

PALLIATIVE CARE SERVICES OPERATIONAL POLICY



Medical Development Division
Ministry Of Health Malaysia



MEDICAL DEVELOPMENT DIVISION
MINISTRY OF HEALTH MALAYSIA

PALLIATIVE CARE SERVICES
OPERATIONAL POLICY

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FOREWORD

DIRECTOR GENERAL OF HEALTH MALAYSIA

Life expectancy in Malaysia is increasing due to better healthcare. This however has also resulted in an increase in the number of Malaysians suffering from chronic incurable illnesses such as cancer, organ failure and neurodegenerative disorders. Comprehensive healthcare development should therefore not only encompass progress in the treatment of chronic illnesses but also in the palliation of the sufferings caused by such conditions.

As our nation develops and the standard of living improves, our society will also become more aware of the need to ensure a good quality of life despite having illnesses and the provision of end-of-life care in conditions where cure is not possible and deterioration inevitable.

Healthcare professionals see increasing numbers of patients with advanced life-limiting illnesses and should be prepared to offer all reasonable options available to them. Patients should have opportunities to receive high-quality palliative care throughout their entire illness trajectory. In addition to traditional treatment goals, relieving patients' suffering and optimizing their quality of life should remain high priorities for all health care professionals.

Palliative care services have been developing in the Ministry of Health hospitals since the mid-1990s. The goals of palliative care, namely to improve the quality of life of patients and families facing problems associated with life-threatening illnesses is very much in keeping with the Ministry of Health's mission emphasizing caring and respect for human dignity. The sub-specialty of Palliative Medicine should therefore be encouraged to grow further and more specialised palliative care units should be developed in order to meet the needs of our society.

I would like to congratulate the Medical Programme, in particular the Medical Development Division and Dr. Richard Lim for their efforts in developing this operational policy. It is only appropriate that palliative care services be

developed based on a well documented operational policy similar to other clinical disciplines, more so because it is a relatively new clinical discipline within the Ministry of Health.



Tan Sri Dato Seri Dr. Hj. Mohd. Ismail Merican

DEPUTY DIRECTOR GENERAL OF HEALTH (MEDICAL)

It is said that the duties of a doctor is ‘to cure sometimes, to relieve often and to comfort always’. Hence, it is the responsibility of every healthcare professional to provide palliative care whenever necessary. International bodies including the World Health Organisation have emphasized that palliative care is an essential part of healthcare particularly for those with life limiting illness and it has even been argued that palliative care should be recognized as a human right. The relief of suffering in the dying particularly the relief of pain should always be recognized as a humanitarian need.

In Malaysia, dedicated palliative care units have been developing in the Ministry of Health hospitals since the mid-1990s and in 2005, the field of Palliative Medicine was recognized as a medical sub-specialty by the Ministry of Health. These developments have been necessary in order to improve the effectiveness, efficiency and equity of palliative care services throughout the country. At present the number of palliative care services and consultant palliative medicine physicians are still not adequate, but efforts are being made to address this.

Although palliative medicine is a relatively new field within the Ministry of Health, it is hoped that this operational policy will serve as a guide for those who are pioneering and working towards developing palliative care services. This policy will also serve to enlighten other clinicians and healthcare managers on the roles and functions of a palliative care service including the scope of service, types of service components, essential drugs and equipment required as well as staffing and the organizational structure of the services.

I would like to congratulate the Medical Development Division for initiating and coordinating the development of this policy. I would also like to commend the drafting committee led by Dr. Richard Lim for their commitment in developing this policy. I sincerely hope that in years to come, palliative care will be a service accessible to all patients who require it, be it in a community

setting or a hospital, and that quality of life and dignity be the common goal of all healthcare providers managing patients with incurable life-threatening illnesses.

A handwritten signature in black ink, appearing to read 'Hisham', with a long horizontal stroke extending to the right.

Datuk Dr. Noor Hisham Abdullah

NATIONAL ADVISOR FOR PALLIATIVE MEDICINE SERVICES

It is a great honour and delight to produce this operational policy for palliative care services in the Ministry of Health. Over the past 10 years, the understanding of palliative care has gradually increased not only amongst healthcare professionals but also among the lay public. At present, most state hospitals have some form of palliative care service; some with dedicated in-patient units and some without. A few services have fulltime specialists and medical officers but many others are still lacking in organisation and dedication to a fulltime service. This operational policy highlights the ideals and goals that the Ministry of Health aspires to achieve for palliative care services.

Palliative care is a service provision that all healthcare services should make available and this is emphasized by the local as well as international hospital accreditation organisations such as the MSQH and JCI (Joint Commission International). Standards on pain management, end-of-life care and patient dignity are always emphasised as patient and family rights. This not only emphasizes the fact that Palliative Care is an important area to develop if we want our healthcare services to be of good standard but also emphasizes the fact that palliative care is a service that must be fulfilled as a basic human need to comfort and relieve those who suffer from their illnesses. Hence we should not look at development of palliative care services solely from the perspective of fulfilling a hospital accreditation standard, but really to improve care for patients and their families.

The scope of palliative care in developed nations is rapidly evolving to include not only incurable cancer patients but also many chronic life-threatening medical conditions as well such as end-stage organ failure and neurodegenerative diseases. The scope for further development is therefore vast and the needs are endless as people who are living longer with chronic illnesses are more likely to face a protracted and lingering death. As we are all at risk of this, we should therefore ensure that good palliative care services exist in our country in order to meet with these challenges as healthcare

advances. As the sanctity of life will always be a major principle to our goals as healthcare providers, so to should comfort, relief of suffering and dignity at the end-of-life be remembered as being equally important.

With the development of Palliative Medicine as a subspecialty, it is hoped that these aspirations will become a reality in the near future as more dedicated specialists endeavour to pursue fellowship training in Palliative Medicine in order to provide the clinical leadership for its further development.

I would like to express my heartfelt thanks to our Director General of Health Tan Sri Dato' Seri Dr. Mohd. Ismail Merican, Deputy Director General of Health (Medical) Datuk Dr. Noor Hisham Abdullah, Dato' Dr. Azmi bin Shapie and the Medical Development Division for their continued guidance and unending support towards the development of Palliative Care in Malaysia.



