

Government of Karnataka

Palliative Care Policy

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1 PRE-AMBLE

1.1 The suffering in incurable and debilitating diseases:

- 1.1.1. The morbidity and mortality from non-communicable diseases are on the increase. The problems of people living with incurable and debilitating diseases are different from those of people having acute illnesses. Apart from the physical problems arising out of the disease, these men, women and children also suffer from social, emotional, financial and spiritual issues caused by the illness. In the state of Karnataka, more than 1.8 lakhs of people with cancer, 2 lakhs people with HIV and a larger unknown number of people with other incurable illnesses are in pain and suffering.
- 1.1.2. Pain is not the only symptom adversely affecting quality of their life. Intractable breathlessness, nausea and vomiting, paralysis of limbs, fungating ulcers and many other symptoms can make life a living hell for these patients. Prolonged disease, the bed-ridden state, and various disabilities, all can cause intense psychological distress. Many persons with chronic incurable illnesses are said to have clinical states of anxiety or depression. The distress is not only for the patient but the whole family also suffers with the patient.
- 1.1.3. People with incurable illness and their families also have to go through intense social suffering. When wage-earners get the disease, in the absence of any social security system, families often get financially ruined. Cost of treatment adds to the problem. It may lead to their children dropping out of school; families losing their homes, and often going into debt.

1.2 The relevance of palliative care:

- 1.2.1. Modern Principles of palliative care can take care of the suffering in patients with incurable diseases, considerably diminishing the anguish for the patient and the family. Palliative care is aimed at improving quality of life, by employing what is called “active total care”, treating pain and other symptoms, at the same time offering social, emotional and spiritual support.
- 1.2.2. The World Health Organization 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.

Palliative care:

- Provides relief from pain and other distressing symptoms
 - Will enhance quality of life, and may also positively influence the course of illness
 - Affirms life and regards dying as a normal process
 - Intends neither to hasten or postpone death
 - Integrates the psychological and spiritual aspects of patient care
 - Offers a support system to help patients live as actively as possible until death
 - Offers a support system to help the family cope during the patient's illness and in their own bereavement
 - Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
 - Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
 - uses ethical principles, shared decision-making and advance care planning to identify patients' priorities and goals for care at the end of life
 - can be provided in any healthcare setting and in patients' homes;
 - can be successfully implemented even if resources are limited.
- 1.2.3. The early introduction of palliative care into the management of patients with a life-threatening illness has a number of benefits, to the patient and to health systems:
- *Improved quality of life of patients and their families*
- Early integration of palliative care can improve the quality of life of patients and their families, by preventing and relieving of suffering , including physical, psychosocial and spiritual distress . It can also result in higher satisfaction of patients and their families, including better quality of life for health caregivers. Patients who have early palliative care have double the odds to die at home and there is also evidence to suggest that patients who have early palliative care may also have improved survival.

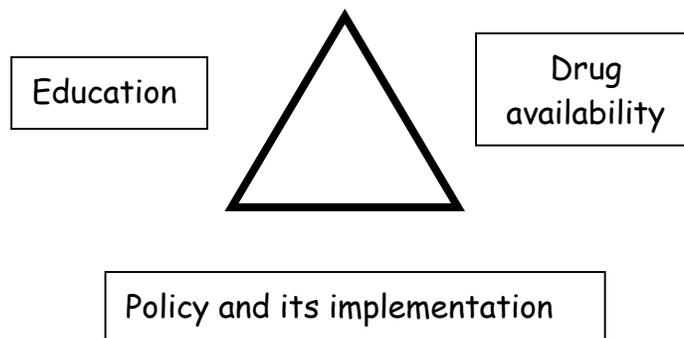
- *Cost reductions to health systems*

Appropriate palliative care can reduce costs, through reduction of hospital stays & emergency department use , lower cost of palliative care beds, and a higher probability of death at home. For example, a palliative care program in Catalonia found that introducing an early system of palliative care had significant cost savings for a regional health system by decreasing the number of hospital admissions, shortening the lengths of hospital stay, diminishing the frequency of emergency room consultations, shifting the use of acute hospital beds to palliative care beds for treating advanced disease inpatients, and substantially improving the use of opioids in the community.

1.2.4. It is estimated that in our country at least 80% of all cancers are detected when it is too late for cure. This means that all of them will need palliative care. As in cancer, palliative care is equally relevant in other incurable diseases like HIV/AIDS, and many neurological, pulmonary, End Stage Renal Diseases, cardiovascular diseases, peripheral vascular diseases, incapacitating mental illnesses and problems of old age. It is necessary in many debilitating diseases involving paralysis of limbs causing bed-ridden state. According World Health Organisation, globally for millions of people with such diseases access to palliative care will be the core essential need.

1.2.5. World Health Organization observes that “The fundamental responsibility of health profession is to ease the suffering of patients cannot be fulfilled unless palliative care has priority status with in public health and disease control programme; it is not an optional extra. In a country irrespective of available resources, policies should be balanced to support therapies that benefit patients in the curable stage of illnesses, while also ensuring comfort care and symptom control to those patients presenting in the advanced stage of the disease.

1.2.6. The WHO guidelines to countries – essential elements of palliative care development:



- 1.2.7. The Sixty-seventh World Health Assembly has unanimously passed the resolution urging the member states to implement palliative care policies and strengthen the public health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes. The resolution emphasizes the member states to ensure necessary domestic funding, human resources, and implementation of policies, education and training to support availability and appropriate use of essential medicines, including controlled medicines for symptom management.
- 1.2.8. The prime guidelines include ----

WHO guidelines developed by the National Consensus Project for Quality Palliative Care in 2004 suggest domains for the effective provision of Palliative Care at every Centre.

