

# Kerala State Policy on Palliative Care

2019

GOVERNMENT OF KERALA |

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## Glossary

AYUSH	Ayurveda, Yoga, Unani, Siddha and Homeopathy
CBO	Community Based Organization
CHC	Community Health Centre
KMSCL	Kerala Medical Service Corporation Limited
NCC	National Cadet Corps
NGO	Non-Governmental Organization
NNPC	Neighbourhood Network in Palliative Care
NSS	National Service Scheme
PHC/FHC	Primary Health Centre / Family Health Centre
SC / ST	Scheduled Caste/ Scheduled Tribe
SDG	Sustainable Development Goals
SHS	Serious Health-Related Suffering
UHC	Universal Health Coverage
WHO	World Health Organization

## Introduction

In much of history, the reduction of suffering was at the core of medicine. As medical science evolved and better diagnostic and treatment modalities became available, the focus shifted to successful treatment and cure of diseases and illnesses. While this benefitted humankind in countless ways, paradoxically, there has been unintended neglect and marginalization of palliating health-related suffering <sup>1</sup>. In order to address this, now there is a need for special attention and action.

The World Health Organization (WHO), in 2002, defined Palliative Care as “an approach that improves the quality of life of **patients and their families** facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”<sup>2</sup>.

The Lancet Commission Report on Palliative Care (2017) has widened the scope and considers Palliative Care as “an essential component of comprehensive care for persons with complex chronic or acute, life-threatening, or life-limiting health conditions that should be practiced by all health-care and social care providers and by palliative care specialists, and that can be provided in any health-care setting, including patients’ own homes” <sup>3</sup>. The Commission particularly highlights the special needs and requirements of children who are in need of Palliative Care.

Palliative Care aims at reducing Serious Health-related Suffering that is, suffering associated with illness or injury of any kind and which cannot be relieved without special interventions failing which it impairs physical, social and emotional

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<sup>1</sup>Krakauer, *To Be Freed from the Infirmities of Age. Subjectivity, Life-Sustaining Treatment and Palliative Medicine.*; Gawande, *Being Mortal. Medicine and What Matters in the End.*

<sup>2</sup>“WHO | WHO Definition of Palliative Care.”

<sup>3</sup> Knaul et al., “Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage.”

functions. Attention has to be given to social and psychological suffering as much as it is given to physical suffering.

Palliative Care is now seen from a human rights perspective as an integral part of the right to enjoy the highest attainable standard of physical and mental health<sup>4</sup>. The UN Committee on Economic, Social and Cultural Rights states that it is critical to provide “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity”.

## Global Scenario

Goal No. 3 of the Sustainable Development Goals (SDGs) calls for the attainment of Universal Health Coverage (UHC)<sup>5</sup>. UHC by definition is about providing access to all people to promotive, preventive, curative, rehabilitative and **palliative** health care as per need and of sufficient quality to be effective, while also guaranteeing that the use of these services does not expose them or their families to financial hardships<sup>6</sup>. This makes Palliative Care an integral part of Universal Health Coverage without which the goal of Universal Health Coverage cannot be attained.

The Astana Declaration of 2018 reiterates this by stating that it aims to “prioritize disease prevention and health promotion and will aim to meet all people’s health needs **across the life course** through comprehensive preventive, promotive, curative, rehabilitative services and **palliative** care”<sup>7</sup>.

The global community has the responsibility to “close the abyss in the relief of pain and other types of suffering throughout the life course and at end-of-life, caused by

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<sup>4</sup> Brennen, “Palliative Care as an International Human Right”; United Nations, “International Covenant on Economic, Social and Cultural Rights.”

<sup>5</sup> “The Sustainable Development Agenda - United Nations Sustainable Development.”

<sup>6</sup> WHO, “What Is Universal Coverage?”

<sup>7</sup> WHO, Declaration of Astana.

life-limiting and life-threatening health conditions”<sup>8</sup>. Barriers that exist to the access of palliative care include the focus on cure and extending life, opiophobia, limited patient advocacy and the focus on existing measures of health outcomes that give little weight to interventions that alleviate suffering and increase dignity particularly at the end of life<sup>9</sup>.

In 2015, 45% of all global deaths (25.5 million of 56.2 million deaths) involved serious health related suffering. 80% of all deaths with serious health related suffering were from developing countries and the vast majority of these countries lacked access to palliative care services. 2.5 million children died with SHS in 2015 and 98% of these deaths were from developing countries. In high-income countries, children account for only 1% of all deaths with SHS whereas in developing countries children form 30% of deaths with SHS<sup>10</sup>.