Dr. Richard Lim Boon Leong

ARTICLES



1. INTRODUCTION

- 1.1 Palliative medicine is a new service which was formally introduced in the Ministry of Health (MOH) in 1995.
- 1.2 In 1997 a directive by the Ministry of Health ordered all MOH state hospitals to develop palliative care units by the year 2000.
- 1.3 In 2005, Palliative Medicine was officially recognized as a medical subspecialty and gazetted internal medicine physicians were eligible to train in a three- year fellowship programme. It has however also been suggested that other routes of entry for palliative medicine training should also be considered in the future.
- 1.4 Palliative Care is clearly defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. The complete definition is stated in Appendix 1.
- 1.5 The Ministry of Health regards palliative care as an important component of care which should be made available in all Ministry of Health Hospitals and also at the level of community health care services.
- 1.6 At present the strategic plan for palliative care in the Ministry of Health is to eventually develop specialized units in all state hospitals in the country especially in hospitals where there are increasing specialist services dealing with more complex and technical disease processes involving patients with life threatening conditions and significant disease related morbidity. Until then, resident palliative medicine subspecialty services shall be developed in identified hospitals on a regional basis.

- 1.7 Although Palliative Medicine is now established as a medical sub specialty in the Ministry of Health, the availability of Palliative Care services is not solely dependent upon the availability of trained Palliative Medicine Specialists. Basic palliative care (ie. pain and symptom management , counselling, good nursing care and discharge planning) should still be available to all patients who require it wherever they may be and it is the responsibility of every health care professional dealing with patients with life threatening conditions to ensure that comprehensive care is provided not only during the active management of a life threatening condition but also during discharge and the dying phase. (refer to Principles of Palliative Care Management; Appendix 2)
- 1.8 This policy covers key areas of palliative care service provision such as organization, human resource, asset requirements, drug requirements, training, work processes, ethics and clinical governance.
- 1.9 It is intended to guide health care providers, hospital managers and policy makers on the requirements, operation and development of palliative care services in Ministry of Health hospitals.
- 1.10 The document outlines optimal achievable standards in accordance with best practices and guidelines. In hospitals where these standards are not fully met, necessary steps need to be taken to meet these standards.
- 1.11 The document shall be reviewed and updated every 5 years or when the need arises.

2. OBJECTIVES OF SERVICE

- 2.1 To provide comfort and relief of distressing physical symptoms related to advanced and incurable progressive life threatening conditions.
- 2.2 To provide support to patients and family members facing psychosocial and spiritual issues related to incurable progressive life threatening conditions.
- 2.3 To prevent and minimize suffering by early identification, impeccable assessment and prompt intervention of physical, psychosocial and spiritual problems related to incurable progressive life threatening conditions.
- 2.4 To promote understanding and respect towards patients at the end of life and to prevent unnecessary and futile interventions in order to allow a peaceful and dignified death.
- 2.5 To promote education in the field of palliative medicine and palliative care for both healthcare and non-healthcare professionals.

3. SCOPE OF SERVICE

3.1 In the present era of modern palliative medicine, the scope of service covers both cancer and non-cancer patients with progressive life threatening illness including:

3.1.1 Medical management of chronic cancer pain and other distressing physical symptoms related to advanced cancer.

3.1.2 Medical management of pain and other distressing physical symptoms related to progressive life-threatening non cancerous illnesses. Key areas where palliative medicine in non-cancerous conditions is rapidly developing includes:

- a) End stage cardiac disease with refractory symptoms.
- b) End stage renal disease where dialysis support is not feasible or being withdrawn.
- c) Progressive neurodegenerative disorders (eg. Motor Neurone Disease, Multiple Sclerosis).
- d) Severe chronic airway limitation with deteriorating respiratory function and poor candidate for ventilatory support.
- e) Life threatening paediatric conditions (to be managed by paediatric palliative medicine physician) including life threatening congenital disorders.
- f) HIV / AIDS not responding to anti-retroviral therapy or rapidly deteriorating due to overwhelming disease related complications (infections or malignancy).

- g) Frailty in the elderly with multiple progressive comorbidities (consider collaboration with geriatrician where available).
- 3.1.3 Provision of psychosocial and spiritual supportive care to patients and families facing life-threatening illness.
- 3.1.4 Provision of terminal care for patients at the end of life.
- 3.1.5 Provision of respite care for patients and families.
- 3.1.6 Provision of a holistic management plan to optimize quality of life throughout the course of patients' illness and to apply a multidisciplinary approach to care.
- 3.1.7 Provision of consultative advice and assistance to other medical colleagues regarding palliative management of patients with life threatening situations under their care.
- 3.2 The service should collaborate with oncology services when required for the treatment of cancer pain and other distressing physical symptoms.
- 3.3 The service should collaborate with chronic pain specialists for management of difficult pain.
- 3.4 The service should coordinate and provide community palliative care support where possible.
- 3.5 The service should play a role in the teaching and promotion of palliative care.

4. COMPONENTS OF SERVICE

- 4.1 In-patient palliative care service.
- 4.2 Out-patient palliative care service.
- 4.3 Consultative palliative care service in general wards.
- 4.4 Consultative palliative care service in other hospitals without palliative care units.
- 4.5 Community palliative care service.
- 4.6 Day palliative care service.

5. ORGANISATION

- 5.1 The Palliative Care Unit should ideally be headed by a trained Palliative Medicine Physician credentialed by the Ministry of Health.
- 5.2 When the unit is headed by a palliative medicine physician, the unit may administratively be under the Department of Medicine (or as an independent unit under the Medical Directorate).
- 5.3 The palliative care service can also be developed under any specialised unit/department provided there is a trained, dedicated and committed full time specialist/clinician in charge. The palliative care unit shall then come under the department concerned and the clinician in charge shall be responsible for the day to day running of the unit i.e. conduct ward rounds and review cases.
- 5.4 As the palliative care service is evolving in Malaysia, it may be developed in any hospital/department which has the commitment towards palliative care and has a trained specialist/clinician who is willing to take charge for the provision of such a service. In certain circumstances, it may be acceptable to delegate the responsibility of the specialist-in-charge of the palliative care unit to a senior medical officer with special interest and training in palliative medicine.
- 5.5 In non-specialist hospitals, the palliative care service will be under the responsibility of the hospital director.
- 5.6 The head of the palliative care unit or palliative care service should be responsible for the following:
 - 5.6.1 Clinical management of patients and supervision of medical officers.
 - 5.6.2 Procurement of equipment and consumables.

