Curriculum in Paediatric Palliative Medicine

Association for Paediatric Palliative Medicine
Education Subgroup

And

Paediatric Palliative Medicine
College Specialty Advisory Committee
Royal College of Paediatrics and Child Health

2nd Edition 2015

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Preface

Introduction

The original curriculum for paediatric palliative medicine was written in 2007 following guidance from the RCPCH (1) and Department of Health (2). It formed the basis of the development of children's palliative medicine as a sub-speciality of the RCPCH. The document allowed for the development of Grid trainees and has encouraged more doctors to pursue a specialist career in children's palliative medicine. In addition it has sparked a great deal of interest in other paediatricians to develop level III training within the field. It has encouraged many doctors within the children's hospices to develop their skills and education base through individual learning and attendances at approved courses such as Postgraduate Diplomas in Palliative Medicine (e.g. the Cardiff Diploma).

However, in the last seven years much has changed within the field of paediatric palliative medicine. There is much more reliance on technology in the form of ventilation, as well as improved nutrition through gastrostomies. Specialists within this field are having to develop new skills as the children begin to live longer and many are now involved with looking after young adults. Increasingly many other specialities in paediatrics such as neonatology, intensive care, and oncology are beginning to recognise the value of good paediatric palliative medicine. This interlinking of sub-specialities has meant that doctors within paediatric palliative medicine need to understand and develop skills in all of these sub-specialities.

It became increasingly obvious from feedback from trainees and other doctors in the sub-speciality that the time had come to review and enhance the original curriculum. Under the auspices of the Association of Paediatric Palliative Medicine (APPM) and RCPCH College Specialty Advisory Committee (CSAC), a new group was established to review and improve the original curriculum. Under the chairmanship of Dr Yifan Liang a group formed by some of the original doctors who wrote the curriculum and a number of new doctors within the field, have developed the second edition to the Curriculum for Paediatric Palliative Medicine 2014.

Good palliative medicine skills overlap at one end of the spectrum with much of what makes a good doctor. It is not at all the intention of this document to suggest that all palliative medicine is specialist territory. Rather, it is to clarify the minimum set of paediatric palliative medicine skills that should be achieved by doctors at four different stages in their development. At one end are the generic paediatric palliative medicine skills that any qualifying doctor should possess. At the other, are the specialist skills that would be expected only from an individual who has undergone a period of specialist training in palliative medicine in children.Nor is it the intention of this document to suggest that all palliative *care* in children is palliative medicine. While doctors have an important role in caring for children when cure is no longer possible, many of the skills that are important in maintaining a child's quality of life are better found outside the medical profession. For that reason, in this document the term 'palliative medicine' is used. As in the adult speciality, it refers to the skill set that would be expected from practitioners with a medical degree in contrast with experts from other caring backgrounds, particularly nurses.

Medical support for children's hospices has traditionally been from doctors from a variety of backgrounds, including general practitioners, paediatricians, adult palliative medicine doctors, and other medical specialists, many of whom have been working in a children's hospice for many years and have developed considerable relevant specialist expertise. The working groups feel that this diversity and complementarity of skills and background is to be encouraged. A competency-based rather than qualification-based curriculum has the potential to accommodate such diversity flexibly, whilst ensuring that knowledge and skills specific to the sub-specialty are developed appropriate to the level of expertise required for the individual setting and team.This curriculum should complement the knowledge and skills that a practitioner would have achieved by virtue of his core training e.g. in paediatrics or general practice (3).

How the curriculum was developed

The aim was to define a curriculum for doctors with respect to skills in paediatric palliative medicine (PPM). This was done in four stages:

1. Define the term 'curriculum'

The definition of curriculum we have used as the basis for this document is that **'a curriculum is the combination of a set of competencies (themselves defined as 'testable skills') and a set of tools to evaluate them'.**

2. Describe a list of topics and relate to tiers of expertise

We needed to find some way of organising the enormous variety of palliative medicine competencies into groups. We identified three broad streams running through all topics. They were:

I. **Knowledge:**The cerebral acquisition of facts and understanding of the facts.
II. **Skills:**The practical application of knowledge and understanding to the management of children with life-limiting conditions. Many of these are practical skills, but others are skills in analysing situations or communicating.
III. **Attitude:**The application of professionalism when treating individual children with life–limiting conditions, and their families.

As an illustration, the initiation of major opioids in a child with cancer would require **knowledge** of the range of opioids available and the differing effectiveness and side-effects profile between them. Safe prescription and setting up of the syringe driver would be a **skill**, while recognising the need to discuss it with the family and to work with children's community nurses and specialist paediatric oncology outreach nurses would be an **attitude**. Clearly, they are closely linked.

Having described groups of competencies, we defined four levels of each. (Note, these levels do **not** correspond to training levels of the RCPCH, but only to the field of PPM)

These could correspond, for example, to a:

- **Level 1**: doctor just completing a primary qualification.
- **Level 2**: paediatric trainee after completing higher specialty core training or a GP / children's hospice doctor after a well-supported period of paediatric palliative care experience.
- **Level 3**: a paediatrician (consultant or Staff or Associate Specialist (SAS) doctor) who has developed a special interest in PPM, an established children's hospice doctor or GP with Special Interest (GPWSI) in paediatric palliative care. Likely to have a relevant postgraduate qualification such as the Cardiff Diploma in Palliative Medicine (paediatrics).
- **Level 4**: a consultant paediatrician in PPM, or a small number of children's hospice medical leaders (mainly leaders in sub-specialty formation and development, and with roles beyond their local hospice), and who have a substantive role in children's palliative medicine.

Whilethe specific standards for each competency would, of course, depend on its nature, the following general principles were used to define the different levels:

- **Level 1**. Understand the basic principles, of paediatric palliative care.
- **Level 2**. Apply basic principles of palliative medicine to the care of children specifically. Recognise reversible causes of symptoms in children, whether with a life-limiting condition or not.
- **Level 3**. Be able to manage most common symptoms safely and effectively. Be prepared to recognise need for specialist help and access it where necessary.
- **Level 4**. Manage uncommon symptoms; understand principles in order to develop a logical approach even where there is no evidence basis. Considerable emphasis on leading and developing services within and beyond the local hospice, and on supporting and teaching other professionals involved with children with life-limiting conditions who are not trained in palliative medicine.

These levels correspond roughly with the recommended tiers of palliative medicine expertise in the 1997 RCPCH document (1). Competence at all levels below is a prerequisite for competence at each higher level.

Medical staffing recommendations for paediatric palliative care services:

- The National Review of Long Term Sustainability of Children's Palliative Care Services (2007) (2) has recommended a specialist paediatric palliative care physician for each region. We would expect this to be someone of level 4. The review also recommends a doctor 'with an interest' in each locality. We envisage this should be someone of at least level 3.
- Likewise, each children's hospice should have someone of at least level 3 as part of their regular medical team, and should have specifically agreed support, via telephone access or direct contact, from someone of level 4.
- 'GPs with Special Interest' (GPWSI) in paediatric palliative care, should have achieved level 3 or above. (GPWSI guidelines April 2007 (4)).

3. Identify specific competencies in each

Using the definition of 'testable skills', we considered competencies in each of the categories under three headings:

1) **Technical skills.** Techniques relating to the practice of palliative medicine (for example, symptom control, models of palliative medicine).
2) **Interpersonal skills** (for example communication skills and teaching).
3) **Intrapersonal skills** (for example, coping mechanisms and learning skills).

These broad categories were identified through a national study of the education, training and support needs of children's hospice doctors (5).

4. Consider evaluation tools

The curriculum is designed around the existing training structure for doctors. Evaluation tools for levels 1 and 2 therefore include:

- Ongoing undergraduate assessment using existing special study modules, oncology projects, reflective portfolios etc. as set out by individual medical schools.
- Medical finals degree (vivas, extended match questions).
- Postgraduate qualification of membership of a royal college,
- Evidence of attainment of specific competencies

Some competencies more specific to paediatric palliative medicine are not easily evaluated using these tools and a range of additional tools can be considered. These have all been used in other palliative medicine educational programmes, in particular the Cardiff Diploma in Palliative Medicine (Paediatric Option) and as part of work-based assessment tools used by and recommended by the RCPCH and RCGP:

- **Structured reflective portfolios**.
- **Audit.**
- **Communication skills evaluation.**
- **Structured Reflective Templates.**

5. 'Meta-principles'

Throughout the curriculum, it is anticipated that trainees would acquire, and demonstrate an understanding of some fundamentals that flow from basic ethical and professional principles:

- The need to balance **burden and benefit** when considering any therapeutic intervention and only proceeding with an intervention if it can be reasonably supposed it will do more good than harm.
- The importance of a **rational approach** to management of children, which means evidence based where there is such evidence, and empirical where necessary.
- The importance of a **multi-dimensional approach** involving the whole multi-disciplinary team in the assessment and management of a child with a life-limiting condition. Recognition of medical skills in colleagues who are not doctors (particularly nurses).
- The importance of **exploring individual patient priority** and negotiating achievable goals, rather than assuming perfect control is the only acceptable outcome.

  An example of achieving this in a structured way would be:

  - Principles of assessment
  - Dimensions of a child's needs
  - The process of assessment
  - Identifying family situation, structures and dynamics and key decision-makers

  - Establishing the 'typical day'
  - Establishing functional abilities:
  - Other clinical assessment, including history and examination
  - Special investigations
  - Management planning: (who, what, when, how)

- Throughout the curriculum, the term 'child' is used to denote an individual of 0-19years (i.e. including neonates, babies, children and young adults).
- In all fields a doctor should be able to teach their professional colleagues, multidisciplinary teams and professionals in training. This is particularly integral for doctors performing at level 4 and is therefore an assumed skill for each area.
- Doctors should be aware of the research and evidence base throughout. This is implicit within the approach to each topic rather than repeated in each section.

6. Review

When the original curriculum was published in 2007 it represented a landmark in the development of paediatric palliative care as a sub-speciality. The original curriculum was written by a small group of diverse doctors who had been working independently to develop educational standards. Thus it was written with the best data that was available at the time. However over time and with changing trends in paediatric palliative care there were obvious deficits within the original work. After seven years this current work has been produced not only with members of the original team but also doctors who have gone through the training that the curriculum had developed. As a result there has been a significant enhancement of the curriculum with an improved focus on educational needs. The rate of development and change within paediatric palliative care has been relentless over the last decade and this curriculum will need to continue to develop and change with the speciality. With the help of the Royal College of Paediatrics and Child Health, the new consultants who have and will have completed the training as well as the future need of adding educationalists to the members of the working group, we hope to maintain the living and active nature of the curriculum. One cannot be certain as to when we will need to review this document again as this is dependent on many external factors but on current evidence the document will be reviewed again in the next 5 to 7 years.

