Proposal

Fellowship Training Program of Paediatric Palliative Medicine Subspecialty in Malaysia

2013
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This Proposal was drafted after a series of email communications among the proposal drafting committee members as follows:-

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**Criteria for Registering as a Paediatric Palliative Medicine Physician**

A doctor can apply to be registered as a Paediatric Palliative Medicine Physician if he/she fulfils ALL the following requirements:

1. A recognised basic medical degree
   1.1 A basic medical degree recognized by the Malaysian Medical Council.

2. A recognised postgraduate qualification
   Holds any of the following postgraduate qualification registrable under the National Specialist Register:
   2.1 Sarjana Perubatan (Paed) awarded by Universiti Malaya, Universiti Kebangsaan Malaysia or Universiti Sains Malaysia
   2.2 MRCP (UK) up to year 2000
   2.3 MRCPCH by Royal College of Child Health, UK
   2.4 MRCPI (Ireland)
   2.5 FRACP
   2.6 Any other paediatric postgraduate degrees deemed to be equivalent to the Master programme of the local universities on a case by case basis.

3. Completed subspecialty training in Paediatric Palliative Medicine as stipulated below
   3.1 Minimum duration of training
      3.1.1 Have completed a minimum of 3 years of full-time training in Paediatric Palliative Medicine in accredited centres under the supervision of accredited trainers. The training requirements, criteria for accreditation of training centres and trainers are as in Error! Reference source not found. and 3. This period of training does not include the time the applicant spent during his / her housemanship nor the period when undergoing training for the paediatric postgraduate degrees stated in 2.1 to 2.6

3.2 Evidence of satisfactory subspecialty training in Paediatric Palliative Medicine such as:
   3.2.1 Satisfactory supervisors' reports on the General and Core Competencies as in Appendix 1
3.2.2 Reports and assessments as stated under the Assessment section of Appendix 2

3.2.3 Portfolio with supporting documents where relevant, e.g. a valid certificate of completion of training in the subspecialty, published research papers or abstracts, certificates of attendance at conferences, courses or workshops.

3.2.4 Satisfactory performance during the exit examination in the form of viva-voce.

4 Applications from any doctor with training and experience overseas must be substantiated by documents relating to qualification, supervised training and experience. The Specialty Subcommittee for Paediatric Palliative Medicine may consider such application on a case by case basis and reserves the right to stipulate any conditions which may include additional training or experience.
INTRODUCTION

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 and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” – WHO 2002.

Paediatric Palliative Care (PPC) is active total care delivered to infants, children or adolescents with life-threatening or life-limiting illness supporting their physical, psychological, social and spiritual domains. It aims to optimize quality of life and reduce suffering of infants, children or adolescents and their families. PPC affirms life and supports children and adolescents and their family’s goals for their future. This specialised care begins at diagnosis irrespective of curability and continues to bereavement. Effective PPC is a collaborative effort of an interdisciplinary team and can be provided at hospitals or in the community.

Paediatrics first developed as a discipline in Malaysia in the 1980s, the last three decades has witnessed the growth of 17 paediatric subspecialties (MOH Malaysia 2012). However PPC development has remained dormant and thus lags behind the Adult Palliative Medicine which was formally introduced in 1995, and is now an established medical subspeciality. (MOH Malaysia 2010). In terms of PPC provision around the world, currently Malaysia falls under Level 2 where capacity building has been identified as opposed to PPC having reached mainstream providers Level 4 (Knapp 2011). Care for most children in need of PPC (Kuan 2012) is fragmented, inconsistent, being mainly hospital-based, looked after by paediatricians in government hospitals without a formal PPC program. Malaysian hospitals thus have the unique opportunity to define excellence in end of life (EOL) care for children and adolescents. Models of EOL care that are hospital- and home-based need to be developed and funded.

Twenty nine percent of all deaths in the under 5 age group of children in Malaysia (Wong 2006) is caused by congenital malformations, deformations and chromosomal abnormalities and oncology. In the congenital malformations, deformations and chromosomal abnormalities group, 39.7% were congenital heart disease, 24.6% syndromes, 12.0% gastrointestinal system malformations and 10.6% central nervous system malformations. Under the infectious and parasitic disease group, 19 deaths were from HIV. Deaths were four times more likely to occur in hospital than non-hospital setting (Wong 2006). All the deaths in the oncology group occurred in the hospital, 86% of the deaths in the congenital malformations group occurred in the hospital and 14% were non-hospital. Acuity of care has been shown to be very high prior to death, when children die in hospitals without a formalized PPC programme. (McCallum 2000). To date, there is no published national data on childhood deaths for older children aged between 5 to 18 years old and the implication on their palliative care needs in Malaysia.

