PLANNING INSTRUMENTS

Advance planning instruments

20. An advance planning instrument may comprise:

(a) an advance directive that expresses the wishes of a person to refuse life-sustaining treatment including their wishes regarding the withholding or withdrawing of life sustaining treatment; or

(b) a medical power of attorney appointing a surrogate to take decisions regarding end of life care on behalf of the person executing the medical power of attorney when such person loses healthcare decision-making capacity.

Conditions of validity of an advance planning instrument

21. (1) Any adult person may execute an advance planning instrument.

(2) Every advance planning instrument shall be made in clear and unambiguous terms, shall be in writing and shall be paginated.

Provided that any ambiguous part of the instrument shall be considered void only to the extent of the ambiguity and shall not affect the overall validity of the instrument.

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

(4) Every advance planning instrument shall be accompanied by a certificate by a registered medical practitioner, in such manner as may be prescribed, certifying that the executor possesses healthcare decision making capacity.

(5) An advance planning instrument 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.

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

Provided that if the instrument consists of more than one page, then the executor shall sign or affix their mark on each page.

(7) Every advance planning instrument 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 instrument in accordance with sub-section (5); and each of the witnesses

shall sign or affix their mark to the instrument in the presence of the person executing it.

Provided that if the instrument consists of more than one page then the witnesses shall sign or affix their mark on each page.

(8) An advance planning instrument which has not been executed in accordance with this section shall be considered void.

Explanatory Note to Clause 21

This clause lays down the conditions that must be met for any advance planning instrument to be considered valid, and therefore, given effect to.

The first condition is that a person must be at least 18 years old to execute an advance planning instrument.

The second is that such person must have healthcare decision-making capacity. This capacity must be related to the wishes and preferences that they express in the instrument. At the time of executing the instrument, a registered medical practitioner must certify that the persons executing it possesses such capacity. This reduces the burden at a later stage on the treating medical practitioner who is called upon to implement the instrument. The treating practitioner would not, in any case, be in a position to verify whether the instrument was executed by someone with healthcare decision-making capacity. The prior certificate by a registered medical practitioner does away with this uncertainty and it must be produced along with the advance planning instrument.

The instrument must also be voluntarily executed, just like a will. It will be void if it is was executed as a result of fraud, coercion, inducement or any other factor affecting the free agency of the person executing it. Examples of void instruments are:

- an advance directive refusing life-sustaining treatment executed on the persuasion of family members that failure to execute such an instrument would lead to prohibitive costs and financial ruin for the family
- an advance directive executed in the backdrop of a threat from a spiritual leader that failure to execute such an instrument would invite divine wrath
- a medical power of attorney executed by a person diagnosed with pancreatic cancer on an incorrect understanding of the progression of the diseases, where such information is deliberately supplied by the family physician

In addition to this, the instrument must also be written in clear language that does not leave room for misinterpretation. For example, language in an instrument that requests the withholding or withdrawal of treatment

when 'life becomes unbearable' or 'meaningful existence is no longer possible' should be avoided. As far as possible, specific conditions in which such decisions should be taken should be spelled out, such as the inability to exercise control over bodily functions or loss of vision or speech.

The final set of conditions relates to the manner in which the instrument should be executed, i.e. how it should be signed and dated, and what witnesses should be present.

Special provisions applicable to medical powers of attorney

22. (1) A person executing a medical power of attorney shall appoint one person, who is an adult at the time of execution, as surrogate.

(2) The medical power of attorney may also name other adult persons, up to a maximum of three, in order of preference, to act as surrogates in case the first surrogate is not available or does not possess healthcare decision-making capacity or does not wish to participate in the decision-making process at the time at which decisions are required to be made under this Act.

(3) A surrogate appointed under a medical power of attorney cannot delegate their responsibilities under the provisions of this Act to any other person.

(4) The person appointed as a surrogate under sub-section (1) and the first alternative surrogate named under sub-section (2) may be given copies of the medical power of attorney by the person executing such instruments.

(5) The surrogate shall provide the healthcare establishment and the treating medical practitioner access to the patient's medical power of attorney to enable shared decision-making under section 17.

Explanatory Note to Clause 22

This clause applies specifically to medical powers of attorney. Only persons who are adults at the time of execution of the medical power of attorney can be appointed as surrogates. Up to three persons can be appointed as surrogates, but they not intended to act jointly, but in the order of preference in which they are named in the instrument.

