

A Framework of Competences

for Level 3 Training in Paediatric Palliative Medicine

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FOREWORD

I am very pleased to present this competency framework for the new sub-specialty of Palliative Care Medicine. This adds to the preceding frameworks we have published for Level 3 training, which build on the competency frameworks for Levels 1 and 2. The emphasis is firmly on the achievement of competences and not on a time-based training programme. From August 2007 all trainees entered specialty training within the framework outlined in the Modernising Medical Careers initiative. Achievement of these competences will determine a trainee's progress through the specialty training programme.

The development of this Level 3 framework, together with our other sub-specialty curricula, represents a huge amount of work. I would like to thank all those who have shown their commitment and support to this project.

In particular, we would like to thank Dr Richard Hain and other members of the working group and the sub-specialty who dedicated time to assisting with this. We would also like to thank Dr Edward Wozniak and Dr Gabrielle Laing, Chairs of General Paediatrics and Community Child Health CSACs respectively, who have been involved in the development of the competences at all three levels. Also Dr Mary McGraw and Dr Ian Doughty, the College Officers responsible for training, who have guided and supported this work unstintingly for their commitment and involvement in the project. In addition, we would like to thank Kim Brown for the initial development and co-ordination of this work.

These documents have been prepared for submission to PMETB in February 2008 and we hope to publish them, subject to their approval, by summer 2008.

Patricia Hamilton
President, Royal College of Paediatrics and Child Health 2007

Section 1 Introduction

Who is this book for?

It is for doctors at Level 3 in their training in Paediatric Palliative Medicine, their tutors and educational supervisors.

Why do I need it?

The book gives you and your tutors guidance about the areas you need to cover during your training. It gives a clear picture of what you have to have achieved by the end of this stage of training, before you become a consultant. You need this book as it forms the basis of your assessment at the end of Level 3 Training.

How do I use the book?

You can sit down with the book on your own and use it to help you identify areas of practice that you need to work on and those areas in which you feel fairly confident. You can talk to your tutor about the balance of your experiences and look for ways to ensure that you cover all the areas you need to.

Progression

This is the final stage in your training as a paediatrician. The competences you gained during Level 1 (Basic Specialist Training) and Level 2, Core Higher Specialist Training have formed the basis for your progression into Level 3 training and on to a Consultant post. Table 1 (page 10) illustrates this progression through your training.

A note about the format of this document

This framework sets out the competences that you need to achieve by the end of Level 3 Training. These build on and develop statements of competence set out for Levels 2 and 3. You are expected to work from all three documents throughout this final stage of your training to ensure that you maintain and continue to develop areas of competence already acquired as well as developing new ones.

Sections 2 and 3 present new statements of competence for Level 3 only, in order to keep the focus clear. Trainees will need to refer back to previous documents for Level 1 and 2 competences in General and General Clinical competences

A note about assessment

The statements in this book have been expressed as *learning objectives*. These are the focus of your training.

When it comes to your assessment, at the end of this phase of your training, we will want to know how *well* you have achieved these objectives and to be confident that you are fit to practise as a Paediatric Consultant. This is what we mean when we talk about your *competence*. So while here you may have, for example, a number of detailed objectives relating to consultation skills or communicating with children, in your assessment we will want to see how you bring all these together and how competent you are overall in your communication skills. This document is not intended as an assessment document but to support training. The assessment of your competence will be by work-based assessments already in use and currently being developed.

Working group:

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Progression in the Professional Development of a Paediatrician

During Level 1	During Levels 2 and 3	Continuing development as a consultant
Acquires fundamental knowledge base	Applies knowledge base to provide appropriate clinical care	Evaluates knowledge and modifies clinical care pathways to enhance patient care
Acquires clinical examination and assessment skills and applies these in clinical practice	Analyses clinical findings to derive appropriate differential diagnosis and management plans	Evaluates assessment findings; refines and modifies management plans
Acquires all basic technical skills and basic life support	Proficient at all basic technical procedures, some complex procedures and provides advanced life support	May relinquish some skills in these areas dependent on area of clinical practice. May acquire specialty specific skills
Performs allocated tasks and begins to plan tasks	Plans and prioritises tasks appropriately	Increasing expertise with evaluation of priorities and appropriate delegation across a wide range of professionals
Performs allotted teaching tasks	Plans and delivers teaching to trainees and other professionals. Develops peer mentoring skills	Plans and modifies curricula. Performs assessment and appraisal. Able to provide mentorship
Aware of management issues	Develops management skills and able to take responsibility for a defined project. Contributes to Committees	Can negotiate and deal with conflict. Can contribute to and lead committees. Evaluates and modifies management structures
Performs allocated audit projects and understands the audit cycle	Designs audit project and understands risk management. Able to write appropriate clinical guidelines. Understands the Clinical Governance implications	Facilitates audit, and evaluates results. Evaluates guidelines and ensures implementation of appropriate changes
Understands the principles of critical appraisal and research methodology	Able to appraise the literature critically and apply to clinical practice	Able to evaluate critical appraisal performed by others. Able to lead research projects and support others in research
Works in multi-professional team	Able to take the lead and accept leadership from other members of the multi-disciplinary team	Evaluates and modifies multi-professional team-working

