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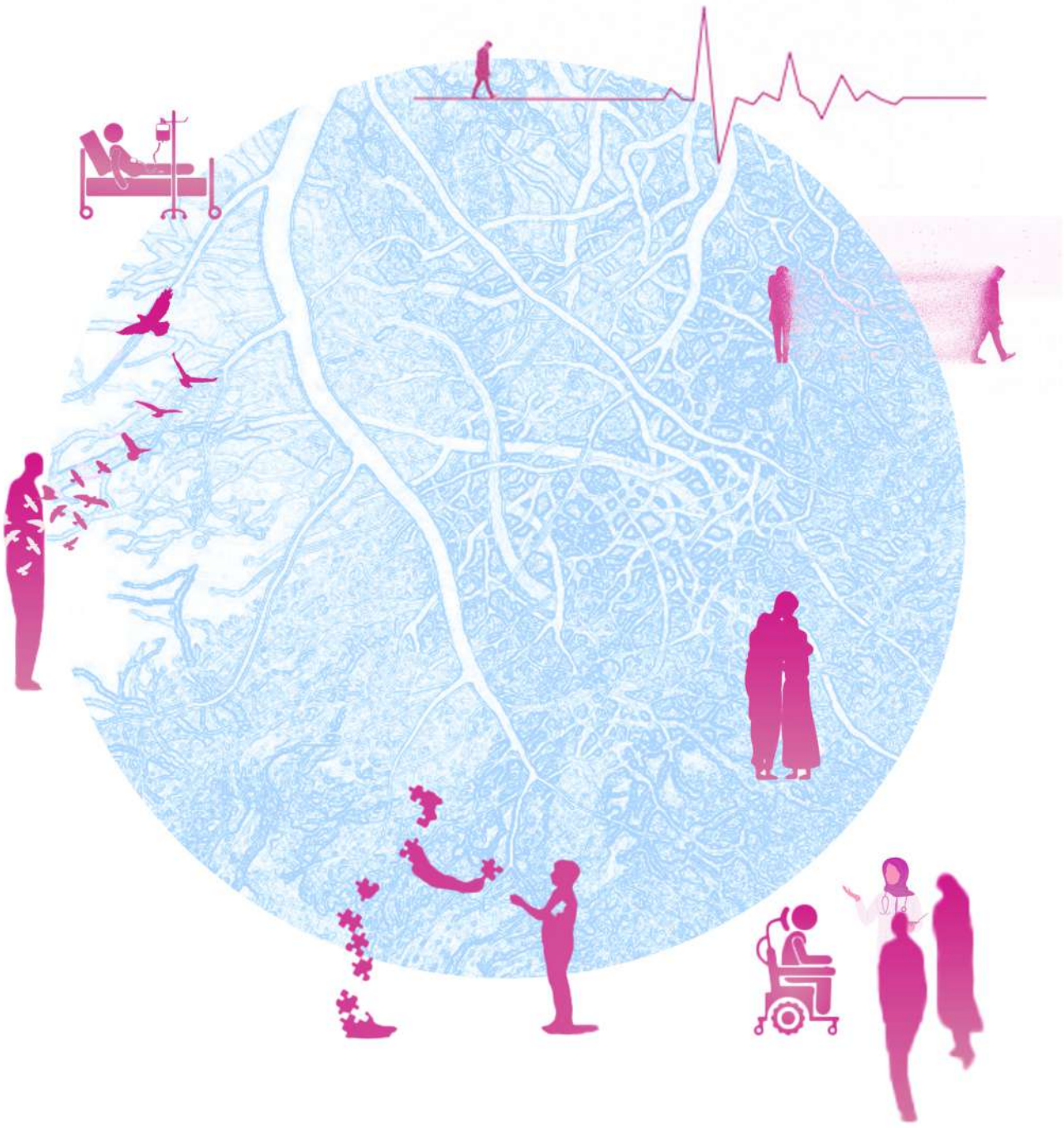
# End-of-Life Care and the Law in India
# Addressing Common Concerns



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Since this is an evolving area of the law, parts of the toolkit may be updated. You can view the most recent updates at vidhilegalpolicy.in/eolctoolkit.

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# Contents

# Chapter 1

# Introduction

This guide is intended to answer legal questions surrounding end-of-life care in India.

Chapter 2 addresses concerns that doctors, nurses and other healthcare workers might have while treating and caring for terminally-ill patients or patients in a persistent vegetative state. Is it legal to stop life-support? If the patient is unconscious, who should the treating team consult? What should doctors do if the patient's family disagrees with them about the course of treatment? Is a DNR order the same as an advance medical directive?

Chapter 3 of this guide answers legal questions that patients and their caregivers might have during a terminal illness. Can patients choose how to die? What if they are in a coma? How can they get their loved ones to respect their wishes about death? What can they do if their doctor disagrees with them about their course of treatment?

These are important questions about care and medical treatment at the end-of-life. A very important resource for the answers is a judgment of the Supreme Court passed in 2018, Common Cause v Union of India, and modified by an order of the Court in 2023. This judgment is now the law in India on these questions. It protects the following rights and actions.

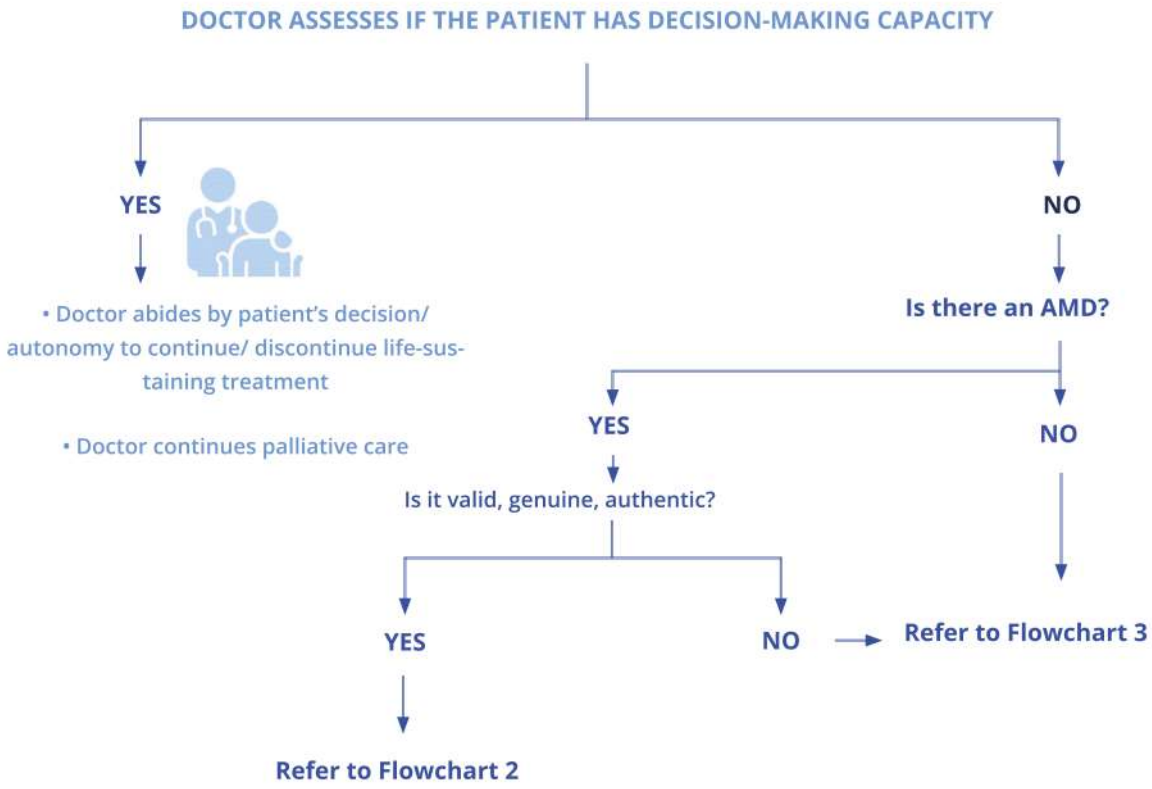
**Right to Refuse Treatment** Any person who is capable of taking decisions about their own healthcare can also refuse any medical treatment, even if this means that they will die. Doctors must respect this decision.

**Advance Medical Directives/Living Wills** Any person above the age of 18 can make an advance medical directive or living will to plan for a time in the future when they might no longer be able to take decisions about their healthcare.

In an advance medical directive, a person can refuse different kinds of medical treatment (cardio-pulmonary resuscitation, ventilation, dialysis) at the end-of-life. They can continue to request that their symptoms are managed and that they do not suffer any pain.

Doctors must respect the wishes expressed in a valid advance medical directive.

