Guidelines for

Developing Palliative Care Services

Recommendations of an Expert Group Meeting

17th–18th June 2008

MNJ Institute of Oncology and RCC
Hyderabad

Developed under the
Government of India – World Health Organization
Collaborative Programme-2008–2009

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Foreword

I have great pleasure in writing the foreword to *Guidelines for Developing Palliative Care Services*.

In India, where chronic diseases account for 53 percent all deaths, long-term care of chronically ill patients like those with cancer is emerging as a major healthcare issue. India has many centres offering palliative care services, and there is need to develop and expand such centres across the country. This manual has been developed through an expert committee to help interested institutions to start palliative care services in hospital and community settings.

The manual has been divided into three sections. Since oral morphine availability is critical to the establishment of palliative care services, an entire section has been devoted to the current procedures for ensuring oral morphine availability. Section II and III outline the process of developing a palliative care service in a hospital and within a community respectively. The manual also includes information on training facilities and training programmes on palliative care available in different parts of India.

All the three sections are supported by flow charts, tables and examples, which make the text more lucid and enable a better grasp of the content. Attention has been paid to both the basics as well as advanced aspects, making it a useful manual for both the uninitiated and the expert.

I am certain that any individual interested in contributing to palliative care will find this manual useful. It serves both as an introduction and a practical guide.

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Acknowledgements

We thank all the experts who attended the workshop and helped us in creating the guidelines for developing palliative care services and opioid availability. The contribution of other professional colleagues and experts in the field of palliative care and opioid availability is also gratefully recognized. We would like to specially acknowledge and thank the Ministry of Health & Family Welfare, Government of India - WHO India Country Office for their support for their technical & financial support.

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SECTION 1

Introduction

There are an estimated 2.5 million cases of cancer in India at any given time[1]. About 2.5 million people in India, aged between 15 and 49, are estimated to be living with HIV/AIDS[2].

More than 70% of all cancers are found when the disease is so advanced that treatment is much less effective and palliative care becomes necessary. It is estimated that 50–80% of patients with HIV/AIDS would also benefit from palliative care services.

Modern principles of palliative care can take care of the suffering in patients with incurable diseases, considerably diminishing the anguish of the patient and the family. Palliative care is aimed at improving quality of life, by employing what is called "active total care", treating pain and other symptoms, at the same time offering social, emotional and spiritual support.

The World Health Organization in 2002[3], defined palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- 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

Palliative care is a **continuum of care** (*See Figure 1*). When the disease is amenable to curative treatment, especially if the treatment is a long-drawn out process like in cancer, all principles of palliative care need to be applied starting from the time of diagnosis. This is commonly called supportive care and needs to be incorporated into the disease-specific treatment programme. As the illness progresses, the treatment intended to modify the disease decreases, while the role of palliative care increases. As the person reaches the end of life, palliative care is provided as terminal/end of life care. After the patient dies, the care is extended as bereavement counselling and support for the grieving family and friends.

Pain relief is an extremely important component of palliative care, and can ensure improved quality of life for the patient. In 1986, the World Health Organization (WHO) published guidelines for cancer pain management based on a three-step analgesic ladder (*See Figure 2*).

These steps comprise a sequential approach to pain management according to the individual pain intensity. It begins with non-opioid analgesics for mild pain and progresses to weak opioids like Propoxyphene, Codiene and Tramadol for moderate pain, and strong opioids like oral morphine and Transdermal Fentanyl Patch for severe pain.

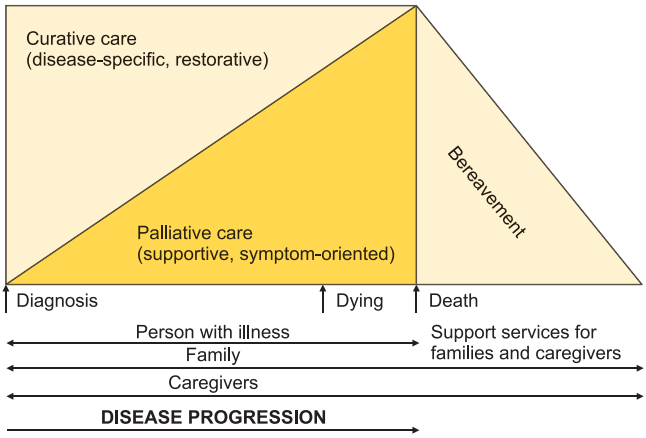


Figure 1: *The continuum of care associated with curative and palliative care in chronic progressive illnesses*

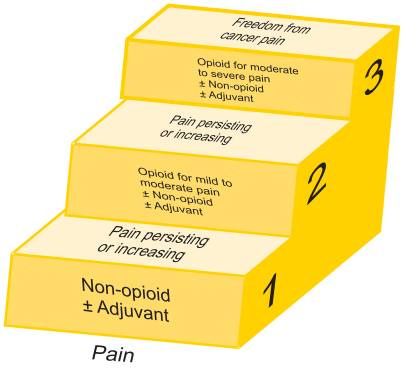


Figure 2: *WHO's three steps analgesic ladder*

Box 1 Common opioids available in India	
Weak Opioids (Step 2)	***Strong Opioids (Step 3)***
Codeine	Morphine
Dextropropoxyphene/ Propoxyphene (usually in combination with Paracetamol)	Pethidine
Pentazocine	Fentanyl
Tramadol	
Buprenorphine	

Morphine is the only oral opioid belonging to Step 3 (strong opioid) of the WHO analgesic ladder available in India (*Box 1*). Codeine, Dextropropoxyphene, Tramadol and Pentazocine are available from pharmacies on ordinary prescription. Tablet/injection Buprenorphine requires double prescription. Morphine, Pethidine and Fentanyl belong to controlled group of drugs and require special licensing.

Extensive and carefully documented clinical experience has shown that when used appropriately the fear of addiction to morphine is unfounded[4, 5].

SECTION 2

Making Oral Morphine Available

In India, the manufacture, possession, sale and availability of morphine and other narcotic drugs are governed by the Narcotic Drugs and Psychotropic Substances (NDPS) Act 1985. The Act is aimed at preventing the easy availability of such substance for misuse and addiction.

In 1998, the Government of India (GOI), realising the importance of making morphine available for pain relief, proposed a model amendment to the NDPS Act. The amendment simplifies the procedure for licensing of medical institutions providing palliative care to possess and prescribe morphine. Some states have amended their regulations, based on the GOI recommendations, while others still follow the unamended Act (*Box 2*).

Box 2 States with Amended Narcotic Rules in India.	
Arunachal Pradesh	Jammu and Kashmir
Delhi	Goa
Dadra and Nagar Haveli	Karnataka
Kerala	Madhya Pradesh
Orissa	Uttar Pradesh
Sikkim	Tamil Nadu
Tripura	Andhra Pradesh

I. State with Amended Regulation

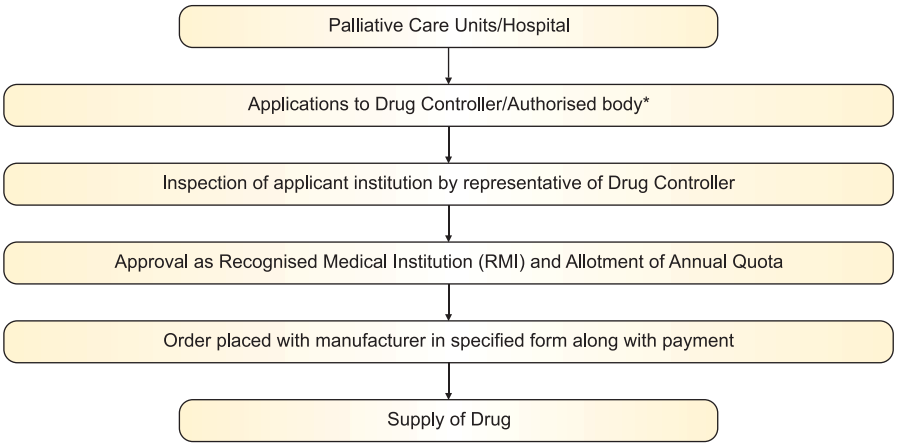
Some states have amended the narcotic rules, with the controlling responsibility resting only with the Drugs Controller in the State Health Department. The Drugs Controller approves palliative care programmes/hospitals who require morphine as "Recognized Medical Institutions" (RMIs) based on their application, and grants them a morphine quota. This simplifies the whole licensing process because only one licensing body is involved instead of the multiple involved in the older NDPS rule (*See Appendix I*).

Palliative care units/hospitals have to apply to the Drugs Controller or to a representative appointed by him. If found satisfactory, the unit will be approved as a Recognized Medical Institution by the Drugs Controller who will then allot a specified quota of morphine in the specified form. In some states like Kerala, the Drugs Controller has appointed a panel of palliative care physicians to inspect the applicant institution and make the necessary recommendations. AppendixIII describes the special provision for the use of oral morphine following amendment in the NDPS act in Tamilnadu.

(For the formats prescribed for the application, and for the details of the provisions involved for the RMIs in amended state, Refer to Appendix I & II).

'Recognized Medical Institution (RMI)' is a hospital or a medical institution recognized for the purposes of obtaining morphine in a state with amended regulations.

The following flow chart (*See Figure 3*) indicates the steps involved in proing oral morphine in states with amended regulations.



*The Drugs Controller may ask for evidence of qualification and registration of the doctor.

Figure 3: *Steps to procure oral morphine in a state with amended regulation*

II. State with no amendment (which follows the NDPS Act, 1985)

There are four types of licensing involved in the NDPS Act (*See Appendix I*) to procure oral morphine.

a. Possession license (specified in terms of drug, formulation, and quantity; for example, one licensed to hold injection morphine will have to get a fresh license for oral morphine. One who has a license for morphine tablets will still need a separate one for liquid morphine)
b. Import permit (to bring it from the state of manufacture)
c. Export permit (to send it out of the state of manufacture)
d. Transport permit from district to district within the state (in some states).

The detailed steps for procuring oral morphine in a typical state following the NDPS Act are given in (*Figure 4*).

