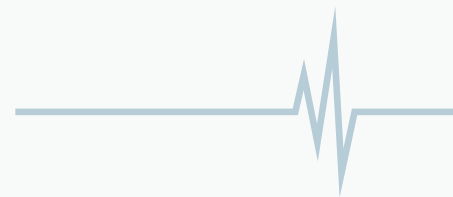


END OF LIFE CARE AND THE LAW IN INDIA

READY RECKONER



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It is part of Vidhi's Toolkit on Legal Aspects of End-of-Life Care in India. We thank our partners, Godrej Seeds and Genetics Limited, and Bajaj Finserv Limited. Their continued support and encouragement on our legacy work, related to advance care planning and end-of-life care, is the reason we are independently able to produce valuable resources like these.

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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India recognises the right to die with dignity as a fundamental right.

What does it mean to have this right?

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

- A person who has the **capacity** 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 (AMD). 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- Life-sustaining treatment can be legally withheld or withdrawn from persons without the capacity to take decisions about their healthcare, either in accordance with their advance medical directive or even if they have not made one.

A person refusing life-sustaining treatment is still entitled to palliative & other forms of healthcare

What is decision-making capacity?

In the context of healthcare, this 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.



What is life-sustaining treatment?

Any medical treatment that artificially supports or replaces, a body function essential to the life of the person, including cardiopulmonary resuscitation, mechanical ventilation, antibiotics and more.



What is palliative care?

The 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.



Did you know?

In India, **withholding** or **withdrawing of life-sustaining treatment** is legal under certain conditions but **euthanasia** is illegal.

I. Choices at the End of Life

Terms	Definitions
Do-Not-Attempt Resuscitation	A decision not to initiate or perform the cardiopulmonary resuscitation (CPR). This is usually when the patient is terminally ill and their survival after the CPR is low, and the patient understands this. If the patient loses decision-making capacity, their healthcare representative can choose for them.
Euthanasia	When a doctor directly intervenes to relieve the patient of their suffering, at the request of the patient, in a manner that causes the death of the patient
Palliative Sedation	Administering minimal medication to a terminally ill patient to lower their consciousness level, either for a short time or permanently, to relieve them from distress.
Physician Assisted Suicide	When a physician, on the request of a terminally ill patient, intentionally provides them means to end their life.
Withholding of life-sustaining treatment (WH-LST)	A decision made not to initiate or escalate a life-sustaining treatment in terminal illness in accordance with expressed wishes of the patient or their designated healthcare representative.
Withdrawal of life-sustaining treatment (WLST)	A decision made to cease or remove a life-sustaining intervention in terminal illness in accordance with expressed wishes of the patient or their designated healthcare representative.

