

# Living Will DECLARATION

## ADVANCED MEDICAL DIRECTIVES

**END OF LIFE CARE : LIVING WILL**

**INFORMATION BOOKLET**

**INDIAN MEDICAL ASSOCIATION, GOA STATE**

*Initiative*

*Supported by*

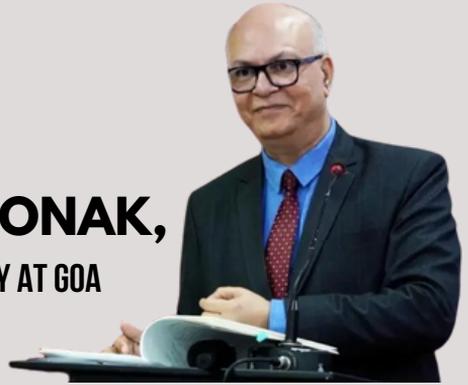
**GOA STATE LEGAL SERVICES AUTHORITY**



# MESSAGE BY EXECUTIVE CHAIRMAN GSLSA

## SHRI JUSTICE M.S.SONAK,

SENIOR JUDGE OF HIGH COURT OF BOMBAY AT GOA



### MESSAGE

1. The Indian Medical Association Goa State Branch, the State of Goa and the Goa State Legal Services Authority (GSLSA) have undertaken a commendable task. Their pioneering work in creating a mechanism for the effective implementation of the Hon'ble Supreme Court's directives on the crucial subject of "LIVING WILL" or the "ADVANCED MEDICAL DIRECTIVES" (AMD) is truly noteworthy. This information booklet disseminates information on AMD and how to make and register/record an AMD.

2. Medical professionals are dedicated to prolonging their patients' lives. However, end-of-life situations remain largely unexplored among patients and their families. This booklet aims to change that by providing comprehensive information on AMDs. This is not about the right to die but the right to live with dignity. So this booklet and its information are an impetus to start the conversation.

3. This booklet is a testament to the collaborative effort of medical, legal, and administrative professionals, highlighting the steps taken by the IMA Goa state branch, the State of Goa and the GSLSA. It includes drafts of AMDs and provides clear explanations of their execution and registration with the specified authorities. This is a significant stride towards a comprehensive approach to AMDs. While there may be initial challenges with these life-and-death issues, Goa can take pride in its proactive start. As the saying goes, 'The secret of getting ahead is getting started.'

4. In one of his addresses, Oliver Wendell Holmes quoted a line from Latin poetry: “Death plucks my ear and says, Live - I am coming”. That is the significance of living. But when a patient really does not know if she is living till death visits her, and there is constant suffering without any hope of living, should she be forced to wait? Should she be cursed to die as life gradually ebbs out from her being? Should she continue to live with the support system as people around her think that science, in its progressive invention, may bring about an innovative cure method? Does not such survival and uncertain waiting mar the pristine concept of life, corrode the essence of dignity, and erode the possibility of eventual choice, which is pivotal to privacy?

5. As sensations diminish in intensity, the sense of vitality fades. The desire for life gives way to indifference and patient waiting. The fear of death is then strangely mingled with the longing for repose. With ageing populations, withering of joint families, medical innovations, hospital costs spiralling uncontrollably, and a focus on dignified living rather than merely survival, all these questions have become increasingly relevant and must be urgently addressed.

6. On the other hand, the counterarguments must also be deliberated upon and cannot be ignored. Are there any judicially manageable standards to deal with these life-and-death issues? Are these not the issues of ethics and philosophy that are best left to Moralists and Philosophers so that some consensus evolves in civil society? There is a need to deliberate on the sanctity of life doctrine. There is the Hypocritic oath by which medical professionals swear to do everything within their means to save a life, unto the last. Arguments about prognostic uncertainty and misdiagnosis also need to be addressed.

7. Presently, there is no clarity on what is in the patient’s best interest. Would not the hospital or clinic costs cloud our decisions? Could it not be that the relatives opt for a speedy exit not because it is in the patient’s best interests but to save costs or, worst still, to speed up the inheritance of the patient’s property? Then, there is always the slippery slope argument. The right to die under certain circumstances must not be transformed into an expectation to die and, finally, a duty to die. All these arguments and counterarguments do not always admit easy solutions. But that is no good reason not to discuss, deliberate and make some beginning.