Diseases that cause SHS in the developing world include malignant neoplasm's(26%), cerebrovascular diseases(17%), lung diseases (11%), Injuries (6%), Tuberculosis (6%), premature birth and trauma (5%), HIV (5%), Liver disease (5%), Non Ischemic Heart Disease (4%), Dementia (4%). 11% of the SHS were from other diseases<sup>11</sup>.

## Kerala Scenario

Kerala has been acknowledged as a successful model, not only in India but in the entire developing world, through its path-breaking work in Community Based Palliative Care<sup>12</sup>. The ‘Quality of Death’ study by Economist Intelligence Unit states

<sup>8</sup> Knaul et al., “Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage.”

<sup>9</sup> MD Magazine, “Why Are We Still Talking about Opiophobia?”

<sup>10</sup> Knaul et al., “Alleviating the Access Abyss in Palliative Care and Pain Relief—an Imperative of Universal Health Coverage.”

<sup>11</sup> Knaul et al.

<sup>12</sup> Hockley, Froggatt, and Heirmerl, *Participatory Research in Palliative Care: Actions and Reflections - Oxford Scholarship*; Bollini, Venkateshwaran, and Sureshkumar, “(18) (PDF) Palliative Care in Kerala, India.”

that ‘amid the lamentably poor access to palliative care across India, the southern state of Kerala stands out as a beacon of hope <sup>13</sup>. The Palliative Care movement in Kerala began with the Pain and Palliative Care Society in Kerala and quickly grew with the formation of the Neighbourhood Networks in Palliative Care (NNPCs)<sup>14</sup> providing home-based palliative care. NNPC is aimed at motivating and capacitating local communities to look after chronically ill and dying patients in their neighbourhoods.

The Palliative Care movement in Kerala which had its roots in NGO action soon attracted a high level of political ownership. Kerala declared Palliative Care Policy in 2008. Realizing the necessity to modify the Palliative Care Policy incorporating the existing situation, discussions were held among the experts from different sectors and a new comprehensive Palliative Care Policy is being formulated. Local governments and over 350 non-government and community-based organizations are now providing Palliative Care services, largely home-based. The Kerala Model places a strong emphasis on community participation and volunteerism integrated with Primary Health Care system especially through dedicated nurses under the overall leadership of local governments.

## Goal

The Goal of the Policy is to ensure that every person in Kerala has access to effective palliative care services of good quality with a focus on community-supported home-based care without getting exposed to hardships- financial, social or personal.

## Guiding Values and Principles

### **1. Rights-Based Approach**

Palliative Care would be treated as a right of every person who is in need of such care.

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<sup>13</sup> The Economist, “The Quality of Death-Ranking End of Life Care across the World.”

<sup>14</sup> Kumar and Numpeli, “Neighborhood Network in Palliative Care.”

## **2. Universality**

No one who requires palliative care would be left behind. The Antyodaya approach would be followed to ensure the poorest and weakest person is reached first.

## **3. Integration**

Palliative Care would be mainstreamed in all disciplines of medicine. It will be fully integrated into the health care system and will not be seen as a standalone activity.

## **4. Multi-Sectoral Approach**

The multi-sectoral approach would be followed to converge different services and resources of palliative care involving the relevant departments especially Health and Family Welfare, AYUSH, Education, Local Self Government, Social Justice, Youth Affairs, Scheduled Caste/Scheduled Tribe Development, Revenue and Home, coordinated by the local governments at the field level. The government will involve private, not-for-profit and NGOs and CBOs in ensuring palliative care services to the community

## **5. Clarity, fairness, precision and timeliness**

These would characterize the delivery of palliative care services to every patient in need and the individual. Family and the society would be made aware of the norms and levels of support guaranteed to them including the quality, quantity and timelines through a Citizen's Charter at the level of the local government concerned.

## **6. Respect and Patient Centeredness**

All the patients and family members would be treated with utmost politeness and courtesy fully ensuring the dignity of the individual. The system will enable patients to choose care providers and care provisions from all available options.

## **7. Ethics**

Highest standards of ethics would be ensured in the field of Palliative Care with a published Code.



### **8. Accountability**

A bouquet of accountability measures would be put in place to ensure total transparency. Accountability to the community will be promoted through community involvement and ownership in the program.

