



Proposal  
of  
**Strategies for Palliative Care in India**  
(Expert group report)

Directorate General of Health Services  
**Ministry of Health & Family Welfare**  
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## Glossary and the Terminologies

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### **Palliative Care**

*It is an approach to care, 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.*

### **Quality of life**

*It is all those components which makes life worth living for a person*

### **Home based care**

Maintaining a standard of care at the place of stay for a bedridden patient, through family / community empowerment, and / or home visits by trained teams; usually inclusive of a nurse.

**NDPS Act** – Narcotics & Psychotropic Substances Act

**Rules** – NDPS Rules

**RMI** - “Recognized Medical Institution” means a hospital, hospice or other medical institution, recognized by the Controller of Drugs for the purpose of special provisions for use of defined manufactured drugs for medical purpose.

**NCD** – Non Communicable Diseases

**NPCDCS** – National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke

**NLEM** – National List of Essential Medicines

**MCI** – Medical Council of India

**NCI** – Nursing Council of India

**WHO CC – Trivandrum**- WHO Collaborating Centre for Training and Policy on Access to Pain Relief

**WHO CC – Calicut** - (WHO Collaborating Centre for Community Participation in palliative Care and Long Term Care

**NACO** – National AIDS control Organisation

**IAPC** – Indian Association of Palliative Care

**IMA** – Indian Medical Association

**ISSP** – Indian Society for Study of Pain

**ISCCM** - Indian Society of Critical Care Medicine

**AROI** – Association of Radiotherapists of India

## Executive Summary

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People with life-limiting diseases including cancer, other non-communicable diseases and communicable diseases like HIV / AIDS have pain, other symptoms and psychosocial distress which can dramatically decrease quality of life, place a burden on the family's economy and on health care system. For example, cancer has become one of the leading causes of death in India. There are approximately 28 lakh cancer cases at any time and more than 10 lakh Indians are diagnosed with cancer each year. There are approximately 5 lakh cancer deaths per year in the country. These chronic disease states require management of their distresses based on chronic care principles in continuum with acute episodic care.

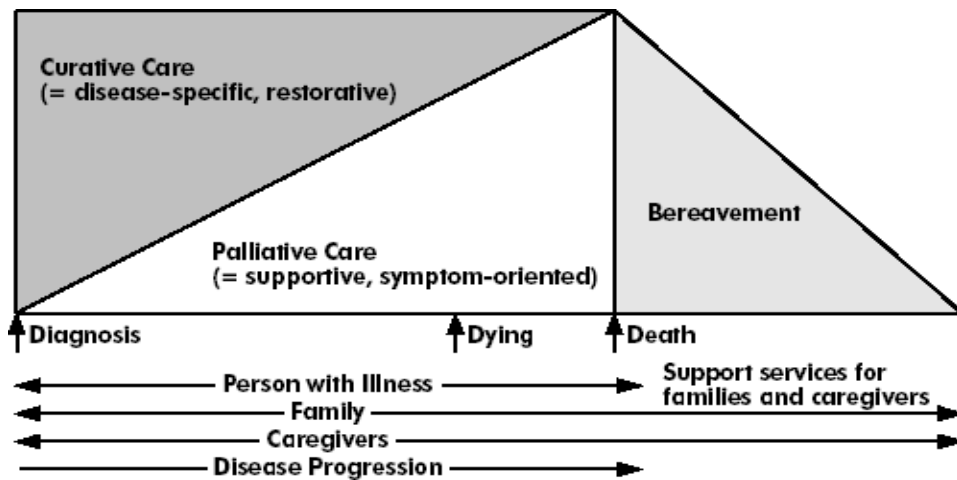
Approximately 80% of these patients with cancer are diagnosed in advanced stage and more than 1 million cancer patients are estimated to be suffering from moderate to severe pain every year. There are approximately 2.7 million people are living with HIV in India and about 1.89 million suffer from pain. The large number of bed-bound people with non-communicable diseases in the community has poor access to health care and when available, the care may not be appropriate.

Experts estimate that 80% of people dying from cancer and 50–80 % of people dying from AIDS will need relief from moderate to severe pain during the course of their illness on average for 90 days. All these patients also require palliative care.

Palliative care improves the quality of life of people with life-threatening or debilitating illness by providing relief from pain and other physical symptoms and care for psychosocial needs. To ensure the most effective care for patients, palliative care begins at the point of diagnosis, continues throughout treatment, and bereavement support is offered to the family after the patient's death. If cure is possible, palliative care provides essential care to provide pain relief, control symptoms, and minimize suffering. Recent research has shown that early palliative care with standard cancer treatment extended survival when compared to standard cancer treatment alone<sup>1</sup>. The figure below illustrates a "continuum of care" for cancer, HIV/AIDS, and other life-limiting diseases by integrating curative and palliative care:

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<sup>1</sup> Temel, New England Journal of Medicine 2010



It is the integration of palliative care with curative treatment that constitutes quality comprehensive cancer and other disease-specific care. The World Health Organization recognizes palliative care as an essential component of comprehensive cancer and AIDS care.

In India, currently there are approximately 908 palliative care services delivering palliative care through either through home care, outpatient basis and in patient service. More than 841 of these centres are in Kerala. Therefore, for the vast majority of Indians across the country, there is extremely limited access to quality palliative care services.

In response to this essential public health need, the Ministry of Health and Family Welfare would initiate activities related to palliative care with a vision of facilitating access to affordable, safe and quality pain relief and palliative care to all those requiring it in the country.

The objectives include:

1. Improve the capacity to provide palliative care service delivery within government health programs such as the National Program for Prevention and Control of Cancer, Cardiovascular Disease, Diabetes, and Stroke; National Program for Health Care of the Elderly; the National AIDS Control Program; and the National Rural Health Mission.
2. Refine the legal and regulatory systems and support implementation to ensure access and availability of Opioids for medical and scientific use while maintaining measure for preventing diversion and misuse

3. Encourage attitudinal shifts amongst healthcare professionals by strengthening and incorporating principles of long term care and palliative care into the educational curricula (of medical, nursing, pharmacy and social work courses).
4. Promote behaviour change in the community through increasing public awareness and improved skills and knowledge regarding pain relief and palliative care leading to community owned initiatives supporting health care system.
5. Encourage and facilitate delivery of quality palliative care services within the private health centres of the country.
6. Develop national standards for palliative care services and continuously evolve the design and implementation of the National program to ensure progress towards the vision of the program.

The strategies are based on the WHO stepwise framework<sup>2</sup> for planning and effective implementation for countries<sup>3</sup>.

**Section A** is on the present background and analysis of the situation in the country. This discusses an understanding of where we are now i.e. needs, available services or programmes and also where do we want to be i.e. setting the vision, goals, guiding principles and objectives.

**Section B** broadly deals with implementation planning. Discussions would be on defining the target population, priority of interventions across the spectrum, identifying the strategies and activities needed appropriate implementation of the policy with the proposed strategies and actions.

**Section C** would present the governance structure and processes based on the activities discussed under strategies. Annexure clarifying concepts presented through the text of the document would follow this discussion.

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<sup>2</sup> Palliative Care Module - Cancer Control; Knowledge into Action WHO Guide for Effective Programmes, WHO 2007

<sup>3</sup> WHO guidelines to governments for incorporating PC - <http://www.who.int/cancer/media/FINAL-Palliative%20Care%20Module.pdf>



**It is envisaged that activities would be initiated through National Rural Health Mission or ensuing National Health Mission.** The integration of national programs are being attempted under the common umbrella for synergistic activities. Thus strategies proposed will provide essential funding to build capacity within the key health programs for non-communicable disease, including cancer, HIV/AIDS, and efforts targeting elderly populations. Working across ministries of health and finance, the program will also ensure that the national law and regulations allow for access to medical and scientific use of Opioids.

**The major strategies proposed are provision of national and state cells for palliative care. Additional manpower would also be required. 1 physician & 2 nurses at 150 RCCs & Govt. Medical Colleges and 200 Distt Hospitals are proposed. Provision needs to be made for 1 nurse at 700 CHCs under the selected 100 Districts in the country covering all states. Training, IEC and miscellaneous activities by Deptt. of Revenue, DCG(I) and other agencies would also be required.**

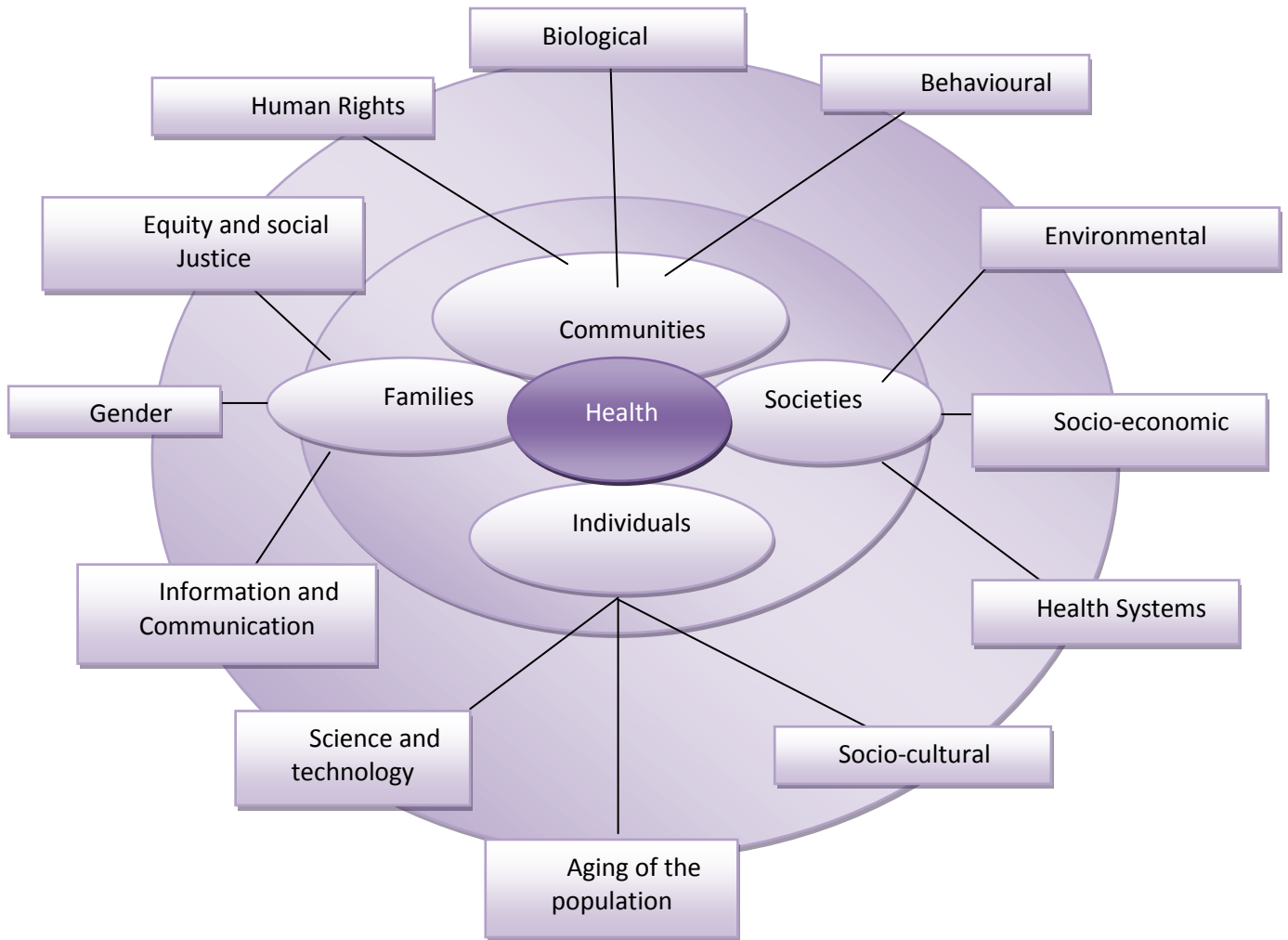
The regulatory aspects as mentioned in objective 2 of the Program, for increasing Morphine availability would be addressed by Department of Revenue in coordination with Central Drug Standards Control Organization. Cooperation of international and national agencies in the field of palliative care would be taken for successful implementation of the program.

## Introduction

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The widely accepted definition of Health is that given by the World Health Organisation[1948] in the preamble to its constitution as *“Health is state of complete physical, mental and social wellbeing and not merely an absence of disease or infirmity”* and [1978<sup>4</sup>] *“ability to lead a socially and economically productive life”*.

**Fig 1 - Health Determinants<sup>5</sup>**



<sup>4</sup> WHO 1978 – health for All Sr No 1

<sup>5</sup> WHO 1998 – International Digest of Health Legislation, Vol 49, No 1

Disease has many shades [spectrum of disease] ranging from inapparent [subclinical] to severe manifest illness and hence it has not been clearly defined. However, it may be taken as a condition in which there is 'a departure from a state of health'. The term 'illness' refers not only to the presence of disease, but also to the individual's perceptions and behaviour in response to the disease as well as the impact of that disease on the psychosocial environment<sup>6</sup>.

The noted medical historian Henry Siegerist defined Medicine as 'Medicine, by improving health and preventing illness, endeavours to keep individuals adjusted to their environment as useful and contented members of society; or by restoring health and rehabilitating the former patient, it endeavours to readjust individuals to their environment'<sup>7</sup>.

This understanding is significant to fathom the impact of the chronic non-communicable diseases [NCDs] such as cancer, Chronic Obstructive Pulmonary Disease, cardiovascular diseases, diabetes, stroke etc. and others like geriatric health issues, chronic communicable disease like HIV / AIDS which as described above, have become the largest health burden in India. Patients with these conditions experience ill-health of varying degrees with multiple intermittent hospitalisations, which affect the physical, social, emotional and economic dimensions of their lives. They go through long term distresses throughout their life along with their families. Presently, the number of lives lost due to ill health, disability and early death constitute 62% of the total disease burden in India.

Chronically ill patients have complex medical needs. Elderly patients, in particular, are unable to coordinate their own care. However, when a palliative care team is involved, care becomes less fragmented. Palliative care brings in caring and improves the quality of life for patients and families throughout an illness experience by addressing all these dimensions and bringing in a person centred care within the health delivery system. It is applicable right from diagnosis of a chronic disease up to the end of life. Today, there is the evidence based knowledge and skills available to relieve much of the unnecessary suffering due to pain and other distressing physical and psycho-social concerns. Flexible use of palliative care also supports the primary care physicians in several areas: care co-ordination, patient-family communication, pain and symptom management, co-ordination of safe and effective discharge planning and overall patient satisfaction. Even where patients reach hospitals earlier have a better chance of cure, integrating palliative care with curative management measures definitely improves quality of life<sup>8</sup>.

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<sup>6</sup> Ouslander, JG. J C Beck [1982] in Ann Rev Public Health 3: 58

<sup>7</sup> Public Health and Preventive Medicine – The Red Book AFMC Jubilee Edition 2008

<sup>8</sup> Stjernsward J, Clark D. Palliative medicine – a global perspective. In: Doyle D, Hanks G, Cherny N, Calman K, eds. Oxford textbook of palliative medicine, 3rd ed. Oxford: Oxford University Press, 2004:1197e1224

A survey by Centre to Advance Palliative Care has shown that palliative care decreases length of hospital and ICU stays, eases transitions between care settings, and increases hospital compliance with care quality standards<sup>9</sup>.

The WHO has recognized palliative care as an integral and essential part of comprehensive care for cancer, HIV, and other health conditions. It has defined Palliative care (WHO, 2002a) *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*. Unfortunately, palliative care is only reaching a fraction of the people who need it in our country.

It further states that Palliative care:

- provides relief from pain and other distressing symptoms;
- 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 patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- 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.

WHO recommends to all countries that they should adopt a national palliative care policy, ensure the training and education of health professionals and promote public awareness, ensure the availability of morphine in all health care settings, and ensure that minimum standards for pain relief and palliative care are progressively adopted at all levels of care. It recognizes the need for developing palliative care with a public health approach that targets all age groups suffering from diseases or conditions in need of palliative care. These conditions include cancer, HIV/AIDS, congestive heart failure, cerebro-vascular disease, neurodegenerative disorders, chronic respiratory diseases and diseases of older people, among others.

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<sup>9</sup> Transforming Healthcare: End-of-Life Care. Gunderson Lutheran Health System, Feb. 3, 2009.

*The key messages from WHO to governments are*

- Palliative care is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases. Palliative care is particularly needed in places where a high proportion of patients present in advanced stages and there is little chance of cure.
- Ideally, palliative care services should be provided from the time of diagnosis of life-threatening illness, adapting to the increasing needs of cancer patients and their families as the disease progresses into the terminal phase. They should also provide support to families in their bereavement.
- Effective palliative care services are integrated into the existing health system at all levels of care, especially community and home-based care. They involve the public and the private sector and are adapted to the specific cultural, social and economic setting.
- In order to respond to the cancer priority needs in a community and make the best use of scarce resources, palliative care services should be strategically linked to cancer prevention, early detection and treatment services for both adults and children.

Three measures are recommended as a foundation for developing palliative care through the public health approach (WHO, 1996):

1. A government policy to ensure the integration of palliative care services into the structure and financing of the national health-care system
2. An educational policy to provide support for the training of health-care professionals, volunteers and the public
3. A drug policy to ensure the availability of essential drugs for the management of pain and other symptoms and psychological distress, in particular, opioid analgesics for pain relief.

All three of these measures are necessary, along with committed leadership, to achieve an effective palliative care programme.

The enhanced public health model includes implementation of palliative care services at all levels throughout the society<sup>10</sup>. This process is always implemented within the context of the culture, disease demographics, socioeconomics, and the health care system of the country. For India all the components, inclusive of supportive policies, drug availability as well as creating strategies on education, capacity building and implementation are all relevant.

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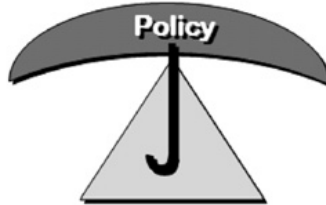
<sup>10</sup> Stjernsward J, Gomez-Baptiste X. Palliative care: The public health strategy. *J Public Health Policy* 2007;28:42e55.

## Policy

- Palliative care part of national health plan, policies, related regulations
  - Funding / service delivery models support palliative care delivery
    - Essential medicines
- (Policy makers, regulators, WHO, NGOs)

## Drug Availability

- Opioids, essential medicines
  - Importation quota
  - Cost
  - Prescribing
  - Distribution
  - Dispensing
  - Administration
- (Pharmacists, drug regulators, law enforcement agents)



## Implementation

- Opinion leaders
  - Trained manpower
  - Strategic & business plans – resources, infrastructure
  - Standards, guidelines measures
- (Community & clinical leaders, administrators)

## Education

- Media & public advocacy
  - Curricula, courses – professionals, trainees
  - Expert training
  - Family caregiver training & support
- (Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

**Fig 2 - Foundation Measures for Implementation Of Palliative Care.**

The Ministry of Health and Family Welfare has recognised and acted on the increasing incidence of long term and chronic diseases through its comprehensive National program for managing NCD plan since 2010. It now recognises absolute necessity for starting Palliative Care activities to address the concerns regarding inadequacies in pain relief and palliative care facilities in the country. The activities are being planned and charted out with the explicit purpose of improving the quality of life of those with long term and life limiting illnesses after a detailed situational analysis. Target population for palliative care has been determined to be those with cancer, HIV/ AIDs and the elderly in India.

The Palliative Care activities proposed are based on the WHO stepwise framework<sup>11</sup> for planning and effective implementation for countries<sup>12</sup>.

**Section A** is on the present background and analysis of the situation in the country. This discusses an understanding of where we are now i.e. needs, available services or programmes and also where do we want to be i.e. setting the vision, goals, guiding principles and objectives.

**Section B** broadly deals with implementation planning. Discussions would be on defining the target population, priority of interventions across the spectrum, identifying the strategies and activities needed appropriate implementation of the policy with the proposed strategies and actions.

**Section C** would present the governance structure and processes and the budgetary requirements based on the activities discussed under strategies. Annexure clarifying concepts presented through the text of the document would follow this discussion.

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<sup>11</sup> Palliative Care Module - Cancer Control; Knowledge into Action WHO Guide for Effective Programmes, WHO 2007

<sup>12</sup> WHO guidelines to governments for incorporating PC - <http://www.who.int/cancer/media/FINAL-Palliative%20Care%20Module.pdf>

## SECTION A - The present background and analysis of the situation in the country

India is home to millions of patients suffering from chronic and life limiting illnesses such as cancer, AIDS, dementia, heart, liver or renal disease and other debilitating conditions or incapacitating injuries. Non-communicable Diseases (NCDs) account for more than half of all deaths in India. NCDs are on the rise within our country. In terms of the number of lives lost due to ill-health, disability, and early death (DALYs), NCDs (inclusive of injuries) accounts for 63% of the total disease burden while 37% is from communicable diseases, maternal and child health, and nutrition all combined<sup>13</sup>. Due to the development of effective anti - retroviral therapy, HIV/AIDS is now a chronic manageable disease.

With respect to cancer, for example, it has been noted that, despite improvements in survival rates, the majority of cancer patients will need palliative care sooner or later. In developing countries, the proportion requiring palliative care is at least 80 percent. Worldwide, most cancers are diagnosed when already advanced and incurable; for these patients, the management of pain and other symptoms is the only realistic option for care and treatment.

Table 1 - The dimensions of the problem of NCD in India

Item	Past	Present	Future
Cancer India			
Incidence	8 lakhs (2004) ICMR	11 lakhs (2012) ICMR	12.5 lakhs (2020) ICMR
Prevalence	-	28 lakhs (2012) ICMR	-
Mortality	2.6 lakhs (2004) ICMR	5 lakhs (2012) ICMR	-
Diabetes India			
Prevalence	25.8 million (2000) NCMH	61 million (2011) IDF	101 million (2030) IDF
Mortality	1.1 lakh (2004) ICMR	1.75 lakhs (2005) WHO	2.36 lakhs (2015) WHO
Heart Disease India			
Prevalence	27 million (2000) WHO PCD 2005 29.9 lakhs (2005) WHO	22.3 million (2004) ICMR	61 million (2015) WHO PCD 2005
Mortality	2.7 million (2005) WHO PCD 2005	-	

Abbreviations used in table:

1. ICMR: Burden of Disease Publication 2006 (data for 2004)
2. IDF: International Diabetes Federation
3. PCD: Preventing Chronic Diseases by WHO 2005
4. NCMH: National Commission on Macroeconomics & Health

<sup>13</sup> World Health Organization - NCD Country Profiles , 2011



The number of people in need of palliative care in India may be estimated from the mortality rates of diseases requiring this dimension of care<sup>14</sup> e.g. for cancer<sup>15</sup>

1. Number of cancer deaths / year = 5,00,000
2. For Cancer B = 80%
3. 80% of A = C = 350,000
4. No of family members / patient = 3.8 for India
5. C X D = would be the number needing PC for that disease / year in the country. for India –this would be 1,520,000/-

For HIV the factor B is 70%. Based on the latest data on HIV prevalence in India as 2.7 million, estimated number of patients requiring palliative care is 1,890,000/-

In addition<sup>16</sup>, there has been a steady rise in the share of elderly population (aged 60 years or above) in the total population over the decades. As against 5.6% in 1961, the proportion goes up to 7.4% in 2001 and most of them are illiterate and poor. The size of the elderly population has risen from 12.1 million in 1901 to approximately 77 million in Census 2001. According to official population projections, the number of elderly persons will rise to approximately 140 million by 2021. The elderly population (aged 60 years or above) accounted for 7.4% of total population in 2001. Demographic projections indicate that it would be 12.17 per cent of overall population by 2026 with many of them poor.

NCDs largely affect middle aged and older populations, the groups growing the fastest. About 64 per thousand elderly persons in rural areas and 55 per thousand in urban areas suffer from one or more long term disabilities.

The section of population needing palliative care usually needs caring for distresses at physical, psycho-social and spiritual dimensions. The patient, family and carer needs are depicted in the figure below. For patients the needs are until the end of their lives and for carers and family this extends beyond death to bereavement period.

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<sup>14</sup> *Palliative Care Module - Cancer Control; Knowledge into Action WHO Guide for Effective Programmes, WHO 2007*

<sup>15</sup> Deriving the total no of people needing palliative care. A= no of cancer deaths, B = % needing PC in case of cancer this is 80 %; A X B= C. D is the number of family members affected. Hence the final figure of number of people requiring palliative care is derived from C X D

<sup>16</sup> *Situation Analysis Of The Elderly in India; June 2011 - Central Statistics Office Ministry of Statistics & Programme Implementation Government of India*

**Fig -3 : Quality of life dimensions required to be addressed through Palliative Care from diagnosis onwards, throughout during a chronic, life limiting illness.**

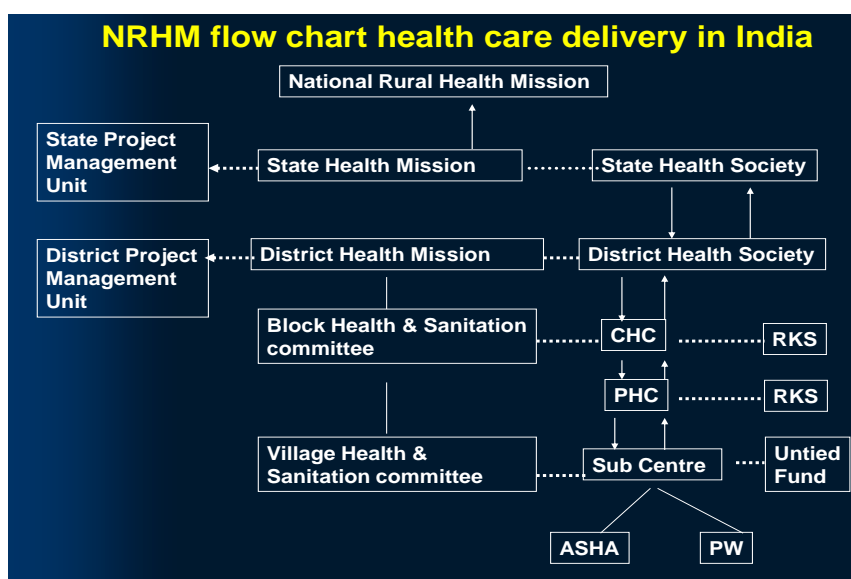


As only a small percentage of their time is spent in the presence of trained medical or paramedical professionals, family members and relatives are the main caregivers. However, they generally lack the knowledge and skills to perform the tasks adequately. Their empowered participation not only enhances the quality of care provided, but the family also experiences increased sense of fulfilment and satisfaction in giving that care by. While planning strategy, this important resource for continuity and quality of care has been taken into account.