What is a Paediatrician?

Paediatricians have a detailed knowledge and understanding of diseases in children. They are skilled in looking at health and ill-health in babies, children and adolescents, and at specific health issues, diseases and disorders related to these stages of growth and development. They develop expertise in practical procedures specifically related to the good clinical care of small babies and children. Paediatricians work in multi-disciplinary teams and with colleagues from a wide range of professional groups in hospitals, general practice and in the community, in social services and schools and with the voluntary sector. They have strong communication and interpersonal skills and take on a variety of roles within their different communities of practice. They share expertise effectively and assume the responsibilities of teaching, leadership and management roles where appropriate. They work with colleagues to ensure consistency and continuity in the treatment and care of children and young people in all aspects of their well-being. They are committed to a policy of advocacy for a healthy lifestyle in children and young people and for the protection of their rights.

Paediatricians are doctors who have a particular compassion and respect for children, young people and their families and enjoy working with them. They have an expert understanding of the ways in which illness affects the child, the parents and the rest of the family and are skilled in the management of emotionally complex family situations. They show patience and sensitivity in their communications with children and their families and a particular ability to explore each individual's perspectives of a problem. They are aware of religious and cultural beliefs that parents might hold about the treatment of their children. They know how to respond in these cases, when to seek support and where to find legal and ethical guidelines to support their practice.

Paediatricians ensure that they are up-to-date in their practice and endeavour to promote evidence-based medicine where possible. They are keen to develop innovative approaches to teaching in paediatrics and to research. They are committed to the highest standards of care and of ethical and professional behaviour within their specialty and within the medical profession as a whole. Central to their work is the principle that all decisions should be made in the best interests of the child or young person in their care.

Contexts for Learning

In drawing up this framework of competences, we have envisaged a wide range of opportunities in which trainees will learn. They will be expected to work on their own, using databases and electronic libraries to research particular conditions or areas of professional practice. This work might be in preparation for a clinic, or a presentation to a group of trainees and supervisors. Trainees may engage with a distance-learning programme in order to develop greater expertise in an area that interests them or that they need to strengthen. Supervisors will need to ensure opportunities for trainees who have undertaken independent study of this kind to share their learning with others. It is through teaching about something you have read or learned or understood differently that learning is consolidated and questioned.

Feedback is essential at all stages of the teaching and learning process. Even in the course of a lecture or on a ward round trainees can communicate important messages about their learning needs through facial expressions and body language as well as in their answers to questions. Tutors need to be ready to pick up on these, to seek out actively trainees' responses to their teaching so that they can make adjustments accordingly and ensure that effective learning takes place.

As well as independent study, trainees will find themselves in a number of different communities of practice. In many cases, their learning will result from shared discussion around the diagnosis of a condition, for example, or the identification of an injury. Experienced colleagues from a range of disciplines may join a specialist team, each sharing their expertise, in order to come to a safe diagnosis or decision about how to proceed, for example in the case of suspected abuse. Trainees need to be encouraged to join these discussions so that they develop confidence in their communication skills with colleagues and in their ability to contribute to clinical decision-making.

Supervisors need to be aware of the importance of asking questions in these situations and of the most effective way to do this, so that trainees are fully engaged and learning as they listen. Closed and open questions have their place, and explicit educational strategies such as 'scaffolding' are essential. The teacher takes the learners, step by step, from their initial level of understanding of a condition or a process, for example, to a deeper or more extensive understanding, through a formal cycle of informing, questioning, informing, testing out and

consolidating new information. Ward rounds and clinics offer good opportunities for this kind of interaction, with individual trainees and groups. The exchange may be brief or sustained and it is the close focus on understanding which gives this teaching technique its power. Trainees are also encouraged to write a reflective log and it is important to make clear that this needs to go beyond a narrative of events to an analysis of the process of learning they are experiencing. This, in turn, will equip them well to become teachers themselves of less experienced colleagues.