**Allowing Natural Death** There may be cases where a person is terminally ill and loses the capacity



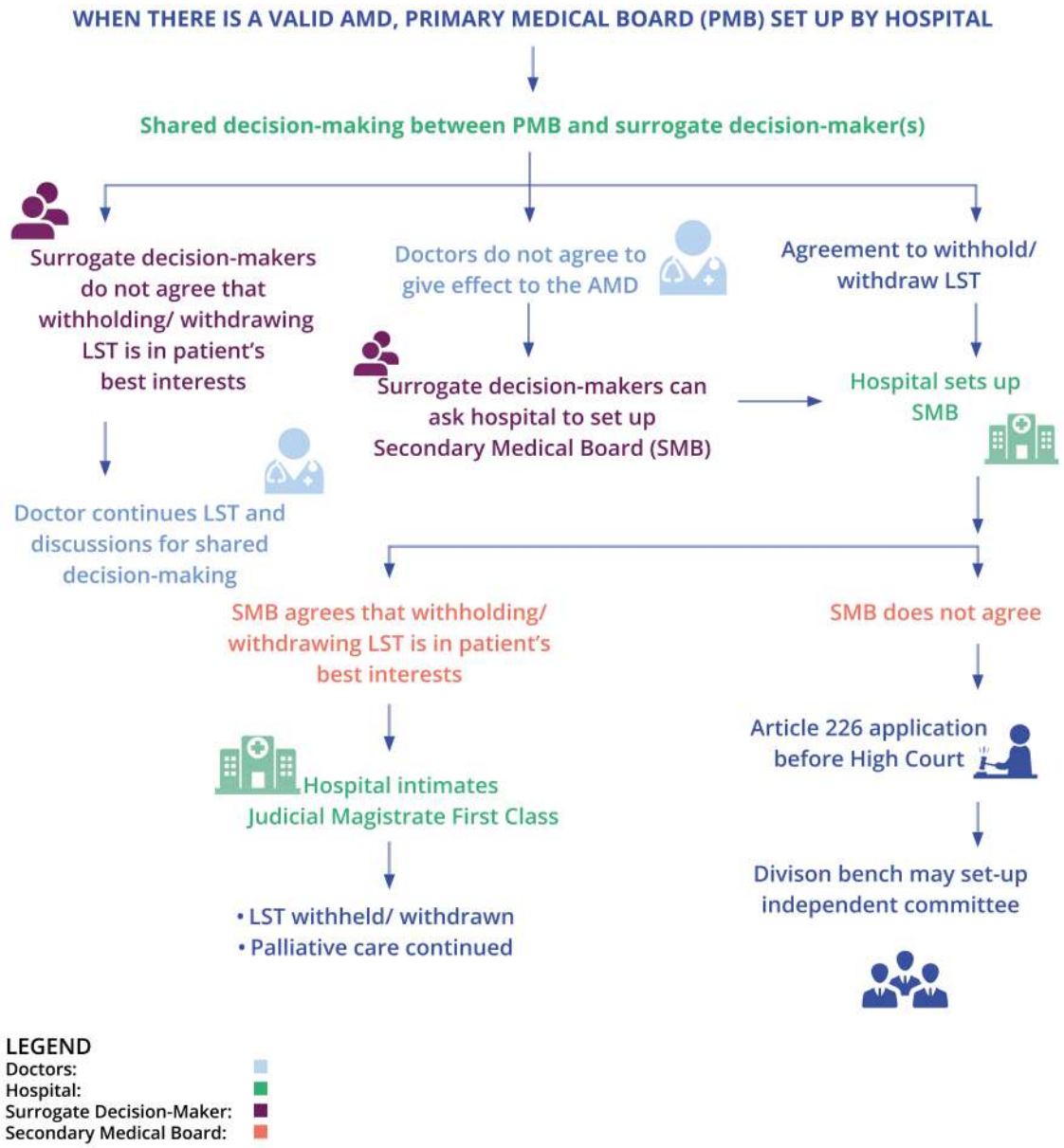

Flowchart 1: Process for implementing AMDs

to take decisions about their healthcare. If they have not made an advance medical directive in which they have expressed their wishes about certain kinds of treatment, a decision will have to be made about providing or continuing certain kinds of life-sustaining treatment.

This decision will be made jointly by the treating doctor/team and the patient's family or other representative.

The decision must be made in the patient's best interests. If providing or continuing such treatment is likely to cause more harm than benefit to the patient, it can be withheld or withdrawn. In such cases, the patient will be provided pain management and other comfort care and allowed to have a natural death.

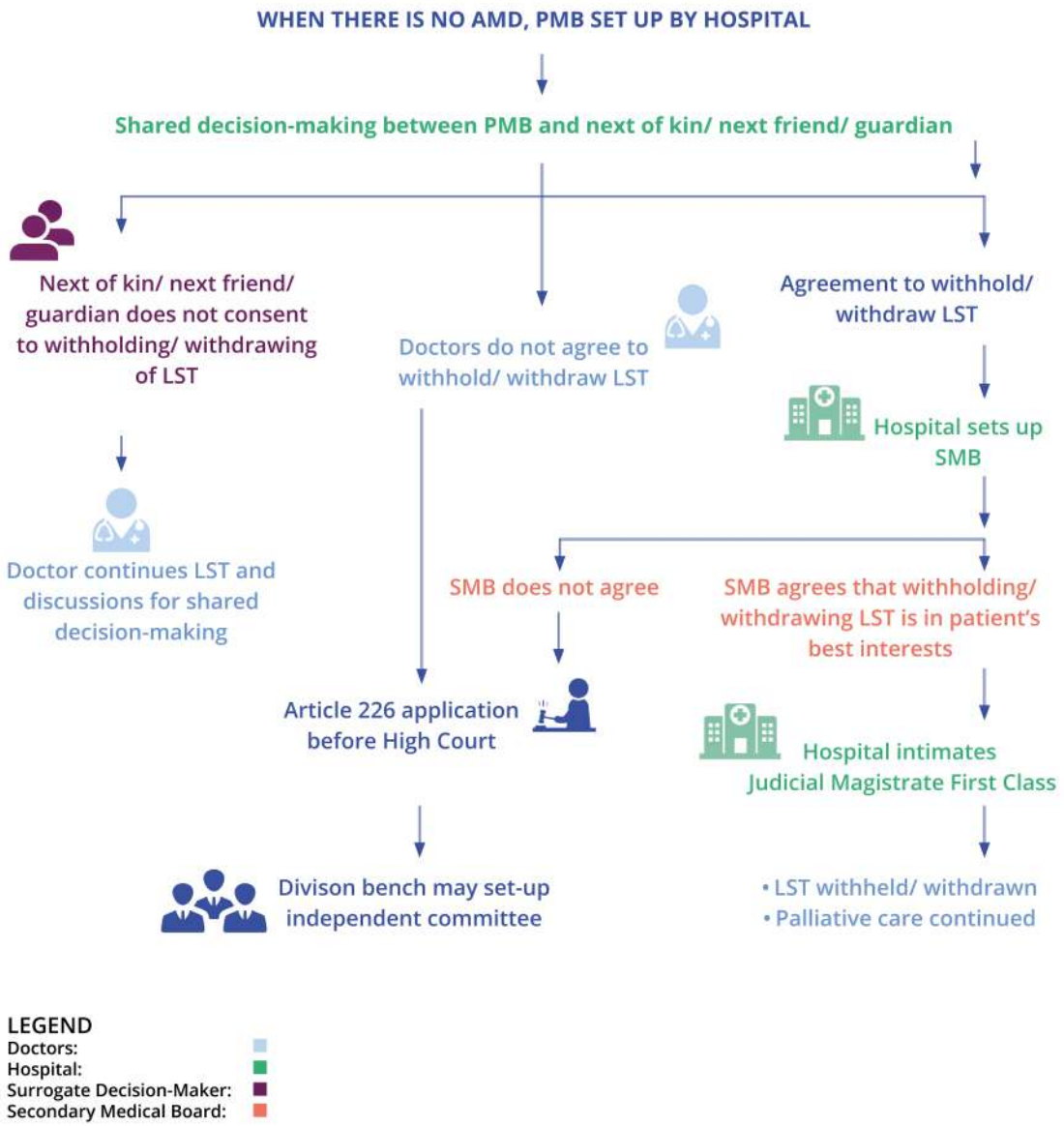
The Supreme Court has laid down guidelines for different actions related to care and medical treatment at the end-of-life.




Flowchart 2: Process for implementing AMDs

**What is shared decision-making?**
A dynamic exercise in which the healthcare team, for a patient without capacity, undertakes shared decisions with an appointed proxy/family regarding the medical treatment of a patient. *(Source: Indian Society of Critical Care Medicine and Indian Association of Palliative Care: Expert Consensus and Position Statements for End-of-Life and Palliative Care in the Intensive Care Unit, 2024)*

**About primary medical board**
It is a board comprising treating doctor as well as at least two subject experts of at least 5 years' experience. It can be constituted by the hospital from among the treating team.




Flowchart 3: Process for withholding/withdrawal LST when there is no AMD

**About secondary medical board**
It is a board comprising one registered medical practitioner nominated by the district Chief Medical Officer as well as at least two subject experts of at least 5 years' experience. All members of the Secondary Medical Board must be different from those of the Primary Medical Board.

**Who is part of an independent committee?**
Medical experts with at least 20 years' experience to decide whether life-sustaining treatment should be withdrawn

# Chapter 2

# Doctors, Nurses and Other Healthcare Workers

## 2.1 Withholding and Withdrawal of Life-Sustaining Treatment

**1.** Are the withholding and withdrawal of life-sustaining treatment legally permissible?

Yes, there is no legal prohibition on withholding or withdrawing life-sustaining treatment. If the patient has the capacity to take decisions about their healthcare and refuses treatment, the treating team must respect their wishes, and withhold or withdraw life-sustaining treatment as requested. If the patient does not have the capacity to take such decisions, life-sustaining treatment can still be withheld or withdrawn in accordance with guidelines that the Supreme Court has laid down especially for this purpose.

**2.** Is there a legal difference between withholding and withdrawing life-sustaining treatment?

No, the Supreme Court's guidelines apply to both the withholding and withdrawal of life-sustaining treatment, and do not make any distinction between them. Please see the Ready Reckoner for more details.

**3.** Can medical treatment be withheld or withdrawn from a person in a persistent vegetative state?

Yes, medical treatment can be withheld or withdrawn from a person in a persistent vegetative state, in accordance with the Supreme Court's guidelines. The Court's guidelines apply to two categories of persons–first, terminally-ill persons without any hope of cure or recovery; second, the kind of situation dealt with in Aruna Shanbaug's case, i.e. a patient in a persistent vegetative state.