*Current structure and financing of health delivery in the country*

The existing palliative care plan and activities are minimal in the country. In terms of structure, the Public health system in India is spread as accessible units, from the village level up to the state level.

**Figure-4 : Hierarchy of Public health Care system in India**



**Rural Areas:** There are District Hospitals, Community health Centres, Primary Health centres and Sub Centres

**Urban Areas:** There are Medical Colleges, Apex institutions, State institutions, Municipal Hospitals etc.

Until recently, the national programs were disease focused vertical programs which resulted in development of a fragmented approach. The much needed convergence is being brought in by the Ministry of health and family welfare [MoHFW], through the national programs on NCDs and the National Rural Health Mission.

At state level, most health care policies do not recognize palliative care as a discipline and hence it is not included in the public or private health delivery systems. Kerala is the one state that has a state policy that supports provision of palliative care through the public health system in the state. This state provides a model for others, to incorporate the simple principles of palliative care in the public health care programs at each of these levels.

Seven out of every 10 Indians live in rural areas, which are served by about 2% of qualified medical doctors<sup>17</sup>. Rural and economically disadvantaged populations have poor health outcomes. The ratio of population utilisation of private health services is 76 in comparison to 24 for public health care system. The percentage of population with access to insurance coverage for health is low. Also, as there is yet to be a system for assessing the relevance of an intervention in a clinical situation, payment for futile interventions is common. At the same time, due to lack of awareness about the scope of palliative care inputs, the insurances do not pay, or they do not pay enough, for palliative care interventions. Healthcare expenditure on chronic diseases was 70% of the average monthly income for people in low-income groups and 45% for those in the highest income group<sup>18</sup>. More than 30 million people in India were pushed below poverty line due to high out of pocket payments for healthcare.

Palliative care is not as cost intensive in comparison to most other speciality interventions. The cost – benefit ratio is very high. The minimal allocation that may be needed to achieve quality care may be hoped to be achieved through the strategic presentation of its needs for the country.

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<sup>17</sup> Healthcare in India. Columbia University continuing education.

<http://ce.columbia.edu/files/ce/pdf/actu/actu-india.pdf>

<sup>18</sup> Levesque JF, Haddad S, Narayana D, Fournier P. Aff ording what's free and paying for choice: comparing the cost of public and private hospitalizations in urban Kerala. *Int J Health Plann Manage* 2007; 22: 159–74.

## ***Current status of Opioid availability and accessibility***

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Treatment of pain can bring remarkable improvements in the quality of life for patients' with chronic and debilitating diseases. Pain management is also imperative for "adding life to the days" of terminally ill patients. If left untreated, persistent pain severely impairs the patient's dignity and quality of life. According to one estimate, more than seven million people with life-limiting illnesses need pain relief in India each year.<sup>19</sup>

Opioids are among the world's oldest known drugs for pain relief. Opioid use leads to decreased perception of pain, diminished reaction to pain as well as increased tolerance of pain. With such strong analgesic properties, opioids remain the drugs of choice for the treatment of moderate to severe, acute and chronic pain. Opioids like oral Morphine are inexpensive, in addition to being safe and effective when used appropriately for patients with moderate to severe pain and are indispensable in managing moderate to severe pain as seen in cancer patients. It is for this reason that Morphine Sulphate and Codeine Phosphate find a place in the National List of Essential Medicines of India, 2011, compiled by the Ministry of Health of Health and Family Welfare, Government of India.

Much of the supply for the rest of the world comes from licit cultivation of poppy in three Indian states, yet only a trickle was reaching India's domestic market<sup>20</sup>. This poor availability of strong opioids has been recognised to be due to un-balanced regulatory policies focusing on preventing abuse. Procurement and distribution of morphine and other opioid analgesics is being affected by the licensing requirements under the present Narcotic Drugs and Psychotropic Substances Act, 1985 (hereinafter "NDPS") and the Rules there under.<sup>21</sup>

International Narcotic Control Board has encouraged India to ensure that simplified rules are implemented in all States and Union Territories of India to facilitate the availability of opioid analgesics.<sup>22</sup> In May 1998, the Central Government advised all State governments to amend and simplify their NDPS Rules, in line with the "Model Rules" developed by the Department of Revenue (hereinafter "the Department") in consultation with the Drugs Controller General of India.<sup>23</sup> Access to morphine, however, did not improve as most States did not take action in accordance with the model rule/ procedure recommended by the Central Government.

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<sup>19</sup> Human Rights Watch, "*Unbearable Pain: India's Obligation to Ensure Palliative Care*", October 2009 at pg 15.

<sup>20</sup> Rajagopal MR. The challenges of palliative care in India. *Natl Med J India* 2001;14:65-67

<sup>21</sup> David E. Joranson, M. R. Rajagopal, and Aaron M. Gilson, 'Improving Access to Opioid Analgesics for Palliative Care in India', *Journal of Pain and Symptom Management*, Vol. 24 No. 2 August 2002 at pgs 152-59.

<sup>22</sup> See Annexure to the National Policy on Narcotic Drugs and Psychotropic Substances – Plan of Action, at S.no 8. 3 at pg. 45

<sup>23</sup> Letter F.No. 664/63/97-NC dated May 8th, 1998 written by Revenue Secretary, Department of Revenue, Ministry of Finance, Government of India to the Chief Secretaries of all State Governments.

Due to all the reasons discussed above, an average medical practitioner is untrained in using strong opioids as these drugs have been unavailable for use since few decades. Even when available, there is poor accessibility because of high cost, lack of training among health personnel on how to prescribe and use opioids, and restrictive regulations.

The Palliative Care requires the efforts that are underway to amend the required sections of the NDPS Act to ensure balance to the regulations by including provisions for medical and scientific use; and help create supportive NDPS Rules for improving the availability of these essential medications within the country along with providing adequate training for its usage to professionals.

Table below provides the comprehensive list of states with modified rules and availability of centres.

**Table 2--- Distribution of States with modified NDPS Rules and PC centres**

S. No.	State	Modified Rules	No. of Palliative care services
1.	Jammu Kashmir	✓	1
2.	Punjab		2
3.	Haryana		0
4.	Delhi	✓	2
5.	Dadra Nagerhaveli	✓	Nil
6.	Rajasthan		3
7.	U P		1
8.	Gujarat		2
9.	M P	✓	4
10.	Jharkand		1
11.	Assam		6
12.	Manipur		1
13.	Mizoram	✓	1
14.	Tripura	✓	1
15.	Orissa	✓	1
16.	Uttaranchal		1
17.	Arunachal Pradesh	✓	Nil
18.	Himachal Pradesh	✓	Nil
19.	Chattisgarh		Nil
20.	West Bengal		4
21.	Maharashtra		4
22.	Andhra Pradesh		4
23.	Goa	✓	1
24.	Karnataka	✓	12
25.	Tamil Nadu	✓	12
26.	Bihar		1
27.	Kerala	✓	184
	<b>Total</b>		<b>251</b>

New services developed within the public health system since implementation of State Palliative Care Policy [2008] of Kerala with NRHM funding is 657/- Source: IAPC

### ***Awareness in public and health care professionals regarding palliative care***

The awareness regarding the scope of palliative care and pain relief is low amongst professionals as well as the public. An average patient in India with moderate to severe pain from a disease for e.g. due to cancer, is unaware that there are effective medications for her/his pain and that it may be relieved.

Although the WHO encompasses physical, mental and social wellbeing in defining health, medical and paramedical curricula address only the acute care aspects of mainly the physical issues. This comprises a small fraction from the overarching wellbeing viewpoint. None of the doctors or nurses who deliver palliative care presently have received specific undergraduate education on that subject.

These gaps in education are reflected in clinical care, practice, infrastructural facilities and approaches; each of which are geared towards acute or episodic care with gaps in symptom relief, psycho-social care or continuity of care, leaving the patient with long term illness to endure un-acknowledged, unmet continued suffering.

Health professionals are increasingly interested in understanding palliative care, and this interest needs to be paralleled by increasing learning opportunities. However, most have acquired knowledge and skills after graduation, through teaching programmes with differing formats.

## ***Current activities in the country on palliative care***

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Except for those in Kerala, there is limited information on the number of teams or programmes providing palliative care services, and the type of care they deliver. There is no available information on how effective palliative care is or which factors determine its effectiveness.

The teams and programmes differ according to their development: community- or hospital-based; with one or more disciplines; with mixed or exclusive home, outpatient or inpatient care. Most services provide care for cancer patients. Table – above depicts the available information on state wise availability of palliative care services.

There is limited information about how and where patients die, how many receive palliative care, and the characteristics of the caring process.

The Indian Association of palliative Care [IAPC] was formed in 1994 in consultation with World Health Organisation and Government of India. Its activities are aimed at the care of people with life limiting illness such as Cancer, AIDS and end-stage chronic medical diseases including access to pain relief, palliative care capacity building and advocacy. The Children’s Palliative Care program was launched by IAPC in 2010, which focuses on pain relief in HIV positive children. IAPC has also charted minimum standards for palliative care services at different levels.

There are several non-profit non-government organisations [NGOs] that have palliative care as their primary mandate. Most NGOs providing for care, are run by volunteers, with resources from charities, national / international funding agencies and other nongovernmental organizations, and, where possible through payments from patients. Two centres of excellence in the country have been recognised as WHO Collaborating Centres. Thiruvananthapuram [Kerala] has WHO Collaborating Centre for Training and Policy on Access to Pain Relief and Calicut [Kerala] has the WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care. The facilities and faculty of these centres may be leveraged for guidance and support in the implementation and monitoring of the tenets of the national program.

The coverage of services in terms of availability, accessibility and affordability of palliative care are grossly inadequate. It is estimated that: only 1% of patients that need palliative care receive it; the majority of all palliative care services in the country are available in one state; Kerala. There are few states in the country without a single centre for Palliative care service provision.

The **on-going training programs** in the country are

1. MD courses in Palliative care with 2 seats per year at Tata Memorial Hospital, Mumbai
2. 1 year residential fellowship program - CMC Vellore, Tamil Nadu, Kidwai Memorial Institute of Oncology, Bangalore and Tata Memorial Hospital, Mumbai
3. 1 year distance education fellowship program – Institute of Palliative Medicine
4. 8 weeks Certificate course in essentials of palliative care by the Indian Association of Palliative Care with an optional clinical placement component happening simultaneously at 30 centres across India
5. 6 weeks and 4 weeks residential training programs for doctors and nurses at the WHO collaborating Centres, Calicut and Thiruvananthapuram, Institute of Palliative Care, Thrissur, Kerala, District Hospital, Ernakulam, Kerala and MNJ Institute of Oncology, Hyderabad.
6. The post graduate diploma course in Oncology Nursing, recognised by the Nursing College of India, has palliative care component integrated into it.

Thus there is a huge, yet most essential responsibility to bring in the dimension of ‘Long term care principles’ and “palliative care principles” within the Health Care systems. The focus needs to be re-directed on the person suffering due to the disease to ensure his/ her quality of life. This would involve capacity building for caring for dimensions beyond physical, improving drug availability through policies along with empowering the family through informed decision making, and modifying awareness and attitudes both amongst public and amongst professionals.

The social context of the palliative care plan and activities has been analysed below prior to embarking on the details of the program, through the strengths, weaknesses, opportunities and threats (SWOT) methodology.

### ***SWOT - What are the strengths and weaknesses associated with plan development and implementation?***

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The main gaps for creating adequate availability of palliative care services in India are

- Lack of palliative care services in most of the country.
- Lack of awareness among professionals, administrators and the public.
- Lack of facilities for palliative care education in the country.
- Unrealistic narcotic regulations preventing access to opioids for those in pain.
- Lack of clear guidelines and resources for those wishing to provide palliative care services.



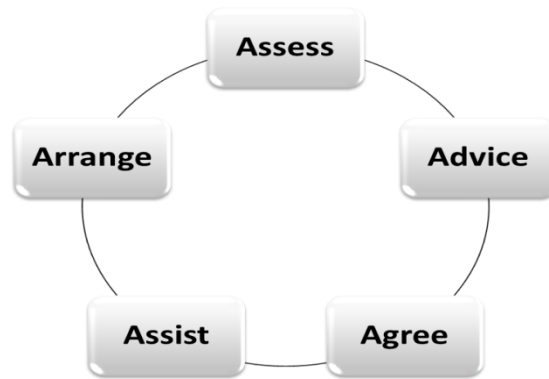
The chief area of weaknesses is attitude at many levels. Those concerned at various levels of decision making see the focus on curative treatment as being a more attractive approach. Most are unaware of the relevance and scope of palliative care. There is a concern that by emphasizing palliative care they are somehow failing in their roles of contributing towards overcoming the disease.

This is a matter of perception, based mainly on bio-physical acute care model of health care. Although acute care would greatly benefit by incorporating principles of palliative care in its approach to a given clinical situation, patients with chronic diseases have most overt needs in this area due to their advancing disease state over time and sometimes non- response to or non-availability of curative interventions. They inherently require relief from their symptoms, support for psycho-social concerns and attention to their quality of life issues with its obligation for shared decision making. All these are fundamental tenets of palliative care interventions. Such perceptions can be modified through actual experience in a given situation.

Moreover, given the present global scenario of prevalence of chronic illnesses, there is an emphasis on integrating chronic care principles for managing long term illnesses by WHO – Annexure - WHO IMAI Chronic Care Module [Pg 6]

<b>Table3- 5 A's of CHRONIC CARE PRINCIPLES</b>	
<b>ASSESS</b>	Assess patient's status of disease, and identify relevant treatment, advice and counselling. Identify individual elements of suffering of patient and family, including pain and other symptoms and social (including financial), emotional and spiritual issues. Assess patient and caregiver knowledge, concerns and skills related to his/her condition and treatment.
<b>ADVISE</b> Provide information to enhance patient's understanding of his/her condition and treatment options along with pros and cons of each	Demonstrate skills such as the correct method for range of motion or how to use medicine such as morphine. Ask if they have questions or will have problems giving the care at home. Ask them to demonstrate the skill or ask a good checking question.
<b>AGREE</b> Interact with and allow a shared decision making process to evolve that reflects the patient's priorities	After giving information and teaching skills, make sure that they know what to do and that they want to do it. Empower them to stay in charge. Support patient self-management and family care.
<b>ASSIST</b>	Provide the patient with the necessary interventions, supplies and support required to meet their treatment goals
<b>ARRANGE</b> Ensure that the patient is linked to other services/ support and the next follow up visit is scheduled	Ask them to return, or to ask an experienced caregiver in the community, if they have questions or are confused or concerned about how to give the care. Make sure they know when and who to call for help. Let them know how you can provide backup to their home care. Ensure that visit records are complete

**Figure 4- the '5 A's of**



Due to the perceived ineffectiveness within the quality of care delivery, the technocratic model of care is being challenged globally, and the need for the humanitarian holistic model is being insisted. Medical management is slowly moving towards recognising the person coming to health care system as central in all transactions.

**Table-4 Comparison Of Models Of Care**

<b>Bio-physical Acute care model</b>	<b>Psychosocial whole person model</b>
Hierarchical organization and Standardization of Care that is "disease centered"	Networking organizational structure with systems in place that is "person centered" and facilitates individualization of care
Authority and responsibility inherent in practitioner, not patient	Information, decision making and responsibility shared between practitioner and patient and family
Super valuation of Science and Technology	Science and Technology placed at the service of the individual
Aggressive intervention with focus on the immediate results	Focus beyond short term, based on what the individual values with respect to quality of life and well being
Acknowledges Rationality	Acknowledges emotions
Compatible with strong paternalism	Compatible with supportive paternalism
Death as a failure	Death as an eventuality in the process

When we take an overview of the internal forces, such as political support, leadership, stakeholder involvement and the resources available, we are in the premises of strength where the on-going independent activities within the country have reached adequate momentum to have influenced the policy decisions. Charting out of this program would be a strong impetus to make a nationwide difference.

More than 75 % patients who present to health care set up in the country are in the late stages of the diseases. Fair allocation of resources should allow this essential service to take root within the health delivery system at all settings bringing relief to suffering millions.

The existence of expertise and inspired leadership within the country is a tremendous strength to the actualisation of the national program. Presence of two WHO CCs in palliative care in the country is also a unique asset for any country. Also the experience of the Kerala model for community involvement and the State policy on Palliative Care are other features adding power to planning appropriate implementation.

### ***SWOT - What are the opportunities and threats associated with plan development and implementation?***

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The recognition by the ministry of health, of the rising proportion of non-communicable diseases in the overall incidences and mortalities within India has given thrust to the necessity of recognising the field of palliative care and developing a suitable program for access to its services.

The National Rural Health Mission [NRHM] has revolutionised possibilities of achievements through public health care system. The NRHM provides an overarching umbrella, subsuming the existing programs of the Ministry of Health including all NCD programs. The principal merits brought in through NRHM are,

- Health and health determinants have been brought under a single umbrella
- There is decentralisation of functions, functionaries and finances
- AYUSH and allopathy have opportunity to integrate their systems of care with their inherent strengths, for best outcomes in a given situation

The National Program on NCDs has made provisions for including palliative care as an important component of comprehensive cancer care plan, with infrastructural allocation and raising the resources for personnel training.

National Rural Health Mission in Kerala has proven by its work over the last five years that NRHM can act as an effective facilitator for the development of palliative care services within the states.

National AIDS Control Organisation has taken successful measures to contain the epidemic of HIV infection and is now looking beyond anti - retroviral therapy, towards palliative care for improving the quality of life of patients who are now living longer functional lives.

India's National List of Essential Medications [NLEM] 2012 has included several weak and strong opioid analgesics in it, further mandating its availability.

India as signatory to International Drug Conventions that form the basis for enacting the NDPS Act has recognized that the use of narcotic drugs and psychotropic substances for medical and scientific purposes is indispensable.<sup>24</sup> The concerned department from the ministry of finance is working on bringing in suitable modifications to the NDPS Act and Rules to address the issue of opioid non-availability for pain relief.

India is also a signatory to the International Covenant on Economic, Social and Cultural Rights. [ICESCR]. The Committee overseeing the ICESCR issued a 'General Comment' on the right to health, stating the "core obligations" of all signatory nations, irrespective of resources. These include obligations to ensure access to health facilities, goods and services on a non-discriminatory basis; to provide essential drugs as defined by the WHO; and to adopt and implement a national public health strategy. Interpreting this Comment in the context of palliative care, this would oblige India to ensure a universal access to services, the provision of basic medications for symptom control and terminal care, and the adoption and implementation of national palliative care policies<sup>25</sup>.

The fact that WHO and international partners are advocating a public health approach to palliative care and is providing details for its implementation to countries, represents another opportunity for adopting approved methods for influencing the development of national policies<sup>26</sup>.

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<sup>24</sup> See Article 4 of the Single Convention on Narcotic Drugs, 1961 as amended by the 1972 Protocol amending the 1961 Single Convention on Narcotic Drugs, 1961 and the Preamble to the Convention on Psychotropic Substances, 1971

<sup>25</sup> International Covenant on Economic, Social and Cultural Rights (1966), Article 12 and Committee on Economic, Social and Cultural Rights. General Comment No. 14. "The rights to the highest attainable standard of health (Article 12 of the Covenant)." 22nd Session April-May 2000 E/C 12/2000/4, para 3 & 43.

<sup>26</sup> *Palliative Care Module - Cancer Control; Knowledge into Action WHO Guide for Effective Programmes, WHO 2007*

Considering the geographical and populous size of the country and the socio-economic, cultural diversity in the demography, an approach with a “rights” based perspective can be effected with collaborative effort from public, private, and non-government organisations, both national and international.

Most of the patients in need of palliative care would eventually need to be looked after by health care professionals in the primary health care level in the future. Involvement of the local governments and the community through bottoms up approach in the provision of care in the locality will be essential for ensuring sustainability of the projects at the primary health care system level. The strong family structure still observed in India can be utilised as strength if the families are empowered to provide emotional and spiritual support, prophylaxis for avoiding bedsores, appropriate food, changing of bandages, etc. at home.

The risk of developing another vertical program when pain alleviation and PC should be seen as integral part of the essential services package is real. Yet in a field that is still new to the health care sector, a concurrent vertical system cannot be done away with in the early years; it is needed to develop benchmarks for quality and to further academic activity and research. The essential long term goal is nevertheless emphasised to be able to integrate.

## **Vision**

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All those requiring pain relief and palliative care in the country have access to affordable, safe and quality care

## **Goal**

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Availability and accessibility of rational, quality pain relief and palliative care to the needy, as an integral part of Health Care at all levels, in alignment with the community requirements

## **Guiding Principles**

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1. Pain relief and Palliative care are recognised as essential components of health care
2. The care delivery is necessitated at all levels of the health delivery systems, from primary to tertiary levels
3. Fostering partnership among public, private as well as non-profit systems of health care is identified as basic to fulfil requirements of reach, quality and sustainability
4. Adequate resources should be ensured for field implementation of the program.
5. Recognises multidisciplinary team approach, inclusive of person and family as necessary to fulfil the diverse care needs in an individual situation
6. Recognises the role and facilitates the integration of complementary systems of Medicine in providing for a holistic care
7. Encourages innovations and adoption of successful models into care delivery systems
8. Mandates systematic integration of program planning, implementation and monitoring into the existing health care delivery system.

## Objectives

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1. Improve the capacity to provide palliative care service delivery within various government programs like National Program for Prevention and Control of Cancer, Cardiovascular Disease, Diabetes, and Stroke; National Program for Health Care of the Elderly; the National AIDS Control Program; and the National Rural Health Mission.
2. Refine the legal and regulatory systems and support implementation to ensure access and availability of opioids for medical and scientific use while maintaining measure for preventing diversion and misuse
3. Encourage attitudinal shifts amongst healthcare professionals by strengthening and incorporating principles of long term care and palliative care into the educational curricula (of medical, nursing, pharmacy and social work courses).
4. Promote behaviour change in the community through increasing public awareness and improved skills and knowledge regarding pain relief and palliative care leading to community owned initiatives supporting health care system.
5. Encourage and facilitate delivery of quality palliative care services within the private health centres of the country
6. Develop national standards for Palliative Care services and continuously evolve the design, and implementation of the National Program to ensure progress towards the Vision of the program

## SECTION B - Implementation Planning

### Priorities of the Palliative Care

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The process requirements of the Palliative care would be initiated for all the objectives. However, for the initial years, particular emphasis would be given for the following aspects.

1. The activities would be initiated in 1/3<sup>rd</sup> of districts per state or 10 districts per state whichever is higher. A maximum of 200 districts is envisaged to be covered during the five year period. However CHC would be limited to 700 only and expected to be operationalized in 50% of the districts undertaken out of 200 districts. The expected outcome of interventions would be based on the current status of policies, leadership and the existing palliative care facilities within the states of different regions of the country<sup>27</sup>. Table below denotes the projected outcome goals within the program for the different sets of states in the country.
2. Building systems to ensure services within the public sector health delivery systems would be an emphatic component of the pilot program. The target population for palliative care would be those coming under the various National programs on NCDs, Elderly & HIV/ AIDS and requiring Palliative Care.
3. Target objectives would be those related to opioid availability and capacity building through training and incorporating palliative care principles within the curriculum.
4. The vision requires universalisation of care services. Hence all sectors of health care delivery would be included for IEC and capacity building opportunities to bridge the gap that presently exists in relation to availability of pain relief and palliative care within the country<sup>28</sup>.

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<sup>27</sup> North, northeast, west, east, central and south of India

<sup>28</sup> Since 24% of services are being provided through the public sector and the remaining 76% is delivered through the private sector, opportunities for capacity building would be made available to all health care professionals, [with voluntary enrolment of private and NGO sector]



Table – 5-Goals for the states, grouped on the basis of existing capacity

<b>Region and States</b>	<b>Present situation</b>	<b>Goals</b>
*High level of capacity	Several palliative services including centres of excellence available. Many champions are active in the region. Government policy makers already aware of needs. Kerala already has a declared state palliative care policy	State steering committee to oversee. 2 RMIs per district, aim for declaration of state palliative care policy. Model Rules for opioid access to be implemented with Standard Operational Procedures in place and operational programs up to peripheral health care delivery units.
*Medium level capacity	Some professional services exist. There are few champions in the field at present. State government is aware of policy requirements	Activate State steering committee Appropriate Rules in place for implementing the program through national programs and NDPS Regulations. Program frame work defined. Professional capacity building Awareness & IEC for professionals
*Average level capacity	Minimal to nil services. No experts or champions in the field. Implementation to be initiated.	Activate State steering committee to have appropriate regulations including NDPS Regulations in place for implementing the program through state channels of the National programs. Program frame work defined. Initiate sensitisation & capacity building programs for professionals.

## Objective 1

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**Improve the capacity to provide palliative care service delivery within various government programs of Ministry of health and Family Welfare E.g. National Program for Prevention and Control of cancer, CVD, Diabetes & Stroke, National AIDS Control Program, National Program for Health Care of the Elderly, National Rural Health Mission etc.**

## Strategies

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- a. Develop clear protocols, guidelines, systems and budget for ready application with in the states which are able to implement it. The guidelines would be clear for each setting e.g. RCCs, HIV [ART and care and support] centres, district, community and primary levels of public Health Care systems, medical colleges, private institutions and NGOs.
- b. Recognise centres of excellence or regional resource centres in each region to innovate and demonstrate models of care and also contribute resource pool for capacity building <sup>29</sup> - WHO Collaborating Centre [WHO CC] at Thiruvananthapuram, for Training and Policy on Access to Pain Relief and the WHO CC at Calicut for Community Participation in Palliative Care and Long Term Care are already working as centres of excellence and may continue to serve in the same capacity. More resource centres are to be recruited in each region.
- c. Integrate training modules of Palliative care into the on- going training activities related to each of the on-going the national programs
- d. For universalisation of care,
  - a. Include private institutions and NGOs in the capacity building initiatives at program cost.
  - b. Provide training for General Practitioners, Community Workers, and of future Home care Nurses at the district hospitals and cancer centres with palliative care facilities. This is intended to achieve a meaningful coverage, reaching all and for guaranteeing, together with referral institutions, continued care for patients discharged from specialist centres and for freeing expensive hospital beds from incurable patients.