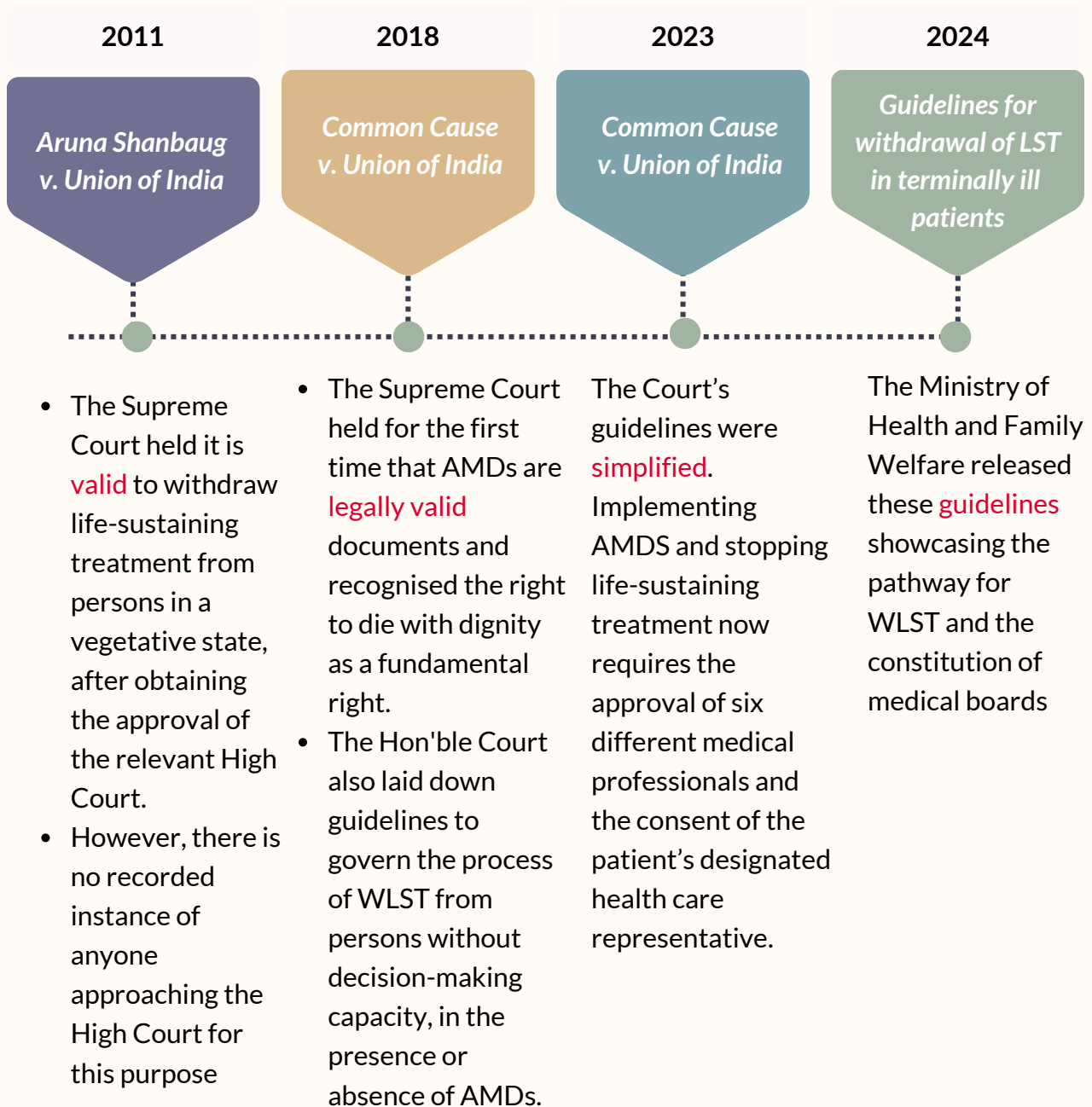
Source: Definition of terms used in limitation of treatment and providing, palliative care at end of life, ICMR 2018

Then, what is passive euthanasia?



Incorrectly used to describe WH/WLST, passive euthanasia is an outdated term which should be avoided so that the legal act of withholding or withdrawing life-sustaining treatment is not confused with the (currently) illegal act of euthanasia.

II. Historical and Legal Developments



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What are the differences between the guidelines released in 2018 & those modified in 2023?

2018 Guidelines	2023 Guidelines
AMDs had to be executed in the presence of the Judicial Magistrate of First Class (JMFC)	AMDs only have to be attested before a notary or a Gazetted Officer
Primary & Secondary Medical Boards (PMB & SMB) had to have medical experts from particular specialities with at least 20 years of experience	PMB & SMB can have medical experts with at least 5 years of experience
Prior approval of the JMFC was required for WH/WLST	Prior approval no longer needed. The JMFC only has to be intimated about WH/WLST decisions

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

III. Advance Medical Directives and Advance Care Planning

What is Advance Care Planning?

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

treatment options, risks, consequences of refusing treatment

priorities, preferences, concerns regarding healthcare & other aspects prior to and after death

Advance Care Planning 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.

If you are a doctor, you should encourage advance care planning and inform your patients about their right 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. It is a tool for ACP and is also commonly referred to as 'living will'.

written document

made by an adult (18+) and with decision-making capacity

names 2 or more health care representatives



executed in the presence of 2 witnesses & a notary or gazetted officer

Who is a witness?

Anyone other than your treating team/doctor and persons mentioned as your designated healthcare representative can be a witness.



What should you do once your AMD is made?

-  Inform your designated health care representatives and hand over a copy to them
-  Hand over a copy to the custodian appointed by the local authority

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

IV. Nominating your designated health care representative

Conditions for nomination

Anyone who

- is at least 18 years old;
- is familiar with your healthcare preferences;
- understands what values are important to you

Who can it be?

- Does not have to be a family member;
- Could be a friend or partner (in this case, ideally inform your family members about this)

Best Practices

Ideally, choose more than one health care representative and name them in order of preference. They will be approached in that order. Choose someone who

- can be physically present at the hospital during emergencies;
- ideally, lives in the same country;
- is not likely to die before you.

What to avoid?