### 2.1.1 Brain stem death and withdrawal

**4.** Should life-sustaining treatment be withdrawn when a person is brain-dead? Can this be done even when the person or their family or other representative has not consented to organ donation?

Yes, life-sustaining treatment should be withdrawn when a person is brain-dead. Continuing to provide life-sustaining treatment to a brain-dead person is not in accordance with professional medical guidance. Consent for organ donation is not necessary to make a declaration of brain-stem death. In fact, the states of Kerala and Tamil Nadu explicitly require doctors to declare brain-stem death, irrespective of organ donation. Brain-stem

death must be declared in accordance with the process prescribed under the Transplantation of Human Organs and Tissues Act, 1994, as well as any additional requirements that individual states might have imposed.

**5.** When life-sustaining treatment is withdrawn from a brain-dead person, is it necessary to follow the Supreme Court's guidelines on withholding/withdrawal?

No, the Supreme Court's guidelines do not apply to the withdrawal of life-sustaining treatment from a brain-dead person. Only the process prescribed under the Transplantation of Human Organs and Tissues Act, 1994, as well as any additional requirements relevant to a particular state, need to be followed in order to certify that a person is brain-dead, and to withdraw support after that.

### 2.1.2 Withholding or Withdrawal and Euthanasia

**6.** Is withholding/withdrawing life-sustaining treatment the same as euthanasia? Is euthanasia legal?

Withholding or withdrawal of life-sustaining treatment is not the same as euthanasia. However, many publications, including the Supreme Court's order refer to the withholding or withdrawal of life-sustaining treatment as 'passive euthanasia'. The use of the phrase 'passive euthanasia' is not recommended by experts. The withholding or withdrawal of life-sustaining treatment is legally permissible in India. Euthanasia, which refers to measures that are actively taken to bring about death, is not legally permissible in India. It is different from the withholding or withdrawal of life-sustaining treatment, where the underlying cause of illness is allowed to run its natural course.

**7.** Is palliative sedation legal?

Yes, it is. Under Indian law, doctors are not allowed, for any reason, to perform actions with the intent of bringing about the death of the patient. But palliative sedation, if done with the intent of relieving refractory symptoms and alleviating suffering in the process of dying, is legal in India.

**8.** Is physician-assisted dying legal?

No, it is not. Under Indian law, doctors are not allowed, for any reason, to perform any action with the intent of bringing about the death of their patient.

## 2.2 Decision-making capacity

**9.** Is there a legal standard to confirm that a patient has decision-making capacity?

Adults are presumed to have decision-making capacity unless there is reason to believe otherwise. It is incorrect to conclude that a person does not have decision-making capacity solely because they have a mental illness or a history of mental illness. While there is no definitive test to establish decision-making capacity under Indian law, section 4 of the Mental Healthcare Act 2017, provides guidance on decision-making capacity in relation to mental healthcare or treatment.

A person is said to have decision-making capacity in relation to that treatment if they are able to

- Understand information relevant to take a decision about treatment
- Appreciate the consequences of their decision or lack of it
- Communicate their decision whether through speech, expression, gesture or otherwise

**10.** Does a patient with Alzheimer's disease or dementia have decision-making capacity?

There is no absolute answer to this question. Whether such a patient has decision-making capacity depends upon the point in time at which the assessment is being made, the stage of the disease or condition in question, and the complexity of the decision regarding their treatment.

**11.** Can a patient refuse life-sustaining treatment?

If a patient has decision-making capacity, they have the right to refuse medical treatment, including life-sustaining treatment, even if the consequence of such refusal is death. The treating team, however, should ensure that they have given the patient all the information that is needed to make such a decision and that the patient has understood it, as well as the consequences of their decision. Expressly disregarding your patient's wishes and treating them despite their refusal is illegal and could make the treating team liable to civil as well as criminal legal action.

**12.** If my patient has verbally indicated their refusal of life-sustaining treatment, should I also obtain their written consent? Where and how should I record it? What do I do if my patient cannot sign?

If your patient is capable of providing their written consent, it is always advisable to obtain it. It should be documented in the patient's health records in a way that is accessible to all members of the patient's treating team. There is no official format for recording such consent, although you can refer to formats used by hospitals who have put in place end-of-life care protocols, as well as to the format set out in the guidelines of the Indian Council of Medical Research on Do Not Attempt Resuscitation orders.

If your patient cannot sign, you can use their thumbprints or record their consent through an audio-visual medium. If your patient is not literate, you should also obtain the signature of an impartial witness who can confirm that the patient has understood the information in the consent document.

**13.** My patient has an incurable illness which is in the terminal stages. They no longer wish to continue dialysis and have understood the consequences of their decision. Their family is not happy with this decision and want the dialysis to continue. Do I need the family's consent before stopping the treatment?

No, you do not need the family's consent before stopping the treatment if the patient has decision-making capacity. A patient with decision-making capacity has the right to take decisions about whether to begin, continue or stop a particular treatment.

Nevertheless, it is good practice to counsel family members about this and to hold joint meetings with them and the patient to explain the reason for the decision.

**14.** My patient has been diagnosed with Stage IV pancreatic cancer. Her family members do not wish me to tell her about her diagnosis because they do not want her to feel anxious. Am I bound to respect their wishes?

You must first assess whether your patient has decision-making capacity regarding healthcare. If she does have such capacity, you may then ask her whether she wishes to receive information about her condition and to what extent. If she refuses, ask her to indicate her preferred surrogate decision-maker, and proceed to communicate with them.

However, if she wishes to receive information, you have a duty towards her to provide it, irrespective

of her family members' wishes.

Observe best practices on communication while conveying such information to the patient or her surrogate decision-makers.

**15.** If my patient no longer has decision-making capacity, how do I make a decision about withholding or withdrawing life-sustaining treatment?

If your patient no longer has decision-making capacity, you should inquire whether they have made a valid advance medical directive. If yes, you should verify whether it is genuine and authentic, and then decide whether to withhold or withdraw life-sustaining treatment in accordance with the Supreme Court's guidelines.

If there is no valid advance medical directive, you should be guided by the patient's best interests and make a decision about withholding or withdrawing life-sustaining treatment, also in accordance with the Supreme Court's guidelines.

In both cases, the Court's guidelines require the approval of two boards of medical experts and the consent of the patient's family/surrogate decision-maker.

**16.** If my patient has decision-making capacity and refuses life-sustaining treatment, do the Supreme Court's guidelines still apply to withholding or withdrawing such treatment?

No, the process laid down in the Supreme Court's guidelines is not applicable when your patient has decision-making capacity and refuses life-sustaining treatment.

In such cases, maintain appropriate case notes that document your own assessment of the patient's condition. Ensure that you have provided the patient with all the information that is relevant to their decision and document this as well. Finally, obtain and record the patient's consent to the withholding or withdrawal of life-sustaining treatment.

## 2.3 Surrogate Decision-Makers

**Who can be a surrogate decision-maker?** A surrogate decision-maker is empowered to decide or opine on your behalf when you do not have decision-making capacity. You can choose any adult person to be a surrogate decision-maker, and name them in your advance medical directive. They do not need to be your spouse, parent, child, or a person related to you in any capacity.

**17.** If my patient loses decision-making capacity, how do I identify who is authorised to take decisions on their behalf regarding withholding or withdrawing life-sustaining treatment?

If your patient has a valid advance medical directive, it will contain the names of the persons authorised to take decisions on their behalf, in order of preference. It may be the case that these named persons are not family members of the patient. You should be guided by their wishes, even if the patient's family members express a different opinion.

If there is no advance medical directive or other named surrogate decision-maker, some best practices that you can follow are:

- Consult the person whom your patient may have indicated to you as their preferred surrogate decision-maker;
- Consult the persons who are regularly visiting and attending to the patient at the hospital. Typically, such persons include a spouse or a person with whom the person has a relationship in the nature of marriage, children, parents, siblings, grandparents and

grandchildren.

- Enquire if there are any other persons who might not be physically present, but who should also be consulted, for example, a son or daughter living abroad.
- If there are no identifiable family members, consult any other person who has regularly been visiting to and attending to the patient at the hospital, and confirm with such person that there are no known family members who should be consulted.

Please note that Indian law does not tell us who the default next of kin/next friend/guardian should be in a healthcare context when the patient loses decision-making capacity. This allows doctors and hospitals to develop their own protocols to govern such situations. For example, the All India Institute of Medical Sciences suggests consulting the following persons, in order of preference:

- spouse/de facto spouse/ friend of long-standing regularly visiting and attending to the patient
- available adult sons and daughters
- parents
- adult siblings
- any other lineal ascendants/descendants of the patient who are regularly present in hospital

Exercise your discretion and rely on your experience in identifying key decision-makers. You are not obliged to consult every distant relative who visits the patient at the hospital. At the same time, where there is no advance medical directive naming a surrogate decision-maker, do not take a decision to withhold or withdraw while there are strong differences between key decision-makers, for example, a spouse and an adult son, or between two siblings. Continue to hold meetings and communicate with the relevant decision-makers to arrive at a consensus.

**18.** My patient's wife, mother, and daughter all attend to him in the hospital and I have had discussions with all of them about his treatment because the patient himself no longer has decision-making capacity. I am now of the opinion that life-sustaining treatment should be withdrawn and need the consent of his family. Do I need the consent of all three members? If not, which family member will take precedence?