The college is committed to an explicit educational approach. Identifying contexts for learning is the first step. But it is important to go beyond this to a consideration of the way in which different contexts influence the teaching and learning that take place or that are required. It is helpful to be able to identify apprenticeship models, or experiential learning but these alone do not tell us much about the teaching and learning process. The curriculum sets out *what* is to be learned and we know *where* these things will be learned. But it is also essential to understand *how* teachers and trainees will learn.

With the completion of the curriculum, the college is now working on resources to support the teaching and learning of its contents and on guidance for trainees and supervisors on the pedagogical process of training in Paediatrics.

For an overview of teaching and learning in postgraduate medicine, see *Liberating Learning* (COPMED, 2002).

Section 2 General Competences

Knowledge and Understanding

Substantial re-wording or new statements of competence for Level 3 Training

- understand the value and limitations of evidence-based medicine
- be familiar with the theory, evidence-base and potential risks associated with common complementary therapies
- understand the impact of physical illness on mental functioning, for both children, young people and their parents and the effect of each upon the behaviour and functioning of the other
- understand the impact of relations and mental health upon a child's or young person's current and past emotions and behaviour
- understand the impact of culture and ethnicity in presentations of physical and psychological conditions
- know, understand and be able to compare and contrast medical and social models of disability
- understand the relationship between local health, educational and social service provision
- know about the agencies, both statutory and voluntary, that can provide general and condition-specific support to children, adolescents and their families in coping with their health problems
- know the objectives of paediatric follow-up
- understand and take account in their practice of risk issues to themselves and others, including those related to personal interactions, and bio-hazards
- have a working knowledge of risk assessment and its application to personal, professional, clinical and organizational practice
- understand and take account in their practice of measures to reduce clinical risk
- know how relative and absolute risks are derived and the meaning of the terms predictive value, sensitivity and specificity in relation to diagnostic tests
- know the legal and ethical guidelines to support their work, management and challenges and where to find more information when required
- be aware of the multidisciplinary investigation of sudden unexpected death in infancy
- understand the management of bereavement and be aware of national guidance documents on this
- understand the purpose of post-mortem examinations and know about procedures
- understand the process of bereavement in children and families and recognise abnormal grieving patterns

Competences specific to the specialty

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

- be able to balance burden and benefit when considering any therapeutic palliative intervention, only proceeding with an intervention if it can be reasonably supposed it will do more good than harm
- demonstrate understanding of the importance of a rational approach to palliative management of children, that it should be evidence-based where there is such evidence, and empirical where necessary
- demonstrate understanding of 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, and recognition of medical skills in colleagues who are not doctors, particularly nurses
- demonstrate understanding of the importance of exploring an individual family's priorities and of negotiating achievable goals, rather than assuming perfect control is the only acceptable outcome
- know about current local, national and international policy in Paediatric Palliative medicine service development
- know about the advantages and disadvantages of various models of care
- understand the importance and limitations of therapeutic approaches based on published evidence alone
- know about and be able to work with the specific organisational structures commonly needed in the holistic support of children with life-limiting conditions
- know about the importance of establishing close links with relevant support services, including child and adolescent psychiatric services, counselling and support groups
- know about new approaches in the management of conditions and of difficult and intractable symptoms common in paediatric palliative medicine, such as emergencies, seizures, spasm and pain
- know how to obtain advice through the paediatric palliative medicine community
- recognise the need to minimise hospital admission
- understand the value of music, art and play therapy services
- understand the impact of anxieties about death, hidden or overt, among professionals, patients and families and how these might affect the multi-disciplinary team
- understand common family responses to the impending death of a child
- understand specific issues in bereavement, including a family's loss of the child they once knew, as well as issues related to death
- understand the need for urgent genetic counselling when certain life-limiting conditions are discovered in a family.

