A Framework of Competences for the Level Special Interest Module in Paediatric Palliative Medicine

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Section 1  Introduction

Who is this book for?
It is for doctors at Level 3 in their General Paediatric training who wish to work towards an expertise in Paediatric Palliative Medicine during Level 3 training. It is also there to guide tutors and educational supervisors.

Why do I need it?
This book gives you and your tutors guidance about the competencies you need to cover in addition to the Framework of Competences for Level 3 Training in General Paediatrics. It provides a clear picture of what should be achieved by the end of this module of training in order to begin to develop expertise in this area, upon which to build post-CCT.

How do I use the book?
You can sit down with the book on your own and use it to help you identify areas of practice that you need to work on and those areas in which you feel fairly confident. You can talk to your tutor about the balance of your experiences and look for ways to ensure you cover all areas you need to. It should be used by Schools and Educational Supervisors to ensure that a programme of training is developed in Level 3 which will allow the trainees to achieve these competencies. In determining this programme, liaison with the CSAC is recommended. In the appendix, there is guidance for training in the module which the programme must adhere to.

Progression
Following completion of Level 3 training and the module, the CCT holder should be competent to take up a post as a General Paediatrician with special expertise provided by the module. The hope would be the consultant post allows development of the trainee’s special expertise. The Consultant should join the Regional clinical network of Health Care professionals in the specialist area.
Assessment
The RCPCH Assessment Strategy (PMETB approved) for Level 3 Training will be used. Trainees working with their educational supervisors should ensure that the guidance presented on assessment covers the additional competences with it as well as the General Paediatric Assessment Standards. Trainees should submit their ‘Palliative portfolio’ to the CSAC at the time of their penultimate ARCP for review. They will then be invited to a CSAC meeting to discuss their training. Trainees fulfilling the criteria for SPIN training will be given a ‘letter of commendation’.

Pilot
This special expertise module is being introduced as a pilot. Trainees interested in pursuing a special interest in paediatric palliative medicine should also refer to the Trainees handbook and contact the CSAC. The College will seek feedback from trainees.
Section 2 General Competences in Paediatric Palliative Medicine

By the end of Level 3 module in Paediatric Palliative Medicine, trainees will:

General principles of Palliative Medicine in Children

- demonstrate a working understanding of a multi-dimensional model of human experience (physical, psychosocial and spiritual or existential), specifically applied to the experience of symptoms in the dying child
- demonstrate understanding of the contribution of psychological and spiritual issues in all symptoms, particularly pain, nausea and vomiting and dyspnoea
- demonstrate understanding of the benefits and limitations of extrapolating information from evidence in adult medicine to paediatric palliative medicine
- be able to facilitate access to the range of benefits, financial and practical, available to children with life limiting conditions, their families and carers
- be able to negotiate, for all symptoms, realistic treatment goals commensurate with the distress caused by the symptom bearing in mind the potential burdens and benefits of intervention
- be able to access published material, current knowledge and expertise (e.g. major textbooks, current research and reviews in journals and on-line), relevant to symptom management in paediatric palliative care
- seek advice, where appropriate, from related specialist paediatric colleagues, particularly neurologists, oncologists or pain services
- be able to work with multidisciplinary teams in managing symptoms

Ethics and the Law

- be able to apply basic medical ethical principles to complex decision-making in children with life-limiting conditions with ‘attention to scope’
- be familiar with basic ethical theory, such as deontology, consequentialism and virtue ethics and therefore be able to critically evaluate potential outcomes
- understand principles of double effect and ‘unintended consequences’
- be familiar with ethical and legal debates surrounding euthanasia and physician-assisted suicide and aware of global differences in legislation

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Section 3: Specific Clinical Competences in Paediatric Palliative Medicine

By the end of Level 3 module in Paediatric Palliative Medicine, trainees will:

Pain

• understand the nature of total pain and the limitations of pharmacological therapy alone
• have knowledge of developments in pain assessment in normal and developmentally disordered children and young people
• be able to recognise and manage specific pain syndromes, particularly neuropathic pain, bone pain, muscle spasm and cerebral irritation
• have a basic understanding of the mechanisms of major non-pharmacological approaches to pain management
• understand the indications, mechanisms and adverse effects of major non-opioid and opioid analgesics
• be able to prescribe opioids safely in disease (particularly renal failure, liver failure or delirium)
• be able to recognize and manage adverse effects of opioid therapy
• know about alternative major opioids to morphine, their potency, advantages and disadvantages compared to morphine
• understand urgent opioid titration intravenously, including calculation of regular dose