- 5.6.3 Development of clinical care pathways and protocols to cater to local needs. However policies/guidelines should be developed at the national level and disseminated throughout the Ministry of Health hospitals.
- 5.6.4 Continuing medical education programme.
- 5.7 All state hospitals should eventually develop palliative care units headed by trained palliative medicine physicians who shall be responsible for the following:
 - 5.7.1 Developing specialist palliative care in the respective state hospitals.
 - 5.7.2 Collaborating with other hospitals within the state to establish effective palliative care services.
 - 5.7.3 Coordinating the development of palliative care services throughout the state.
 - 5.7.4 Collaborating with the National Advisor for Palliative Medicine Services in formulating a strategic plan for service development, policies and procedures.
- 5.8 The assigning of human resources for the provision of palliative care services shall be under the purview of the hospital director. Nursing staff should be dedicated staff specific to the palliative care unit and should be encouraged to receive advanced training in palliative care nursing if eligible.
- 5.9 Requirements for staffing of palliative care services are dependent on the level of palliative care services provided and the expected patient load. A guide for ideal staffing of palliative care services is outlined in Appendix 9.

6. GENERAL STATEMENT

6.1 Criteria for patients referred to the palliative care department include the following:

- a) Patients with advanced cancer who are suffering from physical, psychosocial or spiritual distress. Patients who are actively receiving cancer treatment may still be referred. (refer to Integrated Model of Palliative Care in Appendix 4).
- b) Patients with incurable chronic medical illnesses which are progressively fatal with no further options for active medical management or who request to withhold all further active management (e.g. haemodialysis) which will inevitably result in deterioration and death.
- c) Patients who have acute medical or surgical conditions which are not reversible and will inevitably deteriorate rapidly in an acute ward or ICU and require terminal care.

6.2 Palliative Care Services comprise of **3 main components** namely;

- a) In-patient palliative care
- b) Consultative palliative care
- c) Community palliative care

Ideally, each component should have its own dedicated specialist, medical officers and nursing staff. However due to lack of human resource, all 3 components of care may need to be managed by a single team playing interchangeable roles to fulfill each component of care.

- 6.3 All equipment and stock of disposables are the responsibility of the palliative care unit nursing sister who may delegate the duties of keeping track of palliative care equipment in the ward or on loan to her subordinates.
- 6.4 Equipment belonging to the palliative care service may be loaned to patients who are discharged home and require specialized equipment to ensure the continuity of care and comfort. In such circumstances, the palliative care service should have its own local policy regarding how this should be done and whether a cash deposit is required to ensure safe return of equipment. Patients and their families should be aware that the equipment is the property of the Ministry of Health Malaysia and that failure to return equipment is equivalent to theft and will be reported.
- 6.5 Record keeping of all opioid drugs used by the department should be kept and is the responsibility of both the nursing staff and doctors.
- 6.6 Department meetings are to be held as required with all members of staff and should be minuted by an appointed department secretary.
- 6.7 All palliative care services should keep up-to-date records of their activities and patient statistics as well as perform regular auditing of services.
- 6.8 Auditing of services shall be determined by the head of the individual palliative care service and should observe issues of efficiency, effectiveness, patient safety and patient satisfaction of services.
- 6.9 The Ministry of Health Malaysia in liaison with the National Advisor for Palliative Medicine Services shall develop Key Performance Indicators and other QA Indicators for palliative care services which will serve to monitor the performance of the various palliative care services in the country.

7. PALLIATIVE CARE SERVICES

7.1 Inpatient Palliative Care Unit

- 7.1.1 The criteria for admission to the palliative care unit includes:
- a) Patients known to the palliative care service presenting with acute deterioration of symptoms or condition requiring stabilization.
 - b) Patients known to the palliative care service who are dying and the family request for terminal care in hospital.
 - c) Patients known to the palliative care service and require minor procedures such as pleural tap or peritoneal tap.
 - d) Patients known to the palliative care service who require respite care due to social issues.
 - e) Patients known to the palliative care service who are in acute psychosocial crisis and require a safe place to work out issues.
 - f) Patients seen by consultative teams and felt appropriate for transfer to the palliative care unit after approval of specialist in charge.
- 7.1.2 Patients requiring admission during office hours may be admitted directly to the palliative care ward after being reviewed as a “walk-in-review” (refer to 7.3.2), from the outpatient clinic, from casualty or as a scheduled admission from the community after review by the community palliative care service.

- 7.1.3 After office hours, patients known to the palliative care unit should be admitted to the unit through casualty unless stated otherwise in the local hospital policy. In such situations the medical officer on call should be informed and appropriate management and investigations should be organized in casualty before admission to the ward.
- 7.1.4 Patients who are admitted after office hours and are in severe distress or acutely/rapidly deteriorating should be seen upon admission by the medical officer on call.
- 7.1.5 Patients who are not known to the palliative care team and are referred by casualty after office hours should NOT be admitted to the palliative care unit directly. This is to prevent misunderstandings among the family and carers who may not be familiar with the role of the palliative care unit or may not be adequately informed regarding the patient's condition and prognosis. They should therefore be admitted to the primary team in charge of the patient's prior care after advice on symptom management given by the medical officer on call. The patient should then be seen the following morning by the medical officer or specialist on call and may be transferred to the palliative care unit if deemed appropriate after adequate counselling and discussion with the family on the prognosis and advanced care plan for the patient in the palliative care unit.
- 7.1.6 The family and carers of all patients admitted to the palliative care unit should be made aware of the role of the palliative care unit and the status of the patient's disease as well as intent of treatment. They should be aware that in palliative care patients, resuscitation is often inappropriate and futile if deterioration is due to their primary disease. All discussions with the family regarding advanced care plans and resuscitation should be well documented.