If your patient has a valid advance medical directive, you will need the consent of the person named in the directive as the person authorised to take decisions on their behalf. If there is no valid advance medical directive, it would be good practice to continue to have discussions with all three family members and aim to achieve consensus among them regarding the withdrawal of life-sustaining treatment. No single family member will take precedence unless the patient himself has communicated to you that one of them is his preferred surrogate decision-maker. It is advisable not to withdraw life-sustaining treatment while there are strong differences of opinion among the available family members. If your hospital has a Clinical Ethics Committee, you may consider using it to help resolve such differences.

**19.** I have a critically ill patient in the ICU. Multiple family members attend to him and different members have been a part of different meetings with the treating team. At our last meeting, where we discussed a 'Do Not Attempt Resuscitation' order for the patient, I asked whichever family members were present to sign a document confirming that they represented the entire family's wishes regarding treatment decisions. Will this protect me from legal liability if a family member who was not present at the meeting objects later?

When dealing with multiple and different family members at different times, it might be helpful first to identify key decision-makers among them. For example, make best efforts to enquire about a spouse or partner, adult children, parents and siblings, and attempt to convene a family meeting with as many such key decision-makers as possible. The patient may also have previously indicated his preferred surrogate decision-maker to you or someone in your treating team.

If you know that a key decision-maker is not present, and if it is possible to wait, hold off on meetings where important decisions like 'Do Not Attempt Resuscitation' are to be taken until such a person can attend, whether physically or virtually.

**20.** My patient has named her friend as her surrogate decision-maker in her advance medical directive. She has consented to the withdrawal of life-sustaining treatment in accordance with the directive, but her family disapproves. Can I still proceed with withdrawal?

Yes. If the patient has made a valid advance medical directive naming her friend as the person authorised to take decisions on her behalf, then you need only obtain the friend's consent regarding the withholding or withdrawal of life-sustaining treatment.

Nevertheless, it would be good practice to counsel family members about this, even if you are not formally required to obtain their consent.

**21.** My patient has advanced pulmonary fibrosis and is no longer able to make decisions about her treatment. She has only two adult family members–a daughter, whom she lives with, and a son, who lives abroad. Her daughter would like aggressive treatment to be withheld, but her son disagrees and wants everything possible to be done. How do I resolve this difference? Can I withhold treatment against the son's wishes?

You should continue to build consensus between the two family members, observing best practices on communication. If your hospital has a Clinical Ethics Committee, you may consider using it to help resolve such differences.

As a doctor, you cannot be compelled to provide medical treatment that you do not believe to be in the best interests of the patient. If you are withholding life-sustaining treatment, please comply with the Supreme Court's guidelines, which requires two boards of medical experts to agree that withholding such treatment would be beneficial to the patient. Until the son's consent to withholding life-sustaining treatment has been obtained, continue to treat the patient in accordance with the most up-to-date professional medical guidelines.

**22.** My patient's advance medical directive names multiple people authorised to take decisions on his behalf. Do I require consent from all of them before implementing the directive?

Advance medical directives are supposed to list persons authorised to take decisions on their behalf in order of preference. You should first contact the person who is listed as the first preference by your patient. Only if this person is not available should you go on to contact the next person and so on.

**23.** What should we do if the patient meets the criteria for withholding or withdrawal of life-sustaining treatment but none of the persons named in the patient's advance medical directive is available?

Until you are able to find the persons named in your patient's advance medical directive, you must continue to provide medical treatment in the best interests of the patient and in accordance with the most up-to-date professional medical guidelines.

If the persons named in your patient's advance medical directive continue to remain unavailable, you should identify the patient's surrogate decision-maker as if there were no advance medical directive. A decision about withholding or withdrawing life-sustaining treatment will require the consent of such surrogate decision-maker, in accordance with the Supreme Court's guidelines.

**24.** What should the treating team do when there is neither an advance medical directive nor any identifiable family/surrogate decision-maker?

In such instances, the hospital can consider making an application to the High Court under Article 226 of the Constitution of India to withhold or withdraw medical treatment. The High Court will either appoint a guardian who can take decisions about withholding or withdrawing medical treatment, or will take such decision itself by acting as the guardian of the patient. In any case, the High Court will set up an independent committee of expert doctors to assist with its decision.

## 2.4 Advance Care Planning

**25.** What is advance care planning? Is it different from an advance medical directive?

Advance care planning is a process through which the goals of care are mutually decided through discussion between the patient and their doctor or treating team, if the patient has decision-making capacity. The discussion is held with the patient's family/surrogate decision-maker if the patient lacks capacity.

Advance care planning is typically undertaken when a patient is diagnosed with a terminal illness or a progressive condition. It involves a discussion about the patient's prognosis, the different treatment options available, and the resultant quality of life that the patient can expect. It also involves a discussion of the patient's values, preferences and wishes regarding the kind of treatment they would or would not like to receive.

It may be the case that a patient makes an advance medical directive as an outcome of advance care planning. However, they may also choose not to, in which case, the decisions mutually agreed on are recorded in the patient's health records. These will act as a guide for the treating team should the patient lose decision-making capacity in the future.

### 2.4.1 Advance Medical Directives

**26.** What is an advance medical directive?

An advance medical directive, often referred to as a living will, is a document in which you can record your wishes about your medical treatment in the future. This document is intended to be used only at a time when you are not able to take decisions on your own about your medical treatment. This might be because you no longer have the capacity to understand information provided to you, to analyse such information, and on that basis, to decide whether or not you wish to receive certain kinds of medical treatment.

People lose such decision-making capacity for a variety of reasons—they may be in a coma, or have dementia, or be under the influence of medication that doesn't allow them to think clearly,

or may simply have lost consciousness. In such situations, a living will can act as a guide to the team of doctors, nurses and other healthcare practitioners treating such patients, by giving them an indication of the kind of medical treatment the patient may or may not have wanted.

**27.** My patient is terminally-ill but has not made an advance medical directive. Should I ask them to make one?

It is good practice to encourage patients who are terminally ill or with a progressive disease to make advance medical directives. These directives can act as useful guides if there are decisions to be made in the future about withholding or withdrawal of medical treatment.

Even if your patients do not wish to make advance medical directives formally, it would be good practice to undertake advance care planning. This involves enquiring about their wishes regarding withholding or withdrawal of medical treatment at a time when they are still capable of making such decisions. These wishes can then be noted in the patient's health records.

**28.** Do I have a duty to inquire about the existence of an advance medical directive?

If your patient is terminally ill or has a progressive disease, and still has decision-making capacity, it is good practice to ask them whether they have made an advance medical directive, and to request them for a copy of it for your records. This will allow you to be prepared should they lose decision-making capacity in the future and you are required to take a decision about the withholding or withdrawal of life-sustaining treatment.

If your patient has already lost decision-making capacity and you are required to take a decision about the withholding or withdrawal of life-sustaining treatment, the Supreme Court's guidelines technically impose an obligation on the treating doctor only to determine whether an advance medical directive is genuine or authentic when they are made aware of its existence. Although this makes it seem that the treating team does not have a legal obligation to find out about the existence of an advance medical directive, it would still be good practice for them to ask the patient's next of kin/next friend/guardian whether the patient had executed such a document.

**29.** How can I incorporate my patient's advance medical directive in a digital health record?

If your hospital has a system in place for maintaining digital health records, it should be possible to incorporate a scanned copy of your patient's advance medical directive in the records. Once it is incorporated, do make sure that it is available to everyone at the hospital who needs to access the patient's health records. Ideally, it should also be available, with the patient's consent, to any other hospital or doctor to whom the patient wishes to transfer.

**30.** Am I legally bound to carry out the wishes mentioned in my patient's advance medical directive?

There are several conditions that must be met under the Supreme Court's guidelines before you can give effect to the wishes expressed in your patient's advance medical directive.

First, as your patient's primary treating doctor, you must assess whether the patient is terminally ill or in a persistent vegetative state and has no hope of cure or recovery.

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If this criterion is met, you should also be satisfied that withholding or withdrawing life-sustaining treatment, as expressed in your patient's advance medical directive, is in their best interests. This opinion must be confirmed by two boards of medical experts.

↓

The named surrogate decision-maker in their advance medical directive must also consent to the withholding or withdrawal of life-sustaining treatment, where such withholding or withdrawal is in furtherance of the patient's wishes in their directive.

↓

You are not legally bound to give effect to an advance medical directive that is not valid. You must be guided by the patient's best interests in such a case.

### 2.4.2 Verifying the genuineness and authenticity of Advance Medical Directives

**31.** The Supreme Court's guidelines require the treating physician to verify whether an advance medical directive is genuine or authentic. How should I do that?

There is no official procedure in place yet to verify the genuineness and authenticity of advance medical directives. The guidance in this document consists of good practices that you can follow until your local authority or state government or the central government prescribes an official process.

If your patient's next of kin/next friend/guardian hands over an advance medical directive to you, you should check whether a copy of this directive already exists as part of the digital health records of the patient, if any, that are being maintained by your hospital. If it does, you should compare the directive handed over to you with the one incorporated in the digital health records, and make sure that they are identical.

If no such copy exists in the patient's digital health records, you should ask the patient's next of kin/next friend/guardian for details of the custodian with whom the patient's advance medical directive has been deposited. The custodian is an officer nominated by the local government (panchayat or municipality or municipal corporation) to store copies of advance medical directives so that they can assist doctors and hospitals in determining whether the directives are genuine and authentic.

Once you receive the custodian's details, you can ask them to confirm whether the directive in your possession is genuine and authentic.

If neither of these options is available, for example, no copy of the directive has been incorporated in the digital health records of the patient or no custodian has been appointed, there are still steps that you can take to determine whether an advance medical directive shared with you is at least valid. An advance medical directive is valid only if:

- It is made by a person when they were at least 18 years old
- It is signed by all the persons who are required to sign it, i.e. the person making the directive, the two witnesses, and the notary or the Gazetted officer
- It names the persons who are authorised to take decisions on behalf of the patient.