Nausea and Vomiting

• be able to formulate a rational approach to anti-emesis, based on an understanding of the likely mechanism, including the consideration of more unusual medications such as steroids and octreotide
• recognise the holistic nature of nausea and vomiting in children with life-limiting conditions
• be able to consider psychological aspects of nausea and vomiting, and to explore the use of psycho-active medications, counselling, hypnosis, acupuncture and other complementary therapies
Constipation, Anorexia, Cachexia, Hiccough

- be able to devise and implement a rational, evidence-based approach to the management of constipation, anorexia, cachexia and hiccough
- be able to work with the multi-disciplinary team in managing constipation and faecal impaction by dietary measures, medications and lifestyle modification
- be able to identify and modify other symptom control measures which may contribute to constipation, for example, the use of non-constipating opioids or baclofen

Mouthcare, Feeding, Hydration

- have knowledge of ethical and current legal issues surrounding feeding and hydration and their withholding or withdrawal
- be able to manage changing feeding and hydration needs of children with life-limiting conditions

Dyspnoea

- be able to provide support for professionals in other specialities, for example, respiratory or neurological teams, in the management of dyspnoea in terminally ill children (including in cases of rapid home discharge planning)
- understand that dyspnoea is a subjective experience which does not necessarily correlate with related objective observations such as tachypnoea
- know when to seek specialist help in the management children with life-limiting conditions on artificial ventilation
- recognise and know how to treat causes for dyspnoea including panic, anxiety, painful breathing, breathlessness, cough, haemoptysis and excessive secretions in cases of dyspnoea
- know about multi-disciplinary team approach to the management of dyspnoea, involving, for example psychologists and play leaders
- recognise when oxygen therapy is inappropriate
Seizures and other neurological problems

- know and be able to manage common complex symptoms likely to be associated with common neurological or neuromuscular conditions, particularly Duchenne muscular dystrophy, spinal muscular atrophy and cerebral palsy
- be able to manage terminal status epilepticus
- recognise that some neurological symptoms are more distressing to watch than to experience, and some may not be fully controllable; to negotiate treatment goals that are appropriate

Psychological symptoms

- understand, recognise and respect the distinction between a coping strategy and psychopathology
- be able to diagnose depression, adjustment disorder, anxiety and delirium in paediatric palliative medicine
- be able to work with adult or child and adolescent psychiatry and psychology services in managing psychopathology in children with life-limiting conditions

Skin symptoms

- have an awareness of skin disorders (causes and multi-disciplinary team management) in children with life-limiting conditions, including pruritus
- have an awareness of epidermolysis and other life-limiting skin conditions, including restrictive dermopathy and ichthyoses
- have an understanding of the different types of dressing available and when they can be used
- be aware of the limitations of the management of some skin symptoms and disorders; some symptoms may not be fully controllable or may progress
- understand the need to address emotional, psychological, social and spiritual needs as well as physical ones in managing children with life-limiting skin conditions
Emergencies

• be able to identify likely emergencies early in the palliative course of life-limiting conditions
• have the skills and knowledge to effectively support colleagues caring for a child or young person in an emergency, if necessary by telephone
• be able to prepare a detailed management plan for all five palliative medicine emergencies (cord compression, haemorrhage, SVC obstruction, uncontrolled pain and seizures), accessing support from tertiary palliative services as necessary
• know the ethical considerations of managing palliative medicine emergencies at the end of life, particularly those relating to euthanasia, the principle of double effect and terminal sedation

Malignant diseases

• know the symptoms that are likely in acute leukaemia, and major tumours
• understand the distinction between chemotherapy that is palliative, experimental, potentially curative or futile
• understand the mechanism of common oncology modalities used for palliation, particularly radiotherapy, antimetabolites and steroids
• know how the main types of tumour are likely to spread
• be familiar with the extent and the limitations of oncology outreach, inpatient and children’s hospice models for providing palliative medicine for children with cancer

Non-malignant diseases

• know how to access information on current management strategies for rare disorders
• demonstrate an empirical approach to symptom management of rare disorders where there is little published evidence-base
• demonstrate knowledge of common symptom patterns (e.g. pain, nausea and vomiting and constipation) in life-limiting conditions, be able to anticipate and formulate appropriate management plans involving the multidisciplinary team and other specialists
• know about the role of rehabilitation specialists and services and be able to facilitate access to them
• understand the specific needs of families whose children have non-malignant life-limiting conditions with regard to disease trajectory and uncertain prognosis, interaction with other professionals, support in loss and bereavement, and perception of quality of life