Avoid appointing members of your treating team. Your treating team must consult with your health care representative about WLST, so they should not be the same person.

Who is a custodian?

A competent officer of the local Government or the Municipal Corporation or Municipality or Panchayat who has been nominated to receive and store AMDs



What is a digital health record?

Also known as electronic health records, these are data stored in a digital form that can be used by healthcare professionals and health facilities, upon the consent of the patient.



Conditions for withholding or withdrawing life-sustaining treatment

The process for withholding or withdrawal of life-sustaining treatment can only begin when the following conditions are fulfilled:



Person in a vegetative state

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



Terminal Illness

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



What is end-stage condition?

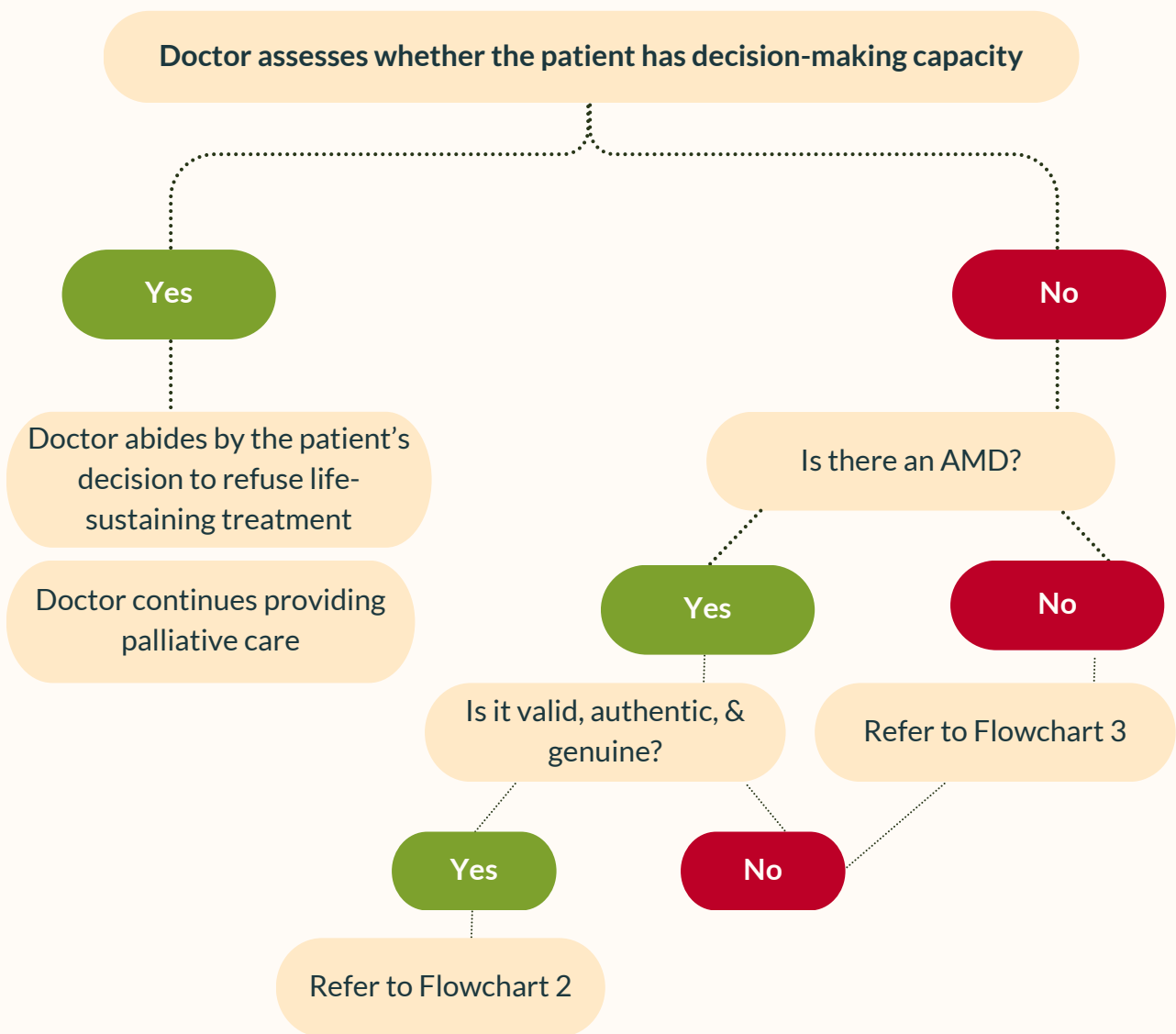
It is an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and where, to a reasonable degree of medical probability, treatment of the condition would be ineffective.