- know about the epidemiological and resource aspects of bereavement
- know about the impact of multiple bereavements on staff, recognize where help might be needed by an individual or the team and facilitate support where appropriate

(see Good Medical Practice (GMC, 2001, 2006) - *Good Clinical Care: 2, 3; Delegation and Referral: 45, 46.*)

Skills

Substantial re-wording or new statements of competence for Level 3 Training

- recognise the breadth of different presentations of common disorders
- recognise features of undifferentiated illness which suggest serious or unusual pathology and initiate the appropriate clinical response with appropriate urgency
- recognise the diseases and host characteristics which make certain presentations life-threatening and manage these situations with vigilance and appropriate urgency
- be able to recognise when both physical and psychological problems are present and when more than one condition or disorder may be present
- be able to assess and manage co-morbidities associated with the range of paediatric presentations

- take a history from a child, young person and parent of the presenting difficulties to acquire information in sufficient breadth and depth in a range of possible symptom areas to allow accurate formulation of the problem
- be able to undertake an assessment of the mental state of children and young people, taking into account their age and stage of development and know whether they have the skills to help them and when to seek more expert paediatric, mental health or psychiatric assessment
- have developed observation skills to support their interpretation of children's or young people's developmental levels and possible physical signs when they are unable to co-operate with formal assessments
- be able to supplement clinical assessment with standardised instruments or questionnaires
- know when to gather information from other professionals eg those working in education, social work or from others who see the child in a variety of settings
- be able to seek the views of children and young people, whatever their illness, regarding individual care and service planning, using expert resources appropriately

- be able to make a decision on the ‘most likely’ diagnosis and discuss this effectively with children and young people and their parents or carers, and with other colleagues, in the context of a plan of investigation and management
- be able to formulate a management plan for complex cases
- be able to review and modify a management plan as appropriate and know when to request help from senior colleagues or other services
- be able to take responsibility for the longer-term management of common acute and chronic cases leading or working with the multi-disciplinary and multi-agency teams, sub-specialists or networks as appropriate
- have developed expertise in practical procedures specifically related to the clinical care of small babies and children, and young people
- be able to develop and work within care pathways
- be able to manage and know how to obtain support for the consequences of chronic illness for a child, young person and their family

- be able to work effectively in multi-disciplinary teams and with colleagues from a wide range of professional groups
- be able to interact effectively with professionals in other disciplines and agencies and from the voluntary sector
- be aware of their role in the team and of their impact in the team
- have developed skills in recording consultations accurately and sensitively whilst maintaining a good rapport with the young person and family
- have developed a wide range of effective age-appropriate communication skills specific to their work with babies, children, young people and their families
- have developed credibility in their relationships with children, young people and their families, and with colleagues through their knowledge and skills and experience in clinical practice and in their ability to work independently
- have developed strategies to manage a child’s or young person’s anxiety and personal anxieties
- have developed basic behavioural management skills with parents, children and young people and with other professional colleagues
- be able to recognise, acknowledge and manage different levels of parental anxiety
- be able to assess patterns of relationships and functioning within a family and how these might impact on a child’s or young person’s illness, seeking professional advice where appropriate
- have developed effective skills in the management of emotionally complex family situations

- be able to recognise indicators of stress or mental health problems in family members and communicate appropriately with relevant professionals
- be able to remain calm in stressful or high-pressure situations and take a timely, rational approach to the problem
- be able to approach new situations which require good clinical judgement with an analytic and informed approach
- show confidence and independence in decision-making in the care of patients
- be able to apply effectively to their practice the knowledge and understanding acquired during training
- have developed a reflective approach to their practice, with an awareness of their level of expertise and limitations and their development needs
- show an ability to learn from their previous good practice, and from clinical errors
- be able to practise evidence-based medicine and understand and analyse critically its limits
- be able to understand the limitations of guidelines, how to use guidelines effectively and when it is appropriate to work outside guidelines
- have skills in managing perceptions of presenting complaints and illness
- have developed skills in maintaining appropriate confidentiality in relation to the social situation of the child
- be able to discuss an assessment of the psychosocial health of a child or young person with the multi-disciplinary team while respecting patient confidentiality

Competences specific to the specialty

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

- be able to apply the principle of balancing burden and benefit in considering practical interventions in children with life-limiting conditions, taking into consideration physical, spiritual, social, psychological and emotional issues
- be able to evaluate critically new pain scales
- be able to facilitate the implementation of new pain scales where appropriate
- be willing to consider novel techniques for pain assessment when conventional knowledge is inadequate
- be able to recognise 'total pain'
- be able to facilitate planning for end-of-life care
- be able to work with his/her own feelings around advancing disease and death, and understand the impact this work has on the practitioner and his/ her family
- be able to recognise and manage constructively emotional reactions and responses, and relationships with patients and colleagues

- be able to recognise, reflect on and deal with conflicts of belief and values within the team
- be able to ask for help and hand over to others appropriately
- be able to use a range of methods to receive support from, and give support to colleagues
- recognise the need to balance work and their personal life, and to balance patients' needs with the needs of the doctor

(See Good Medical Practice (GMC, 2001, 2006) - Good Clinical Care: 2, 3; Maintaining Trust: 19; Working with Colleagues 34, 36; Probity: 50.)

