# Palliative Care From Compassion to Commitment

# **Naresh Dua**

We extend our heartfelt thanks to Dr. Naresh Dua for his unwavering dedication to our campaign to promote awareness about palliative care. Over the past year, Dr. Dua has consistently contributed insightful and thought-provoking articles on this vital subject. In this concluding piece, he revisits the essence of palliative care—its definition, historical context, key challenges, and a thoughtful roadmap for the future—culminating in a powerful and comprehensive reflection. We sincerely hope his work sparks greater understanding and acceptance of palliative care within society, however modest the shift may be. Thank you, Dr. Dua.

— Editor

In a country as vast and diverse as India, where healthcare challenges are both deep-rooted and complex, one aspect of care continues to remain largely overlooked: **palliative care.** As the country battles with rising cases of cancer, heart disease, neurological disorders, and age-related illnesses, the need for a compassionate, holistic approach to care has never been more urgent. This is where palliative care steps in as a transformative approach to medical treatment, prioritising quality of life alongside traditional curative methods.

### What is Palliative Care?

Palliative care is a specialised branch of healthcare that focuses on **relieving pain**, **symptoms**, **and emotional distress** associated with serious or life-threatening illnesses. Unlike traditional treatment, which primarily aims at curing disease, palliative care centres on **comfort**, **dignity**, **and support**. It addresses not just physical symptoms like pain, fatigue, or breathlessness, but also provides **psychological**, **social**, **and spiritual support**.

Palliative care can be provided at any stage of illness, including from the time of diagnosis, and is often delivered alongside curative treatments such as chemotherapy, dialysis, or surgery. It is beneficial





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for patients with chronic conditions like cancer. heart failure, kidney disease. Alzheimer's, and motor neuron disorders. The goal is to ensure patients live as well as possible, for as long as possible, with control over their treatment and decisions.

The care typically is delivered by multidisciplinary team consisting of doctors, nurses, social workers. counsellors. and spiritual advisors, working together with patients and families to create a care plan tailored

to individual needs and values. It also involves continuous communication and shared decisionmaking that respects the cultural, religious, and personal values of the patient and their family.

Palliative care is not only confined to hospitals or hospices but can also be provided in the patient's home or in community settings. It serves to ease the journey through serious illness by focusing on what matters most to the patient whether that's being free from pain, staying at home, or having meaningful conversations with loved ones.

# A Brief History of Palliative Care

The roots of palliative care can be traced back to ancient civilisations, where communities cared for the sick and dying at home or within religious institutions. In ancient India, systems like Ayurveda offered holistic approaches that included spiritual and psychological care.



The modern palliative care movement emerged in the 20th century with the pioneering work of Dame Cicely Saunders in the UK. In 1967, she founded St. Christopher's Hospice in London, combining medical care with emotional and spiritual support. She introduced the concept of "total pain," recognising that suffering extends beyond the physical to include emotional, psychological, and social dimensions.

This movement soon spread globally. In Canada, Dr. Balfour Mount coined the term "palliative care" to give it broader medical legitimacy. The United States, Australia, and many European nations developed comprehensive hospice and palliative care systems backed by insurance and government support.

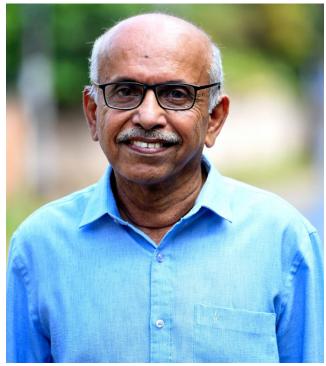
In India, palliative care took root in 1986 with the establishment of Shanti Avedna Sadan in Mumbai. A major boost came with the efforts of Dr. M.R. Rajagopal, who not only

set up community-based care in Kerala but also championed policy reforms for easier access to pain-relief medications. His advocacy led to the simplification of India's narcotics regulations and spurred public health policies supportive of palliative care. The government responded with the launch of the National Programme for Palliative Care (NPPC) in 2012, aiming to integrate palliative care into primary health services. However, progress has been uneven across states, often hindered by lack of awareness and funding.

# **Challenges of Palliative Care in India**

Despite decades of progress, palliative care in India faces several critical challenges:

- Limited Awareness: Many patients, families, and even healthcare professionals remain unaware of what palliative care truly offers. It is often misunderstood as care only for the terminally ill or as a last resort. The lack of public discourse results in underutilisation of available services.
- **Urban-Rural Divide:** Most palliative care services are available only in large cities or specialised cancer centres. Rural and remote areas, where a majority of the population lives,



Dr. M.R. Rajagopal

often lack even basic pain relief services. This leads to geographic and socioeconomic inequalities in care access.

 Lack of Trained Workforce: There is a severe shortage of trained palliative care professionals, including doctors, nurses, and allied health staff.



Very few medical colleges include palliative care in their curriculum, resulting in a workforce illequipped to handle end-of-life care needs. This scarcity results in overburdened care providers and fragmented services.