	Aspects of Care	Approach
1.	<p><u>Structure and Process of Care</u> – Access and availability of services</p>	<p>The Centres are to be identified and developed in joint collaboration with the state Govt. commitment *PHC's/ Rural Hospitals/ Tertiary Hospitals/ Urban Hospitals*Encourage service development in the NGO / private sector – through policy support, training opportunities *Public Private Partnership initiatives *Community participation through awareness, education and ownership in involvement</p>
2.	<p><u>Physical</u> Pain and other symptoms management</p>	<p>Assessment and management of pain and other symptoms. Training of Doctors/ Nurses. Availability and accessibility of drugs, policies, infrastructure and training facilities</p>
3.	<p><u>Psychological and Psychiatric</u> Emotional support to be integrated into the overall care as the suffering of patients and their families is multi-factorial.</p>	<p>Awareness and training programs in the field of palliative care for professionals and volunteers *basic communication skills and responses to emotional situations *specialized training for persons with determined aptitude to provide basic emotional counselling *red flags on when a reference to a Clinical Psychologists or a Psychiatrist is indicated</p>
4.	<p><u>Social</u> burden of a prolonged complicated disease is enormous. There is loss of employment, social isolation, impoverishment; and adverse impact on dependants</p>	<p>Support social reintegration of the patient and family *Rehabilitation of Family *Support to the care giver through engagement and training *Information on available resources: government, non-government *Family empowerment through linkages with supportive networks*Bereavement support [?]</p>
5.	<p><u>Spiritual, Religious & Existential</u> Address spiritual issues</p>	<p>Identify spiritual concerns and facilitate support * Role of communication skills to elicit concerns, allowing expression and venting, facilitating closures</p>

		at religious and emotional realms, respecting personal ethics and values
6.	<u>Cultural</u> Respecting Cultural differences	Understanding and appreciation of different cultures Acknowledging cultural aspirations of the patient and family. Aligning rituals and bereavement support appropriate to the patient's culture due
7.	<u>Care of the Imminently Dying Patient</u> Place of Dying	*Facilitate expression of preferred place of care for end-of-life care and support it. * Studies on preferred place of death have shown patient preference to be 70-80% achievable in 50% of patients in the developed world. *Reorientation of Health care delivery for the chronically ill
8.	<u>Ethical and Legal</u> Support medical decision making in advanced stages of the disease in the best interests of patients	* Whole person approach * Facilitate shared collaborative decision making inclusive of patient and family * Apply principles of medical ethics, to help guide transitions in goals of care *Clinical Guidelines for effective provision of Palliative Care along the disease trajectory *promote clarity in the legalities that influence transitions in goals of care e.g. Withholding and Withdrawing futile treatments and the concept of Euthanasia

1.2.9. Active Total Care as described in the table, with treatment of pain and other symptoms, along with social, emotional and spiritual support improves Quality of Life (QOL)'. When incorporated into the disease-specific treatment program, it is called 'supportive care'.

1.2.10. Simultaneous therapy - During the period when the disease is amenable to curative treatment, but the process is long drawn and complex, for instance in a cancer patient or HIV infected patient, principles of palliative care when applied early, from the time of diagnosis and throughout the trajectory improves the overall outcome significantly.

1.2.11. Palliative care is a well-established branch of health care in most developed countries and the simultaneous therapy described above is now widely practiced in developed nations.

1.3 State of Palliative care in Karnataka:

- 1.3.1. Global estimates show that there are 300 to 400 people in need of palliative care for 1,00,000 population. In Karnataka, with a population of 64 million and a crude death rate of 7.1 (Reference: SRS 2013) around 448,000 people are dying. It is estimated that around 60% of the people who are dying would benefit from palliative care into their management plan.
- 1.3.2. In Karnataka, approximately 1.8 lakh cancer patients are registered for treatment, to which around 60000 new patients are added every year. Most of them are in an advanced stage and not amenable to curative treatment. Added to this is the burden of other chronic illnesses like HIV, chronic kidney, heart, neurological or hepatic diseases which also require Palliative Care and not to ignore the elderly. **It is estimated that less than 2% of these patients receive palliative care.**
- 1.3.3. Palliative care units in Karnataka are mainly hospital based, with a couple of hospices and very few home care units. These units are mostly present in the urban areas and practically none exist for the rural population.
- 1.3.4. Kidwai Memorial Institute of Oncology (KMIO) which is a Regional Cancer Centre sees the maximum number of cancer patients in Karnataka. Patients from neighboring states like Andhra Pradesh, Tamilnadu, and as far as West Bengal, Orissa, Nepal and Bangladesh reach out to KMIO. It registers nearly 20000 new cancer patients every year and caters to 2.5 lakh patients on follow-up. From this nearly 10000 patients are referred to palliative care. Out of this, approximately 5000 patients receive opioids for their pain control. Many of these patients have to travel distances of nearly 200- 300 kms to reach KMIO to refill the medications (oral morphine solution). Palliative Care department at KMIO has been actively involved in patient care, education and training for the last 25 yrs.
- 1.3.5. Palliative care units are also functional in St.Johns Medical College, Baptist Hospital, Bangalore Institute of Oncology, Karunashraya etc. However almost all of them have been located in the state capital – Bengaluru.
- 1.3.6. Some voluntary organizations like Swami Vivekananda Youth Movement in Mysuru are providing home based palliative care in peri-urban areas of Mysuru.

- 1.3.7. The above stated health care institutions are also training medical and nursing professionals in Palliative care.
- 1.3.8. Karnataka has approximately 2353 Primary Health Care Units. 39 District level Hospitals 146 General Hospitals, 206 Community Health care units 2207 Primary Health care units including Mobile units. Nearly 150 hospitals are empaneled to Vajpayee Arogyashree Scheme – A health insurance scheme for patients suffering with lifestyle diseases and trauma hailing from families Below Poverty line patients. Capacity building of staff in the primary health care system in the state, network hospitals, and collaboration of General Practitioners, specialists and civil society will be helpful in developing a comprehensive system for delivery of palliative care in Karnataka.
- 1.3.9. The availability of social capital in the state is also good. This can contribute voluntary manpower for providing essential aspects of palliative care, which do not necessarily require a trained healthcare professional.