If the advance medical directive does not meet any one of these criteria, it is not a valid document and you are not required to give effect to it.

**32.** How do I find out whether our local government has nominated an officer as the custodian of advance medical directives and who they are?

You can write a letter addressed to the head of your local government (Commissioner, Sarpanch/President) enclosing a copy of the latest Supreme Court order on this issue, dated January 24, 2023.

In your letter, you may state that the Supreme Court of India, in an order dated January 24, 2023 (Miscellaneous Application No. 1699 of 2019 in Writ Petition (Civil) No. 215 of 2005), at paragraph 198.3.6, has stated that local governments must nominate an official to act as the custodian of advance medical directives. You should also state that, as a doctor/hospital, you are required to ascertain the genuineness and authenticity of advance medical directives from this custodian. In accordance with this order of the Hon'ble Court, you should request the local government to nominate an official to act as such custodian.

If you have an advance medical directive whose genuineness and authenticity you wish to verify, you should also forward a copy of this directive along with your letter.

In Maharashtra, the Urban Development Department has also notified a list of the custodians across all local bodies in the State, as of 5 March 2024.

### 2.4.3 Do Not Attempt to Resuscitate Orders / DNAR / DNR

**33.** What is a DNR/DNAR order? Do the Supreme Court's guidelines on withholding/withdrawing life-sustaining treatment apply to DNR/DNAR orders?

A DNR/DNAR order is a decision to withhold cardio-pulmonary resuscitation from a patient. It is made by the treating team in consultation with the patient or their family/surrogate decision-maker. It is a decision to withhold a specific type of life-sustaining treatment. The Supreme Court's guidelines apply to DNR/DNAR orders in the same way that they apply to decisions to withhold other types of life-sustaining treatment.

**34.** What is the legal validity of the guidelines issued by the Indian Council of Medical Research on Do Not Attempt Resuscitation orders?

Guidelines issued by the Indian Council of Medical Research (ICMR) in relation to the treatment of patients are in the nature of standard treatment guidelines, and should be treated in the same way as guidance issued by a professional body of medical experts. They carry added weight because of the official nature of the ICMR.

The ICMR's guidelines on Do Not Attempt Resuscitation orders (DNAR orders) continue to be valid for patients with decision-making capacity. However, for patients without decision-making capacity, the ICMR guidelines will have to be modified in light of the new guidelines laid down by the Supreme Court in 2023.

As a result, DNAR orders will require the consent of the person named in the advance medical directive or the patient's next of kin/next friend/guardian if there is no valid directive. They will also require the approval of two boards of medical experts and the intimation of the DNAR order to a judicial magistrate, in the same way as these requirements apply to other instances of withholding life-sustaining treatment.

## 2.5 Implementing the Supreme Court's guidelines

**35.** What are the responsibilities of the treating doctor of a terminally ill patient without hope of cure or recovery?

- If your patient has decision-making capacity, undertake advance care planning to arrive at goals of care, such as making decisions about withholding or withdrawing life-sustaining treatment in the future. Provide them with appropriate information to help them arrive at an informed decision.
- Record these discussions and decisions in the patient's health records.
- Encourage your patient to make an advance medical directive, preferably as an outcome of advance care planning.
- If your patient has decision-making capacity, respect their decision to refuse life-sustaining treatment.
- Keep track of your patient's decision-making capacity.
- Assess whether providing or continuing life-sustaining treatment would be beneficial to your patient in accordance with the most up-to-date professional medical guidance/standard treatment guidelines.
- If your patient loses decision-making capacity, inquire about the existence of an advance medical directive. When made aware of its existence, find out whether it is genuine and authentic.
- If you are of the opinion that withholding or withdrawing life-sustaining treatment is in the patient's best interests, request your hospital to set up a board of experts to confirm this opinion.
- Identify the persons authorised to take decisions on your patient's behalf, whether these are persons named in an advance medical directive or other identified surrogate decision-makers. Provide them as well with the appropriate information to help them arrive at an informed decision.

**36.** My hospital does not have a process in place for setting up a Primary Medical Board. What can I do about patients for whom I have to make a decision about withholding or withdrawing life-sustaining treatment?

According to the Supreme Court's guidelines, the Primary Medical Board should consist of the treating doctor as well as two subject experts with at least 5 years' experience. In large, tertiary care hospitals, it is common to have a multidisciplinary team for critically ill patients. The Primary Medical Board can be set up from among the members of the treating team, provided the members meet the criteria set out in the Supreme Court's guidelines.

As the treating doctor, you can consult with other members of your treating team and record their opinions about withholding or withdrawing life-sustaining treatment. This can then be presented to your hospital administration as the opinion of the Primary Medical Board.

You can also draw the attention of your hospital administration to Vidhi's Hospital Guide, as well as end-of-life care policies and processes set up by other hospitals as well as to guidance from professional medical bodies to assist them in setting up a Primary Medical Board.

**37.** My hospital does not have a Secondary Medical Board. As the treating doctor, can I still withhold or withdraw life-sustaining treatment?

You should first get in touch with your hospital administration to understand the barriers to setting up a Secondary Medical Board. If the reason is a lack of awareness, you can assist them by referring them to the Supreme Court's guidelines, end-of-life care policies and processes set up by other hospitals, as well as to guidance from professional medical bodies.

If the situation demands that you act immedi-

ately in the best interests of the patient, the hospital may set up both the Primary and Secondary Boards to the best of its capability, ensuring that all the persons appointed to such Boards are experts with at least 5 years' experience. The non-availability of a doctor nominated by the district Chief Medical Officer should be recorded in the case notes and the hospital should maintain records of all its communications with the relevant authorities requesting the nomination of a doctor to the Secondary Medical Board.

Alternatively, the treating doctor of the hospital may also file a petition in the relevant High Court to withhold or withdraw life-sustaining treatment in the best interests of your patient.

## 2.6 Conflict and Legal Liability

**38.** Is there a risk that I will face legal action from a patient's relatives who claim that they were coerced by us into withdrawing life-sustaining treatment?

It is important to ensure that patients and their family members understand the rationale underlying a decision to withhold or withdraw life-sustaining treatment. The possibility of litigation is a feature of any professional practice, whether or not you are providing end-of-life care. You can mitigate those risks by building consensus, following the prescribed legal protocols, keeping clear and comprehensive records, communicating decisions clearly, and following best practices. See here for a more comprehensive set of duties for doctors in charge of treating terminally-ill persons.

**39.** Who will be responsible if an action is brought by a patient's relatives for what they believe to be inappropriate withdrawal of life-support? The hospital, the Primary and Secondary Medical Boards or individual doctors?

Actions like this are typically brought against the hospital as well as individual doctors that the litigants believe are responsible for any alleged wrongdoing. The Primary and Secondary Medical Boards are not separate legal entities themselves. The hospital is required to set them up, and any action that is brought will typically lie against the hospital itself as well as the individual doctors who are members of these Boards.

The court will look at the situation as a whole, examine whether the appropriate steps were taken, decide whether the resulting harm, if any, can be attributed to the actions of the doctors or the hospital, and fix responsibility accordingly. For example, hospitals will have to take responsibility for delays in setting up a Primary or Secondary Medical Board or failing to appoint the appropriate experts. Individual doctors could be held liable for failing to act in accordance with professional guidelines on withholding or withdrawing life-sustaining treatment. The hospital and doctors might both have to take joint responsibility for failing to obtain the consent of the patient's relatives to the withholding or withdrawal of life-sustaining treatment.

**40.** As the patient's treating doctors, we do not think that initiating, escalating or continuing further life-sustaining treatment is beneficial. However, the family insists that such treatment be provided or continued. What should we do?

If the person named by your patient in their advance medical directive or their surrogate decision-maker (where there is no valid advance medical directive) does not consent to the withholding or withdrawing of life-sustaining treatment, you should continue your current treatment and care of the patient.

You may initiate more discussions with the representatives of the patient to see if you can reach an agreement about withholding or withdrawing life-sustaining treatment. If no agreement can be reached, you should continue your ongoing course

of treatment.

However, do note that you cannot be compelled to provide treatment that you do not believe to be in the patient's best interests. For example, the patient's family cannot demand that an ECMO machine be used. In such a scenario, you should suggest that the patient be transferred to another hospital and continue to provide appropriate treatment and care until the transfer is effected.

### 2.6.1 Leave against medical advice/discharge against medical advice

**41.** The family of a terminally-ill patient admitted to a tertiary care hospital wishes medical treatment to be discontinued, and for the patient to be discharged. The patient's treating team does not agree with this decision, and believes that continuing treatment may be beneficial for the patient. Can the patient be 'discharged against medical advice'?

Treatment cannot be provided against the wishes of the patient's family members. Continue to communicate with the patient's family to understand their reasons for wishing to discontinue treatment and make every effort to arrive at a consensus. If the family wishes to discontinue treatment for financial reasons, discuss different options with them, within and outside the hospital, to see what will work in the best interests of the patient. In particular, discuss the option to move to palliative and comfort care.

**42.** Once ventilation is withdrawn against medical advice, does the treating team have any other obligations towards the patient and their family/surrogate decision-maker?

Yes, it is the duty of the treating team to make appropriate arrangements for them to receive comfort care from the point of discharge till the next place that the patient is being taken to.

## 2.7 Withholding or withdrawal of life-sustaining treatment in children

**43.** Is it legal to withhold or withdraw life-sustaining treatment in children?

Yes, life-sustaining treatment can be withheld or withdrawn in children in accordance with the Supreme Court's guidelines.