The person executing the medical power of attorney should ideally provide their surrogate with a copy of the instrument to make them aware of their duties. Similarly, a surrogate who is aware of this responsibility and has a copy of the medical power of attorney has a duty to share this instrument with the healthcare establishment and the treating medical practitioner when the conditions set out in Chapter III of this bill are triggered.

Alteration, revocation and renewal of advance planning instruments

23. (1) An advance planning instrument may be altered or revoked at any time after its execution by the person who executed it, and the alteration must comply with the conditions for validity of execution under section 21 of this Act.

(2) An advance planning instrument shall be revoked by an express written statement of revocation which must be signed by the person who had executed the advance planning instrument:

Provided that the earlier advance planning instrument should be destroyed once this statement of revocation has been made.

Provided further that a subsequent advance planning instrument shall automatically revoke the advance planning instrument which was executed earlier in time.

(3) An advance planning instrument shall be valid for a period of ten years from the date of its execution, after which it must be explicitly renewed for subsequent ten year periods by the person who originally executed it, to retain its validity.

(4) For the purposes of sub-section (3), the advance planning instrument shall be renewed through re-endorsement of the instrument by the person who executed the advance planning instrument, and such re-endorsement shall also be accompanied by a certificate by a registered medical practitioner, in such manner as may be prescribed, certifying that the executor possesses healthcare decision-making capacity at the time of the re-endorsement.

Explanatory Note to Clause 23

This clause lays down the conditions for three different things that may be done to an advance planning instrument—alteration, revocation, and renewal.

Of these, alteration is treated on the same plane as the execution of an advance planning instrument. Therefore, all the conditions that apply to the execution of such an instrument, such as certification of healthcare decision-making capacity by a registered medical practitioner, signing and dating, and the presence of two witnesses, will apply to the alteration of the instrument as well.

Revocation merely requires a signed written statement from the person who executed the original instrument. The effect of a revocation will be the same as if no advance planning instrument had been made, unless, of course, a subsequent instrument is executed in accordance with clause 21.

Renewal involves a re-endorsement of the original advance planning instrument. Given that ten years will have passed since the execution of the original instrument, the re-endorsement must also be

accompanied by a certificate from a registered medical practitioner that the person in question continues to retain healthcare decision-making capacity.

However, the other conditions for execution, such as the presence of two witnesses, are not required for renewal, since this simply requires the executor to revisit their wishes and preferences ever year. If they make no change to these wishes and preferences, then the renewal does not amount to an alteration of the instrument, and therefore requires fewer safeguards, since all the conditions for a valid execution were met in any case in the first instance.

Applications for reviewing advance planning instruments

24. Where the registered medical practitioner or the healthcare establishment treating the patient or a next friend or surrogate is of the opinion that:

(a) the advance directive is not applicable in accordance with the provisions of section 16 or the advance planning instruments are not valid under section 21;

(b) the advance planning instruments require clarification since the patient's wishes regarding end of life care are unclear; or

(c) the advance planning instruments have been executed in a country not notified by the Central Government under section 29,

they may make an application to the concerned Mental Health Review Board, in such form and manner as may be prescribed, to review the advance planning instruments.

Explanatory Note to Clause 24

There may be several reasons to doubt the validity of an advance planning instrument. This clause lists these reasons:

- altered circumstances since the execution of the instrument, as set out in clause 16
- where the instrument does not meet the conditions set out in clause 21, such as voluntary execution, signing and dating in the presence of two witnesses etc
- where the language of the instrument leaves room for interpretation regarding the patient's wishes and preferences
- where the instrument has not been executed in India or in a country that has been notified by the Central Government under clause 29 (the Government can notify countries in which the execution of advance planning instruments will be treated as valid).

If these doubts exist, it would be unfair to impose the burden on the treating medical practitioner or healthcare establishment to resolve such doubts, especially since this might also involve a conflict of interest.

Instead, the bill recommends using an existing body for the resolution of such doubts, i.e. the Mental Health Review Board, set up under the Mental Healthcare Act, 2017. These boards already have the necessary expertise and power to review, alter, cancel or modify advance directives framed under the Mental Healthcare Act. Rather than create a new body specifically for the resolution of doubts relating to advance planning instruments in the context of end of life care, this bill will make use of an existing mechanism. Do note, however, that Mental Health Review Boards under the Mental Healthcare Act are still to be constituted.

The treating medical practitioner or a healthcare establishment or the next friend of a patient or their surrogate can all make an application to the Mental Health Review Board.