1.4 National Developments relevant to Palliative care policy:

- 1.4.1. Kerala is the first state in India to draft a Palliative Care Policy. The Government of Kerala declared a palliative care policy in April 2008 ((GO.(P) No. 109/2008/H&FWD dated 15 - 4 – 2008) incorporating palliative care into the primary health care system in the state. Around 900 Gram Panchayats have established home care programs for bed ridden patients by a nurse trained specifically for the purpose under the project. Recently, Government of Maharashtra and Government of Manipur have finalized their respective State Palliative Care Policy.
- 1.4.2. In 2010, the Medical Council of India (MCI) approved palliative medicine as a medical specialty. In 2012, an MD program in Palliative Medicine was started at Tata Memorial Hospital in Mumbai.
- 1.4.3. In 2012, The Government of India formulated a National Program for Palliative Care (NPPC)¹. Budget allocation for individual states is made possible from NCD flexi-pool on submission of state Program Implementation Plan (PIP).
- 1.4.4. In February 2014, the Indian Parliament passed an amendment of the NDPS Act of India to ensure access to essential narcotic medicines for medical use while preventing its misuse and diversion. It makes the law for Essential Narcotic Drugs (ENDs) uniformly applicable across all states. The revised rules are published in the Indian Gazette (the

¹ http://palliumindia.org/cms/wp-content/uploads/2014/01/National-Palliative-Care-Strategy-Nov_2012.pdf

Gazette of India no. 923 dated May 5, 2015). It also eliminates the complex licensing system by transferring the power of authorizing an institution for opioid stocking to a single agency, the State Drug Controller. It ensures safe prescribing of these medicines by linking training on medical use of opioids to stocking permissions.

- 1.4.5. In a meeting held under the Chairmanship of the Principal Secretary to Govt., Department of Health & Family Welfare, Government of Karnataka on the 4th December 2015 between 10.30 am and 12 noon in the Committee Room No 123, Vikas Soudha, Bengaluru, it was decided to declare a Palliative Care Policy for Karnataka. The meeting also decided to entrust the task of drafting this policy to a select panel of experts.
- 1.4.6. This policy is aimed at ensuring that palliative care services are established and integrated into routine health care in the state, thus fulfilling its obligation under Article 21 of the constitution of India, to ensure the fundamental right to life with dignity.

2 Palliative Care Policy Framework

2.1 Guiding Principles:

World Health Organization observes that the fundamental responsibility of the Health profession is to 'ease the suffering of patients'. Thus, Palliative Care is not an 'optional extra' and needs 'priority status' within public health and disease control programs

- 2.1.1. The Government of Karnataka recognizes Pain relief and Palliative care as essential components for addressing the problems of patients with advanced progressive diseases as well as terminally ill patients.
- 2.1.2. The Government commits to establish foundation measures, such as needed rules and regulations, education, capacity building, drug availability and advocacy for an interdepartmental (Departments of Health, Excise, Drug Controller, Police, Customs etc) coordinated approach for implementation of the policy
- 2.1.3. Detailed action plans for State level Palliative Care Program and District Palliative Care Programs in the state are in alignment with the 'National Strategy document for Palliative care'
- 2.1.4. The program approach would be as per the guidelines of public health approach outlined by World Health Organisation.

- 2.1.5. Palliative care would be integral part of the health care system, at all levels with major thrust from primary health care. This includes –
 - 2.1.5.1. Institutional health care and home based health care in the community
 - 2.1.5.2. Health care provided by the Government, NGO and Private sector
 - 2.1.5.3. State level to Sub-taluk level
 - 2.1.5.4. Urban and rural area
 - 2.1.5.5. Harmonization of efforts of Government, Non Governmental Organizations (NGOs) and Private Hospitals delivering palliative care
- 2.1.6. Assures access to all in need of palliative care - patients with progressive diseases like cancer, the larger population of non-cancer patients i.e. with neurological disorders, advanced systemic diseases, people living with HIV/AIDS, children with long term illnesses, terminally ill, the elderly etc
- 2.1.7. Leverages existing state level and national expertise in palliative care for effective palliative care program implementation in the state
- 2.1.8. Incorporates palliative care principles and supportive care into the disease specific treatment programmes like National Cancer Control Programme, National AIDS control Programme, National Non-Communicable Disease Control Programme, National Health Mission etc.
- 2.1.9. Emphasizes focus on 'family' as a unit of care and 'home setting' as the preferred place of care
- 2.1.10. Focuses on rational drug policy to assure long term drug efficacy, safety and affordability to the state and the individual
- 2.1.11. Care modalities to continually focuses on scientifically valid and culturally acceptable Integration of Allopathy and Indian System of Medicine
- 2.1.12. Emphasizes contextually relevant audit and research at all levels of care for continual improvement in program design and delivery
- 2.1.13. Satisfies minimum standards of palliative care
- 2.1.14. Ensure monitoring mechanism and Governance to assure quality at each level of service provision.

2.2 AIM:

To assure in Karnataka, palliative care of appropriate standards, available and universally accessible to all individuals suffering from life limiting illness and their families in the spirit of self determination, at a cost that the community and the state can afford”

2.3 Objectives:

1. To educate and empower communities in the state to be aware of the scope of palliative care services and their right to access it for all needy patients in the state
2. To establish Palliative care as an integral part of the health care system delivering palliative care at both health care institutions and at home to all the patients with life limiting illnesses.
3. To develop inter-agency participatory action [health, excise, drug controller, police, etc] to ensure uninterrupted supply and access to essential opioids for medical use while preventing is misuse and diversion
4. To identify and establish centres for providing state of art training in the field of palliative care to - medical, nursing professionals, para-medical workers and volunteers
5. To continually develop capacities of health care providers at all levels to deliver appropriate palliative care services
6. To ensure availability of essential drugs for Pain relief and Palliative care including narcotics at all health care units
7. To establish institution based palliative care units within the existing health care units of Government, NGO and Private, for inpatient facilities as well as monitoring of the home based services
8. To establish ‘Home based’ palliative care services in the state in partnership with NGOs and Private agencies
9. To maintain continuity of services using efficient home based care networks, by identifying personnel, building their capacity as well as monitoring the home services
10. To undertake clinical and behavioral research for continual improvement in palliative care services
11. To institutionalize mechanisms for inter-sectoral coordination to ensure effectiveness and efficiency in palliative care program