Hence, there is a need to develop the paediatric palliative medicine as a subspecialty in response to the rapid recognition towards the needs as well as family and societal demands for holistic care of infant, children and adolescents with life-limiting disorders. The need for
PPC service was duly recognised by the Ministry of Health when the Dasar Baru was accepted in 2012. Since then there has been a growing interest and development in this field.

The objectives of this training programme is to ensure the trainee is equipped with the expertise to plan, organise, administer and review appropriate and comprehensive palliative care management plans, utilising and coordinating the skills of interdisciplinary palliative care teams and communicating effectively with patients, families and others. He is expected to be able to manage complex pain and other symptoms, able to understand the range and complexity of life-limiting conditions (LLC) across all ages, understand how children may die and experience the dying process, develop skill in planning and facilitating family choices about care, advanced communication skills, knowledge and experience in managing complex ethical dilemmas.

ENTRY REQUIREMENTS

i. A registered basic medical degree recognised by the Malaysian Medical Council (MMC).

ii. Paediatricians registered with the National Specialist Register (NSR).

iii. Of a suitable character and with a good work attitude (references will be required from 2 Consultants). In the event that there are more applicants than training posts, additional criteria for selection will be based on:

   a) Research output, publications and presentation at scientific meetings

   b) Seniority in service

   c) Having worked in a district hospital after passing his/her postgraduate examinations

   d) Participation in professional bodies relevant to the subspecialty

iv. Final selection of training candidate will be done by National Paediatric Palliative Care Reference Group (Appendix 4) until such time when the Paediatric Palliative Medicine subspecialty committee is established.
TRAINING

1. Training Philosophy

The fellowship training programme aims to provide a conducive learning environment supported by a learning framework and appropriate guidance. Trainees are expected to participate actively in their education and training. Reflective practice is encouraged by constant enquiry and personal reflection. While trainees work to achieve competencies in the areas listed in this document, the learning process continues life-long.

2. Training duration

The minimum duration of training will be 3 years in accredited centres, under the supervision of accredited trainers. This period of training does not include the time the applicant spent as a houseman nor the period when undergoing training for the paediatric postgraduate degrees or gazettement.

3. Components of Training

3.1 Paediatric Palliative Medicine – 2 years

A total of 12 months should be spent within local accredited centres providing paediatric palliative care service, under the supervision of a paediatric palliative medicine physician. The trainee is required to rotate through paediatric subspecialties with high prevalence of children with life-limiting disorders including oncology, neurology, metabolic/genetic, neonatology, cardiology, respiratory, nephrology, HIV and PICU. The trainee should acquire experience in identification of children likely to have life-limiting disorders, assessment on the child’s symptoms, psychological and spiritual needs, appropriate symptom control measures and treatment, develop good communication skills such as breaking bad news, organising and conducting family conference, discussion on end of life issues and provision of bereavement care.

The trainee will be required to work within a local palliative care team as well as with relevant primary referral team. In the final year training, the trainee should seek clinical attachment with hands-on experience with an accredited overseas training centre for paediatric palliative medicine.

Since there is no certified paediatric palliative medicine physician in Malaysia at the present moment, it is proposed that training for this component be supervised by appointed supervisors from National Paediatric Palliative Care Reference Group (Appendix ). The accredited centre must be one that provides active paediatric palliative medicine services.
3.2 Adult Palliative Medicine (with in-patient palliative unit) – 6 months

The trainee should have at least 6 months training within a centre accredited for training in adult palliative medicine that has consultative service, clinics and in-patient palliative unit. The trainee should acquire experience in identification of young adults with life-limiting disorders, assessment on the young person’s symptoms, psychological and spiritual needs, appropriate symptom control measures and treatment, develop good communication skills such as breaking bad news, organising and conducting family conference, discussion on end of life issues and provision of bereavement care.

3.3 Community Palliative Care Medicine – 6 months

The trainee should have at least 6 months of training in an accredited centre (such as Hospis Malaysia). This is to expose the trainee to the provision of palliative care at home for children with life-limiting disorders. The trainee should acquire experience in collaborating the transition from hospital to home care, managing pain and other symptoms at home, service coordination and collaboration with related agencies and various NGO-run centers that provide palliative care services. The trainee is expected to conduct periodic home visits with the palliative care team, support end of life option at home and provide bereavement counselling.