*This information booklet and the referred material are only a beginning. But I am confident that it will go a long way in simplifying procedures, establishing protocols and reigniting discussions and deliberations on this all-important subject affecting life-and-death issues. So, I once again compliment the collaborative efforts the IMA Goa state branch, State of Goa and GSLSA have put in and wish them the best for the future.*

JUSTICE MAHESH S. SONAK

# MESSAGE BY PRESIDENT IMA GOA STATE 2024

## **DR SANDESH CHODANKAR,**

MBBS, DNB (E.N.T)

PRESIDENT IMA GOA STATE



**Greetings from IMA GOA STATE !**

**One of the pain points in modern medicine has been futility of further care and end of life care decisions.**

**Families of such patients are confused or feel burdened with the decision to withdraw or withhold life support. Many a times these families lose a last chance to say goodbye to their loved one while futile care or aggressive resuscitation is being carried out by the medical team, a medical team who themselves feel that they have reached a communication impasse and/or a moral distress on whether to continue or withdraw or withhold life support in case of futile care in certain patients.**

**While earlier concerted efforts have been made by the Indian society of critical care medicine, the Law commission of India and 2018 Directives by the Supreme Court; more clarity has emerged with the recent January 2023 guidelines issued by the Supreme Court.**

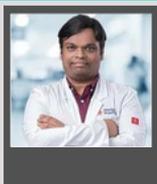
**The IMA Goa state has worked diligently with Goa state Legal Services Authority towards operationalizing these guidelines by lobbying with the Government of Goa to define and give a structure for the Primary and Secondary Medical Board.**

**We will continue to work in association with GSLSA towards creating awareness in the community about Living will/Advanced Medical Care Directives and Medical Fraternity about identifying Futility by the primary and secondary board and enable end of life care decision, ensuring the right to leave this world in a most dignified manner in case of progressive illness with no hope for cure.**

***We thank all stakeholders for their yeoman contribution in creation of these guidelines in booklet form.***

**Dr. Sandesh Chodankar**

# OPERATIONALIZING END OF LIFE CARE IN GOA



## DR AMOL MAHALDAR

MD (MEDICINE), DNB (NEPHROLOGY),

POST GRADUATE DIPLOMA IN TRANSPLANT MANAGEMENT (BARCELONA)

DOMAIN EXPERT

**Often we perceive the healthcare systems role as to cure, continue attempts towards a cure and prolong life at every cost.**

**Although it might be applicable in most clinical practices, we often encounter situations where illnesses are far advanced and overmaster a person.**

**Continuing invasive medical intervention in these circumstances could be potentially inappropriate or futile and might not be in a person's best interest. The culture in our healthcare delivery systems has long been skewed towards aggressive life support till the very end, no matter the disease, trajectory or the prospects of meaningful outcome.**

**Excessive treatment in both ICU and general healthcare settings is rife, resulting in intolerable burden to the patient and the family and adverse consequences to the healthcare environment. Overwhelming focus on technological advances in organ support, contrast sharply with the declining priority accorded to the human centricity in healthcare.**

**End of life care (EOLC) practice varies across national, cultural, religious diversity, and even within nations.**

**The first ethical position statement for limiting life support and applying palliative care was published by the Indian Society of Critical Care Medicine (ISCCM) as early as in 2005.**



The “Aruna Shanbaug” judgment queered the pitch further. They continued with the reservations articulated in the 1967 report in letting the physicians and families together decide for the incapacitated patient. Though the Supreme Court (SC) accepted “passive euthanasia,” a procedure mandating validation by a high court was prescribed. It proved to be unworkable on the ground, leading to, paradoxically, less confidence among physicians in making these decisions than earlier.

A brace of landmark SC judgments in 2017 and 2018 enabled a paradigm shift in the legal provisions for Advanced Medical Directive (AMD) and withdrawal (WD) and withholding (WH) decisions. Article 21 of the “Right to Life” enshrined in the Constitution of India was expanded to identify privacy and autonomy as inalienable rights.