2.4 Governance framework:

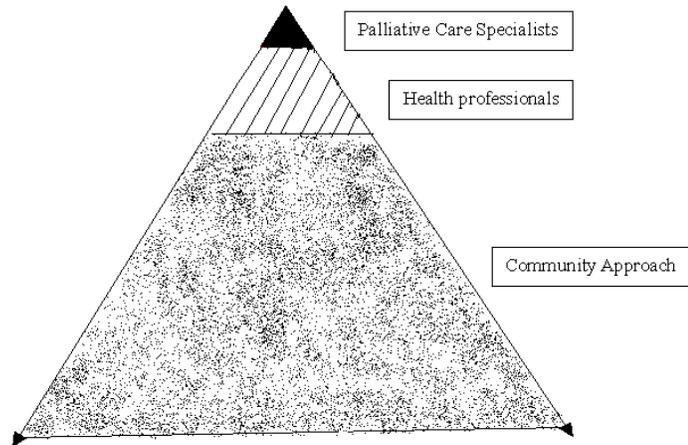
The State Health Department would spearhead the Palliative Care Program in the state. A State Palliative Care Cell under National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases & Stroke (NPCDCS) in the State Health Mission would be established. The Cell would be headed by a State Palliative Care Coordinator who would be a person with minimum of 5 years of experience in the field of palliative care.

Functions of the State Palliative Care cell:

- i. Ensure implementation of the Palliative care program as per the State Palliative Care Policy
- ii. Liaison between districts, state and the Centre.
- iii. Spearhead simplification of laws pertinent to essential narcotic drugs & palliative care, ensure implementation of the simplified laws upto the grassroots
- iv. Define the framework for District level Palliative care services including empanelment of NGO and Private health care institutions
- v. Empanel NGOs and Agencies with proven experience in Palliative Care and collaborate with them to undertake Home base care in the districts.
- vi. Approve content for training of various cadres of personnel, Identify training partners, and monitor training programs
- vii. Prepare annual program implementation plan (PIP) and financial budget for the palliative care services in the state and negotiate allocation of finances with appropriate authorities
- viii. Approve District plan for palliative care services and authorize grants/financial allocation for the services at the District level
- ix. Oversight and monitoring of Palliative care Services in the state to ensure quality standards in service

At the District level, the District Health and Family Welfare Officer will oversee the performance of palliative care services in the district. The District Program Management Officer (DPMO) would be responsible for preparation of annual plan and budget for the palliative care services in the district.

2.5 Development of Services:



- 2.5.1. Palliative care shall be part of general health care system of the state
- 2.5.2. The role of family in the care of chronically ill patients shall be recognized. The patient and the family should be the focal points of the palliative care programmes. They shall be socially supported and empowered to cope with the situation. Home-based care should be the cornerstone of palliative care in the state.
- 2.5.3. The State Health Mission shall wrap the Non Communicable Disease Program with palliative care services to ensure the program is comprehensive and holistic. Ensure adequate emphasis for palliative care services for chronic communicable diseases like HIV, Tuberculosis etc. Explore integration of Ayurveda and other systems of medicine to expand access to Palliative Care services.
- 2.5.4. All existing media and communication means shall be adopted to build awareness in the communities and promote behavioral change in them regarding Palliative Care. Thrust shall be on innovations in communication for effective reach.
- 2.5.5. Expeditiously implement modified NDPS regulations as per 2014 amendment to NDPS act to ease the access and availability of Essential Narcotic Drugs [ENDs - as listed by the central department of Revenue] for medicinal and scientific use through the process of Recognizing Medical Institutions (RMIs), while maintaining measures for preventing diversion and misuse.
- 2.5.6. There shall be adequate facilities in Government hospitals for providing palliative care services at the institutional level and field level. They are expected to work closely with the NGOs actively involved and experienced in providing palliative care services.

- 2.5.6.1. *All tertiary and secondary levels of health care institutions including medical colleges and Regional Cancer Centres shall have palliative care services including inpatient, outpatient and home based care as envisaged in National Program for Palliative Care.*
- 2.5.6.2. *The District Hospitals shall provide specialist Palliative Care services both as outpatient and inpatients services; They shall have trained doctor and nurse*
- 2.5.6.3. *The Community Health Centres / Taluk Hospital shall provide of basic palliative care services comprising of out-patient care, inpatient care, dispensing of essential medicines including opioids for pain relief, nursing care within the existing facilities.*
- 2.5.6.4. *Primary Health Centers shall be empowered to provide necessary institutional level palliative care with adequately trained staff and availability of all necessary drugs for service. The Medical Officer shall be the coordinator of these activities at the PHC level.*
- 2.5.7. The services of the Private sector would be enlisted to extend palliative care services to the needy. Palliative care initiatives by private hospitals shall conform to the quality control and training criteria set by the state palliative care policy.
- 2.5.8. Many NGO institutions in Karnataka are providing charitable palliative care services to the needy both at the level of institution and home. Those satisfying certain minimum standards of care (Ref: Indian Journal of Palliative Care, 2014;20:3; 201-7), shall be enlisted as collaborators or delivery arms for expanding the palliative care services.
- 2.5.9. The Community based Home care model shall largely be carried out through identified NGOs or Private agencies. The persons to be involved in offering palliative care to the needy at home would include – family members, community volunteers apart from nurses, doctors and other health care workers
- 2.5.10. Networking of Palliative Care teams, community healthcare professionals [including General Practitioners], providing care ‘beyond working hours’ and the family-caregivers would be the foundation on which continuity of care is based. The modality to achieve this would depend on locally developed care pathways appropriate to community dynamics.