Values and Attitudes

Substantial re-wording or new statements of competence for Level 3 Training

- be committed to a policy of advocacy for a healthy lifestyle in children and young people and for the protection of their rights
- understand national and contribute to local initiatives aimed at reducing inequalities in child health and well-being
- practise with compassion and respect for children, young people and their families and act as a role model for others
- adopt an open-minded approach to equality and diversity in their practice
- be aware of the effects of social, cultural and religious context and conflict upon families
- understand the importance of cultural diversity and the difficulties where religious and cultural beliefs that parents might hold about the treatment of their children are in conflict with good medical practice and know when legal and ethical guidelines will support your management or view of the situation
- have developed strategies to manage relationships where health-care beliefs might cause conflict
- be able to advise patients appropriately on debates and controversies in health care
- be sensitive to the effects of stigma on children and families in relation to medical conditions

- be able to work effectively with children, young people and parents or carers, to agree and help them follow management plans
- be able to work effectively with young people who may have or may develop health care beliefs which are in conflict with those of parents or professionals, and know when legal and ethical guidelines will support your management or challenge of the situation
- be able to accept complex and difficult challenges

- show an understanding of the importance of ensuring a healthy balance between professional and domestic priorities
- have the willingness to acknowledge and reflect on the way in which they may, influenced by their earlier life experiences, have an impact on perceptions of and interactions with young people, their families and professionals

Competences specific to the specialty

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

- demonstrate a broad knowledge of the needs of the dying child and family, including cultural and religious aspects of care
- know about current research in religious and spiritual dimensions of palliative medicine and be able to teach colleagues and trainees about this
- know about the range of attitudes to life and death, food restrictions, festivals and modesty rules for the main religious faiths in this country and where to find out more information on these issues
- be able to formulate an individual spiritual needs care plan for the family of a child with a life-limiting condition
- develop an open-minded approach to innovative techniques for pain assessment where conventional knowledge and skills are inadequate
- develop an understanding of quality of life issues from the child's perspective

(See Good Medical Practice (GMC, 2001, 2006) - Good Medical Practice: 1; Good Clinical Care: 5; Maintaining Trust: 19; Working with Colleagues: 36.)

Teaching and Research

Substantial re-wording or new statements of competence for Level 3 Training

- have developed a range of effective teaching and learning skills in a range of clinical contexts
- be able to identify learning needs in a wide range of professionals and build on this in their teaching
- be able to elicit and act upon feedback on content and presentation of teaching
- be able to participate in teaching and research on topics within their specialty and in related areas
- conduct research with honesty and integrity, seeking ethical approval where appropriate and safeguarding the interests of patients
- demonstrate an understanding of 'good clinical practice' for all aspects of the conduct of clinical trials

- demonstrate an understanding of the role of ethics committees for clinical studies and the process of ethics applications
- understand the techniques used in epidemiological studies

- demonstrate an understanding of how to perform and interpret systematic reviews, how they differ from narrative reviews and understand the principles of meta-analysis
- understand the difference between population-based assessments and unit-based studies and be able to evaluate outcomes for epidemiological work
- be able to develop clinical guidelines, understand how they are produced nationally and how these should be used to guide their own practice
- be able to evaluate research effectively in paediatrics and child health
- take responsibility for the training, supervision and assessment of undergraduates and trainees and other professionals such as nurses, teachers and social workers in and outside the specialty
- have developed skills in the presentation of information relevant to their clinical practice for a range of audiences, including spoken presentations at meetings, written information for children and families and training materials for different groups of colleagues
- be able to lead departmental teaching programmes, including journal clubs
- be willing to accept mentoring as a positive contribution to their own professional development
- be willing to learn from others, to discuss cases openly and to seek advice as appropriate and as necessary

Competences specific to the specialty:

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

- know the curriculum and scope of paediatric palliative medicine
- know sources of information, advice and training specific to the subspecialty
- be able to identify and assess the training needs of specialists and local professionals in relation to paediatric palliative medicine
- be able to facilitate an open and reflective learning culture, in a context of mutual respect, valuing and sharing knowledge and expertise within paediatric palliative medicine
- be able to support, teach, assess, appraise and supervise trainees sensitively and effectively, especially as they encounter the unexpected, uncertain, unfamiliar and unknown
- be able to offer advice, support and teaching to colleagues, other teams, and family carers supporting a child or young person, including telephone advice at a distance (in hours, out of hours and emergencies)

- take responsibility for the dissemination of new techniques and approaches to emergencies and Paediatric Palliative Medicine
- be able to teach professionals about the management of conditions and symptoms common in or specific to Paediatric Palliative medicine, such as seizures, spasm and pain
- be able to teach effectively the diagnosis of dying in children

(See Good Medical Practice (GMC, 2001, 2006) - *Teaching and Training, appraising and assessing: 13, 14, 15, 16; Probity: 51.*)

Leadership and Management

Substantial re-wording or new statements of competence for Level 3 Training

- be able to provide specialist support to hospital- and community-based paediatric services including primary care
- be able to take on a leadership role in a multi-disciplinary team when appropriate, for example by representing the health needs of a child, young person and their family at a discharge meeting, and know when it may be inappropriate to do so
- be able to work effectively in multi-agency teams, for example, with social workers and teachers, and have developed an awareness of their own role within the team and of the skills and expertise of others
- be able to assess a team that is experiencing problems and work with them effectively to improve the situation
- be confident to make decisions within a team and be aware of their impact on other team members
- be able to support junior medical staff and non-medical colleagues in making difficult decisions, and after the death of a child has occurred
- be able to advise the team providing advanced life support and to liaise effectively with anaesthetic and PICU staff
- demonstrate effective leadership skills in clinical situations, for example through their ability to organise, prioritise and delegate, and be able to help others to develop these skills

- have skills and strategies to manage conflict effectively
- have understanding and skills to be able to participate effectively in clinical and management meetings
- have developed effective cross-cultural communication skills
- have developed effective administrative skills including ways to make best use of secretarial resources

- be able to handle enquiries from the press and other media effectively
- recognise their own working preferences and accept different approaches of colleagues
- know how to respond appropriately to health service targets and be able to participate in the development of services
- be able to work with stake-holders so that a client- or patient-centred service is created and sustained
- have gained an understanding of national and local regulatory bodies, particularly those involved in standards of professional behaviour, clinical practice and education, training and assessment
- use principles of evaluation, audit, research and development in standard-setting and in improving quality
- demonstrate responsibility for ensuring reliability and accessibility of both themselves and others in their team
- have effective skills in ensuring the responsible approach of others in their team to health, stress and well-being

Competences specific to the specialty

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

- be able to co-ordinate and/or lead a multi-disciplinary team caring for children and young people with life-limiting conditions, based in hospital or in a hospice and/or in the community
- recognise the importance of the roles of non-medical professionals in providing holistic care, especially nurses, social workers, psychologists and chaplains
- work with professional colleagues with sensitivity and humility
- recognise the vulnerability of colleagues in caring for a child with a life limiting condition, and be able to facilitate appropriate support
- be able to manage effectively conflict and communication between professionals and families regarding potentially challenging issues in Paediatric Palliative medicine, such as feeding, hydration, ventilation, advance care planning, consent and confidentiality
- recognise the need to involve colleagues in other professions and disciplines in the management of pain
- recognise their role within the wider community of palliative medicine, locally, nationally and internationally

(See Good Medical Practice (GMC, 2001, 2006) - Working with Colleagues: 34, 35, 36, 39, 42.)