**44.** Does the procedure prescribed by the Supreme Court–approval of two medical boards and intimation to the judicial magistrate–apply to the withholding/withdrawal of life-sustaining treatment in children?

Yes, this procedure applies to children as well. Since children cannot make advance medical directives, that part of the Supreme Court's guidelines titled 'Cases where there is No Advance Directive' will apply to children in whom a decision about withholding or withdrawing life-sustaining treatment has to be made.

**45.** Is the child's consent required to withhold or withdraw life-sustaining treatment?

If the child, irrespective of their age, has decision-making capacity, assess whether they would like to receive information about their condition and to participate in decisions about their treatment.

If they wish to participate, convey information about withholding or withdrawing life-sustaining treatment in a sensitive, age-appropriate way, with their parents or legal guardians present.

Please note that the child's assent, by itself, will not be sufficient to withhold or withdraw life-sustaining treatment. The consent of their parents or legal guardians is necessary.

**46.** Is the consent of both parents required to withhold or withdraw life-sustaining treatment in children? What if there is a difference of opinion between the parents?

As is the case when there are multiple surrogate decision-makers for adult patients, the consent of both parents should ordinarily be obtained before withholding or withdrawing life-sustaining treatment in children.

No decision to withhold or withdraw life-sustaining treatment should be taken if there is a difference of opinion between the parents. Communication and a process of shared decision-making should be continued to reach a consensus. If the hospital has a Clinical Ethics committee, it could be used to resolve differences between the parents.

## 2.8 At-home End-of-Life Care

**47.** I am a palliative care physician who makes home visits. I have an elderly patient with a progressive lung disease. Should the need arise, she does not wish to be ventilated, and we have accordingly agreed on a treatment plan. Do we need anyone else's consent or approval to carry this plan out?

This treatment plan has been made with a patient who has decision-making capacity. Her decision to refuse a particular kind of treatment must be respected. This plan does not require the consent of a family member or any other person, although they should be informed of the plan, the reasons underlying it, and the chosen course of action should the need for ventilation arise. This plan does not require the approval of two boards of medical experts as required by the Supreme Court's guidelines. This is because this plan has been made by a person with decision-making capacity.

**48.** I am a palliative care physician attached to a hospital that provides 'home-ICU' services. One of my patients is on a ventilator at home, but her family and I agree, given her prognosis, that withdrawing the ventilator and moving her to palliative care would be in her best interests. Can we do this without setting up two medical boards and informing the judicial magistrate?

No, in this case, the correct course of action would be to comply with the Supreme Court's guidelines. Even though the patient is at home, there is no substantive difference between her situation and a patient like her who is admitted to an ICU. Apart from the physical location, this patient is for all intents and purposes, admitted to a hospital.

The withdrawal of the ventilator would require the approval of the Primary and Secondary Medical Boards, whose members will have to visit the patient at home. The decision to withdraw the ventilator will also have to be communicated to the relevant judicial magistrate.

**49.** I am a palliative care physician who makes home visits. One of my patients is in a persistent vegetative state and receives artificial nutrition through a PEG tube. I have discussed withdrawing the PEG tube with her family, but they are concerned about the legality, even though we agree that it would be in her best interests. What advice do I give them?

You should let the family know that there is no legal barrier to withdrawing the PEG tube, as long as this is in the patient's best interests.

The question in this case is whether the withdrawal of the PEG tube should comply with the Supreme Court's guidelines, i.e. whether it requires the approval of two boards of medical experts and the consent of the family/surrogate decision-maker. However, the Court has not provided a clear answer for a situation like this.

There are two options that you could provide her family: First, that the withdrawal of the PEG tube should take place after admitting the patient to the hospital, in which case it is clear that the withdrawal will take place in accordance with the Supreme Court's guidelines.

Second, that even if the withdrawal is to take place at home, the approval of two boards of medical experts should be obtained and the decision to withdraw should be intimated to the relevant judicial magistrate. As the attending physician, you can request a hospital that you are attached to or associated with to constitute these two boards for this purpose.

# Chapter 3

# Patients and Caregivers

## 3.1 End-of-Life Care and Palliative Care

**50.** What is end-of-life care?

It is an approach to the care of terminally ill patients where the emphasis is on comfort, the management of symptoms, the quality of life and the dying process rather than on curing the illness or prolonging life.

Source: Definition of terms used in limitation of treatment and providing palliative care at end of life (Indian Council of Medical Research 2018).

**51.** What is palliative care?

Palliative care is an approach that focuses on improving the quality of life of patients and their caregivers, with an emphasis on preventing and relieving suffering. Palliative care is not only about providing medical treatment. It also addresses the psychological, social and spiritual issues that patients (and caregivers) of chronic, incurable, or life-threatening diseases face.

Source: Definition of terms used in limitation of treatment and providing palliative care at end of life (Indian Council of Medical Research 2018).

A person with end stage renal disease chooses to stop dialysis and opts for palliative care. They will receive painkillers to manage their symptoms, counselling for their mental state of mind, and advice on diet and nutrition that is best suited to their condition. Their family may also receive counselling to prepare them for their loved one's death. All of this is palliative care.

**52.** Are palliative care and end-of-life care the same thing?

Palliative care is broader than end-of-life care. It does not mean that someone is dying simply because they are receiving palliative care. It can apply to non-terminal illnesses too, including chronic diseases such as diabetes or rheumatoid arthritis. Even in patients with terminal illnesses, palliative care can be provided several months or even years before a person is close to death.

End-of-life care, on the other hand, is the care that is typically provided in the last 6 months of a person's illness. Unlike palliative care, which can be provided side by side with curative treatments, end-of-life care does not aim to provide a cure or prolong life.

## 3.2 Advance Care Planning and Advance Medical Directives

**53.** What is advance care planning?

Advance care planning involves discussing and preparing for future decisions about your care and medical treatment if you become seriously ill and unable to communicate your wishes. Such planning involves conversations with your doctor or treating team as well as your loved ones.

Through advance care planning, your doctor or treating team can give you more information on the nature of your illness, how it is likely to progress, and the different options available to you. They, as well as your loved ones will have an opportunity to learn about your values and preferences, especially the kind of treatment that you might not want to receive. This can guide them at a point in the future when you may no longer be able to take decisions about your healthcare.

Advance care planning could simply involve verbal conversations. If there are certain decisions that are taken as an outcome of these conversations, they might be recorded by your doctor or treating team in your health records.

You could also choose to record your preferences by executing an advance medical directive or a living will.

*Source: National Institute of Aging, United States of America*

**54.** What is an advance medical directive?

An advance medical directive, sometimes referred to as an "advance directive", "advance healthcare directive" or 'living will" is a document in which you can record your wishes about your medical treatment in the future and nominate someone to take a decision on your behalf at a time when you are not able to make decisions on your own about your medical treatment. This could occur because you no longer have the capacity to understand information provided to you, to analyse such information, and on that basis, to decide whether or not you wish to receive certain kinds of medical treatment.

People lose such decision-making capacity for a variety of reasons and to varying degrees — they may be in a coma, or have dementia, or be under the influence of medication that doesn't allow them to think clearly, or may simply have lost consciousness. In such situations, your living will can act as a guide to your doctor or treating team, as well as your family or any other person taking decisions for you, by giving them an indication of the kind of medical treatment you may or may not have wanted.

**55.** Is there a difference between an advance medical directive and a living will?

A 'living will' is simply another term for an 'advance medical directive' or 'advance directive', or 'advance healthcare directive'. The term advance medical directive is used more commonly in official documents like hospital forms and records.

**Terminal Illness** An irreversible or incurable disease condition from which death is expected in the foreseeable future. Source: Definition of terms used in limitation of treatment and providing palliative care at end of life (Indian Council of Medical Research 2018).

**Persistent vegetative state** A form of altered consciousness in which the person appears to be awake but does not respond meaningfully to the outside world. Source: Harvard Health Online

**56.** Is there a difference between an advance medical directive and a healthcare power-of-attorney?

A healthcare power-of-attorney is an instrument through which you can authorise another person to take healthcare decisions on your behalf if you are no longer capable of taking such decisions yourself. This includes deciding the kind of medical care a person should receive, whether they should undergo a surgical procedure, and who their treating team should be.

In India, an advance medical directive is a specific kind of healthcare power-of-attorney–it gives authority to another person to take decisions about providing or discontinuing life-sustaining treatment in the case of terminal illness or when someone is in a persistent vegetative state.

## 3.3 Making Advance Medical Directives: Who, What, How, When

### 3.3.1 Capacity to Make Advance Medical Directives

**57.** Can anyone make an advance medical directive?

If you are an adult (18 years old and above), and if you have the capacity to take decisions about your healthcare, you can make an advance medical directive.

**58.** How do I know if I have the capacity to make decisions about my healthcare?

Whether a person has the capacity to take decisions about your healthcare is usually decided by answering the following questions:

Does the person in question understand the information that they need to be able to take a decision about their treatment? Do they understand the consequences of their decision? This includes deciding to opt for or to refuse treatment Can they communicate their decision? This could be by speaking or through a facial expression or a gesture or anything else that conveys their decision.

If the answer to all three questions is 'yes', there is capacity to take decisions about healthcare. It is not a legal requirement for a doctor to assess whether you have capacity before you make an advance medical directive, although it will help should someone raise a doubt about this in the future and challenge your directive.

It is sufficient to make a declaration in your advance medical directive that you have the capacity to take decisions about your healthcare.

**59.** Can I make an advance medical directive even if I have a mental illness?

Yes, provided that you meet the three conditions that are necessary to establish that you have the capacity to take decisions about your healthcare. Simply because you have a mental illness does not mean that you do not have such capacity.