- 7.1.7 New admissions should be seen by the specialist in charge within 24 hours of admission. The specialist in charge must then be informed of the case and should review the patient within 48 hours of admission.
- 7.1.8 Nursing staff should work on a shift basis and the number of beds available in the ward depends on the number of staff nurses available.
- 7.1.9 Nurses are required to be familiar in basic palliative care nursing skills including appropriate use of analgesics and the use of simple devices such as syringe drivers.
- 7.1.10 Observation of vital signs is not essential but all patients should be monitored at least once per shift for symptoms that may need attending to.
- 7.1.11 All patients should have appropriate discharge planning before discharge from the ward. Referral to an appropriate community care team should be made and follow up dates in the clinic arranged.
- 7.1.12 Patients who are extremely unwell but request to be discharged should still be provided all medication deemed essential. If medication required include parenteral drugs, then an appropriate amount should be provided in the form of ampoules or pre-filled syringes and the patient's carers should be advised on how they are to be administered. The respective palliative care service should develop a local policy as to how much medication can be supplied at one time and if further medication is required. An appropriate system should be in place to enable the family /carers to obtain such medication.

7.1.13 For patients who are taking large amounts of opioid analgesia home upon discharge, a covering letter should be provided to explain the need for this medication which comes under the Dangerous Drugs Act 1952.

7.2 Consultative Palliative Care Service

7.2.1 All referrals must be made by the primary team with a proper referral letter summarizing patients' history and problems.

7.2.2 Referrals should be seen during office hours and new cases seen within 24 hours of referral. Patients with severe distressing symptoms should be seen immediately.

7.2.3 New referrals should be reviewed by a specialist palliative medicine physician at least once within the week of referral.

7.2.4 Patients under the care of the consultative team may require review by the medical officer on call over weekends and public holidays if deemed necessary.

7.2.5 Large units may employ the services of a nurse coordinator who will follow up all new referrals and look into all palliative care nursing issues with relation to the patient. Education of staff in other wards with regards to pain management techniques and monitoring of syringe drivers is also the role of the nurse coordinator.

7.2.6 If no further active management is planned by the referring team and the patient's care is primarily palliative, the patient may then be taken over to the palliative care unit for further care if agreed upon by the family.

- 7.2.7 Good collaboration between the consultative team and the primary team should exist throughout the care of the patient and active discussions regarding the best management options for the patient should be facilitated to encourage holistic multidisciplinary care.
- 7.2.8 Patients who are discharged from the primary team ward may either be followed up by community care teams or be given a follow up appointment in the palliative care outpatient clinic. Discharge medication and planning should be organized by the primary team.
- 7.2.9 If patients previously seen by the palliative care consultative team come into the emergency department, the patient should not be automatically transferred under the care of the palliative care team. The primary team should still be informed and if the reason for the emergency department visit is related to previous intervention by the primary team such as post-op sepsis, neutropenic sepsis, deconditioning post-procedure etc. then the patient should be admitted under the primary team. The palliative care consultative team will still avail themselves for assistance in managing symptoms in such cases.

7.3 Outpatient clinic

- 7.3.1 The outpatient palliative care clinic is for follow up of patients who are still fairly ambulatory and have a good performance status.
- 7.3.2 The clinic should be at fixed times. However if patients have urgent problems, walk-in reviews are acceptable. The respective palliative care service should develop its own local policy regarding “walk-in-reviews” as to how and where this should be conducted and what patients should expect in order to be reviewed ad-hoc.

7.3.3 Clinic reviews should be conducted by the specialists and medical officers of the palliative care unit and consultative team. If there is a community team available they should also assist in clinic reviews.

7.3.4 Medications should be provided in sufficient amounts till the next clinic review.

7.3.5 Patients who are becoming too ill to attend regular clinic appointments should then continue follow up by means of community care alone. Medications may be continued either by the community team or may be obtained from the clinic by proxy.

7.4 Community Palliative Care Service

7.4.1 At present the majority of community palliative care services are run by Non-Governmental Organizations (NGOs) - hospice organizations, hence where such NGOs are available, this component of care need not be duplicated.

7.4.2 Good collaboration however must exist between the palliative care service in the hospital and the NGOs in order to provide 'seamless care'.

7.4.3 If there is no NGO palliative care service available, then efforts should be made to develop a community service within the hospital palliative care service or within the public health sector in the MOH, i.e. clinics with resident family medicine specialist.

7.4.4 The community care team comprises of a specialist, preferably a family medicine specialist, a medical officer and a nurse coordinator.

- 7.4.5 The role of the community team is to review patients as and when necessary in their homes, so as to provide continuity of care after discharge from hospital.
- 7.4.6 Minor procedures may also be performed at home as long as consent is given.
- 7.4.7 The community team should meet regularly with the entire palliative care department to discuss all cases on their list of patients to ensure all issues are covered.
- 7.4.8 An after office hours contact number should be available for patients requiring assistance at home and the community nurses should have an on call roster in order to answer calls to the contact number. The medical officer on call should be available to assist the community nurse in handling after office hours problems.

7.5 Daycare Services

- 7.5.1 Daycare services refer to a palliative daycare centre where patients come for respite during the day and engage in social activities and interact with other patients who are of relatively good performance status.
- 7.5.2 Daycare activities may be jointly organized with the help of volunteer organizations who will provide the main human resource of this service.
- 7.5.3 The nurse in charge is responsible for coordinating volunteers and patient daycare activities .
- 7.5.4 Patients requiring medical review may also have this done during daycare sessions.

7.5.5 Daycare is not an essential service but is included as a useful component of a complete palliative care service.

8. TRAINING AND EDUCATION

8.1 All palliative care services should ensure that a reasonable level of knowledge, skills and competence exists among within all its personnel. As palliative care is a fairly new subspecialty, experience and knowledge may be lacking in many services. A continuous effort however should be made to obtain as much formal or informal training for staff working in palliative care services and it should be understood that although palliative care comprises of a lot of good basic medical care, there are specific areas of care that require specialized training and knowledge just like any other medical subspecialty.

8.2 Training of nurses

8.2.1 Nurses new to the concept of palliative care should also undergo a period of in-house training and supervision to introduce them to the field.