The progressive Mental Healthcare Act of 2017 also validated AMD. The most important of these judgments for End Of Life Care (EOLC) was the Common Cause vs The Union of India, explicitly established the right to execute an AMD and to refuse life-sustaining treatments. When it came to voluntary decisions, there was no procedural complexity. However, with respect to decisions made for the incapacitated patient, the procedure laid down was complicated. The mandated three-tier process involving the district collector and the Jurisdictional Magistrate of the First Class (JMFC) had few takers.

To simplify the procedure, an appeal was submitted to the SC by the ISCCM, represented legally by the Vidhi Center for Legal Policy and supported by End-of-Life Care in India Task Force (ELICIT), a multi-disciplinary advocacy group. In a momentous development, a 5-judge constitutional bench allowed a simplification acceptable to both the appellant and the Government of India. In its amended form, the AMD need not be attested by the JMFC, either notarization or attestation by a gazetted officer will do.

A two not three-tier process, for WD/ WH finally emerged, whether or not an AMD/appointed proxy was in place. Accordingly, now two medical boards need to be set up by the hospital/institution.

The District Magistrate, in contrast to the previous ruling, needs only to be “intimated” (informed) of the decision, not requiring his/her authorization.

**[CLICK HERE TO READ THE SC JUDGMENT](#)**

Within a month of this SC Order Mumbai Gynaecologist Dr. Nikhil Datar became one of the first in the country to notarise a living will in February 2023. However in December 2023 Dr. Nikhil Datar, filed a public interest litigation (PIL) in the high court regarding the poor response from the state government on the issue. While mentioning the matter to the Chief Justice in the High court of Bombay, he stated that

*“Although the Supreme Court had laid down the framework for a living will on January 23, The state has not yet created a mechanism for the purpose or nominated a custodian of the AMD.”*

Indian medical Association Goa State under the leadership of President Elect Dr. Sandesh Chodankar had taken cognition of this situation and as early as October 2023 had taken on the challenge of setting up the mechanism of implementing the Supreme Court directives in the state of Goa.

As serendipity would have it in late 2023, DILASA and IMA Ponda Charitable Trust organised a public event wherein Justice M.S. Sonak, Senior judge of High Court of Bombay Goa was the chief guest and Dr. Roopkumar Gurusahani was the keynote speaker.

Inspired by his personal keen interest in this subject, a team of IMA Goa State doctors met with the senior judge in his private chambers to consult on how to take the process forward.

On January 7th 2024, the occasion of the installation ceremony Dr Naveen Salins Chief of Palliative Care at Kasturba Medical College Udupi gave a well received talk on End of Life care. He outlined a road map and shared valuable insights on Documentation.

On 16th of February 2024 a meeting was convened by GSLSA in association with IMA Goa state to take on board all the stakeholders. This was followed by multiple rounds of consultative meeting of which you can find detailed minutes and outcomes below.

# TIMELINE

**16/02/2024**

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**Agenda: Preliminary Discussion with Stakeholders**

**Outcome: Agenda Finalized for operationalizing EOLC**

**05/03/2024**

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**Agenda: Constitution of Medical Boards**

**Outcome: Primary & Secondary Board Forms Finalized**

**07/03/2024**

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**Agenda: Finalization of AMD**

**Outcome: AMD Forms finalized**

**11/03/2024**

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**Agenda: Digitization and Online Uploading**

**Outcome: Framework Under Process by ITG**

**14/03/2024**

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**Agenda: Office Order North/South Goa Collectorate**

**Outcome: Order Issued**

**21/03/2024**

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**Agenda: Interactions with medical fraternity**

**Outcome: Information, Education, Communication**

**28/03/2024**

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**Agenda: Review of Operationalization of EOLC**

**Outcome: Govt. orders and guidelines issued**

# WHAT IS AMD OR LIVING WILL?



## DR SANDESH CHODANKAR

MBBS, DNB (E.N.T)

PRESIDENT IMA GOA STATE

**A 'Living Will' in legal terms is known as an 'Advance Medical Directive' which empowers a person, to assign another person, power to make decisions regarding their medical treatment when the former is in a comatose or unconscious state.**

**It is a document prescribing a person's wishes regarding the medical treatment the person would want if he/she was unable to share his/her wishes or not in a position to make an informed decision by reason of being unconscious or in a coma.**