3.4 Other Optional Subspecialties and clinics.

The trainee is also encouraged to attend the following additional clinics / sessions during the training:

- Acute and Chronic Pain Management clinic
- Child Psychiatry clinic
- Community-based Rehabilitation
### TRAINING SCHEDULE SUMMARY

<table>
<thead>
<tr>
<th>Training Component</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic Paediatric Subspecialty Rotations (with special emphasis in those children with life-limiting disorders)</td>
<td>12 months</td>
</tr>
<tr>
<td>1. Oncology</td>
<td>4 months</td>
</tr>
<tr>
<td>2. Neurology / Metabolic / Genetic</td>
<td>4 months</td>
</tr>
<tr>
<td>3. Others (Cardio / Respiratory / PICU / NICU, HIV, etc)</td>
<td>4 months</td>
</tr>
<tr>
<td>Adult Palliative Medicine / In-patient services (with special emphasis on in-patient services and on teenagers and young adults with life-limiting disorders)</td>
<td>6 months</td>
</tr>
<tr>
<td>Community Palliative Care Medicine</td>
<td>6 months</td>
</tr>
<tr>
<td>Paediatric Palliative Medicine (overseas)</td>
<td>12 months</td>
</tr>
<tr>
<td></td>
<td>6 months (in 2 centres)</td>
</tr>
<tr>
<td></td>
<td>or 12 months (in 1 centre)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>36 months</strong></td>
</tr>
</tbody>
</table>

The durations of training stated in the table above are time-equivalent. Often it is advisable to combine 2 to 3 specialities in the training schedule simultaneously as that will allow the candidate to learn the management of a condition across disciplines. It will also allow a longer follow up opportunities and perspective for each patient.

The sequence of the training at each discipline or sub-discipline stated on the table is just a guide. Some flexibility should be allowed as long the objectives for their training could be achieved.

The actual training schedule of a particular candidate will be determined by the training coordinator assigned to that candidate.
TRAINING CONTENT

The trainee is expected to

A. Acquire general competency in core general paediatrics, neonatology and its various subspecialties dealing with infants, children and young persons with life-limiting disorders. (Appendix 5)

B. Acquire specific knowledge, skills and attitudes in the following aspects:

1. History, Philosophy and definition of palliative care

2. Care of the patient
   a. History taking
   b. Clinical examination
   c. Decision making and clinical reasoning
   d. Disease process and management
   e. Management of concurrent clinical problems
   f. Principles of pain and symptom management
   g. Pain management
   h. Management of gastrointestinal symptoms
   i. Management of respiratory symptoms
   j. Management of genitourinary symptoms
   k. Management of musculoskeletal and skin symptoms
   l. Management of neurological and psychiatric problems
   m. Management of other symptoms
   n. Management of emergencies in palliative care
   o. Infection control
   p. Pharmacology and therapeutics in palliative care
   q. Rehabilitation
   r. Delivery of shared care
   s. Care of the dying patient and his/her family

3. Communication
   a. Relationships with patients and communication within a consultation
   b. Communication with patients and caregivers
   c. Breaking bad news
   d. End of life issues discussion and planning

4. Psychosocial care
   a. Social and family relationships
   b. Psychosocial responses of patients and carers to life-threatening illness and loss
   c. Management of violent and suicidal patients
   d. Grief and bereavement
   e. Patient and family finance
5. Attitudes and responses of doctors and other professionals
   a. Self awareness
   b. Self management
   c. Doctor – patient relationship
   d. Supporting professional colleagues

6. Culture, language, religion and spirituality
   a. Culture and ethnicity
   b. Religion and spirituality

7. Ethics
   a. Principles of medical ethics and confidentiality
   b. Theoretical and applied ethics in clinical practice of palliative care

8. Legal frameworks
   a. Valid consent
   b. Aspects of law related to palliative care practice

9. Team work
   a. Team work and patient safety

10. Learning and teaching
    a. Learning and self development
    b. Teaching and training

11. Research
    a. Evidence and guidelines
    b. Ethical research

12. Management
    a. Human resource
    b. Leadership skills
    c. Time management and decision making
    d. Information management
    e. Managing a palliative care service
    f. Running a palliative care unit
    g. Financial management

13. Clinical governance
    a. Complaints and medical error
    b. Patient safety in clinical practice
    c. Principles of quality and safety improvement
    d. Audit