Procedure and powers of the Board

25. (1) Upon receipt of the application under section 24, the Board shall, as expeditiously as possible, after giving an opportunity of hearing to all concerned parties, exercise its powers of review and communicate its decision to uphold, cancel or clarify the advance planning instrument.

(2) In reaching a decision under sub-section (1), the Board shall consider both the conditions of applicability and validity of advance planning instruments under this Act and any other circumstances which may cast a reasonable doubt on the applicability of the instrument.

(3) The provisions of section 76, section 78 and sub-sections (5), (6), (7), (11), (12) and (14) of section 80 of the Mental Healthcare Act, 2017 shall, *mutatis mutandis*, apply to the Board in the discharge of its proceedings under this Act as they apply to the Board in the discharge of its proceedings under that Act and the Board shall follow such other procedures as may be prescribed.

Explanatory Note to Clause 25

This clause clarifies the powers of the Mental Health Review Board when an application is made to it under this bill. It may uphold, cancel or clarify an advance planning instrument. The following provisions of the Mental Healthcare Act, 2017, shall apply to the proceedings of the Mental Health Review Board under this bill as well:

- Decision of the Board to be by consensus, failing which, by a majority of votes of members present and voting, with the president or chairperson to have a casting vote in case of equality of votes
- Proceedings before the Board to be judicial proceedings under sections 193, 219 and 228 of the Indian Penal Code
- Proceedings of the Board to be held *in camera*
- Adjournments should not ordinarily be granted for a hearing

- Parties to an application may appear in person or be represented by a counsel or representative of their choice
- Power to require the attendance and testimony of such witnesses as the Board deems appropriate
- Parties to the application to have the right to inspect any document relied upon by another in party in its submissions to the Board and to obtain copies of it
- Members of the Board who might be directly or indirectly involved in a particular application are not to sit on the Board during its hearings of such application

Appeal to high court

26. Any person or healthcare establishment aggrieved by the decision of the Board under section 25 may, within a period of thirty days, prefer an appeal to the High Court of the state in which the Board is situated and such High Court shall decide such appeal as expeditiously as possible.

Advance planning instruments not to be confused with other testamentary instruments

27. For the removal of doubts it is hereby clarified that advance planning instruments executed in accordance with the provisions of this Act shall not constitute wills or other testamentary instruments executed in accordance with the Indian Succession Act, 1925 or any other law for the time being in force.

No levy of stamp duty etc.

28. All advance planning instruments executed in accordance with the provisions of this Act shall not be subject to the levy of stamp duty or any other duties or fee under any applicable laws for the time being in force.

Validity of advance planning instruments executed in other countries

29. (1) The Central Government may, from time to time, notify countries whose advance planning instruments substantially comply with the condition of validity of instruments in this chapter and are considered valid in India.

(2) An advance planning instrument executed in any country not notified by the Central Government under sub-section (1), shall be valid in India if the Board, pursuant to an application under section 25, determines that such an instrument substantially complies with the conditions of validity of advance planning instruments in this Chapter and upholds such an instrument under section 26.

Explanatory Note to Clause 29

This clause is necessary, keeping in mind that there may be patients from other jurisdictions being treated at healthcare establishments in India. Such patients may have executed advance planning instruments in accordance with the laws of other countries. There must be a formal process for recognising the validity of such instruments as well. In this regard, the Central Government has an obligation to notify countries in which the execution of advance planning instruments will be considered valid for the purposes of this bill. Before notifying such country, the Government ought to be

satisfied that the conditions for the valid execution of advance planning instruments in another jurisdiction are substantially similar to the conditions under this bill.

If a country has not been notified, but a question arises regarding the validity of an advance planning instrument executed there, an application should be made to the Mental Health Review Board. The Board will also consider whether the conditions for the validity of advance planning instruments in that jurisdiction are substantially similar to those under this bill.

CHAPTER V
END OF LIFE CARE COMMITTEE

End of life care committee

30. (1) All healthcare establishments with more than 50 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 Medical Director or equivalent, or their nominee, of the healthcare establishment;

(b) two senior registered 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;

(c) an expert with relevant experience in law or bioethics, to be nominated by the healthcare establishment;

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

Explanatory Note to Clause 30

This provision defines the kinds of healthcare establishments that must establish their own end of life care committee. A threshold of 50 beds or the existence of an intensive care unit has been prescribed, because it is presumed that such establishments will have a higher volume of cases that involve end of life decision-making.