### **9. Continuum of Care**

Palliative care will be provided across the course of the suffering with definite roles for all levels of healthcare – community-based, primary, secondary and tertiary- public and private.

### **10. Decentralized approach**

A bottom-up approach would be followed with primacy given to local governments in planning and providing palliative care services in partnership with Community-Based Organisations (CBOs) and people in general, coordinating all agencies, public and private.

### **11. Convergence**

All relevant programmes of the central, state and local governments would be converged to enhance the coverage and quality of palliative care.

### **12. Community-based care.**

The cornerstone of the policy is to achieve maximum participation and empowerment of the community ie. interested citizens, NGOs, and CBOs in Palliative Care with a focus on the patient and the family. In all matters, patient will have the final choice.

### **13. Continuous improvement**

Based on constant feedback and regular measurement of performance, there would be continuous improvement. The policy will strive to ensure the adaptability of the palliative care system to keep up with global advancements.

## Objectives

1. To ensure that every needy patient gets the required palliative care in appropriate quantity and quality within a reasonable time with an emphasis on home-based care with no one left behind.
2. To enhance the capability of the health system to meet the palliative care requirements of the state.
3. To build the capacity of all the stakeholders to equip them to perform the tasks required to achieve universal palliative care.
4. To improve access to essential medicines needed for pain and palliative care including the required controlled medicines while putting in place strict measures to prevent inappropriate and non-medical use.
5. To develop a functional partnership with NGOs and CBOs and also hospitals outside the government sector to expand the service provision in palliative care
6. To develop capacity for documentation, research and development.
7. To develop medical colleges as centers of excellence in palliative care.
8. To put in place support systems to achieve the above objectives to ensure sustainability.

## Palliative Care at the Primary Level

There will be a significant role for the community in the planning and implementation of the programme at the level of the Village Panchayats, Municipalities and Corporations. Strong and active Neighbourhood Network in Palliative Care would be put in place in each Ward of every local government in the State. All patients in need would be identified and comprehensive plan prepared for each patient, detailing the services to be provided and specifying who would provide each service, at what frequency – with the patient having the final choice. All staff and field workers at the primary level would be trained to provide outreach care in the patient's homes. The strengths of NGOs and CBOs shall be leveraged to ensure the provision of optimum service to the community.

## Palliative Care at the Secondary Level

The Community Health Centres (CHCs) would be developed to act as the first referral centres with earmarked beds to provide inpatient palliative care inclusive of physiotherapy and specialist home visit services. The CHC will also facilitate services at the primary level.

Taluk Hospitals will serve as FRUs for palliative care emergencies. Staff at the Taluk hospitals will be equipped to deal with such emergencies.

Private hospitals and care providers who voluntarily undertake secondary palliative care service will be included in the service provision for secondary palliative care.

## Palliative Care at the Tertiary Level

As part of Community Medicine a Division of Palliative Medicine would be set up in all Medical Colleges and in General/District Hospitals in the initial stage. The Division would coordinate with the support of the provision of palliative care by the relevant departments with the support of expertise from NGOs/CBOs/Individuals as per need. The Division of Palliative Medicine would initially consist of existing trained personnel including doctors, nurses and allied health professionals and provide Out-Patient Care /Ward Consultations and Home Visits. Home Visits will be made in collaboration with Community Medicine in the current service area with NGO/ CBO collaboration. This will be upgraded to a full-fledged 'Department of Palliative Care' with service, training and research capability in time in Medical Colleges.

## Training and Capacity Building

Standards for Training Centres would be developed and the existing centres duly accredited to facilitate minimum standards. Common training modules would be developed for different types of courses. High-quality training of trainers programmes would be conducted and trainers formally accredited for conducting

training for various stakeholders. Doctors and other health personnel working in primary, secondary and tertiary levels would be given mandatory training according to a training calendar for which they would be deputed before the start of the financial year. Refresher courses would be regularly conducted at periodic intervals for those who have been trained. All elected heads of local governments and members of the health standing committees would be trained on different aspects of Palliative Care. Similarly, training would be conducted for NGOs and CBOs working in the area to develop their capacity for service delivery and training. The Government would also provide training free of cost to the staff of the hospitals in the private sector which volunteer to join the Palliative Care programme. Sensitization training would be organized for students in schools and colleges and for interested citizens.

High-quality handbooks would be prepared for different stakeholders. Also, distance learning would be facilitated through Certificate and Diploma courses. A knowledge portal would be developed.