1. Application to local Excise Office for grant of license
2. Inspection of applicant institution by local Excise Official
3. Forwarding of application to Excise Commissioner at state capital
4. Forwarding of application to Drugs Controller in capital
5. Forwarding of application to local office under Drugs Controller
6. Inspection of the institution by Drugs Inspector
7. Transmission of approval of Drugs Inspector to Drugs Controller
8. Forwarding to Health Authority for approval
9. Forwarding to relevant official for inspection/recommendation
10. Transmission of approval to Health Authority
11. Transmission of approval from Health authority to Drugs Controller
12. Transmission of approval of Drugs Controller to Excise Commissioner
13. Transmission of approval to local Excise Office
14. Issue of possession license and import permit
15. Order placed with manufacturer of drug formulation in another state along with payment
16. Application by manufacturer to Excise Office in that state for export permit (if the manufacturer is in another state)
17. Granting of export permit by Excise Office to manufacturer
18. Drug dispatched by registered post parcel
19. Receipt of parcel by applicant institution
20. Intimation to local Excise Office
21. Visit by Excise Official for parcel to be opened in his presence

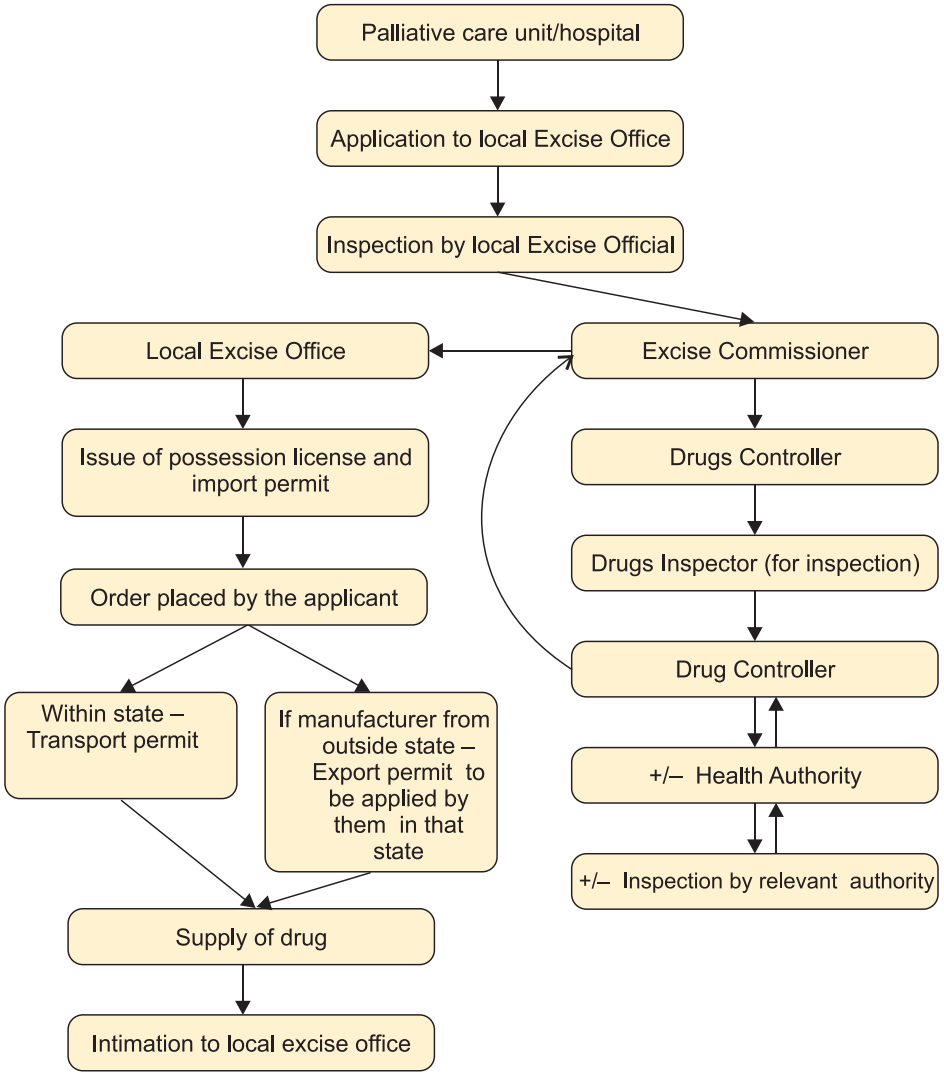


Figure 4: *Steps to procure oral morphine in a state without amended regulation*

Procedure to Amend the Law Related to Procurement of Oral Morphine in a State where it is not Amended

Simplification of the law will make oral morphine more easily available for medical use. The Government of India has given clear recommendations to all the states to amend the regulation according a to model procedure/rule (*See Appendix I*). This will simplify the licensing requirements under the NDPS Act for easier availability of morphine for medical use. For an amendment to occur, it is essential to have

- A concurrence of different departments involved in licensing and regulations namely, health, revenue and law.
- Doctors working in the ministry of health and senior doctors of specialty concerned like oncology sensitized enough to give expert opinion in favour of required action.

It is also important to have the presence of a consultant who has worked in the area of opioid availability and amendment in other states for expert opinion/clarifications.

Steps to Amend the Rules

In some states, the government amended the law straightaway following the directive given by the Government of India (e.g. in Sikkim, Tripura and MP). To make oral morphine available in the respective states (*See Figure 5*), it is useful to arrange workshops involving all the officials concerned. It is essential that such a meeting be chaired by either a Minister or a Government Secretary—to ensure participation of officials (Minister/Secretary of Health, Minister/ Secretary of Revenue, Drugs Controller, Directorate of Medical Education, Directorate of Health Service, representative of the Law Department, public health specialist, and consultants who are familiar with the previous work done in other states).

Sometimes a series of meetings are required by different departments at various stages of amendment. The proceedings of each meeting should be filed and used for the purpose of future meetings and clarifications.

Important

1. It is essential to brief as many of the officials as possible in advance, particularly doctors (DME, DHS).
2. The support of media, press reports/TV programmes appearing in a few days before the workshop is helpful.
3. Once the law is amended, it will be helpful if the Drugs Controller frames a standard operating procedure to guide the processing of application for the Recognized Medical Institution (RMI) status.

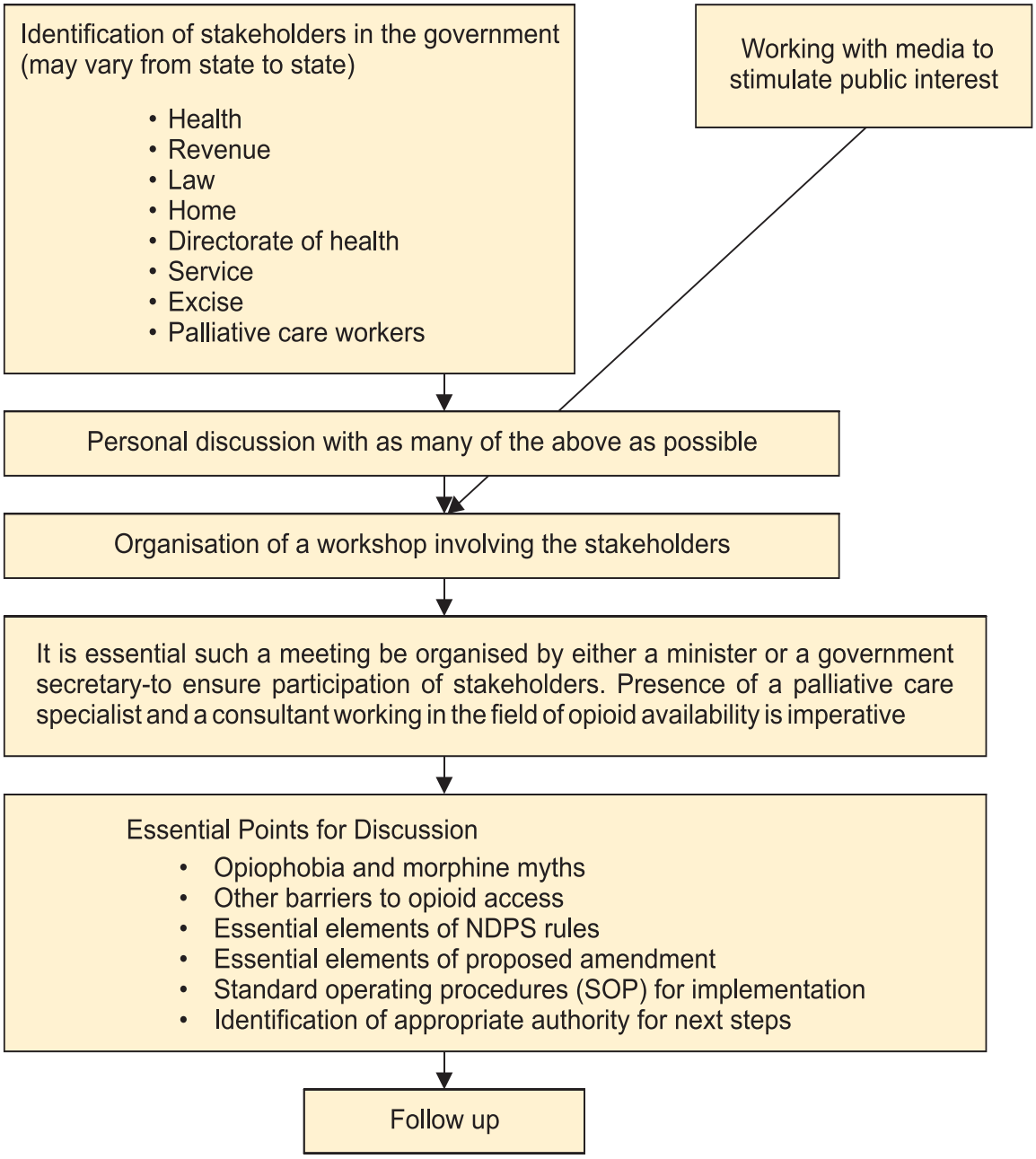


Figure 5: *Usual procedure to facilitate simplification of narcotic regulations in states*

Key Messages

- Oral morphine is the drug of choice for severe pain in cancer patients
- If used judiciously for patients in pain, oral morphine does not produce addiction
- Both healthcare professionals and law enforcement and regulatory personnel share a responsibility for ensuring that prescription pain medications are available to the patients who need them and for preventing these drugs from becoming a source of harm or abuse
- Every state should amend the rule as per GOI directives and develop a mechanism to recognize RMIs
- Capacity building in palliative care can ensure increase in both demand and supply of opioids for people in pain.

SECTION 3

Setting up of a Palliative Care Service within a General Hospital

There are different models of palliative care delivery and they play complementary roles in addressing different needs of patients and their families at different stages of their illnesses. Establishing a palliative care service in a hospital is one such model.

Rationale of a Hospital-based Palliative Care (HBPC)

There are compelling reasons for delivering palliative care in an acute-care setting and alongside other disciplines. Some distinct advantages are as follows.

1. **From a care perspective**

   Availability of HBPC will help to maintain the continuity of care for patients suffering from chronic illness and to have a smooth transition from curative to palliative care. The environmental and psychological adjustments are minimal for patients and their caregivers. Easy cross referral to other specialities, when needed, is possible.

2. **From a team perspective**

   On-site availability of different specialities makes care more comprehensive and effective. It encourages the palliative care team to use evidence-based principles and treatments. Pooling of manpower resources makes it an efficient option, providing skill and expertise, and facilitates sharing of costs.

3. **From a perspective of common facilities**

   Appropriate basic and advanced diagnostic and therapeutic procedures can be easily offered to patients, thus making care more comprehensive and efficient.

4. **From a perspective of promoting palliative care in the institution**

   Keeping palliative care in the 'mainstream' helps other specialists and disciplines to learn better end-of-life care and symptom management. It affords an excellent opportunity to demonstrate the positive impact of palliative care on the lives of patients and their families to health professionals, opinion makers, administrators and the general public.

5. **Fosters goodwill and greater public involvement**

   With the philosophy of palliative care percolating to all levels in the hospital, the overall environment is one of compassion and care. This offers immeasurable benefits to the institution. It also encourages greater public involvement in supporting palliative care and other charitable activities of the hospital.