## Activities

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- a. Plan and allocate Budget for collaborating with the existing WHO Collaborating Centres in Palliative Care in the country for the required training
- b. Identify centres which may be promoted as Regional Resource Centres for Palliative Care with necessary capacity building inputs
- c. Identify the pool of master trainers based on regions, from different regions of the country to undergo TOT<sup>30</sup> program. They would be made available for regular capacity building workshops at the above organisations and government training programs.
- d. Identify settings, contents, transactional tools and budget for the TOT programs and for their subsequent utilisation.
- e. Design the details of capacity building workshops for different levels and disciplines

*There would be two levels of training. The essential training in pain relief and palliative care would be for 3 days at the identified training hubs and the other in depth residential training for 6 weeks in pain relief and palliative care would be made available at the approved centres of excellence*

The activities under each of section of existing National program are discussed below

## Through the NPCDCS Cancer Program

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Plan and allocate budget for infrastructure, training and personnel for Palliative Care Wing within the region based finite number Cancer care centres; 25 RCCs and 125 medical college based services(Oncology Wings), identified through the State Government [health department].

The aim is to bridge the gaps in infrastructure, capacity and drug availability. To facilitate creation of services, following strategies are recommended:

- a) Recognised Medical Institute [RMI] status (for the purpose of NDPS Act related to Morphine) would be mandatory for all RCCs
- b) All RCCs are to stock essential medications for pain relief and palliative care

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<sup>30</sup> Training of trainers

## Infrastructure

There is already provision proposed for palliative care wing with defined beds, Out Patient and home based care within the district, State and National Cancer Institute described in the Section 1 on Cancer of the 12<sup>th</sup> Plan on NCDs, in the National programmes for prevention & control of chronic diseases [Annexure 5 Content of incorporating palliative care within the NPCDCS for Cancer in the 12<sup>th</sup> plan for NCD by the MoHF W]

It is **recommended** that this may be implemented through defined infrastructure and facilitating trained personnel to provide care. Hence the following recommendations

- a. RCC – 2- 4 beds reserved / allocated specifically for palliative care and daily OPDs
- b. Cancer services within the government medical colleges – 4- 8 beds dedicated to Palliative care and twice a week afternoon OPD services
- c. Equipment for palliative care unit as per standards

## Personnel and Capacity building

- a. One qualified Palliative care physician with at least 6 weeks training from authorized centres, as regular/ contractual staff within the RCC. [TOR as annexure] *Ongoing clinical support through discussion group and visits of experts.*
- b. Specialist palliative care nurse on 1:3 ratio with number of patients with 6 weeks training as regular/ contractual staff within the RCC. Two counsellors appointed under the NPCDCS, would be specially trained for 6 weeks in palliative care 3 days training on essentials in pain relief, long term care and palliative care for all medical and nursing professionals of RCCs and within the cancer services of selected government medical colleges.
- c. 3 days training on essentials in pain relief, long term care and palliative care for district Surgeon, Physicians, Gynaecologist at the cancer services within District hospitals in conjunction with the training programs under the NPCDCS.

## **Through the DCS component of NPCDCS district program**

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Plan and allocate budget for infrastructure, training, personnel for Palliative Care Wing within the region based, finite number of institutions: under the co-ordination of the State NCD cells, for each year of the program utilising the approved centres of training.

State NCD cell also would plan for a systematic capacity building at all levels of health care delivery system through capacity building, infrastructural support and drug availability.

Infrastructure according to levels of care

- a) District hospital would have 2-4 beds dedicated to Palliative care and develop capacity for twice a week afternoon palliative care OPD services
- b) Government medical colleges should have 4-8 beds dedicated to Palliative care and have afternoon twice a week palliative care OPD services
- c) Community health centre are to have palliative care OPD services and home based services at least three times / week within an area of 25 kilometres around its radius and also empower families to care for the patient through IEC.
- d) Primary health care would coordinate the referrals of patients requiring palliative care support and also empower families to care for the patient through IEC through the senior Health Assistant.

### **Personnel requirement on regular / contractual basis**

- a) District hospital- 1 trained palliative care physician and specialist nurses at 1:3 ratio to number of patients with at least 6 weeks training within the approved training centres
- b) Government Medical College- 1 trained palliative care physician and 2 specialist nurses with at least 6 weeks training within the approved training centres (already described in cancer component for 50 such medical colleges)
- c) Community health centre, Primary health centres utilises the existing personnel deployed under NPCDCS and NPHCE programs

### **Recommended Trainings for Palliative care:**

- a) 6 weeks training from the approved centres for palliative care physician and nurses
- b) On-going clinical support through discussion group and 4 visits over 6 months period by trained faculty from WHO CCs and approved centres [Annexure -6 and 12]
- c) 3 days training on essentials in pain relief, long term care and palliative care would be included within the training programs for all doctors as per the NPCDCS [Ref: 2.3.4 C] and National Program for Health Care of the Elderly
- d) 3 days training on essentials in pain relief, long term care and palliative care would be included within the training programs for nurses as per the NPCDCS [Ref: 2.3.4 C]
- e) 3 days training on essentials in pain relief, long term care and palliative care would be included within the training programs for counsellors as per the NPCDCS [Ref: 2.3.4 C]
- f) Training of the senior Health Assistant at the PHC for providing IEC

**Brief training programs would be integrated with on-going training programs of national programs and separate focussed training for palliative care as notified from time to time in different settings.**

### **Through the National AIDS Control Program [NACP]**

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NACO envisions an India where every person living with HIV has access to quality care and is treated with dignity. It has been committed to containing the spread of HIV in India by building an all-encompassing response reaching out to diverse populations. This has been very successful as evidenced by the declining incidence and mortality from the disease. NACO is built on a foundation of care and support, and has always been committed to consistently fabricate strategic responses for the requirements of HIV/AIDS situation in India.

NACP-III integrated with various development programmes like the National Rural Health Mission (NRHM), Reproductive and Child Health (RCH) programme and the Revised National Tuberculosis Control Programme (RNTCP). The focus of all these programmes was prevention of HIV transmission.

With the advent of anti-retroviral therapy, India's policy of universal access to HIV treatment and the free ART rollout in 2004, HIV has gradually moved from being a terminal condition to largely a chronic one. Thus, the numbers requiring end of life care have come down in the last decade. It is evident now that anti-retrovirals have transformed lives of huge number of people with HIV. Yet, late diagnosis and late entry into the treatment loop, creates situations of severe morbidity causing significant

distress and disruption of daily living, where pain and symptom control become critical. Even when a person is on anti-retrovirals, side effects such as severe anaemia and the pain and symptoms caused by it, peripheral neuropathy and the disruption of daily living due to it, can be addressed through palliative care interventions.

Palliative care, thus, is a part of HIV continuum of Care as the WHO guidelines elaborate, palliative care is an integral aspect of HIV care for people living with HIV because of “the variety of symptoms they can experience - such as pain, diarrhoea, and cough, shortness of breath, nausea, weakness, fatigue, fever, and confusion”. In individuals with severe wasting, reactions to drugs for opportunistic infections also require supportive management. In terms of pain management, the protocols used in cancer and other non-communicable diseases can be extended to HIV and the use of WHO Ladder for Pain Management is recommended. At the community level, lack of palliative care is a reality that needs to be addressed as this places an unnecessary burden on hospital or clinic resources (WHO). The National Program for Palliative Care is committed to meet critical unmet needs in HIV Care systematically.

All the care providers involved will need to get oriented to the communities from which many HIV affected people come, including sex workers and sexual minorities. Negative experiences of care, especially in the initial interactions can discourage them from all further contact with the service; therefore care providers need to be sensitised regarding the fundamental principles of NACO on patient care policies. This background call for a wider choice in service setting and support systems. The National HIV programme has always taken cognizance of this and engaged with the social capital of these communities to reach out to them. Palliative Care services designed through the NPPC would be in alignment with this approach and keep in mind these vital human resources and would include them in the capacity building plan.

While on one hand care providers who are going to be providing palliative care services need to be oriented to these issues, there is also a substantial pool of human resources within the HIV sector itself, in the form of outreach workers, counselors, peer counsellors doctors and nurses who are currently focused on early detection and early linkage with treatment. With appropriate training on basic principles of palliative care approach, they can be developed into useful resource persons in improving the quality of on-going care and also support delivery of palliative care services. Given their understanding of the contexts of the affected people, they will be best equipped to make sensitive responses, and handle issues of stigma and discrimination.

Overall, the plans designed for the Cancer Palliative Care can be extended to the HIV palliative Care services. This calls for coordination between NPPC and NACO. The Palliative Care Training to health care providers (doctors, nurses, and ward attendants) under NPPC would be extended to the NACO resource personnel to help to address the gaps: end of life care, pain beyond the physical (psychological, social and spiritual) care of HIV patients and their family. Counselling resources at ICTCs<sup>31</sup>, ART and Community Care Centres are already involved in care of psychosocial need of HIV patients and hence the concept can be comfortably integrated within the system.

It is envisioned that all the technical training programs through NACP should include PC component. The Care & Support centres budget, MIS and monitoring systems shall incorporate focus on palliative care. The Technical Resource Group [TRG] of the NACO care and support wing shall include at least two Palliative care experts and officials to discuss strategies and policies for incorporating availability and access to pain relief and palliative care for HIV/AIDS patient care seen through NACO centres. Incorporation of the required educational material on palliative care service delivery within the guidelines and training modules of the NACO training manual for the health care professionals<sup>32</sup> would be done as collaborative activity.

In addition to what has been envisioned for Cancer Palliative Care, the capacity building for HIV Palliative Care would extend to training of counsellors and peer counsellors in TI programmes and Care and Support centres and community volunteers.

Confidentiality and sensitivity to disclosure of status issues are critical components that need to be integrated into the palliative Care training when addressing personnel working predominantly in the area of HIV / AIDS as well for NRHM service providers as well as volunteers.

### **Sub activity- outside the purview of NPCDS and NACO programs**

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This is completely focused on capacity building of teams coming forward from health care institutions of the country, from any sector, through training from the approved centres utilising the master trainers. This is envisaged to be a collaborative venture involving the identified Centres of excellence [the two WHO CCs], Indian Association of Palliative Care [IAPC], other national medical and nursing associations [Indian Medical Association, Association of Radiation Oncologists of India, etc.] and the MOHFW.

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<sup>31</sup> Integrated Counseling and Testing Centres

<sup>32</sup> This would be done in collaboration with the WHO Collaborating Centre for Training and Policy on Access to Pain Relief [Trivandrum]



Training should be on essentials in pain relief and palliative care for 3 days with an option to 10 days of practical exposure at the approved centres.

### *Summary of activities*

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1. Identifying the stakeholder agencies
2. National workshop with stake holders
3. Identify TOT personnel, centres, contents, course material, plan of each program with budget
4. Training manual with modules for each setting and level inclusive of knowledge and skills required to provide pain relief and palliative care as well as information regarding how to access required medications and avoiding diversion and misuse.
5. Send directive for the state health and excise departments regarding the policy decisions and guidelines from the Department of Revenue and Ministry of Health and Family welfare
6. Finalise the list of RCCs, medical colleges, district hospitals and other centres participating in the training through this program for each year through collaborative effort between MOHFW and the concerned state bodies.
7. Send directive for the institutions identified for IEC, collaboration, training and services from the Department of Revenue and Ministry of Health and Family welfare
8. Identifying and grouping states within a region for the workshops
9. Contents and modules for the state level workshops
10. Contents and modules for facilitating palliative care wings within RCCs and medical colleges with cancer care program.
11. Contents and modules for ART centres and care/support centres.
  - a) Contents and modules for general practitioners
  - b) Plan and allocate budget for IEC in sensitisation programs and for conducting regular training programs for health care professionals
  - c) Planning IEC through the associations and organisations for sensitisation of professionals from different specialities and sectors.
  - d) Design the IEC material for sensitizing professionals through collaborative workshops.
    - a. For example Poster - "Treat That Pain" along with the WHO Ladder for pain control, as a poster
    - b. Production of a training tool [video] designed by the expert committee as an IEC tool on basics related to the field of palliative care. This may be used for sensitisation to professionals in all sectors e.g. during professional CME meetings of National associations such as IMA, AROI etc as well as those for nursing.
    - c. Evolve web based learning programs with evaluation and certification in collaboration with WHO CCs Thiruvananthapuram and WHO CC Calicut – This may be linked to clinical practice exposure for 10 days.

- e) Identify Centres of training and the master trainers that would be utilised for the trainings.
- f) Fix the time frames and the details of the training program for the year.
- g) Solicit certification for the course by universities and –examination boards.
- h) Aim for defined number of medical and nursing professionals for training per year e.g. 50 participants / batch; at least 1 workshop / month at each of the identified centres [10-12] for 3 days each. Details - number of attendees, periodicity, trainers, tools, transactions
- i) External funded ad hoc projects and activities may be considered according to merit as joint collaboration with the MOH FW and the state governments
- j) Other activities that may need to be initiated for creating awareness and for changing the attitudes

## Objective 2

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### **Refine the legal and regulatory systems and support implementation to ensure access and availability of opioids for medical and scientific use while maintaining measure for preventing diversion and misuse**

#### **Strategies**

1. Ensure alignment of India's Central narcotic drug regulations with the UN Single Convention on Narcotic Drugs, 1961 through amendments in relevant sections of the NDPS Act, ensure uniform and simplified regulations pertaining to opioids for pain relief throughout the country and modifying NDPS Rules suitably.. This to include appropriate provisions to ensure cost control and peripheral reach as per the primary health care mandate<sup>33</sup>
2. Build capacity at state level, to absorb and translate the modifications in the NDPS regulations for ensuring availability and accessibility to opioids for medical use within respective states.
3. Recognise the institutions as per the provisions of Recognized Medical Institutions (RMI) as well as facilitate the development of more [RMI] as a channel for ensuring availability and accessibility to opioids for medical use along with preventing diversion and misuse
4. Evolve mechanism of assuring uninterrupted availability of opioids through the SOPs of the RMI while assuring prevention of diversion and misuse
5. Facilitate mechanisms for appropriate implementation of the NDPS Rules in the state and monitoring mechanisms by the state level committee, to ensure adequate supply of affordable opioids for medical and scientific use to the peripheral RMIs while assuring prevention of diversion and misuse.
6. Empower primary health care institutions to achieve the RMI status so as to stock and dispense opioid medications for medical and scientific use as per the National List of Essential Medication<sup>34</sup>
7. Institute measures for community education about concepts, safety aspects and access to pain relief measures.

#### **Activities/Sub-activities:**

1. Amendment of NDPS Act to incorporate medical and scientific use within its scope and thus "ensure balance" within the Act, as per the UN Single convention 1961

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<sup>33</sup> Primary Health Care is the essential health care based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible to individuals and families in the community through full participation and at a cost that the community and the country can afford to maintain at every stage of the development in the spirit of health determination. Alma Ata 1978

<sup>34</sup> . The Essential medicine List has a 'core' list and a 'complementary' list. The complementary list comprises of essential medicines for priority diseases, for which specialist training is required. Strong opioids can be placed under the 'complementary' list mandating training for its usage.

- a. Submission has been made with details of the amendment needed in the Act, to make opioids available for medical use, by the National association of palliative care professionals.
- b. Members of the expert committee would support the Department of Revenue during consultative meetings
  - i. Communicate with policymakers and administrators on the need for “balance” within India’s narcotic drug law.
  - ii. formulate appropriate amendments and modifications within the regulations
  - iii. receive feedback from Indian and international pain policy experts to help ensure alignment with UN convention
2. Develop and implement systems for accurate estimation of requirement and of reporting the opioid consumption statistics
3. National workshop with stake holders including excise officials from state levels for dissemination of information on balanced regulations and transition to facilitate medical use
  - a. Two national level workshops to be organized in the first year after amendment and one workshop in every subsequent year
  - b. Proposed participation by about 125 – 150 officials in the workshop
  - c. Duration of the workshop would be of 1 day
  - d. Departments / organizations that would be represented are as follows:
    - (1) Central Government:
      1. Ministry of Health incl. DGHS/ DCGI
      2. Department of Revenue/Central Bureau of Narcotics
      3. Chief Controller, Government Opium and Alkaloid Factories
      4. Authority responsible for framing of medical curricula (MCI, NCI)
    - (2) State Governments:
      - i. Department of Excise (including Excise Commissioner, Principal Secretary Excise)
      - ii. Department of Health
      - iii. State Drug Controller/ FDA
      - iv. Representatives of Government Medical Colleges
    - (3) Members of Civil Society:
 

WHO CCs in the country & NGOs in the palliative care
4. Department of Revenue (DoR) to notify new regulations which shall also include SOPs to be followed by the concerned regulatory agencies at central as well as state levels [state government health policymakers, drug controllers, and those involved in delivering pain relief medications through government health system]; DoR and Ministry of Health (MoH) may consider bringing out a handbook / ready reckoner regarding the rules/ procedure

5. Conduct workshops in every state **by respective State Govts.** to ensure understanding of the modifications and smooth implementation of NDPS regulations to facilitate access to opioids for medical use
  - a. Two State level workshops may be organized every year after amendment
  - b. Duration of the workshop would be of 1 day
  - c. Departments / organizations represented:
    - i. State Governments:
      1. Department of Excise (including Excise Commissioner, Principal Secretary Excise and district level excise functionaries)
      2. Department of Health (including district hospitals)
      3. State Drug Controller/ FDA (including Drug Inspectors)
      4. Representatives of Government Medical College
    - ii. Members of Civil Society:
      1. WHO CCs in the country
      2. NGOs working in the field of palliative care

**Table -11 - Concepts to be addressed through the collaborative workshops by Departments of Revenue and Health at national / state levels**

1. Endorse World Health Organization Guidelines for management of pain.
2. Endorse the 'Principle of Balance' within Narcotic regulations as per the UN Single convention 1961 and its application for opioid medications
3. The purpose for uniform rules and protocols
4. The framework of drug control policy and administration in the country and information about prevalence of pain, need for relief from pain and checks to prevent diversion and misuse
5. Support government's efforts to obtain adequate personnel to administer drug control functions under the Single Convention.
6. Mechanisms to maximize patient access to opioid medications and safety norms
7. Identify blocks and weaknesses in the distribution system that lead to shortages.
8. Inform requirements from the health professionals to prevent diversion, legal requirements through safe practices and discuss any concerns
9. Open forum to address health professionals' concerns about prescription requirements and fears regarding regulatory measures.

6. Have systems in place at the office of the Drug controller within states
  - a. to grant the RMI status to the health care institutions based on the procedures comprehensively defined in the Central Regulations
  - b. Have SOPs for RMIs to cover possibilities of stock-out of opioids at the dispensing units especially that of immediate release oral Morphine tablets, i.e. RMIs to maintain a minimum stock of 20% of their annual requirement of immediate release Morphine as buffer at all times
  - c. Mandate maintenance of precise record of existing RMIs and all their transactions to ensure prevention of diversion and misuse
  - d. Regularise the appraisal mechanisms to ensure standards and prevent misuse
7. To ensure accurate estimation of opioid requirement for the country, create a computerised system for RMIs to report consumption statistics directly to the Narcotics Commissioner
8. Ensure dissemination of IEC materials containing information on WHO Ladder drugs and clarifications on misconceptions in both public and private health care delivery sectors to ensure universal reach of concepts. This may be as pamphlets with answered FAQs or as posters or laminated charts.
9. Ensure dissemination information on training opportunity in usage of strong opioids in both public and private health care delivery sectors to ensure universal reach of concepts
10. Support innovative concepts e.g. door-step education as per medical representative model, web based education programs, web site of MoH, IAPC & WHO CCs have a link to FAQs on opioid usage, interactive discussion group, helpline on issues related to Morphine etc.
11. Utilise the platforms and academic meetings or CME programs of medical associations to disseminate awareness focused on making pain relief available and accessible and the safe practices regarding the same
12. Design IEC material for public awareness regarding concepts of pain and right to pain relief

### **Objective 3**

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**Encourage attitudinal shifts amongst healthcare professionals by strengthening and incorporating principles of long term care and palliative care into the educational curricula (of undergraduate / postgraduate medical, nursing, pharmacy and social work courses)**

#### **Strategies**

1. Ensure reorientation of the undergraduate curriculum and selected postgraduate curricula of medical, nursing, pharmacy and social work colleges, in alignment with a palliative care and person centred model of care.
2. Build capacity of faculty in the respective fields so that the students learn and adapt the essential principles of palliative care and management of moderate to severe pain and symptom relief
3. Reorient the evaluation process inclusive of the theme of pain relief and palliative care within the specification table of examinations in respective fields
4. Escalate the number of centres offering MD in Palliative medicine
5. Create overarching models in the 1<sup>st</sup> 5 years of the program in collaboration with the respective council and universities, for overcoming the shortage of teaching faculty within the field during the initial period.
6. Encourage employment opportunities for the trained professionals within public sector [as part of the national program on NCDs etc.] and facilitated positions within the private sector through public awareness, IEC and RMI status requirements.
7. Enhance awareness amongst students through pro-active and stimulating IEC regarding clinical relevance, scope and information on opportunities for training in the field.
8. Encourage clinical and action research with appropriate resource support to enhance body of knowledge related to PC and strengthen the curriculum.
9. To enhance the quality of education and development of global standard of care, encourage national and international collaborations with relevant academic bodies and palliative care institutions.

#### **Activities**

1. Sensitize the MCI, NCI, PCI and the collegiums of universities regarding the relevance of PC within the present health care spectrum through national / regional workshops.
2. Promotion of faculty workshops through the Universities in each state with appropriate resources
3. Facilitate up-gradation of departments of selected institutions to have MD in Palliative Medicine
4. Activities to ensure adequate teaching of principles of palliative care

- a. Reviewing pre-service educational curricula to ensure that knowledge and skills required for essential NCD health care are “effectively” included in appropriate sections of healthcare and allied training programs
  - b. Find windows within the medical and nursing curriculum to convey chief concepts of long term and palliative care
  - c. Pool of master trainers to evolve the modules to support faculty workshop as well as conduct it
  - d. Teaching tools to support training and subsequent teaching of students
  - e. Conduct faculty workshop for capacity building in teaching principles of palliative care, inclusive of information on gaining access to essential medicines and preventing misuse or diversion
  - f. On-going clinical support through discussion group and 4 visits over 6 months period by trained faculty from WHO CCs
  - g. Faculty and staff positions to be posted on the web sites of MoH program sites and WHO CC sites
5. Plan and allocate Budget per activity

Annexure – 8 lists the suggested contents regarding the principles of Palliative Care that needs incorporation into undergraduate medical curriculum



**Table 12- Action Plan to incorporate principles of palliative care into the undergraduate and postgraduate curriculum of medical, nursing colleges**

Action Plan	Who	Out put	Outcome Measures	Time line from start of activity
Preparing and presenting the concepts for a preliminary session with MCI, NCI, Pharmacy and Social Work Councils	Faculty of WHOCCs, IAPC faculty pool	Contents for Slide presentation on the need for palliative care in the curriculum and the presentation	Decision by the councils regarding inclusion of Palliative care in The UG and PG curricula followed by Fixing the date and participants for a collaborative workshop for faculty training	One month to prepare the presentation  Making the presentation as per granted appointments
Collaborative Workshop for designing the sections of incorporation	PC Faculty with officials from Medical and nursing Councils  Core group Faculty from the university colleges	Re-orientation of curriculum incorporating Palliative Care principles as part of the UG. / PG curriculum  Choosing the PG specialties to incorporate	Steering committee formation Defined slots within each of the curricula Themes of modules required Allocation of modules for content creation amongst faculty Budget Dates of review workshop for content finalization	Within 4 months from the 1 <sup>st</sup> meeting
Collaborative Workshop for finalizing the transactions required	Steering committee along with invited palliative care professionals	Presentation and finalization of contents for the UG and PG Curriculum by the core group	Handbook of Course material for the faculty workshop Preparation of Directives to the colleges Timetable for the faculty workshop Quarterly / year	Within 8 months of 1 <sup>st</sup> meeting
Identifying training centres and faculty pool for each centre	University registrar with the steering committee	Meeting with the administrative heads of institutions	Identified centres List of faculty pool members	10 months from beginning
Directives to the colleges	University registrar	Enrollment of colleges	List from colleges with names of faculty to be trained / session	12 months from 1 <sup>st</sup> meeting
To begin the training activity as per timelines in table				

## Objective 4

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### **Promote behaviour change in the community through increasing public awareness and improved skills and knowledge regarding pain relief and palliative care leading to community initiatives supporting health care system**

Health is on one hand a highly personal responsibility and on the other hand a major public concern. It involves the joint efforts of the whole social fabric viz. the individual, the community and the state to protect and promote health<sup>35</sup>.

### **Community responsibility**

Health can never be adequately protected by health services without the active understanding and involvement of communities whose health is at stake. The average duration of contact of the person with the qualified doctor / nurse is minimal; usually around 10 minutes during each admission or during outpatient visits with an interim period of weeks to months without any trained support. The needs of patients with chronic disease are throughout; from diagnosis onwards up to dying phase and for the family it extends beyond that.

Human beings are capable of supporting each other. Most of the communities still retain the ability to work together for common causes or for other people in or outside the community. Until recently, people were neglected as a health resource; they were viewed merely as sources of pathology and as target for preventive /therapeutic services. Crises are valuable opportunities for empowerment. Life threatening illness and dying in the community have a huge potential to act as the entry point to empowerment and building /enhancing social relationships as the problem is universal and visible. Community participation in the care of the incurably ill, elderly, bed ridden and dying people can bring solace to millions of people and also act as a powerful medium for empowerment.