## Citizen Education

In order to sensitize citizens, the following steps would be taken

1. Training sessions for High School and Higher Secondary School and colleges including professional colleges students with home visits as part of community outreach.
2. Practical training for National Cadet Corps (NCC), and Student Police Cadets and all NSS volunteers.
3. Promotion of students palliative care Units in all educational institutions.
4. Sensitization training for all Neighbourhood Groups of Kudumbasree, other Self Help Groups and Residents Associations.
5. Introduction of a module in all programmes of the State Literacy Mission.
6. Sensitization training for Youth Clubs, village libraries and other social groups.

In addition, conventional and social media would be widely utilized to highlight the importance of Palliative Care.

## Access to opioids and other essential medicines and supplies relevant to Palliative Care

The state government will revise the essential drug list to include drugs and supplies relevant for palliative care. These drugs would be made available to all government hospitals where a trained doctor is available. Proper documentation would be ensured to avoid inappropriate use. Mechanisms will be put into place for effective delivery of medicines and supplies as per a standard list through home visit teams, whether government or accredited non-governmental agencies.

## Role of Non-Governmental Organizations and Community Based Organizations.

NGOs and CBOs would be active partners in the Palliative Care movement. All NGOs and CBOs providing medical and nursing services at home would be accredited on the basis of transparent norms by a group of experts constituted for the purpose. All NGOs and CBOs providing only social support who would like to work with local governments would be registered at the level of the local government concerned. Names and services by such NGO/CBO will be published. There would be a training plan to ensure that all accredited and registered NGOs are suitably trained to attain minimum standards in the provision of palliative care. Medicines and other aids can be made available free of cost by the local governments to the accredited NGOs and CBOs which do voluntary work without charging for their services with appropriate monitoring mechanisms in place.

The government would facilitate the development of capacity of NGOs and CBOs to initiate and upgrade primary, secondary and tertiary programmes.

## Role of Local Governments

Local Governments, Village Panchayats, Municipalities and Corporations would incorporate the preparation of a comprehensive palliative care plan as part of the People's Plan. They would coordinate and support all the care providers in their jurisdiction, accredited or registered. They will assign the care providers to different patients according to the need with the preference of the patient given priority. Local governments would facilitate the convergence of palliative care services of different systems of medicine. Local Governments also would nurture the Neighborhood Networks in Palliative Care in their Wards. They would formulate schemes for the socio-economic rehabilitation of palliative care patients. They would facilitate all the monitoring arrangements. Block and District Panchayats would prepare plans for the institutions under their control and can also supplement the plans of village Panchayats.

## Role of Private Hospitals

The private hospitals including private Medical Colleges would be brought into the palliative care network through a process of advocacy & dialogue. Training would be provided free of cost by the government to such hospitals and institutions to improve capacities to provide good quality palliative care.

## Role of AYUSH

The Department of AYUSH would come out with a plan of action for providing palliative care through their institutions in consonance with the general parameters of this policy including quality assurance, procurement and distribution of medicine.

## Special focus on Vulnerable Population

As children are estimated to constitute almost 30% of patients with serious health related suffering, special efforts would be taken to provide palliative care to the children in need. This would include all elements of palliative care for adults with an emphasis on the growth and, emotional & cognitive development ensuring their entitlement to education and recreation. The role of family & home as the centre of care and the necessary link between pediatric care providers and palliative care will

be emphasized.

Care Compromised groups including people belonging to scheduled tribes, people living in geographically inaccessible areas and other vulnerable groups and people living with HIV/AIDS would be reached out to proactively. Palliative care services would also be extended to all migrants working in Kerala irrespective of their period of stay. To the extent possible these measures would be done in convergence with existing programmes for different vulnerable groups.

## Livelihoods.

Efforts would be taken to ensure the socio-economic rehabilitation and promotion of livelihoods of people with debilitating illnesses. Such persons will be provided the requisite skills and raw materials for taking up livelihood related activities. Local governments would provide avenues for marketing the products of such enterprises including quality assurance and branding in association with Kudumbasree, NGOs and CBOs with such competence. Appropriate support systems will be developed at local level to take care of the well-being of dependents of those persons who are on palliative care.

## Documentation and Research

There would be extensive documentation of all aspects of the programmes. High-quality research is essential for policy interventions. Research fellowships and grants would be provided for research in palliative care. Action research to try out new models will be done through institutions in the public sector as well as in the non-government sector. This would aim at nurturing “resource clusters” in the field which could then be developed as “schools of practice” for others to learn from.