Starting a Palliative Care Service in a Hospital

Before starting a HBPC service, it is strongly recommended to do a *Needs Assessment*.

Defining the Target Population

The selection of the target population for a palliative care plan will depend on the number of patients (adults and children); the urgent need of those patients and their family members and caregivers; and the resources available.

To start with the focus may be on terminal cancer patients and their caregivers as the majority of them (over 80%) suffer from severe pain and other serious symptoms that require urgent relief. But later on the scope of such a service should extend to patients with other chronic life - threatening conditions and geriatric patients.

All hospitals involved in the treatment of cancer patients are strongly encouraged to have a palliative care service. Any hospital that caters to people with chronic illnesses like HIV/AIDS, chronic respiratory disease and chronic renal disease may also consider having an HBPC.

Setting Priorities

It is essential to set priorities, because resources will never be able to meet all health needs. Careful priority-setting is particularly relevant in resource-constrained contexts where it is important to make the best use of very limited resources. The criteria for selecting priorities for palliative care need to be discussed by the steering committee

To set priorities, first identify the patients who need palliative care and assess:

- the burden they represent in terms of mortality and morbidity;
- the proportion of cases in advanced stages;
- the urgency of their needs (pain relief, control of other symptoms, social support);
- the societal impact of the disease (for example, whether the disease affects children, underprivileged communities and caregivers).

Then choose the type of palliative care strategy depending upon:

- cost-effectiveness of the startegy;
- affordability;
- sustainability;
- political will.

The Process to Start a HBPC

Once the initial needs assessment is done, the following steps are recommended before starting the process of setting up a HBPC (*Box 3*).

Box 3 Pre-requisites for setting up a HBPC
• Garnering the support of the top management (like the hospital governing committee and the hospital chief executive) for the project. Seeking their support and involvement at an opportune moment is of paramount importance.
• Promoting the palliative care concepts to the key stakeholders (e.g. head of other departments).
• Identifying a nodal perc son to lead the intiative.
• Sensitizing the staff members to the philosophy and need for palliative care.
• Making efforts to promote palliative care using public awareness campaigns.
• Setting up a minimal budget and recurrent cost. Allocating resources for this activity.
• Identifying the gaps in infrastructure in the hospital.
• Identifying the source of funding for the set-up cost and the recurrent expenditure.
• Ensuring referrals from the health professionals in the community being served.
• Looking for patients acceptance to the care setting and care model that are being planned.
• Monitoring & evalution of HBPC to observe whether programme is meeting it's objectives.

Models of Palliative Care Services

There are different models of palliative care services that can be followed in a hospital-based setting.

a. Out-patient (hospital consultation) services only
b. Out-patient with day-care facilities
c. Out-patient with in-patients care
d. Dedicated in-patient unit
e. Home care

Depending on the requirements, infrastructure and resources, the hospital can begin with a model and expand the services as needed.

a. Out-patient/Consultation Service in a Hospital

The out-patient unit performs the important role of offering low-cost care to a large number of patients who are ambulatory and mobile.

The personnel for a consultation team can be simply a nurse, social worker or physician alone or combination of all. Patients can be referred to this team for help in sorting out difficult pain, symptom control, nursing issues and psychosocial support. The team can provide advice on palliative care without major infrastructure needs. Consultancy can also be provided to patients admitted to different units of the hospital. This model can also facilitate training of other health professionals.

This is the best model, if resources are limited or with minimal institutional needs e.g. a small local hospital with no oncology with minimal service and for a 'start-up' palliative service. funding is still required and should be arranged before any such service is started.

Advantages of an Out-patient/Consultation Service in a Hospital over a Dedicated Unit include:

- Constraints for space, equipment and facilities are absent.
- Minimal personnel commitment (no night call, no holiday relief unless readily available)
- Ability to train other disciplines on issues like end-of-life care
- Use of pre-existing diagnostic and therapeutic resources and other hospital staffs
- Use of the hospital pharmacy and its specialist pharmacists

However, experience shows that it is much more challenging to bring the suffering under control in a general ward, even with a palliative care consultation service than in a separate Palliative

Care Unit (PCU) with its dedicated trained staff.

Some Limitations of an Outpatient/Consultation Service:

- Inadequate capacity to use opioids among health care providers (e.g., a ward doctor discontinues morphine when the patient vomits it is only after a day or two that the palliative care consultant learns of this).
- The policy of a unit may not make it easy/possible for a family to remain near a dying patient
- Overcrowding of patients is a problem
- Staff in the unit have limited experience of talking to/listening to a dying patient
- Staff have inadeqate skills to manage "death rattle" and fail to call for help
- Junior staff are unclear whether to consult their senior doctor or the physician of the palliative care team when a crisis arises.
- Some senior doctors take offence when changes in a regimen are suggested.

b. Day Care Service

The **day care service** could also be a part of the consultation service. It offers stabilization of symptoms, respite care for relatives, counselling of the patient and the family on a day-care basis. Various minor procedures like ascitic or pleural fluid tapping, wound care, enema, lymphedema management, injections and educatin the family may be carried out in a day care service.

c. In-patient Service

With increasing demand, the hospital may create a **dedicated in-patient service** by designating some beds for the use of the palliative care team. The staff trained and familiar with every aspect of palliative care will be there round the clock to look after the patients. This may be a better approach as the quality of care can be more consistent and monitored better. This could also serve as a *demonstration unit* and act as a hub of training.

d. Home-Based Care

A **home care-based service** is another way of reaching out to those who are very sick and need palliative care but cannot travel to the hospital. It harnesses the strengths of the family and imposes far less financial and infrastructure demands on the hospital. The community-based palliative care is described in detail in Section 3. The guidelines for home-based palliative care services are available at http://www.whoindia.org/LinkFiles/Cancer_cansupport.pdf.

Building a Team

This is a very crucial step in getting started. While there are many ways of staffing, the minimum persons needed are listed with their responsibilities in the matrix given below.

Box 4 Staffing required and their responsbilities[6]

Personnel	*Role*	*Capacity/skills*	*Position*	*Availability*
Doctor*	Team Manager/ member	Training in PC and communication skills as per IAPC recommendation	Regular staff	Full time/ part time depending on load
Nurses*	Team member	Training in PC and communication skills as per IAPC recommendation	Regular staff	Full time
Counsellor	Team member	Orientation in palliative care Special needs in palliative care Communication skills	Regular/visiting	Full time
Social worker	Team member	Training Communication skills Networking	Visiting/Regular	Full time/part time
Volunteers	Additional support to the team	Specific to the role	Visiting	Part time

**Currently, there are very few structured training programmes for palliative care in India. The current biannual 8-week course (distant- education) run by the Indian Association of Palliative Care, with a supervised 10-day clinical training in a palliative care unit may be considered as a minimum requirement. This would apply both doctors and nurses.*

Counsellors and social workers will need additional training which could be accessed from existing palliative care units in India. All levels of staff are encouraged to seek suitable higher level training. For details of various training programmes being offered in different parts of the country, refer to the website of Indian Association of Palliative Care.
(www.palliativecare.com)

Additional manpower like psychologist, pharmacist, physiotherapist and dietician would strengthen the team.

Infrastructure

Great care must be taken while planning the infrastructure (*Box 5*). Keeping in mind the conditions of patients coming for palliative care, care must be taken to ensure that all facilities are easily accessible by walking and for a wheel chair/ trolley. Very often patients become very sick and they may need more than one caretaker to look after them. There should be a

provision in a palliative care facility allowing family members to be there with the patient. The cleanliness and ambience must be of high standards and there must be adequate privacy. Sufficient space for storage must be provided.

Ensuring the Availability of Essential Drugs for the Management of Pain and Other Symptoms

A hospital palliative care plan must include policy measures to provide the wide range of drugs required to manage common symptoms, including pain, nausea, vomiting, delirium, agitation, insomnia, fatigue, depression and anxiety. The preparation of an essential drugs list and a palliative care protocol should be done by a multidisciplinary team. The WHO and International Association of Hospice and Palliative Care (IAHPC) provide a model list of essential medicines (WHO, 2007), including palliative care drugs, as a guide for countries to develop their own essential drugs list (refer to *Appendix IV*).

The hospital must fulfil all criteria as per current laws to be authorized to procure, store and dispense morphine—both oral and parenteral. Details are available under the section of *Opioid availability*.

The hospital must ensure that it has an adequate and uninterrupted supply of oral morphine.

Box 5 Matrix for different types of HBPC services[6]

Service	*Infrastructure*	*Personnel*	*Services*	*Drugs*	*Comments*
OP	Waiting area, consulting room, procedure room, toilets	Trained doctor and two nurses	Pain and symptom management Ostomy care, Lympho edema etc.	As per essential drugs list	Provision for patient and family counselling.
OP+ Day care	+ facilities for comfortable stay from 8 am to 8 pm (beds, reclining chairs, reading material, music, TV, bath room, toilet)	+ volunteers One family member to stay with the patient	+ Social, psychological and spiritual support + Procedures like wound care, bowel care, stoma care, empowerment of the family etc.	As per essential drugs list	
In-patient care	Designated beds if possible, otherwise provision of beds in the wards. Number depending on patient load	Palliative care physician should see the patients regularly, nurses in the ward to be trained in palliative care		As per essential drugs list	To be adapted as per the convenience of the hospital
Home care	In a defined catchment area, for e.g. within a radius of 25 km from the hospital	Home care team consisting of doctor, nurses and volunteers	Care as required and as appropriate to the situation	Minimum package	Care givers to be trained and supported

Resource Mobilization

To make sure that the necessary human and financial resources are available to implement the strategies and actions included in the palliative care plan, the following questions will need to be answered:

- What resources are currently dedicated to palliative care? How can current resources be reallocated or shared to achieve plan outcomes?
- What potential sources of funding or other resources are available to meet these needs?
- How can partners work together to raise funds from the government or private sector?

The palliative care plan should be accompanied by a resource plan that outlines existing resources, needed resources and possible strategies for acquiring the needed resources from both governmental and nongovernmental sources.

Documentation and Record Keeping

The documentation of clinical notes, treatment prescribed and details of follow-up must be done meticulously. Necessary formats, fulfilling all statutory and legal requirements may need to be created. All efforts must be made to ensure that patients coming to a palliative unit are able to get their records with ease, without making them spend unnecessary time and effort in the hospital. These documents must be stored safely and easily retrieved.

The service should have in place a system for assessment, documentation, and management of patient that includes at minimum

- On-going assessment and documentation of pain with at least the body chart and pain scale
- On-going assessment and documentation of other symptoms
- On-going assessment and documentation of psychosocial and spiritual issues of the patient and the family (documentation of the family tree).
- Documentation and monitoring of amount of morphine being dispensed and consumed against each patient.

A template of a case sheet being used by a few palliative care centers for assessment and documentation is attached as *Appendix V*.

Expansion of Services

Initially, every HBPC service must provide certain basic services—relief of pain and other systems, counselling and appropriate spiritual care.