The period immediately before death
• recognise that home is the preferred place of death for most children in most families. Some families may choose hospice or hospital for end of life care.
• know how to access relevant funding to support care at home
• know about the final pathway of disease processes, prognostic indices and their application and limitations and be able to make a diagnosis of imminent death
• be able to support colleagues, sometimes at a distance, in recognising that a child’s death is imminent
• be able to prescribe a subcutaneous syringe driver confidently and accurately
• be able to work with a wide variety of models delivering care to the child whose death is imminent, including specialist outreach teams, community paediatric teams, primary care teams and children’s hospices as well as acute paediatric wards
• be able to anticipate specific likely symptoms in the period immediately before death, and ensure that appropriate medication is available by the appropriate route in good time
• be able to explore, record and communicate effectively to other professionals (especially ambulance and out-of-hours services in the community) the wishes of families regarding resuscitation of their child

Practicalities after death
• know the distinction between verification and certification of death
• know who can issue a death certificate
• know who can complete the different parts of a cremation form
• understand the role and powers of the coroner, when to refer and be able to advise on the procedures they will follow
• know the practicalities relating to organ donation
• understand and be able to advise on the legal implications of moving a child after death
• understand the importance of post mortem and be able to organise one
Section 4 Practical Procedures and Investigations in Paediatric Palliative Medicine

By the end of Level 3 module in Paediatric Palliative Medicine, trainees will:

• have a working knowledge of indications for and practical management of gastrostomies, in particular common practical problems (tube blockage etc)
• know about indications for and practical management of tracheostomies
• be aware of the range of anaesthetic and neurological procedures that may help neurological symptoms, for example the intrathecal baclofen pump, nerve blocks
• have a working knowledge of the indications for, and day-to-day management of invasive and non-invasive ventilation, cough assist machines and suction apparatus

Pharmacology and Therapeutics

• understand the concept of oral morphine equivalence, the conversion ratios for enteral and parenteral administration of alternative opioids to morphine
• know the symptoms, signs, causes and management of narcotisation
• understand the reluctance of family members and professionals to use medications with respiratory depressant side-effects in the treatment of children and young people with life-limiting conditions and respiratory symptoms
• understand the concept of receptor complementarity and be able to prescribe anti-emetics based on their mechanism by an appropriate route
• know how some anti-emetics may interact with each other
• be able to prescribe empirically and appropriately in the face of incomplete clinical data including being able to explain the implications of treatment (or not), side effects and potential adverse interactions
• know about the correct practical set-up and use of a syringe driver
• know which medications can be mixed in the same syringe driver
• be able to calculate syringe doses subcutaneously or intravenously
• anticipate, recognise and appropriately manage complications of syringe driver use, including precipitation and irritation
• be able to prescribe adjuvant therapy appropriate to the nature of pain
• know the classification and mechanisms of action of laxatives and rectal measures
• understand the types of medication used for appetite stimulation in anorexia, and their use, limitations and risk
Appendix 1

Paediatric standards checklist for Special Study Module in Paediatric Palliative Medicine

These standards were derived to assist in the assessment of the paediatric training standards of in your deanery. The programme may be fulfilled over a prolonged period (including post-CCT) and should provide:

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<thead>
<tr>
<th>1. Supervision</th>
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<tbody>
<tr>
<td>1.1 Regular educational supervision meetings with a Consultant with responsibility for paediatric palliative medicine trained in assessment and appraisal</td>
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<tr>
<td>1.2 Evidence that the assessment strategy is being delivered</td>
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<td>1.3 Appropriate clinical supervision: you should be able to discuss every patient contact with an appropriate senior healthcare professional</td>
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<tr>
<th>2. Educational activities and training</th>
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<tr>
<td>2.1 Exposure to patients from all four ACT/RCPCH categories, malignant and non-malignant life-limiting conditions</td>
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<tr>
<td>2.2 Experience of palliative care in children’s hospice, hospital ward, home, school and outpatient settings</td>
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<tr>
<td>2.3 Time with an adult palliative medicine team in order to achieve some of the competences in the curriculum</td>
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<tr>
<td>2.4 Time with a specialist acute or chronic pain team</td>
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<td>2.5 Structured teaching to achieve all the competences in the curriculum</td>
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<th>3. Assessment</th>
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<tr>
<td>3.1 Logbook of cases seen. It is better to have experience with a few patients thoroughly than many patients. At the same time it is equally important to learn symptom management in a wide range of conditions. 50-100 patients would be reasonable.</td>
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<tr>
<td>3.2 Portfolio should include:</td>
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<tr>
<td>10 mini-CEX (mini clinical examinations)</td>
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<tr>
<td>6 CBD (case-based discussions)</td>
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<tr>
<td>5 DOPS (directly observed procedures)</td>
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<tr>
<td>2 SAIL assessments</td>
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<tr>
<td>1 multi-source feedback</td>
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<tr>
<td>1 audit</td>
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<tr>
<td>4 detailed cases</td>
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