- Regulatory Barriers: Access to essential pain medications such as oral morphine is restricted by complex narcotics regulations, despite recent legal reforms. Bureaucratic hurdles make it difficult for healthcare institutions to stock and dispense opioids legally and safely.
- Social and Cultural Stigma: Talking about death and dying is often seen as inauspicious. This cultural silence prevents open communication, advance care planning, or timely referral to palliative care services. Families may avoid palliative care thinking it means giving up hope.
- Policy Gaps and Underfunding: While the NPPC provides a framework, the absence of dedicated budget allocations and implementation mechanisms limits its effectiveness. Palliative care is still not seen as a public health priority. It lacks integration into national health missions and insurance programs.

# **Creating Awareness and Building Capacity**

To address the growing need for palliative care, India must focus on a multipronged strategy that includes awareness-building, education, workforce training, and policy reforms.

- Incorporating palliative care into medical and nursing education is a crucial first step. MBBS, BSc Nursing, and postgraduate medical programs should include modules on palliative care to ensure that future healthcare providers are equipped with the right knowledge and attitude. This will also help remove misconceptions and equip professionals to initiate end-of-life conversations.
- Mass awareness campaigns using digital media, television, and community outreach can help shift public perception. Highlighting real-life success stories, patient testimonials, and stories of dignified death can humanise



the subject and break taboos surrounding palliative care.

- Task-shifting to trained nurses, community health workers, and allied professionals can significantly expand reach. With over 34 lakh registered nurses and 13 lakh allied health professionals, India has the workforce what's needed is targeted training. Training modules, continuing education, and online certifications can help empower this group.
- Insurance coverage and funding mechanisms need to evolve. Programs like Ayushman Bharat must include palliative services, reducing financial strain on families. Insurance companies should be encouraged to cover home-based palliative care and hospice services, making them accessible to all income groups.
- Public-private partnerships, involving NGOs and philanthropic foundations, can accelerate the availability and quality of palliative services. Community-based models, especially those pioneered in Kerala, can be replicated nationwide. Collaborations with spiritual leaders, community influencers, and social workers can also promote culturally sensitive care.

# **Champions of Palliative Care in India**

India's progress in palliative care has been shaped by tireless individuals and institutions:

Dr. M.R. Rajagopal, founder of Pallium India, has been a national leader in communitybased palliative care and pain relief advocacy. His efforts led to amendments in the Narcotic Drugs and Psychotropic Substances (NDPS) Act, improving morphine access. His vision of 'pain relief as a human right' continues to inspire national and global advocacy.

- CanSupport, led by Harmala Gupta, has offered home-based palliative care to thousands of cancer patients in Delhi since 1997. The organisation combines clinical care with counselling, community mobilisation, and patient empowerment.
- The Indian Association of Palliative Care (IAPC) has been instrumental in policy advocacy, professional training, and awareness building across the country. It has also collaborated with international organisations to publish guidelines and curricula.
- Premier institutions like AIIMS, Tata
   Memorial Hospital, and regional cancer
   centres have also started integrating palliative
   care into oncology and chronic illness
   programs. Many medical colleges now run
   palliative care electives and community-based
   projects for students.

These trailblazers have proven that dedicated effort, even on a small scale, can make a tangible difference to thousands of lives. Their work also showcases the power of compassion-driven care in a system largely dominated by curative models.

## The Future of Palliative Care in India

India's demographic trends—an ageing population and rising burden of chronic diseases—make it clear that palliative care must become a **mainstream component** of healthcare.

Future steps include:

- Establishing dedicated palliative care units in all district hospitals and medical colleges. These should be equipped with trained staff, essential medications, and counselling rooms for patients and families.
- Rolling out **nationwide training programs** with certification for doctors, nurses, and allied staff. The Medical Council of India and Indian Nursing Council must mandate such training.
- Creating region-specific care models that consider local languages, beliefs, and

- healthcare infrastructure. This ensures contextual care that respects traditions and encourages family involvement.
- Encouraging research and innovation in pain management, psycho-social support tools, and digital health interventions for palliative care delivery. Academic partnerships with engineering and design institutes can foster low-cost, tech-enabled solutions.
- Adapting best practices from countries like the United States, where hospice and insurance-backed models support a broad spectrum of patient needs—but tailoring these approaches to fit India's social, cultural, and economic fabric. Lessons from Sri Lanka, Bangladesh, and Nepal can also offer scalable, regional solutions.

#### Conclusion

Palliative care is not just about dying well—it's about living well despite illness. It restores dignity, reduces suffering, and empowers families during the most vulnerable periods of life. India has the talent, the tradition of caregiving, and the community structures to build a world-class palliative care system. What is needed now is sustained political will, policy support, and societal engagement.

The time to act is now. Palliative care must be recognised as a **fundamental component of universal health coverage**, and every individual must have the right to a pain-free, dignified existence regardless of their diagnosis, location, or income level.

By embracing palliative care as a human right and an essential health service, India can ensure that no one suffers needlessly, and every individual receives the care they deserve—with compassion, dignity, and hope.

For more on this subject, or to get involved with community-based palliative initiatives, visit **shantifoundation.global**.

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