The training will be done in the form of case-based discussions (CBD), direct observation of consultation or clinical evaluation exercise (CEE), service provision, supervision of junior doctors and other health professionals, interdisciplinary meetings, family conferences (eg
breaking bad news and end of life discussion and planning), counselling / bereavement sessions and CME activities (e.g. journal discussions, case presentations and palliative care lecture series and workshops). Trainees should directly observe and work jointly with primary team specialists / subspecialists, therapists, as well as observe and perform appropriate pain and symptom assessments of children with life-limiting disorders. In addition trainees will be required to make school and home visits. Trainees will need to be self-motivated to direct their own learning using the available opportunities. In addition, trainees will need to develop skills in self-assessment and critical evaluation of their own consultations.
Appendix 1

COMPETENCIES IN PAEDIATRIC PALLIATIVE MEDICINE

General Competencies

1. Know the broad definition of palliative care in childhood.
2. Recognise factors which determine when care of a patient becomes palliative.
3. Know the importance of seeking advice when treatment may not be in the best interests of a child.
5. Be aware of the legal and ethical issues relating to withdrawing of life support.
6. Be familiar with the ethical and legal debates on euthanasia.

Core Competencies

1. Clinical history and assessment which includes medical, psychosocial, family / social history, physical examination, including a detailed assessment of pain and other symptoms.
   i. Formulate likely disease trajectories
   ii. Formulate the palliative care needs for the child and the family.
   iii. Formulate, apply and continue to reappraise an appropriate palliative care management plan, taking into consideration the various factors (e.g. child, family, community and economics), which are present in each child. This includes medical and health-based therapies, behavioural and psychological options.
   iv. Participate and lead interdisciplinary paediatric palliative care team meeting.
   v. Conduct or participate in family conference to communicate bad news, end of life issues and advance care directive discussion and planning effectively to parents and caregivers.
   vi. Where appropriate to also participate in the breaking of bad news, end of life issues and advanced care directive discussion and planning effectively to adolescents and young adults with life-limiting disorders.
   vii. Have the team-working skills to work in partnership with other professionals in health, education, social services and towards child and family-centred palliative care.
   viii. Know when to seek advice where appropriate from related paediatric subspecialty colleagues, particularly neurologists, oncologists, or pain services and able to work with multidisciplinary teams in managing symptoms.
ix. Identify and manage the functional consequences associated with life-limiting, life-threatening and severe medical conditions, including dying and death.

x. Plan and conduct grief and bereavement care services for the family including the affected siblings and staff.

xi. Write letters or medical reports from the palliative medicine perspective to other professionals and government agencies.

xii. Collaborate in the transition palliative care plan from hospital to home, by tapping into the available community resources and palliative care services such as hospice.

xiii. Give a balanced view on curative and palliative care options (including traditional and complementary methods) and managing conflicts with regards to the treatment goals.

xiv. Learn and be conversant with regards to medical ethics in the practice of palliative medicine and making end of life decisions.

xv. Work in a variety of settings outside the hospital environment e.g. community based palliative day-care centres and schools by doing home and school visits.

xvi. Learn to practice the principles of palliative medicine across various ethnic, cultural and religious settings.

xvii. Plan, promote and evaluate palliative medicine services for children with life-limiting disorders from neonates to young adults.

xviii. Teach and disseminate paediatric palliative medicine knowledge in health and non-health contexts.

xix. Undertake audit and research in paediatric palliative medicine.

2. Understand, select, apply and interpret appropriate paediatric pain assessment tools based on the age, developmental level and cognition of the child including FLACC, Riley Infant Pain Scale, Faces Scale, Visual Analogue Scale, etc.

3. Identify and manage common symptoms in children with life-limiting disorders such as:

i. Pain
   a. Familiar to the total pain concept and its components (physical, psychological, social and spiritual).
   b. Recognise and manage specific pain syndromes, particularly neuropathic pain, bone pain, muscle spasm and cerebral irritation.
   c. Understand the mechanism of all major non-pharmacological approaches to pain management.
d. Know the indications, mechanism and adverse effects of all major non-opioid analgesics

e. Able to prescribe opioids safely including rapid intravenous opioid titration and calculation of regular dose, understand the concept of oral morphine equivalent, opioid substitution and able to manage adverse effects associated with opioid therapy

f. Know about alternative major opioids to morphine and their conversion ratios.

g. Know the range of neurolytic procedures available.

ii. Dyspnoea (including at end of life)

iii. Skin symptoms and wound management (including pressure ulcers and stoma care)

iv. Anaemia, bleeding and blood product transfusion

v. Nutrition, swallowing, feeding and drooling problems

vi. Nausea, vomiting and gastroesophageal reflux

vii. Constipation

viii. Sleep disorders

ix. Ventilatory support and tracheostomy care

x. Seizure management

4. Able to prepare a detailed management plan for palliative medicine emergencies such as cord compression, haemorrhage, SVC obstruction, uncontrolled pain and seizures. This includes giving advice and support effectively to colleagues in such difficult situations if necessary by telephone.