Personal Commitment to Professional Standards

Substantial re-wording or new statements of competence for Level 3 Training

- understand the duty of all professionals working with children to report concerns about child protection issues to Social Services
- be able to contribute to the implementation of national and local health policy initiatives
- know and follow key legal and ethical guidelines relating to confidentiality, consent to treatment, the right to refuse treatment, continuing changes in the law and its interpretation and be aware of variability in Scotland, Wales and Northern Ireland
- be able to generate local and evaluate national clinical guidelines and protocols in paediatric practice and public health and recognise the individual patient's needs when using them
- participate and take responsibility for clinical governance activities, and encourage and support colleagues in their participation
- know the appropriate legal and professional guidelines and regulations relating to employment, discrimination, charity and company law, charity commissioners, and corporate governance trusteeship
- be able to carry out audit in a range of settings in partnership with all stakeholders in order to identify best practice
- know about and participate in clinical and research special interest groups relevant to their specialty

- know when in the interest of the child it may be necessary to break confidentiality

- know how to find, review and maintain relevant knowledge in their specialty in order to maintain their fitness to practise
- ensure that they are up-to-date in their practice and promote evidence-based medicine where possible
- be able to evaluate their own performance critically
- be able to deal effectively with uncertainty and errors
- be open about sharing and reviewing their practice with others
- be aware of local processes for dealing with and learning from clinical errors and to be able to work within them

Competences specific to the specialty

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

- be able to demonstrate skills in ethical reasoning and decision-making in end-of-life care, for their own patients and those referred in their advisory capacity
- be able to advise on the ethical aspects of withdrawing or withholding treatment for children and young people, based on a rational and holistic balance of burden and benefit
- know the appropriate legal and professional guidelines and regulations specific to Paediatric Palliative medicine, including those relating to hospices, nursing homes, and charity and company law and be able to apply these in practice
- know about local and specialised support for ethical decision-making, for example, local ethics committees, and Trust legal advisors and **be able to** contribute to committees where appropriate
- recognise the need to update their knowledge of symptom management issues, including emergencies, pain, anti-emetics as new research becomes available
- know where to find recent information on the management of rare disorders
- recognise the benefits and limitations of extrapolating to paediatric palliative practice information from research evidence in the treatment of adult patients
- know about potential conflicts in Paediatric Palliative medicine, such as in artificial feeding or hydration, and know when it is appropriate to seek a legal ruling
- recognise the need to ask advice from specialist palliative medicine teams or paediatric palliative medicine teams, where appropriate, and demonstrate this understanding in their everyday practice
- be aware of personal values and belief systems and how these influence professional judgements and behaviours in provision of paediatric palliative medicine.
- be aware of individual personality traits, strengths and vulnerabilities and effects of these on team-working
- understand the threats to personal well-being when dealing with the psychological problems in palliative medicine and have appropriate personal support mechanisms in place
- be aware of the dangers of burnout specific to palliative medicine, introduce sound personal and organisational practices to reduce the risks of this, and be able to offer or arrange support for colleagues and for themselves where appropriate
- understand guilt, anger and sadness in grief and coping mechanisms and be able to distinguish normal reactions from those which may be harmful
- be able to anticipate likely issues of guilt, sadness and anger in families and be able to recognise and explore these with them
- recognise the limitations of their ability to evaluate and intervene in complex emotional situations and know when to make appropriate referrals to other professionals

(See Good Medical Practice (GMC, 2001, 2006) - 1; *Maintaining Good Medical Practice*: 10, 12; *Relationships with Patients*: 17; *Working with Colleagues*: 35; *Dealing with Problems in Professional Practice*: 26, 27, 29, 30. *Probity*: 58.)

See also for all of these sections: *Good Medical Practice in Paediatrics and Child Health*,² London: Royal College of Paediatrics and Child Health (2002).

Communication Skills in Paediatrics

Substantial re-wording or new statements of competence for Level 3 Training

- understand the importance of good communication skills and barriers to these, for example, pressures of time
- understand the importance of directing communications to the baby, child or young person as well as to parents and carers
- have developed skills to establish a child's or young person's and family's understanding of a situation from what has been said and written, to build on this effectively in discussion about the condition and its management
- understand the importance of seeking the views of all children and young people to inform decisions about their individual care and to encourage their participation in their care
- encourage children and young people to participate in their individual care and in the development of services, using expert resources appropriately
- have effective active listening skills in consultations with children and young people and understand the need to respect their views in accordance with their age and maturity and to respond appropriately where, for example, a child or young person is felt to be vulnerable
- have developed effective skills in working with children, young people and families to achieve concordance in planning management and treatment, enabling children and young people to maximise control over their illness and its management
- be able to respond appropriately, and know where to find assistance, in cases where a child, young person or family may not all speak English or where there is a sensory impairment that may affect understanding
- be able to respond to babies, disabled children or young people who may not be able to express themselves verbally, including those who might be in pain or distress
- be able to recognise, interpret correctly and respond to verbal and non-verbal cues from children, young people and parents