Smaller healthcare establishments are, however, free to set up their own end of life care committee, even though they are not required to do so under this bill.

The Chairperson of the end of life care committee is to be a senior registered medical practitioner from outside the healthcare establishment to ensure the independence of the committee.

All members of the committee are, however, to be nominated by the healthcare establishment itself.

District end of life care committee

31. (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 registered medical practitioners from the district with relevant expertise in end of life care:

Provided that one of the registered medical practitioners will also be appointed as Chairperson by the Chief Medical Officer;

(b) an expert with relevant experience in law or bioethics;

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

(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.

Explanatory Note to Clause 31

The district end of life care committee is intended to serve those healthcare establishments that do not have their own end of life care committee.

All members of the district end of life care committee are to be nominated by the Chief Medical Officer.

Training of members of end of life care committees

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

CHAPTER VI
MISCELLANEOUS

Registered medical practitioners not to be compelled to provide treatment not in

33. Nothing in this Act shall be construed as requiring a registered medical practitioner to provide a specific treatment or intervention on the request of a patient or next friend, where such practitioner is of the opinion that the treatment or interest would not be in the best interests of the patient and such opinion is in accordance with recognised professional standards.

the best interests of the patient

Explanatory Note to Clause 33

This provision codifies a principle recognised by the Supreme Court in *Common Cause*, that a medical practitioner cannot be compelled to provide treatment against their medical judgment. No person has a right to demand that a particular kind of treatment be provided to them. This is not to be confused with the right of a patient to access end of life care or not to be discriminated against in the provision of end of life care, as set out in Chapter II of this bill.

A medical practitioner should refuse to provide care only when they are of the opinion that this would not be in the best interests of the patient and that this opinion has been reached in accordance with recognised professional standards.

Use of services of counsellors and social workers

34. Healthcare establishments may use the services of counsellors and social workers to assist healthcare practitioners to perform their functions under this Act.

Effect of advance planning instruments on life insurance

35. (1) The execution of advance planning instruments 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 instrument.

(2) The withholding and withdrawing 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

36. No civil court shall have jurisdiction to entertain any suit or proceeding in relation to which the High Court or the Mental Health Review Board under this Act is empowered 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

37. (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 rate at which end of life care services shall be provided by healthcare establishments under sub-section (2) of section 3;

(b) the manner in which costs will be reimbursed to private healthcare establishments providing end of life care services to below poverty line patients under sub-section (3) of section 3;

(c) the manner in which the identity of the patient's next friend and their heirs shall be verified to access patient records after the patient's death under sub-section (2) of section 10;

(d) the format of the medical orders for life-sustaining treatment to record the wishes and preferences of the patient under sub-section (3) of section 14;

(e) the manner of reporting instances of withholding and withdrawing of life-sustaining treatment decisions to the district end of life care committee under sub-section (2) of section 19;

(f) the form of the audit report to be prepared by end of life care committees under sub-section (4) of section 19;

(g) the format of certificate certifying that the person executing the advance planning instrument has healthcare decision making capacity under sub-section (4) of section 21;

(h) the qualifications of the witnesses who shall witness the execution of the advance planning instrument under sub-section (7) of section 21;

(i) the form and manner in which applications to review advance planning instruments may be made to the Mental Health Review Board under section 24;

(j) the procedures that the Mental Health Review Board may follow during proceedings to review advance planning instruments under sub-section (3) of section 25;

(k) the procedure for meetings, allowances and terms and conditions of service of members of the district end of life care committee under sub-section (4) of section 31;

(l) the manner in which members of the relevant end of life care committee shall undergo training in issues relating to end of life care under section 32;

(m) 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

38. 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.

39. 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

40. (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.

Amendment of Act 18 of 1969

41. The Registration of Births and Deaths Act, 1969 (18 of 1969) shall be amended in the manner set out in the First Schedule of this Act.

THE FIRST SCHEDULE

SEE SECTION 41

AMENDMENT OF REGISTRATION OF BIRTHS AND DEATHS ACT, 1969

18 OF 1969

Amendment of Section 2

1. In place of the current clause (b) of sub-section (1) of section 2 of the Registration of Births and Deaths Act, 1969 the following clause (b) of sub-section (1) of section (2) shall be substituted, namely: —

"(b) "death" means the permanent and irreversible cessation of the heart and circulatory function, or neurological function of the brain including the brain stem."

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