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Royal College of General Practitioners	(RCGP)
Royal College of Paediatrics and Child Health	(RCPCH)
Together for Short Lives	(TfSL)

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Abbreviations

APPM	Association of Paediatric Palliative Medicine
CYA	Children and Young Adults
CF	Cystic fibrosis
CNS	Central nervous system
DMD	Duchenne muscular dystrophy
ICP	Intra-cerebral pressure
LLC	Life-limiting condition
MDT	Multi-disciplinary team
MPS	Mucopolysaccharidosis
NIV	Non-invasive ventilation
OT	Occupational Therapy
PN	Parenteral nutrition
PPC	Paediatric Palliative Care
PPM	Paediatric Palliative Medicine
RCGP	Royal College of General Practitioners
RCPCH	Royal College of Paediatrics and Child Health
TfSL	Together for Short Lives

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3. Speciality Training Curriculum for Palliative Medicine. Joint Royal Colleges of Physicians Training Board, 2007 (May)
4. The Accreditation of General Practitioners and Pharmacists with Special Interests Dept of Health 2007 (May)
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A. Technical

Technical 1. Philosophy of palliative care (holism)

Level	Knowledge	Skills	Attitude
1	Be familiar with term 'holistic' (or synonyms) and understand its definition.Understand how it applies to medical care of children. Understand what is meant by the terms 'physical', 'spiritual', 'social' and 'psychological/emotional' in relation to children needing medical care. Understand principle of balancing burden and benefit in considering intervention.	Identify physical, spiritual, social and psychological/emotional aspects of medical problems.	Recognise importance of other disciplines and professions in caring for children.
2	Know what agencies are available to support children and families for problems in each dimension. Understand definitions of 'rational', 'evidence-based' and 'empirical'.	Be able to analyse practical problems of child and family, recognising physical, social, psychological/emotional and spiritual issues. Work effectively with other professions and disciplines.	Recognise universal application of holistic philosophy to care of children. Appreciate roles of non-medical professionals in providing holistic care, especially nurses, social workers, psychologists and chaplains.
3	Recognise importance and limitations of therapeutic approaches based on published evidence alone. Be familiar with specific organisational structures that are commonly needed in holistic support of children with LLC, especially social services, education, hospital and community paediatric units, primary care teams, children's hospices andfaith communities.	Be able to apply principle of balancing burden and benefit to considering practical interventions in children with LLC, taking into consideration physical, spiritual, social and psychological/emotional issues. Demonstrate working with multidisciplinary and multi-professional team in caring for child with LLC. Be able to communicate sensitively and effectively with other disciplines and professions.	

		Be able to anticipate and plan for transition between the phases that constitute an illness journey. Be able to facilitate advance planning for intercurrent illness, symptom management, acute emergencies, resuscitation etc.	
4	Understand application of holism, balance of burden and benefit and rational management to the development of palliative care services to children.	Be able to coordinate and/or lead a multi-disciplinary team caring for children with LLC, based in hospital, in the community or in a children's hospice. Be able to advise on ethical aspects of withdrawing or withholding treatment for children, based on rational and holistic balance of burden and benefit. Be able to supervise, support and teach junior medical staff sensitively and effectively.	Recognise responsibility for training others, and for maintaining own learning and skills. Recognise role within wider palliative care community, nationally and internationally.

Technical 2. Symptom control

i) Pain evaluation

Level	Knowledge	Skills	Attitude
1	Understand the existence of pain assessment tools for infants and children and that there is no 'gold standard' indicator, measure or approach. Understanding that pain may be evaluated in the normal child through verbal and non-verbalcommunication and basic pain scales. Understand the importance of developmental phase in the assessment of pain.	Recognise the importance of tripartite assessment (professional, patient, parent / carer) and believing the child or carer who reports pain. Be aware of simple pain scales such as poker chip and face scales.Be aware that development alters the interpretation of these scales.	Appreciate the importance of age-appropriate communication with the child and family in assessing pain.
2	Understand the differences between assessment and measurement in evaluating pain in children. Understand the range of pain assessment tools (VAS (visual analogue scale), descriptive, objective, behavioural and multidimensional).	Be able to use appropriate pain assessment tools effectively within the context of the pain to which they apply. Understand the limitations of pain scales in children with developmental delay and/or other communication difficulties.	Recognise the potential of a multidisciplinary team to draw together all the information to assess pain effectively.
3	Have a good understanding of the basic principles underlying development and validation of novel pain scales. Have a detailed knowledge of different types of pain assessment tools andtheir differing application including limitations and challenges. Understand the limited scope of applicability of pain scales which have been validated only in	Be able to assess, measure and interpret pain in all infants and children including those with cognitive and behavioural issues, using the best tools currently available.	Understand the need to communicate with parents, family, teachers and carers in order to do an effective assessment of pain.

	certain clinical situations (eg acute vs chronic). Know the developmental stages of how children and adolescents understand pain. Know about the varying measures of pain in children, specifically behavioural and physiological measures and self report.		
4	Have detailed knowledge of new developments in pain assessment in normal and developmentally delayed children. Be able to evaluate critically and facilitate implementation of new pain scales where appropriate. Understand the complex relationship between pain, social context, culture and ethnicity.	Be able to recognise impact of cultural factors and social context on pain management.	Be willing to consider novel techniques for pain assessment when conventional knowledge is inadequate.

ii) Pain management

Level	Knowledge	Skills	Attitude
1	Know that pain is poorly recognised, under-estimated and under-managed in children and infants Understand the physiological basis of pain management including use and rationale for pharmacological and non-pharmacological approaches. Understand the concept of total pain (physical, psychological, social, spiritual).	Recognise signs that a patient is in pain. Refer appropriately (ie to the right agency and with appropriate urgency). Recognise the need for continual assessment and evaluation of pain and pain intervention.	Be an advocate for improving the recognition of pain in infants and children. Understand the subjective nature of pain. Be familiar with the concept of ‘total pain’ Be responsive to the continuous nature of pain management.

	Be familiar with WHO Pain Guidelines for children. Understand definitions of simple analgesics, adjuvants and opioids.		
2	Understand that differing pain states can exist in isolation and/ or in parallel: acute pain, persisting pain, pain at end of life. Know about indications and side effects of simple analgesics, and opioids. Know (or be able to access) appropriate starting doses for simple analgesics and opioids. Understand prescribing of opioids (low dose vs. standard dose) pertains to assessment of level of pain (moderate vs. severe) and if child is 'opioid naïve'. Know the definition of adjuvant therapy and be familiar with most common adjuvants used in children. Recognise opioid toxicity and be aware of dangers of inappropriate Naloxone therapy. Know the range of routes available and be able to access conversion factors for opioids.	Be able to initiate, titrate, maintain and review opioid therapy in a child who is opioid naïve or already on opioids. Be able to prescribe regular and breakthrough opioids at appropriate intervals and by appropriate route. Be able to titrate appropriately on the basis of breakthrough requirements. Be able to calculate conversions of opioids by different routes. Know how to source guidance about the use of opioids.	Recognise the need to address emotional, psychological, social and spiritual needs as well as physical ones in managing pain. Recognise the need to ask advice if first line measures fail or are not tolerated. Recognise need to minimise invasive procedures.
3	Understand the biological basis of paediatric pain. Understand the long-term effects of pain in infants and children. Understand the scientific principles behind non-pharmacological aspects of pain management	Be able to prescribe adjuvant therapy appropriate to the nature of pain. Be able to calculate infusion doses subcutaneously or intravenously. Be familiar with the correct practical setup and usage of continuous subcutaneous infusion pump.	Recognise the need to ask advice from specialist palliative medicine or paediatric palliative medicine team. Understand total pain and the limitation of pharmacological therapy alone. Respect and be sensitive to patient and family

	and the appropriate application Understand the physiology, mechanismsand role of non-pharmacological approaches to pain management (e.g.TENS (Transcutaneous Electrical Nerve Stimulation), acupuncture, other complementary therapies). Understand the principles of pharmacology in paediatrics including the developmental impact on pharmacokinetics and pharmacodynamics with regard to analgesic medication. Know the pharmacokinetics of major opioids, adjuvants and other medication commonly used in health and in disease. Know alternative major opioids to morphine. Know their advantages, disadvantages and relative potency. Know where to access conversion ratios for enteral and parenteral administration. Understand concept of oral morphine equivalence. Understand drug compatibility and interactions and infusion compatibility. Know the symptoms, signs & causes of narcotisation and how to reverse toxicity safely. Be familiar with the range of relevant published resources to inform pain management.	Recognise complications of continuous subcutaneous infusion pump use, including precipitation and irritation (see separate topic).	preferences to management, including use of non-pharmacological and complementary therapies. Recognise that for many children there is a need to minimise hospital admission.
4	Understand central nociceptive pathways and descending modulation and the mechanism and effect of analgesics on these. Know the pharmacological principles that cause	Be able to recognise the impact of cultural factors and social context on pain management. Be familiar with the range and logic of pain classification systems. (i.e. pain type	Recognise the biopsychosocial models of paediatric pain. Recognise the need to update knowledge as new research becomes available.

	drug interaction in polypharmacy, particularly with adjuvant use. Understand the concept of rationalising analgesia and how to wean medications. Know the range and mechanism of adjuvant medications including those used in pain syndromes (e.g. neuropathic and bone pain; dystonia). Know the range and mechanism of major non-opioid or mixed opioid analgesics. Understand urgent opioid titration during pain crisis, including use of PCA (patient-controlled analgesia)/ NCA(nurse controlled analgesia) / infusion based calculations via all routes (intravenous and subcutaneous). Understand more complex issues in opioid management e.g. incomplete tolerance, opioid induced hyperalgesia, opioid genomics.Understand differences between opioid rotation and switching. Know the range of neurolytic procedures available and be familiar what they entail for the patient (especially intrathecal, epidural, coeliac access, block and regional nerve blocks). Be familiar with the theory, evidence base and potential risks associated with common alternative and complementary therapies (see separate topic). Know where to obtain specialist pain management advice (on line research databases, textbooks, adult literature, colleagues elsewhere in UK and beyond).	bone/neuropathic/ visceral vs. opioid / non-opioid / partial opioid sensitivity vs. neuropathic/ nociceptive etc.) whilst appreciating there is no gold standard measurement. Be able tomanage difficult pain (neuropathic bone pain, cerebral irritation, muscle spasm and dystonia). Be able to rotate or substitute opioids. Prescribe opioids in disease (particularly renal failure, liver failure or delirium). Be able to dose all forms of intravenous / subcutaneous pain management systems including PCA/ NCA/ infusion Be able to recognise and manage adverse effects of opioid therapy. Be able to safely wean analgesic medications. Be able to work with colleagues to develop pain assessment and management services.	Recognise the need to involve other professionals and disciplines in the management of pain.

iii) Psychological symptoms (see also Bereavement and existential aspects)

Level	Knowledge	Skills	Attitude
1	Understand the basic features in depression and anxiety. Be familiar with normal bereavement reactions in adults and children (see Interpersonal 4). Understand the basics of management (both pharmacological and non-pharmacological) of children and families with psychological problems.	Be able to recognise the risk factors for, and early symptoms of depression and anxiety.	Be able to communicate with children with LLCs and their families in an empathetic manner.
2	Be familiar with the special features of depression, anxiety, agitation and delirium in children. Understand the distinction between adjustment disorder and depression. Have knowledge of the features and causes of agitation and delirium. Know and understand features of non-pathological behaviours and psychological responses associated with LLC e.g. anger, adjustment reaction. Be familiar with the benefits and appropriateness of the various non-pharmacological therapies available. Understand the risks and benefits of pharmacological management.	Be able to distinguish between normal and abnormal behaviour in children, their families and siblings. Be able to assess psychological problems in children and their families and be able to treat and/or refer appropriately. Distinguish between the various causes of agitation and delirium and manage these appropriately.	Understand how specific diagnosis and family dynamics, both personal and cultural, can affect behaviour.
3	Understand the impact of anxieties about death (hidden, repressed or overt) among professionals,	Be able to assess the various psychological reactions in children.	Be able to provide support to children, families and the multidisciplinary team.