Once the service is well established, the team can embark on expansion. The additional services could include:

- Lymphoedema Clinic
- Stoma Clinic
- Complementary therapies like Yoga and Aromatherapy
- Bereavement services
- Educational activities
- Support services
- Research
- Rehabilitation programmes

Integration with Other Services Within and Outside the Hospital

The HBPC team must develop an excellent working relationship with other departments within the hospital. They should use every opportunity to sensitize the hospital staff and other personnel about the concept, relevance and role of palliative care.

Similarly, linkages must be made with other organizations in the community who provide additional services relevant to palliative care; e.g. a home care service, other service organizations like Rotary, Lions, Roundtable, organizations working for cancer, HIV/AIDS, children's welfare etc. Major corporate organizations may also be contacted. This will foster continuum of care, reach out to more people, help raise necessary funds and improve the quality of the service. Networking with other hospitals and hospices providing similar palliative care will help share vital information and assist in developing a robust HBPC service.

Education of the General Public and Policy-Makers

In order to increase the likelihood of reaching out to people who would be benefited by palliative care, it is important for the general public to understand what palliative care is, who should be referred for services, what those services are, and how patients and families may benefit from palliative care programmes. The general public can play a role in palliative care, for example, by volunteering to help teams of health professionals.

It is particularly important for policy-makers to understand that palliative care is part of the continuum of care for cancer and other diseases, that it can be integrated into the existing

health-care system at a relatively low cost, and that it requires opioids to be available across all levels of care. The media need to be involved in disseminating reliable information, while avoiding sensationalism. Safeguards should be put in place to ensure that the media respect the dignity and rights of patients and their families.

Evaluation and Monitoring of a Palliative Care Plan and Activities

Both the development and the implementation of a palliative care plan need to be monitored and evaluated periodically in order to ensure that the objectives of the plan are achieved. Evaluation requires careful design and planning. A basic information system needs to be put in place early on so that the necessary data for monitoring and evaluation are collected on a regular basis. This may be done by looking at certain indicators on a monthly basis and could include:

1. Coverage Indicators

- What percentage of the target population of patients is covered by the palliative care activities?
- What percentage of children?
- What percentage of adults?

2. Activity level Indicators

- Are there palliative care services (medical, psychosocial and spiritual) at the different levels of care for patients?
- Are there services for end-of-life care?
- Are there services for bereavement care?
- Are there in-patient, out-patient or home palliative care services? How are they organized?

3. Indicators related to successful pain relief programme

Opioid consumption is a direct indicator of a successful pain relief programme.

Quality Assessment of Palliative Care Activities

Quality can be assessed through the system model of inputs, process, outputs and outcomes (short-, medium- and long-term). Quality assessment can also be based on the continuous quality improvement framework, which uses a number of quality dimensions that can be explored through questions such as:

- Are all the services of the palliative care programme accessible (to ensure coverage and timeliness) to the target population?
- What are the sources of referral?
- What is the place of death of a terminally ill patient—home, ward or ICU?
- What is the patient palliative care staff ratio?
- Are there uninterrupted supply of drugs for pain relief, in accordance with the WHO's ladder for cancer pain relief?
- Are there drugs accessible for the control of other symptoms?
- Are the services acceptable (ensuring providers' and patients' satisfaction) and appropriate (based on established standards) for the target groups?
- Are the competences (knowledge and skills) of the providers appropriate for the services needed?
- Is there continuity (integration, coordination and ease of navigation) in palliative care activities for cancer and other chronic fatal diseases? Is there continuity among the levels of care? Is there a system of follow-up of patients in the community?
- Are the palliative care activities effective (do they improve quality of life)?
- Are palliative care activities efficient (do they provide the best results at the lowest cost)?

Box 6 Example of a Stand-alone, Comprehensive Palliative Care Unit

The Bangalore Hospice Trust is an independent, stand-alone institution set up to provide ***free*** palliative care for advanced cancer patients and their families. It covers all of Karnataka and surrounding states. Of late, patients are being referred from distant states like Madhya Pradesh and West Bengal.
Services offered: Home care and institutional care of advanced cancer patients, symptom control, counselling, physio therapy, occupational therapy, education of families of patients, training of caretaker, training of medical and psychological counsellors.

Infrastructure: Stand-alone in-patient facility with fifty beds dedicated to palliative care, home care teams which render palliative care in the homes of patients, training of medical and psycho social professionals. Own 40,000 square feet building specially designed for rendering palliative care.

Range of care: Care starts from the time patients are ready for discharge from hospitals after curative treatment and ends with the bereavement visit to the homes of deceased patients. The sequence is: counselling by our staff at the hospital prior to discharge – home care – admission to fifty-bed in-patient unit (Karunashraya) – discharge after symptoms are controlled and families have been trained to care for the patients when our home care team takes over – re-admission at need – death – bereavement visit.

Team: Two full-time medical officers, consultant in palliative care, visiting consultants in different disciplines (medical oncology, radio therapy, psychiatry, physiotherapy, etc – all for palliative purposes), six resident nurses, two full-time counsellors plus volunteer counsellors, spiritual counsellors, ten ANMs, seventeen fully trained health care assistants, house-keeping and support staff.

Drugs: All necessary drugs, including opioids are available and provided to all patients, including those discharged.

Linkage with other local institutions: Close liaison with local Regional Cancer Hospital, all other hospitals with oncology departments, private medical consultants and general practitioners.

Linkage with overseas institutions: Twinning arrangements with Severn Hospice, Shrewsbury, UK. Their multi-disciplinary team visits Bangalore Hospice Trust in February every year. Local resource centre for the Palliative Care Course of Cardiff University.

Referrals: from Regional Cancer Centre, other cancer hospitals, private practitioners, families of previous patients, from word of mouth, from media coverage etc.

Resources: all care and facilities (both home and in-patient) being free of charge, financial resources come only from donations. Trustees render free service but all other staff members are paid market salaries.

Box 7 Example of a Hospital-Based Palliative Care in a Regional Cancer Center

Coverage: MNJ Institute of Oncology is a Regional Cancer Center for the state of Andhra Pradesh.

Services offered: Palliative care is given only to patients with cancer. The services offered are outpatient, day care,In-patient, pediatric palliative care and pain relief services and home- based care in collaboration with a NGO. It also offers several training and research activities. Majority of referrals are sent for outpatient consultation. The team has a privilege to admit patients in the hospital In-patient facility. The day care room provides the space for symptom stabilization, psychosocial care, education of the family and to undergo day care procedures like care of the wound, injections, getting enema, stoma and lymphedema care, pleural and ascites fluid aspiration and counseling.

Infrastructure: The outpatient unit is housed on the second floor which is accessible by staircase, a ramp and a lift. It consists of two consultation room, a day care room and a waiting area. On an average, 40-50 patients are seen per day for six days a week.

Team: It consists of three doctors, one visiting consultant, five nurses, a social worker and a secretary.

Referral: Referral are usually from various departments of the hospital like medical, surgical, radiation and pediatric oncology and from other cancer centers in the state.

Documentation: There is a separate case sheet charting system with a palliative care registration in addition to hospital registration. A detail psychosocial and symptom evaluation and documentation is done in each visit.

Drugs: Essential drugs including oral morphine are issued free from the pharmacy. The patients below poverty line are eligible for and are enrolled in the state sponsored insurance scheme to get free treatment for cancer including palliative care (Aaryogyashree Health Care Trust, http://aarogyasri.org). Oral morphine is purchased from pharmaceutical company offering the cheapest deal on quotation.

Training and Education: It is the regional center for palliative care training and education in the state.

Linkage with Other Services within and Outside the Hospital: It is a resource center for palliative care training and advocacy for various governmental and other non governmental organizations, media and public. The center has managed to influence the government to include palliative care in the state insurance scheme and to amend the law related to opioids.

Resources: The program is supported by the government, the International Network for Cancer Treatment and Research (INCTR) and by donation from the public. Various national and international organizations support and endorse the clinical services, training, education and advocacy.

SECTION 4

Setting up of a Community-Based Palliative Care Service

Many chronically ill people spend most of their time at home and are in need of regular care for the rest of their lives. Unlike patients with acute illness, in-patient and out-patient units alone cannot address these needs. Majority of these patients wish to die at home but barely a quarter manage to do so. For example, over 90% of all patients with cancer spend some time in hospital during the last year of life and more than 70% die in hospital or in a hospice. The desired place of death may change with altered circumstances, the most obvious being difficult symptoms and lack of practical help at home. Patients who are frightened, insecure, or lack confidence in their support network are more likely to seek urgent admission to hospital or hospice. Equally, if informal carers are physically or mentally tired, they are more likely to seek admission, even when death is imminent.

Across the whole range of health services, an increasing amount of care is being provided on an out-patient basis or through the hospitals. Putting the concept of 'total care' with continuous support in physical, psychosocial, and spiritual realms into practice is very difficult through institutionalized care. It offers a patchy service through which the patient and family have access to care for only a few hours/days.

Rationale for a Community Approach to Palliative Care Service:

- Patients with advanced diseases require continuous care and attention for the rest of their lives
- They are also in need of regular social, psychological and spiritual support in addition to medical and nursing care
- Care should be readily accessible and available as close to home as possible
- There is enough social capital available to build a 'safety net' in the community around these patients

The physical complexities of progressive and life threatening disease, coupled with the attendant emotional and psychological consequences, demand careful coordination between primary, secondary, and tertiary care (*See Figure 6*). The community approach is the only realistic model for achieving significant coverage and continuity of services for the terminally ill. This is a realistic option in most communities where interpersonal relationships have not yet fully died out.

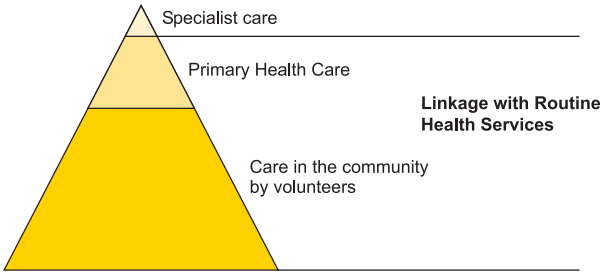


Figure 6: *The proposed model for Long Term Care (LTC) and Palliative Care (PC)*
(Adapted with permission from Stjernsward 2005, Indian Journal of Palliative Care 11(2))

Community

Traditionally in *sociology*, a "community" has been defined as a *group* of interacting people living in a common location. However, the definition has evolved and been enlarged to mean individuals who share characteristics, regardless of their location or type of interaction. In this sense, "community" can mean a community of interest or an ethnic group.

What these various meanings have in common is that they refer to the strength of the ties between the members of the group, of whatever nature—cultural, ethnic, or moral—they may be.

When we talk about community, it is important to remember that the community is not monolithic. Each community has a dynamic interaction between different interests—supporting each other, competing with each other and sometimes in conflict with each other.

Community Participation

Community participation can be loosely defined as the involvement of people in a community to solve their own problems. It is a very broad concept and in the context of a programme, it can mean anything from simple feedback from the community to major involvement in all the phases and areas of the programme.