5 Able to anticipate, recognise and teach features of imminent death and support dying at home or other preferred localities.

6 Know the principles and tests for brain stem death.

7 Know the practicalities after death, such as post-mortem, organ donation, issuance of death certificate, burial permit and ambulance services.

8 During the training, the trainee must be able to evaluate and prescribe where appropriate assistive devices and technology such as beds, oxygen concentrator, feeding pumps, infusion pumps for morphine, various adaptive equipment / walking aids (with occupational therapist) and ventilator devices (with respiratory physician).

9 Learn principles of psychological and behavioural intervention as well as use of various pharmacological managements of psychiatric comorbidities such as anxiety, depression,
aggression, delirium and suicidal ideation in collaboration with child and adolescent psychiatrist.

10 Learn and collaborate with appropriate professionals and agencies in order to improve social well-being and quality of life of the child and the family. This include utilization of local community palliative care services such as hospice, respite care and bereavement support services.
Appendix 2

ASSESSMENT

The trainee will be required to fulfil the following components of the assessment as evidence of satisfactory training.

I. Portfolio

The trainee will be required to keep careful records of learning experiences and progress. This will include:

1. Documentation of completion of training in Paediatric Palliative Medicine as well as other rotations.
2. Copies of palliative medicine evaluation, planning, prescription and re-evaluation reports. These documents should be assessed by the trainer and copies of the assessment sheets kept. (Appendix 6)
3. Certificates of attendance at conferences, workshops and courses.
4. Reflective notes from conferences, workshops and courses.
5. Copies of presentations given during the training duration.
6. Reflective notes from interdisciplinary case discussions, school and home visits.
7. Formative evaluation reports from case-based discussion (CBD) and clinical evaluation exercise (CEE).
8. Summative evaluation reports at the end of the each core training components in paediatric palliative medicine and any other optional postings. (Appendix 7)
9. The trainee will also need a report from the overseas supervisor during the overseas posting.

II. Formative Evaluation

1. Case based discussion (CBD) – at least one every 2 months

   This is a review of a clinical case between trainee and supervisor. The discussion evaluates the level of professional expertise and judgment exercised in clinical cases by a trainee. The trainee is given feedback from the supervisor relating to clinical knowledge, clinical decision-making and patient management.

2. Clinical evaluation exercise (CEE) – at least one every 2 months

   This is an evaluation of the performance of trainee in a real life clinical situation. Various skills are assessed during the patient consultation, including medical interviewing, physical examination, professional qualities, counselling skills, clinical judgment, organisation and efficiency. The trainee receives feedback relating to professional qualities and clinical competency from the supervisor immediately after the observation.

III. Summative Evaluation (Also see Appendix 7)

   This is an end of each rotation evaluation. It will be graded into five levels and the
evaluation report will be submitted by the posting supervisor to training coordinator

1. Medical Knowledge
   - Demonstrates knowledge required to manage patients

2. Application of medical knowledge
   - Shows ability to use the knowledge and other derived evidence-based information

3. Interpersonal/communication skills
   - Demonstrates ability to relate to and communicate with patients and their families

4. Clinical Judgment
   - Demonstrates ability to integrate cognitive and clinical skills and consider alternatives in making diagnostic and therapeutic decisions

5. Responsibility
   - Accepts responsibility for own actions and understands the limitations of own knowledge and experience

6. Problem solving skills
   - Critically assesses information, identify major issues, makes timely decisions and acts upon them

7. Humanistic qualities
   - Demonstrates integrity and compassion in patient care

8. Respect
   - Shows personal commitment to honouring the choices and rights of other persons

9. Moral and ethical behaviour
   - Exhibits high standards of moral and ethical behaviour towards patients and families

10. Professional attitudes and behaviour
    - Shows honesty at all times in their work and puts patient welfare ahead of personal consideration

11. Patient management
    - Shows wisdom in selecting treatment; adapts management to different circumstances and to provide comprehensive quality care