	patients and families. Understand the effects of psychological problems and how they may affect the multidisciplinary team. Have a full working knowledge of available pharmacological interventions. Understand the impact of behavioural difficulties in children with neurological, neuromuscular and neurometabolic disorders.	Be able to distinguish between normal and abnormal psychological responses in a child with LLC and their family. Be able to explain to families the nature of these reactions and set in place a management plan to help children and families cope with them, including use of appropriate local resources. Be able to refer appropriately to child / adult psychiatry, family therapy, psychology, play therapy and counselling services. Be able to prescribe appropriate medication after assessment, and monitor children appropriately.	Be aware of the skills and value of music therapy, play therapy, art therapy etc. Understand the dangers to the doctor's own psychological wellbeing when dealing with psychological problems, and have in place appropriate personal support mechanisms.
4	Be familiar with latest research in behavioural reactions and psychological problems in children and families.	Be able to advise, teach and support the multidisciplinary team in relation to psychological and behavioural problems affecting children and their families. Be able to support professional teams in managing complex family dynamics and their impact on a team.	Be aware of the need to have close links with relevant support services, including local child and adult psychiatric services, psychological services, counselling / support groups.

iv) Nausea, vomiting, reflux and hiccough

Level	Knowledge	Skills	Attitude
1	Recognise most common mechanisms for emesis in children with LLC, particularly chemotherapy, drug related, feed-related, reflux and metabolic causes. Know major receptors and chemical messengers involved in mediating emesis. Know all major organs involved in mediating emesis.	Take a history related to vomiting. Be able to consider implications of vomiting, distress, weight loss etc.	Be aware of the emotional upset associated with nausea and vomiting.
2	To have a basic understanding of the causes of hiccoughs. Know all major classes of antiemetic and their mechanism. Know adverse effects of major antiemetics and how likely they are to occur in each age group. Know routes by which antiemetics can be given.	Where possible, be able to identify likely cause(s) for nausea and vomiting. Be able to prescribe appropriate antiemetic by appropriate route and at appropriate dose. Recognise anticipatory or psychogenic nausea and vomitingand refer appropriately. Recognise likely gastro-oesophageal reflux and be able to institute appropriate management (feed manipulation, non-drug, drug, referral for surgery). Refer appropriately when initial management fails e.g. palliative care, surgery.	Recognise need to identify cause wherever possible in order to prescribe rationally in nausea and vomiting. Be aware of range and complexity of emotional responses affecting management of feed-related symptoms.
3	Know rational therapeutic strategy for each antiemetic, based on understanding of mechanism.	Be able to commence a management plan for hiccoughs in patients. Recognise holistic nature of nausea and vomiting in	Recognise need to negotiate acceptable and achievable goals before prescribing antiemetics.

	Have knowledge of the causes and management of hiccough (pharmacological and non-pharmacological). Know receptor interaction of all common antiemetics, and how some anti-emetics may interact with one another. Be aware of non-pharmacological approaches to management of nausea and vomiting in children with LLC, including acupuncture, hypnosis and counselling. Know major receptors and chemical messengers involved in mediating emesis. Understand concept of receptor complementarity and of first- and second line antiemetics based on understanding of their mechanism.	children with LLC, and role of psycho-active medications in managing nausea and vomiting. Have basic counselling skills to enable identification and exploration of anxiety-related nausea and vomiting. Be able to prescribe appropriate antiemetic by appropriate route and at appropriate dose depending on cause for nausea and vomiting. Be able to prescribe empirically and appropriately in the face of incomplete clinical data. Be able to provide appropriate care to families when gastric stasis (intolerance of feed) occurs at end of life.	Understand importance of multi-disciplinary and multi-professional approach that may include family, other carers, doctors, nurses, surgeons, complementary therapists etc. Have awareness of the need to judge how far to investigate causes for nausea and vomiting.
4	Understand the mechanism and role of unusual medications such as steroids and octreotide in managing nausea and vomiting. Know mechanism of emesis in liver damage, metabolic derangement, gastrointestinal damage and intracranial causes, irrespective of underlying LLC. Be familiar with emerging classes of antiemetic as they develop. Be able to manage different routes of enteral feeding, nasogastric, gastric and jejunal.	Be able to devise a patient-specific, evidence-based approach to the management of hiccoughs. Be able to formulate a rational approach to antiemesis when first and second lines fail, based on understanding of the likely mechanism. Be able to advise parents on the benefits of different routes of enteral feeding.	

v) Constipation and Diarrhoea

Level	Knowledge	Skills	Attitude
1	Have knowledge of the definitions of constipation and diarrhoea. Have a basic understanding of the common causes of constipation and diarrhoea in LLC. Have a basic understanding of dietary measures and use of laxatives/rectal measures in the management of constipation.	Be able to take a comprehensive dietary and bowel habit history. Be able to perform a comprehensive abdominal examination, demonstrating faecal loading.	Appreciate the psychosocial impact of constipation and chronic diarrhoea.
2	Have knowledge of specific causes and pre-disposing factors for constipation and diarrhoea in advanced malignant and non-malignant disease. Have basic knowledge of the classification and mechanisms of action of laxatives and rectal measures.	Be able to anticipate and identify risk factors for constipation (e.g. poor hydration and immobility). Be able to initiate investigations which may be appropriate in constipation in advanced malignant and non-malignant disease. Be able to counsel patients on dietary measures and use of common laxatives and rectal measures for simple constipation. Be able to distinguish between acute and chronic causes of diarrhoea from their clinical features.	Be aware of the role of other specialists e.g. paediatric gastroenterologists in management of constipation and chronic diarrhoea. Appreciate the need to involve and empower family and other carers in managing these symptoms at home.
3	Have detailed knowledge of the classification and mechanisms of action of laxatives and rectal measures, their use, limitations and risk.	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 titrate laxative medications and select appropriate combinations according to the degree	Appreciate the role of the multidisciplinary team in managing constipation. Recognise when to liaise with specialist paediatrician to manage complications associated with advanced constipation and chronic diarrhoea e.g. bowel obstruction, pain,

		of constipation. Be able to identify and modify other symptom control measures which may contribute to: (i) Constipation e.g. use of non-constipating opioids, drugs with anti-muscarinic effects. (ii) Chronic diarrhoea e.g. modification to feeding regimen, judicious use of anti-motility drugs.	nausea/vomiting.
4	Have knowledge of the current and evolving theories of constipation and chronic diarrhoea in children with advanced LLC.	Be able to manage advanced constipation and associated complications requiring specialist palliative measures e.g. use of opioid-receptor antagonist, palliation of intestinal obstruction. Recognise the nutritional implications and morbidity of chronic diarrhoea, its impact on quality of life and be able to counsel patients appropriately.	Recognise benefits and limitations of extrapolating information from evidence in adults.

vi) Anorexia, cachexia and fatigue

Level	Knowledge	Skills	Attitude
1	Have knowledge of definitions of anorexia, cachexia and fatigue.	Be able to take a comprehensive dietary habit history and assess significant weight loss.	Appreciate the psychosocial impact of cachexia, anorexia and fatigue.
2	Have a basic understanding of mechanisms of anorexia, cachexia and fatigue.	Be able to anticipate and identify risk factors for anorexia, cachexia and fatigue. Be able to explain simple dietary changes to patients and families in managing cachexia and anorexia.	Appreciate the need to involve and empower family and other carers in management of these symptoms at home.
3	Have an understanding of the types medications used for appetite stimulation in anorexia, their use, limitations and risk. Have an understanding of the theoretical mechanisms that link anorexia, cachexia and fatigue in both malignant and non-malignant conditions.	Be able to devise and implement a management plan for anorexia, cachexia and fatigue. Be able to take a rehabilitative approach to fatigue management even in advanced disease, supporting structured incremental activity.	Appreciate the role of the multidisciplinary team in managing anorexia, cachexia and fatigue. Awareness of possible anorexia or over-feeding in non-verbal children and/or children fed artificially where feed adjustments may be appropriate, particularly towards the end of life.
4	Have knowledge of the current and evolving theories of anorexia, cachexia and fatigue in children with LLC.	Be able to teach professional colleagues about anorexia, cachexia and fatigue.	Recognise benefits and limitations of extrapolating information from evidence in adults.

vii) Feeding and hydration

Level	Knowledge	Skills	Attitude
1	Have basic knowledge of methods of feeding and hydration in LLC.	Be able to assess hydration and nutritional status of a child. Be able to formulate a hydration plan for a child.	Be aware of the role of MDT professionals in feeding and hydration. Appreciate the psychosocial and ethical issues surrounding feeding and hydration in children with LLC and at the end of life.
2	Have knowledge of RCPCH and GMC guidelines for withholding and withdrawing life-saving treatment (see ethics section)	Be able to explain the benefits and risks of artificial feeding and hydration to families. Be able to manage artificial feeding regimes in children with LLC. Be familiar with different types of feeding tubes, e.g. Mic-Keys, buttons. Be able to manage problems with artificial feeding devices(blockage, infection, displacement).	Appreciate the need to share decision-making with families and other professionals re nutrition and hydration issues.
3	Have knowledge of national and international frameworks and legal aspects of withholding and withdrawing life-saving treatment (see ethics and law section).	Be able to anticipate and manage changing feeding and hydration needs of LLC with malignant and non-malignant conditions. Be able to identify ethical dilemmas surrounding feeding and hydration and seek appropriate support.	Be aware of local and specialised support for ethical decision-making. e.g. local ethics committee, Trust legal adviser, tertiary ethics specialist.
4	Have detailed knowledge of ethical and current legal issues surrounding feeding and hydration. Be able to work with colleagues to establish a diagnosis of gut failure and then support discussions about the appropriate use of parenteral nutrition.	Be able to manage conflict between professionals, families and patients in feeding and hydration issues. Be able to facilitate MDT ethical decision-making process concerning feeding and hydration issues. Support families and nursing staff establish home	Be aware of potential conflicts in artificial feeding and hydration legal policy. Be aware of the need to seek legal ruling where appropriate. Being able to support families and the patient when feeding and hydration are withdrawn.

		based parenteral nutrition regimens.	Knowing when to stop hydration if nutrition is no longer possible.

viii) Mouthcare

Level	Knowledge	Skills	Attitude
1	Have knowledge of the symptoms of oral diseaseand management principles of mouth care.	Be able to recognise and appropriately treat oral candidiasis. Be able to assess the mouth.	Appreciate the psychosocial impact ofmouth care.
2	Have knowledge of the oral side effects of not eating and the impact of chronic illness on oral health.	Be able to devise a mouth care regime including pharmacological and non-pharmacological interventions.	Work with others to ensure best advice is obtained. i.e. dental staff, oncology.
3	Have knowledge of the impact of specific illnesses on oral health. Be aware of the need to assess the mouth looking for causes of distress.	Be aware of the range of topical and systemic treatments.	Be aware of the balance between obtaining information by examination and the risk of upsetting the child.
4	Be aware of methods of prevention. Have knowledge of systemic medications that can affect mouthcare	Be able to manage severe mucositis in collaboration with colleagues. Recognise the need for preventative management.	Ensure that those at risk have good assessment.