Community-based palliative care services are those run with community participation. An ownership of the programme with participation of the local community in the need assessment, planning, implementation, resource mobilization, day to day management and evaluation of the programme is desirable. It may not be possible for each and every member of the affected population to contribute to a programme equally but attempts can be made to actively involve as many key groups and individuals as possible.

Components of Community-Based Palliative Care Services

Two major components of a community-owned/based palliative care system (*See Figure 7*) are

- community volunteers and
- health care professionals

Community volunteers play a major role in the programme. Their activities related to the care of the patient and family need to be supported by health care professionals at various levels.

Figure 7: *Components of a community-based palliative care programme*

Community Volunteers

A **volunteer** is someone who works for a community or for the benefit of the environment primarily because they choose to do so. Many serve through a non-profit organization—sometimes referred to as formal volunteering, but a significant number also serve less formally, either individually or as part of a group.

Volunteering in palliative care may come in many forms: serving food to a starving family, spending time with a lonely patient, mobilizing support for the patient and family from the community, fund raising for the initiative, offering emotional support to the patient and family, providing administrative support to the group etc.

Community volunteer manpower is mainly of two types:

- The Untrained Volunteer
- The Trained Volunteer.

Untrained Sensitized Volunteers

They provide the groundwork for the palliative care service by establishing a social support system eg. food for patients, transport, educational support for children and working with the local government. Such volunteers can be motivated and mobilized by several initial sensitization programmes in the community (*See Box no* 9).

Trained Volunteers

Some of the sensitized volunteers undergo a more intensive training programme (*See Box no* 9). With proper training, many of them are able to involve in patient care in a bigger way by offering

- Emotional support
- Basic nursing chores
- Help with mobility

Health Care Professional Component

The community volunteers need to be supported by health care professionals trained in palliative care. The team should essentially have doctors and nurses, but can also include other health care professionals.

Unlike the volunteers from the community, most health care professionals in the team are paid. This core team can be supplemented with additional voluntary efforts from other health care professionals if available.

Nurse-led home care should be the key professional service in community palliative care programmes. Nurses in the team can be staff nurses with training in palliative care or auxiliary palliative nurses trained for the purpose. Custom made training for local men or women or local health workers is a good option.

This service is to be supported by regular medical inputs by doctors and doctors' led home-based care. This, in addition, can be supplemented by outpatient clinics and inpatient services. A community level care service should have good linkages with the primary, secondary and tertiary health care system for any referral or interdisciplinary support.

Initiation of a Community-Based Palliative Care Service

A community-based palliative care service is essentially a matrix of four components (*See Figure 8*).

The entry point for initiating the service can be any component in the matrix—starting a community volunteer programme, a nurse-led home care programme or a doctor-led-out-patient/in-patient/home care unit. Experience has shown that the best option from the point of sustainability is to start with a community volunteer programme. Sensitization of the local community is very often the best possible first step.

Community Mobilization

Community mobilization applies to the way in which people can be encouraged and motivated to participate in programme activities. In order to mobilize a community successfully, it is important to identify where people's priority lies and what it is that motivates them.

The development of a service in the community can be facilitated by anyone interested in palliative care. To raise levels of awareness and sensitization can be a key aspect of engaging and mobilizing a community.

Community-owned services are likely to be successful in any community where people have the willingness to help each other. It is important to make sure that minority groups, low status groups and poorer groups in the community are not left out and that women, men and children are specifically included in consultation processes. The experience in Kerala has been

Figure 8: *Matrix of a community-based programme*

that people belonging to the lower socio-economic strata participate in the programme in a more active way than those from the upper strata of the society.

Defining a clear 'catchment area' and target group for patient care is advisable in the initial phase of the project. These can be expanded later as the project develops.

Beneficiaries

The patients and families benefit directly from the services. The local community also benefits through enhancement of social capital, improving skills and confidence and the process of empowerment. Building awareness and acceptability to palliative care and developing a more positive outlook towards incurable diseases are also benefits. The major long-term advantage of a community-owned project in palliative care is that it makes the community more confident and self-sufficient.

Raising level of awareness and sensitization can be a key aspect of engaging and mobilizing a community.

Services Provided

The range of services that can be provided through a community-based palliative care programme is very much in line with the concept of total care in palliative care.

Home care is the mainstay of these services. The home care team consisting of health care professionals and community volunteers visit the patient and family at home, discuss the problems and offer appropriate services. Development of the wider network of community volunteers in the neighbourhood ensures continuity of services between home visits and also the necessary social support for the patient and family. Technical details of home care services are discussed in the home care manual available on line at http://www.whoindia.org/LinkFiles/Cancer_cansupport.pdf.

Professionals

Health care professionals with possible role in community-based palliative care services include nurses, doctors, physiotherapists and counsellors. Services of nurses and doctors are essential; others if available can play their roles. The nature of problems of patients with advanced diseases makes nurses with good communication skills, the lead professional in home care services.

- Nurses are the main stay of home care services. Nurses in the team can address nursing needs, help the community volunteers in offering emotional support, ensure proper documentation and seek support from the doctor in the team while handling other physical problems

- A doctor with necessary training in palliative care plays the major supportive role for the home care team. The doctor offers advice and consultations and makes home visits when suggested by the home care team. Very often, the doctor is part of the team that maintains the palliative care out-patient clinic or in-patient unit. This person can also be the local general practitioner or any their doctor, provided they have had their training in palliative care.

Community Volunteers

Community volunteers are the backbone of home care programmes. Volunteers, as mentioned earlier, depending on their training, skills and experience, can offer a variety of services to the patients and families. These include,

- Emotional support
- Basic nursing
- Follow-up of professional home care
- Linking up with the professional team
- Social support to the affected family by way of
  - — Food for the family
  - — Educational support for children
  - — Helping with transport to hospital
  - — Linking with other support groups
  - — Helping to make potential benefits from government/NGOs available
  - — Rehabilitation

Community volunteers can also take up responsibilities related to organization and administration of services. Examples include

- — Regular awareness programme in the community
- — Training the family members to look after the patient
- — Training volunteers in the community
- — Administrative management of the unit
- — Resource mobilization

The home care team should be equipped with essential medicines and consumables for their job. Details of the Home Care Kit to be carried by the home care team are available in the home care manual (http://www.whoindia.org/LinkFiles/Cancer_cansupport.pdf)

Resource Mobilization

Community ownership of the programme usually ensures good financial support from the community. Community participation can include finance generating activities and this may be a key starting point in giving communities greater responsibility, removing dependence on external support and promoting sustainability. It may be in the form of donation boxes at public places, collections from student community, donations of cash and kind during festive occasions etc. Economic activity through trade and service provision like setting up a small grocery or vegetable shop, tailoring, haircutting saloon etc can also be considered depending on existing skills and needs within the communities.

Micro funding: Small donations from a large number of people in the community are found to be one of the best ways to ensure sustainability and local ownership to community-owned programmes (*See Box no* 8).

Where programmes are externally assisted, like by non-governmental organisations or philanthropic individuals or trusts, the implementing agency generally takes responsibilities for procuring and managing funds and the community is neither expected to contribute nor have any direct involvement in how this money is spent. Such programmes owned by external agencies have the major disadvantage of lack of sustainability once the agency/funder leaves/gets disinterested.

Box 8 Fund Raising by Community-Owned Palliative Care Units in Kerala – The Strength of Micro Funding

More than 100 palliative care units belonging to the Neighbourhood Network in Palliative Care depend on local donations for their activities. For example, the total recurring expenses for the 28 palliative care units in the district of Malappuram in 2007 was more than three crore rupees. 30% of this budget came as support from local self government institutions in the region. The other 70% (about two crore rupees) was raised locally. 75% of this money (150 lakh rupees) came as donations of less than fifty rupees. Ways to generate funds included

- Donation boxes in almost all the shops and establishments in the region
- Regular donations by the crew of buses pulling into particular bus stations (each member of the crew donating 50 paisa a day)
- 'A rupee a day' donation programmes for households
- 'A rupee a month' donation programmes for school children
- Donations during festive occasions

Partnership with the Government

If a programme is effective and successful, it is easier to convince the government to integrate it into the mainstream health policy and implementation.

Example 1: In the state of Kerala, at present, there are around 130 palliative care units. Majority of them are organized and supported by Community-Based Organizations (CBO). Most of them are independent units, but some are based in government and private hospitals. The CBOs are mostly supported by local communities, are self-sustainable in terms of manpower, money and other amenities and dependent on trained volunteers for organizing services and psychosocial support. In many places, Local Self Government Institutions (LSGI) have come forward to work with these groups in providing home visits, out-patient service and free drugs for the poor. Recognizing the need of palliative care as a primary health care and the importance of home care services for patients with long-term/ incurable diseases, the Government of Kerala recently brought out a Kerala State Policy for Pain and Palliative Care Services[8] (*See Appendix VI*).

Recognizing the need of palliative care as a primary health care and as a supportive care for disease-specific treatment, the government of Kerala has introduced a Kerala State Policy for Pain and Palliative Care Services.

Example 2: The National Rural Health Mission (Kerala) has initiated a major project in Kerala this year to facilitate the development and expansion of community-owned palliative care services in collaboration with Local Self Government Institutions in the state[9].

Example 3: The government of Andhra Pradesh has recently started a health insurance system for people below poverty line. The insurance also covers palliative care for cancer patients (refer Aaryogyashree Health Care Trust, http://aarogyasri.org).

Training

Capacity building through skill training and confidence building can be a key ingredient in motivating and mobilizing different sections of a community like

- Doctors
- Nurse /auxiliary nurse and other allied professionals
- Other health care workers
- Volunteers
- Policy-makers

It is important to make sure that the health care professionals and community volunteers involved in home care activities have the necessary knowledge, skills and attitude. Various training programmes are available for doctors, nurses and community volunteers interested in palliative care[7].

Box 9 describes a volunteers training programme being followed in a well known community-based programme in kerala called Neighbourhood Network in Palliative Care.

Box 9 Module of a volunteers training Program

Sensitisation Course: 2 Hours

Topics covered

Basics of palliative care, concept of community participation, home care and basics of communication (stressing on don'ts)

Course on Basics of Palliative Care for Volunteers:

16 hours + Four home visit days

- Topics covered
- Communication skills /emotional support, Patient assessment, nursing care, home care, basics of chronic diseases and management issues

Integration

Integration with different organizations gives better sustainability, provides coverage a better multidisciplinary approach to the programme. The home care programme can be linked up with organisations/ institutions

- Institution-based palliative care services,
- Local Self Government Institutions (LSGI), especially in view of the constitutional amendment which makes it mandatory for state governments to transfer responsibility and funds in health to LSGI
- Existing health care system in the region and
- Social organisations in the region

Arogya Keralam Project for Community-Based Care of the bedridden, elderly, chronically and incurably ill in Kerala is an example of integration of a community-based palliative care with a state-based central government organization called National Rural Health Mission[9] (NRHM)

Quality Assurance

1. There should be mechanisms in place for regular monitoring and feedback. The regular appraisal may consist of
   - Mapping: Community mapping is a useful tool for collecting information from the community concerning the location of activities
   - Ranking: listing of the community's priorities
   - Regular evaluation and feedback from all the stake holders through review meetings
   - Discussion: A regular focus group (e.g. women or community leaders) or more general discussion with the help of a facilitator to focus and steer the discussion.
   - Problem-tree analysis: This is an interactive process whereby a community identifies the existing problems, formulates objectives and selects appropriate future action plan.
2. A continuous training/updating programme for volunteers and health professionals is essential to raise and maintain the standard of palliative care service delivered. Stagnant programmes tend to deteriorate.
3. Outcome measurement

   There is no validated way of measuring the outcome of a delivery of a community-based palliative care. There are several indirect ways of measuring the outcome like patient/family satisfaction surveys, number of volunteers enrolled, number of training and sensitization programmes conducted, coverage, patient population, opioid consumption, number of rehabilitation programmes being implemented, expansion of services, fund generated, governmental involvement etc.

