End-of-Life Care and the Law in India

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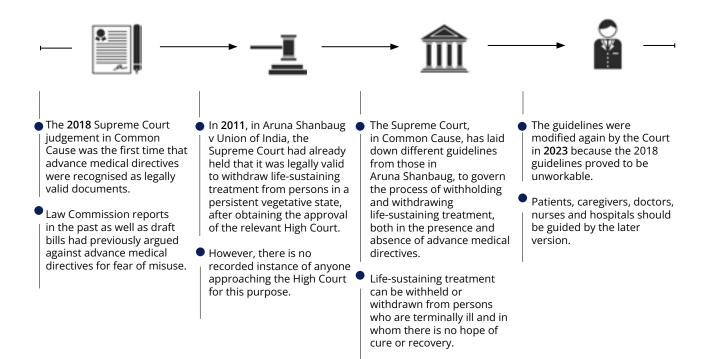
# THE RIGHT TO DIE WITH DIGNITY IN INDIA - WHAT DOES IT MEAN TO HAVE THIS RIGHT?

In 2018, the Supreme Court of India, in <u>Common Cause v Union of India</u>, recognised that the right to die with dignity is a fundamental right protected by Article 21 of the Indian Constitution. The Court identified three specific components of this right:

	A person who has the capacity <sup>1</sup> to take decisions about their healthcare has the right to refuse life-sustaining treatment
	An adult person has the right to make an advance medical directive or living will. In this document, they can express their wishes about their future medical treatment for situations when they may not have the capacity to make decisions about their health care.
_	Life-sustaining treatment can be legally withheld or withdrawn from persons without the capacity to take decisions about their healthcare, even if they have not made an advance medical directive.
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<sup>1</sup> What is decision-making capacity? In the context of healthcare, "decision-making capacity" means a person's ability, at a particular time, to understand the nature and consequences of health care options, make an informed decision, and communicate their decision through speech, expression, gesture or otherwise.	A person refusing life-sustaining treatment is still entitled to palliative care <sup>2</sup> and other forms of health care.
<sup>2</sup> What is palliative care?	
Palliative care is treatment of serious health-related suffering. It includes management of pain and other symptoms and addresses psychological, social and spiritual suffering of patients and their families. Palliative care can be initiated in various stages of an illness in a patient's life, including terminal stages.	
What is end-of-life care?	
End-of-life-care is an approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life.	
(Source: Indian Council of Medical Research)	

**Common Cause v Union of India** URL: https://indiankanoon.org/doc/184449972/

## **HISTORY & LEGAL DEVELOPMENTS**



## Key differences between guidelines laid down by the Supreme Court and those modified in 2023:

#### **2018 GUIDELINES**

#### **2023 GUIDELINES**

Advance medical directives had to be executed before judicial magistrates of the first class.	Advance medical directives only have to be attested before a notary or Gazetted officer.
Primary and Secondary Medical Boards were to have medical experts from particular specialties with at least twenty years' experience.	Primary and Secondary Medical Boards can have medical experts with at least 5 years' experience.
Prior approval of the judicial magistrate of the first class was required before withholding or withdrawing life-sustaining treatment.	Prior approval is no longer needed, the judicial magistrate only needs to be intimated before withholding or withdrawing life-sustaining treatment.

The 2023 guidelines have the force of law until Parliament or State Legislatures pass legislation to replace them.

### **ADVANCE CARE PLANNING<sup>3</sup> AND ADVANCE MEDICAL DIRECTIVES (AMDS)**<sup>4</sup>

## WHAT IS ADVANCE CARE PLANNING?

#### Advance care planning involves having meaningful discussions with your loved ones and your doctor(s) about:

Treatment options, risks, implications	Priorities, preferences, concerns regarding healthcare and other aspects prior to and after death
This helps prepare for future decisions about your healthcare if you become seriously ill or unable to communicate your wishes. Many people also choose to put their preferences in writing through documents called advance medical directives (AMDs).	
If you are a doctor, you should encourage advance care planning and encourage your	

patients to execute AMDs.

## WHAT IS AN ADVANCE MEDICAL DIRECTIVE?

In the context of healthcare, advance medical directive is a legal document made by a person with decision-making capacity, stating their wishes regarding how to be treated or not treated at a stage when they lose such capacity.

#### Elements of a valid AMD:

Written document	Made by a person who is at least 18 years old and has decision-making capacity
Names two or more surrogate	Executed in the presence of two witnesses
decision makers	and a Notary or Gazetted Officer

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### 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.

#### Choosing a Surrogate Decision-maker

Nominate someone who:

ls at least 18 years old	ls familiar with your healthcare preferences	Understands the values that are important to you
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Your Surrogate Decision-maker:

Does not have to be a family member	Could also be a friend or a colleague (in such cases, ideally inform your family of this)
Can be physically present at a hospital in an emergency	Ideally, lives in the same country
Is not likely to die before you are	Avoid appointing a member of your treating team*

\*(the treating team is required to consult with the surrogate before making treatment decisions - indicating that the surrogate should be outside the treating team)



## WHAT ELSE SHOULD YOU DO WHEN EXECUTING AMDS?

Inform surrogate decision-makers and hand over a copy to them

You can also choose to incorporate the AMD in your digital health records.