ix) Respiratory issues

Level	Knowledge	Skills	Attitude
1	Have knowledge of the definition and subjective nature of dyspnoea. Have knowledge of diagnosis and treatment of major reversible causes of dyspnoea in LLC.	Be able to perform and interpret a respiratory examination on a child.	Be aware of the subjective nature of dyspnoea. Be aware of the psychosocial influences ofand impact of dyspnoea.
2	Have knowledge of the pathophysiology of respiratory failure and implications for symptom management. Have knowledge of the principles of pharmacological and non-pharmacological management of dyspnoea, including the place of oxygen therapy. Be familiar with principles of obtaining oxygen supplies, oxygen delivery devices and methods of non-invasive ventilation. e.g. CPAP, BiPAP	Be able to formulate a management plan for dyspnoea.	Appreciate the need for balancing subjective burden and benefit in managing a child with dyspnoea. Be aware of the need to refer to appropriate specialists.
3	Have knowledge of pathophysiology of dyspnoea in children with malignant and non-malignant conditions e.g. CF, DMD, children with lung metastases. Have knowledge of the objective and subjective investigation techniques for dyspnoea e.g. pulmonary function tests, visual analogue scales. Recognise whether oxygen therapy is appropriate, or not, for management of dyspnoea.	Be able to explain management of dyspnoea to families. Recognise and know how to treat panic/ anxiety, painful breathing, breathlessness, cough, haemoptysis and excessive secretions. Be able to anticipate and plan management of children at risk of sudden acute episodes of dyspnoea e.g. airway obstruction, haemoptysis.	Be aware of MDT approach to management. e.g. psychologist, play specialist, physiotherapy. Appreciate when investigation is necessary and when it is inappropriate. Be aware of the need to seek specialist support in management of artificially ventilated LLC. Be aware of the reluctance of family and professionals to use medications with

			respiratory depressant side effects in LLC with respiratory symptoms.
4	Have knowledge of the current evidence base for management of dyspnoea.	Be able to support other specialties eg. respiratory and neurology teams in management of dyspnoea in terminally ill children (including rapid home discharge planning). Be able to manage withdrawal of invasive and non-invasive ventilatory support and oxygen therapy. Be able to recognise and discuss that there may be a time when the benefits of NIV no longer outweigh the burdens.	Appreciate that NIV may not be psychologically appropriate for all children.

x) Neurological, neuromuscular and neurometabolicproblems

Level	Knowledge	Skills	Attitude
1	Understand the types of neurological problems that occur in children. Be familiar with the different types of epilepsy. Be familiar with the types of illness in children that are associated with neurological symptoms.	Be able to do a full neurological assessment on a normal child. Be familiar with the management of epileptic seizures and status epilepticus.	Understand the fears felt by family and children in the management of epilepsy and other neurological symptoms. Be aware of how society behaves towards children with neurological problems and the effect that this can have on the child and family. Understand the need for multidisciplinary team working and the role of the individuals in the team in managing neurological symptoms.
2	Have core knowledge of the common types of life limiting neurological and neuromuscular conditions seen in paediatrics. Understand the natural aetiology of these conditions, clinical presentation, main symptoms,treatment options and prognosis. Be familiar with the various types of neurological symptoms. Have awareness of emergency regimes for metabolic conditions.	Be able to do a full neurological assessment on a child with neurological symptoms. Have clinical experience in managing children in simple status epilepticus. Have a working knowledge of basic drug medication needed to manage the common neurological symptoms.	Understand the difficulties of neurological assessment on children with special needs. Understand the need for specialist referral for diagnosis and management of epilepsy. Be aware of the need to seek specialist help in managing intractable epilepsy. Understand the impact of severe disability on a child and family.
3	Have detailed knowledge of the commoner life limiting neurological and neuromuscular conditions including: *Cerebral palsy with epilepsy,* *Muscular dystrophies,* *Mucopolysaccharidoses,*	Have a working knowledge of and ability to treat and manage the common neurological / neuromuscular symptoms seen including: *Seizures (also status epilepticus and terminal)* *Dystonia* *Myoclonus*	Appreciate the need to negotiate realistic treatment goals appropriate to the level of distress caused by the symptom. Understand the limitations of therapies and the side effects that the therapies themselves can

	Tumours affecting the nervous system Have basic knowledge of management of intractable epilepsy including surgical and dietary. Have knowledge of the range of aids and support services for children with physical and learning disability and how to access them (e.g. communication aids, wheelchairs, splints, standing frames etc).	*Spasticity* *Chorea* *Akathisia* *Raised ICP* *Spinal cord compression* *Cerebral irritability* *Severe learning disability.* Be familiar with the different types of assessment tools used to assess children with neurological and neuromuscular disorders. Be able to facilitate multidisciplinary management of severe disability. Be able to access appropriate aids and support services.	manifest. Have a working knowledge ofthe roles of the multidisciplinary team and how they can individually aid the child and family. Appreciate the burden that multiple therapies and services place on children and families.
4	Have detailed knowledge of neurological, neurometabolic and neuromuscular disorders.	Be able to manage terminal status epilepticus / intractable epilepsy. Be familiar with anaesthetic and neurosurgical procedures that may help neurological symptoms (baclofen pump, nerve blocks etc). Know of novel approaches to manage intractable symptoms and obtain advice through the PPC community. Be able to teach professionals about the management of symptoms in neurological, neuromuscular and neurometabolic disorders.	Understand when specialist advice should be sought (neurologist, oncologist, pain clinic). Be able to accept and inform the family, child and team that symptoms (particularly seizures and spasm) may not be fully controllable.

xi) Sleep

Level	Knowledge	Skills	Attitude
1	Be aware of the impact of a child's poor sleep on the whole family.	Understand the importance of asking about sleep.	Be sympathetic about sleep problems and understand that there often is no simple solution.
2	Be able to take a good sleep history including who is affected, is it an issue and what are the maintaining factors. Be aware of the many drugs that can interfere with sleep. Know of the limitations of sedative medication.	Understand the importance of sleep and be able to provide simple non-pharmaceutical advice. Establish bedtime routine, ensure sleeping area is different from daytime area, anchor waking time. Be aware of and be able to access special sleep clinics. Be able to prescribe medication for insomnia including Melatonin effectively.	Be supportive and positive.
3	Be able to review sleep difficulties in light of the child's underlying condition.	Be able to access short break services.	Support families to access short break services in and out of the home as appropriate.
4			Work with psychological and other teams to help support parents.

xii)Skin symptoms

Level	Knowledge	Skills	Attitude
1	Have core knowledge of common dermatological conditions in children including eczema.	Recognise the common dermatological conditions in children.	Be aware of the need to communicate effectively with parents and children regarding the causes and management of common dermatological conditions.
2	Have basic knowledge of how LLC can affect the skin Be familiar with causes and basic management of pruritus, pressure sores and fungating tumours in children. Be aware of the range of dressings used to treat pressure sores and fungating tumours and the role of specialist nurses.	Refer appropriately patients with pressure sores and fungating tumours. Recognise the need to ask advice if first line measures fail or are not tolerated.	Recognise the importance of medical and non-medical expertise e.g. district nurses, tissue viability nurses, and the need to work in a multidisciplinary way. Have an empathetic understanding of the commitment required to manage these conditions and the effect this has on the child and family. Recognise need to address emotional, psychological, social and spiritual needs as well as physical ones in managing children with life limiting skin conditions.
3	Be familiar with epidermolysisbullosa and other life limiting skin conditions, including restrictive dermopathy, ichthyoses and Neu-Laxova. Have knowledge of the different types of dressing available and how and when they should be used.	Understand the causes of pruritus, and be able to manage it. Understand when specialist advice should be sought.	Be able to accept and inform the family, child and team that symptoms may not be fully controllable or may progress.
4	Maintain up to date knowledge of the causes and management of all types of skin disorders in LLC.	Be able to facilitate and participate in a MDT approach to management of skin symptoms and disorders.	Be aware of the limitations of management of skin symptoms and disorders.

Technical 3. Emergencies

Level	Knowledge	Skills	Attitude
1	Be aware of emergencies that can occur in a palliative care setting: • Uncontrolled pain • Seizures/spasms/dystonia/epileptic status • Acute respiratory deterioration • Cardiac failure • Haemorrhage • Cord compression • Superior Vena Cava (SVC) obstruction • Safeguarding/child protection(see communication with families) Understand principles of management for each.		
2	Know where to seek specialist advice or information if palliative care emergencies occur. Know when palliative as opposed to resuscitative management of an emergency may be appropriate.	Be able to recognise palliative care emergencies (as above) in children. Be able to identify LLC in which each of the emergencies is likely. Be able to recognise when the course of a LLC has reached a point where specialist palliative care advice should be sought.	Have understanding of possible emergencies as part of the course of LLC, and the impact this can have on a child and family. Have understanding of the need to involve specialist PPC early enough to anticipate and address issues.
3	Understand the need to prepare a plan for management of an emergency in a timely fashion.	Be able to identify likely emergencies early in the palliative course of life-limiting conditions. Be able to communicate sensitively and appropriately with a child and family concerning	Be aware that paediatric emergencies may need to be managed very differently in a palliative setting and the context for treatment is important.

		anticipation of emergencies, and formulate a plan as appropriate. Be able to prepare detailed management plan for emergencies, including correct drug, dose and route for specific situation and child.	Develop an approach of anticipation of problems and planning ahead. Be aware of the need to support others sensitively in a difficult situation; e.g. nursery, school, nursing staff. Understand the fear and anxiety that the child and family may experience when an emergency is possible.
4	Know where to look in order to identify and become familiar with new approaches to emergencies.	Be able to manage, lead management and give senior advice for palliative emergencies. Be able to teach about management of palliative care emergencies, and disseminate new techniques and knowledge. Be able to offer and facilitate support of colleagues in caring for a child with one of the emergencies, on site and at a distance.	Have a positive, collaborative and flexible approach to managing emergencies in all care settings.

Technical 4. Critical care liaison

Level	Knowledge	Skills	Attitude
1	Be aware of local and national guidelines on withdrawing and withholding life-sustaining treatment.	Recognise that palliative care input can be delivered alongside life-prolonging treatment, including critical care.	
2	Be aware of legal and ethical issues relating to withdrawing life sustaining treatment. Be aware of the ethical issues of therapeutic intervention in children with LLC, including the need to consider an ethical decision making framework for treatment limitation. Be aware of local bereavement support services. Be aware of practical guidelines relating to organ and tissue donation.	Implement local and national guidelines on withdrawing and withholding life-sustaining treatment Be able to discuss potential treatment limitationwith clinicians and families. Be able to seek advice (legal and clinical) when there is disagreement about pursuing treatment options. Understand the need to respect the wishes of a child particularly when these are different from those of the family and/or health professionals.	Appreciate the importance of promoting a child's best interests. Appreciate that in LLC the balance of burdens and benefits of treatment will be different. Recognise loss and grief and their effects on the health and well-being of children, families and professionals. Acknowledge personal needs for support and the needs of other professionals involved in the care of dying children.
3	Be familiar with local opportunities and services that are available to support acute palliative needs. Be familiar with local and national guidance on compassionate extubation and palliative care pathways.	Be able to explore end of life care options and places with families. Be able to liaise appropriately with Intensivists, local paediatricians, hospice and community teams, to manage end of life care options. Be able to institute appropriate supportive therapy and symptom care. Be able to support and facilitate difficult MDT decision making, including parallel planning	Be supportive of the family and professionals through the potential uncertainty in the trajectory of the end of life phase in a child with a LLC.