An Action Plan for Initiation of a Palliative Care Service in the Community

Step I: Sensitization: In any region, there will be people interested in helping others. Many of them might already have been helping others in their individual capacities. The idea is to sensitize them to the problems of patients with incurable diseases and also to get as many of them together as possible. The first step is to get those who are likely to be interested to an awareness meeting/discussion. Make sure that all the groups/organizations involved in social/health care activities in the region are invited. This meeting should ideally be convened by a "neutral" local group or institution to ensure participation from the different interest groups/organizations in the region. Explain the issue of incurably ill/bedridden patients in the region. Discuss possible ways 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. The training should be done locally and also at a time and venue convenient to the majority of the participants. (Topics to be covered suggested earlier in this

section). Get the trained volunteers to document the problems of bedridden/incurably ill patients in their neighbourhood (Use a proper form like the community volunteers patient care protocol). It is important to have weekly review meetings of the new volunteers at this stage. These review meetings can be used to discuss solutions to the problems documented by the volunteers. Initiate a social support programme to support food for starving families, educational support to the patients' children, emotional support to patients and families by trained volunteers etc. Establish a contact point for giving and taking information. A space available with one of the new volunteers or well wishers can be used (for example, a local shop, public library premises etc.) Start collecting money, manpower and other resources. Link with the nearest palliative care unit if one is available.

Step III: Adding a nursing component to the programme is the next step. It may take 1–2 months for the local group to establish a stable social support system and to raise money to employ a part-time nurse. Getting the services of a nurse in the neighbourhood is the best option from the long-term point of view. Encourage the nurse to get trained in palliative care. Initiate nurse led home care programmes. In certain situations, help of the nurse from a nearby palliative care unit might be available. Use the nurses' protocol as a guide to nurse-led home care. Establishing a culture of meticulous documentation and review is important.

Step IV: Getting the medical component in is very often the most difficult part due to 'scarcity' of trained doctors. One possible option is to get help from a local doctor in medical issues. Self study by the doctor can be facilitated by regular supply of reading material. Encourage the doctor to get trained in palliative care.

Step V: Once the home care service starts getting established, there will be a need for a regular out-patient clinic. Availability of a trained doctor and nurse is a pre requisite. Remember that starting an institution (Outpatient clinic/Inpatient services) is more expensive than initiating a home care programme. The facility can very often be linked to a local hospital.

Step VI: Establish a system of regular review and evaluation. Any palliative care or supportive service usually generates good appreciation from the local people. It is important not to get carried away by the good words. Active attempts at identifying areas for improvement should always be there.

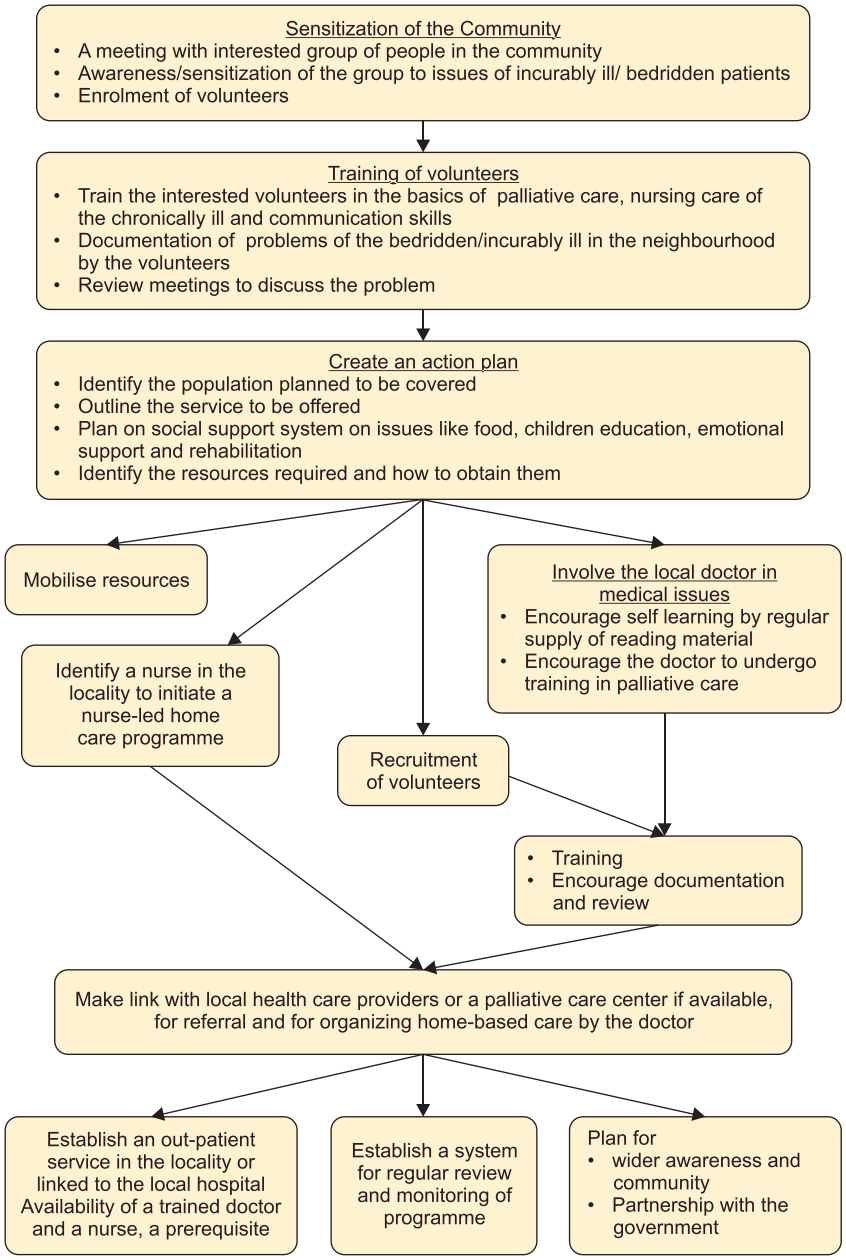


Figure 9: *Setting up of a community-based palliative care programme*

SECTION 5

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Appendix I

Laws on Procuring Opioids for Medical Use

The Narcotic Drugs and Psychotropic Substances (NDPS) Act[10]

The NDPS act of 1985 (subsequently amended) sets out the statutory framework for drug law enforcement. Some of the main provisions of the NDPS Act are as follows:

1. The cultivation, production, manufacture, possession, sale, purchase, transportation, warehousing, consumption, inter-state movement, transshipment and import and export of narcotic drugs and psychotropic substances is prohibited, except for medical or scientific purposes and in accordance with the terms and conditions of any license, permit or authorization given by the Government. (Section 8)
2. The Central Government is empowered to regulate the cultivation production, manufacture, import, export, sale, consumption, use etc of narcotic drugs and psychotropic substances. (Section 9).
3. State Governments are empowered to permit and regulate possession and inter-state movement of opium, poppy straw and the manufacture of medicinal opium[11] (Section 10).[12]

The Drugs and Cosmetics Act

This act of 1940 regulates the manufacture and domestic distribution of psychotropic substances.

Amendment of NDPS Act for Easy Availability of Oral Morphine for Medical Use

In 1998, the Department of Revenue of GOI, which is responsible for the manufacturing and control of opioids in the country, drafted a model regulation in consultation with various experts in the field to simplify the licensing requirements under the NDPS Act for easier availability of morphine for medical use. Instructions were sent to all state governments in the country to amend their narcotic regulations and simplify their licensing requirements[12]. The amendment sought to exempt institutions delivering palliative care from the need for the complicated licensing process administered by the excise officials in the state revenue departments. The amendment shifted the licensing responsibility to the Drugs Controller in the State Health Department who would approve palliative care programmes to obtain morphine as "Recognized Medical Institutions" (RMIs) and grant them a morphine quota.

Special Provisions Relating to the Use of Morphine by Recognized Medical Institutions in the Amended State

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. 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 (*Appendix V*) to the Drugs Controller appointed by the State Government who shall convey his decision within three months of the receipt of the application.
   ii. If it comes to the notice of the Drugs Controller that morphine obtained by a 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 Drugs Controller may revoke the recognition accorded under these rules.
4. Duties of a 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 over-all 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 (*Appendix V*) 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 (*Appendix V*) by 30th 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.
6. Approval of estimates by the Drugs Controller

   The Drugs Controller who receives the annual requirement shall consider it, and may if necessary call for necessary clarification. A reply on approved estimates or not accepting the estimates shall be sent before 21st 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 Drugs Controller of that state, the Drugs 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 Drugs Controller, the recognized medical institution may send a supplementary estimate at any time

to the Drugs Controller which shall be considered and dealt with by the Drugs 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 to a recognized medical institution. Possession, transport, purchase, sale, import inter-state, export inter-state or use of morphine in respect to a recognized medical institution shall be in accordance with the following provisions:

   i. The recognized medical institution shall place orders for purchase to a manufacturer/supplier in the format at (*Appendix II*) along with a photocopy of the communication of the Drugs Controller vide which the institution was recognized for the purpose 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 Commissioner of India.

   ii. 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 Drugs Controller and the approved estimates communicated by the Drugs Controller. The manufacturer/supplier shall dispatch the morphine consignment note in quintuplicate in the format given in (*Appendix II*). Copies of the consignment note shall be sent by the manufacturer/supplier to the Drugs Controller of the state in which the manufacturer/ supplier is located, the Drugs 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.

   iii. 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 Drugs Controller, the quadruplicate to the Drugs 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 be kept for a period of two years from the date of transaction. They 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 Drugs Controller or any other officer subordinate to him or the officers of other departments of the State Goverment empowered under Section 41 and 42 of the Narcotic Drugs and Psychotropic Substances Act 1985.

11. Appeals

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

The Government of India Directive to the State Government to Use the Model Draft for the Amendment of Narcotic Law[13]

GOVERNMENT OF INDIA
MINISTRY OF FINANCE(DEPT OF REVENUE), NORTH BLOCK, NEW DELHI-110001
F-No.664/63/97-NC

May 8, 1998

Dear Chief Secretary,

The All India Lawyers Forum for Civil Liberties have recently filed a Public Interest Litigation before the honorable High Court of Delhi seeking the Court's intervention to issue appropriate directions to the concerned authorities for making availability of morphine easier for cancer patients. As you may be aware, in terms of Section 10 of the NDPS act, it is the responsibility of the State Government to permit and regulate the possession, transport, sale etc, of any manufactured drug including morphine. A number of states have since noticed their rules regarding regulating movement etc. of morphine. It is however, noticed that the procedures laid down are often too strict and cumbersome and deny easy availability of morphine to even terminally ill cancer patients. This has caused undue sufferings and harassment which have led to the filing of the above Public Interest Litigation.