2.6 Drug availability

- 2.6.1. An essential list of pain control and palliative care drugs shall be created. World Health Organization's Pain ladder shall be adapted for appropriate management of pain
- 2.6.2. The legal and regulatory systems in the state shall be appropriately reoriented in alignment with the modified Narcotic Drugs and Psychotropic Substance (NDPS) Act to ensure access and availability of opioids for medical and scientific use while maintaining measure for preventing diversion and misuse
- 2.6.3. Staff of relevant departments like Department of Health, Department of Medical Education, Department of Drugs Controller, Department of Excise, Department of Police etc shall be oriented on the purpose and contents of the modified NDPS Act, to assure inter-departmental participatory action in implementation of the revised act and rules.
- 2.6.4. Where strong opioids needed, generic immediate and slow release morphine are recommended, as both are found to be not only cost effective but also scientifically appropriate. Immediate release morphine is recommended for controlling acute pain and is the drug of choice for controlling break-through pain. Once the patient's pain is controlled the patient can be switched to slow release morphine tablets. It is recommended that all palliative care units in the state have adequate stock of both immediate release and slow release formulations of Morphine tablets. In line with the modified Narcotic Drugs and Psychotropic Act passed by the Indian Parliament in 2014, steps shall be taken to assure training in essential medical use of opioids, of all health care professionals in primary, secondary and tertiary levels of the health care system, thus enabling pain relief to be incorporated in the health care system.

2.7 Training:

- 2.7.1. A State Level Resource Centre for Palliative Care shall be established in the state. This shall be the nodal agency for training and research in Palliative care. Also, Centre of Excellence – one each in each of the revenue divisions of the state shall be established and nurtured. Palliative care initiatives in the state by NGO and Private agencies would also be graded and listed as training cum demonstration sites. The district hospitals which incorporate functioning units of palliative care too shall be training sites.
- 2.7.2. A pool of experts from Government, NGOs and Private health sector with knowledge and experience in palliative care would be enlisted as trainers.

- 2.7.3. Identified training centers especially the Centers of Excellence and demonstration sites shall be responsible for development of curricula for training of various cadres of health care providers from diverse institutions – Government, NGO and Private
- 2.7.4. There is poor awareness and several misconceptions amongst medical and nursing professionals regarding Palliative Care and pain management. The urgent need is for the health care professionals and community health workers to acquire the knowledge, attitude and skills necessary for palliative care. A suggested pattern of courses for doctors, nurses and community health workers (including volunteers) is as below
- 2.7.4.1. **Sensitizing courses** (3 - 6 hrs.) for maximum number of doctors, nurses and community volunteers in the country. Training to cover the scope and framework of palliative care
- 2.7.4.2. **Basic training** in Palliative Care (2 days/16hours) for doctors and for nurses. Training to include palliative care scope, framework, basic concepts & clinical application
- 2.7.4.3. **Intermediate level Courses** (six weeks) for doctors and nurses; This would be the minimum required qualification for holding positions in palliative care units approved as per state palliative care policy
- 2.7.4.4. **Long Term Courses** (1-2-year Fellowship Programs and Post Graduate Diploma and Degree Courses) for Doctors and Nurses interested in specializing in the field of palliative care.
- 2.7.5. Undergraduate training for doctors and nurses: Basic principles of Pain management and palliative care shall be included in the curriculum and shall be part of the semester end assessment in theory and clinical examination.
- 2.7.6. Training and empowerment of the Primary Health Care System: The long term focus is to ensure most of the patients in need of palliative care receive the same from health care professionals at the primary health care level. Training these doctors and nurses to improve their clinical and communication skills along with supportive net works of trained community workers and home care nurses, shall assure care for all in need of palliative care. The training of General Practitioners and private doctors in rural areas in Palliative Care shall be important as well. The training for General Practitioners shall be provided at the district hospitals/Non Governmental Organizations working in the field. Under the new NDPS act, General Practitioners having undergone this approved training will be licensed to stock and prescribe morphine.

- 2.7.7. Training of family members of the patients in need of palliative care shall be focused on practical aspects of supportive care at home like prophylaxis for bedsores, appropriate food, mouth care, change of wound dressings, urinary catheter care, etc and spiritual support component of palliative care.
- 2.7.8. Sensitization and training of community volunteers can be done through three levels of training programs. one hour (sensitization), three hour (foundation) and twelve hour (basic). Where paid staff is inadequate, trained volunteers shall make up a work force complementing the existing staff. The force of local trained committed volunteers and their networks can absorb the tremendous psycho-social burden experienced by the patient and their family. Awareness programs and volunteer training activities would activate this force. In order to maintain the contents and quality of care, the training and activities of volunteers need to be closely aligned with training centres and centres of excellence in the field.
- 2.7.9. Proactively, young people, particularly students would be encouraged to be involved in awareness generation about palliative care in the community and also palliative home care programs. They too would be trained as above.
- 2.7.10. The State Health Mission shall extend financial support for the training program.

2.8 Research:

The program support shall emphasize on innovation in program design and implementation, evidence building for program modification and continual improvement. All relevant patient care and program data would be compiled for research and evidence based decision making. Periodic program audits including financial audits would be carried out. The State Palliative Care Cell would be responsible for defining the themes and approving research proposals.

2.9 Advocacy

- 2.9.1. The limiting factor for the success of palliative care in the state would be the Education of policy makers, social activists, health care professionals/providers and public at large
- 2.9.2. Proactive efforts to enlist the collaborative support of the above sections is essential. The following shall be the key points to emphasized in the communication.