12. Psychological development
    - Demonstrates ability to recognize and/or respond to psychological aspects of illness
13. Record keeping
   - Maintains complete and orderly records and up-to-date progress notes

14. Relationship with health professionals
   - Maintains the respect of his/her colleagues. Demonstrates ability to work well and efficiently in the health care team; values the experience of others. Relates easily with members of staff; maintain team spirit and encourages cooperation

15. Organisational skills
   - Demonstrated ability to plan, coordinate and complete administrative tasks associated with medical care

16. Self assessment
   - Accepts the limits of own competence and functions within own capabilities, seeks advice and assistance when appropriate ; accepts criticism

17. Continuing education
   - Shows a resourceful attitude towards continuing education to enhance quality of care

IV. Clinical Audit and Research Project
   - Completed one clinical audit by the end of first year
   - Completed one research project by the end of training
   - The trainee is encouraged to present these audit and research findings at local or international conferences

V. At least one publication in a peer reviewed journal
ACCREDITED CENTRES AND SUPERVISORS

An accredited centre for paediatric palliative medicine training is a tertiary referral centre with a team of multidisciplinary professionals that has on-site paediatric palliative care services. The core team must be headed by a palliative medicine physician or a paediatrician with appropriate palliative medicine training and comprise of other relevant trained professionals such as palliative care nurses, pharmacist, social worker / counsellor / clinical psychologist, and occupational therapist. There should be in-patient referral and follow-up palliative care clinics as well as access to community palliative care services. The centre must also have links with other government and voluntary agencies. There should be on-going combined / joint interdisciplinary palliative care meetings and CME sessions within the centre e.g. lecture series, case discussions, journal sessions.

A trainer / supervisor in paediatric palliative medicine is one who has been registered as a Paediatric Palliative Medicine Physician by the Paediatric Specialty Committee of the National Specialist Register and working in an accredited training centre for Paediatric Palliative Medicine. Each trainer is allowed to supervise the training of two trainees (maximum) at any one time. However, as at the moment there is no accredited paediatric palliative medicine physician, paediatricians that have appropriate palliative medicine training and experience will be appointed as supervisors by the National Paediatric Palliative Care Reference Group until such time when the Paediatric Palliative Medicine Subspecialty Committee is established.

Accredited centres for training in Adult Palliative Medicine are those centres which have been approved for training in Adult Palliative Medicine with in-patient palliative unit. Accredited centres for Community Palliative Care Medicine are those centres that actively provide community palliative care for children identified by National Paediatric Palliative Care Reference Group until such time when the Paediatric Palliative Care Subspecialty Committee is established.
Below is the list of **PROPOSED** accredited training centres:-

<table>
<thead>
<tr>
<th>Duration</th>
<th>Proposed Training Centres</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 months</td>
<td>HKL, UMMC</td>
</tr>
<tr>
<td>4 months</td>
<td>Hospital with dedicated unit (HKL, UMMC)</td>
</tr>
<tr>
<td>4 months</td>
<td>Hospitals that are accredited for the specialties training (HKL)</td>
</tr>
<tr>
<td>6 months</td>
<td>Selayang Hospital, UMMC</td>
</tr>
<tr>
<td>During posting to APM</td>
<td>Selayang Hospital</td>
</tr>
<tr>
<td>6 months</td>
<td>Hospis Malaysia</td>
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</tbody>
</table>

Below is the list of **PROPOSED** accredited trainers / supervisors:-

<table>
<thead>
<tr>
<th>Accredited Trainers</th>
</tr>
</thead>
</table>
| **Paediatric Oncology, Neurology, Metabolic / Genetics and Miscellaneous subspecialty postings with special emphasis in paed palliative care** | Hospital that are accredited for these specialties training where palliative care services are available.  
HKL & UMMC  
(The accredited trainers are paediatricians with the necessary training and experience in paediatric palliative care. They will be identified and appointed by the National PPC Reference Group at the moment until such time when there are credentialed PPM physicians) |
| **Adult Palliative Medicine / Pain management services** | Hospital Selayang (Dr. Richard Lim / Dr. Mary Cardosa)  
UMMC (Dr. Loh Ee Chin) |
| **Community Palliative Care Medicine** | Hospis Malaysia (Dr. Ednin Hamzah, Dr. Chong Lee Ai) |
| **Paed. Palliative Medicine (overseas)** | Accredited trainers in paediatric palliative centres in Australia, UK, India, USA, Canada |
# NATIONAL PAEDIATRIC PALLIATIVE CARE REFERENCE GROUP