Medical Colleges and centres of excellence will undertake health technology assessment (HTA) to enable evidence-based management of patients at primary, secondary and tertiary levels.

## Monitoring and Evaluation

Multiple levels of monitoring would be put in place. These include:

1. Community-based monitoring
2. Monitoring by Committee at the level of the local government, district and state
3. Independent monitoring by specially trained quality monitors.
4. Social audit at the level of the local governments
5. Independent assessment by a reputed external agency once in every five years

## Specialization in Palliative Care

The following special courses on Palliative Care would be introduced in the State within five years.

- i. MD Palliative Medicine Programme in a minimum of two Government Medical Colleges
- ii. M.Sc Palliative Nursing Programme in a minimum of two Nursing Colleges in the state
- iii. Residential Fellowship in Palliative Medicine Programme in a minimum of two Medical Colleges in the state
- iv. PG Diploma course in Palliative Care Nursing in a minimum of two Nursing Colleges in the state
- v. Curriculum and training will be linked with all primary and secondary care programmes in the state

## Institution of Excellence in Palliative Care

Within five years, an institution of excellence in Palliative Care would be set up by the government attached to a government medical college which would conduct high-quality research and strengthen the community-based palliative care system in the State. It would function as a National Resource Organization proactively sharing the Kerala experience with the rest of the country and the world and acting as an



advocacy agent for mainstreaming palliative care in the health system all over. It will also identify national and international practices for suitable adaptation.

## Palliative Care Grid

A Palliative Care Grid would be set up on the lines of the National Cancer Grid. It would serve the following purposes.

- i. Networking of institutions providing Palliative Care according to levels and kinds of care providing information, education, mentoring and quality assurance and developing an authentic directory of palliative care service providers including NGOs and CBOs
- ii. Facilitating mutual consultation and sharing of experience including tele consultation
- iii. Sharing of data
- iv. Conducting joint research

Palliative care grid will enable the continuum of care of patients across various levels of the health system. The Grid will exist as an omnichannel portal being largely hosted online while ensuring that measures are in place to ensure that people who do not have access to the internet are included in the network.

## Targets

### ***By the end of the First year***

1. *To develop training facilities in the state so as to provide high-quality training in palliative care across the state.*
  - 1.1. To accredit and recognize existing training centres based on common standards.
  - 1.2. To develop at least one government training centre in each district in the state for advanced training in palliative medicine and nursing satisfying minimum standards covering doctors, nurses and other health professionals.

- 1.3. To develop a common curriculum/set of guidelines for sensitization programmes, volunteer training programmes, 10-day training courses, 6-week training courses and foundation courses
- 1.4. To develop and incorporate palliative care modules in medical, dental, nursing, pharmacy and allied health courses.
2. *To build the capacity of palliative care services by providing adequate training and sensitization to the personnel involved, including volunteers, elected members of local government and laypersons as detailed below.*
  - 2.1. To provide two-day refresher training of trainers to a minimum of 75% of the existing practitioner-trainers.
  - 2.2. To train at least 500-1000 volunteers in Palliative Care with three days of hands-on training in each district (depending on population) with special emphasis on hitherto lagging areas.
  - 2.3. To sensitize at least 100 NGOs/ CBOs from lagging areas in the basics of palliative care to be followed by three-day training for volunteers from these CBOs.
  - 2.4. To conduct one-day sensitization programmes in pain relief and Palliative Care for all government doctors, nurses and other health / social welfare workers who have not been covered so far.
  - 2.5. To conduct one-day sensitization programmes in pain relief and Palliative Care for one-third of all employees of the Social Justice department.
  - 2.6. To conduct sensitization programmes for all CDS chairpersons and one-third of the ADS chairpersons of Kudumbasree.
  - 2.7. To conduct sensitization programmes for all Scheduled Caste /Scheduled Tribe promoters.
  - 2.8. To conduct sensitization programmes for minimum 10% of all doctors, nurses and health care personnel of the private hospitals in the state.
  - 2.9. To conduct five-day training programmes for care providers of all care homes and daycare centres.
  - 2.10. To provide six-day refresher training for all existing community nurses in primary and secondary systems.