2.9.2.1. Palliative care approach is critical to improve Quality of life of patients and family members' suffering from progressive and incurable diseases

- 2.9.2.2. *Treatments for pain and many other common symptoms does exist. There is no need for patients to suffer pain or other distressing symptoms.*
- 2.9.2.3. *Narcotic drugs for the relief of pain are not meant to be used only in terminal stages. Their use is determined by the severity of pain and not by the stage of illness.*
- 2.9.2.4. *For persistent severe pain, the medicines are required to be given regularly as per prescription, without interruption. It is to be available in all regions of the state.*
- 2.9.2.5. *Drugs for pain relief are ought to be inexpensive*
- 2.9.2.6. *Drugs for the relief of pain can be taken indefinitely without losing their effectiveness. "Addiction" (Psychological dependence) is different from the need to take the medicines for ongoing severe pain. Psychological dependence is not common when nacoitics/opioids are prescribed after due evaluation of the symptoms and continuous monitoring.*
- 2.9.2.7. *Through short term training of healthcare professionals, pain and many other common symptoms of advanced illness can be managed*
- 2.9.2.8. *Family, volunteers and the community support system can do much to improve the quality of life.*
- 2.9.2.9. *It is essential to reach palliative care services to all those who need them in the state, through partnerships with other stakeholders and the community*

3 ACTION PLAN

3.1 Short-term objectives for the first year:

3.1.1 GOAL:

To assure availability and accessibility of appropriate palliative care services to all needy patients in 6 districts of Karnataka viz., Bengaluru, Mysuru, Hassan, Dakshina Kannada (Mangaluru), Dharwad and Raichur as an integral part of the NPCDCS

3.1.2 OBJECTIVES:

- i. To establish a State cell for palliative care with requisite human resources, infrastructure, monitoring and Governance systems
- ii. To establish palliative care wing in the district hospitals and Suvarna Arogya Suraksha Trust (SAST) - Vajpayee Arogyashree empaneled hospitals in each of the target districts
- iii. To train healthcare professionals in the concepts of palliative care approach to chronic illness conditions, principles of pain and symptom management in advanced disease states and medical use of opioids.
- iv. To ensure processes to make essential palliative care drugs including narcotic drugs available, for uninterrupted dispensing in these hospitals
- v. To identify and establish *centres of excellence* for clinical care and training purposes – e.g. the department of palliative care at the Kidwai memorial hospital, identified medical colleges and Non-Government health institutions in the state
- vi. To prepare guidelines for partnership between the Government system and non-government organizations.
- vii. To establish demonstration sites in community based palliative care in Bengaluru and Mysuru in PPP model
- viii. To work with recognized universities for incorporating palliative care modules into undergraduate medical and nursing curricula
- ix. To train all doctors and nurses and paramedical staff in the PHC and CHCs in the target districts in Pain Management and Palliative Care in PPP model so as to improve the awareness and utilisation of palliative care services
- x. To sensitize enforcement agencies – excise, home departments on the purpose and impact of the reorientation of drug policy; to develop inter-agency cooperation in the implementation of the NDPS Regulations
- xi. To establish system for documentation, reporting and monitoring of palliative care services and accurate opioid consumption records in the state.

3.1.3 ACTIVITIES:

1. STATE LEVEL:

- A. Creation of a Cell for Palliative Care under the NPCDCS in the National Health Mission
- B. Appointment of State Coordinator with at least five years of experience in the filed of

palliative care and Office support Staff for the cell

- C. Organize workshops for engaging and empowering District Health Department in provisioning of Palliative Care services to respond effectively to their mandate in this venture
- D. Assuring SAST – Vajpayee Arogyashree empaneled hospitals in the target districts to deliver palliative care
- E. Identify NGO partners for Community Based Palliative Care demonstration project and approve the proposal with its financial needs
 - a. The Community based palliative care program shall focus on Community-based prevention, management and care of chronically ill and bedridden patients including old age using a palliative approach. Its Goal would be *'To create a collaborative platform for a patient-centric community-based, integrated model of holistic care that adopts a 'lifespan approach' to chronic disease that emphasizes and supports quality services through awareness, education and monitoring strategies'*
 - b. The project shall have the following objectives
 - i. *To engage trained multi-disciplinary professionals [doctors, nurses, physiotherapists, counsellors, social workers etc.] to provide holistic care required for patients with chronic conditions – at physical, mental, emotional, socio-economic and spiritual dimensions.*
 - ii. *To raise the awareness and adoption of appropriate health seeking behaviour to prevent/for early detection/ for treatment of common chronic ailments like HIV/AIDS, Hypertension, Diabetes , Cancer etc*
 - iii. *To provide outpatient facilities to all chronic illness patients who are at risk of becoming bedridden, in addition to providing a forum for these individuals and caregivers to share their experiences with other caregivers and takers.*
 - iv. *Network and build linkages with selected primary, secondary and tertiary hospitals in the area. Involvement through building capacity for health education, training, screening for preventable chronic conditions, [e.g. NCDs, HIV] Outpatient care, investigational, in-patient and home based care support*
 - v. *To facilitate and support care at out patient and inpatient facilities for needy patients at networked hospitals*
 - vi. *To provide both medical, nursing and support services (like psychosocial, nutrition social entitlements etc.) to bedridden patients (as a result of chronic disease or old*

age conditions) in the project area at their homes for at least 300 unique patients in a year in each district

vii. To empower government health functionaries and community based volunteers to assure sustained palliative care for needy patients in the district

viii. To create a collaborative platform of relevant Government departments, Non Profit organizations, Corporate and Community for program implementation and monitoring

- F. Communicate modified NDPS policy and rules to District Health Departments, office of the drug controller to activate standard operating processes for Recognizing Medical Institutions (RMI) for stocking and dispensing essential narcotic drugs
- G. Communicate purpose and relevance of the amended NDPS regulations to the departments of excise as well as the enforcing agencies [police, justice] to ensure balance in uninterrupted availability opioids for medical use on one side and prevention of misuse on the other while implementing revised narcotic regulations. This to be done through workshops as outlined in the national strategy document for palliative care in India.
- H. Support development of Recognized Medical Institutions adequate for the program are, with systems in place, with registered medical officers trained in the medical use of essential narcotic drugs and aware of the documentation and record keeping necessary to monitor and prevent misuse and diversion
- I. Standardize curriculum and method of training/orientation of
- a. Six weeks residential training program at the identified centres of excellence- e.g. Kidwai memorial hospital – as required for the posting of in charge doctors and nurses at district and higher level hospitals*
 - b. Medical Students, Para-medical Students,*
 - c. Medical professionals and nurses in PHC and CHC*
 - d. Medical Professional, Nurse in RMIs*
 - e. All other health care staff*
 - f. Community volunteers*
- J. Identify training partners - from within the state and in the neighboring states
- K. Allocate financial resources to District health authorities, Training partners and NGO partners