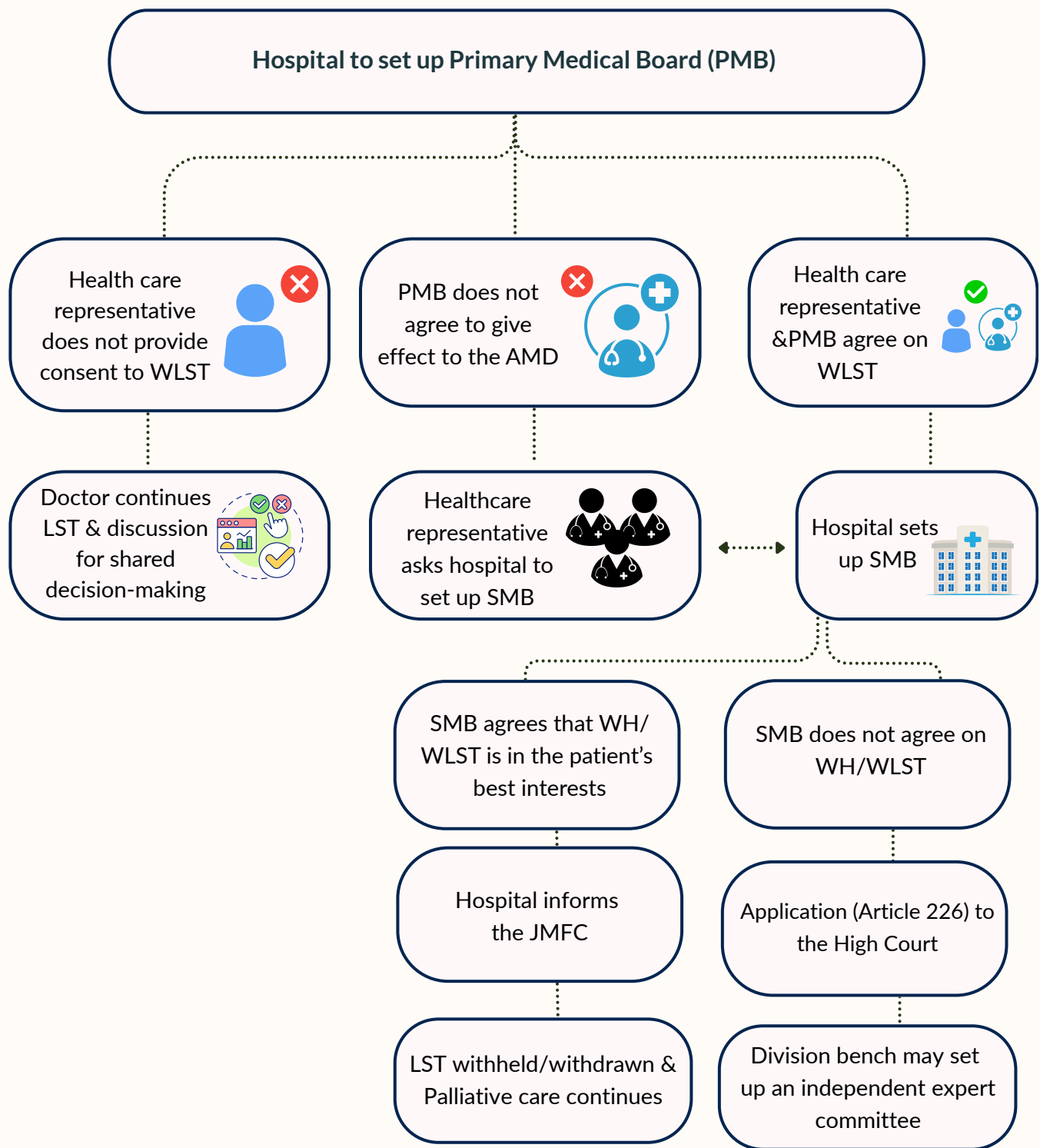
What is 'vegetative state'?

It is a state where a person is awake but does not show any signs of awareness. A person is unlikely to recover when they have been in a vegetative state for more than 6 months (if caused by a non-traumatic brain injury) or more than 12 months (if caused by a traumatic brain injury).





Flowchart 1: Decision-Making Capacity and Care Route



Flowchart 2: Process when an AMD is in place

What is shared decision-making?