**60.** Who needs an advance medical directive? When should you make one?

An advance medical directive is advisable for anyone (whether in good health or not) who would like to ensure that they receive treatment in accordance with their own wishes and preferences at a time when they are unable to take these decisions for themselves.

It can be made at any time by a person aged 18 and above. You do not have to visit a doctor or be in hospital in order to make an advance medical directive.

If you have been diagnosed with a condition that is likely to affect your ability to make healthcare decisions in the future, you should consider mak-

ing an advance medical directive once you have the information you need to enable you to make one. It is advisable to do this after discussions with your treating team as well as your loved ones.

### 3.3.2 Scope and Content

**61.** Can I make an advance medical directive for all healthcare / medical decisions?

There are two specific types of advance medical directives that the law in India recognises:

- A directive that will apply in the case of terminal illness or a persistent vegetative state when decisions have to be made about providing or discontinuing life-sustaining treatment
- A directive where you can express your wishes and preferences and appoint someone to take decisions about the treatment of a mental illness

Under Indian law, there is no specific provision for a directive about other kinds of healthcare/medical decisions that need to be taken at a time when you do not have the capacity yourself. This does not mean that there is a bar on making directives like this, it is just that the law does not have a process in place for making them or giving effect to them.

Instead, in such instances, your doctor is likely to consult with the person on hand who seems to be the most credible surrogate decision-maker–your spouse/partner, other family members, or a friend or guardian if the others are not available.

**62.** Can I refuse any kind of medical treatment in my advance medical directive?

Yes, you cannot be compelled to accept any kind of medical treatment against your wishes. The following are some examples of the kinds of medical treatment that you can refuse in your directive (this is not an exhaustive list):

- Intravenous fluids or medication, including antibiotics
- Artificial feeding - by a nasogastric tube or a gastrostomy
- Blood transfusion
- Dialysis
- Artificial respiration, including mechanical ventilation - being put on a mechanical ventilator that breathes for you when you cannot breathe on your own
- Cardio-pulmonary resuscitation (CPR)
- Chemotherapy
- Surgery

Without naming any specific treatment, you can say that you wish to refuse any treatment that only has the effect of artificially prolonging your life, or causes more harm than benefit in the opinion of your treating team.

On the other hand, you may refuse only certain kinds of treatment (e.g. chemotherapy, CPR), while still wishing to receive others (e.g. ventilation, artificial nutrition and hydration) if your treating team thinks it might be of some benefit. In such cases, you must express your wishes very simply and clearly.

**63.** Can I request a particular kind of medical treatment in my advance medical directive?

You can state that you would like your treating team to manage your symptoms, provide you pain relief, and comfort care.

However, the treating team is not under any compulsion to offer medical treatment that they believe is not in your best interests. Therefore, your

advance medical directive cannot state that doctors must provide every available treatment in all circumstances. For example, you cannot demand the provision of extra-corporeal membrane oxygenation, irrespective of what your treating team believes.

**64.** How do I decide who to nominate in my advance medical directive to take decisions about my care and treatment on my behalf?

How do I decide who to nominate in my advance medical directive to take decisions about my care and treatment on my behalf? The Supreme Court of India has stated that you should nominate at least two persons who can take healthcare decisions on your behalf. You should name these persons in order of preference.

These persons should be at least 18 years old, familiar with your preferences regarding medical treatment, and should know and understand the values that are important to you. You should discuss your advance medical directive with whomever you choose to nominate.

You can nominate people outside your family, like friends or colleagues. However, in such cases, you should communicate this to your family members as well, so that they are aware of the persons you have nominated.

Preferably, you should nominate people who are able to be physically present at a hospital in the event of a medical emergency. Avoid nominating someone who does not live in the same country as you. It is also preferable that you nominate someone who is not likely to die before you are.

You should avoid nominating a member of your treating team. This is because the law requires your treating team to consult with the person named in your advance medical directive. If you nominate a member of the treating team in your advance medical directive, this will limit the number of people who can discuss your values, preferences and best interests.

**65.** Is there a specific format in which I must make my advance medical directive? What should my advance medical directive contain?

No, there is no single template that the law requires for an advance medical directive. There are different templates available in the public domain that you can rely on and customise to make your own advance medical directive. However, your advance medical directive must contain the following elements, in whichever form you choose:

- Your full name (as it appears in government-issued identity documents/cards)
- The number on any government-issued identity card that displays your date of birth (passport, voter identification, driving licence, ration card or AADHAR card)
- Specific instructions about your treatment and care should you lose your capacity to take decisions about your healthcare. This will include the situations in which, and the kinds of medical treatment that should be withheld or withdrawn
- Any other wishes regarding your care that you would like your treating team and loved ones to know of, for example, palliative care, spiritual care
- The names, contact details (residential and office address, mobile number, email address) and proof of identity (the number on any government-issued identity card that displays the date of birth) of the persons you have nominated to take decisions on your behalf
- A declaration that you have the capacity to understand the meaning and implications of your advance medical directive and that you are making the directive voluntarily, free from any force or undue influence

- The signatures of two witnesses who confirming that they have seen you execute the advance medical directive voluntarily, free of any force or undue influence
- The signature and stamp of a notary or Gazetted officer confirming that the advance medical directive has been executed in their presence, free of any force or undue influence

### 3.3.3 Process

**66.** How do I execute my advance medical directive?

You should print out or hand-write your advance medical directive on some sheets of paper. There are no requirements regarding the size of the paper, or the font or colour of ink in which it should be printed.

You must then sign the document in the presence of two witnesses, who are at least 18 years or older. The law states that these witnesses should preferably be independent, i.e. someone who does not have an interest in the kind of treatment decision that you take at the end-of-life.

This means that you should try and find witnesses who are NOT:

- The persons you have nominated in your directive
- Your family doctor, primary treating doctor or any other member of your treating team
- Close family members or friends, who are likely to qualify as your next of kin. This includes your parents, children, siblings and your spouse or any person with whom you share a relationship in the nature of marriage.

The two witnesses must countersign the advance medical directive in the presence of a notary or a Gazetted officer.

A list of notaries along with their addresses may be found here.

After executing your advance medical directive, you should share a copy with:

- an officer nominated for this purpose by your local authority (panchayat, municipality, municipal corporation)
- your family doctor (if you have one), or your primary treating doctor, if you are already undergoing medical treatment for an illness/condition at the time of executing your directive
- the persons nominated in your directive to take decisions on your behalf

**67.** Is an oral advance medical directive valid? Can I have a video advance medical directive?

No, the law requires your advance medical directive to be in writing, so an oral advance medical directive, even if it is video recorded and stored cannot substitute a written one. However, there is no bar to making a video advance medical directive in addition to a written one. It might even help your treating team and loved ones to understand your values and preferences better.

**68.** Is a digital advance medical directive valid?

No. When you first execute an advance medical directive, it must be a physical document. However, many hospitals maintain an electronic medical record/digital health record system, which they use to store patient records. Under the law, hospitals can maintain a digital version of your advance medical directive in their health records. Once this has been done, the treating team can refer to this digital version when they need to rely on an advance medical directive.

**69.** Does an advance medical directive have to be made in English?

No, there is no legal requirement for the directive to be made in English. It can be made in any language. However, please keep in mind that English is more likely to be understood than any other language by most doctors across the country.

**70.** Do I need a lawyer to execute an advance medical directive?

No, the only requirement is that an advance medical directive be executed before a notary or a Gazetted officer. You do not have to go to a lawyer to draw up the directive.

**71.** Does my advance medical directive have to be registered?

No, there is no requirement to register an advance medical directive. The law does, however, require you to provide a copy of your advance medical directive to the following persons:

- an officer nominated for this purpose by your local authority (panchayat, municipality, municipal corporation)
- your family doctor (if you have one), or your primary treating doctor, if you are already undergoing medical treatment for an illness/condition at the time of executing your directive
- the persons nominated in your directive to take decisions on your behalf

**72.** Can my advance medical directive be a part of my will?

No, this is not recommended. A will, through which you dispose of your property and other assets, only comes into effect on your death. An advance medical directive, on the other hand, will come into effect while you are still alive, but have lost your capacity to take decisions about your healthcare. If your advance medical directive is a part of your will, you run the risk of no one knowing about its existence until it is too late.

You will also typically share your advance medical directive with your treating doctor. If it is a part of your will, this means that your doctor will also have access to confidential financial information about your property and other assets. This is not advisable. An advance medical directive and a will should be executed separately.

**73.** I do not know whether my local government has nominated an officer to receive a copy of my advance medical directive. What should I do?

You can write a letter to the person in charge of your local government (Commissioner/Sarpanch/President) enclosing a copy of the latest Supreme Court order dated January 24, 2023 (a copy of the order can be accessed here), and your advance medical directive.

In your letter, you may state that the Supreme Court of India, in an order dated January 24, 2023 (Miscellaneous Application No. 1699 of 2019 in Writ Petition (Civil) No. 215 of 2005), at paragraph 198.3.6, has stated that local governments must nominate an official to act as the custodian of advance medical directives. In accordance with this order of the Hon'ble Court, you should request the local government to nominate this official to receive and preserve a copy of your advance medical directive.

You can access a draft letter here.

**74.** Can I cancel or change my advance medical directive once I've made it?

Yes, you are entitled to cancel (revoke) or change your advance medical directive at any time before it has been acted upon and implemented.

You must follow the same process to cancel or change it as you did to execute the original directive. This means that the cancellation or change will also have to be in writing, need two (preferably) independent witnesses and be countersigned by a notary or Gazetted Officer.

If you have cancelled or changed your advance medical directive, you should communicate this to all the people with whom you shared a copy of your original directive.

