

References and Resource Material

Indian Publications (Academic)

- ISCCM-IAPC integrated care plan for the dying <https://www.ncbi.nlm.nih.gov/pubmed/25249748>
- IAPC: EOLC Position statement <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4154162/>
- India: Not a Country to Die in <https://ijme.in/articles/india-not-a-country-to-die-in/?galley=html>

International Publications

- Planning for future care – NHS, UK https://www.dyingmatters.org/sites/default/files/user/Planning_for_your_future_care_FINAL_0102122.pdf
- Person centered care at the End of Life, by Bud Hammes https://respectingchoices.org/wp-content/uploads/2017/07/15-RC-0702_LE_HYOSCh2_web_rev.pdf
- Being Mortal: Atul Gawande <http://beingmortal.net/pdf/BeingMortal-Excerpt.pdf> or <http://1.droppdf.com/files/aYRWL/being-mortal-medicine-and-what-matters-in-atul-gawande.pdf>
- How the US system manages the end of life <https://polst.org/about/>
- Sample Advance Medical Directive from Five Wishes <https://fivewishes.org/docs/default-source/Samples/five-wishes-sample.pdf>
- What Doctors think about all this <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2013.0517>
- Quality of Death: India and the World from the Economist 2010 & 2015 http://www.lienfoundation.org/sites/default/files/qod_index_2.pdf <https://eiperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20index%20Oct%2029%20FINAL.pdf>

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About FICCI

Established in 1927, Federation of Indian Chambers of Commerce and Industry (FICCI) is the largest and oldest apex business organization in India. Its history is closely interwoven with India's struggle for independence, its industrialization, and its emergence as one of the most rapidly growing global economies.

A non-government, not-for-profit organization, FICCI is the voice of India's business and industry. From influencing policy to encouraging debate, engaging with policy makers and civil society, FICCI articulates the views and concerns of industry. It serves its members from the Indian private and public corporate sectors and multinational companies, drawing its strength from diverse regional chambers of commerce and industry across states, reaching out to over 2,50,000 companies.

FICCI provides a platform for networking and consensus building within and across sectors and is the first port of call for Indian industry, policy makers and the international business community.



About ELICIT

End of Life Care in India Taskforce (ELICIT) was formed as a joint initiative of the Indian Academy of Neurology, Indian Society of Critical Care Medicine (ISCCM) and Indian Association of Palliative Care (IAPC) at a meeting held in Mumbai on 15-16 August 2015. Members of this task force have been involved in the following initiatives and activities:

- Draft End of Life Care legislation covering Advance care planning, Foregoing Life sustaining treatment (Medical futility) and a Uniform definition of death to cover brain death. This draft was submitted to the Ministry of Health and Family Welfare in June 2016
- Impleader (Dr Raj Mani) in the Common Cause judgment of 9 March 2018, which made living wills possible for all Indians
- Collaboration with the ICMR to prepare a booklet on Definition of terms and to formulate actionable recommendations for Foregoing Life support
- Collaboration with Manipal Hospital to prepare the Blue Maple document on EOLC SOPs for the group's hospitals
- Lectures, symposia and courses on End of Life and Palliative care in diverse parts of the country
- Setting up a website www.onelittlewish.org for a public conversation



Improving End-of-Life Care & Decision-Making

Information guide to facilitate execution of End-of-Life Decisions - For Patients and their Families



End-of-Life Care & Decision-Making

Ensuring a Death with Dignity

- While the right to die with dignity is a fundamental right, reaching end-of-life decisions for themselves or for a loved one is one of the most difficult decisions people face
- A primary goal of medical care is preservation of life, however when life cannot be preserved, the task is to provide comfort and dignity to the dying person, and to support others in doing so
- Of the multiple parameters that assess care at the end-of-life, India scores poorly on availability, cost and quality of end-of-life care. Since there is no provision for this kind of care, a poor quality of death is common to all, irrespective of their economic status. In a scientific survey undertaken by The Economist, UK, India was cited as amongst the most adverse places in the world to die in
- Even in cases like cancer, organ failure or old age, where it is possible to medically identify patients who are terminally ill and are likely to pass away in the next 6 months to 1 year, patients, their families and doctors all struggle to prepare for what lies ahead
- Due to reluctance in facing the inevitable, valuable days are lost and life in the final days becomes a nightmare, with mounting emotional and financial burdens on the family

Goals for End-of-Life Care

- Improve quality of life by focusing on relieving physical distress and suffering
- Respect patient's wishes and maintain dignity
- Understand their cultural, religious, social or spiritual preferences
- Provide comfort and emotional support

Action Plan: End-of-Life Care and Decision-Making

- For Individuals/Patients

Plan in Advance

Self-awareness is the beginning of any journey. Think about how and where you would like to die.