Another recent trend in health care is self- care. It is defined as “those health generating activities that are undertaken by the persons themselves”. The generic attribute of self -care is its non-professional, non-officious, non -industrial character and it has a natural place in social life. The shift in disease patterns from acute to chronic makes self-care both a logical necessity and an appropriate strategy. In India, with the advantage of close knit family system, self-care involves mean to include both the patient and the family as a cohesive unit. Observing simple rules of behaviour can maintain positive healthy states. Teaching patients/family units more about preventing, detecting and handling health related concerns would tremendously add value to on-going care and reduce the burden on the official health services.

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<sup>35</sup> K Park, Park's Text Book of Preventive and Social medicine, 21<sup>st</sup> Ed, Pg 22-24, Banarsi Banot, Jabalpur, India 2011

One of the challenges before health care workers in low and middle income countries [LMIC] is to develop a culturally and socio-economically appropriate and acceptable system for long-term and palliative care, accessible to most of those who need it. This can be possible only if the service is part of a community based primary health care system using local manpower and resources. Palliative care has much to gain from the trend of involving communities in a meaningful manner. There are three ways in which a community can participate (i) the community can participate in the shaping of facilities, manpower, logistic support and funds (ii) it can be actively involved in planning, management and evaluation and (iii) people can participate by utilisation of services<sup>36</sup>.

Participation by an empowered community can address the issue of suffering at the end of life care in a big way. It can help people living and dying with dignity. Less than 15% of people die suddenly. Most of the others die after a period of illness and debility. It has been estimated that less than 2% of these people in India have access to palliative care which can relieve suffering at the end of life to a great extent. This is mainly because the existing institution based models of care have their limitations in quality, coverage and affordability of care. Death and dying have become issues associated with hospitals causing disempowerment of the communities to intervene.

Social experiments with the above theme in palliative care in recent years in Kerala have demonstrated that it is possible to improve the quality of life of incurably and terminally ill people through empowerment of local communities. Neighborhood Network in Palliative Care (NNPC), a community owned program in Kerala, India, is a project that evolved out of a series of 'need based' experiments in the community. Essentially, NNPC aims to empower local communities to look after the chronically ill and dying patients in the community. It follows the concept of primary health care described by the World Health Organization in the Declaration of Alma-Ata<sup>37</sup>. In this programme, volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively, with active support from a network of trained professionals<sup>38</sup>.

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<sup>36</sup> Djukanovic V, Mach E P(1975)Alternative approaches to meeting basic health needs in developing countries, A joint UNICEF/WHO study

<sup>37</sup> "Primary health care is essential health care based on appropriate and acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost the country and the community can afford, to maintain the spirit of self-reliance" (World Health Organization 1978)

<sup>38</sup> Kerala now has more than 200 palliative care services run by local community based organisations, each one of them owned and supported by the local community and organised in a decentralised manner. More than 15,000 patients and families benefit from this initiative at any point of time

The activities by the communities led the State Government to eventually acknowledge the importance of the pain and palliative care services and declare a state Pain and Palliative Care Policy in 2008; the only government in the country to have declared a policy in Palliative Care.

National Rural Health Mission palliative care project has been instrumental in facilitating the implementation of palliative care in Government Sector as per the guidelines in the policy. Local Self Government Institutions (LSGI) responded in a very positive and dynamic way to the Government of Kerala's directive to take up palliative care activities at the local government level. Kerala now has more than 650 LSGI with palliative care projects. More local governments are expected to take up palliative care projects this year<sup>39</sup>. Most regions in Kerala have coverage of more than 50% as against the national coverage of less than 2%.

### **Strategies**

1. Support incorporation of palliative care within the community health care and the primary health care system by the state government to bring it close to people
2. Have a mechanism in place to link the peripheral units with higher centres of palliative care (Palliative Care wings in the CHC, district hospitals and cancer centres)
3. Promote awareness amongst public and policy decision makers regarding the scope of pain relief and palliative care services
4. Collaborate with NGOs to act as technical advisory agencies for the process of community awareness, mobilisation and empowerment in the field of palliative care programs. E.g. WHOCC – Calicut and WHO CC - Thiruvananthapuram
5. Empower the palliative trained staff at the CHC and 'senior health assistant' at PHC in selected districts to orient and educate the family carer in providing home based care
6. Empower community and family participation in continued care for the patient through structured care & support educational activities
7. Support community empowered initiatives in identified regions in the country which fulfil following criteria
  - a. a state government and the community acknowledging unmet need and willing to develop the services for palliative care as a priority
  - b. presence of adequate service providers and leadership in the field
  - c. community already participating actively in policy matters as reflected in the on-going civil society activity in health / development
8. Ensure involvement of the Local Self Government Institutions through sensitisation workshops for the members
9. Ensure active support from the media

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<sup>39</sup> 850 of the 925 palliative care units in India are in Kerala

## Activities

1. Train doctors and nurses from public health care system in palliative care as per objective 1
2. Plan and allocate budget to support awareness campaigns regarding the scope of pain relief and palliative care
3. Design IEC, course modules and manuals for sensitisation and training programs for general public
4. Initiate pilot program in 100 districts.
5. Incorporate palliative care in the responsibilities of ASHA in the selected districts. Establish a scheme for remuneration of ASHA. Link up the trained ASHA with trained volunteers in the area
  - a. Formulate three month course for ASHA in Community Palliative Nursing. The existing course material for three month course in Kerala can be modified and used
  - b. Link up the ASHA led, community involved palliative care with existing primary health care system in the district.
6. Select districts according to the guidelines mentioned in strategy for proceeding with activities related to community empowerment programs. Steps of the process in the Kerala Model is shown in the table below

<b>Table 13 - The Process Of Community Empowered Initiatives - the Kerala NNPC model</b>
Use existing civil society organisations [CSO] and facilitate the formation of new CSOs
Generate structured sensitisation and training programs for lay person in the community
<b>Step I: Sensitisation:</b> Get those who are likely to be interested to an awareness meeting / discussion. Make sure that all the groups / organisations involved in social / health care activities in the region are invited. Explain the issue of incurably ill / bed ridden patients in the region. Discuss possible way to help them. Register those who are willing to spend a couple of hours every week for such patients as volunteers.
Step II: Train those who are willing to get trained in basic nursing care and communication skills / emotional support. Get them to document the problems of bed ridden / incurably ill patients in their neighbourhood (Use a proper template -the community volunteers protocol). Discuss solutions in the group. Initiate a social support program. Start collecting money, manpower and other resources. Link with the nearest palliative care unit if one is available.
Step III: Get the services of a nurse. Encourage the nurse to get trained in palliative care. Initiate nurse led home care programs. <b>ASHA can be given three months structured training and used as the key professional in palliative care in the community</b>
Step IV: Get help from a local doctor in medical issues. Encourage the doctor to get trained in palliative care.
Step V: Initiate Outpatient clinic / Inpatient services with the trained doctor and nurse
Step VI: Continue with steps I and II

## Supportive activities

- One or two consultants at central level to coordinate planning committee and implementation of the palliative care related IEC program plan.
- Core planning committee
- Content and creative development for pamphlets; workbooks; video; and for all other activities as needed. Target 4-5 regions of the country to get visuals that can be used across the board.
- Creation of video that highlight need of PC in India
- Creation of video that discusses what patients can do
- Printing of materials
- Buy air time for PSAs on Doordarshan during prime time
- Funds for mass media airtime in states that have medium level of PC services established
- Develop and conduct workshops in medical and para-medical colleges. [allocate HR either as consultant, grant to NGOs, or other arrangement]
- Develop and conduct workshops for govt health sector. [allocate HR either as consultant, grant to NGOs, or other arrangement]
- Develop training content and pilot for self-help groups, ASHAs, ANMs, and Anganwadi workers. [allocate HR either as consultant, grant to NGOs, or other arrangement]
- Sensitize healthcare professionals in private and public-private health facilities. [allocate HR either as consultant, grant to NGOs, or other arrangement]
- Conduct awareness programs and trips to PC centres for regulatory and administrative nodal officers in each state. [funds for program, travel, and HR to conduct such programs]

## Objective 5

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### Encourage and facilitate delivery of quality palliative care services within the private health centres of the country

#### Strategy

- Encourage higher quality of care, standards, policies, requirements and accountability of health delivery institutions through provisions of the 'Clinical Establishment Act'
- Inspire private sector health delivery systems to incorporate palliative care services through awareness, educational activities and regulatory/accreditation requirements
- Influence Accreditation Boards for hospitals, NABH<sup>40</sup> to develop policies with emphasis on improved quality of care and patient satisfaction with incorporation of long term care and palliative care components.
  - a. make RMI status mandatory for accreditation so as to facilitate incorporation of the concept into non-governmental health delivery systems
  - b. Emphasise requirement of 'an implemented hospital pain policy and end of life care'
  - c. Facilitate continued care in through standards for home discharge inclusive of family education on further home based care through care and support booklets.
- Create inroads into the private sector through collaboration with national associations [e.g. IAPC, IMA, ISSP, ISCCM, AROI etc.] for IEC
- Strengthen and popularize on-going fellowships, six-week courses, and basic certification course conducted by WHO CCs, Medical colleges and IAPC
- Support initiatives by WHO CCs and NGOs with experience in training students / professionals and facilitating community owned initiatives in long term care and palliative care.
- Centre and state led health insurances may reorient their reimbursement plans for supportive, rehabilitative care, and pain relief.
- Encourage private insurance or work place sponsored reimbursement plans to cover preventive/ promotive and palliative care services
- Make available the identified training centres within the region for conducting academic programs.

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<sup>40</sup> National Accreditation Board for Hospitals

## Activities

- Activate public-private partnerships to upscale access to palliative care across the health system
- IEC program for administrators and decision makers of major private medical institutions with cancer wing and chains of multispeciality hospitals in collaboration with professional bodies and WHO CCs.
- Sensitize the Insurance Regulatory and Development Authority of India [IRDA] to raise proposal for coverage of PC interventions as, high out of pocket spending and the insufficient financial protection is one of the major barriers to access this essential care.
- Palliative Care IEC video for general awareness, sensitisation and relevance to practice during conferences by identified professional bodies – IMA, speciality associations like AROI<sup>41</sup>, ISSP<sup>42</sup>. The aim would be to enrol professionals into the on-going training programs
- Activities that emphasise respect for the rights of cancer patients and survivors, AIDS patients, patients with NCDs and all others dealing with long term, life-threatening diseases and life-limiting conditions

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<sup>41</sup> Association of Radiation Oncologists of India

<sup>42</sup> Indian Society for Study of Pain



## Objective 6

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### **Develop Standards for Palliative Care services and continuously evolve the design, and implementation of the activities**

#### **Strategy**

1. Have a mechanism in place to monitor, supervise, and evaluate the strategies and activities while expanding access to palliative care and pain relief across the country – through effective governance of the program
  - a. Periodic, time bound monitoring and evaluation at state level that would provide feedback into the system in order to fine tune it and improve efficiency and impact. This would be through a method of coordination, agreeing on a general framework for monitoring (including common indicators), compiling States report on progress and organizing a yearly meeting at which the progress made and experiences of States would be compared.
  - b. Plan and allocate budget for operational research in this field as PC is definitely an area where piloting activities are necessary to study how best practices and solutions for specific groups and situations, as one approach or solution can not fit all
2. A comprehensive monitoring and evaluation framework for the program would be established for this purpose as per the WHO 2007 guidelines within 6 months of the National Steering committee formation
3. Evolve a mechanism to comprehend palliative care needs from each region
  - a. elicit reflective data on morbidity due to chronic diseases that is relevant in understanding need and to designing emphasis of palliative care programs<sup>43</sup>
  - b. Incorporate “number of bedridden patients per family” as one of the survey information to be collected during the ‘National Family Health Survey’ [NFHS] and the District Family Health Survey [DFHS] of India.
  - c. Encourage a regional network of surveillance and burden assessment to improve national capacity through knowledge sharing and experience exchange
4. The mandate for adequate pain relief and palliative care would be incorporated into the set of standards by the National Council within the Clinical Establishment Act<sup>44</sup> by including experts of palliative care into its consultative process

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<sup>43</sup> e.g. Health Adjusted Life Expectancy [HALE] and Disability Adjusted Life Year [DALY] as measure of lost time of healthy life and reflects burden of disease

<sup>44</sup> Clause(i) subsection(1) section 12. The National Council has been notified under the Act under the Chairmanship of DGHS. It has members from all councils like MCI, CCIM, Central council of homoeopathy, Indian Nursing Council, Pharmacy Council, Paramedical systems, Zonal council, North Eastern Council, IMA, BIS, AYUSH association, Consumer groups and QCI.

5. Establish 'Minimum standards' within the recommended models of clinical care, for a degree of consistency in practice, standardized protocols and treatment guidelines.
6. Create regional education and training capacity to complement the national needs for human resources in order to improve both staffing and skill levels
7. Quality control in the drug sector in India through Central Drugs Standard Control Organisation [CDSCO]<sup>45</sup> for safety, efficacy, quality, criteria for import, manufacture, distribution, sale and standards<sup>46</sup>.
8. Establish systems in place for outcome assessment and evolve performance improvement strategies
9. Utilising the regional health technology assessment institution of the NCD program to collect information on the comparative effectiveness of interventions NPPC
10. Re-orientation Health Management Information System [HMIS] for long term care that allows collation of data without loss to follow-up. The 11th Five-Year Plan for NCDs includes development of a comprehensive national health information system, integrating information from various reporting elements and including systematic monitoring and evaluation. Ultimately, this system could be further improved to maintain the quality of information available for policy decision-making.
11. Collaborating on group purchasing of essential medications to assure quality, increase their access and affordability
12. For neutrality of inputs, autonomous bodies may be involved in this process<sup>47</sup>

## Activities

1. Establishing a mechanism at the State level to assist in the monitoring of quality of palliative care provided – as described under the section on governance
  - a. Constitution of a model steering committee [chairman – state health secretary, member secretary – state nodal officer[technical person]; other stake holders [excise, revenue, drug inspectors, health] agencies and experts
2. Creative planning of activities inclusive of Local bodies
3. Develop and disseminate the palliative care standards for all levels [Annexure 9 - Clinical care standards for palliative care]  
A factual reporting system from peripheral functioning units to the governing bodies [Annexure 7 – Reporting system of Kerala State palliative care policy]

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<sup>45</sup> headed by the Drug controller General in the Directorate of Director general of Health Services [DGHS] office and State Drug Control Organisation headed by the Drug Controllers

<sup>46</sup> GOI 2007, Annual Report 2006 -07, Ministry of Health and Family Welfare, New Delhi.

<sup>47</sup> National / state health system resource Centre [NHSRC and SHSRC] which are autonomous . an e.g. for Karnataka is Karnataka Evaluation Authority

## SECTION C - Governance Structure and Processes

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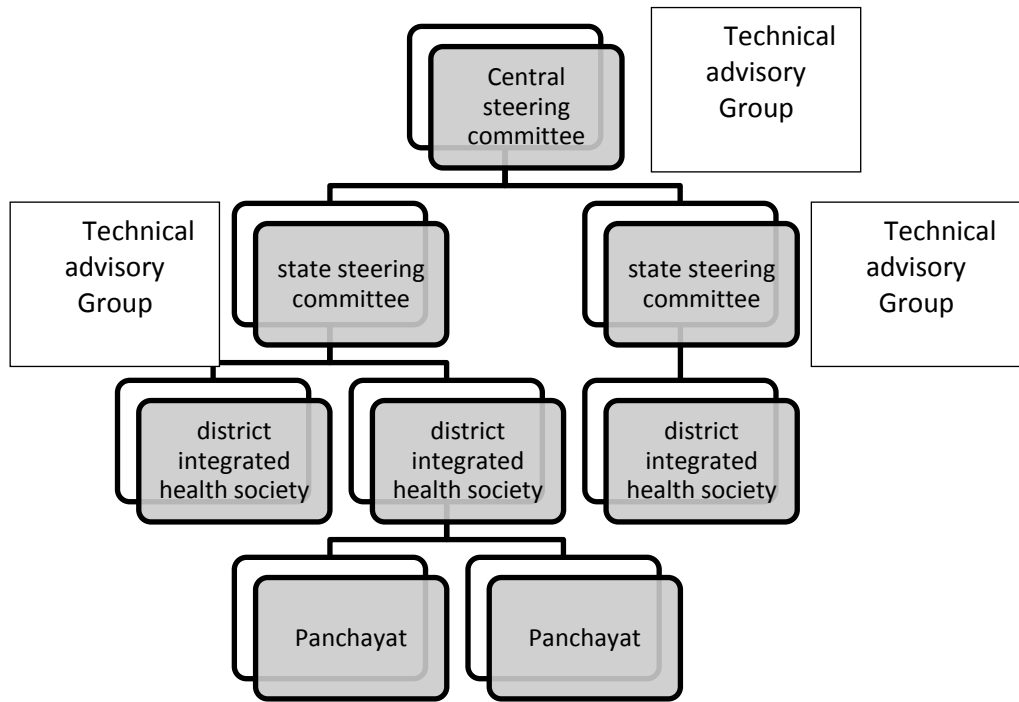
The constitution of India provides that health is a responsibility of the government. In India, health comes in the concurrent list with centre and state participating in its assigned capacities<sup>48</sup>. [Schedule VII of the constitution]

**The activities for palliative care would work essentially through the state governments.** In the case of Palliative Care, this would require sensitisation, awareness and wilful action from the health, excise and related departments of respective state.

To ensure successful implementation of the activities for Palliative Care within the states, there needs to be a clarity regarding the policies, resources and allocation of funds, so that the machinery and the available funds from the centre are channelled and utilised appropriately. Hence, as a central strategy would be to support evolution of a mechanism [a steering committee] at state level, to work in co-ordination with the centre that would initiate, facilitate and roll out the programs suitable and sustainable for all levels for that state and also provide the necessary feedback to refine the program further. To ensure that the introduction of the new program helps to strengthen the existing health care system and is 'mainstreamed', the existing health care system in each state needs to be taken into confidence. Hence the steering committee will be headed by the Secretary to the Government (Health) and supported by the heads of health services, medical education and state mission director of National Rural Health Mission. At the same time, since Palliative Care is relatively new area professionals with expertise and experience in this area of care also need to be part of the steering committee either as members of the committee or as members of the Technical Advisory Committee supporting the program. The strategy would include planning and allocating budget for conducting workshops for health, excise and related departments aimed to evolve state level palliative care steering committees.

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<sup>48</sup> The Directive Principles of State Policy, The Constitution of India: Part IV



**Structure of the Governing mechanism for Palliative care**

Table 14 - **Members and functions of the Governing mechanism**

<b>Functional Body</b>	<b>Members</b>	<b>Functions</b>	<b>Periodicity</b>
Central steering committee with office at MOHFW/ DGHS GOI	Chairman – Spl. DGHS + MoHFW officials, DoR officials, DCGI, NACO, experts, NGO representatives MCI, NCI, IMA representatives	Policy issues Program design Budgeting Internal co-ordination between departments within the government Oversight monitoring	Quarterly
State steering committee with office at State Capital health department	Secretary Health - chairperson Representative from planning and finance department Director of health services – member Secretary Director of Medical Education – Member State Mission Director, NRHM - Member Commissioner – excise Head of the NCD cell State drug controller SACS representative NGO representatives Health university representatives	Policy Design State plan Budgeting Internal co-ordination between departments within the government Oversight monitoring Liaison with central steering committee	Quarterly
District Health Society	District Collector as chairperson DHS, Nominated District nodal officer overseeing the program at district level District Aids Prevention Control Unit- officer	Policy related Internal co-ordination Oversight monitoring Liaison with state steering committee	Monthly

## *Monitoring and evaluation*

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There should be national Palliative care cell consisting of National program manager with 2 program assistants and 5 data entry operators. Similarly in states there would be one program coordinator along with a data entry operator provided under the program. This will be linked with NCD cell of NPCDCS with support of NRHM. Existing Management Information system of NRHM and/or NPCDCS would be utilised.

## *Monitoring and evaluation*

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The procurement and information processing would be within the existing norms of the NRHM in each state. This would need modifications within each of the national plan as part of the NRHM monitoring systems.

Once the Management Information system is ready, all personnel from PHC medical officer up to DPM Officer and district nodal officer and the state level functionaries would be trained on monitoring needs, using monitoring tools, evaluation and reporting.

## *Management information system*

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To fulfil the gaps existing in terms of data capture related to Palliative Care services delivery in the country, the current pattern of reporting from PHC → Taluk → District → state levels needs to be strengthened. The activity tracking can be designed to collate data in terms of gender, age, disease, out- patient or in patient settings. This would overcome the barriers and meet the challenge of acquiring adequate feedback and subsequent fine-tuning of the program.

The home based services could be considered as a pilot in select locations in the state with community support. In such instances, the Medical Information System would be suitably modified to include data related to these services provided outside institutions. Government Health Services in Kerala, the state with an extensive palliative care network, has evolved a reporting system for palliative care which can be adapted by other states also. Reporting system of Kerala State palliative care policy is attached as Annexure for reference.

Financial report would depict budget wise cash availability as well as utilisation of funds with the aim of total administration cost not to exceed 15% of total.

PC service component along with the data captured would be reviewed on a monthly basis at the Taluk and district level and on a quarterly basis at the state level. The state would provide the financial report to the centre at quarterly intervals per year. Centre would have bi-annual meeting along with the state nodal officers during the pilot period of five years for measuring, analyzing and discussing outcomes and effective monitoring during the 1<sup>st</sup> five nascent years.

Quality standards for all programmatic areas will be established as per recommendation of Technical Advisory Group. This would be used for measuring performance, analysing variances from defined norms, identifying bottle necks, alerting program managers and facilitating corrective measures.

## **Focus areas in the reviewing mechanism for monitoring and fine tuning the activities for Palliative Care**

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1. Tracking flow of overall funding
2. Effectiveness of the Program per state
  - a. percentage of funding utilised for administrative expenses not > 15 % of the total, and infrastructure [ need based only in the initial phase of the program
  - b. percentage of funding utilised for providing program expenses and for providing clinical services
3. Number of patients reached through the Palliative Care wings within the government sector
4. Number of home based care programs within the government sector
5. Trends in the opioid consumption data – as an indicator for pain relief services for moderate to severe pain
6. Accuracy of data for opioid estimation / consumption etc.
7. Mechanisms in place for allowing RMI status
8. Barriers to the program – non amended laws, non- cooperation between departments, lack of trainers, lack of enrolment to training programs, reasons for lack of access and non-availability of medicines

## **Indicators for effectiveness of the palliative care within states**

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- Number of state level multi sectorial workshop
- Number of States forming steering committee following the workshop
- Number of active state government owned action plans to initiation and flow of activities within the states
- Number of states utilising allocated central budget
- Number of states untying the required budget from state
- Number of RMIs
- Number of professionals trained in each region of the country through the identified training hubs – Nurses and doctors
- Number of staff positions in palliative care within RCCs, Medical colleges per state
- Number of Patients seen in department of palliative medicine – OP/IP/home-based
- Number of departments of Palliative Medicine within private sector
- Inclusion of RMI status as requirement by accreditation bodies
- Inclusion of supportive and home based services within the state and centre owned insurance bodies
- Regular clear data on Morphine consumption with a trend reflective of the estimated needs.



- Modified UG and PG curricula with inclusion of X number questions on pain relief and palliative care within the specification table of the qualifying examinations reflecting effectiveness of changes
- Number of faculty workshops conducted for university teachers
- Number of centres offering MD in palliative Medicine within the country
- Number of states with declared State Palliative Care Policy

### **Supportive policies**

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- Policy changes within Accreditation Bodies for active integration of chronic care and palliative care principles as requirement for quality of care by the institution
- National and state insurance bodies to review policies to support long term care inputs and palliative care inputs
- Indian Penal Code and MCI – to incorporate sections to clarify legal and ethical stand on the concepts regarding care of patients with advanced stage of disease for guiding decisions
  - terminally ill patients, rights of the patients with advanced disease, competent patient, informed consent, best interest decision for incompetent patient, surrogate decision maker, withholding / withdrawing life support, anticipatory decision making / living will, choosing / offering palliative care as an option in terminal stages
- Awareness campaign policy - Developing an communications & mass media policy for the country– for awareness of the concepts and decisions for different sections of the society and in complex situations

## **Interim actions**

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1. NDPS Act amendment and revised NDPS Rules
2. Directives to states and stake holders on policies through national programs and NACO
3. Training related
  - a. Identification of centres
    - i. Training hubs
    - ii. NPCDCS – cancer centres for each year
    - iii. NPCDCS – medical colleges for each year
  - b. Designing contents of IEC materials
  - c. Creating modules / manuals for each setting
  - d. Public awareness
4. Collaborations
  - a. WHO CCs
  - b. National associations
  - c. Civil society organisations
  - d. International agencies
  - e. Defining terms and purpose of collaboration
5. Curriculum related directives to the stake holders
6. Defining Minimum standards for each setting

## **Non - Governmental Organisations**

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Non-Governmental Organisations who can supplement and collaborate with the Government to help implement the palliative care programs would be of two levels of capacity.

1. Regional NGOs which have evolved in the background of a high level of palliative care activity in the area, formed by trained volunteers (Community Based Organisations – CBOs) who can supplement the existing programs with additional home care and or psycho social support to the patients. Government programs can also facilitate the formation of more such CBOs through community volunteer training programs. Formation of a platform to ensure proper exchange of information between the CBOs in palliative care and government palliative care programs can help shape relevant policies for the region and also in synchronising the delivery of care
2. Non-Governmental Organisations working in larger geographical areas. These can be NGOs with palliative care as their primary or major mandate or NGOs which are established in the area of health, development and social empowerment which are inclined, inspired by the vision to include palliative care activities into their mandate. NGOs already working in palliative care in the country have acquired considerable expertise and experience which can be used in establishing palliative care programs by the Government. Government machinery need to collaborate with NGOs in Palliative Care in areas of sensitisation and capacity building at the health care professional and community level, expansion of services and also in getting technical advice.