Mr. David Johnson, a WHO Expert who has reviewed the problem of non-availability of morphine to cancer patients in India, has suggested certain legislative measures in this regard. A copy of his report is enclosed for your guidance. The matter has been discussed in consultation with the Drugs Controller of India and it is suggested that certain recognized institutions and Government hospitals be empowered to sell morphine to the needy out-door patients. They may keep sufficient stocks and formulate a procedure to guard against any abuse of morphine use.

Keeping in view the above facts, a model procedure/rule has been formulated, a copy of which is enclosed for your consideration (*See 'Special Provisions Relating to the Use of Morphine by Recognized Medical Institutions in the Amended State' in the section 'Procuring opioids like oral morphine in states with amended regulations' in the main text*).

The same may be incorporated in the rules to be framed by your Government under the NDPS Act. I am writing separately to the Ministry of Health and Family Welfare to make suitable changes in the Drugs and Cosmetics rules 1945. It is hoped that the matter would be accorded utmost priority so that the new procedure may be in place at the earliest, say by 30th June 1998. A copy of the State rules as notified by you may be enclosed to us for placing before the Honorable High Court of Delhi, if need be.

With Regards

Yours sincerely
-Sd-
(N.K.Singh)

To All Chief Secretaries

1. Copy to Secretary, Department of Legal Affairs, New Delhi
2. Mr. David Johnson, WHO for information with reference to his letter dated 3.11.1997

Appendix II

Format to Apply for Oral Morphine by a Recognised Medical Institute

5.1. Application for Grant of Recognition of Medical Institution to Director of Drugs Control

1. Name of the institution and address
2. Name of the head or 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. In-patient
   ii. Out-patient
5. Whether the hospital has facility to treat cancer patients: Yes/No
6. No. of cancer patient treated during previous calendar year:
   i. In-patient
   ii. Out-patient
7. Name of the qualified medical practitioner who would prescribe morphine (if there are more than one qualified medical practitioner who would prescribe morphine, indicate the name of the medical practitioner who would be overall in-charge)
8. Whether institution's recognition for the purpose was withdrawn earlier (if the recognition was withdrawn earlier, the details are to be given) Yes/No

Station:

Date:

Signature of the Head/In-charge
of the Institution with name

5.2. Record of Receipt, Disbursement and Balance of Morphine

Date:

Quantity in the hand at the beginning of the day	Details of quantity received				Details of quantity disbursed				Quantity in hand at the close of the day
	S.No.	Qty	From whom received	Consignment note/Bill or Entry No.	S.No.	Qty	Name of the person & address whom disbursed	Name of the medical practitioner who prescribed	

Signature

Note:

1. This record is to be maintained on a 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 from them shall initial after entry of each day with date. The pages of the register shall contain the necessary number.
2. This record shall be retained for two years from the date of the last entry.
3. This record shall be produced to the authorized officers whenever called upon during the course of annual inspection.

5.3. Estimate of Annual Requirement of Morphine

1. Name and address of recognized medical institution
2. Period for which the estimate is submitted
3. Quantity estimated to be 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

S.No	Name and address of the supplier	Quantity

6. If this is 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

5.4. Orders for Purchase

To

(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 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.

S.No	Quantity	To whom order was placed

Station:

Signature of the person authorized to
place order with name and designation, if any)

Date

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.

FORM ND/M5
(See rule 52)
Consignment Note
(To accompany a consignment of morphine)

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

1. Name and address of the consignor:
2. Name and address of the consignee (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

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 an 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 notes brought in use during the particular year
4. Each consignment of morphine shall be accompanied by this consignment note in quintuplicate.
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 to 5 above in this note shall be produced to the authorized officers whenever called up on, during the course of inspection.

Appendix III

Special Provisions for procurement of Oral Morphine in the Amended State of Tamilnadu

Minimum Requirement for Accreditation of Palliative Care Unit for Cancer Patients

The objective of this regulation is to ensure that any Palliative Care Unit which is accredited to store and to supply of morphine tablets is able to give a certain minimum quality of care to the terminally ill cancer patients to relieve the pain and / or palliative care apart from regular treatment given to them. This requirement is classified as essential and desirable.

Essentials of Recognized Medical Institution

1. Recognized Medical Institutions shall be a hospital or medical institution with facilities to treat in-patient and out-patient having adequate clinical testing facilities or hospice center to give palliative care to in-patients and out-patients.
2. One or more qualified medical practitioners shall prescribe morphine tablets.
3. The drugs shall be kept under the custody of the Medical Officer in-charge of the Centre as per Clause 29(ii) of Schedule K of the Drugs and Cosmetics Rules, 1945.
4. The drugs shall be purchased from a dealer or a manufacturer who holds licences under Drugs and Cosmetics Rules and records of such purchases showing the names and quantities with Batch Nos. and names and addresses of manufacturers or dealers and the names and addresses of the patients to whom supplies have been made shall be maintained.

Procedure of Application Process

1. The application form ND/M1 (*Appendix II*) along with requisite documents shall be submitted to the Director of Drugs Control, Tamil Nadu, Chennai.
2. After receipt of application, it shall be forwarded to the Asst. Director of Drugs Control of the concerned zone, who in turn forward the same to the concerned Senior Drugs Inspector/ Drugs Inspector for inspection and report in a prescribed format along with his specific recommendation for approval of recognized medical institution status and remarks regarding quantity of drug requirement by the institutions.
3. The Asst. Director of Drugs Control, shall forward the application along with the report of Drugs Inspector to the Director of Drugs Control, Tamil Nadu, Chennai with his recommendation within 10 days (copy of the Inspector Report enclosed)

4. The Director of Drugs Control, Tamil Nadu shall scrutinize the application and based on the recommendation, necessary approval for Recognized Medical Institution Status will be issued to the institution and also necessary quota of morphine tablets shall be allotted along with recognition.
5. The application and issue of recognition will be quickly processed.
6. Final orders of the Director of Drugs Control will be given within one month from the date of submission of the application.

Procedures to Apply for recognized Medical Institution Status

Application shall be made in form ND/M1 of the Tamil Nadu Narcotic Drug Rules, 1985 along with the following documents for Recognised Medical Institution Status:

1. Application in form ND/M1 (*Appendix II*)
2. Copy of qualification certificate of a Medical Officer of Palliative Care Centre.
3. Experience of the Medical Officer, if any.
4. Constitution of the Firm/Medical Institution.

Recognition of Medical Institutions

On completion of application process, issue of recognition to the medical institution, shall be decided on merit by the Director of Drugs Control, Tamil Nadu, Chennai within one month from the date of receipt of the application (specimen copy of Recognition Certificate enclosed).

Responsibilities of Recognized Medical Institution

1. Designate one or more qualified medical practitioner, who may prescribe oral morphine for medical purposes. When more than one qualified medical practitioner have been designated, 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 ND/M2 (*Appendix II*).
   d. Ensure that estimates, and other relevant information required to be sent by the recognized medical institution are sent to the authorities concerned.

Annual Requirement of Morphine by the Recognized Medical Institution

Application for the Estimate

Every recognized medical institution shall send their estimate of annual requirement of morphine in form ND/M3 (*Appendix II*) along with the name and address of the supplier from whom they intend to buy it to the Drugs Controller by 30th November of the preceding year.

Approval of Estimates by the Drugs Controller

On receipt of the estimate of annual requirement from the recognized medical institution, the Drugs Controller shall consider the annual requirement of morphine and if required, call for necessary clarifications.

A reply on the estimate of the annual requirement accepting or rejecting such estimate shall be sent before 21st December of the preceding year.

A copy of the communication shall be sent each to the supplier whose name has been in the estimate, if the supplier is located in another state, the Drugs Controller of that state, the Drugs Controller General of India and the Narcotics Commissioner of India.

Supplementary Estimates

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

Procuring the Drug

Provisions/Procedures to be followed in respect of possession, transport, purchase, sale, import inter-state, export inter-state import, possession or use of oral morphine in respect of a recognized medical institution shall be in accordance with the following provisions, namely—

1. The recognized medical institution shall place orders for purchase to a manufacturer or supplier in form ND/M4 (*Appendix II*) along with a photocopy of the communication of the Drugs Controller in which the institution was recognized and a copy of the communication of the Drugs Controller in which the approved estimates were conveyed.

   Another copy of the order for purchase shall be sent to the Drugs Controller and the Narcotics Commissioner of India.

2. Any manufacturer of supplier shall send morphine to the recognized medical institution only on the basis of an order for purchase received in form ND/M5 along with copies of recognition granted by the Drugs Controller and the approved estimates communicated by the Drugs Controller.

   The manufacturer or supplier shall dispatch the morphine consignment along with a consignment note in quintuplicate in ND/M5 (*Appendix II*). Copies of the consignment note shall be sent by the manufacturer or supplier to the Drugs Controller of the state in which the manufacturer or supplier is located, the Drugs 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.

3. On receipt of the consignment, the recognized 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 Drugs Controller, the quadruplicate to the Drugs 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.

Maintenance of Records

All records generated 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 Government.

Periodical Inspection

The stock of morphine tablets kept under custody of Recognized Medical Institutions shall be kept open for inspection by the Senior Drugs Inspector/Drugs Inspector of the concerned zone whom also takes sample for test. The concerned Senior Drugs Inspector/Drugs Inspector shall inspect periodically the Recognised Medical institutions to ascertain the stock of the morphine tablets, the maintenance of records and the use of said tablets for medical purpose only. The report shall be submitted to the Asst. Director of Drugs Control concerned in the prescribed format (specimen format enclosed).

Cancellation of Recognition of Medical Institution Status

If it comes to the notice of the Drugs Controller that morphine obtained by the recognized medical institution is supplied for non-medical use or that any of the rules are not complied with, for reasons to be recorded in writing, the Drugs Controller may revoke the recognition accorded under these rules.

Appeals

Any institution aggreeved 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, Health and Family Welfare Department within ninety days from the date of receipt of the communication of such decision or order.

Transparency

The Director of Drugs Control, Tamil Nadu, Chennai shall submit the quarterly report about the status of the Recognised Medical Institutions periodically on or before 15th of succeeding month, to the Secretary to Government, Home, Prohibition and Excise Department, Tamil Nadu. (Specimen copy of quarterly report enclosed).

Quarterly Report of Status of RMI
(Recognized Medical Institution) in Tamil Nadu

For the Quarter ended.....