8.2.2 Formal training in the form of an advanced diploma in palliative care nursing may be available in the near future and all services should look towards encouraging such formal training among staff who are interested.

8.2.3 Clinical attachments and short courses in palliative care are also helpful to provide informal training by centres where more expertise is available.

8.3 Training of medical officers

8.3.1 All medical officers newly assigned to a palliative care unit or service should undergo a period of basic training in palliative care skills and knowledge in order to enable them to understand the philosophy of care and management of patients in the palliative care setting.

8.3.2 In units where there is a consultant palliative medicine physician, medical officers new to palliative medicine should undergo in-house training and a period of supervised “tagging” before they can independently be placed on call and the specialist in charge should determine the readiness of the medical officer to handle on-call duties.

8.3.3 If there is no experienced consultant available, training can be obtained through clinical attachments in centres such as in the Palliative Care Unit in Hospital Selayang, Hospital Ipoh or Hospital Pulau Pinang where trained consultants in palliative medicine are available. Short courses run by NGOs and other palliative care organisations where expert speakers are employed also provide a good resource for training of medical officers.

8.3.4 Areas of basic knowledge for medical officers managing palliative care services include the following:

- Introduction to palliative care
- Cancer pain management and using opioid analgesia
- Management of respiratory symptoms in advanced disease
- Management of GIT symptoms
- Managing delirium and confusion
- Palliative care emergencies
- End-of-life care
- Basic communication skills
- Ethics and clinical decision making
- Communication at the end of life

8.4 Training of Specialists in Palliative Medicine

8.4.1 Palliative Medicine is a recognized medical sub-specialty. Hence doctors intending to train as Consultants in Palliative Medicine should undergo basic specialist training in internal medicine prior to sub-specialty training. The required qualification at present includes MMed, MRCP(UK), MRCP (Ire), FRACP or any equivalent qualification and completion of gazettement in internal medicine.

8.4.2 The MOH currently has a 3 year fellowship training programme available to physicians intending to undergo consultant training in palliative medicine. This includes 2 years of local training in an accredited palliative care unit under the supervision of a recognized consultant palliative medicine physician and 1 year of overseas training in a recognized palliative care service.

8.5 CME

CME sessions for both doctors and nurses should be conducted weekly and contributions by all doctors and nurses are compulsory. A CME committee for the department must determine the CME programme for the department including journal club discussions, case presentations, academic meetings, workshops and CME talks by the pharmaceutical industry.

9. WHOLE HOSPITAL POLICY

9.1 The Palliative Care Unit shall comply with the Whole Hospital Policy in the following areas:

9.1.1 Hospital admission and discharge

9.1.2 Transportation service

9.1.3 Infection control

9.1.4 Sterilization service

9.1.5 Management of waste products

9.1.6 Supply of pharmaceuticals and consumables

9.1.7 Acquisition of assets and equipment

9.1.8 Catering service

9.1.9 Laundry and Linen supply

9.1.10 Cleaning service

9.1.11 Engineering service including preventive and maintenance services

9.1.12 Security service

9.1.13 Fire precaution

9.1.14 Medical record management


9.1.15 Communication system

9.1.16 Quality Assurance

9.1.17 Occupational and Safety Health Assurance (OSHA)

9.1.18 Public relations, release of information and confidentiality.

- 9.2 With regards to palliative care drugs, certain drugs may be used for indication outside that of standard hospital policy (blue book indication). This is acceptable provided the indication is supported by evidence in current palliative medicine literature and approved by the relevant authorities. A list of essential medications for palliative care and their indications is provided in Appendix 9.
- 9.3 All patients in the hospital who have incurable and progressively fatal illness should have a care plan outlined by the specialist in charge with or without the assistance of a palliative care team. The patient's prognosis and issues of CPR, intubation, ICU admission in the event of rapid deterioration and cardio-respiratory collapse due to their illness should be discussed with the patient and/or family and clearly documented in the patient's clinical notes. Resuscitation status is a medical decision and should be made by the treating clinicians. Discussions regarding this should therefore not imply that the family is being asked to make such a decision but merely to inform and understand the rationale for such a decision being made.



APPENDICES



WHO DEFINITION OF PALLIATIVE CARE

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, 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 patients illness and in their own bereavement.
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- will enhance quality of life, and may also positively influence the course of illness.
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO DEFINITION OF PALLIATIVE CARE FOR CHILDREN

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

DEFINITION OF PALLIATIVE MEDICINE

The medical speciality which concerns itself with the appropriate medical care of patients with progressive disease. This should be distinguished from "Palliative Care" which is the approach to care for patients with progressive disease.

PRINCIPLES OF PALLIATIVE CARE MANAGEMENT

1. Scope of care

Includes patients of all ages with life-threatening illness, conditions or injury requiring symptom relief from physical, psychosocial and spiritual suffering.

2. Timing of palliative care

Palliative care should ideally begin at the time of diagnosis of a life threatening condition and should continue through treatment until death and into the family's bereavement. Patients with distress should be managed in a timely manner so as to shorten the duration of suffering.

3. Patient and family centred care

The patient and family constitute the unit of care which should be managed as a whole. Goals of care should be determined by the patient and family after the healthcare team has provided relevant information and guidance to enable decision-making.

4. Holistic care

Palliative care must endeavour to alleviate suffering in the physical, psychological, social and spiritual domains of the patient in order to provide the best quality of life for the patient and family.

5. Multidisciplinary care

Due to the holistic nature of palliative care, a multidisciplinary team approach is essential to address all relevant areas of patient care. Care may also cut across to mainstream disciplines such as surgical or oncology teams where active interventions may still remain relevant in order to alleviate symptoms in patients.

6. Effective communication

Good communication skills are essential tools in palliative care and healthcare providers must develop this in order to provide effective palliative care. This includes effective listening, providing information, facilitating decision making and coordinating care among the patient, family and other healthcare providers.

7. Knowledge and Skills

Palliative care is active care and requires specific management for specific conditions. Healthcare providers have a responsibility to acquire proper knowledge and skills in order to deliver effective palliative care and maintain patient safety. Knowledge and skills in disease processes and prognostication are essential in order to determine management plans and set goals of care.