4	Know how to facilitate rapid discharge of a child for end of life care at home or at a hospice.	Be able to co-ordinate, leadand support multi-disciplinary professionals to manage symptoms in a dying child in the community.	Appreciate the organisation of critical care networks and the importance of developing pathways and guidance in conjunction with local networks.

Technical 5. Neonatal issues

Level	Knowledge	Skills	Attitude
1	Be aware of local and national guidelines on withdrawing and withholding treatment in neonates.	Recognise as early as possible (antenatally, neonatally) when a patient has a candidate condition likely to require palliative care.	
2	Be aware of legal and ethical issues relating to withdrawing life-sustaining treatment in the neonatal period. Be aware of the ethical issues in therapeutic intervention in babies with LLC. Have knowledge of local opportunities for respite care, including hospice care. Have knowledge of the national and local policies on the management of sudden infant death.	Be able to identify and manage distressing symptoms in neonates. Be able to address maternal health needs in the post-natal period and also the potential genetic implications of a neonatal LLC.	Appreciate the importance of seeking advice when treatment may not be in the best interests of a baby. Recognise the unique impact of the loss and grief following a neonatal death, and how this can affect the health and well-being of children, families and professionals.
3	Be familiar with local and national guidance on neonatal palliative care pathways. Be aware of specialised neonatal bereavement support for families.	Be able to implement local and national guidelines on withdrawing and withholding treatment and on the management of sudden infant death. Be able to counsel parents who have been given an antenatal diagnosis of a LLC, regarding supportive care. Be able to help families and clinicians to formulate a potential care plan. Be able to explore end of life care options and institute appropriate supportive therapy and	Recognise when to liaise with a specialist in paediatric palliative care to manage end of life care options. Acknowledge and address personal needs for support. Acknowledge the support needs of other professionals involved in the care of the dying neonate.

		symptom care including appropriate management of feed and fluids.	
4	Know how to facilitate rapid discharge of a neonate for end of life care at home or at a hospice.	Be able to co-ordinate multi-disciplinary services to manage symptoms in a dying neonate in the community. Support the family and professionals through the potential uncertainty in the trajectory of the end of life phase in a neonate with a LLC.	Appreciate the organisation of neonatal networks. Understand the importance of developing neonatal palliative care pathways and guidance in conjunction with the local neonatal network.

Technical 6. Transition issues

Level	Knowledge	Skills	Attitude
1	Recognise that in many conditions, making accurate prognoses about individuals is very difficult. Recognise that paediatric and adult services are organised differently and that patients & families have to negotiate a challenging process of change through the transition period.	Be able to communicate the difficulty of looking into the future for children with LLC and their families.	Exhibit sensitivity and honesty in communication with the patient / family and MDT.
2	Have knowledge of the importance of planning ahead for transition to adult services.	Recognise the necessity of parallel planning. Help to ensure that transition is considered in early teenage years in a structured fashion. Prepare young people for the move to adult care, providing them and their carers with knowledge and understanding of their illness.	Be aware of the concerns families will have about changing to adult services and support the families through the change.
3	Have knowledge of pathways of transition and those that are present in your area.	Make appropriate, skilled referral to adult services, including supporting the GP to be involved in the young person's care. Communicate non-judgemental acceptance and professional comfort with the cultural preferences of child and family.	Demonstrate respect for the wishes of the dying child and family, and willingness to work with the MDT to meet their needs. Demonstrate sensitivity to the wishes of the child and family, recognise and respond to distress in others and in him/ herself, and use reflective practice. Appreciate the anxiety, fear and even sense of loss that children and families may experience during the transition phase.

4		Ensure that transition is at a pace suitable for the young person. Provide flexible support over this difficult period.	

Technical 7. Ethics and law

Level	Knowledge	Skills	Attitude
1	Know the four main principles of: autonomy, non-maleficence, beneficence and justice. Understand ethical and legal principles of patient confidentiality.	Awareness of ethical dimension in clinical cases.	Be aware of emotional issues of family, staff and the child when dealing with difficult ethical decision-making processes.
2	Have basic knowledge of moral arguments underpinning palliative care as an active alternative to life-sustaining treatment. Have knowledge of the RCPCH framework for withholding life-sustaining treatment. Have awareness of the United Nations Convention on the Rights of a Child. Have knowledge of the nature of end-of life care pathways, and the extent and limitations of their ethical and legal authority. Have knowledge of legislation, parental responsibility and consent issues (including those pertaining to Looked After Children). Have knowledge of legal aspects of capacity in adults and children. Have basic knowledge of the role of judicial review in ethical decision-making for LLC. Be aware of special issues in application of four principles to ethical quandaries in children.	Be aware of possible ethical issues in decision-making and be aware of possiblefora for discussion, e.g. ethics review meeting. Be aware of mechanism for referring to the local Clinical Ethics Committee	Be aware of the nature and risk of collusion and coercion in these situations. Be aware of conflict regarding these issues due to different people holding differing moral, religious and cultural principles. Understand the significance of personal value judgements in considering ethical issues. Be aware that conflict with staff and families does not justify withdrawing support.

	Be aware that Scottish and Northern Ireland law are distinct from the law in England and Wales. Understand the Principle of Double Effect and its relationship to therapeutics of symptom control.		
3	Have basic knowledge of classical moral theories, particularly utilitarianism, deontology and virtue ethics. Have basic knowledge of specific legal frameworks relevant to children and young people in the UK: • Children Act 1989 (particularly concepts that underpin the welfare checklist in Section 1) • Children Act 2004 • Mental Capacity Act 2005 • Mental Health Act 1983 Have a detailed knowledge of the role of judicial review. Be aware of the limitations of the four principles in considering end-of-life ethical quandaries in children. Understand the concept of a child's interests, and how they might complement or conflict with the interests of relevant others in the care of a child, such as parents and clinicians. Have basic understanding of arguments in specific key end of life ethical and legal debates issues in children, especially: • Sharing of confidential information • Refusal of treatment (life-sustaining or otherwise)	Be able to introduce discussions about changing the goals of care in LLC to families. Be able to explain issues around ethical decision-making in LLC to families and professionals Be able to chair MDT discussions concerning ethical decision-making in LLC.Be able to identify and present key features of a case at ethics review meetings. Be able to chair debrief meetings and staff support sessions after "difficult" decisions have been made for patients. Be able to proceed with application for judicial review.Be able to support families going through judicial review process- identify other sources of support, e.g. Patient Advisory Liaison Service (PALS), chaplaincy. Be able to seek advice appropriately from other sources. e.g. local or other Clinical Ethics Committee. Be able to distinguish where practical between the interests of the child and those of relevant others (especially clinicians and family). Be able to reassure families appropriately about interventions with more than one possible effect.	Be aware that conflict with staff and families does not justify withdrawing support. Be aware that relationships with families may break down, and be able to identify alternative support for families. Be aware that bereavement support may need addressing differently where conflict at end of life has occurred.

	• Euthanasia • Physician-assisted suicide • Infanticide.		
4	Be aware of the value and limitations of utilitarianism, deontology and virtue ethics in considering end of life ethical quandaries in children. Understand some of the debates around the Principle of Double Effect. Have good understanding of arguments in key end of life ethical and legal debates issues in children, especially: • Sharing of confidential information • Refusal of treatment (life-sustaining or otherwise) • Euthanasia • Physician-assisted suicide • Infanticide.	Be able to identify and help resolve conflict between parents, clinicians and patients that arises from differing perception of interests and other divergent ethical perspectives. Have experience of sitting on ethical review committees.	Feel comfortable expressing an ethical viewpoint to a colleague who disagrees. Be able to work alongside others whose viewpoints diverge strongly from your own.

Technical 8. Non-malignant diseases

Level	Knowledge	Skills	Attitude
1	Have a basic knowledge of types of common non-malignant conditions in LLC.	Be able to identify key problems through comprehensive history and examination. Be able to utilise a MDT approach to management plans in hospital and at home.	Be aware of communication difficulties with non-verbal children. Be aware of prognostic uncertainty of some conditions. Be aware of other agencies involved with the child. e.g. education.
2	Have knowledge of the ACT/RCPCH classification of life-limiting and life-threatening disorders.	Demonstrate skills in developmental assessment appropriate to the stage of training. Be able to assess symptoms in a child with severe developmental delay. Be able to manage common general paediatric problems in LLC e.g. gastro-oesphageal reflux, persistent crying, respiratory distress, stridor, feeding difficulties.	Appreciate the impact of a genetic diagnosis on family and future children. Be aware of the likelihood of symptoms in certain conditions, e.g. dystonia or spasticity in severe cerebral palsy. Be open to the possibility of symptoms especially when children are non-verbal. Appreciate ethical dilemmas in management. e.g. use of non-invasive ventilation in DMD.
3	Have knowledge of broad principles of management of some non-malignant conditions. e.g. Congenital heart disease, MPS, cerebral palsy, DMD. Have knowledge of how to access information on current management strategies for rare disorders.	Be able to formulate a child-centred symptom management plan with MDT and specialist involvement. Be able to manage specific common symptoms e.g. pain, intractable seizures, spasm, nausea and vomiting, constipation, dyspnoea, colic. Be able to identify and address ethical dilemmas in management and issues of conflict. e.g. autonomy	Appreciate the differing disease trajectory in non-malignant LLC. Be able to deal with the associated uncertainty and with dilemmas regarding management of intercurrent illness. Appreciate quality of life from child's viewpoint. Be aware of bereavement issues. e.g. loss of

		and consent. Be able to facilitate planning for end of life care.	children with same condition, or loss of the child they once knew. Appreciate the need for early genetic counselling.
4	Have detailed knowledge of specific non-malignant disease groups. e.g. Congenital heart disease, MPS, Cerebral palsy, DMD, HIV/AIDS. Have knowledge of disease-specific national guidance in LLC, e.g. Spinal muscular atrophy	Demonstrate an empirical approach to symptom management in rare disorders, even in the absence of a published evidence base. Be able to anticipate probable symptoms even when they are not articulated, by having knowledge of symptom patterns in specific groups of LLC e.g. muscle spasms in adrenoleukodystrophy, screaming episodes in children with pulmonary hypertension. Be able to identify and address training needs in specialist and local professionals with reference to palliative care of patients with non-malignant conditions. Be able to formulate treatment plans in children with rare life-limiting diseases or without formal diagnoses.	Appreciate the need to balance burden and benefit. Appreciate the specific needs of families whose children have non-malignant LLCs, with respect to interaction with professionals, dealing with loss and bereavement and perception of quality of life.