<table>
<thead>
<tr>
<th></th>
<th>Name</th>
<th>Position</th>
<th>Current Place of Work</th>
<th>Current Designation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Datuk Dr. Kuan Geok Lan</td>
<td>Chairperson and Head of Service Provision Division</td>
<td>Hospital Melaka</td>
<td>Senior Consultant Paediatrician</td>
</tr>
<tr>
<td>2.</td>
<td>Dr. Chong Lee Ai</td>
<td>Member &amp; Head of Research Division</td>
<td>Hospis Malaysia</td>
<td>Palliative Care Physician</td>
</tr>
<tr>
<td>3.</td>
<td>Dr. Khoo Teik Beng</td>
<td>Member &amp; Head of Training Division</td>
<td>Paediatric Institute, HKL</td>
<td>Consultant Paediatric Neurologist</td>
</tr>
<tr>
<td>4.</td>
<td>Dr. Fahisham Taib</td>
<td>Member</td>
<td>Hospital USM, Kubang Krian</td>
<td>Consultant Paediatrician</td>
</tr>
<tr>
<td>5.</td>
<td>Dr. Yeoh Seoh Leng</td>
<td>Member</td>
<td>Hospital Pulau Pinang</td>
<td>Consultant Paediatric Oncologist</td>
</tr>
<tr>
<td>6.</td>
<td>Dr. Ch'ng Gaik Siew</td>
<td>Member</td>
<td>Genetic Department, HKL</td>
<td>Clinical Geneticist</td>
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<td>7.</td>
<td>Dr. Zainah bt Shaik Hedra</td>
<td>Member</td>
<td>Hospital Batu Pahat</td>
<td>Consultant Paediatrician</td>
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<td>8.</td>
<td>Dr. Intan Shukor</td>
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<td>9.</td>
<td>Dr. Maznisah Mahmood</td>
<td>Member</td>
<td>Paediatric Institute, HKL</td>
<td>Consultant Paediatric Intensivist</td>
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<td>10.</td>
<td>Dr. Ong Gaik Bee</td>
<td>Member</td>
<td>Sarawak General Hospital</td>
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<td>11.</td>
<td>Dr. Khoo Kim Kea</td>
<td>Member</td>
<td>Hospital Raja Permaisuri Bainun, Ipoh</td>
<td>Paediatrician</td>
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<td>12.</td>
<td>Dr. Farah Khalid</td>
<td>Member</td>
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<td>Paediatrician</td>
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<td>13.</td>
<td>Dr. Lee Chee Chan</td>
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<td>Paediatrician</td>
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<td>14.</td>
<td>Dr. Emie Alias</td>
<td>Member</td>
<td>Hospital Sultanah Aminah, JB</td>
<td>Paediatrician</td>
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The National PPC Reference Group will function as the training committee until such time when there are enough Paediatric Palliative Medicine Physicians in Malaysia.
Paediatric Life-Limiting Disorders That Needs Palliative Care

1. Any child with chronic, complex or life-limiting condition who is / has
   - Conflicts regarding use of medical nutrition / hydration in cognitively impaired, seriously ill or dying patients
   - Difficult pain or symptom control problems
   - Family with limited social supports
   - AND (Allow natural death) or DNR order
   - Complex care coordination and/or home care needs
   - Need a referral to hospice

2. Oncological disorders including:-
   - Progressive metastatic cancer
   - Bone marrow / stem cell transplant
   - Relapsed malignant disease following BMT
   - Diffuse pontine glioma
   - Stage IV neuroblastoma
   - Any newly diagnosed malignant disease with an EFS of <40% with current therapies
   - Any relapsed malignant disease
   - Metastatic solid tumours
   - New case with complex pain or symptom control issues

3. Neurological disorders including:-
   - Progressive neurodegenerative conditions
   - Neuronal ceroid lipofuscinosis
   - Leukodystrophies (MLD, XLD)
   - Muscular dystrophy / myopathies with sleep hypoventilation (inadequately treated or opted for conservative care)
   - Spinal muscular atrophy
   - Quadriplegic / Severe cerebral palsy +/- comorbidities
   - Persistent vegetative state
   - Severe traumatic brain injury
   - Severe post-neonatal HIE