8. Seamless care

Palliative care is integral to all healthcare settings (hospital, emergency department, health clinics and homecare). Successful palliative care is dependent on the existence of a system integrating care across all settings in order to provide continuity of care for the patient and an effective support system from hospital to home. Patients and families should be provided with a care plan on how to obtain help in a crisis at anytime in any place in a timely fashion.

MOH VISION AND MISSION STATEMENT FOR PALLIATIVE CARE

VISION

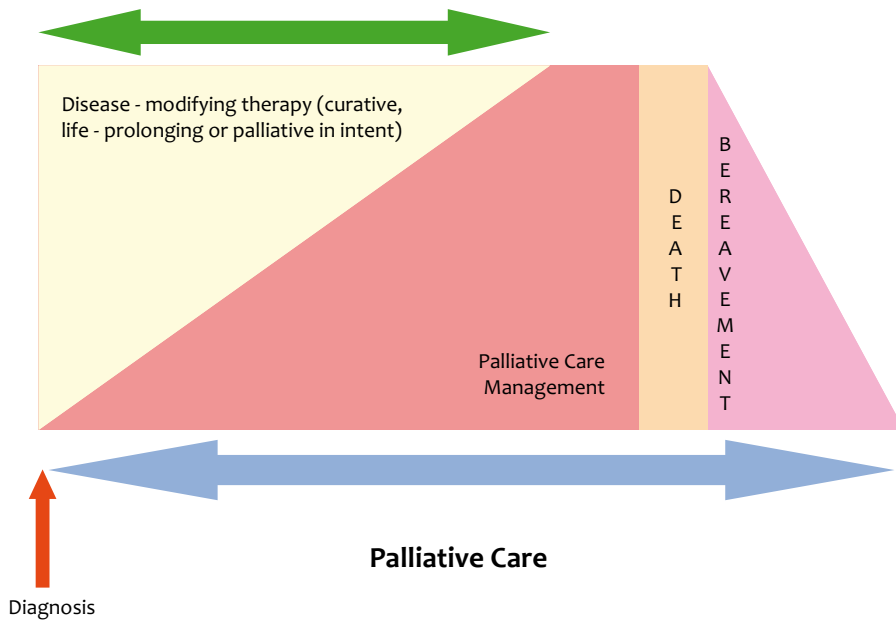
Comforting all who are in need.

MISSION

- To achieve universal pain and symptom relief in all cancer patients.
- To achieve pain and symptom relief in non-cancerous life threatening conditions.
- To create a unified effort by all healthcare providers to ensure holistic and comprehensive palliative care throughout the country providing a support system for patients wherever they may be.
- To promote universal understanding on end-of-life issues maintaining the ethical principles of medicine while upholding human dignity.

INTEGRATED MODEL OF PALLIATIVE CARE

Co - management with Mainstream



Adapted from "Introducing Palliative Care" 4th Edition 2002 by Robert Twycross

COMPONENTS OF PALLIATIVE CARE SERVICES AND THEIR RELATIONSHIPS

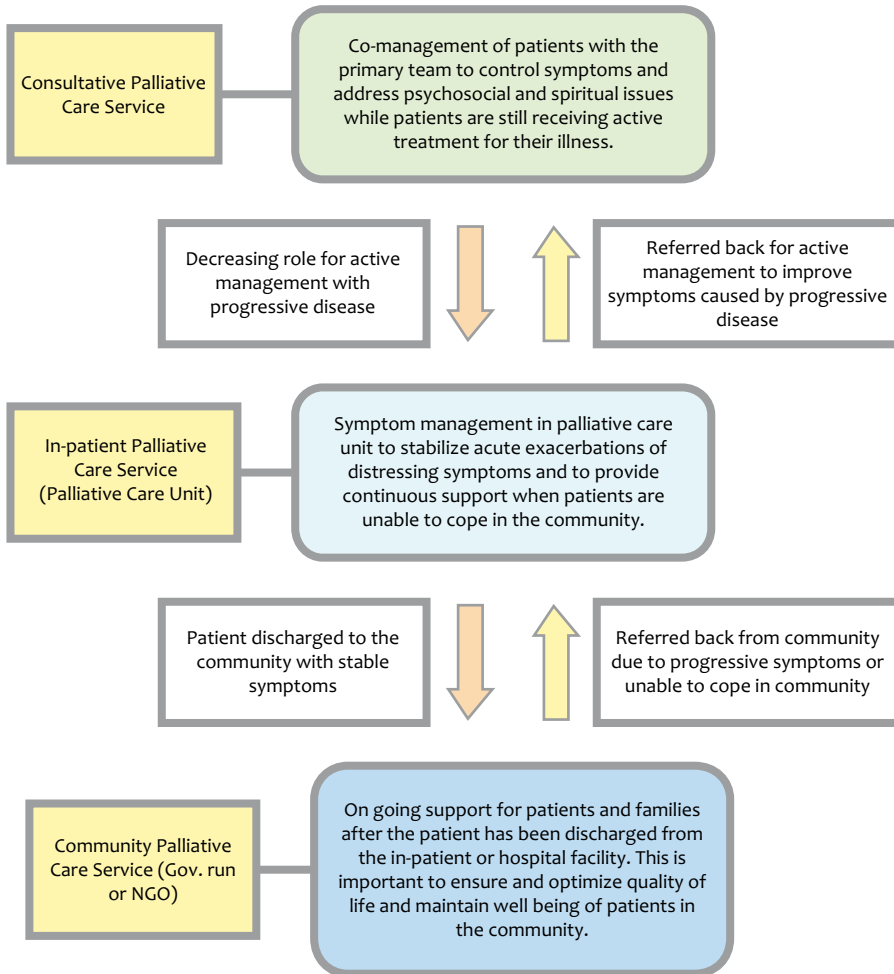


CHART 1: IDEAL ORGANISATIONAL STRUCTURE FOR PALLIATIVE CARE SERVICE IN HOSPITALS WITH RESIDENT PALLIATIVE MEDICINE PHYSICIAN