Technical 9. Malignant diseases

Level	Knowledge	Skills	Attitude
1	Know the broad categories of malignancies; haematological, solid tumours and CNS tumours	Elicit symptoms and physical signs and recognise typical presentations.	Appreciate the emotional impact of a cancer diagnosis on a child and family. Recognise the need to elicit fears and prior experiences.
2	Know in general terms the mechanism of action of three modalities available to treat cancer in children: chemotherapy, radiotherapy and surgery.Know the most likely adverse effects of each of these modalities, both during and after treatment. Recognise common symptoms and know the mechanisms involved: pain, nausea and vomiting, dyspnoea, constipation. Be aware of presentations of palliative care emergencies in the context of cancer.	Elicit symptoms occurring in children with cancer. Recognise symptoms and initiate appropriate symptom management in the acute stage. Seek advice if symptoms not quickly controlled. Be able to diagnose palliative care emergencies complicating cancer, and to seek advice or refer appropriately.	Appreciate the significance of symptoms occurring in child with cancer as indicators of progression or relapse. Understand the need to collaborate closely with oncology and palliative care teams.
3	Know how the main tumour types are likely to spread.Know which symptoms are likely in major tumour types. Know strategies for managing 'palliative care emergencies' that can complicate palliative care in cancer: acute obstruction, superior vena cava obstruction, haemorrhage, seizures, cordcompression, crescendo pain. Understand how malignant conditions or	Be able to explore sensitively the fears of the patient and family before death. Be able to support the family after a child's death. Be able to manage palliative care emergencies in the context of cancer. Anticipate and proactively elicit possible symptoms. Formulate appropriate plans for their management, including advance prescriptions.	Recognise skills of non-medical staff with expertise in palliative care, particularly paediatric oncology outreach nurses. Have a collaborative approach to care.

	treatment for them can impact on symptom management (e.g. effect of renal dysfunction on opioid metabolism).		
4	Understand the indications for and common side effects of palliative chemotherapy agents. Be familiar with the extent and limitations of oncology outreach, inpatient and children's hospice models for providing palliative care for children with cancer.	Have the skills to support families with difficult decision making. Be able to support junior medical staff and non-medical staff in making difficult decisions, and after death of a child has occurred. Be able to teach professional colleagues about the likely symptoms of haematological, solid and CNS tumours.	Appreciate need for close liaison with oncology colleagues throughout the course of a child's illness. Appreciate the vulnerability of non-medical, primary care and junior medical staff caring for child dying from cancer.

Technical 10. The period when death is thought to be inevitable

Level	Knowledge	Skills	Attitude
1	Know of different routes to administer medication, including subcutaneous and buccal routes.	Be able to describe features that might suggest that death is approaching quickly.	Understand that the last few days of life necessitate specific approaches to therapy that are different from rest of palliative phase. Consider the child and family's preference for place of death.
2	Understand the need to consider appropriate route of administration and dosage interval in palliative care. Have knowledge of the existence of continuous subcutaneous infusions, and syringe pump drivers. Be aware of issues of solubility, mixing and precipitation. Be aware of choices of location for palliative care, and the advantages and limitations of all. These should include: home, children's hospice, hospital ward and special school. Be aware of services, particularly nurses, in primary, secondary and tertiary care that may be available to facilitate death at home for children.	Be aware of subcutaneous, transdermal, rectal, transmucosal and intranasal routes of administration in children. Be aware of advantages and limitations of each, bearing in mind issues of speed of onset of action, acceptability to parents and child, pain, and personal dignity. Be aware of possibility of mixing commonly used palliative care drugs in syringe driver, in particular morphine / diamorphine, Levomepromazine, Midazolam, Hyoscine, Cyclizine and / or Haloperidol.	Recognise the need to solicit and take seriously diagnoses of imminent death by non-medical personnel, particularly experienced nurses and parents. Recognise the importance of good liaison and communication between child, family and professionals, and between primary, secondary and tertiary paediatric teams, both medical and nursing. Recognise the skills of specialists from other disciplines, particularlynursing, in advising on palliative care and symptom management in the final few hours and days of life.
3	Be aware of compatibility issues of drugs combined in a continuous subcutaneous infusion. Have knowledge of how to prescribe these drugs by alternative routes as listed above.	Be able to make a diagnosis of imminent death. Have an awareness of the different modes of death and an understanding of the difficulties of predicting timing in children. Be able to explore this sensitively with family, child	Be sensitive to the needs of professional colleagues, the child and the family in addressing diagnosis of imminent death. Recognise the need to withdraw unnecessary medications, and be able to advise colleagues

	Recognise that home is preferred place of death for most children in most families. Be familiar with services in locality (as below) and know how to make and expedite a referral. Have knowledge of how to access relevant funding (especially 'urgent continuing care' funds that allow support in the home).	and colleagues. Have knowledge of appropriate pathways and tools that optimise end of life care. Be able to set up and supervise continuous subcutaneous infusions, including appropriate drug combinations, doses and diluents. Be able to 'trouble-shoot', anticipating and identifying problems and being able to rectify them. Be able to identify and work with agencies (including social services, primary care and children's hospices) to facilitatea child to be in the preferred place of care. Be able to advocate for the family in providing letters and completing forms effectively.	sensitively in this respect. Recognise when to involve tertiary specialists in paediatric palliative medicine.
4	Be aware of the most recent evidence regarding compatibility and solubility of medications in a continuous subcutaneous infusion. Be aware of the most recent evidence regarding alternative routes of administration, particularly those that avoid pain or personal indignity.	Be able to teach effectively about the diagnosis and management of the dying phase in children. Be able to support colleagues, sometimes at a distance, in recognising that imminent death is likely to occur, and in managing the dying phase. Be able to anticipate specific likely symptoms and ensure appropriate medication is available by the appropriate route in good time. Be able to manage complex symptoms near time of death.	Understand need to develop services in a way that supports the child and family in dying at home where that is preferred, but also allows support in other locations, particularly hospice, hospital and school. Understand need to visit patients at home, school or hospice to facilitate care. Have an awareness of the balance between symptom control and sedation. Be able to explain this in ethical terms to parents, family and nursing team.

Technical 10. Practicalities around death

Level	Knowledge	Skills	Attitude
1	Have knowledge of the clinical features and essential examination for the diagnosis and confirmation of death.	Be able to confirm death. Be able to certify death. Be able to break bad news about a person having died.	Exhibit sensitivity and honesty in communication with the patient / family and MDT.
2	Have knowledge of the legal, ethical and practical issues surrounding death: -Difference between verification and certification of death - Completing the documentation for the disposal of the body, including cremation -The role and powers of the Coroner (Procurator fiscal in Scotland), when to refer and the processes they will follow -Moving a child after death -Organising a post mortem - Rules and regulation around retaining body parts by hospital -Practicalities for organ or tissue donation -DNAR (Do Not Attempt Resuscitation proforma) at home and how to communicate this to ambulance and out of hours services in the community -Disposal of controlled drugs. Have knowledge of the child death reporting process in country of work e.g. Child Death Overview Process in England.	Demonstrate good judgement in correctly recognising and anticipating transition into the dying phase.	Be aware of difficulties others may have in the recognition and acceptance of the dying phase.

3	Demonstrate knowledge of the final pathway of disease processes, prognostic indices and their application and limitations. Demonstrate broad knowledge of the needs of the dying child and family, in terms of culture and religion including issues relating to handling, burial and cremation.	Be able to exercise good judgement in formulating flexible management plans in relation to the chosen place of death. Be able to facilitate child and family's wishes with respect to rituals and practices around death. Communicate non-judgemental acceptance and professional comfort with cultural preferences of the child and family.	Demonstrate respect for the wishes of the dying child and family, and willingness to work with the MDT to meet their needs. Demonstrate sensitivity to the wishes of the child and family, recognise and respond to distress in others and in him/ herself, and use reflective practice. Be aware that death in LLC may still be 'unexpected' and need further investigation. Be able to support family and the MDT with this.
4	Understand the processes for moving a body abroad and transferring remains.	Be able to teach others about management of practicalities after death. Be able to support the wider team after a child has died. Be able to facilitate a supportive, constructive debrief process for the team.	

B. Interpersonal

Interpersonal 1. Communication skills with children and parents / carers

Level	Knowledge	Skills	Attitude
1	Understand theory of communication and be aware of factors influencing understanding and communication. Have knowledge of language and psychosocial developmental milestones in children. Have knowledge of non-verbal communication tools e.g. picture boards, Makaton, computer programmes. Know what is meant by collusion of parents and professionals, and how it can lead to withholding of information from child or young person. Have knowledge that children with disability are at increased risk of harm. Know that safeguarding is everyone's business, no matter how junior.	Be able to communicate appropriately with both parents and child. Use open and closed questions appropriately. Be able to take a comprehensive paediatric history collaborating information from the child, family and other sources. Be able to recognise and describe ideas, concerns and expectations of the child and family. Be able to engage with children in a relaxed manner, build relationships and gather information from the observation of play and other activities. Recognise collusion. Understand your role in safeguarding children and your duty to share concerns.	Be aware of the need to involve both the child and parents in appropriate communication regarding the condition and management options. Understand that communication with children needs to be opportunistic and facilitated within a safe environment. Be aware that children communicate by language, play and artistic expression. Recognise that collusion is undesirable and counterproductive. Be open to the possibility of safeguarding issues in discussions with and around the child and family.
2	Be aware of factors influencing understanding and communication, including developmental stage and education. Know risk factors for dysfunctional coping by the family. Know the developmental model of children's views of death and that their perceptions are based on	Demonstrate the use of empathic listening to facilitate appropriate open discussion with both the child and parents / carers. Be able to communicate appropriately with people with learning and communication difficulties. Be able to explain treatment, procedures and address questions at the child's level of	Recognise the importance of listening, rather than simply imparting information. Be aware that children who are ill may demonstrate apparent psychosocial developmental regression. Be aware that children have the right to information regarding themselves.