4. Genetic / Metabolic disorders including:-
   - Trisomy 18, 13, 15
   - Asphyxiating thoracic dystrophy
   - Severe forms of osteogenesis imperfecta (Type 3 or 4)
   - Potter syndrome
   - Epidermolysis bullosa
• Rett syndrome
• Other rare chromosomal anomalies with known poor neurologic prognosis
• Lysosomal disorders (such as Krabbe’s disease, Niemann-Pick disease, etc)
• Mucopolysaccharidosis (such as Hunter’s/Hurlers disease)
• Mucolipidosis (such as I-cell disease)
• Menke’s disease
• Pompe disease
• Severe mitochondrial disorders
• Other severe metabolic disorders for which BMT is a consideration

5. Cardiac disorders including:-

• Single ventricle cardiac physiology
• Down syndrome with severe cardiac abnormality
• Ebstein’s anomaly
• Pulmonary atresia (esp if a/w hypoplastic PA)
• Eisenmenger’s syndrome
• Cardiomyopathy (hypertrophic or severe dilated)
• Ongoing discussion of cardiac transplant
• Combination of cardiac with neurologic/chromosomal diagnosis
• Other complex congenital heart disease
• ECMO candidate, severe myocarditis

6. Gastrointestinal disorders including:-

• Biliary atresia
• Progressive hepatic encephalopathy
• Total aganglionosis of colon
• Multi-visceral organ transplant under consideration
• Short-gut syndrome with TPN dependence
• Severe feeding intolerance
• Long-segment Hirschprung’s
• Tube feeding for any neurological condition

7. Renal disorders including:-

• Neonatal polycystic kidney disease
• Renal failure, not transplant candidate

8. Infectious diseases including:-

• HIV/AIDS resistant to antiretrovirals
• SCID
• Congenital CMV/toxoplasmosis with neurological sequelae
• Severe encephalitis
• Severe immunodeficiency syndromes, particularly those for which BMT is a consideration

9. Intensive care patients including:-

• Prolonged or failed attempt to wean mechanical ventilation
• Multi-organ system failure
• Compassionate extubation
• Severe head injury following NAI
• PICU stay longer than 2 weeks
• Irreversible brain injury that will impact functional status
• Immersion injury

10. Neonatology / Fetomaternal medicine, including:-

• Extreme prematurity with concomitant severe BPD, Grade IV IVH, PVL, etc
• Moderate / severe HIE
• Thanatophoric dwarfism
• Severe cerebral malformations
• Anencephaly
• Hydranencephaly
• Lissencephaly
• Severe schizencephaly
• VLBW infants with neurological sequelae

11. Miscellaneous

• Organ transplant candidates
• Neonates and children with severe surgical life-limiting conditions
• All other paediatric conditions with life-limiting or life-threatening conditions.
Fellowship Training in Paediatric Palliative Medicine Subspecialty in Malaysia

Log Book

Name:

Training year:

Supervisor:
Date: __________ to __________

Rotation: ______________________________________________

Supervisor/s: _____________________________________________

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SUMMATIVE EVALUATION (by supervisor at the end of each rotation)

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OVERALL ASSESSMENT & COMMENTS

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___________________________________________________________________

Signature of Supervisor: ________________________________

Name of Supervisor: ________________________________

Date: ______________
Appendix 8

RECOMMENDED BOOKS AND JOURNALS

Books

1. Oxford Textbook of Palliative Medicine by Derek Doyle
3. Textbook of Interdisciplinary Pediatric Palliative Care by Joanne Wolfe, Pamela Hinds and Barbara Sourkes
4. Palliative Care for Infants, Children and Adolescents: A Practical Handbook. Edited by Brian S. Carter and Marcia Levetown

Journals

1. Archives of Disease in Childhood
2. Pediatrics
3. Journal of Palliative Medicine
4. Journal of Palliative Care
5. BMC Palliative Care
6. American Journal of Hospital Palliative Care
7. Journal of Pain
8. Journal of Pain Symptom Management
9. Journal of Pediatric Nursing
10. Journal of Oncology Nursing
12. Journal of Medical Ethics
REFERENCES

1. Curriculum for Paediatric Training in Paediatric Palliative Medicine, Royal College of Paediatrics and Child Health, UK, September 2010

2. Advanced Training in Palliative Medicine, 2013 Program Requirement Handbook – Australasia Chapter of Palliative Medicine

3. Palliative Care Services Operational Policy – Medical Development Division, Ministry of Health Malaysia, 2010

4. Pediatric Palliative Care Referral Criteria - prepared by Sarah Friebert, MD and Kaci Osenga, MD (Source: Center to Advance Palliative Care)