## Role of International Agencies:

Palliative Care is an area in which quite a few international agencies are keen to support national initiatives. The list of organisations with platforms and programs to help member countries with policy formation, evaluation of services and suggest improvements is given below. A well-defined National Program for Palliative Care will be able to make use of all of these possibilities.

<b>International Organisation</b>	<b>Supportive Mandates</b>
World Health Organisation	Provides Guidelines to countries Collaborating partnerships to support and facilitate the mandate to reach quality care and quality of life to patients
Pain and Policy study Group – WHO CC university of Wisconsin (USA)	Its mission is to improve global pain relief by achieving balanced access to opioids in an effort to enhance the quality of life of people living with cancer and other painful diseases. PPSG’s work, guided by a public health approach, aims to address governmental and regulatory environments governing professional healthcare practice relating to pain management, including barriers to legitimate access of prescription opioid analgesics that are essential for severe pain relief and palliative care. Such efforts are achieved through effective public policy, communications, and outreach efforts. The PPSG is nationally and internationally recognized for its work and leadership to improve availability of opioid pain medicines, having been at the forefront of such efforts since its creation in 1996, at which time it was designated a as a WHO collaborating centre.
International Association for Hospice and Palliative Care	IAHPC focuses on advancing palliative care programs, education, research and policies to improve the care provided to patients around the world. It supports programs, projects and individuals around the world, through bursaries and travelling scholarships especially in developing countries in Africa, Eastern Europe, Asia and Latin America.
International Atomic Energy Agency	The Programme of Action for Cancer Therapy (PACT) was created within the IAEA in 2004 to build upon the Agency’s experience in radiation medicine and technology, and enable developing

	<p>countries to introduce, expand or improve their cancer care capacity and services in a sustainable manner by integrating radiotherapy into a comprehensive cancer control programme that maximizes its therapeutic effectiveness and impact. Such a programme integrates and aligns cancer prevention, surveillance, screening and early detection, treatment and palliative care activities and investments, and is set up based on the Guidelines of the World Health Organization (WHO). It also addresses other challenges such as infrastructure gaps and, through partnerships, builds capacity and long term support for continuous education and training of cancer care professionals, as well as for community-based civil society action to combat cancer</p> <p>The IAEA's human health activities give top priority to the curative and palliative treatment of cancer and the establishment of comprehensive quality assurance programmes</p>
<p>Indo-American Cancer Association(IACA)</p>	<p>The Indo-American Cancer Association is an organization of cancer specialists of Indian Subcontinent heritage with a mission to advance cancer care wherever its members live.</p>
<p>The Worldwide Palliative Care Alliance(WPCA)</p>	<p>The Worldwide Palliative Care Alliance(WPCA) promotes universal access to affordable quality palliative care through the support of regional and national hospice and palliative care organisations. The WPCA is a global action network focusing exclusively on hospice and palliative care development worldwide. Its members are national and regional hospice and palliative care organisations and affiliate organisations supporting hospice and palliative care.</p> <p>WPCA's vision is a world with universal access to hospice and palliative care and its mission is to foster, promote and influence the delivery of affordable, quality palliative care.</p> <p>WPCA operate through work groups based in</p>

	<p>different national hospice and palliative care organisations around the world and support its membership to achieve their aims by developing quality and standards and organisation and association development. WPCA also work to tackle barriers at the international level to the development of hospice and palliative care through policy development and advocacy work.</p>
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**Note: The list of International agencies in Palliative care is indicative and not exhaustive and efforts would be made to take technical support from any of the agencies as appropriate and feasible in accordance with the Govt. of India guidelines in this regard.**

## List of Contributors

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The experts group on Palliative care constituted by Govt. of India has provided the guidance and material in the development of the document. Many experts and officials who are not member of the expert group have also been consulted. Some of the names are given below for their active support in development of the document:

<b>Sr. No</b>	<b>Name</b>	<b>Affiliation</b>
1	Dr M R Rajagopal	Chairman, Trivandrum Institute of Palliative Sciences, Pallium India, Trivandrum, Kerala
2	Dr Suresh Kumar K	Director, Institute of Palliative Medicine, Calicut, Kerala
3	Dr Nandini Vallath	Palliative Care consultant and HOD, Department of Integrative Oncology, HCG - Bangalore Institute of Oncology, Consultant Community palliative care program, SVYM, Mysore, Karnataka (co-ordinator of the sub group)
4	Dr Sushma Bhatnagar	Head of the Department of Anaesthesia and Palliative care, Dr. B.R.A. I.R.C.H. - A.I.I.M.S., New Delhi
5	Dr M A Balasubramaniam	Co-ordinator, Community Initiative in Palliative care and CEO Swami Vivekananda Youth Movement, Mysore, Karnataka
6	Dr Shalini Vallabhan	Trustee, Pallium India, Trivandrum, Kerala

**Names of the Government of India officials and WHO experts have not been mentioned but the support and guidance of the experts and invitees from GOI & WHO have been crucial.**

## ANNEXURES

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1. Government Order for constitution of the expert group on palliative care by the Ministry of Health & Family Welfare
2. NDPS Rules - 1998 Special provisions relating to the use etc. of Morphine by Recognized Medical Institutions
3. April 2006 Strategy document for palliative care: National Cancer Control Program, 11<sup>th</sup> five year plan – 2007- 2012
4. Integrated management of adolescent and adult illness : Palliative Care module ©World Health Organization 2004
5. Provisions for palliative care within the 12<sup>th</sup> plan for NCD
6. Approved centres of excellence in the country – WHO collaborating centres
7. Reporting System of the Kerala Palliative Care Policy
8. Principles of Palliative Care that need incorporation into Undergraduate medical curriculum
9. Draft of the Standards for palliative care services
10. List of Drugs for the special provisions of RMI
11. Details of allocation, consumption, etc. of Morphine Sulphate for the year 2010, 2011 & 2012.
12. Possible Resource and training centres in the country
13. Excerpts from NABH accreditation requirement relevant to palliative care
14. Figurative representation of the National Program for Palliative Care
15. Amended Rules [1999]in Kerala Narcotic Drugs and Psychotropic Substances Rules, 1985



**ANNEXURE – 1 – Government order for constitution of expert group on Palliative care by the ministry of health and family welfare**

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Directorate General of Health Services  
Nirman Bhawan, New Delhi 110011

5<sup>th</sup> July 2012

**ORDER**

**Sub: Constitution of expert group on Palliative Care; convening first meeting regarding**

It has been decided to constitute an expert group on Palliative Care. The composition and terms of reference of the TRG will be as follows:-

Members

1. Dr. S. Y. Kothari, Spl DG (Chairman)
2. Joint Secretary (D/o revenue) concerned with NPDS Act
3. Drug Controller General of India
4. Dr. M. R. Rajgopal, Director, Thiruvanthapuram Instt. Of Palliative Sciences
5. Dr. Sushma Bhatnagar, Prof. of Anaesthesia, IRCH-AIIMS
6. Representative of WHO country office India
7. Dr. Sudhir Gupta, Addl DDG (Member Secretary)

Terms of reference

- The committee would deliberate and develop contour/framework of the program on palliative care.
- Expert group will be operational for one year from the date of constitution. The group will meet as often as required. Sub groups may be formed as per requirement. Additional experts may be co-opted as invitees at the discretion of the chairman. However such invitees should not be more than 25%. TA/DA would not be paid to invitees.
- The expenditure for organizing the meetings of TRG including TA/DA of the members will be borne by and regulated-in accordance with instructions issued from time to time by Cancer Research section in the ministry under the supervision of Under Secretary (CR).

It has been decided to hold the first meeting on 10<sup>th</sup> July 2012 at 3.00 PM in room no. 439 A-I, Nirman Bhawan, New Delhi. You are requested to kindly make it convenient to attend the same. TA/DA may be drawn from source of salary.

Dr. Sudhir Gupta

Encl: background papers on palliative care  
To all members & invitees as per list

Invitees

1. Special Secretary (H)/ Joint Secretary (SG)/(AG)/ DDG (NCD)
  3. Mr. K. P. Krishnan, Rangarajan Committee on economic affairs
  4. Ms Shalini vallabhan, Pallium India
  5. Ms Tripti Tandon, Lawyer, Lawyers' collective, New Delhi
  6. Dr V Nandini, Palliative Care Physician, Bangalore
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## **ANNEXURE 2- Special provisions relating to the use etc. of Morphine by recognized medical institutions**

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### Special provisions relating to the use etc of Morphine by recognized medical institutions

1. Notwithstanding any provisions to the contrary in these Rules, possession, transport, purchase, sale, import inter-state, export inter-state or use of morphine or any preparation containing morphine in respect of a recognized medical institution shall be as per the following provisions.
2. Definitions –In this chapter, unless the context otherwise requires:-
  - i. 'morphine includes any preparation containing morphine
  - ii. 'Recognized medical institution' means a hospital or medical institution recognized for the purposes under this chapter facilities and . It is the responsibility of the institution so recognized to ensure that morphine obtained by them is used for medical purposes only.
3. Recognition of medical institutions:-
  - i. Every medical institution which intends to be recognized for the purpose under this chapter shall apply in the format at Annexure 1 to the Drug Controller appointed by the State Govt who shall convey his decision within three months of the receipt of the application.
  - ii. If it comes to the notice of the Drug Controller that morphine obtained by recognized institution was supplied for non-medical use or that any of the Rules under this Chapter is not complied with, for reasons to be recorded in writing, the Drug Controller may revoke the recognition accorded under these Rules.
4. Duties of Recognized Medical Institution:-

Every recognized medical institution shall

  - i. Designate one or more qualified medical practitioner who may prescribe morphine for medical purposes. When more than one qualified medical practitioner have been designated, one of them shall be designated as overall in charge:
  - ii. The designated medical practitioner or the overall in charge, as the case may be, shall-
    - a) Endeavour to ensure that the stock of morphine is adequate for patient needs,
    - b) Maintain adequate security over stock of morphine ,
    - c) Maintain a record of all receipts and disbursements of morphine in the format enclosed as Annexure 2. And
    - d) Ensure that estimates and other relevant information required to be sent by the recognized medical institution under this chapter are sent to the authorities concerned

### 5 Sending of Estimates of requirement of morphine by the recognized medical institution

Every recognized medical institution shall send their annual requirement of morphine in the format at Annexure III by 30<sup>th</sup> November of the preceding year along with the name and address of the supplier from whom they intend to buy it to the drug controller.

### 311 Approval of estimates by the Drug controller

Drug Controller who received the Annual requirement shall consider it, who may if necessary call for necessary clarification. A reply on approved estimates or not accepting the estimates shall be sent before 21<sup>st</sup> of December of the preceding year. A copy of the communication shall be sent each to the supplier whose name has been given in the estimate, if the supplier is located in another state, the Drug controller of that state, the Drug Controller General of India and the Narcotics commissioner of India

#### 7. Supplementary estimates:

If the requirement of the recognized Medical Institution exceeds the annual estimate approved by the Drug Controller, the recognized medical institution may send a supplementary estimate at any time to the Drug Controller which shall be considered and dealt with by the Drug Controller in the same manner as the annual estimates.

8. The provisions of these Rules in other chapters in respect of possession, transport, sale, import, inter-state export inter-state or use of manufactured drugs shall not apply to possession, transport, purchase, sale, import inter-state, export inter-state or use of morphine in respect of a recognized medical institution. Possession, transport, purchase, sale, import inter-state, export inter-state or use of morphine in respect of a recognized medical institution shall be in accordance with the following provisions:

- a) The recognized medical institution shall place orders for purchase to a manufacturer/supplier in the format at Annexure IV along with a photocopy of the communication of the Drug Controller vide which the institution was recognized for the purpose of this chapter and a copy of the communication of the Drug Controller vide which the approved estimates were conveyed. A copy of the order for purchase shall be sent to the Drug Controller and the Narcotics Commissioner of India.
- b) Any manufacturer or supplier shall send morphine to the recognized medical institution under this chapter only on the basis of an order for purchase received in the format of Annexure IV along with copies of recognition granted by the Drug Controller and the approved estimates communicated by the Drug Controller. The manufacturer/supplier shall dispatch the morphine consignment note in quintuplicate in the format given in Annexure V. Copies of the consignment note shall be sent by the manufacturer/supplier to the Drug Controller of the State in which the manufacturer/supplier is located, the Drug Controller of the State in which the recognized medical institution is located and the Narcotics Commissioner of India. He shall also keep a copy of the consignment note.
- c) On receipt of the consignment the medical institution shall enter the quantity received with date in all the copies of the consignment note, retain the original consignment note, send the duplicate to the supplier, triplicate to the Drug Controller, the quadruplicate to the Drug Controller of the State (in cases in which the consignment originated outside the State) in which the supplier is located and the quintuplicate to the Narcotics Commissioner of India.

#### 9. Maintenance of Records:-

All records generated under this chapter shall not be kept for a period of two years from the date of transaction which shall be open for inspection by the officers empowered by the State Govt. under sections 41 and 42 of the Narcotic Drugs and Psychotropic Substances Act.1985.

#### 10 Inspection of Stocks of Morphine

The stocks of Morphine under the custody of a recognized medical institution shall be open for inspection by the Drug Controller or any other officer subordinate to

him or the officers of other departments of the State Govt empowered under section 41 and 42 of the Narcotic Drugs and Psychotropic Substances Act 1985.

**312 Appeals**

Any institution aggrieved by any decision or orders passed by the Drug Controller relating to recognition, revocation of recognition of any institution or estimates any appeal to the Secretary, Department of Health of the State Govt. within 90 days from the date of communication of such decision or order.

**1998 Special provisions relating to the use etc. of Morphine by Recognized Medical Institutions – Annexure-1**

1. Name of the Institution and Address :
2. Name of the Head/In-charge of the Institution :
3. Number of persons employed :
  1. Doctors
  2. Nursing Staff
  3. Others
4. Number of patients treated during the previous calendar year :
  1. in patients
  2. out patients
5. Whether the hospital has facility to treat cancer patients : YES/NO
6. Number of cancer patients treated during previous calendar year :
  1. in patients
  2. out Patients
7. Name of the qualified medical practitioner who would prescribe :  
Morphine (If there is more than one qualified Medical Practitioner who would prescribe Morphine, indicate the name of the Medical Practitioner who would be overall in charge)

**313** Whether the institutions recognition for the purpose was withdrawn earlier (If the recognition was withdrawn earlier the details are to be given) :

Station:

Date :

Signature of the Head/In Charge  
of the Institution with Name

**1998 Special provisions relating to the use etc. of Morphine by Recognized Medical Institutions Annexure -2**

Record of Receipt | Dispensement and Balance of Morphine

Date

Qty in hand At the beginning of the day	Details of quantity received				Details of quantity disbursed				Qty in hand at the close of the day
	S.No	Qty	From whom received	Consignment Note/Bill or Entry number	S.No	Qty	Name of the person and address to whom disbursed	Name of the Medical Practitioner who prescribed	

Signature

Note

1. This record is to be maintained on day to day basis and entries shall be made for each day the institution functions. Entries shall be completed for each day before the close of the day. The authorized Medical Practitioner/In Charge or any person authorized by them shall initial after entry of each day with date. The pages of the register shall contain necessary number
2. This record shall be retained for 2 years from the date of last entry.
3. This record shall be produced to the authorized officers whenever called upon during the course of their inspection.

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1998 Special provisions relating to the use etc. of Morphine by Recognized Medical Institutions – Annexure -3

Estimate of Annual requirement

1. Name and address of the recognized medical institution.
2. Period for which the estimate is submitted.
3. Quantity disbursed during the previous year.
4. Quantity estimated to be disbursed during the year for which estimate is submitted.
5. Supplier who would supply the quantity.

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S.No	Name and address of the supplier	Quantity
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6. If this is a supplementary requirement, give details of annual requirement sent earlier and the reasons for giving a supplementary requirement.

Station

Date

(Signature of the authorized  
 medical practitioner /  
 In-charge with name)

1998 Special provisions relating to the use etc. of Morphine by Recognized Medical Institutions – Annexure-4

Orders for purchase

To

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(Name and address of the supplier)

1. Name and address of the recognized medical institution which places the order.
2. Description of the quantity for which the order is placed.
3. Whether the institution has been recognized by the Drug controller (A photocopy of the recognition is to accompany each order for purchase).
4. Whether this order is covered by the estimate approved by the Drug controller (A photocopy of the approved estimate is to accompany each order of purchase).
5. Details of other orders for purchase made during the year.

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S.No.	Quantity	To whom order was placed
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Station:

(Signature of the person

Date

authorized to place order with  
Name and designation if any)

Note

1. A copy of this order shall be kept by the recognized medical institution which places the order.
2. This shall be retained for two years from the date of transaction.

S.No-\_\_\_\_\_

---

CONSIGNMENT NOTE

(To accompany a consignment of morphine)

Date and time of dispatch  
of the consignment-\_\_\_\_\_

1. Name and address of consignor.
2. Name and address of the consigned i.e., recognized medical institution.
3. Description and quantity of the consignment.

---

No. of packages	Quantity	
	Gross	Net
4. Mode of transport (particulars of the transporter, Registration number of the vehicle, RR., if the transport is by railways etc.)		

Signature of the Consignor with date  
(Name and Designation if any)

To be filled by consignee

5. Date and time of receipt by the consignee and his remarks.
6. Quantity received by the consignee-

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No. of packages	Quantity	
	Gross	Net

---

Signature of the Consignor with date  
(Name and Designation if any)

Note

1. This consignment note shall be serially numbered on annual basis.
2. The consignor should record a certificate on the cover page of each book containing consignment notes indicating the number of pages contained in the consignment note-book.
3. The consignor should maintain a Register showing the details of the books of consignment note brought in use during a particular year.
4. Each consignment of morphine shall be accompanied by this consignment note is quintuplicate (i.e., five).
5. This consignment note shall be retained for a period of two years from the date of transaction.
6. The records referred to at items 2 and 5 above in this note shall be produced to the authorized officers whenever called upon during the course of their inspection.

**Strategy for palliative care:  
National Cancer Control Program  
11<sup>th</sup> five year plan – 2007- 2012**

**Report submitted to Government of India, Ministry of Health and Family Welfare**

**By**

**Palliative care and Rehabilitation committee of the National Task Force constituted to formulate strategy for Cancer Control in India during the 11<sup>th</sup> Five Year Plan**

Vide

F.No.T.20015/24/2005-R dated 7<sup>th</sup> October 2005.

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**EXECUTIVE SUMMARY**

**1. Current Status and Need:**

- In the year 2004, over 20 lakhs Indians had cancer.
- More than 80% (16 lakhs) of them were incurable at the time of diagnosis, and needed palliative care.



- By year 2015, it is projected that the total prevalence of cancer in the country would be 25 lakhs.
- By 2015, even if the mortality rate were to come down to the international standard of 50%, 12.5 lakh Indians would still need palliative care.
- All patients need supportive care during treatment.
- Palliative care is mentioned as pain relief and terminal care in NCCP; but not practiced as an integral part of cancer care in most RCCs and oncology wings.
- Oral morphine, the most important medication for relief of cancer pain, is not available to more than 99% of patients.
- There are very few doctors and nurses in the country with any palliative care education.

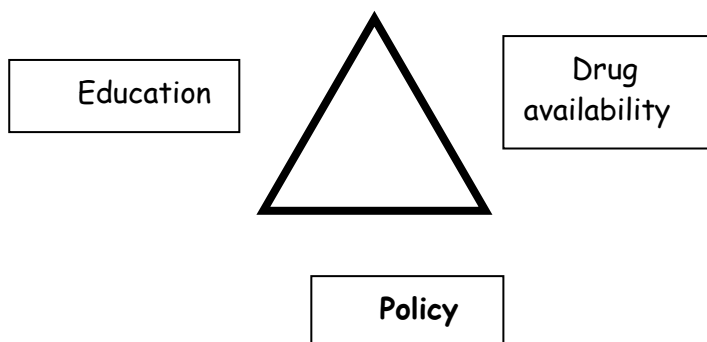
## 2. What is palliative care, and what is supportive care?

Palliative care attempts to improve quality of life of patients and families through assessment and management of factors reducing quality of life, like pain and other symptoms, as well as psycho-socio-spiritual problems. Most of those undergoing curative treatment need supportive care – application of principles of palliative care – reducing suffering and improving compliance to treatment.

## 3. Common barriers to access to palliative care that have been identified are:

- 3.1. Lack of palliative care services in most of the country.
- 3.2. Lack of awareness among professionals, administrators and the public.
- 3.3. Lack of facilities for palliative care education in the country.
- 3.4. Unrealistic narcotic regulations preventing access to opioids for those in pain.
- 3.5. Lack of clear guidelines for those wishing to provide palliative care services.

## 4. WHO recommendation for palliative care development: The World Health Organization (WHO) recommends that, to be effective, any palliative care policy has to address all three sides of the following triangle with the State Policy at the base, their broad objective being to improve access to palliative care to all those who need it.



5. **Broad objectives:** To develop

- A. Strategy for formulation of Palliative Care Policy, including involvement of non-governmental organizations
- B. Strategy for development of Palliative Care Delivery services including manpower
- C. Strategy for improved, safe, availability of opioids for pain relief
- D. Strategy for Palliative Care Education and Training of professionals and others including volunteers.
- E. Strategy for Advocacy, Awareness Building and Community Participation

6. **POLICY:**

6.1. **Objective:**

- 6.1.1. Declaration by NCCP that palliative and supportive care should be essential parts of cancer care.
- 6.1.2. Declaration by all states & Uts that palliative and supportive care should be essential parts of cancer care.

6.2. **Strategy**

- 6.2.1. Include 'provision of palliative and supportive care with community participation' as a separate objective of the revised NCCP
- 6.2.2. Inclusion of a palliative care provision in the Health Policy of State Governments

6.3. **Coverage:** Health policy of centre and 50% of states/Uts

6.4. **Timeline:**

- 6.4.1. Inclusion in NCCP before 11<sup>th</sup> FYP
- 6.4.2. Inclusion in State Policy – over first 2 years of FYP

6.5. **Budgetary requirement:** Nil

7. **DEVELOPMENT OF PALLIATIVE CARE SERVICES:**

7.1. **Objective:**

- 7.1.1. Integrate Palliative Care into cancer care in all RCCs and 100 other cancer treatment facilities in the country

7.1.2. **Strategy:**

- 7.1.2.1. **RCC Scheme:** Starting palliative care service in all Regional cancer centers

- 7.1.2.2. **Out-of-RCC Scheme:** Starting palliative care services in 100 other institutions (DCCP/Oncology Wings of Medical Colleges/NGOs)

- 7.1.2.3. **Coverage:** 25 RCCs and 100 other institutions in the country.

7.1.2.4. **Timeline:**

- 7.1.2.4.1. Year 1: 5 RCCs and 10 other Cancer treatment centres

- 7.1.2.4.2. Year 2: 5 RCCs and 25 other Cancer treatment centres

7.1.2.4.3. Year 3: 5 RCCs and 25 other Cancer treatment centres

7.1.2.4.4. Year 4: 5 RCCs and 25 other Cancer treatment centres

7.1.2.4.5. Year 5: 5 RCCs and 15 other Cancer treatment centres

7.1.2.5. **Budget:**

7.1.2.5.1. RCC Scheme: Rs 8.625 crores and

7.1.2.5.2. Out of RCC Scheme: Rs 32.828 crores

## 8. OPIOID AVAILABILITY

### 8.1. Objective:

8.1.1. Ensuring simplified narcotic regulations in all states and union territories of India with realistic standard operating procedures.

8.1.2. Ensuring uninterrupted availability of oral morphine in all regional cancer centers and in all hospitals where palliative care facilities have been started.

### 8.2. Strategy:

8.2.1. Opioid Availability Workshops: Up to 3 workshops in 5 years by each RCC involving palliative care professionals, NGOs and officials from concerned Departments in the State, and of the adjoining State/UT where there is no RCC.

8.2.2. NGOs in the field are already involved in this work to a limited extent. This task force can find a team of facilitators, who can be available to extend expert help at these workshops.

8.3. **Coverage:** All States and Union Territories

8.4. **Timeline:** 3 workshops each year for every year of FYP in every RCC.

8.5. **Budget:** Rs 1.125 crores

## 9. PALLIATIVE CARE EDUCATION AND TRAINING:

### 9.1. Objectives:

9.1.1. Develop training modules for

9.1.1.1. Doctors

9.1.1.2. Nurses

9.1.1.3. Social workers/83ouncil83n83s

9.1.1.4. Volunteers

9.1.2. Provide palliative care education to professionals and volunteers.

9.1.3. Ensure effective training in palliative care at least in all oncology post graduate programs including practical exposure and inclusion in the examination process.

9.1.4. Develop tools and methods for Qualitative Assessment of Palliative care Services

9.1.5. Development of at least one nodal palliative care training center in five geographical regional zones – North, Northeast, West, East and South of India.

