

Why do we need a living will?

Failing to plan ahead is often what separates a peaceful, dignified passing from a prolonged and distressing ordeal for the patient and their family; a living will might be all that humans have available to speak on our behalf when we no longer have a voice, in a life filled with unpredictability



The focus of a living will is specifically for situations in which the person develops a medical condition that is terminal or irreversible. Without a living will, many terminally ill patients spend their final days in the ICU, attached to numerous tubes, unable to speak, and cared for by strangers. - **Photo:** Getty Images

RAJEEV JAYADEVAN



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- A living will is a legal document that safeguards the individual's treatment preferences for certain irreversible conditions, essentially taking the burden off relatives and doctors in deciding on treatments in specific situations

- Studies have shown that having a living will does not affect total survival. At the same time, it helps reduce unnecessary medical interventions and expenses. Discussing one's preferences with close relatives and the family doctor is helpful to receive guidance and clarity while planning a living will

- A living will is not just for older people. Young adults may be involved in road accidents or other sudden catastrophic events and hence benefit from having one

Birth and death represent the two ends of a person's timeline. A disproportionate amount of preparation, attention and care is given to the first half — ranging from the anticipation of pregnancy, counselling and check-ups, to delivery and extravagant first birthday celebrations. Unfortunately, the same attention is rarely given to the opposite end — that is death. It is often left to chance, fuelled by the vague hope that 'the right treatment decision will somehow be taken at the right time by someone.'

Therein lies the problem. No one — not even a doctor — knows exactly how their life will end, or whether they will be able to speak for themselves in their final days. It could be a relatively sudden event or a long-drawn-out process following a severe, irreversible illness. That choice isn't ours to make. Ultimately, failing to plan ahead is often what separates a peaceful, dignified passing from a prolonged and distressing ordeal for the patient and their family.

A living will is a legal document that safeguards the individual's treatment preferences for certain irreversible conditions, essentially taking the burden off relatives and doctors in deciding on treatments in specific situations. Not having one could sometimes lead to crucial treatment decisions that the patient would not have made by themselves, needlessly prolonging their suffering.

The focus of a living will is specifically for situations in which the person develops a

medical condition that is terminal or irreversible. There will be no compromise in routine treatment measures for other illnesses. For instance, a college lecturer suffers a brain injury from hypoxia after a near-drowning incident in a river. The person is paralysed, opens their eyes but cannot recognise anyone or respond — a condition commonly referred to as a persistent vegetative state. This could also happen following head injury, choking on food, strangulation or a stroke.

In such situations, not only is recovery not generally possible, but the person may remain in that condition for prolonged periods — painful for the family to watch and also expensive in the long run. Another example is a person with metastatic cancer at a stage where further treatment offers no improvement, where the person may be better off receiving comfort care (palliative care) than remaining in the ICU receiving more rounds of chemotherapy that only diminish quality of life in the limited days that remain.

Most people would expect their family members or close friends to step in and take the right decisions along with the doctors. However, in reality, the situation can turn chaotic because of emotional conflict, guilt, differences of opinion and contrasting attitudes among several decision-makers — at the end of which doctors will often take the safest route possible: continuing every treatment measure prescribed in the books, without consideration for quality of life or prospects for recovery. In addition, our next of kin may not be alive or available to make these decisions for us in the distant future. A safer alternative is for individuals to document their preferences ahead of time, when they are still in good physical and mental health, and also discuss it in advance with family members so that there is no conflict if and when the time comes.

The living will does not need to be invoked for everyone who is dying, especially when the person is still able to discuss their wishes with their doctors. The danger of not preparing one is that sometimes, other people may end up making life-changing decisions on our behalf when we are not in a position to indicate our preferences.

For instance, if a person enters an irreversible persistent vegetative state, doctors may place a feeding tube that pierces the stomach wall—because the patient can no longer swallow. Such individuals can remain in a paralysed, bedridden state for several years, sometimes a decade or longer. This may not be what the person would have wanted. In contrast, if this person had previously made a living will (advance directive) stating they did not want artificial feeding in the event of an irreversible illness, the treatment plan could shift to comfort care. This gives the person a chance to pass away gradually, in peace, and surrounded by loved ones.

The Supreme Court legally recognised these “advance directives” in the *Common*

Cause vs. Union of India (2018) case. More recently, in the case of Harish Rana — where no living will existed — the Supreme Court enabled doctors to stop artificial feeding by classifying it as a treatment measure, while continuing comfort care until a natural death occurred.

Without a living will, many terminally ill patients spend their final days in the ICU, attached to numerous tubes, unable to speak, and cared for by strangers. This “disconnected” mode of dying not only results in poor quality of life for the patient but also causes profound emotional distress for the family left behind.

Clarity on treatments

A living will typically specifies which life-sustaining treatments to withhold or withdraw — such as ventilators, feeding tubes, or CPR — only if the patient has no hope of recovery. It does not apply to routine hospitalisations, surgeries, or the treatment of common illnesses. For example, a person with metastatic cancer who has written a living will to avoid ICU care and artificial feeding for their underlying terminal illness will still receive full treatment for a limb fracture or appendicitis. In such cases, if they are temporarily unable to eat, they will receive artificial feeding and post-operative ICU care just like any other patient — to help them recover.

Artificial feeding is a life-saving tool for reversible conditions; it only becomes a point of concern when used to indefinitely prolong a state of irreversible suffering.

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Discussing one’s preferences with close relatives and the family doctor is helpful to receive guidance and clarity while planning a living will. Guidelines for EOLC (End Of Life Care) by The Indian Association of Critical Care Medicine and the Indian Association of Palliative Care have been published. Templates available online can be customised — as each individual may have different viewpoints for end of life care.

For instance, one person may not want any form of artificial feeding if an irreversible illness is confirmed — that is, if they become unable to swallow or feed themselves. Others may agree to artificial feeding, but may not want to be attached to a ventilator if their breathing becomes weak. A third person may agree to ventilator care but will not want CPR, and a fourth may want everything possible to be done. Patient autonomy dictates that individuals have the right to decide the treatment measures they will receive — as long as these decisions are taken in a state of sound mind.

Once drafted, the document requires the signatures of two witnesses and that of a public notary or gazetted officer. A magistrate's signature is no longer a requirement in India, thus the process has been simplified.

A living will is not just for older people. Young adults may be involved in road accidents or other sudden catastrophic events and hence benefit from having one. They can always update their living will depending on any change in preferences as they get older.

To sum it up, a living will might be all that we have available to speak on our behalf when we no longer have a voice, in a life filled with unpredictability. Reserved for irreversible or terminal illnesses, it cannot be invoked for recoverable illnesses, and therefore will not affect routine medical or surgical care.

*(Dr. Rajeev Jayadevan is convener, research cell, Kerala State IMA and honorary senior consultant gastroenterologist, Sunrise Hospital Cochin.
rajeevjayadevan@gmail.com)*