**The concept of a Living Will or an Advance Medical Directive permits family members to respect the wishes of a terminally-ill patient and to direct the doctors to end their medical treatment.**

**Additionally, it facilitates people to record their wishes when it comes to the family person/guardian that they trust to take the ultimate decision for them.**

**The directive also acts as a relief for the family members, knowing that the person has entrusted them or given them the authority to make a decision, as stated by them in the directive when they were in a conscious state before such an unfortunate incident.**

*The "Living Will" is a written record of person's wishes that will help the nominated person(s) or your family to carry out person's wishes at the appropriate time without any guilt or angst.*

In the 21st century due to unimaginable advancement in the field on medical science, it is possible for a human to stay alive with the help of machines for months or even years. Under these circumstances AMD: Living Will gives the patient a condition right to refuse treatment.

# WHO CAN MAKE A LIVING WILL?

- **An adult of above 21 years who is of a sound and healthy mind and in a position to communicate, relate and comprehend the purpose and consequences of executing the document.**
- **Comprehend the purpose and consequences of executing the document.**
- **It must be voluntary.**

# HOW TO MAKE A LIVING WILL?

## IMPORTANT ASPECTS

- **It should be in writing and should clearly state as to when medical treatment may be withdrawn or if specific medical treatment that will have the effect of delaying the process of death should be given.**
- **Instructions must be absolutely clear and unambiguous.**
- **It should mention whether the patient may revoke the instructions/authority at any time.**
- **It should specify the name of a guardian or close relative who, in the event of the patient becoming incapable of taking decision at the relevant time, will be authorized to give consent to refuse or withdraw medical treatment**
- **If there is more than one valid Advance Directive, the most recently signed Advance Directive will be considered as the last expression of the patient's wishes and will be implemented.**

Dictates End of Life medical Care

Activates when unable to communicate due to terminal illness



Guides medical team on treatment preferences

Prevents financial strain on unwanted medical care

# PURPOSE TO EXECUTE AMD?



## **DR SHAILESH KAMAT**

**MBBS, MD (OBG)**

**CHAIRMAN LEGAL CELL IMA GOA STATE**

- **The executor can specify:**
- **As to when medical treatment may be withdrawn or**
- **That no specific medical treatment shall be given that will only have the effect of –**
- **Delaying the process of death that may otherwise cause him/her pain, anguish and suffering, and further put him/her in a state of indignity.**

# WHAT SHOULD IT CONTAIN?

- **It should indicate the circumstances in which withholding, or withdrawal of medical treatment can be resorted to.**
- **The contents must be absolutely clear and unambiguous.**
- **It should mention that the executor may revoke the instructions/authority at any time.**
- **It should disclose that the executor has understood the consequences of executing such a document.**
- **It should specify the name of a guardian or close relative who, in the event of the executor becoming incapable of taking a decision at the relevant time, will be authorized to give consent to refuse or withdraw medical treatment in a manner consistent with the Advance Directive.**

# HOW SHOULD IT BE RECORDED?

- **The document should be signed by the executor in the presence of two attesting witnesses, preferably independent, and attested before a Notary or Gazetted Officer.**
- **It is advisable to mention the family physician's name in the document.**

- The witnesses and the Notary or Gazetted Officer shall record their satisfaction that the document has been executed voluntarily and without coercion or inducement or compulsion and with full understanding of all the relevant information and consequences.

## HOW SHOULD IT BE PRESERVED?

- A copy shall be handed over to the Main Mamlatdar of the Taluka as the case may be. The Nodal Officer designated by the District Collector shall be the custodian of the said document.
- The executor may also choose to incorporate their Advance Directive as a part of the digital health records, if any.

## SALIENT FEATURES OF THE GUIDELINES ISSUED BY THE HON'BLE SUPREME COURT.



### DR. SHEKHAR SALKAR

MBBS, MS, FICS ONCO

PRESIDENT IMA BICHOLIM BRANCH

- The wishes of the executor are to be given primacy however, the medical opinion will prevail.
- The Hon'ble Supreme Court has given legal sanctity to the wishes of the common man.
- The executor can revoke the advance directive in writing at any time by following the same procedure as provided for recording the Advance Directive.
- If there are multiple directives, the most recently executed shall be given effect.