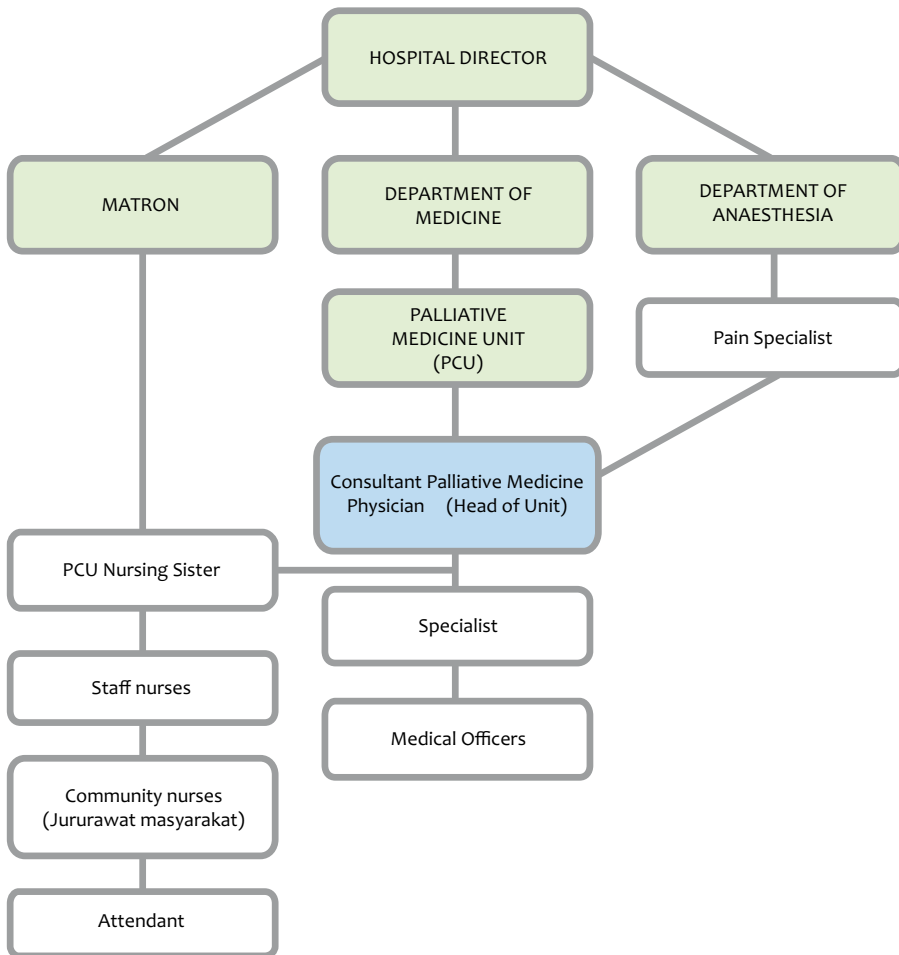
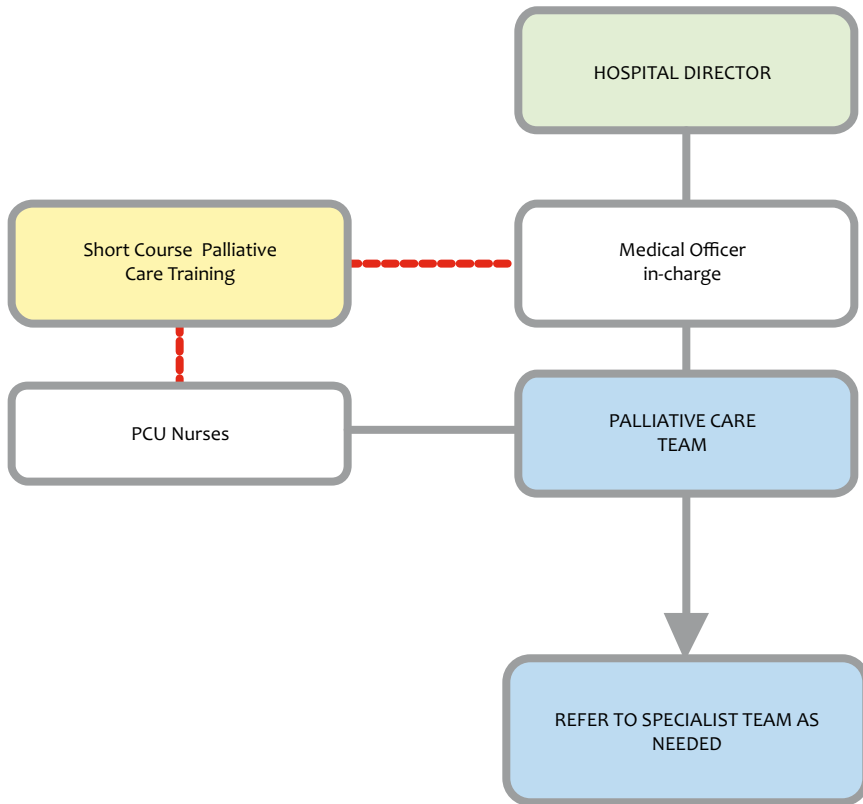


CHART 2: ORGANISATIONAL STRUCTURE OF PALLIATIVE CARE SERVICE IN HOSPITALS WITH NO RESIDENT PALLIATIVE MEDICINE PHYSICIAN



CHART 3: ORGANISATIONAL STRUCTURE OF PALLIATIVE CARE SERVICE IN NON-SPECIALIST HOSPITALS



RECOMMENDATIONS FOR IDEAL STAFFING OF PALLIATIVE CARE SERVICES

A. In-patient Palliative Care Unit with resident palliative medicine physician (20 bedded)

Consultant / Specialist	Medical Officer	Ward Sister	Staff Nurses	Community nurses (JM)	Attendants
1	2	1	20	-	5

- The general formula for number of nurses required is equal to the number of beds allocated to the palliative care unit provided the BOR is continuously high.
- Where staff nurses are not available, community nurses (jururawat masyarakat) may take on the role.