Do not be afraid to bring up the subject of death if you feel it is relevant to you

Senior citizens or those with serious or life limiting illness should proactively assume the responsibility of discussing their future medical care preferences with family and loved ones and their treating doctors.

Ask your treating doctor and medical team about various options available to you and the advantages and disadvantages associated with each of them

It is important to remember that you cannot be forced to accept life-sustaining treatment against your wishes. Your treating doctor and medical team have an ethical and legal obligation to respect your wishes if you refuse any offered treatment, after understanding the consequences of such refusal.

To prepare for situations when you may not be in a position to express your wishes, **make an Advance Medical Directive (AMD)**

An Advance Medical Directive has two components:

1. The **Living Will**, which expresses your wishes for care clearly so that doctors can understand and follow them
2. The **appointment of a healthcare proxy**, through a power-of-attorney, who can speak for you when you are no longer capable of doing so. Your healthcare proxy could be a member of your family or a friend, but should not be your treating doctor. This saves the family the agony of taking decisions on your behalf without any guidance or without knowing your wishes

Discuss your directive with your family and/or healthcare proxy and make sure that they accept the appointment. It is advisable to make the directive in the presence of two witnesses, who will attest to the fact that you have made the directive with a sound mind. This directive can be revoked verbally/in writing. Although at present the Supreme Court has mandated a rather cumbersome process for using these directives, rationalization of the process is being advocated for.

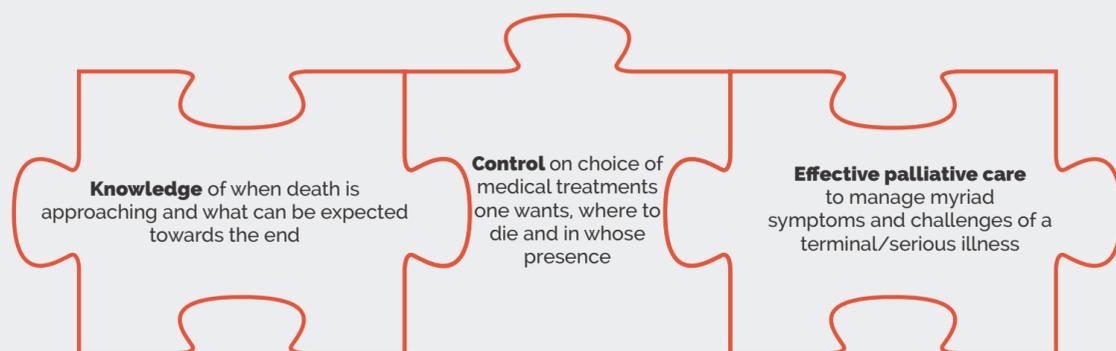
Take charge and accept death as part of life

If a serious or terminal illness is diagnosed, prepare to take charge of the last days of your life. Use all sources- medical, social, psychological and spiritual, to live well till the end. Do not resist the natural course of death. Discuss your needs and expectations now and in the future with family members, doctors and trained counsellors.

If you realize that you would rather not know or engage with such matters, appoint a trusted surrogate decision maker.

Disclaimer: This document has been developed and compiled by experts from the health sector for assistance of patients with simple practical steps for end-of-life decision making within the framework of Indian Law and Constitution. Information provided in this document is not intended to supplant or supersede any applicable Law/s. In the event of any conflict between the information provided in this document and those prescribed under any applicable Law/s, the latter shall prevail.

The Concept of a Good Death



This is crucial to prepare one for what lies ahead and be in charge of one's last days.

Besides settling one's affairs, it includes emotional and spiritual closure- saying goodbyes and giving and seeking forgiveness.

Worldwide 80-90% of people would prefer to spend their last days at home.

The law has always recognised the right of individuals to refuse medical treatment.

The Supreme Court judgment of 9 March 2018 specifically confirmed individual autonomy in healthcare choices and the right of refusal in the context of life-sustaining treatment.

Palliative care aims to maintain quality of life as long as possible till natural death occurs, it is all about 'adding life to days and not days to life'.

Palliative care services go beyond hospitals, providing care at homes of patients, ensuring a good quality of life till the end and empowering and supporting the family.

India currently has limited number of expert doctors, nurses, counsellors, social workers, physiotherapists and other required professionals for palliative care.

Examples of Life Sustaining Treatments



Cardiopulmonary resuscitation (CPR) to revive heart and lung function



Intravenous fluids, blood products and medications including antibiotics



Artificial respiration or respiratory assistance (Ventilation)



Dialysis and other Extracorporeal therapies



Chemotherapy



Radiotherapy



Surgery



Oxygen



Artificial feeding by tube in the nose (nasogastric) or stomach (gastrostomy)