	developmental age and previous experience. Be aware of models of interpersonal communication and dynamics. Have knowledge of legal issues regarding confidentiality and consent as they relate to children and young people. Have knowledge of how to minimise risk of collusion at the time information is given to families. Have knowledge of the risk factors that can increase the vulnerability of children with LLC.	understanding. Be able appropriately to involve MDT to facilitate communication e.g. play specialist, therapists. Be able to discuss new information appropriately with the child and parents, in order to minimise risk of collusion developing. Have knowledge of the local safeguarding procedure for raising concerns and the importance of an individual's duty to share information and concerns. Recognise signs and symptoms that may require safeguarding investigations.	Recognise that collusion can transgress ethical and legal rights of a child or young person. Recognise the need to involve teams with advanced communication skills (e.g. palliative care team) with some families. Recognise that the child's welfare is of primary concern, even with LLC. Be aware of the need for a range of communication skills, and of the need for reflective practice and updating in order to maintain skills.
3	Have knowledge of factors influencing communication, including personal and organisational barriers to communication (e.g. time, tiredness, stress, language and cultural barriers, not valuing communication). Have understanding of transference and counter-transference. Have knowledge of the common family responses to the impending death of a child. Have knowledge of the impact of illness on the developmental model. Have knowledge ofthe practical risks of collusion jeopardising good palliative care. Have knowledge of the history, signs and symptoms that may raise safeguarding concerns.	Be able to empower children and families, involving both at appropriate levels in communication. Be able to share information and decision-making with the child and family to plan management as appropriate. Be able to demonstrate a range of styles of communication to: • Elicit concerns across physical, psychological and social areas • Establish extent of awareness of illness and prognosis • Impart information sensitively according to wishes and needs of the parents and child • Facilitate decision-making and promote autonomy • Be able to identify barriers to communication and strategies to overcome them. Be able to demonstrate skills in verbal and non-verbal communication:	Be aware of different techniques to aid expression in children e.g. music and art therapy, creative writing and fantasy. Be aware of siblings' need to communicate. Be aware that parents and carers may be reluctant to address difficult issues with the child.Be aware that children understand a great deal from inference even if not given information. Be able to deal with uncertainty and mistakes. Have awareness and the ability to recognise parental distress. Communicate effectively with parents in distress. Be sensitive to the extreme stresses families may be under, possible feelings of guilt, and not being able to cope with the situation. Be able to support families during safeguarding

		• Questioning and listening (including summarising and paraphrasing) • Seeking clarification, checking for understanding • Allowance for cultural aspects • Breaking bad news • Opening and closing consultations • Dealing with difficult questions • Conducting telephone interviews. Be able to listen to children, open dialogue and deliver information at a pace which suits them. Be able to "break bad news" to children of different ages appropriately. Be able to counsel parents and carers on how to deal with "difficult questions" from their children. Have strategies for understanding and dealing with requests from children or parents for euthanasia. Be able to apply ethical and legal principles to recognising and evaluating collusion. Be able to formulate communications strategies for undoing collusion sensitively when appropriate and also recognise when it is not appropriate to undo collusion. Be able to elucidate whether risk factors for safeguarding concerns are present; e.g. are carers coping, feeling stressed or angry?	investigations. Recognise the need for clear pathways.
4	Have knowledge of the current understanding and assessment tools to assess communication with children.	Be able to access resources for specialist therapies and provide information of this to other professionals.	Recognise that for some families collusion is part of the coping mechanism. Recognise the emotional burdens for the MDT

	Have undergone advanced communication skills training Have knowledge that interpretation of injuries in children with LLC can be complex, e.g. fractures with minimal trauma.	Be able to teach professionals about communicating with healthy and life-limited children. Be able to source relevantinformation and opinions to help conclude a safeguarding investigation.	during safeguarding proceedings, the need for support and clear pathways.

Interpersonal 2. Communication skills with professionals

Level	Knowledge	Skills	Attitude
1	Understand the basic structure and the working of a MDT.	Be able to communicate constructively in a MDT. Learn the skill of listening and actually hear what is being said.	Learn to value the views of all MDT members. Value other professionals, both within and outside medicine, as equal contributors to the care of a child with LLC.
2	Understand the importance of a key worker in the management of children with complex needs. Understand how teams work within other organisations such as education and social services. Understand structure and hierarchy of teams in primary care, hospital, hospice and community paediatrics.	Be able to chair or lead a MDT. Be able to contribute effectively to MDTs led by others. Be able to work within ethical and legal principles of confidentiality in clinical practice when discussing patients with other professionals. Use clear written communicationin records and lettersof clinical contact.	Appreciate the value of team working across settings of care, e.g. hospital, hospice, community, school and family practice. Appreciate the value of team working with other healthcare professionals (OT, physiotherapy, etc.) and agencies (education and social services). Have acceptance that non-medical members of the MDT may be more appropriate to lead a team. Understand the need to avoid appearing to criticise other professionals in written or verbal communications. Understand and be sensitive to the perception of ‘ownership’ of patients among other professionals.
3	Have an understanding of team dynamics, stages of development in a team, why teams fail and how this can be avoided	Be able to coordinate all the different services and thus provide holistic care to the child and family. Be able to give clear written advice and recommendations to other professionals in clinical letters or medical notes. This should include unambiguous immediate recommendations,	Be aware of the need to act as an advocate for the best interests of a child, where necessary amongst other professionals. Recognise that other professionals may also believe they are advocating for the best interests of the child whilst holding differing

		suggestions and reasoning for alternatives, plans for future review and other possible interventions. Be able to give encouragement (including positive feedback) to other professionals in the palliative care of children with LLC. Be able to manage cross-cultural communication. Be able to facilitate support for staff.	views. Be prepared to negotiate and compromise where necessary. Recognise when to offer to take over as lead clinician in the care of a family and when to share care. Recognise the emotions and emotional needs of team members and when these may affect the team working. Recognise the stress staff may feel during safeguarding investigations.
4	Be able to set up effective communication systems in and between teams.	Be able to take a failing team, assess the reasons for this and take appropriate measures to rescue the team. Be able to manage appraisals, career profiling, staff interviews.	Recognise the need for developing appropriate support for the team and its members.

Interpersonal 3. Spiritual issues

i) Religion and ritual

Level	Knowledge	Skills	Attitude
1	Have knowledge of the difference between religion and spirituality. Have knowledge of a definition of religion (e.g. a particular system of faith and worship). Have knowledge of the role of chaplains and pastoral carers.	Be able to anticipate and identify religious and ritualistic needs of families with children withLLC.	Be aware that families who do not follow a particular religion still have spiritual needs. Appreciate that families approach death and dying through varied belief systems and rituals. Be aware of the implications of yourown faith, especially in relation to death and bereavement. Be aware of the impact of palliative care work on yourown faith.
2	Have a basic knowledge of the issues of last rites and particular funeral practises of common religions e.g. Christianity, Judaism, Islam, Hinduism, Sikhism, Buddhism.	Be able to access a pastoral carer within yourplace of practice.	Be aware that within the same religious group interpretation and practice can vary. Be aware that families may be unfamiliar with the expressed religious rituals at end of life in relation to their own faith.
3	Have basic knowledge of attitudes to life and death, festivals, modesty rules and food restrictions (including fasting periods) for the main faiths e.g. Islam, Judaism, Christianity, Sikhism, Hinduism and Buddhism.	Be able to formulate an individual spiritual needs care plan for the LLC patient and family. Be aware of how religious and spiritual context may affect interpretation of illness, decision-making and priorities for a child with LLC. Be able to access information about religious practises and rituals. Be able to access local faith leaders.	Be aware of how a child and family members may be both helped and/or challenged by aspects of their religious faith. Be aware of actual and potential conflict within families concerning religious beliefs and practices.

		Be able to organise staff support addressing religious and spiritual aspects of PPCin yourworkplace.	
4	Have knowledge of current research in this area of PPC e.g. religious orientation scales, inter-relationship between religion, ritual and symptom management in LLC and families.	Be able to teach colleagues and trainees about religious and spiritual issues in PPC.	

ii) Existential and spiritual aspects (including guilt, anger, sadness)

Level	Knowledge	Skills	Attitude
1	Understand the impact of faith (including atheism) and religion on spiritual/existential issues. Understand that guilt, anger and sadness can be an expression of spiritual / existential issues.		
2	Know what appropriate professional resources are available locally to support patients and families experiencing guilt, anger or sadness.	Be able to recognise the potential for guilt, anger and sadness to occur among families and children with LLC. Be able to identify guilt, anger and sadness in specific individuals and families. Be able to explore guilt, sadness and anger with individuals and families when necessary and appropriate.	Understand the importance of addressing spiritual/existential issues in palliative care. Recognise when to involve senior or specialist colleagues. Recognise the limitations of your own ability to evaluate and intervene.

3	Know risk factors for harmful or abnormal responses to stress, conflict and loss. Be aware of theories of spiritual development. Be aware of tools for spiritual assessment.	Have good basic communication skills Be able to recognise cues, make holistic assessment and sensitively explore issues of guilt, sadness and anger in the child and family. Be able to accompany children with LLC and their family members, as they grapple with unanswerable questions and search for meaning. Be able to distinguish between sadness, guilt and anger which are part of a *normal* response to loss or LLC, and responses, including depression, which are *pathological* or harmful. Be able to initiate appropriate support for the team caring for a child or family member experiencing prolonged guilt, sadness, distress or anger. Be able to anticipate likely issues of guilt, sadness and anger among families in discussion with consultant colleagues.	Know when to involve specialist support services such as counsellors, psychologists or representatives of a faith community. Recognise that some issues will remain unanswered. Be aware of the impact on the health care team of caring for a child or family experiencing significant guilt, sadness or anger. Make appropriate referrals to other professionals including spiritual carers and representatives of relevant faith communities.
4	Understand tools for spiritual assessment for children and adults. Understand theories of spiritual development.	Be able to anticipate and manage impact on staff in caring for a child or family experiencing significant guilt, sadness or anger. Be able to teach communication skills that facilitate recognition and sensitive handling of these issues in others working with children.	

Interpersonal 4. Bereavement

Level	Knowledge	Skills	Attitude
1	Understand general concepts of loss, grief and mourning. Understand basic theories about bereavement: - process of grieving - adjustment to loss	Be able to support a bereaved adult. Have demonstrable listening skills.	Have awareness of significant personal losses and their effect. Be able to recognise the need for personal support and access it as appropriate.
2	Understand physical, psychological, social and spiritual dimensions of grief. Be aware of theoretical models of grief (Bowlby's attachment theory, Parkes' phases of grief, Worden's tasks of grieving). Understand children's attitudes and responses to both death and bereavement and how they change with developmental age. Beaware of the particular needs of bereaved children, and of parents whose children have died. Know about helping factors and resources for bereavement support (written, telephone, face to face, for children and adults). Be aware of factors influencing how a family and its members mourn the death of a child. Understand risk factors for adverse outcomes of bereavement.	Be able to help prepare a child and family for bereavement (carers, spouse, siblings, parent, grandparents, index child). Be able to support a bereaved individual (child or adult). Be able to recognise multiple losses, anticipated and actual, and their impact. Be able to identify, advise about and access appropriate bereavement support services for children and families. Be able to risk assess a child, family or carer for vulnerability to dysfunctional grieving. Be able to anticipate and identify abnormal, prolonged and complicated grief in children and adults. Know how to access support in complicated grief.	Be aware of the importance of bereavement care. Adopt an empathic and proactive approach.

3	Be aware of practical modelsof grief (e.g. Dual Process model, Continuing Bonds, Growing around grief).	Be able to recognise an individual member of staff who is grieving and facilitate their obtaining appropriate support.	Be aware of the impact of multiple bereavements on staff.
4	Know about the epidemiological and resource aspects of bereavement. Know about the impact of multiple bereavements on staff and ways to address them.	Be able to anticipate and recognise staff need for bereavement support. Be able to facilitate the availability and accessibility of such support. Be able to anticipate and manage the implications of bereavement for the work of an individual and the team.	