- L. Governance structure, reporting processes, oversight and monitoring of the Palliative care program implementation in the various districts
- M. Compilation of data, trend analysis and facilitate evidence based modification of implementation process

2. DISTRICT LEVEL:

- A. Establishing Palliative Care wing in the District hospital with atleast 10 bed in-patient facility, Outpatient services
- B. Appointment of One Doctor, 4 nurses trained for six weeks as defined in the national strategy document and a support staff for the Palliative Care unit
- C. Ensuring training and certification of registered medical officer in charge of RMIs in both PART A and PART B of Certificate course in Essentials of Palliative care (CCEPC) offered by Indian Association of Palliative Care (IAPC) essentials course by deputing the team to IAPC recognized training centre in the district/state.
- D. Implementation of Community based Palliative care services in PPP model
- E. Training and orientation of all health care team in the district hospital as per the state approved training content and method
- F. Training of the PHC/CHC medical professionals, Nurses, Para medical staff, medical/nursing/ students and community volunteers
- G. Field monitoring and program audits

3.1.4 OUTPUTS:

1. Establishment of State Palliative care cell with requisite human resources, infrastructure, monitoring and Governance systems
2. The state level government agencies concerned with essential opioid access and availability as well as their prevention and misuse are aware and confident of their mandates and supportive to the state palliative care project.
3. Processes are in place for making Essential Narcotic Drugs available, safe, accessible and affordable to the needy through Interagency dialogue and cooperation while ensuring prevention of misuse and diversion

4. Outpatient and inpatient palliative care services wing established in 6 district hospitals and 15 SAST empaneled hospitals
5. 2 district level demonstration sites for Community based palliative care services established – one under the aegis of Kidwai Memorial Institute of Oncology and another through a non-governmental institution like Swami Vivekananda Youth Movement
6. Assured uninterrupted availability of palliative care drugs and oral morphine in 17 RMIs
7. Appropriately trained palliative team available and functioning in each of the 6 district hospitals and 15 SAST empaneled hospitals
8. At least 300 bed ridden patients treated and reported in Community based palliative care program
9. 500 doctors, 500 nurses, trained and aware of the scope of Pain management and Palliative care – a 3 day module
10. 1000 community volunteers oriented about the program and their role.
11. Trainees of the medical and nursing undergraduate programs through universities in the state, are exposed to the concepts of palliative care and pain management

3.2 Intermediate term objectives for 2nd to 5th year:

- 3.2.1. Learnings from the program implementation in limited districts in the first year documented and assimilated.
- 3.2.2. Palliative Care Program shall be essential part of the Annual Program Implementation Plan of the State Health Department.
- 3.2.3. Program with modifications based on the learnings of the first year expanded to all districts in the state with adequate financial allocation in a phased manner.
- 3.2.4. Medicines commonly needed for palliative care included in the essential drug list of the government hospitals. (*Appendix II: List of medicines to be added to the present 'Essential Drug List'*)
- 3.2.5. All Government supervised medical colleges in the state certified as “Recognized Medical Institutions (RMI)” by the drug controller, for stocking and dispensing Essential Narcotic Drugs (ENDs) - as per the NDPS Regulations.

- 3.2.6. Identify Training Centers in each district and enable them to undertake 6 weeks training programs for in-service doctors and nurses on a quarterly basis. All doctors and nurses in the Government to complete one round training by 5 years.
- 3.2.7. Develop at least 5 centres of excellence in the state for advanced training in palliative medicine and nursing including about 3 in Medical Colleges in various districts.
- 3.2.8. Finalize and incorporate palliative care modules in medical, dental, nursing, pharmacy and paramedical undergraduate courses.
- 3.2.9. Institutionalize annual common review mechanism for departments of Health, Excise, Drug controller and enforcement agencies of narcotic control.
- 3.2.10. The State Palliative Care Policy reviewed at the end of 4 years.

3.3 Long term objectives - ten years

- 3.3.1. Palliative care services integrated into basic health care training and practices
- 3.3.2. Leverage ASHA workers for taking palliative care to the community. ASHA workers shall be trained and incentivized to carry out the following tasks
 - 3.3.2.1. Identifying patients requiring palliative care in the population covered by them
 - 3.3.2.2. Working with concerned health care unit for the care of the above patients
 - 3.3.2.3. Following up these patients at their home biweekly /as required and delivering the required drugs.
 - 3.3.2.4. Linking other services necessary for the patient as advised by health care provider
- 3.3.3. Ensure availability of adequate number of trained community volunteers for palliative care services at the taluk level
- 3.3.4. Make available community based palliative care programmes with home care services to most of the needy in the state with active participation of community volunteers
- 3.3.5. Empower community to share the care and support of people needing palliative care by organizing human and financial resources available locally
- 3.3.6. Adopt a system of monitoring of palliative care service in the state to facilitate quality assurance as per applicable standards. [A guideline for quality control would have been developed for all levels in the state during the 1st two years].

- 3.3.7. Develop state university recognized post graduate courses in palliative care in the Medical and Nursing Colleges with availability of faculty as per MCI requirements and providing full-time service in the field at out-patient, in-patient, home based care setting as well as in training programs.
- 3.3.8. Develop a system through the State PC Officer, to document and report the data on the palliative care related activities and patient population from the districts and state levels.

4 Monitoring and Evaluation

4.1 Monitoring

4.1.1 State Level:

At the state, the Program officer, in-charge of Non-Communicable Diseases (NCD) would be directly responsible for monitoring the program. The State Palliative Care Cell would function along with the Program Officer NCD in this regard. The State Health Mission Steering/Executive Committee would review the program on a quarterly basis. Additionally, representatives of Departments of Medical Education, Social Welfare, Youth Affairs, Education, representatives of Centres of Excellence in Palliative Care would be invitees for the review meetings.