B. Consultative Palliative Care service in hospitals (state hospital > 700 beds) without inpatient palliative care units

Consultant / Specialist	Medical Officer	Ward Sister	Staff Nurses	Community nurses (JM)	Attendants
1 (resident or visiting)	1	-	1	-	-

In a large specialist hospital without a palliative care unit that has patients who require palliative care and advice, there should be an attempt to establish a consultative palliative care service, which should comprise of at least 1 consultant, 1 medical officer and 1 nurse. The consultant may be visiting from another regional hospital. The medical officer and nurse should be based in that hospital to maintain care on a daily basis.

C. Community Palliative Care Service (covering a single district)

Consultant / Specialist	Medical Officer	Ward Sister	Staff Nurses	Community nurses (JM)	Attendants
1 (visiting from main hospital)	2	-	2	2	2

A community palliative care service requires its own staff. This is something that has yet to be developed but is important particularly in areas not covered by NGO services. The mainstay of medical personnel will be the medical officers and staff nurses / community nurses. The justification for the numbers includes the population size covered by the service, population density and also the size of the area covered. The consultant of the service may be a family medicine specialist with training in palliative medicine or a visiting palliative medicine consultant from a regional hospital who should be available for advice whenever necessary.

RECOMMENDED ESSENTIAL DRUGS FOR PALLIATIVE CARE SERVICES

A. Pain Medication

No.	Drug Name	Formulation	Indication
1.	Diclofenac	50mg tab 75mg inj.	Step 1 analgesic for mild to moderate somatic pain (caution in elderly)
2.	Ibuprofen	200mg tab	Step 1 analgesic for mild to moderate somatic pain (caution in elderly)
3.	Paracetamol	500mg tab	Step 1 analgesic for mild pain or used in combination with stronger opioids for additional effect.
4.	Dihydrocodeine (DF118)	30mg tab	Step 2 weak opioid analgesia for moderate pain.
5.	Tramadol	50mg cap/tab	Step 2 weak opioid analgesia for moderate pain. Useful in patients with renal impairment requiring opioid analgesia.
6.	Morphine	2mg/ml liquid 10mg/ml injection 10mg, 30mg, 60mg tab (slow release)	Step 3 analgesia of choice for moderately severe to severe cancer pain. Used for relieving dyspnoea
7.	Oxycodone	10mg, 20mg slow release tab.	Step 3 opioid analgesia for moderately severe to severe cancer pain. Useful as second line or alternative

No.	Drug Name	Formulation	Indication
8.	Fentanyl	12mcg/h ,25mcg/h, 50mcg/h transdermal patch 50mcg/ml inj.	Step 3 opioid analgesia for moderately severe to severe cancer pain. Useful as second line or alternative opioid during opioid rotation. Useful for patients with renal failure requiring opioid analgesia. Useful for patients who are unable to swallow medication orally.

B. Anti-emetics

No.	Drug Name	Formulation	Indication
1.	Metoclopramide	10mg tab 10mg/ml inj	1 st line anti-emetic for any cause of vomiting except complete bowel obstruction.
2.	Haloperidol	1.5 mg, 5mg tab 5mg/ml inj	2 nd line anti-emetic particularly for central nausea Also useful for delirium and terminal restlessness.
3.	Promethazine	50mg/ml inj	3 rd line anti-emetic

C. Laxatives

No.	Drug Name	Formulation	Indication
1.	Bisacodyl	5mg tab / suppository	Constipation
2.	Lactulose	100 mls/bottle	Constipation (Lactulose may cause bloating in some patients and alternative laxative to consider is macrogel)
3.	Glycerine enema		Constipation with impacted stools in lower rectum

D. Sedatives

No.	Drug Name	Formulation	Indication
1.	Lorazepam	1mg tab	Insomnia Anxiety / Panic attacks
2.	Midazolam	5mg/ml inj 7.5 mg tab	Anxiety Terminal restlessness
3.	Diazepam	5mg tab 5mg/ml inj 10mg suppository	Anxiety Also as a muscle relaxant and anticonvulsant.
4.	Zolpidem	10mg tab	2 nd line drug for cancer related insomnia

E. Adjuvant Analgesics

No.	Drug Name	Formulation	Indication
1.	Amitriptyline	10-25mg tab	Depression 1 st line for Neuropathic pain
2.	Carbamezepine	200mg tab	Epilepsy Neuropathic pain
3.	Sodium Valproate	200mg tab	Epilepsy Neuropathic pain
4.	Gabapentin	300mg, 600mg tab	2 nd line in neuropathic pain

F. Corticosteroids

No.	Drug Name	Formulation	Indication
1.	Dexamethasone	0.5mg tab 4mg/ml inj	Main role in reducing peri-tumour oedema which may relieve symptoms due to mass effect of tumour. Neuropathic pain Anorexia Nausea and vomiting
2.	Prednisolone	5mg tab	Anorexia

G. Anticholinergic agents

No.	Drug Name	Formulation	Indication
1.	Hyoscine butylbromide	10mg tab 20mg/ml inj	Relieving colicky visceral pain Reducing terminal secretions Nausea & vomiting from bowel dysfunction
2.	Loperamide	2mg	Diarrhoea

LIST OF ESSENTIAL EQUIPMENT IN A PALLIATIVE CARE UNIT

Equipment for ward

Medical equipment

- Beds Hi / Lo
- Cardiac tables
- Drip stands
- Bedpans
- Urinals
- Syringe drivers
- Ripple mattress
- Oxygen concentrator
- Manual hydraulic hoist
- Walking frames
- Suction machine
- Lockers
- Comode chair
- Dressing trolley
- TENS machine
- Wheelchairs (detachable and adjustable)
- Nebuliser
- Drug trolley
- Glucometer
- Ophthalmoscope
- Examination couch (Hi Lo)
- Tendon hammer
- Tuning fork (128Hz)
- Transportation trolley
- Personal computer
- Pulse Oximeter
- Stethoscope

- Blood Pressure Set
- Infusion pump

Non-medical equipment

- Lounge set
- Television set
- DVD/VCD player
- Mini Hi Fi
- Dining Table and chair sets
- Air-conditioner 1.5 H
- Bookshelf
- Drinking water dispenser
- Microwave oven
- Electric kettle
- Refrigerator
- Teacups and plates sets
- Stand fans
- Plastic chairs
- Lazy chairs
- Instant hot water shower

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