S.No.	No. of RMI as on previous quarter	No. of application received during this inspection	No. of RMI issued during quarter	Name and address of the institution	Qty. of morphine tablets allotted to each institution	No. of RMI institution derecognized during the quarter with name and address	Total No. of RMI as on this quarter

Total Quantity in Gms./Kg of Morphine allotted in this quarter

Inspection of Recognition of Medical Institution for Palliative Treatment of Terminally Ill Cancer Patients

1. Name of institution with complete address :
2. Date of inspection :
3. Name of inspection officer :
4. Name of medical officer in charge of the hospital/hospice with designation :
5. Name of the medical officer in charge of pain and palliative care (medical officer can also be in charge of institution) :
6. Name of oncologist (optional) Full time/Part time :
7. Nature of Hospital
   a. General Hospital :
   b. Specialty Hospital :
   c. Common Hospital :
   d. Hospice
8. Bed strength of palliative care :
   a. For treating terminally ill cancer patients only
   b. For in-patients only
9. No. of terminally ill cancer patients treated during the previous year :
10. Total consumption of oral morphine during the preceding years :
11. Requirement of oral morphine of the current year with justification :
12. Details of NDRC permit if any with possession limit :
13. Storage facilities for storing oral morphine :
14. Whether records of purchase maintained :
15. Whether records of issues maintained :
16. Remarks :

Recognition to Medical Institution for Possession and Use of Morphine Tablets for being Supplied to the Terminally Ill Cancer Patients

Recognition No: Date of Issue:

1. Recognition is hereby granted to the Medical Institution of
   Situated at run by Dr. Managing Director
   for the purpose of possession and use of following morphine tablets being supplied to the terminally ill cancer patients, under the supervision of the following qualified medical practitioners and technical staff.

   a. Name of the drugs / strength possession limit.

      i.

      ii.

   b. The names, qualification and experience of technical staff.

      i. Name of medical practitioner who prescribe morphine tablets.

2. The recognition shall be in force from

3. The recognition is subject to the conditions stated below and to such other conditions as may be specified in the chapter IX of the Tamil Nadu Narcotic Drugs Rule, 1985.

Date: DIRECTOR OF DRUGS CONTROL

Appendix IV

IAHPC List of Essential Medicines for Palliative Care[6u]

IAHPC LIST OF ESSENTIAL MEDICINES FOR PALLIATIVE CARE ©			
Medication	Formulation	IAHPC Indication for PC	WHO Essential Medicines Model List Section, subsection and Indication
Amitriptyline*	50–150 mg tablets	Depression Neuropathic pain	24.2.1 - Depressive dissorders
Bisacodyl	10 mg tablets 10 mg rectal suppositories	Constipation	Not included
Carbamazepine**	100–200 mg tablet	Neuropathic pain	5 - Anticonvulsants/ antiepileptics 24.2.2 - Bipolar disorders
Citalopram (or any other equivalent generic SSRI except paroxetine and fluvoxamine)	20 mg tablets 10 mg/5ml oral solution 20–40 mg injectable	Depression	Not included
Codeine	30 mg tablets	Diarrhea Pain - mild to moderate	2.2 - Opioid analgesics 17.5.3 - Antidiarrheal
Dexamethasone	0.5–4 mg tablets 4 mg/ml injectable	Anorexia Nausea Neuropathic pain Vomiting	3 - Antiallergics and anaphylaxis 8.3 - Hormones and antihormones
Diazepam	2.5–10 mg tablets 5 mg/ml injectable 10 mg rectal suppository	Anxiety	1.3 - Preoperative sedation short term procedures 5 - Anticonvulsants/ antiepileptics 24.3 - Generalized anxiety, sleep disorders

Diclofenac	25–50 mg tablets 50 and 75 mg/ 3 ml injectable	Pain - mild to moderate	No included
Diphenhydramine	25 mg tablets 50 mg/ml injectable	Nausea Vomiting	Not included
Fentanyl (transdermal patch)	25 micrograms/hr 50 micrograms/hr	Pain - moderate to severe	Not included
Gabapentin	tablets 300 mg or 400 mg	Neuropathic pain	Not included
Haloperidol	0.5–5 mg tablets 0.5–5 mg drops 0.5–5 mg/ml injectable	Delirium Nausea Vomiting Terminal restlessness	24.1- Psychotic dissorders
Hyoscine butylbromide	20 mg/1ml oral solution 10 mg tablets 10 mg/ml injectable	Nausea Terminal respiratory congestion Visceral pain Vomiting	Not included
Ibuprofen	200 mg tablets 400 mg tablets	Pain - mild to moderate	2.1 - Non opioids and NSAIMs
Levomepromazine	5–50 mg tablets 25 mg/ml injectable	Delirium Terminal restlessness	Not included
Loperamide	2 mg tablets	Diarrhea	Not included
Lorazepam***	0.5–2 mg tablets 2 mg/ml liquid/ drops 2–4 mg/ml injectable	Anxiety Insomnia	Not included
Megestrol Acetate	160 mg tablets 40 mg/ml solution	Anorexia	Not included
Methadone (immediate release)	5mg tablets 1 mg/ ml oral solution	Pain - moderate to severe	24.5 - Substance dependence
Metoclopramide	10 mg tablets 5 mg/ ml injectable	Nausea Vomiting	17.2 - Antiemetics

Morphine	Immediate release: 10–60 mg tablets Immediate release: 10mg/5ml oral solution Immediate release: 10 mg/ml injectable Sustained release: 10 mg tablets Sustained release: 30 mg tablets	Dyspnea Pain - moderate to severe	2.2 - Opioid analgesics
Octreotide	100 mcg/ml injectable	Diarrhea Vomiting	Not included
Oral rehydration salts		Diarrhea	17.5.1 - Oral rehydration
Oxycodone	5 mg tablet	Pain - moderate to severe	Not included
Paracetamol (Acetaminophen)	100–500 mg tablets 500 mg rectal suppositories	Pain - mild to moderate	2.1 - Non opioids and NSAIMs
Prednisolone (as an alt to Dexamethasone)	5 mg tablet	Anorexia	3 - Antiallergics and anaphylaxis 8.3 - Hormones and antihormones 21.2 - Anti inflamatory agents
Senna	8.6 mg tablets	Constipation	17.4 - Laxatives
Tramadol	50 mg immediate release tablets/ capsules 100mg/1ml oral solution 50mg/ml injectable	Pain - mild to moderate	Not included
Trazodone	25–75 mg tablets 50 mg injectable	Insomnia	Not included
Zolpidem (still patented)	5–10 mg tablets	Insomnia	Not included

◆ This is a reprint of the text taken with permission from the IAHPC website www.hospicecare.com

Complementary: Require special training and/or delivery method

*Side-effects limit dose

**Alternatives to amitriptyline and tricyclic antidepressants (should have at least one drug other than dexamethasone)

***For short term use in insomnia

Note:

Non Benzodiazepines should be used in the elderly

Non Steroidal Anti Inflammatory Medicines (NSAIMs) should be use for brief periods of time

NO GOVERNMENT SHOULD APPROVE MODIFIED RELEASE MORPHONE, FENTANYL OR OXYCODONE WITHOUT ALSO GUARANTEEING WIDELY AVAILABLE NORMAL RELEASE ORAL MORPHINE.

- This is reprint of the text taken with permission from the IAHPC website

Appendix V

A Template of a Case Sheet for Assessment and Documentation

CASE RECORD

Name: Date:
PRPC No.: Age:
Regd. No.: Sex: M/F
Ref By: Address:
Diagnosis:

SOCIAL ASSESSMENT:

Education of patient :
Primary caretaker(s) : (Name & relationship)
Any chronic illness in family :
Habits: Smoking/Drinking/Pan Chewing/
Drug Addiction and other (specify) details

Family tree:
Patient employment:
Employment details of family members:

Name	Relationship	Occupation	Monthly income

Other Sources of Support (Individual/organization):

Name	Relationship	Nature of Support

Financial Status:

Well off	Middle Class	Poor	Very Poor

Psychosocial Check List:

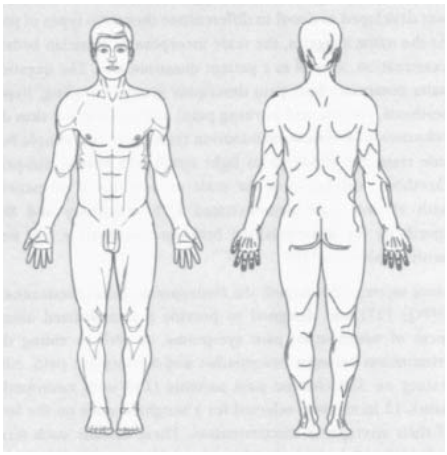
S.No.	CATEGORIES	YES	REMARKS/DATE
1	Have we discussed with patient about		
	(a) Diagnosis		
	(b) Present condition		
	(c) Prognosis/outcome		
2	Have we discussed with family about		
	(a) Diagnosis		
	(b) Present condition		
	(c) Prognosis/outcome		
3	Have we discussed issues related to end-of-life care with		
	(a) Patient		
	(b) Family		

Name and signature of assessor: Date:

Time:

Pain Assessment Chart

Description of pain:



Pain Score:

1. Severity Scale:

0 None	1 Mild	2 Moderate	3 Severe	3 Excruciating

2. Numerical Scale:

Appendix VI

The Palliative Care Policy for the State of Kerala[8]

The Government of Kerala has recently declared a palliative care policy highlighting the concept of community-based care and giving guidelines for the development of services with community participation for the incurably ill and bedridden patients. (HEALTH & FAMILY WELFARE (J) DEPARTMENT GO(P) No 109/2008/H&FWD Dated Thiruvanathapuram 15.4.2008). The new policy aims at providing palliative care to as many needy as possible in the state. The policy which put forth short-term as well as long-term objectives envisage the guiding principle of home-based care, palliative care as part of general health care and adequate orientation of available manpower and existing institutions in the heath care field. The Government has made it clear that the governmental machinery shall work in harmony with Community Based Organization (CBOs), Non-Governmental Organization (NGOs) which have acquired training in delivery of palliative care. In practical terms, the document aims at mobilising volunteers locally, providing them with training in palliative care, empowering these trained groups to work with the health care system. The Government also expects the local self governments to offer good support to the community volunteers in this activity.

The action plan with the policy has the following immediate goals in the next two years

- To train at least 300 volunteers in palliative care in each district
- To conduct sensitisation programmes for 25% of all doctors, nurses and other health/social welfare workers in the state
- At least 150 doctors and 150 nurses in the state to successfully complete the Foundation Course in Palliative Care
- At least 50 more doctors and 50 more nurses in the state to successfully complete six weeks training in palliative care (Basic Certificate Course in Palliative Care).
- To develop more than 100 new community-based palliative care programmes with home care services in the state with active participation of CBOs, LSGIs and local government and other health care institutions
- To develop common bodies/platforms in at least 25% of the LSGIs to coordinate the activities
- To develop at least four more training centres in the state for advanced training in palliative care
- To introduce palliative care into the training programmes for elected members to LSGIs and concerned officials

A Workshop on Developing a Guideline for Setting up of Palliative Care Services in the Hospital and in the Community and Opioid Availability

(A Collaborative Work of WHO-GOI and MNJ Institute of Oncology and RCC)

Venue: MNJ Institute of Oncology and RCC
Date: 17th and 18th June, 2008

List of experts who contributed to the workshop:

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