4.1.2 District level

The District Health and Family Officer through the District Program Management Officer would be responsible for monitoring the program in the district. The program would be essentially reviewed by a District Health Society on a quarterly basis.

4.1.3 Taluk level & below:

The Palliative care services would be an integral part of regular health care delivery system. The community monitoring system in place in the form of Village Health, Sanitation and Nutrition Committee, Primary Health Centre Monitoring Committee, The Arogya Raksha Samithi in the health centres and the Taluk Health Monitoring Committee would review the palliative care program along with all other health programs.

4.2 Evaluation:

The Common Review Mission of the National Health Mission would evaluate the Palliative Care Program on an annual basis. In addition, the State Health Department through the Karnataka Evaluation Authority would carry out an independent evaluation of the program at least once in 2 years.

5 ANNEXURE

5.1 Annexure 1: W.H.O. RECOMMENDATIONS ON PALLIATIVE CARE

5.2 Annexure 2: MEDICINES TO BE ADDED TO THE ESSENTIAL DRUGS LIST

ESSENTIAL DRUGS FOR PALLIATIVE CARE: (TO BE ADDED TO THE ESSENTIAL DRUG LIST OF GOVERNMENT OF KARNATAKA.)

SL NO	NAME OF THE DRUG
I	ANTI INFLAMMATORY & ANALGESICS
1	T. ACECLOFENAC +PARACETOMOL
2	T.MELOXICAM
3	T.PARACETOMOL
4	T. MEFINAMIC ACID
5	T.KETORALAC DT
II	ANTISPASMODICS
1	T.DICYCLOMINE
III	NARCOTIC ANALGESICS
	<i>WEAK OPIOIDS :</i>
1	T.CODIENE
2	T.TRAMADOL
	<i>STRONG OPIOIDS</i>
1	T. BUPRENORPHINE
2	T. MORPHINE SULPHATE
3	BUPRENORPHINE AND FENTANYL TRANSDERMAL PATCHES

IV	ANTI ALLERGIC AND DRUGS USED IN ANAPHYLAXIS
1	T.DEXAMETHASONE
2	T.PREDNIZOLONE
3	INJ. DEXAMETHAZONE
4	T. CETRIZINE
V	ANTI EPILEPTIC DRUGS
1	T. SODIUM VALPROATE
2	T.PREGABALIN
3	T.GABAPENTIN
VI	ANTIDEPRESSANTS AND ANXIOLYTIC DRUGS
1	T. CLONEZIPAM
2	T.ALPRAZOLAM
VII	ANTI FUNGAL DRUGS
1	T. FLUCONAZOLE
VIII	G I T DRUGS
1	Liq. Paraffin + Milk of Magnesia
2	T. METOCLOPRAMIDE
2	T.ONDONSETRON
4	T.HALOPERIDOL
5	T. BISACODYL
6	T.SODIUM PICOSULPHATE

7	SODIUM PHOSPHATE ENEMA
8	GLYCERINE SUPPOSITORY
9	CAP. OMEPRAZOLE
10	T.PANTAPROZOLE
11	T.DOMPERIDONE
12	LIQ.MUCAINE GEL
13	SUCRALFATE SUSPENSION
	OTHERS
1	INJ. NALAXONE
2	LIGNOCANE GEL AND VISCOUS
3	KETAMINE
4	HYOSCINE BUTYL BROMIDE
5	BACLOFEN
6	TIZANIDINE

** The above list is not exhaustive. The List would be modified and updated from time to time by the State Palliative Care Cell based on the recommendations of Centers of Excellence in Palliative Care in the State.*

5.3 Annexure 3: GUIDELINES FOR OBTAINING RECOGNIZED MEDICAL INSTITUTION (RMI) STATUS

The prevalent rules and guidelines for Obtaining RMI to be adopted.

5.4 Annexure 4: PALLIATIVE CARE POLICY KARNATAKA – DRAFTING TEAM

Advisory Group

1. Dr M R Rajagopal, Chairman Pallium India, Trivandrum
2. Dr Suresh Kumar, Director, Institute of Palliative Medicine, Kozikhode
3. Dr Mary Ann Muckaden
4. Dr S N Simha, Medical Director, Karunashraya, Bengaluru
5. Dr.(Brg) R.S Rajan, Program Director, Home based Palliative Care Program, Mysuru, Director – Admin, Vivekananda Institute for Leadership Development, Mysuru

Working Committee

1. Dr K B Lingegowda, Director, Kidwai Memorial Institute of Oncology, Bengaluru
2. Mr R Bhandary, State Drugs Controller, Drugs Control Dept, Bengaluru
3. Ms Saroja G, Pharmacist, Department of Palliative Medicine, Kidwai Memorial Institute of Oncology, Bengaluru
4. Representative of the Director, Department of Health and Family Welfare Services
5. Representative of The Director, Directorate of Medical Education, Government of Karnataka
6. Representative of Director, Department of AYUSH, Govt of Karnataka
7. Dr P V Ramamani, Senior Specialist, Kidwai Memorial institute of Oncology, Bengaluru
8. Dr.(Flt Lt).M.A.Balasubramanya, Secretary and Chief Executive Officer, Swami Vivekananda Youth Movement, Saragur, HD Kote Taluk, Mysore District
9. Dr Jeremy Johnson, Director of Education and Research, Karunashraya, Bengaluru
10. Dr Gift Norman, Deputy Director and Head, Palliative Care, Bengaluru Baptist Hospital, Bengaluru
11. Dr Subash A Tarey, Prof and Head, Department of Palliative Medicine, St Johns Medical College and Research Centre
12. Dr Nandini Vallath, Palliative Care Consultant, Project coordinator, WHO Collaborating Centre for Training and Policy on access to pain relief
13. Dr C Ramesh, Professor and Head, Department of Epidemiology, Kidwai Memorial Institute of Oncology, Bengaluru