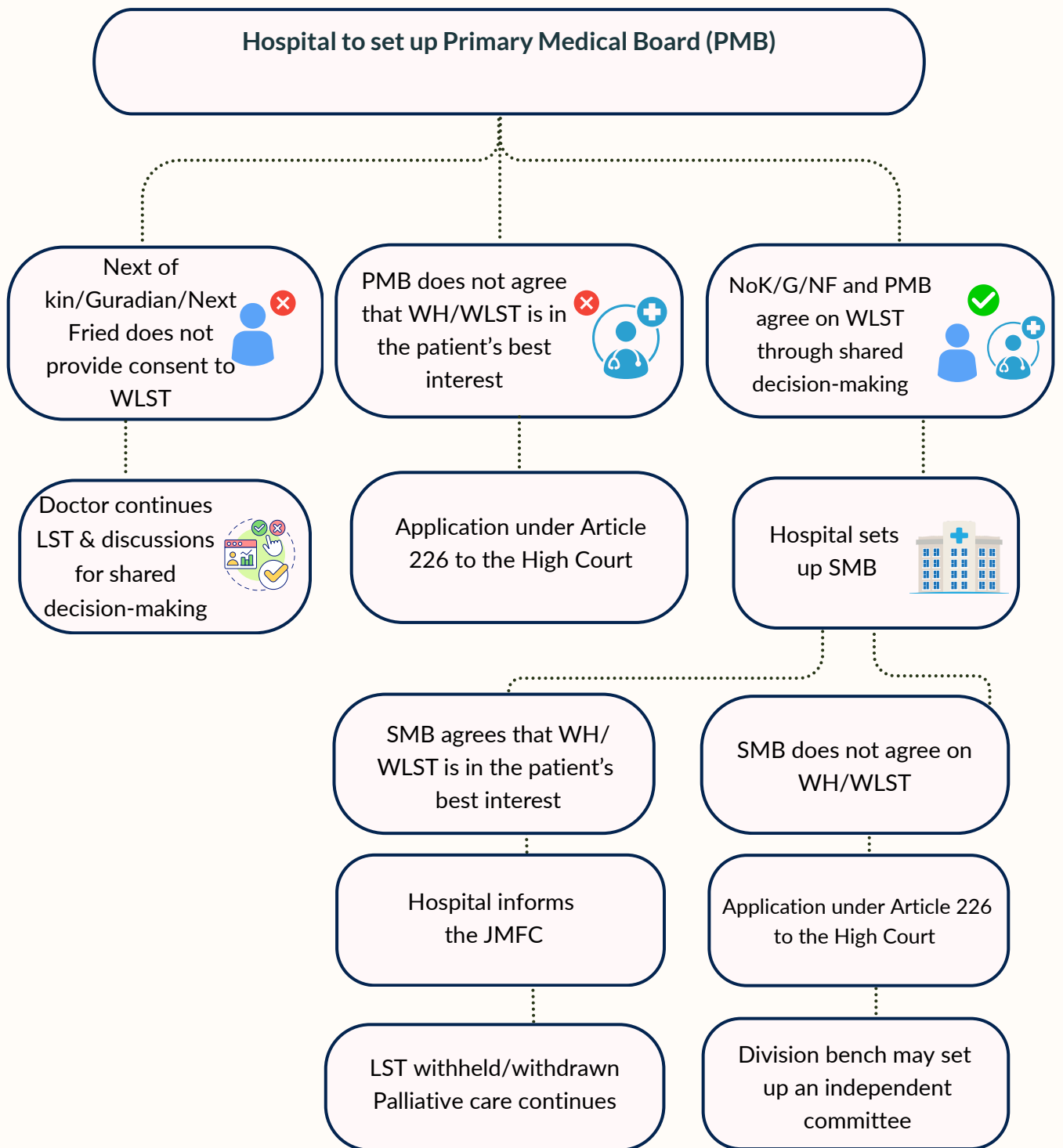
A dynamic exercise where the health care team takes shared decisions with a health care representative regarding the medical treatment of a patient, for a patient, where such patient lacks decision-making capacity.



What is a Primary Medical Board?

PMB comprises of the treating doctor and 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 when there is no AMD

What is a Secondary Medical Board?

SMB comprises of one registered medical practitioner nominated Chief Medical Officer and at least two subject-matter experts of at least 5 year's experience. All members of the SMB must be different from the PMB.



Who is part of an independent committee?

Medical experts with at least 20 years' experience to decide on cases of WH/WLST.



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