- 2.11. A minimum of 25% of all government doctors, nurses and allied professionals and interested professionals from private institutions to undergo a three-day introductory course in palliative care.
- 2.12. At least 150 doctors and 150 nurses from the government in the state to successfully complete Foundation Course in Palliative Care. (Ten days 'hands-on' training in Palliative Care with three days/20 hours of interactive theory sessions).
- 2.13. At least 50 doctors and 50 nurses from the private sector in the state to successfully complete the Foundation Course in Palliative Care. (Ten days 'hands-on' training in Palliative Care with three days/20 hours of interactive theory sessions).
- 2.14. At least 50 more doctors and 50 more nurses from the government to successfully complete six weeks certificate course in Palliative Medicine and Palliative Nursing.
- 2.15. At least 20 more doctors and 20 more nurses from private hospitals to successfully complete six weeks certificate course in Palliative Medicine and Palliative Nursing.
- 2.16. To institutionalize annual training programmes for elected members of local governments and the officials concerned.
- 2.17. To incorporate palliative care as a distinct module in the induction course of all categories of local government leaders.
- 2.18. To incorporate palliative care as a distinct module in the induction course of all categories of health staff.

These training programmes will be repeated every year.

3. *To improve access to essential medicines needed for pain and palliative care including essential narcotic drugs while ensuring appropriate measures to prevent misuse as detailed below.*
  - 3.1. Agreement on standard operating procedures for approval of Recognized Medical Institutions (RMI) involving the department of Health and Family Welfare, Drug Controller and the Departments of Health Services and Medical Education
  - 3.2. The addition of oral and injectable morphine to the KMSCL Essential Drug list.

- 3.3. Ensuring at least 10-day training for a minimum of one doctor and ensure the access of morphine and other essential drugs in all major hospitals, all Community Health Centres (CHCs)
- 3.4. Ensure the access of morphine and other essential drugs in all Primary Health Centres/ Family Health Centres where a trained doctor is available.
- 3.5. Ensuring proper documentation is kept in accordance with the Narcotics Amendment Act 2014 when morphine or opioids are stocked by issuing a clear set of instructions.
4. *To develop palliative care services at the tertiary care level both within the government sector as well as the private sector as detailed below.*
  - 4.1. Establishment of Division of Palliative Care in all Government Medical Colleges and 25% private medical colleges consisting of existing staff including for one doctor each from as many of the following departments preferably on a voluntary basis. (Anesthesia, Internal Medicine, Community Medicine, Radiation Oncology, PMR, Gynecology, Pediatrics, General Surgery, Family Medicine and any other relevant clinical departments)
  - 4.2. In-Hospital Consultation facilities by the Division of Palliative Care in the current ward of the patient.
  - 4.3. Palliative Care Out-patient Departments to be set up by the Division of Palliative Care at a site preferably outside the Department of Oncology to facilitate the access by non-cancer patients with Serious Health-Related Suffering.
  - 4.4. Palliative Care Home Visits on a regular basis with the objective of improving patient care and to improve medical and nursing student learning outcomes.
  - 4.5. Effective follow-up post-discharge of the patient needing palliative care services, integrating with the existing primary palliative care system including home visits.

5. *To further strengthen palliative care facilities at the primary level as detailed below.*
  - 5.1. To set up arrangements for registration of providers of social support at the level of the local government.
  - 5.2. Line List all people in need of Palliative Care support within the local government with details on the type and level of services needed, on a campaign mode.
  - 5.3. To establish NNPC groups in a minimum of 25% of wards in rural areas and 15% of wards in urban areas.
  - 5.4. To ensure the regular monthly visit of care homes and daycare centres by primary/secondary care teams.
6. *To facilitate collaboration between Non-Governmental Organizations, Community Based Organizations and the Government to improve efficiency as detailed below.*
  - 6.1. Complete the process of accreditation of all NGOs providing medical and nursing care at home. Such NGOs will be accredited to provide supportive services in hospitals as well if any hospital so chooses.
  - 6.2. Complete the registration of all NGOs providing social and psychological support at the local government level. Registration means providing basic details to the local governments to enable any agency or individual to utilize their services.

***By the end of the Third year***

7. *To strengthen palliative care facilities at the primary level as detailed below.*
  - 7.1. To have an Integrated plan at the local government level covering every person with serious health-related suffering and their families with special emphasis on particularly care compromised and vulnerable groups including children, tribals, people living in a geographically isolated area, fishermen community, and disaster-affected populations. Patients will be linked with the subcentre / Health and wellness centre concerned. Every patient with serious health-related suffering would be categorized into one of three groups according to established guidelines at the level of the local governments. The categorization is fluid and the

patient should be moved from one category to the other as appropriate after each home visit.