# HOW TO MAKE A LIVING WILL?



The executor should sign the document in the presence of two attesting witnesses, preferably independent, and attested before a notary or Gazetted Officer.



The witnesses and the notary or Gazetted Officer shall record their satisfaction that the document has been executed voluntarily, without coercion, inducement, or compulsion, and with a complete understanding of all the relevant information and consequences.



The executor shall inform and hand over a copy of the Advance Directive to the person or persons named in the Advance Medical Directive and the family physician, if any.



A copy shall be handed over to the Main Mamlatdar, who shall forward to the Nodal officer appointed by the District Collector who shall be the custodian of the AMD,



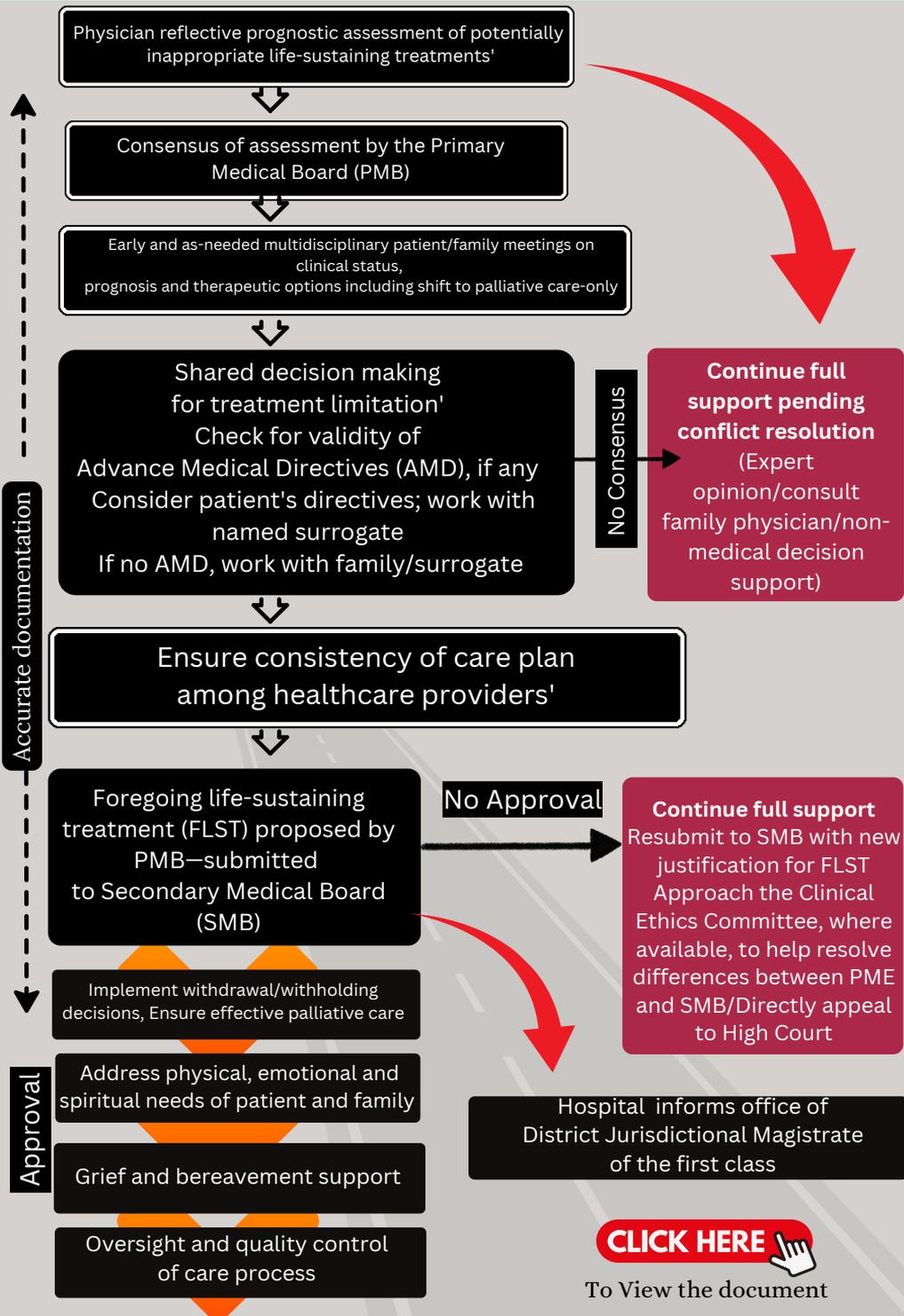
The custodian shall make available a copy of the AMD to hospital /treating doctor as and when needed.