Hand over a copy to the custodian appointed by the local authority

## WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING TREATMENT (LST)

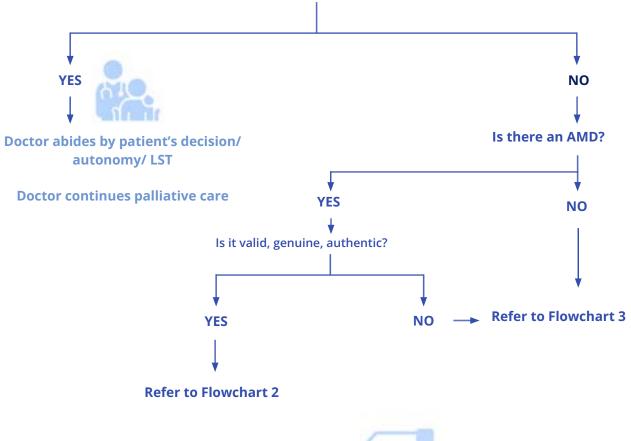
WHEN DOES THE PROCESS BEGIN? When the treating physician determines that:

There is no reasonable medical probability of recovery from a terminal condition, end-stage condition, or vegetative state; and

Any further medical intervention or course of treatment would only serve the purpose of artificially prolonging the process of dying

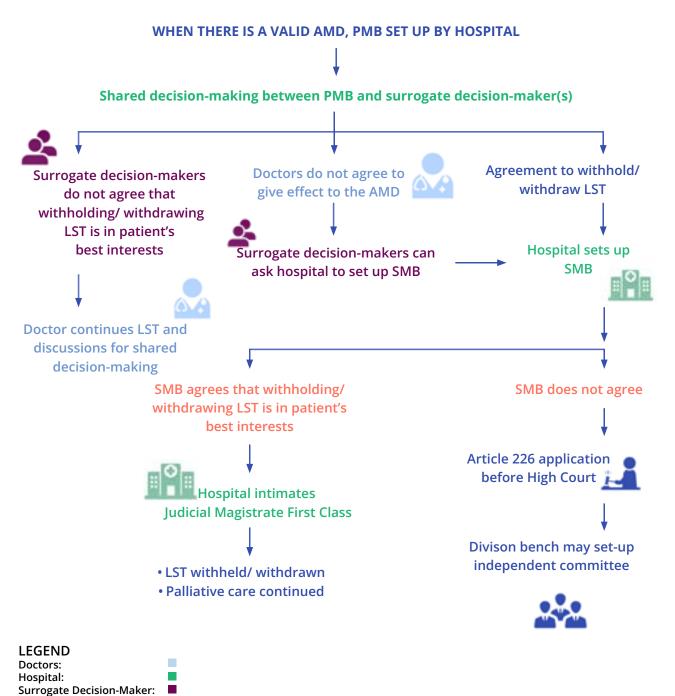
### PROCESS FOR IMPLEMENTING AMDs FLOWCHART 1

#### DOCTOR ASSESSES IF THE PATIENT HAS DECISION-MAKING CAPACITY





## PROCESS FOR IMPLEMENTING AMDs FLOWCHART 2



		What	is	shared	decision-ma	king	?
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Secondary Medical Board:

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)

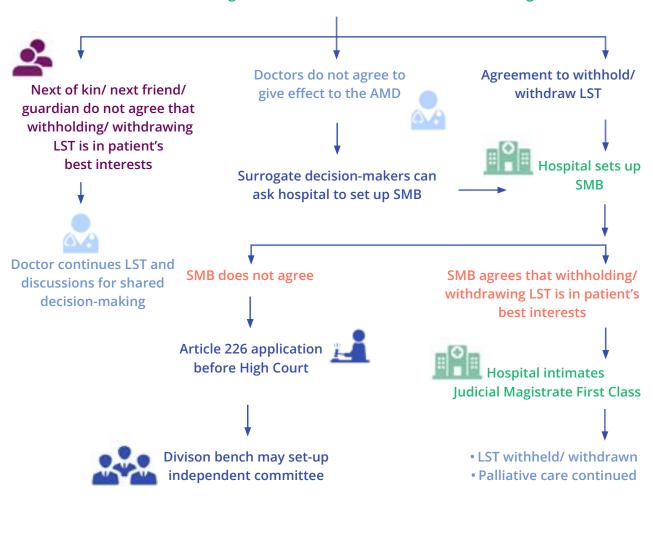
About primary medical board:

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.

#### PROCESS FOR IMPLEMENTING AMDs FLOWCHART 3

WHEN THERE IS NO AMD, PMB SET UP BY HOSPITAL

Shared decision-making between PMB and next of kin/ next friend/ guardian



LEGEND Doctors: Hospital: Surrogate Decision-Maker: Secondary Medical Board:

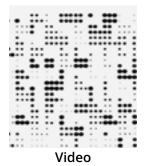
About secondary medical board

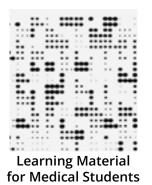
It is a board comprising one registered medical practitioner nominated by the district Chief Medical Officer as well as at least two subject experts of at least 5 years' experience. All members of the Secondary Medical Board must be different from those of the Primary Medical Board.

Who is part of an independent committee?

Medical experts with at least 20 years' experience to decide whether life-sustaining treatment should be withdrawn

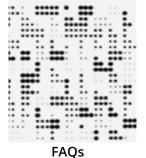
For more detail on the Supreme Court's guidelines, as well as answers to frequently asked questions, please refer to our toolkit:







FAQs (Patients and Caregivers)



(Doctors, Nurses and other Healthcare Workers)



**Guidance for Hospitals** 



Sample Advance Medical Directive/ Living Will