- i. Category A – Need home visit by doctor and nurse and social support
- ii. Category B – Need home visit by a nurse and social support
- iii. Category C – Need only social support.

Patients from each category will receive an appropriate standard of care at the specified time intervals.

- 7.2. To increase the number of palliative care nurses in each local government to ensure a minimum of one palliative care nurse for 20,000 population.
8. *To strengthen palliative care facilities at the secondary level as detailed below.*
  - 8.1. To develop /strengthen physiotherapy units at the Community Health Centres with provisions for facility-based physiotherapy.
  - 8.2. To develop Community Health Centres (CHCs) as Centres for Chronic Illness and serve as a First Referral Inpatient Unit for people with Chronic Diseases.
    - 8.2.1. The CHC will act as an effective support system for home-based primary care with fully functional In-Patient facilities with medical, nursing and physiotherapy services.
    - 8.2.2. The CHC will also provide specialist home visits for addressing special needs including stoma care, lymphoedema care, etc.
    - 8.2.3. The CHC will also serve as a part of the post-discharge plan of patients being discharged from tertiary centres to ease the process of returning to their homes.
    - 8.2.4. CHCs will act as the point of integration of palliative care with vertical programmes like the National Programme for prevention and control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS), National Mental Health Programme ,National Programme for Healthcare of the Elderly and other relevant programmes.

- 8.2.5. To equip all Taluk hospitals for managing palliative care emergencies.
9. *To develop palliative care services at the tertiary care level both within the government sector as well as the private sector as detailed below.*
    - 9.1. Strengthening Palliative Care divisions in Medical colleges
    - 9.2. To develop dedicated beds for patients with serious illness related suffering in all wards of medical colleges, general hospitals, district and taluk hospitals with attendant facilities with privacy, provision for family support and appropriate furniture and equipment.
    - 9.3. To develop management protocols for serious health-related suffering in the emergency department / Intensive Care Unit and any other areas.
  10. *To facilitate socio-economic rehabilitation of patients with a debilitating illness*
    - 10.1. To create a registration system to identify all patients who require rehabilitation support eg patients with hemiplegia, quadriplegia and other debilitating conditions.
    - 10.2. To provide skill development of such patients or immediate caregivers of such patients.
    - 10.3. To provide a consistent supply of quality raw materials that are needed for producing goods.
    - 10.4. To create a common branding for goods made by disabled persons/ caregivers and set mechanisms for quality check of those goods
    - 10.5. To provide avenues for the sale of goods made by disabled persons/ caregivers.
    - 10.6. To facilitate tie-up with corporates/marketing agencies for marketing/promotion of these goods.
    - 10.7. To promote the use of such quality tested goods at government institutions through appropriate purchase preference.

11. *To set up monitoring committees to oversee activities and ensure compliance to policy*
  - 11.1. Creation of common online reporting system for activities conducted by primary, secondary and tertiary hospital level – public and private.
  - 11.2. The regular meeting of the local government level monitoring committee once every month with the presentation of indicators.
  - 11.3. The regular meeting of the District level monitoring committee once in three months with the presentation of indicators.
  - 11.4. Regular meeting of the State level monitoring committee once in six months with the presentation of indicators.
  - 11.5. To create provisions for external evaluation of the model by a top institute in the country.
  - 11.6. Regular Social Audits once a year at the local government
  - 11.7. External general Social Audit once in five years by renowned social auditors using rigorous methodology suitable for large scale Social Audits.

## Financing

Palliative care services should be financed as follows: one-third of the recurring cost through state government and local governments, one-third through contributions from corporates & philanthropists, and remaining one-third by way of voluntary service. There shall be a definite budget item for the programme in the state budget. Local governments should pool resources from various sources to finance palliative care services.

## Implementation of the policy

For translating each element of the policy into action, detailed plans would be drawn through expert and practitioner consultations, indicating activities, timelines, responsibilities, and resources. This would be completed in six months. To oversee this process and the implementation, a High-Power Committee would be set up with the Minister for Health, Family Welfare as the Chairperson, Health Secretary, other secretaries concerned and selected experts and practitioners as Members. This Committee would meet every month on a fixed day and would be empowered to decide on all operational matters where the decision of government or head of departments is required.