If there are multiple valid advance medical directives made by the same person and none of them has been cancelled, it is the one that has been executed most recently that will be given effect to.

**75.** I executed an advance medical directive before a Judicial Magistrate, in accordance with the Supreme Court's guidelines in 2018? Will my directive still be valid now that the 2023 guidelines of the Court require it to be executed before a notary or a Gazetted officer?

Yes, your directive will still be valid. However, it is advisable that you share a copy of this directive with the officer nominated by your local government to act as custodian of advance medical directives.

### 3.3.4 Implementation

**76.** When will my advance medical directive be used?

An advance medical directive is used only if you are no longer capable of making decisions about your healthcare. So long as you retain the ability to make decisions, your treating team must provide you with information about the medical treatment that has been suggested for you, its benefits and side-effects, and the consequences of refusing it. If you decide to refuse medical treatment, your treating team cannot force such treatment upon you against your will.

**77.** How will my treating team know that I have made an advance medical directive?

The persons whom you have named in your advance medical directive to take decisions on your behalf will ordinarily bring it to the attention of your treating team. Alternatively, if you have previously incorporated a digital version of your advance medical directive as part of your digital health records, it will always be available to your treating team.

If you have shared a copy of your advance medical directive with your family doctor, they will also bring it to the attention of your treating team.

While you still have the capacity to take decisions about your healthcare, it is always helpful to let your treating team know that you have made an advance medical directive and to share a copy of it with them to be used when you no longer have the capacity.

**78.** Is my treating team bound to follow my advance medical directive?

The Supreme Court of India has laid down several conditions that must be met before the wishes in your advance medical directive about life-sustaining treatment can be carried out.

If you have refused life-sustaining treatment in your advance medical directive, your treating doctor must first confirm that your directive is valid, genuine and authentic. Next, they must be convinced that you are either in a persistent vegetative state or have a terminal illness which cannot be cured. They must also be convinced that withholding or withdrawing life-sustaining treatment, as requested in your directive, is in your best interests.

Their opinion must be confirmed by two boards of

medical experts. The person nominated in your directive must also give their consent to withholding or withdrawing life-sustaining treatment.

Your treating team is not bound to apply your directive if the instructions in it are not clear.

**79.** Are the persons that I have nominated in my advance medical directive bound to give effect to my wishes?

The persons nominated in your advance medical directive, i.e. your surrogate decision-makers, have a duty to take decisions about providing or discontinuing life-sustaining treatment on your behalf in accordance with your wishes, values and preferences. They might understand what these are from the instructions in your directive or from their knowledge of, and concern for you. They should put themselves in your shoes and think about the kind of decision you would have made if you still had capacity.

They are not bound to apply your directive if circumstances have changed since you made it and they have reason to believe that you did not anticipate this and would have changed your decision. For example, you may have had a child after you executed your advance medical directive which may have influenced your decisions about end-of-life care, although these have not been updated in your directive. As another example, there may be advancements in medical technology since you executed your directive that might change the way you feel about receiving certain kinds of treatment.

**80.** What will happen if my treating doctor refuses to give effect to my advance medical directive?

Your treating doctor may refuse to give effect to your directive for two kinds of reasons—the first relates to your directive itself, the second relates to your medical condition.

In the first category, your doctor might doubt the validity of your directive or its authenticity. They might also find the language in your directive unclear or have reason to believe that circumstances have changed since you made the directive, which makes it inapplicable.

In such cases, the persons you have named as surrogate decision-makers in your advance medical directive may make an application to the appropriate High Court, asking it to settle any disputes about the validity or authenticity of the directive or its interpretation. The High Court will take an independent decision on your directive and pass orders accordingly.

In the second category of cases, your doctor might simply not agree that stopping life-sustaining treatment (as requested in your directive) is in your best interests. This might be because they do not believe that you have an incurable terminal illness or are in a persistent vegetative state. These are the two conditions in which stopping life-sustaining treatment is permissible.

However, doctors should have valid reasons for refusing to give effect to an advance medical directive, this should always be recorded in the case notes, and communication with the family/surrogate decision-maker to reach consensus about the course of treatment should continue to be pursued.

If all communication between the treating team and your family/surrogate decision-maker breaks down, the treating doctor may provide a "discharge against medical advice".

**81.** What will happen if my treating doctor agrees to give effect to my directive but my surrogate decision-makers refuse?

In this case, there will be no change in the treatment that is being provided to you. Your doctor may have more discussions with the surrogate decision-makers named in your directive to see

whether they can agree about withholding or withdrawing your medical treatment. Until agreement can be reached, there will be no change in the manner in which treatment is being provided to you.

If no agreement can be reached even after several rounds of discussions, the treating doctor may recommend a transfer to another hospital. In the meantime, the treatment and care that you are currently receiving will continue. Alternatively, if your treating doctor feels very strongly that withholding or withdrawing treatment is in your best interests, they may make an application to the appropriate High Court. The High Court will take an independent decision on your directive.

**82.** What will happen if the persons that I have nominated in my advance medical directive are not available?

While your treating team attempts to contact the persons nominated by you in your advance medical directive, they will continue to provide you with medical treatment according to the accepted standard of care and in your best interests.

If they are unable to contact any of the persons whom you have nominated, but need to take a decision about withholding or withdrawing life-sustaining treatment, your treating team will identify another surrogate decision-maker and obtain their consent instead.

**83.** I have named a friend as my surrogate decision-maker in my advance medical directive. Can my treating team insist on the consent of my next of kin instead of or in addition to my friend before carrying out the wishes in my directive to withhold or withdraw medical treatment?

No. If you have made a valid advance medical directive, and your treating team is satisfied that it is genuine and authentic, they are only required to obtain the consent of the person nominated by you in your advance medical directive to take decisions on your behalf.

**84.** If both my treating doctor and the person nominated by me agree to give effect to my advance medical directive, will life-sustaining treatment be stopped immediately?

No, there are still three more steps before treatment can be stopped:

1. the hospital must set up a Primary Medical Board. This Board will consist of your treating doctor and two other doctors with expertise related to your condition. These two doctors must have at least 5 years' experience each. They can be doctors from your treating team or from the same hospital or from another hospital. This Board will visit you and decide whether or not to give effect to the instructions in your advance medical directive to withhold or withdraw life-sustaining treatment.

2. if the Primary Medical Board agrees that withholding or withdrawing life-sustaining treatment would be in your best interests, the hospital will set up a Secondary Medical Board. This Board will also consist of a doctor nominated by the district Chief Medical Officer and two doctors with at least 5 years' experience each and expertise related to your condition. This Board will decide whether it agrees with the Primary Medical Board.

3. if the Secondary Medical Board agrees with the Primary Medical Board to withhold or withdraw life-sustaining treatment, the hospital will inform the appropriate judicial magistrate of its decision. Once this information has been sent, life-sustaining treatment can be stopped.

**85.** Do I have to make an advance medical directive? What will happen if I have not made an advance medical directive?

There is no legal requirement to make an advance medical directive, although there are several reasons why it is advisable to make one. The process for withholding or withdrawing life-sustaining treatment when a patient loses the capacity to take decisions about their healthcare but has not made an advance medical directive is almost identical to the process that is involved when an advance medical directive exists.

The difference is that the withholding or withdrawal of life-sustaining treatment will require the consent of your next friend/next of kin/guardian. Where an advance medical directive exists, withholding or withdrawal of life-sustaining treatment requires the consent of the persons nominated in the directive.

**86.** What happens if the Primary Medical Board does not agree to give effect to my advance medical directive or does not agree to withhold or withdraw life-sustaining treatment, where an advance medical directive does not exist?

Where an advance medical directive exists, the person whom you have nominated in your directive can ask the hospital to set up a Secondary Medical Board. If the Secondary Medical Board agrees to give effect to your directive, life-sustaining treatment can be withheld or withdrawn after the hospital informs the appropriate judicial magistrate.

However, it is unlikely that the Primary Medical Board will not agree to give effect to an advance medical directive. This is because a Primary Medical Board is set up only when the primary treating doctor is already of the opinion that the directive should be implemented. The primary treating doctor is also a member of the Primary Medical Board. In practice, it is likely that the other two doctors on the Primary Medical Board are also members of the treating team, and the primary treating doctor has already consulted with them regarding the advance medical directive.

Where an advance medical directive does not exist, your next of kin/next friend/guardian or even your treating doctor or hospital can make an application to the appropriate High Court to withhold or withdraw life-sustaining treatment.

**87.** What happens if the Secondary Medical Board does not agree with the Primary Medical Board?

If the Secondary Medical Board does not agree with the Primary Medical Board's opinion that life-sustaining treatment should be withheld or withdrawn, the persons nominated in the directive (where one exists) or the next friend/next of kin/guardian (where it does not) or even the treating doctor or the hospital may make an application to the appropriate High Court to withhold or withdraw life-sustaining treatment.

In practice, there may be other ways to resolve the difference of opinion between the Primary and Secondary Medical Boards. The Primary Medical Board can approach the Secondary Medical Board again, with new evidence to justify its recommendation to withhold or withdraw life-sustaining treatment. Hospitals with Clinical Ethics Committees may use these committees to resolve this difference.

Until the High Court reaches a decision or until the Primary and Secondary Medical Boards agree with each other, the patient will continue to receive the treatment and care that they were receiving at the time at which a decision about withholding or withdrawing life-sustaining treatment was taken.

**88.** How will the High Court take a decision about withholding or withdrawing life-sustaining treatment?

The High Court will set up a bench of two judges to decide whether or not to give effect to the advance medical directive. They may set up an independent committee of three doctors with specialisations in different fields and twenty years' experience to advise them.

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