### 9.2. Strategy:

9.2.1. Training For palliative care doctors and nurses of 25 RCCs and 100 Out-of-RCC Centres (budget provided in RCC and Out of RCC Scheme in item 7)

- 9.2.2. Sensitisation in Palliative Care for rest of the staff of 25 RCCs and 100 Out-of-RCC Centres (budget provided in RCC and Out of RCC Scheme in item 7)
- 9.2.3. 12 Working Group Meetings, each with 6 faculty members for development of training modules for Palliative Care for Professionals and Undergraduates, and for training for Social Workers/Counsellors (to be done over 3 years)
- 9.2.4. 6 Working Group Meetings for developing tools and methods for Qualitative Assessment of Palliative Care Services rendered to be done over 3 years
- 9.2.5. One month rotation in palliative care for oncology postgraduate residents in RCCs/Palliative Care Centres/Regional Training Centres.
- 9.2.6. Upgradation of one each palliative care centre in five geographical zones in India to Regional Training Centres

**9.3. Coverage:**

- 9.3.1. All States and Uts, 25 RCCs and 100 Cancer Treatment Centres

**9.4. Timeline:** As given in spreadsheet attached.

**9.5. Budget:**

- 9.5.1. Training and Sensitization provided in RCC and Out of RCC Schemes
- 9.5.2. Development of teaching modules: Rs. 0.12 crores
- 9.5.3. Development of Quality Assessment Tools: Rs 0.06crores
- 9.5.4. Development of Regional Training Centres: Rs 2.8 crores

**10. PATIENT ADVOCACY & AWARENESS BY NGOS/INSTITUTIONS**

**10.1. Objective:**

- 10.1.1. Development of Peer Support Groups for cancer Patients and Families
- 10.1.2. Promotion of public awareness and promotion of community and NGO participation in palliative care

**10.2. Strategy:**

- 10.2.1. Hold 4 Peer Support Meetings per year in all 125 Palliative Care Centres
- 10.2.2. 600 Palliative Care Awareness Programs by NGOs/Institutions

**10.3. Coverage:** All States and Uts,

**10.4. Timeline:** Over 5 years

**10.5. Budget:**

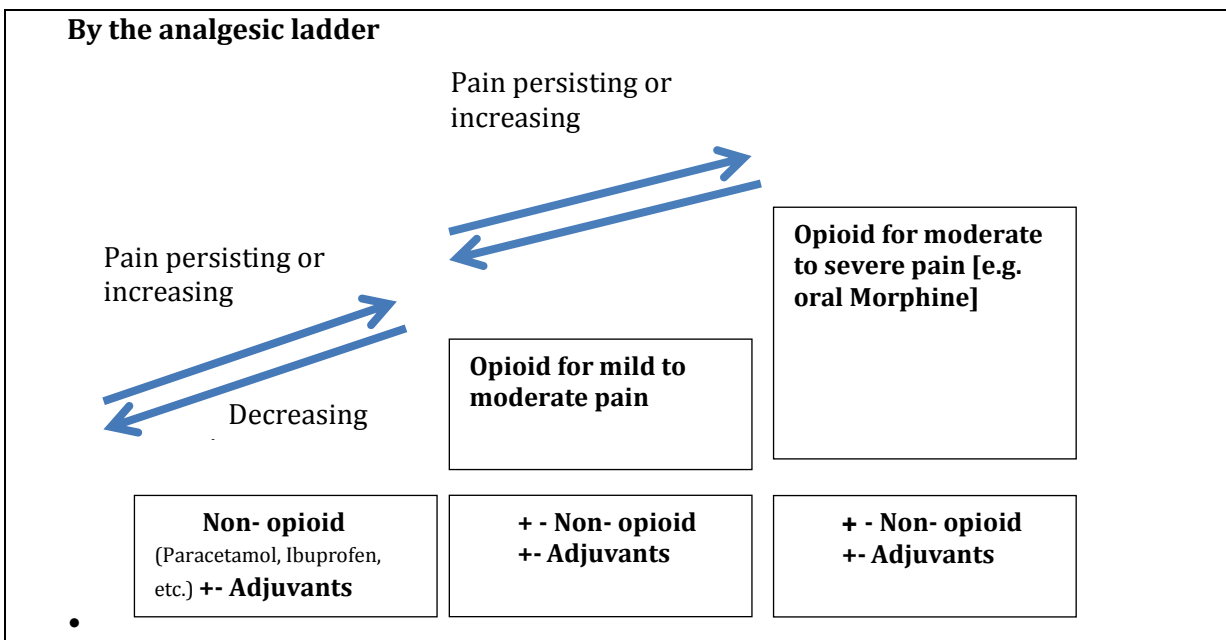
- 10.5.1. For Peer Support Meetings: provided in RCC and Out of RCC Scheme in item 7.
- 10.5.2. Budget for 600 Awareness Programs Rs 0.48 crores

**Note:**

- More specific timelines and outcome measures are attached in spreadsheet
- .

**ANNEXURE 4 Integrated Management Of Adolescent And Adult Illness Palliative Care Module ©World Health Organization 2004**

<b>Pain management using WHO Analgesic Ladder</b>
<p><b>By mouth</b></p> <ul style="list-style-type: none"> <li>• If possible, give by mouth (rectal is an alternative—avoid intramuscular).</li> </ul> <p><b>By the clock</b></p> <ul style="list-style-type: none"> <li>• Give pain killers at fixed time intervals (by clock or radio or sun).</li> <li>• Start with small dose, then titrate dose against patient’s pain, until the patient is comfortable.</li> <li>• Next dose should happen <b>before</b> effect of previous dose wears off.</li> <li>• For breakthrough pain, give an extra “rescue” dose (same dosing of the 4-hourly dose) in addition to the regular schedule.</li> </ul> <p><b>By the individual</b></p> <ul style="list-style-type: none"> <li>• Link first and last dose with waking and sleeping times.</li> <li>• Write out drug regimen in full or present in a drawing.</li> <li>• Teach its use and check to be sure patient <b>and</b> family or assistant at home understands.</li> <li>• Ensure that pain does not return and patient is as alert as possible.</li> </ul>



**Examples of non-medical treatment for pain, in addition to analgesics and special pain medications (adapt locally):**

- Support and counselling.
- Psychological, spiritual and emotional support and counselling should accompany pain medications. Pain can be harder to bear when there is guilt, fear of dying, loneliness, anxiety, depression.
- Answering questions and explaining what is happening is important to relieve fear and anxiety.
- Deep breathing and relaxation techniques unless the patient is psychotic or severely depressed.
- Distraction, music, imagining a calm scene.

**Palliative Care at Home**

**Teach the patient and family how to give good palliative care at home according to the symptoms**

- Give home care interventions which will relieve the patient's symptoms, using the Caregiver booklet.
- Give pain medications (P13-15) and other medications.
- Use other methods for pain control (P16).
- Give information and teach skills.
- Use the Caregiver Booklet to educate the patient, family and community caregivers.
- The content of columns entitled Home Care on pages P20 to P32 is from the Caregiver Booklet. This booklet also has illustrations.

**Record medications with instructions**

- Use a separate sheet of paper with the name of each medication, what it is for, and the dose.

**Leave the patient as much in charge of his or her own care as possible**

- Support the patient to give as much self-care as possible.
  - Discuss with the patient who should provide hands-on care
-

## **ANNEXURE 5 PROVISION FOR PALLIATIVE CARE WITHIN THE NATIONAL PROGRAM ON Prevention & Control Of Non-Communicable Diseases (NCDs) – Proposal For The 12<sup>th</sup> Five Year Plan**

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### **Working group on disease burden: non-communicable diseases (NCDs)**

#### **PROGRAMMES FOR PREVENTION & CONTROL OF CHRONIC DISEASES:**

Cancer pattern is varied in different parts of the country with increasing urbanization, sedentary habits & life style it is becoming a major life style problem. At this juncture the country is equipped with only 450 radiotherapy machines in 250 institutes, where as the requirement is 1160 (1 per million population). The experts felt that Cancer should be a notifiable disease for the whole country like the State of West Bengal.

It is essential that at all levels of the health facilities there is availability and accessibility of facilities for prevention, early detection, diagnosis, treatment and follow up of common cancers. The common cancers namely Oral, breast & cervix cancers can be easily prevented and detected early with simple measures and appropriated training of health professionals. Awareness generation on early warning signals, risk factors will help reduce at least 1/3<sup>rd</sup> of the common cancers. Regular Oral Clinical/ Self/ Examination for prevention of Oral Cancers, regular Physical examination of the breasts for Breast Cancers and r will help in reducing the morbidity on common cancers.

At this juncture emphasis on availability of HPV vaccine at district level may not be required as simple advice on personal hygiene and early symptoms of Cervix Cancer and training of Health worker in VIA techniques will help in prevention & early detection of cervix cancers. Health promotion & life style changes will help in reducing NCDs including cancers. Palliative care is an important and essential part of cancer care therapy, at least 10% of the budget need to be earmarked for these services at level of cancer care services. For availability of health professionals at the districts it may be made mandatory that there be 1 year posting at district hospitals after completion of the courses in Oncology in Medical/Surgical/Radiotherapy/Medical Physicist after which the degrees would be provided.

For radiotherapy, Linear Accelerator requires higher maintenance compared to Cobalt machine and the down time of Cobalt machines is much lower than a Linear accelerator, so Cobalt machine is preferred. It is essential that at the tertiary level for Radiotherapy there should be at least the three: a Cobalt, a High Density Radiotherapy & a Treatment Planning System. In addition to these three any other radiotherapy equipment may be sought according to the requirements. Where feasible Linear Accelerator may be sought.

The District cancer services will be expanded to all 640 Districts. 100 Tertiary Cancer Centres will be strengthened in Govt. Medical Colleges & NGO Institutions Hospitals for comprehensive cancer care services across the country, 20 State Cancer Institutes will be established for all specialized cancer services, Training of specialists & Research during the 12<sup>th</sup> plan period. Support will be provided for 3 National Cancer Institutes including Chittaranjan National Cancer Institute (CNCI). The National Cancer

Registry will be expanded to all Tertiary Cancer centres and cancer institutions. At all levels of health facilities provision is being kept for **palliative care services** including provision specific beds, training and development of required manpower for these services.

- a. **Cancer Services at District Hospitals:** At present the programme is being implemented in 100 districts across 21 States. The programme will be expanded to all the 640 districts in the country. Under this scheme, District Cancer Centre will be established at the selected districts to provide common diagnostic services, basic surgery, chemotherapy and **palliative care**. District Surgeon, Physicians, Gynaecologist will be trained in management most of the common cancers including palliative care. In addition to the existing manpower support is provided for contractual staff.

District hospital is being strengthened for prevention, early detection and management of common cancers especially oral cancer, breast cancer & cervix cancer. Nurse/Health worker will be trained in awareness generation on early warning signals of cancers, Oral self examination, Physical examination of breasts and VIA techniques for cervix cancer. Nurses will be given special training in Stoma care. For diagnosis of Cervix Cancer, white light source will be used as recommended by TMH. It is hand held device that works on regular 220V AC electricity with a 880mW casing for halogen bulbs for shadow free illumination of the cervix.

For **palliative care** there will be dedicated 4 beds at the district hospital. Doctors, Nurses & Health worker will be trained in basic palliative care. One of the doctors in the District hospital need to have a 2 weeks training in palliative care. Along with the local NGOs home care programme will be organized to empower the patient and their families. Necessary medicines including Oral morphine should be made available in the District by amendment of State regulations. Support will be provided for Chemotherapy drugs required for cancer patients in addition to support for a Day care Chemotherapy facility for patients on chemotherapy regimens. Laboratory investigations which are not available at the districts can be outsourced. **A home base team** consisting of nurse and counsellor (from DCS) would be trained in chronic, debilitating and progressive cancer patients.

Support would be given for

- White Light Source (880mW casing with halogen bulbs)
- Manpower: 1 Medical Oncologist, 1 Cytopathologist, 1 Cytopathology technician, 2 Nurses for Day care
- Day care Chemotherapy facilities ( 4 beds)
- Chemotherapy drugs patients @ Rs. 1 lakh per patient for 100 patients/ year/ district
- Outsourcing of Laboratory investigation including Mammography
- Miscellaneous activities including TA/DA, home based palliative care



- b. **Tertiary Cancer Centres (TCC) Scheme:** Support will be given for 100 Govt. Medical Colleges/ NGO Institutions/erstwhile RCCs or institutes supported under Oncology wing scheme to be strengthened as Tertiary Cancer Centres across the country to provide comprehensive cancer care services. The institute/ hospital should have at least 100 general beds or should be 50 bedded exclusively cancer hospital with three years of experience in cancer treatment. There could be exemptions made for hilly/ difficult areas/ NE states and in States where there are no cancer treatment facilities. The TCC should be well within 300 km of identified districts under NPCDCS. The institute should have well equipped and functional departments of Medicine, Surgery, Gynecology & Obstetrics, ENT, Anesthesia, Pathology and Radiology. These departments can be part of the institute or part of hospital attached with a Government Medical College in near vicinity in the same city which has entered into a formal understanding with TCC.

These institutes will be supported with a capital grant for construction, equipments related to cancer care services including *palliative care* & pathology services. Support will also be given for Human Resource development, drugs, consumables etc as a recurring amount. These institutes will have a Palliative Care unit with at least 4 in- patient beds and 2 beds in Day care for palliative care. There will be dedicated staffs in the *palliative care unit*: 2 Doctors, 6 nurses, a part time Pharmacist & a part time Physiotherapist. There will be OPD services for *palliative care*, 3 days per week *and home care facilities*. At least 10% of the total budget for TCC will be for Palliative care services including availability of opioids drugs e.g oral morphine. These centres will also ensure *availability of opioids drugs including oral morphine in the district centres*.

The TCC will give an undertaking to ensure generation of cancer care health professionals by the 3<sup>rd</sup> year (2014-15) of the 12<sup>th</sup> five Year Plan. They shall initiate/increase courses in MD/MS/Mch/DM (Surgical oncology, Medical Oncology, Radiotherapist, *Palliative Care*, Diploma courses in *Palliative Medicine*, Pathologist, Medical Physicists etc.). They shall initiate/increase courses in Oncology Nursing and *Diploma courses in Palliative Nursing*. They should function as institutes to generate cyto-technicians, cyto-pathologists and other paramedicals for cancer care services.

These centres will be referral centres for the District Hospitals and provide comprehensive cancer care services. These institutes will also be training and research centres for cancer care. The TCCs will coordinate with other institutions, NGOs, medical colleges and the general health care delivery infrastructure in conduction of cancer related activities including peripheral outreach services in their respective geographical areas/ region.

- c. **State Cancer Institutes (SCI):** Support will be given to 20 centres in the country to function as Centres of Excellence. These centres will be state-of-the-art treatment centre for different cancers including site specific specialties, minimal

access surgery, multidisciplinary groups and Oncology Nursing care for better delivery of treatment, better outcome results and optimum use of resources.

The institute/ hospital should have at least 150 general beds or should be 100 bedded exclusively cancer hospital with three years of experience in cancer treatment. The institute should have well equipped and functional departments of Medical Oncology, Radiation Oncology, Surgical Oncology and supportive departments of Medicine, Surgery, Gynecology & Obstetrics, ENT, Anesthesia, Pathology and Radiology. The erstwhile Government RCCs/TCCs may be upgraded to State Cancer Institutes.

Like the TCCs these institutes will also have a dedicated Palliative Unit with 10 beds, 4 day care beds, dedicated staff (3 doctors, 10 Nurses, 1 full time Pharmacist and Part time Physiotherapist) for **palliative care services**. The SCI will ensure availability of opioids drugs including oral morphine. These centres will also ensure availability of opioids drugs including oral morphine in the district centres. There will be OPD services for palliative care, 3 days per week and home care facilities. At least 10% of the total budget for SCI will be for Palliative care services.

These institutes will be supported with a capital grant for construction, equipments related to cancer care services including **palliative care** & pathology services. Support will also be given for Human Resource development, drugs, consumables etc as a recurring amount. The SCI will give an undertaking to ensure generation of cancer care health professionals by the 3<sup>rd</sup> year (2014-15) of the 12<sup>th</sup> five Year Plan. They shall initiate/increase courses in MD/MS/Mch/DM (Surgical oncology, Medical Oncology, Radiotherapist, **Palliative Care**, Diploma courses in Palliative Medicine, Pathologist, Medical Physicists etc.). They shall initiate/increase courses in Oncology Nursing and Diploma courses in **Palliative Nursing**. They should function as institutes to generate cyto-technicians, cyto-pathologists and other paramedicals for cancer care services.

These centres will be referral centres for the TCC/District Hospitals and provide specialized cancer care services. These institutes will also be training and research centres for cancer care. The SCIs will coordinate with other institutions, NGOs, medical colleges and the general health care delivery infrastructure in conduction of cancer related activities including peripheral outreach services in their respective geographical areas/ region.

- d. **National Cancer Institute (NCI):** Support will be given for 3 National Cancer Institute in the country one in the North, one in the South & one in the east of India. These will be apex centres for providing training, research and in generating quality manpower related to cancer care services.

NCI will be state of art research & referral which will have comprehensive cancer care facilities. The institute will have department in Medical Oncology, Surgical Oncology, Radiation Oncology, Rehabilitation & **Palliative care centre**.

NCI will also have focus in Urooncology, Gastrointestinal Oncology, Gynaecological Oncology, Community Oncology, Nuclear Medicine, Cell & Tumor Biology, Cancer Immunology, Radiation research etc. Wherever necessary the Medical Social Worker will facilitate the treatment of cancer patients. There will be Bone Marrow transplant facilities for Leukemia, Lymphoma patients supported with blood transfusion. There will be supportive departments in Anaesthesia, Pathology, Microbiology, Biochemistry, Blood Bank etc. There will be enough scope for recreation/ spiritual for all kinds of cancer patients from children to adults. To start with the NCI will have 300 beds with day care facilities and will be expanded to accommodate 500 beds.

The institutes will also have a ***dedicated Palliative Unit Department for training & research in palliative Care***. There will be dedicated staff (5 doctors, 30 Nurses, 2 full time Pharmacist, 2 Physiotherapist, 4 Social workers and other supportive and administrative staff) ***for palliative care services***. The NCI will ensure availability of opioids drugs including oral morphine. ***At least 10% of the total budget for NCI will be for Palliative care services***.

There will be Administrative block, Research block, Academic block, OPD and other service blocks. There will also be facility for a 200 rooms budget hotel, a hyper market, basement parking, a pedestrian plaza. The institute will work in close association with the Tertiary Cancer Centres in the country.

The administration of NCI will be headed by Director who will be assisted by a Joint Director. There will be Medical Superintendent of the Hospital Block assisted with an Assistant Medical Superintendent. There will be a Administrative Officer, Accounts Officer along with other support staffs. Each clinical department will have a Professor assisted by Associate Professor and Assistant Professor. There will be Senior & Junior Residence too. There will be Chief Medical Officer, Medical Officer, Research Associates, Scientist, Veterinary Surgeon and Technical staffs at NCI. The Nursing Services will be headed by the Nursing Superintendent (NS) and assisted, Deputy Nursing Supdt (DNS) and Asst. Nursing Supdt (ANS). The ward duties will be carried out by the nursing sisters and the staff nurses. The Nursing Council of India norms of staffing will be adhered while calculating manpower requirement for different nursing units.

Establishment of NCI will have comprehensive cancer care facilities in Surgical, Medical, Radiation and Community Oncology and ***Palliative care***. The institute will have facilities for Research & Development, Training and Capacity Building. There will be research fellows in areas of Epidemiology, Biostatistics, Cell Biology, Molecular Biology, Genetics, Pathogenesis, Cancer Screening etc. The institute will also have course on Oncology Nursing. The institute will be good source of quality manpower in cancer research. There will be 1-2 research fellowship per year in the different areas related to cancer research totalling to 8-10 per year.

In view of the status of the institute as an apex centre for referral and research, the most sophisticated, state of the art instruments will be procured for both the research and clinical divisions. These institutes will be supported with a capital grant for construction, equipments related to cancer care services including palliative care & pathology services. Support will also be given for Human Resource development, drugs, consumables etc as a recurring amount.

National Cancer Institutes will give an undertaking to ensure generation of cancer care health professionals by the 3<sup>rd</sup> year (2014-15) of the 12<sup>th</sup> five Year Plan. They shall initiate/increase courses in MD/MS/Mch/DM (Surgical oncology, Medical Oncology, Radiotherapist, **Palliative Care**, Diploma courses in **Palliative Medicine**, Pathologist, Medical Physicists etc.). They shall initiate/increase courses in Oncology Nursing and Diploma courses in **Palliative Nursing**. They should function as institutes to generate cyto-technicians, cyto-pathologists and other paramedicals for cancer care services. These centres will be referral centres for research and treatment and provide specialized cancer care services.

Chittaranjan National Cancer Institute (CNCI) is an autonomous organisation jointly funded by Government of India and the Government of West Bengal. Support will be given for the existing institute to be up gradated and for a 2<sup>nd</sup> campus hospital to accommodate the increasing patient load. This will be the NCI for the east of India. There will be one established in the North & South of India.

- e. **Human Resource Development:** Training will be provided at Tertiary Cancer Centers/ State Cancer Institute for the health professionals for cancer care services. (District Surgeons/Physicians/Gynecologists, District Radiotherapist, Medical Physicist and Cyto-pathologist/Cyto-technician).
- f. **Monitoring & Supervision:** Monitoring and supervision of the programme will be carried out at different levels through NCD cell through reports from the state, regular visits to the field and periodic review meetings. State and District NCD cell will be established at the selected States/ Districts for monitoring programme implementation.
- g. **National Cancer Registry Programme & Research:** At present Population based cancer registry is present only in 23 institutes mostly in the urban area. The programme will be expanded to all TCCs and Cancer Treatment Institutes in the country for having a data base for cancer cases in the country including rural areas. Support would be provided for research activities related to cancer including surveillance.
- h. **IEC activities:** Awareness generation about cancer will be done in the community through Inter Personal Communication, education, mass media etc.

## **ANNEXURE 6 –Approved Centres Of Excellence In The Country In The Field Of Palliative Care**

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### **WHO Collaborating Centre - Trivandrum**

Trivandrum Institute of Palliative Sciences (TIPS) is a World Health Organization Collaborating Centre (WHOCC) for Training and Policy on Access to Pain Relief. It was established by Pallium India ([www.palliumindia.org](http://www.palliumindia.org)) in 2006.

TIPS performs the following functions:

1. Run a clinical service developing and operating both institution-based and community oriented palliative care services including service of local volunteers and home visits.
2. Act as the base from which palliative care centers are catalyzed in states which at that point of time have no access (or little access) to palliative care. So far, a palliative care training center has been started in MNJ Institute of Oncology, Hyderabad, and palliative care services have been started in the states of Manipur, Mizoram, Tripura, UP, Bihar, Gujarat and Orissa. Six of these are in Regional Cancer Centres.
3. Run educational programs in Pain and Palliative Medicine for South Asia The following are conducted:
  - i. 6 weeks course for doctors, nurses and other health professionals.
  - ii. 10 days' foundation course for doctors.
  - iii. Three tier training program for volunteers.
  - iv. Short training programs for medical students.

### **Terms of reference of this WHOCC are:**

1. Assessment of barriers to access to pain medication for those who need it in India, including evaluation of drug control and distribution systems, particularly in the social and cultural background in developing countries and providing the resulting information in an organized manner to the WHO Access to Controlled Medications Programme.
2. Development of methods to overcome barriers and to make opioid analgesics adequately available for the relief of pain, by
  - a. establishing dialogue with regulators, and
  - b. training of health professionals to assume responsibility for acquisition, management and proper use of opioids to relieve pain while preventing diversion and misuse.
3. Dissemination of relevant information to the needy in India and in the South East Asian Region, in particular Bhutan, Indonesia, Nepal, Thailand and Sri Lanka.
4. Conduct of educational programs for professionals including doctors and nurses, which incorporate assessment and management of pain, including procurement as well as safe and effective use of opioids.

### **WHO Collaborating Centre Calicut**

The Institute of Palliative Medicine (IPM) is the leading training institution for palliative care in Asia. The team at Institute of Palliative Medicine has done pioneer work in Low and Middle Income Countries for evolving the unique community ownership initiatives within and outside the state of Kerala and integrating it to the Primary Health Care system. IPM has been designated as the World Health Organization Collaborating Center (WHOCC) for Community Participation in Palliative Care and Long Term Care with a mandate to advise WHO and Member states on issues related to community participation in palliative care and long term care. The terms of reference also include development of training modules and guidelines for home care for the Low and Middle Income countries.

Institute of Palliative Medicine is the technical advisor to develop palliative care programs in Bangladesh (in collaboration with Bangabandhu Sheikh Mujib Medical University, the National Medical University and the Bangladesh University Grants Commission), Srilanka (in collaboration with the National Cancer Control Program, WHO Srilanka and Srilankan Medical Association) and Thailand (in collaboration with Khon Kaen University). The institute has also initiated training programs in Ethiopia, Seychelles and Jordan.

IPM is the fifth WHOCC in Palliative Care and the first one in the developing world. It is also the nodal agency for initiating and implementing community based palliative care programme under National Rural Health Mission (Kerala), a Government of India Project.

Institute of Palliative Medicine works closely with local governments in Kerala. IPM is the technical advisor formulation and implementation of Palliative Care Projects by Local Self Government Institutions in Kerala an initiative which has resulted in establishing a primary care network covering more than 70% of the needy patients in Kerala.

Institute of Palliative Medicine runs the following training programs in palliative care:

1. One year Fellowship in Palliative Medicine for doctors
2. Six week Basic Certificate Course in Palliative Medicine for Doctors
3. Six week Basic Certificate Course in Palliative Nursing for Nurses
4. Three day Basic Certificate Course in Essentials of Palliative Care for Doctors and nurses
5. Three month Basic Certificate Course in Auxiliary Palliative Nursing for community nurses
6. One month advanced course for community nurses
7. Structured 15 hour basic courses for community volunteers
8. Train the trainer programs for community volunteers

The following courses accredited by University of Calicut are to be started in 2013

1. One year Post Graduate Diploma Course in Palliative Medicine for doctors

## 2. One year Diploma in Palliative Nursing for nurses

IPM is the fifth WHOCC in Palliative Care and the first one in the developing world. It is also the nodal agency for initiating and implementing community based palliative care programme under National Rural Health Mission (Kerala), a Government of India Project.

Institute of Palliative Medicine works closely with local governments in Kerala. IPM is the technical advisor for palliative care programs by local self Govt. institutions in Kerala. IPM is the Indian partner for the WHO Collaborating Centre in Oxford.

