Living Will and Advance Care Planning: The Need of the Hour

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WHAT IS ADVANCE CARE PLANNING AND WHY DOES IT MATTER FOR CLINICIANS?

Advance care planning (ACP) refers to the process through which patients, their families, and healthcare providers discuss and record preferences for end-of-life care. Internationally, ACP has been shown to reduce unnecessary interventions, align medical decisions with patient wishes, and provide dignity at the end-of-life. In India, however, structured ACP is virtually absent. Good end-of-life care is directly linked to the quality of death that Indians achieve, which has been consistently poor; in the 2021 Quality of Death Index report, India ranked 59 out of 81 countries that were studied.

For physicians, the absence of ACP is more than an ethical dilemma; it is a daily practical challenge. Doctors are frequently caught between offering aggressive interventions that may be futile and the risk of being accused of negligence if they withdraw or withhold treatment. In a country where nearly 80% of deaths now occur in hospitals, ACP offers a path forward by documenting patient preferences. It gives doctors the confidence to respect autonomy while staying within legal and professional boundaries.

DEFINITIONS AND **S**COPE

Advance care planning is defined by the European Association of Palliative Care as planning that "enables individuals to define goals and preferences for future medical

treatment and care, to discuss these goals and healthcare preferences with family and healthcare providers, and to record and review these preferences if appropriate."

The "umbrella" of ACP can include advanced medical directives (AMDs), designation of healthcare power of attorney, do not attempt resuscitation (DNAR) orders, and physicians' orders for limiting life-sustaining treatment (POLST). These terminologies are discussed in Table 1.3

Advanced Medical Directives: The History

The term living will was coined by Luis Kutner, a US-based human rights lawyer in 1969. The power of attorney was added to the living will in the 1980s–90s, so that individuals without capacity also had a way of ensuring their wishes were followed by appointing a designated healthcare representative.⁴

On March 9, 2018, the Supreme Court of India passed a judgment affirming the individual right to autonomy under Article 21. The judgment extended this autonomy to medical decision-making in the event of terminal illness by recognizing and laying down the process of creating AMDs. However, the administrative procedure required for the same was very tedious, and very few individuals were actually successful in creating their AMDs. This procedural complexity was addressed in a January 2023 Supreme Court amendment, which has given the procedure that we currently follow for creating an AMD. The Supreme Court has also retained a set of checks and balances,

including a two-step medical board verification process and a shared decision-making model with the designated healthcare provider.⁵

In parallel, medical and nonmedical societies such as the Indian Society of Critical Care Medicine, the Indian Association of Palliative Care, and the Federation of Indian Chambers of Commerce and Industry have issued guidelines on good end-of-life care, incorporating DNAR orders and administrative procedures for medical institutions.^{6,7}

THE LIVING WILL: PRACTICAL ASPECTS

The Indian ACP pathway has been outlined previously by Damani et al.,⁸ which covers steps from creation to implementation of the living will. The Indian living will, as described in the Supreme Court judgment, has its scope limited to terminal illness.⁵

While an ACP discussion can be done by all healthcare professionals, including doctors, nurses, and social workers, it usually falls within the purview of doctors. The first Living Will Clinic of India was launched at PD Hinduja Hospital, Mumbai, to give guidance and medical information about various aspects of the living will process. In Individuals present to the clinic to understand the various medical procedures that may be performed at the end-of-life and to discuss their preferences.

These individuals fall under three categories:

- Healthy individuals or individuals with stable long-term illnesses, for example, hypertension (HTN) and diabetes mellitus (DM).
- Individuals with serious illness who have required multiple medical interventions, for example, organ failure.
- Individuals in the last year of life, for example, end-stage organ disease and stage 4 cancer.

Table 1: List of terminologies falling under the ACP umbrella³

ACP terms	Description
Advanced care planning	Process of considering and communicating personal values and goals related to medical care over time
Designated healthcare representative	A person nominated to take healthcare decisions when the patient is incapacitated
Living will	A document that records patients' preferences about medical treatment
AMD	A document that (1) records patients' preferences about medical treatment and (2) designates a healthcare representative. In this document, the terms living will and AMD are used interchangeably
DNAR order	A documented decision to withhold cardiopulmonary resuscitation from a patient, taken with the consent of the patient. They are valid as per the ICMR guidelines on DNAR
Physician orders for life-sustaining treatment	Medical documents that translate patient preferences into physician directed order; not valid in India

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How to cite this article: Khanna U, Khanna S. Living Will and Advance Care Planning: The Need of the Hour. J Assoc Physicians India 2025;73(12):13–14.

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The discussion also includes decision-making about a designated healthcare representative who will be responsible for carrying out the patient's wishes once the living will gets activated. Once they have reflected on these aspects, they prepare their final document under supervision for notarization and submission. Patients are encouraged to discuss their medical preferences with their family. The hope is that ACP and Living Will Clinics in the country will enhance death literacy.

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