Interpersonal 5. Teaching

Level	Knowledge	Skills	Attitude
1	Be aware of a range of different approaches for effective teaching in clinical practice.	Develop and apply a basic knowledge of teaching skills and learning styles Observe in-house teaching programmes.	Be willing to contribute to teaching. Recognise the importance of teaching to share knowledge and improve patient care.
2	Understand principles of continuous professional development, life-long learning, learning styles, reflective practice and effective teaching.	Be able to apply principles of life-long learning. Develop a range of teaching skills. Participate in in-house teaching programmes.	Be aware of the value of constructive feedback for professional development for self and learners.
3	Have knowledge of different teaching and assessment methods and when to use them to enhance learning in PPC. Have knowledge of appraisal and mentoring. Have knowledge of the role of the Royal Colleges in monitoring training. Have knowledge of the organisation of medical training as applied to PPC and related specialties. Know the principles of formative and summative assessment.	Be able to facilitate a positive and open learning culture. Be able to offer constructive and supportive appraisal, feedback, professional development advice, performance review and clinical supervision. Be able to apply a variety of assessment methods appropriately, including OSCE (Observed Structured Clinical Examination), modified essay questions, observed cases, project reports and case studies to assess learners in PPC. Be able to review progress, give and receive constructive feedback, and support others in handling uncertainty. Be able to assess training and learning needs of the team and select and employ appropriate	Facilitate an environment of mutual respect, sharing and valuing knowledge and expertise. Demonstrate integrity, objectivity, respect and empathy in carrying out appraisals, assessments and supervision. Demonstrate a learner-centred approach to teaching. Display enthusiasm and commitment for both teaching and learning. Support learners encountering the unexpected, uncertain and unknown in PPC.

		teaching and learning methods for the context and individuals. Be an effective and competent teacher, with good verbal and non-verbal presentation skills. Be able to teach PPC to others within the multidisciplinary team, using a variety of methods appropriate to the context including large and small group teaching, problem-based learning, role play, bedside teaching. Design and use evaluation forms appropriately. Be able to encourage and train others in skills and styles of adult learning, CPD, reflective practice.	
4	Have knowledge of the curriculum and scope of PPC and of sources of information and training within the subspecialty. Have knowledge of the organisation and content of training for professional groups working in PPC.	Be able to devise, deliver and evaluate a suitable teaching programme to cover the PPC curriculum at a level appropriate to the learner. Be able to develop better access to PPM education to disseminate knowledge to a wider audience, including medical, nursing, allied health professionals, social work, and education teams, as well as to parents. Be able to pitch teaching at the optimal level to allow learning by different groups.	Be committed to the effective teaching of PPC to multi-disciplinary professionals, students and families to enhance the standard of care given to children with LLC. Be committed to the wider development of the specialty through education.

Interpersonal 6. Research

Level	Knowledge	Skills	Attitude
1	Understand the importance of research and how it translates into clinical practice.	Be able to do an effective literature search.	
2	Know how to critically review scientific papers.	Undertake research based learning.	
3	Understand the requirement to develop an evidence base to inform practice. Understand the basic principles of research design.	Work collaboratively to facilitate research.	Have a willingness to support and participate in research projects.
4	Identify evidence gaps and promote discussion of them with the research community.	Initiate collaboration and work to build research capability that can be integrated into clinical practice.	Promote the importance of robust evidence to increase understanding and inform practice. Support work that helps understand and tackle the barriers to evidence based practice, including how to make evidence accessible to practitioners.

Interpersonal 7. Models of paediatric palliative care

Level	Knowledge	Skills	Attitude
1	Have knowledge of the Together for Short Lives (TfSL) definition of PPC. .		Appreciate that all models offer a child and family-centred approach to PPC. Be aware of variability of access to services in the UK and worldwide.
2	Have knowledge of the TfSL groups of LLC. Have basic knowledge of different models of PPC and their inter-relationship: hospital-based specialist services, home/community based service, children's hospice movement. Have knowledge of the main similarities and differences between adult and children's palliative care services e.g. smaller numbers, greater emphasis on non-malignant disease, narrower evidence-base, different pharmacology and communication issues with children. However both have a similar MDT approach and need for symptom control expertise. Have knowledge of the concept of key-working.	Be able to access general and specialist PPC services. Be able to identify changing long-term needs in LLC. e.g. symptom management, respite and educational needs.	
3	Have knowledge of the development of PPC in the UKand worldwide. Have knowledge of the range of local models of care which children with LLC may utilise e.g. community nursing teams, outreach services and children's hospices.	Be able to lead a MDT in planning and providing palliative care for a child with LLC in the local area. Be able to access specialist support where necessary. Be able to organise clinical supervision and support	Appreciate the barriers to multi-disciplinary and multi-professional working. Have a collaborative, interdisciplinary, empowering and enabling approach - valuing the contributions of others.

	Have knowledge of voluntary organisations which support PPC services. Have knowledge of the advantages and disadvantages of the various models of care. Have an awareness of national and international directives, frameworks and guidelines which govern the development of PPC services. Have an awareness of the currently changing landscape in PPC.	for the local PPC team. Be able to initiate and support regular audit and contribute to research projects.	
4	Have detailed knowledge of current local, national and international policy in PPC service development.	Be able to initiate a new and/ or innovative PPC service. Be able to network and pool knowledge to promote further service development. Be able to teach about models of PPC. Be able to facilitate in ethical issues.	Be committed to the wider development of the sub-speciality and its evidence base.

C. Intrapersonal

Intrapersonal 1. Coping skills

Level	Knowledge	Skills	Attitude
1	Be aware that the field of PPM can be very challenging at personal and professional levels. Know that advice should usually be sought when undertaking any work in the field of PPM.	Take steps to foster strengths and address weaknesses. Take active steps to balance work and other aspects of life. Begin to develop a reflective diary, including some record of how the practitioner is feeling.	Be aware of your own strengths and weaknesses. Be open to discussion about differing ways in which situations may be handled. Recognise the need to balance work and life, and to balance patient needs with the needs of the doctor.
2	Be aware of personal and professional knowledge, skills and attributes required for effective practice of children's palliative care. Have knowledge of personal beliefs and attitudes and their impact on the team. Be aware of ways staff support can be offered / coordinated, including case discussion, clinical supervision, structured and informal personal / group support. Be aware of patterns of difficulty in the doctor-patient relationship. Demonstrate knowledge of time management principles to enable efficient fulfilment of role.	Be able to work with personal feelings around advancing disease and death, and the impact this work has on the practitioner and his/ her family. Be able to recognise, reflect on and deal with conflicts of belief and values within the team. Be able to recognise and manage yourown personality, reactions and emotions constructively in relation to self, patients and colleagues. Be able to manage anger. Be able to receive criticism constructively. Be able to manage uncertainty, and the unexpected, make difficult decisions and multitask. Be able to ask for help and hand over to others appropriately.	Be aware of personal perceptions, expectations and values around advancing disease and death. Recognise how personal values and belief systems influence professional judgements and behaviours. Demonstrate respect for attitudes and beliefs of others, tolerance and flexibility. Be aware of own skills and limitations and the effects of personal loss or difficulties. Demonstrate self-awareness and insight. Be aware of the needs to set appropriate limits and boundaries and the need to maintain appropriate work-life balance. Demonstrate sensitivity to needs of professional

		Consider stress, mental ill health and burnout in self and other professionals. Be able to use a range of methods to receive support from, and offer support to, colleagues. Be able to recognise and deal competently with potential sources of difficulty (including over-involvement, personal identification, negative feelings, personality clashes and demands which cannot be met). Demonstrate effective time management and the ability to prioritise effectively.	colleagues. Have a non-judgemental attitude. Be able to reflect on time management and be open to suggestions for improvement.
3	Have knowledge of epidemiology, causes and manifestations of work-related psychopathology in carers, and the support systems available. Understand the concept of resilience. Have knowledge of personality types and their associated strengths and vulnerabilities.	Learn strategies for developing and strengthening personal resilience. Recognise other professionals at risk or in difficulty, understanding when and how to take action in the interests of the individual and of patient care. Recognise difficulties within the team regarding prioritising and time and task management. Be able to recognise stress, mental ill health and burnout in self and other professionals. Be able to offer creative and constructive support and coaching. Assess personal and team member safety when conducting visits in the community.	Be aware of the dangers of burnout and compassion fatigue, particularly in palliative medicine but also in other related disciplines of medicine. Be aware of own personality type, its strengths, vulnerabilities and effects on others.
4		Be able to encourage and educate others to recognise and act appropriately when difficulties and conflicts arise.	Lead by example and facilitate a culture of openness, awareness, trust, support and appropriate boundaries in developing services and teams.

Intrapersonal 2. Learning

Level	Knowledge	Skills	Attitude
1	Have knowledge of principles of evidence-based medicine, database searching and critical appraisal. Understand the importance of ongoing learning through Continuing Professional Development in the career of a doctor. Understand principles of adult learning and reflective practice. Understand the range of sources of knowledge to inform clinical decision-making in PPC including reviews, research studies, national and local guidelines, IT and Internet, colleagues, patients and their family / carers.	Be able to critically appraise qualitative and quantitative literature relevant to PPC. Be able to ask a focused question, perform a search to answer it, and know how to apply findings to clinical practice. Be able to direct and plan yourown continuing education appropriately, planning learning aims, objectives, methods and outcomes, in order to practise in a safe, competent, contemporary way. Be able to access a range of information sources appropriately.	Actively seek to apply the best available evidence to clinical practice and encourage others to do so. Be aware of yourown limitations in knowledge and skills, and be willing to seek advice. Adopt a reflective adult learning approach. Be aware of the strengths and weaknesses of each source of knowledge. Show interest when encountering new situations and apply this to self-directed learning.
2	Demonstrate knowledge of assessment, appraisal, supervision, mentoring, learning contracts and feedback in relation to practice in PPC. Consistently demonstrate knowledge of CPD, skills of adult learning and roles and responsibilities of trainee / trainer to ensure self-directed learning and to maintain safe, competent and contemporary practice.	Demonstrate the ability to review progress and engage in appraisal effectively. Demonstrate reflective practice; reflect on personal learning style, assessyour own professional development needs in PPC and set appropriate developmental objectives. Be able to select and engage in a variety of learning methods appropriate to meet the learning need and preferred learning style (e.g. reading, lectures, tutorials, seminars and courses, internet, clinical supervision, case analysis, significant event analysis, video and role play, reflective practice, audit).	Be able to accept and act on feedback. Show eagerness to reflect on own practice to improve skills and knowledge. Demonstrate commitment to CPD and lifelong learning.

		Be able to access local and global sources of advice and information in PPC	
3	Demonstrate specific knowledge of the range of specialised sources of information and advice to inform day to day PPC practice (e.g.Together for Short Lives, Association for Paediatric Palliative Medicine, PaedPallLit, Internet sites, relevant specialist reference publications, individual consultants).	Be able to facilitate a positive and open learning culture. Be able to assess training and learning needs of the team and select the most appropriate methods for the context. Be able to encourage and train others in skills and styles of adult learning, CPD, reflective practice, lifelong learning. Be able to apply adult learning principles to unfamiliar situations encountered in PPC.	Facilitate an environment of mutual respect, sharing and valuing knowledge and expertise. Display enthusiasm and ongoing commitment to both teaching and learning.
4	Have knowledge of the curriculum and scope of PPC and of sources of information and training within the subspecialty. Have a thorough knowledge of the organisation and content of training for professional groups working in PPC.		