*The executor may also incorporate their Advance Directive as a part of the digital health records.*



**To refer at a sample format of living will click here**

# THE EOLC PATHWAY



# STAKEHOLDER RESPONSIBILITIES



## SHRI RAM S. PRABHU DESSAI

REGISTRAR (JUDICIAL)

HIGH COURT OF BOMBAY AT GOA

### GUARDIAN(S) OR CLOSE RELATIVE(S)

To give consent to refuse or withdraw medical treatment in a manner consistent with the Advance Directive, in case the executor is incapable of giving consent on his own.

To discuss with the physician treating the patient and give thoughtful consent to proceed further with the process.

Remain present when PMB visits the patient.

To approach the High Court by way of a writ petition under Article 226 of the Constitution if the Secondary Medical Board refuses permission to withdraw medical treatment.

To approach the concerned Hospital if the Primary Medical Board decides not to follow directives in AMD.

### FAMILY PHYSICIAN

To receive a copy of the AMD from the executor for safe custody.

Where there is no AMD, to discuss with the Primary Medical Board(PMB) regarding the suitability of the withdrawal or refusal of further medical treatment to the patient.

## TREATING PHYSICIAN

When made aware about the Advance Directive, shall ascertain the genuineness and authenticity, after perusal of the directives in custody of the custodian or from digital records

After getting satisfied that instructions in AMD to be acted upon : inform the person or persons named in the advanced directive and obtain his/her consent. To act as one of the members of the Primary Medical Board.

In cases where there is no Advance Directive, to inform the hospital to constitute Primary Medical Board.

To approach the High Court by way of writ petition under Article 226 of the Constitution, if permission to withdraw medical treatment is refused by the Secondary Medical Board.

## NOTARY OR GAZETTED OFFICER

Attest the execution/withdrawal of the AMD in the presence of two witnesses.

To record satisfaction that the document has been executed voluntarily and without any coercion or inducement or compulsion and with full understanding.

# HOSPITAL

To constitute the Primary Medical Board;  
If Primary Medical Board decides to carry out instructions in  
AMD, to form Secondary Medical Board.

To convey the decision of the Primary and Secondary Medical  
Boards and the consent of the person or persons named in  
the AMD to the jurisdictional JMFC before giving effect to the  
decision to withdraw the medical treatment.

Hospital staff can approach the High Court by way of writ  
petition under Article 226 of the Constitution, if permission to  
withdraw medical treatment is refused by the Secondary  
Medical Board.

## JURISDICTIONAL JUDICIAL MAGISTRATE FIRST CLASS

To receive the decision of the Primary and Secondary  
Medical Boards along with the consent of the person or  
persons named in the advanced directive, from the  
concerned Hospital.

## COMPETENT OFFICER'S FOR RECEIVING AND CUSTODY OF AMD.

Main **Mamlatdar** to receive a copy of the AMD from the  
executor and forward to the **Nodal Officer** of the  
District , who shall be responsible for the safe custody  
of the same.

To make available a copy of the AMD to the treating  
physician of the executor/patient

# REPORTS ON AMD



**SMT. VIJAYA V.AMBRE**

MEMBER SECRETARY  
GOA STATE LEGAL SERVICES AUTHORITY  
HIGH COURT OF BOMBAY AT GOA

**OPERATIONALIZING END OF LIFE CARE DECISIONS**

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**INTERACTIVE SESSION ON ADVANCE MEDICAL DIRECTIVE**

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# DOCUMENTS ON AMD



**SHRI. DINESH. R. SHETTY.**

REGISTRAR (ADMINISTRATION)  
HIGH COURT OF BOMBAY AT GOA

**MEETING OF SPECIAL COMMITTEE OPERATIONALIZING END  
OF LIFE CARE DECISIONS**

[CLICK HERE TO VIEW FULL REPORT](#)