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**ANNEXURE 7 – REPORTING SYSTEM OF THE KERALA PALLIATIVE CARE POLICY**

**PALLIATIVE CARE PROGRAMME CONSOLIDATED REPORTING OF PRIMARY CARE**

Name of THQH/D.H./G.H. : \_\_\_\_\_ Month : \_\_\_\_\_

Name of Doctor in charge : \_\_\_\_\_ Reporting Date : \_\_\_\_\_

Name of Staff Nurse in charge : \_\_\_\_\_ Total No. of Units with Primary care : \_\_\_\_\_

\_\_\_\_\_ Total No. of Units with Special OP : \_\_\_\_\_

S l. No	Name of LSGI/In stitutio n	Total Number of Registered pts	Total no. of pts under care	Total Patients on Follow Up.	Total Patients Registered for O.P.	No. of Home Care Days during the	No. of LSGI Members who	No. of Health staff who participated	No. of community volunteers who	No. of O.P. Days during the	Total No. of Cancer Patients	Total No. of patients with	Total no. of Renal failure Patients	Total no. of Spinal cord injured	Totally bed ridden <65 years/	No. of Catheterizations done	No. of wound dressing done	No. of Ryles tube insertion/feeding	No. of PRE Enema	No. of special procedures (Stoma/	Review meeting Date and	Remarks (special I programmes/	
<b>Total :</b>																							





**District level Training Programmes conducted by Tertiary level unit**

**315 For volunteers**

Name of Programme	Date	Venue	No. of Participants

**316 For Professionals**

Name of Programme	Date	Venue	No. of Participants

**317 Certificate Courses**

Name of Course	Batch No.	Date of starting	No. of Candidates
CCCPN/BCCPAN			
BCCPN			
BCCPM			
IAPC Foundation course			

**Special Programmes in the District**

Name, Sign & Seal of the Head of Institution

**Panchayath level reporting system  
Nominal Register (Primary care)**

Sl.No	Reg. No	Date of Regn.	Name & Address of the Patient with Contact No.	Age/Sex	Ward	Name & Phone no. of Contact Person	Diagnosis	Care Plan	Remarks

- Only those Patients who are assessed by Palliative Nurse in Home Care Programme can be registered.

**Nominal Register (Secondary care)**

Sl.No	Reg. No	Date of Regn.	Name & Address of the Patient with Contact No.	Age/Sex	Name of Primary unit	Name & Phone no. of Contact Person	Name of Community Palliative nurse	Diagnosis	Care Plan	Remarks

Only those Patients who are assessed by Palliative Nurse in Home Care Programme can be registered



## ANNEXURE 8 Principles Of Palliative Care That Need Incorporation Into Undergraduate Medical Curriculum

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Modules	Duration	Subject	MBBS term
Management of pain	3 hours	Anaesthesiology	7 <sup>th</sup> term
When to reconsider CPR <sup>50</sup> Guidelines to End Of Life Care	2 hour 2 hours	Intensive care team <sup>49</sup>	
Basics concepts of symptom management in management of chronic illnesses Clinical ethics <sup>51</sup>	10 hours  3 hours	General medicine	3 <sup>rd</sup> and 8 <sup>th</sup> 9 <sup>th</sup> term  9 <sup>th</sup> term
Medical ethics – basics	4 hours	Forensic medicine	5 <sup>th</sup> , 6 <sup>th</sup> , 7 <sup>th</sup> term
Ethics in research	3 – 4hours	Community medicine	6 <sup>th</sup> , 7 <sup>th</sup> term
Principles of communication Specific skills – breaking bad news, handling collusion	6 hours	Community medicine / ?psychiatry	5 <sup>th</sup> , 6 <sup>th</sup> , 7 <sup>th</sup> term
Continuity of care – agree, assist, arrange	2 hours 3 hours <sup>52</sup>	Community medicine General medicine	5 <sup>th</sup> , 6 <sup>th</sup> , 7 <sup>th</sup> term

<sup>49</sup> To use ISCCM, law commission and MCI guidelines

<sup>50</sup> Cardio Pulmonary Resuscitation

<sup>51</sup> Discussion with case scenario, exercises with clinical situations from in-patients

<sup>52</sup> This has to be in synchrony with general medicine, who would have these exercises during clinical discussions

Module 1: basic concepts palliative medicine and pain management – 7 hours

- Introduction to palliative care
- Pathophysiology and assessment of pain
- Identifying and differentiating acute pain, chronic pain and classifying pain and their management

**Transaction strategies**

- **Role play followed by discussion:** assessment of pain (role play will be demonstrated by two faculty members)
- **Lecture:** the WHO analgesic ladder
- **Case demonstration, group work followed by discussion:** management of chronic pain

Module 2 CPR training – 2 hours [besides protocols of BLS and ACLS]

- When to reconsider initiating CPR
- Implications of CPR in advanced multisystem failure patient [ethics]
- Palliative care-critical care interphase - the role of palliative care in the emergency room

**Transaction strategies**

- Group discussion
- Debate: scope of palliative care as an end of life care option
- Case studies

Module 3 – management of chronic illnesses and palliative care – 10 hours

Managing long term chronic conditions e.g. ischemic heart disease, hypertension, chronic obstructive pulmonary disease, acid peptic disease, diabetes, HIV, hypothyroidism etc.

**In addition to medical and surgical management, the following would be included in management of all chronic diseases**

- Principles of prognostication
- Trajectories of chronic illnesses including geriatrics
- Training in the relevance of appropriate communications and clarifications
  - Relevance of education and insight regarding the disease and treatment to improve compliance of patients to prescribed plan of care
  - Relevance of investigations and follow up
  - Harmful impact of inappropriate care
- Life style, activity and diet specific to the particular disease
- Preventive and rehabilitative aspects of the particular disease
- Role of GP<sup>53</sup>
  - In early detection and management at primary level
  - Red flags for referrals
  - During follow up visits / review after interventions at a secondary / tertiary centre

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<sup>53</sup> General Practitioner

- Planning for continuity of care
  - Relevance of communications/ documentations during transition of care between different levels [primary, secondary. Tertiary]

#### Transactional strategies

- Lecture, group work followed by discussion: principles of management of symptoms of long term illnesses.
- Concept/overview of/ “quality of life” suggested transaction process – role play followed by discussion
- Emotional problems, social aspects and psychosocial support in incurable illness – suggested transaction process role play followed by discussion
- Group discussion: how can the principles of palliative care be integrated into routine medical practice?

#### Module 4: medical ethics: 4 hours

- e. Cardinal ethical principles – emphasis on the concepts and practice of appropriate care
- f. Autonomy; beneficence; non-maleficence; distributive justice

In the background of

- Respect for an individual
- Respect for life and the eventuality of death
- Balancing needs of the individual with that of society

#### **a. Autonomy:**

- Empowerment of autonomy through information sharing
- positives and negatives of doing a particular intervention
- Positives, negatives of **not** doing an intervention
- Adequate time and space for absorbing the information, clarifying doubts
- Limits to autonomy
- Autonomy of patient vs. family
- Autonomy vs. society’s needs
- Group work on hypothetical case situations followed by discussion

#### **b. Beneficence / non-maleficence**

- Discussion using hypothetical case histories pertaining to clinical practice and research

#### **c. Distributive justice**

- Discussion using hypothetical case histories including health economics

- g. **Concept of futile care** - disease trajectories and prognostication principles

#### Transactional strategies

#### **h. Case studies**

- Debates : euthanasia - taxonomy; current status

#### Module 5: concept of continuity of care -1 hour

- Community based care including community empowerment
- Role of medical professional in advocacy, training and empowerment
- Follow up, relevance of documentation while linking with other care settings

### **Transactional strategies**

- Exposure visit

### **Module 6 – principles of communication – 6 hours**

- Introduction to communication – the need; the influence of psychosocial stimuli.
- Barriers to effective communication. Patients, families and professionals.
- Truth telling in relation to disease
- Steps to effective communication. “do”s and “don’t”s.
- Communicating bad news

### **Transactional strategies**

- Group work on good and bad communication, followed by discussion.
- Group work on individual needs. Emotional reactions to illness and varying communication needs
- Role play/ group work on distancing tactics followed by discussion

### **Evaluation:**

- a. Ensure that there is at-least one short answer question on palliative care concept
- b. 104 ouncil 104n marks for the dimension of palliative care in student’s answers related to management of chronic diseases in clinical papers**

### **Other areas for reinforcing the concepts**

- Include palliative care principles in the pre-internship orientation program of the interns
  - 2 week posting during 3<sup>rd</sup> year and internship in a palliative care unit
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## **ANNEXURE 9 – The DRAFT Standards Document for Palliative Care Services [IAPC]**

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Palliative Care Service (providing any or all of the following)

### **Set up**

The Hospice/In-patient unit, out- patient service and home care service can exist as stand – alone units or in combination or as part of other health care facilities (eg. Hospitals).

### **Levels**

Level 1: The basic standards marked as 1.

Level 2: The components in Level 1 and those marked as 2.

Level 3: The components in Level 1 and 2 and those marked as 3.

### **Designating Levels:**

If more than one service exists in combination the Level of the service with lowest value will be given to the entire set up. (eg. For the combination of a Level 3 in patient unit and Level 2 home care service the overall level will be 2). I am copying that here.

### **A. Introduction**

A.1. The standards thus framed are on the account of the minimum requirement of this category of health care provider, namely palliative care services. There are no exclusions. They are dependent on the functions of the service provider. All sections are mandatory and include both structure and basic processes.

A.2 The different types of palliative care services available in India are the following. A service may provide any one of them or a combination of them or all of them.

A.2.1 Home based care (which is the identified as the corner stone of care plans for the chronically and incurably ill by the palliative care policy of the government of Kerala. This will be the only way to take care to a bed bound patient suffering from chronic illnesses or due to debility as in old age. Its significance is more in rural areas where health care facilities are far and few.

A.2.2. Out patient services to facilitate all aspects of palliative care for patient and their family.

A.2.3. Hospice /In-patient care services for management of difficult symptoms, terminal phase management or respite care.

## Hospice/In-patient Care In district hospital

<b>Clauses</b>	<b>Sub clauses</b>	<b>Description</b>	<b>Level</b>
<b>B Functions</b>	B.1	<b>Core functions (clinical services)</b>	
	B.1.1.	Clinical services	1
	B.1.1.1	Pain & Symptom management	1
	B.1.1.2	End of life care	1
	B.1.2	Nursing service	
	B.1.2.1	Palliative nursing care	1
	B.1.2.2	End of life care	1
	B.1.3	Respite care	1
	B.1.4	Psyco-social support / counselling / spiritual care	1
	B.1.5	Dispensary	1
	B.1.6	Training family	1
	B.1.7	Access to basic blood/urine investigations	1
	B.2	<b>Auxiliary Functions</b>	
	B.2.1	Access to Physiotherapy/occupational therapy	2
	B.2.2	Specialised care (lymphoedema care, ostomy care)	2
	B.2.3	Bereavement	2
	B.2.4	Access to diagnostics like Xray, USG	2
	B.2.5	Access to specialist consultations where appropriate (eg. Surgery, oncology)	2
	B.2.6	Training non professionals (volunteers)	2
	B.2.7	Engaging community/volunteers	2
	B.2.8	Training professionals	3
	B.2.9	Physiotherapy/occupational therapy services	3
	B.2.10	Access to advanced diagnostics	3
	B.2.11	Grief counselling	3
	C.1	<b>Space requirement</b>	
	C.1.1	Minimum bed numbers 2	1
	C.1.2	Minimum space require per bed: 80 sq feet	1
	C.1.2.1	Extra bed/Space for carers	1
	C.1.3	Functional areas	
	C.1.3.1	Nursing station	1
	C.1.3.2	Waiting area	1

	C.1.3.3	Reception	1
	C.1.3.4	Canteen/kitchen	1
	C.1.3.5	Quiet room	1
	C.1.3.6	Toilets	1
	C.1.3.7	Storage area (medicines/equipments/records)	1
	C.1.4	A signage within or outside the facility should be made available containing the following information in two languages	1
	C.1.4.1	Name of the care provider with registration number	1
	C.1.4.2	Fee structure - Basic data (as applicable)	1
	C.1.4.3	Timing of the facility	1
	C.1.4.4	Services provided	1
	C.1.4.5	List of consultants/facilities with availability days	1
	C.1.4.6	List of holidays	1
	C.1.4.7	Directional signages for Emergencies, Departments, etc (as applicable)	1
	C.1.4.8	Fire Exit	1
	C.1.4.9	Safety, hazard and caution signs (as applicable)	1
	C.1.4.10	Mandatory signs if any	1
	C.2	<b>Furniture &amp; Fixtures</b> (This will entail the details about the furniture and sundry items commensurate to the services delivery requirements.)	
	C.2.1	Furniture / Fixture Requirements . . . as required	
	C.2.2	Sundry Articles Requirement . . . as required	
	C.2.3	Others	
	C.3	<b>Facilities Engineering Requirements.</b>	
	C.3.1	<b>Civil Engineering:</b> Building plans to be approved by local authorities	1
	C.3.2	<b>Mechanical Engineering</b>	
		Equipments	
		Oxygen should be made available in cylinders.	

	C.3.3	Standby generator/battery back up should be provided for patient care areas.	1
	C.4	<b>Public Utilities</b>	
	C.4.1	Safe water for drinking / other uses	1
	C.4.2	Sanitary Requirements	
		Toilets (how many per bed?)	1
		Bathrooms (how many per bed?)	1
	C.4.3	Others (Fire protection)	
<b>D Equipment / Instruments</b>			
	D.1	<b>Therapeutic equipments</b>	
		Stethoscope BP Apparatus Torch Thermometer Tongue Depressors Forceps Water Mattresses Bed pans/Commodes Scissors Dressing Trays Backrests Suction Machines Nebulizers Wheel Chairs Walkers	1
	D.5.1	Sterilizing equipment (steriliser)	1
	D.5.2	Sterilizing equipment (autoclave)	2
<b>E. Human Resources</b>			
	E.1.1	One doctor with MBBS (registered with MCI/state council) for 25 beds with 10 days hands on training in palliative care from a recognised centre	1
	E.1.2	One doctor with MBBS (registered with MCI/state council) for 25 beds with 6 weeks hands on training in palliative care from a recognised centre	2
	E.1.3	One doctor with MBBS (registered with MCI/state council) for 25 beds	3

		with Fellowship/PG Diploma with at least one year hands on experience in palliative care	
	E.2.1	One nurse for 8 beds with Bsc/GNM (registered with state council) with 10 days of hands on training in palliative care from a recognised centre or ANM for 8 beds with 6 months hands on experience from a recognised centre	1
	E.2.2	One nurse for 8 beds with Bsc/GNM (registered with state council) with 6 weeks of hands on training in palliative care from a recognised centre or ANM for 8 beds with one year hands on experience from a recognised centre	2
	E.2.3	One nurse for 7 beds with Bsc/GNM (registered with state council) with one year of hands on training in palliative care from a recognised centre or ANM for 8 beds with two years hands on experience from a recognised centre	3
	E.3.1	One part time Social worker/counsellor	2
	E.3.1	One full time Social worker/counsellor	3
	E.4.1	One administrative staff for every 25 beds (multitasking)	1
	E.5.1	One cleaner for every 10 beds	1
<b>F Drugs</b>			
	F.1	Paracetamol Ibuprofen Diclofenac Codeine Phosphate Tramadol Metaclopramide Domperidone Dexamethasone Bisacodyl Loperamide Oral Rehydration Salts Ranitidine Betadine Lotion and Ointment Metrogyl Jelly	1

		<p>Hydrogen Peroxide  Diazepam  Haloperidol  Amitriptyline  Ciprofloxacin  Metronidazole  Amoxicillin  Fluconazole  Nutritional Supplements  Iron, Vitamin and Mineral  Supplements  Lignocaine Jelly  Ethamsylate  Deriphylline  Cough Preparations</p>	
	F.2	Access to oral Morphine	2
	F.3	Oral morphine Gabapentine	3
	G.1	<p>Dressing Supplies  Cotton  Gauze Pieces  Gauze bandages  Gloves  Micropore Tapes  Transfusion Supplies  IV Sets  Intracath and Butterfly Needles  Syringes and Needles  Tubes and Bag  Suction Catheters  Urinary Catheters  Condom Catheters  Urine Bags  Feeding Tubes  Spirit</p>	1
<b>H. Licenses</b>	H.1	License to possess and dispense strong opioid medications (eg. Recognised Medical Institutions) and the registers required as per regulations	3
	H.2	Others: There are many other Licenses and Statutory Obligations which may be of relevance to palliative care establishments. Some of them are	

		listed at .....	
<b>I. Basic Process</b>			
	I.1.	<b>Registration</b>	
	I.1.1	New Patient Register	1
	I.1.2	Admission Register	1
	I.1.3	Death Register	1
	I.2	<b>Assessment</b>	
	I.2.1	Assessment and documentation of pain	1
	I.2.2	Assessment and documentation of other symptoms	1
	I.2.3	Assessment and documentation including family tree, and of psychosocial issues	1
	I.2.4	Assessment and documentation of spiritual issues.	1
	I.3	<b>Management</b>	
	I.3.1	Management of pain	1
	I.3.2	Management of other symptoms	1
	I.3.3	Management of psychosocial issues	1
	I.3.4	Management of spiritual issues	1
	I.4	<b>Infection control</b>	
	I.4.1	Universal precautions	1
	I.4.2	Hand washing	1
	I.4.3	Vaccination	1
	I.5	<b>Safety Considerations</b>	
	I.5.1	Biomedical waste management	1
	I.5.2.	Fire safety	1
	I.6	<b>Clinical Records (To be kept for 5 years)</b>	
	I.6.1	Patient records	1
	I.6.2	Consents	1
	I.7	<b>Discharge</b>	1
	I.7.1	Discharge summary with reasons for admission, management given and plan for continuity of care	1

### 316 Out Patient Centre

Clauses		Sub clauses	Level
<b>B Functions</b>	B.1	<b>Core functions (clinical services)</b>	

	B.1.1.	Clinical services	1
	B.1.1.1	Pain & Symptom management	1
	B.1.1.2	End of life care (when appropriate)	1
	B.1.2	Nursing service	
	B.1.2.1	Palliative nursing care	1
	B.1.2.2	End of life care	1
	B.1.3	Psyco-social support / counselling / spiritual care	1
	B.1.4	Dispensary	1
	B.1.5	Access to basic blood/urine investigations	1
	B.2	<b>Auxiliary Functions</b>	
	B.2.1	Access to Physiotherapy/occupational therapy	2
	B.2.2	Specialised care (lymphoedema care, ostomy care)	2
	B.2.3	Bereavement	2
	B.2.4	Access to diagnostics like Xray, USG	2
	B.2.5	Access to specialist consultations where appropriate (eg. Surgery, oncology)	2
	B.2.4	Training non professionals (volunteers)	2
	B.2.4	Engaging community/volunteers	2
	B.2.5	Training professionals	3
	B.2.6	Physiotherapy/occupational therapy services	3
	B.2.6	Access to advanced diagnostics	3
	B.2.6	Grief counselling	3
<b>C. Physical facilities</b>			
	C.1	<b>Space requirement</b>	
	C.1.1	Consultation area	1
	C.1.2	Minimum space required	
	C.1.3	Functional areas	1
	C.1.3.1	Waiting area	1
	C.1.3.2	Reception	1
	C.1.3.3	Toilets	1
	C.1.3.4	Storage area (medicines/equipments/records)	
	C.1.3.5	Treatment room	
<b>D Equipment / Instruments</b>	D.1	<b>Therapeutic equipments</b>	
		Stethoscope	1



		BP Apparatus Torch Thermometer Tongue Depressors Forceps Bed pans/Commodes Scissors Dressing Trays Backrests Suction Machines Nebulizers Wheel Chairs Walkers	
	D.5.1	Sterilizing equipment (steriliser)	1
	D.5.2	Sterilizing equipment (autoclave)	3
<b>E. Human Resources</b>	E.1.1	One doctor with MBBS (registered with MCI/state council) for 40 patient visits with 10 days hands on training in palliative care from a recognised centre	1
	E.1.2	One doctor with MBBS (registered with MCI/state council) for 40 patient visits with 6 weeks hands on training in palliative care from a recognised centre	2
	E.1.3	One doctor with MBBS (registered with MCI/state council) for 40 patient visits with Fellowship/PG Diploma with at least one year hands on experience in palliative care	3
	E.2.1	One nurse for 20 patient visits with Bsc/GNM (registered with state council) with 10 days of hands on training in palliative care from a recognised centre or ANM for 20 patient visits with 6 months hands on experience from a recognised centre	1
	E.2.2	One nurse for 20 patient visits with Bsc/GNM (registered with state council) with 6 weeks of hands on training in palliative care from a recognised centre or ANM for 20 patient visits with one year hands on experience from a recognised centre	2

	E.2.3	One nurse for 20 beds with Bsc/GNM (registered with state 114ouncil) with one year of hands on training in palliative care from a recognised centre or ANM for 20 patient visits with two years hands on experience from a recognised centre	3
	E.3.1	One part time Social worker/counsellor	2
	E.3.2	One full time Social worker/counsellor	3
	E.4.1	One administrative staff for every 40 patient visits (multitasking)	1
	E.5.1	One cleaner for every 40 patient visits	1
<b>F Drugs</b>	F.1	Paracetamol Ibuprofen Diclofenac Codeine Phosphate Tramadol Metaclopramide Domperidone Dexamethasone Bisacodyl Loperamide Oral Rehydration Salts Ranitidine Betadine Lotion and Ointment Metrogyl Jelly Hydrogen Peroxide Diazepam Haloperidol Amitriptyline Ciprofloxacin Metronidazole Amoxycillin Fluconazole Nutritional Supplements Iron, Vitamin and Mineral Supplements Lignocaine Jelly Ethamsylate Deriphylline Cough Preparations	1

	F.2	Access to oral Morphine	2
	F.3	Oral morphine Gabapentine	3
	G.1	Dressing Supplies Cotton Gauze Pieces Gauze bandages Gloves Micropore Tapes Transfusion Supplies IV Sets Intracath and Butterfly Needles Syringes and Needles Tubes and Bag Suction Catheters Urinary Catheters Condom Catheters Urine Bags Feeding Tubes Spirit	1
<b>H. Licenses</b>	H.1	License to possess and dispense strong opioid medications (eg. Recognised Medical Institutions) and the registers required as per regulations	3
<b>I. Basic Process</b>	I.1.	<b>Registration</b>	
	I.1.1	New Patient Register	1
	I.1.2	Daily visits Register	1
	I.2	<b>Assessment</b>	
	I.2.1	Assessment and documentation of pain	1
	I.2.2	Assessment and documentation of other symptoms	1
	I.2.3	Assessment and documentation including family tree, and of psychosocial issues	1
	I.2.4	Assessment and documentation of spiritual issues.	1
	I.3	<b>Management</b>	
	I.3.1	Management of pain	1
	I.3.2	Management of other symptoms	1
	I.3.3	Management of psychosocial issues	1
	I.3.4	Management of spiritual issues	1

	I.4	<b>Infection control</b>	
	I.4.1	Universal precautions	1
	I.4.2	Hand washing	1
	I.4.3	Vaccination	1
	I.5	<b>Safety Considerations</b>	
	I.5.1	Biomedical waste management	1
	I.5.2	Fire safety	1
	I.6	Clinical Records	
	I.6.1	Patient records	1
	I.6.2	Consents (if procedures are done)	1
	I.7	<b>Discharge</b>	1
	I.7.1	Prescription (diagnosis, management plan including clearly mentioned dosages of medications, follow up plan)	1

### 318 Home care services

<b>Clauses</b>	<b>Sub clauses</b>	<b>Description</b>	<b>Level</b>
<b>B Functions  (could be clinical, nursing, psycho-social/spiritual support)</b>	<b>B.1</b>	<b>Core functions (clinical services)</b>	
	B.1.1.	Clinical services	1
	B.1.1.1	Pain & Symptom management	1
	B.1.1.2	End of life care (when appropriate)	1
	B.1.2	Nursing service	
	B.1.2.1	Palliative nursing care	1
	B.1.3	Psyco-social support / counselling / spiritual care	1
	B.1.4	Dispensing medicines/supplies	1
	<b>B.2</b>	<b>Auxiliary Functions</b>	
	B.2.1	Access to Physiotherapy/occupational therapy	2
	B.2.2	Specialised care (lymphoedema care, ostomy care)	3
	B.2.3	Bereavement	1
	B.2.4	Access to basic diagnostics	2
	B.2.5	Access to specialist consultations where appropriate (eg. Surgery, oncology)	3
	B.2.6	Training non professionals (volunteers)	2
	B.2.7	Engaging/involving community/volunteers	2
	B.2.8	Developing and encouraging community	

		participation in the care of chronically ill and bedridden.	
	B.2.9	Training professionals	3
	B.2.10	Physiotherapy/occupational therapy services	3
	B.2.6	Access to advanced diagnostics	3
	B.2.6	Grief counselling	3
<b>C. Physical facilities</b>	C.1	<b>Space requirement</b>	
	C.1.1	Contact point for patients/family to contact (can be an existing palliative care facility or stand alone) Minimum space required?	1
	C.1.2	Access to transport (public/own/rented)	
	C.1.3	Functional areas	
	C.1.3.1	Storage space for medicine, equipments, records	1
	C.1.3.2	Communication aids (phones)	1
<b>D Equipment / Instruments</b>	D.1	<b>Therapeutic equipments</b>	
		Stethoscope BP Apparatus Torch Thermometer Tongue Depressors Forceps Bed pans/Commodes Scissors Dressing Trays	1
		Backrests Suction Machines Nebulizers Wheel Chairs Walkers	3
	D.5.1	Sterilizing equipment (steriliser/pressure cooker)	1
	D.5.2	Sterilizing equipment (autoclave)	3
<b>E. Human Resources</b>	E.2.1	One nurse with Bsc/GNM (registered with state council) with 10 days of hands on training in palliative care from a recognised centre or ANM with 6 months hands on experience from a recognised centre with telephonic back up from a doctor with MBBS (registered with MCI/state council) and with a 10 days of hands on training in palliative	1

		care.	
	E.2.2	One nurse with Bsc/GNM (registered with state council) with 6 weeks of hands on training in palliative care from a recognised centre or ANM with one year hands on experience from a recognised centre with a part time doctor with MBBS (registered with MCI/state council) and with 10 days of hands on training in palliative care.	2
	E.2.3	One nurse with Bsc/GNM (registered with state council) with one year of hands on training in palliative care from a recognised centre or ANM visits with two years hands on experience from a recognised centre with a part time doctor with 6 weeks hands on training in palliative care from a recognised centre.	3
	E.2.4	Involving trained volunteers in the nursing/social care of the patients	2
	E.3.1	One part time Social worker/counsellor	2
	E.3.1	One full time Social worker/counsellor	3
	E.4.1	One administrative staff	1
	E.5.1	One additional nurse/ANM	3
<b>F. Drugs</b>	F.1	Paracetamol Ibuprofen Diclofenac Codeine Phosphate Tramadol Metaclopramide Domperidone Dexamethasone Bisacodyl Loperamide Oral Rehydration Salts Ranitidine Betadine Lotion and Ointment Metrogyl Jelly Hydrogen Peroxide Diazepam Haloperidol Amitriptyline Ciprofloxacin Metronidazole Amoxycillin	1