**LIST OF REGISTERED MEDICAL PRACTITIONERS FOR  
EXECUTION OF AMD**

[CLICK HERE TO VIEW FULL REPORT](#)

# ACKNOWLEDGMENTS...

1. HON'BLE SHRI. JUSTICE BHARAT P. DESHPANDE, HIGH COURT OF BOMBAY.
2. SHRI. DINESH R. SHETTY, REGISTRAR, ADMINISTRATION, HIGH COURT OF BOMBAY AT GOA.
3. MS. VIJAYA V. AMBRE, MEMBER SECRETARY, GOA STATE LEGAL SERVICES AUTHORITY.
4. SHRI. RAM PRABHUDESSAI, REGISTRAR, JUDICIAL, HIGH COURT OF BOMBAY AT GOA.
5. SHRI. ARUN KUMAR MISHRA, SECRETARY (HEALTH).
6. MS. SNEHA S GITTE, COLLECTOR/ DISTRICT MAGISTRATE, NORTH GOA.
7. MR. ASVIN CHANDRU, COLLECTOR/ DISTRICT MAGISTRATE, SOUTH GOA.
8. DR. S. M. BANDEKAR, DEAN, GOA MEDICAL COLLEGE.
9. DR. GEETA KAKODKAR, DIRECTOR OF HEALTH SERVICES.
10. MS. SHILPA PANDIT SENIOR CIVIL JUDGE & J.M.F.C.;A COURT MAPUSA.
11. SHRI. CARLO ROHIN SANTAN DA SILVA, SENIOR CIVIL JUDGE & CHIEF JUDICIAL MAGISTRATE, MARGAO.
12. MS. PURVA V. NAIK CIVIL JUDGE, JUNIOR DIVISION & J.M.F.C., COURT, PANAJI.
13. AUDI SHANOR @ JAGDISH PANDURANG, DEPUTY REGISTRAR HIGH COURT OF BOMBAY AT GOA.
14. MS. POOJA PHADTE, JOINT SECRETARY, LAW DEPARTMENT.
15. DIPAK DESSAI, ADDITIONAL COLLECTOR NORTH GOA.
16. SHRI. PUNDALIK KHORJUVENKAR, ADDITIONAL COLLECTOR SOUTH.
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18. MR. PARAG NAGARCENKAR, STATE REGISTRAR-CUM-HEAD OF NOTARY SERVICES SHRI.
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22. DR. RAJESH PATIL MEDICAL SUPERINTENDENT GOA MEDICAL COLLEGE & HOSPITAL.
23. MRS. SUNITA SAWANT SUPERINTENDENT OF POLICE, SOUTH GOA.
24. MR. BRAZ T. MENEZES DY. SUPERINTENDENT OF POLICE NORTH GOA.
25. MR. SURAJ R. VERNEKAR DISTRICT REGISTRAR-CUM-HEAD OF NOTARY SERVICES, GOVT. OF GOA, PANAJI
26. ADVOCATE J. E. COELHO PEREIRA, PRESIDENT, GOA HIGH COURT.
27. ADVOCATE GAURISH AGNI, SECRETARY, GOA HIGH COURT BAR.
28. ADV JATIN RAMAIYA, ADVOCATE
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32. ADVOCATE. DR. AJAY PEDNEKAR PAST PRESIDENT, IMA GOA.
33. DR. DATTARAM DESAI, VICE PRESIDENT IMA, GOA BRANCH.
34. DR. SANTOSH USGAONKAR CHAIRMAN, DILASA.
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41. DR. ALISTER FERNANDES INTENSIVIST, SMRC, VASCO.
42. SHRI SANESH VARGHESE, CTO IT HUB PANAJI.
43. SHRI SUNRAJ NAGVEKAR, TECHNICAL ASSISTANT, IT HUB PANAJI.
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**DESIGN AND DEVELOPED BY DR. DEVDUTT SAIL,  
SECRETARY TELEMEDICINE SOCIETY OF INDIA, GOA STATE**



*Issued in public interest by*  
**INDIAN MEDICAL ASSOCIATION, GOA STATE**  
**GOA STATE LEGAL SERVICES AUTHORITY**