		Fluconazole Nutritional Supplements Iron, Vitamin and Mineral Supplements Lignocaine Jelly Ethamsylate Deriphylline Cough Preparations	
	F.2	Access to oral Morphine	2
	F.3	Oral morphine Gabapentine	3
<b>G Consumables</b>	G.1	Dressing Supplies Cotton Gauze Pieces Gauze bandages Gloves Micropore Tapes Transfusion Supplies IV Sets Intracath and Butterfly Needles Syringes and Needles Tubes and Bag Suction Catheters Urinary Catheters Condom Catheters Urine Bags Feeding Tubes Spirit	1
<b>H. Licenses</b>	H.1	License to possess and dispense strong opioid medications (eg. Recognised Medical Institutions) and the registers required as per regulations	3
<b>I. Basic Process</b>	I.1.	<b>Registration</b>	
	I.1.1	New Patient Register	1
	I.1.2	Home visits Register	1
	I.2	<b>Assessment</b>	
	I.2.1	Assessment and documentation of pain	1
	I.2.2	Assessment and documentation of other symptoms	1
	I.2.3	Assessment and documentation including family tree, and of psychosocial issues	1
	I.2.4	Assessment and documentation of spiritual issues.	1

	I.3	<b>Management</b>	
	I.3.1	Management of pain	1
	I.3.2	Management of other symptoms	1
	I.3.3	Management of psychosocial issues	1
	I.3.4	Management of spiritual issues	1
	I.4	<b>Infection control</b>	
	I.4.1	Universal precautions	1
	I.4.2	Hand washing	1
	I.4.3	Vaccination	1
	I.5	<b>Safety Considerations</b>	
	I.5.1	Biomedical waste management	1
	I.5.2	Travel safety measures (seat belt, helmet)	1
	I.6	<b>Clinical Records</b>	
	I.6.1	Patient records	1
	I.6.2	Consents (if procedures are done)	1
	I.7	<b>Prescription</b>	1
	I.7.1	Prescription (diagnosis, management plan including clearly mentioned dosages of medications if given, follow up plans)	1

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**ANNEXURE - 10 List Of Drugs For The Special Provisions Of RMI**

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Tab – Tablets

IR – Immediate release

SR- Sustained release

<b>Drug</b>	<b>Formats</b>	<b>Strengths</b>
Morphine Sulphate	Injection Tab – IR Tab – SR Capsule  Oral Morphine solution  Suppository	10mg/cc, 15mg/cc 5,10,20,30,50,60 mgs 10,15,20,30,50,60 mgs 10mg  10mg/1 ml ; 5 mg/5 ml ; 10mg/ 5 ml  10mg
Fentanyl citrate	Injection  Oral trans-mucosal preparation Transdermal patch	50ug/cc  200 micrograms 12, 25, 50, 75, 100 micrograms
Methadone	Injection  Tab  Oral solution	10 Mg /ml  5mg  1mg /ml

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**ANNEXURE 11 – Details of allocation, consumption, etc. of Morphine Sulphate for the year 2010, 2011 & 2012.**

Sl. No.	Name of Company	Type of formulation	2010 (Estimate 1000 Kg. (in base))		2011 (Estimate 400Kg. (in base))		2012 (Estimate 600Kg. (in base))
			Qty. of Morphine Sulphate allotted	Qty. of Morphine Sulphate consumed	Qty. of Morphine Sulphate allotted	Qty. of Morphine Sulphate consumed	Qty. of Morphine Sulphate allotted
1.	Pharma Chemo Laboratories, Solan	Injection & Tablet	160 Kg.	38.92 Kg.	60 Kg.	37.675 Kg.	60 Kg.
2.	Lisie Hospital Pharmaceuticals, Kochi	Injection & Tablet	65 Kg.	39.319 Kg.	50 Kg.	45.076 Kg.	60 Kg.
3.	Troikaa Pharmaceuticals Ltd., Mehsana	Injection & Tablet	22 Kg.	14.100 Kg.	29 Kg.	24.031 Kg.	40 Kg.
4.	Tablets (India) Ltd., Chennai	Injection & Tablet	15 Kg.	9.935 Kg.	15 Kg.	9.515 Kg.	15 Kg.
5.	Rusan Ltd., Dehradun	Tablet	40 Kg.	16.576 Kg.	40 Kg.	28.478 Kg.	50 kg.
6.	Modi Mundipharma, Modipuram	Tablet	15 Kg.	0.030 Kg.	27 Kg.	35.315 Kg.	34 Kg.
7.	Kwality Pharmaceuticals (P) Ltd., Amritsar	Injection & Tablet	2.5 Kg.	0.793 Kg.	2.5 Kg.	0.389 Kg.	1.25 Kg.
8.	Cipla Ltd.,	Tablet	Nil	22.981 Kg.	30 Kg.	26.015	20 Kg.

	Patalganga			(from previous year's stock)		Kg.	
9.	Verve Humancare Laboratories, Dehradun	Tablet	15 Kg.	Nil	22 Kg.	30.844 Kg.	31 Kg.
10.	Jackson Laboratories (P) Ltd., Amritsar	Injection	2 Kg.	0.670 Kg.	2 Kg.	1 Kg.	Nil
11.	Astra Zeneca Pharma India Ltd., Bangalore	Injection	5 Kg.	0.960 Kg.	Nil	0.060 Kg.	Nil
12.	BDH Industries Ltd., Mumbai	Injection	2 Kg.	1.270 Kg.	9 Kg.	0.379 Kg.	Nil
13.	West Coast Pharmaceutical Works Ltd., Ahmedabad	Tablet & Syrup	40 Kg.	7.921 Kg.	40 Kg.	3.085 Kg.	Nil
14.	Belco Pharma Ltd., Bahadurgarh	Tablet	4 Kg.	0.633 Kg.	10 Kg.	7.989 Kg.	Nil
<b>Sl. No.</b>	<b>Name of Company</b>	<b>Type of formulations</b>	<b>2010 (Estimate 1000 Kg. (in base))</b>		<b>2011 (Estimate 400Kg. (in base))</b>		<b>2012 (Estimate 600Kg. (in base))</b>
			<b>Qty. of Morphine Sulphate allotted</b>	<b>Qty. of Morphine Sulphate consumed</b>	<b>Qty. of Morphine Sulphate allotted</b>	<b>Qty. of Morphine Sulphate consumed</b>	<b>Qty. of Morphine Sulphate allotted</b>
15.	College of Pharmaceutical Sc.	Tablet & Syrup	Nil	<b>319 Kg.</b> (from previous year's stock)	20 Kg.	5.866 Kg.	Nil
16.	Kidwai Memorial of	Tablet	Nil	<b>320 Kg.</b> (from previous year's stock)	20 Kg.	10.800 Kg.	Nil

	Oncology, Bangalore							
17.	Neon Labs Ltd., Thane	Injection	3 Kg.	0.935 Kg.		10 Kg.	3.045 Kg.	Nil
18.	Sun Pharmaceuticals Advanced Research Ltd., Baroda	Test purpose	Nil	0.130 Kg. (from previous year's stock)		Nil	0.250 Kg.	Nil
19.	Raptim Research, Navi Mumbai	Test purpose	Nil	Nil		0.152 Kg.	Nil	0.152 Kg.
20.	Rusan Ltd., Ankleshwar	Apomorp hine	Nil	7 Kg. (from previous year's stock)		Nil	Nil	Nil
21.	Cadila Healthcare Ltd., Ankleshwar	Apomorp hine	71 Kg.	28.990 Kg.		Nil	Nil	Nil
22.	Standard Pharmaceuticals, Kolkata	Tablet	3 Kg.	Nil		3 Kg.	Nil	Nil
23.	Windlas Biotech, Dehradun	Test Purpose	Nil	Nil		Nil	Nil	0.500 Kg.
24.	Nektar Therapeutics, Hyderabad	Test Purpose	Nil	Nil		0.020 Kg.	Nil	Nil
25.	Wockhardt Ltd., Aurangabad	Test Purpose	Nil	Nil		0.0000 15 Kg.	Nil	Nil
26.	Om Biomedic Pvt. Ltd., Haridwar	-	12 Kg.	Nil		Nil	Nil	Nil
	<b>Total:-</b>		<b>476.5 00 Kg.</b>	<b>206.415 Kg.</b>		<b>389.6 72 Kg.</b>	<b>269.8 12 Kg.</b>	<b>311.9 02 Kg.</b>

**ANNEXURE - 12 Possible Resource And Training Centres In The Country**

<b>Region</b>	<b>Institution</b>
South India	WHO CC – Trivandrum WHOCC – Calicut Kidwai Memorial Oncology Institute [RCC] – Bangalore Karunashraya Hospice, Bangalore General Hospital, Ernakulam, Kerala
East India	MNJ Institute{RCC} – Hyderabad RCC – Bhubaneswar
North India	PGI - Chandigarh
West India	Tata Memorial Hospital – Mumbai RCC – Ahmedabad Cipla Hospice, Pune
North East India	RCC – Guwahati, Assam
Central India	AIIMS New Delhi SGPGI - Lucknow

**AAC<sup>54</sup>.12. Patient care is continuous and multi disciplinary in nature**

**AAC.14. Organization defines the content of the discharge summary**

- e. Discharge summary contains follow up advice, medication and other instructions in an understandable manner

**COP.9<sup>55</sup>. Documented policies and procedures guide the care of vulnerable patients (elderly, children, physically and/ or mentally challenged)**

- a. Policies and procedures are documented and are in accordance with the prevailing laws and the national and international guidelines.\*
- b. Care is organized and delivered in accordance with the policies and procedures.
- c. The organization provides for a safe and secure environment for this vulnerable group.
- d. A documented procedure exists for obtaining informed consent from the appropriate legal representative.\*
- e. Staff are trained to care for this vulnerable group.

**COP16. Documented policies and procedures guide appropriate pain management**

- a. Documented policies and procedures guide the management of pain.
- b. All patients are screened for pain.
- c. Patients with pain undergo detailed assessment and periodic re-assessment.
- d. The organization respects and supports management of pain for such patients.
- e. Patient and family are educated on various pain management techniques, where appropriate.

**COP.20. Documented policies and procedures guide the end of life care**

- a. Documented policies and procedures guide the end of life care.\*
- b. These policies and procedures are in consonance with the legal requirements.
- c. These also address the identification of the unique needs of such patient and family.
- d. Symptomatic treatment is provided and where appropriate measures are taken for alleviation of pain.
- e. Staff are educated and trained in end of life care.

**MOM<sup>56</sup>.9. Documented policies and procedures guide the use of Narcotic Drugs & Psychotropic Substances**

- a. Documented policies and procedures guide the use of narcotic drugs and psychotropic substances which are in consonance with local and national regulations.\*
- b. These drugs are stored in a secure manner.

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<sup>54</sup> Access, assessment and continuity of care

<sup>55</sup> COP stands for "Care of Patients" & a,b,c,d,e,... are the Objective Elements

<sup>56</sup> management of medications

- c. A proper record is kept of the usage, administration and disposal of these drugs.
- d. These drugs are handled by appropriate personnel in accordance with the documented procedure

**PRE<sup>57</sup>.2. Patient and family rights support individual beliefs values and involve the patient and family in decision-making process.**

- a. Patient and family rights include respecting any special preferences, spiritual and cultural needs.
- b. Patient and family rights include respect for personal dignity and privacy during examination, procedures and treatment.
- c. Patient and family rights include protection from physical abuse or neglect.
- d. Patient and family rights include treating patient information as confidential.
- e. Patient and family rights include refusal of treatment.
- f. Patient and family rights include informed consent before transfusion of blood and blood products, anaesthesia, surgery, initiation of any research protocol and any other invasive / high risk procedures/ treatment.
- g. Patient and family rights include right to complain and information on how to voice a complaint.
- h. Patient and family rights include information on the expected cost of the treatment.
- i. Patient and family have a right to have an access to his/her clinical records.
- j. Patient and family rights include information on plan of care, progress and information on their health care needs.

**PRE.3. The patient and/or family members are educated to make informed decisions and are involved in the care planning and delivery process.**

- a. The patient and/or family members are explained about the proposed care including the risks, alternatives and benefits.
- b. The patient and/or family members are explained about the expected results.
- c. The patient and/or family members are explained about the possible complications.
- d. The care plan is prepared and modified in consultation with patient and/or family members.
- e. The care plan respects and where possible incorporates patient and/or family concerns and requests.
- f. The patient and/or family members are informed about the results of diagnostic tests and the diagnosis.
- g. The patient and/or family members are explained about any change in the patient's condition.

**PRE<sup>58</sup>.4. A documented process for obtaining patient and / or family's consent exists for informed decision making about their care.**

- a. Documented procedure incorporates the list of situations where informed consent is required and the process for taking informed consent.\*

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<sup>57</sup> Patient Rights and Education

<sup>58</sup> Patient Rights and Education

- b. General consent for treatment is obtained when the patient enters the organization.
- c. Patient and/or his family members are informed of the scope of such general consent.
- d. Informed consent includes information regarding the procedure, risks, benefits, alternatives and as to who will perform the requisite procedure in a language that they can understand.
- e. The procedure describes who can give consent when patient is incapable of independent decision making.\*
- f. Informed consent is taken by the person performing the procedure.
- g. Informed consent process adheres to statutory norms.
- h. Staff are aware of the informed consent procedure.

**PRE.5. Patient and families have a right to information and education about their healthcare needs.**

- a. Patient and/or family are educated about the safe and effective use of medication and the potential side effects of the medication, when appropriate.
- b. Patient and/or families are educated about food-drug interactions.
- c. Patient and/or families are educated about diet and nutrition.
- d. Patient and/or families are educated about immunizations.
- e. Patient and/or families are educated about organ donation, when appropriate.
- f. Patient and/or families are educated about their specific disease process, complications and prevention of strategies.
- g. Patient and/or families are educated about preventing healthcare associated infections.
- h. Patients and/or family are educated in a language and format that they can understand.

**PRE.6. Patients and families have a right to information on expected costs**

- a. There is uniform pricing policy in a given setting (out-patient and ward category).
- b. The tariff list is available to patients.
- c. Patients and/or family are explained about the expected costs.
- d. Patients and/or family are informed about the financial implications when there is a change in the patient condition or treatment setting.

**CQI<sup>59</sup>.1. There is a structured quality improvement and continuous monitoring programme in the organization.**

- a. The quality improvement programme is developed, implemented and maintained by a multi-disciplinary committee.
- b. The quality improvement programme is documented.\*
- c. There is a designated individual for coordinating and implementing the quality improvement programme.
- d. The quality improvement programme is comprehensive and covers all the major elements related to quality assurance and supports innovations.

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<sup>59</sup> Continuous Quality Improvement



- e. The designated programme is communicated and coordinated amongst all the staff of the organization through proper training mechanism.
  - f. The quality improvement programme identifies opportunities to improvement based on review at pre-defined intervals
  - g. The quality improvement programme is a continuous process and updated at least once in a year.
  - h. Audits are conducted at regular intervals as a means of continuous monitoring.
  - i. There is an established process in the organization to monitor and improve quality of nursing and complete patient care.
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## Kerala Gazette

### GOVERNMENT OF KERALA

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KERALA GAZETTE

Annexure 16

EXTRAORDINARY

PUBLISHED BY AUTHORITY

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### GOVERNMENT OF KERALA

#### Taxes (G) Department - NOTIFICATION

G.O. (Ms.) No. 165/99/TD. Dated, Thiruvananthapuram, 26<sup>th</sup> Nov 1999.

**S.R.O.No. 972/99** – In exercise of the powers conferred by sections 10 and 78 of the Narcotic Drugs and Psychotropic Substances Act, 1985 (Central Act 61 of 1985), the Government of Kerala hereby make the following rules further to amend the Kerala Narcotic Drugs and Psychotropic Substances Rules, 1985 issued under Notification No. G.O. (Ms.) No. 135/85/TD. dated 7<sup>th</sup> November, 1985 and published as S.R.O. No. 1514/85 in the Kerala Gazette Extraordinary No. 966 dated 8<sup>th</sup> November 1985, namely: -

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## RULES

1. *Short title and commencement.* – (1) These rules may be called Kerala Narcotic Drugs and Psychotropic Substances (Amendment) Rules, 1999.

(2) These rules shall come into force at once

2. *Amendment of the Rules.* – In the Kerala Narcotic Drugs and Psychotropic Substances Rules, 1985. –

(1) In rule 2, after 'q' the following clauses shall be added, namely : –

(r) “morphine” means any preparation containing morphine;

(s) “recognised medical institution” means an Hospital or Medical Institution recognised by the Drugs Controller for the purposes for chapter IV A,”

(2) [ In corporation of new part: (1)] after the existing part IV, the following part shall be inserted, namely : –

### PART IV A

#### *Special provision regarding morphine:*

57 A. *Recognition of medical Institutions.* – (1) Every medical institution which intends to be recognised for the purpose under this chapter shall apply in the format at Annexure I to the Drugs Controller appointed by the State Government who shall convey his decision within three months of the receipt of the application.

(2) If it comes to the notice of the Drugs Controller that morphine obtained by recognised institution was supplied for non-medical use or that any of the Rules under this Chapter is not complied with, for reasons to be recorded in writing and after hearing the party, the Drugs controller may revoke the recognition accorded under these rules.

57 B. *Duties of the recognised Medical Institution.* – Every recognised medical institution shall, –

(1) designate one or more qualified medical practitioner who may prescribe morphine for medical purposes. When more than one qualified medical practitioner have been designated so, one of them shall be designated as over –all in charge.

(2) The designated medical practitioner or the over-all in charge, as the case may be shall, –

(a) endeavour to ensure that the stock of morphine is adequate for patient needs;

(b) maintain adequate security over stock of morphine;

(c) maintain a record of all receipts and disbursements of morphine in the format enclosed as Annexure II, and;

- (d) ensure that estimates, and other relevant information required to be sent by the recognised medical institution under this chapter are sent to authorities concerned in time.
- 57 C. *Sending of estimates of requirement of morphine by the recognised medical institution.* – Every recognised medical institution shall send their annual requirement of morphine in the format at Annexure III by 30<sup>th</sup> November of the preceding year along with the name and address of the supplier from whom they intend to buy it, to the Drugs Controller.
- 57 D. *Approval of estimates by the Drugs Controller.* – The Drugs Controller of the State, who receive the annual requirement, shall consider it. A reply on approved estimates or rejection of the estimate shall be sent before 21<sup>st</sup> of December of the preceding year. A copy of the communication shall be sent each to the supplier whose name has been given in the estimate and to the Drugs Controller of the State/
- 57 E. *Supplementary estimates.* – If the requirements of the recognised medical institution exceeds the annual estimate approved by the Drugs Controller of the State the recognised medical institution may send a supplementary estimates at any time to the Drugs Controller which shall be considered and dealt with by him in the same manner as the annual estimates.
- 57 F. *Possession, transport purchase etc.* – The provisions of these rules in other chapters in respect of possession, transport, purchase, sale, import inter-state, export inter-state or use of manufactured drugs shall not apply to possession, transport, purchase, sale, import inter-state, export inter-state or use of morphine in respect of a recognised medical institution, possession, transport, purchase, sale, import inter-state, export inter-state or use of morphine in respect of a recognised medical institution shall be in accordance with the following provisions:
- (a) The recognized medical institution shall place orders for purchase to a manufacturer/supplier in the format at Annexure IV along with a photocopy of the communication of the Drugs Controller vide which the institution was recognised for the purposes for the purposes of this chapter and a copy of the communication of the Drugs Controller vide which the approved estimates were conveyed. A copy of the order for purchase shall be sent to the Drugs Controller and the Narcotics Communication of India.
- (b) Any manufacturer/Supplier shall send morphine to the recognised medical institution under this chapter only on the basis of an order for purchase received in the format at Annexure IV along with copies of recognition granted by the Drugs Controller and the approved estimates communicated by the drugs Controller. The manufacturer/supplier shall dispatch the morphine consignment along with a consignment note in quadruplicate in the format given in Annexure V. Copies of the consignment note shall be sent by the manufacturer/supplier is located, the Drugs Controller of the State in which the recognised medical institution is located and the Narcotics Commissioner of India. He shall also keep a copy of the consignment note.
- (c) On receipt of the consignment, the recognised medical institution shall enter the quantity received with date in all the copies of the consignment note, retain the original consignment note, sent the duplicate to the supplier, triplicate to the Drugs Controller, the quadruplicate to the to the drugs Controller of State (in cases in which the consignment originated outside the State) in which the supplier is located and the quadruplicate to the Narcotic Commissioner of India.
- 57G. *Maintenance of Records.*–All records generated under this chapter shall be kept for a period of two years from the date of transaction which shall be open for inspection by the officers empowered by the State Government under Section 41 and 42 of the Narcotic Drugs and Psychotropic Substances Act, 1985.
- 57H. *Inspection of Stocks of morphine* – The stocks of morphine under the custody of a recognized medical institution shall be open for inspection by the Drugs controller or any other Officer subordinate by his.

571. *Appeals* – Any institution aggrieved by any decision or order passed by the Drugs Controller relating to recognition, revocation of recognition of any institution or estimates may appeal to the secretary to Government, Department of Health, Government secretariat, Thiruvananthapuram within ninety days from the date of communication of such decision or order.

*Note:*

1. This consignment note shall be serially numbered on annual basis.
2. The consignor should record a certificate on the cover page of each book containing consignment notes indicating the number of pages contained in the consignment note book.
3. The consignor should maintain a register showing the details of the books of consignment note brought in use during a particular year.
4. Each consignment of morphine shall be accompanied by this consignment note in quintuplicate (i.e. five)
5. Each consignment note shall be retained for a period of two years from the date of transaction.
6. The records referred to at items 2 to 5 above in this note shall be produced to the authorised officers whenever called upon during the course of their inspection.

ANNEXURE – I of the Amended Rules [1999]in Kerala Narcotic Drugs and Psychotropic  
Substances Rules, 1985  
(See rule 57 a)

1. Name of the Institution and Address :
2. Name of the Head/in-charge of the Institution :
3. No. of persons employed
  - i. Doctors :
  - ii. Nursing Staff :
  - iii. Others :
4. No. of patients treated during the previous  
calendar year :
  - i. Inpatient :
  - ii. Out patient :
5. Whether the hospital has facilities to treat  
cancer patients : Yes/No
6. No. of cancer patients treated during  
previous calendar year :
  - i. Inpatient :
  - ii. Out patient :
7. Name of the qualified medical practi-  
tioner who would prescribe morphine  
(if there are more than one qualified  
medical practitioner who would pres-  
cribe morphine, indicate the name of  
the medical practitioner who would be  
overall in charge) :
8. Whether the institution's recognition  
for the purpose was withdrawn earlier  
(If the recognition was withdrawn earlier  
the details are to be given) :

Station :  
Date

Signature of the Head / in-charge  
of the institution with name

ANNEXURE II

(See Rule 57B)

RECORD OF RECEIPT DISBURSEMENT AND BALANCE OF MORPHINE

Date:

Quantity in hand at the beginning of the day	Details of quantity received					Details of quantity disbursed				Quantity in hand at the close of day
	Sl. No	Quantity	From whom received	Consignment note/bill of entry No		Sl. No	Quantity	Name of the person and address to whom disbursed	Name of the medical practitioner who prescribed	

Signature

*Note:*

1. *This record is to be maintained on day to day basis and entries shall be made for each day the institution functions. Entries shall be completed for each day before the close of the day. The authorized medical practitioner/ in charge or any person authorized by them shall initial after entry of each day with date. The pages of the register shall contain necessary numbers.*
2. *This record shall be retained for two years from the date of last entry.*
3. *This record shall be produced to the authorised officers whenever called upon during the course of their inspection.*





ANNEXURE – IV

(See rule 57 F)

ORDERS FOR PURCHASE

To

.....

.....

(Name and address of the supplier)

1. Name and address of the recognised medical institution which places the order.
2. Description of the quantity for which order is placed.
3. Whether the institution has been recognised by the Drugs Controller (A photocopy of the recognition is to accompany each order for purchase)
4. Whether this order is covered by the estimate approved by the Drugs Controller ( A photocopy of the approved estimate is to accompany each order of purchase).
5. Details of other orders for purchase made during the year.

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<i>Sl No.</i>	<i>Quantity</i>	<i>To whom order was placed</i>
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Station:

Date:

Signature of the person authorised to  
place order with name and designation

*Note:*

1. A copy of this order shall be kept by the recognised medical institution which places the order.
2. This shall be retained for two years from the date of transaction.

ANNEXURE – V

(See rule 57 F)

CONSIGNMENT NOTE

(To accompany a consignment of morphine)

Date and time of dispatch of  
the consignment .....

1. Name and address of consignor
2. Name and address of the consignor i.e  
Recognised medical institution
3. Description and quantity of the consignment

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<i>No. of packages</i>	<i>Quantity</i>	
	<i>Gross</i>	<i>Net</i>

---

4. Mode of transport (particulars of the transporter, Registration number of the vehicle, RR., if the transport is by railways etc).

Signature of the Consignor with  
date (Name and designation)

*To be filled by consignee :*

5. Date and time of receipt by the consignee  
and his remarks.
6. Quantity received by the consignee

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<i>No. of packages</i>	<i>Quantity</i>	
	<i>Gross</i>	<i>Net</i>

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Signature of the Consignor

With date (Name and designation)