²*Good Medical Practice in Paediatrics and Child Health*, London: Royal College of Paediatrics and Child Health (2002). Online at www.rcpch.ac.uk/publications/recent_publications.html

- have developed observation skills to support their interpretation of children's or young people's developmental levels and possible physical signs when they are unable to co-operate with formal assessments
- demonstrate appropriate responses and empathy for children, young people and their families experiencing difficulty and distress
- have developed a range of language strategies, such as the use of metaphor or images which relate to everyday life, to explain clearly to a child or young people and their family, their symptoms, condition or treatment, their feelings or behaviour
- be able to counsel parents about serious conditions and abnormalities within their area of expertise
- have effective strategies for careful and appropriate use of language in difficult and challenging circumstances, for example, at the birth of a baby with disabilities or where there is a conflict with colleagues
- be able to discuss the indications, benefits and adverse events of a procedure to patients, relatives and carers in a manner that will allow informed consent
- have developed a range of approaches to communicating the breadth of diagnostic possibilities and other clinical information to children, young people and their families so that consent is always informed and the plan and progress of treatment understood
- be able to advise children, young people and their families about the importance of concordance and about medication interactions and side-effects
- be able to convey and share effectively difficult or bad news, including end-of-life issues, with children, young people, parents or carers and help them to understand any choices they have or decisions to be made about ongoing management
- be able to prepare and discuss with parents, carers and other professionals "Do not attempt resuscitation" policies as appropriate, taking due account of the Human Rights Act (1998), ensuring that the best interests of the child are held as paramount at all times
- be able to seek consent for post-mortem examinations and communicate effectively with the Coroner
- be able to explain the role of other professionals and agencies to children, young people and their families
- have the confidence to be firm and diplomatic in difficult situations, for example, when dealing with angry parents
- understand the limits of their competence, particularly in stressful situations and be willing to seek help in managing sensitive and complex situations
- be able to demonstrate to trainees how to communicate a diagnosis and prognosis effectively to children, young people and their families
- be able to demonstrate and explain to trainees strategies used to conduct effective consultations with babies, young children, adolescents and their families

- have effective skills in written communications for a range of audiences, for patients and their families, colleagues and other professional organizations
- ensure that spoken and written communications with patients and families are presented in clear, straightforward English, avoiding jargon whenever possible
- ensure that written information in the form of booklets, leaflets, information sheets and websites support verbal communications wherever possible
- ensure that written communications summarise accurately discussions with children, young people and parents or carers, and, to avoid confusion and anxiety, do not include information that was not part of the original discussion
- be able to liaise with parent support and self-help groups when necessary
- be able to prepare a court report as a professional witness and develop the skills to present such material in court
- know how to write reports about alleged abuse of children and young people for social services or the courts
- be able to write reports that explain the condition of a child or young person to non-health personnel working in the courts, social services or education
- be able to use electronic communication media, taking into consideration the principles of confidentiality outlined in the Data Protection Act
- have developed effective professional networks to support clinical practice and other activities, including research, education and management

Competences specific to the specialty

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

- have training in Advanced Communication Skills as stipulated by current professional guidelines
- know the common family responses to receiving a diagnosis of life-limiting illness, to common disease trajectories in paediatric palliative medicine, and to the impending death of a child
- understand that unwillingness to explore issues may represent damaging ‘denial’ or be a useful coping strategy, and be able to distinguish between these.
- understand the needs of relatives of a sick and dying child (including siblings, parents, grandparents) to talk about their experiences and to be heard
- be aware that children understand a great deal by inference, even when information has not been shared with them
- understand collusion between parents and professionals to deny a child’s impending death, and the impact this may have on children and young people
- understand the ways in which collusion can jeopardize good palliative medicine

- be able to challenge collusion effectively if necessary, but recognise when such challenge is inappropriate
- be able to communicate sensitively and effectively with colleagues in other disciplines and professions in caring for children and young people with life-limiting conditions
- understand the processes of transference and counter-transference in interpersonal relations
- be able to explain to children, parents and non-professional carers the pathophysiology and management of conditions commonly found in children with life-limiting conditions, for example, constipation, spasm, dyspnoea so that they can engage with decision-making and management
- be able to support a family after the death of a child

Section 3 General Clinical Competences

Development

Substantial re-wording or new statements of competence for Level 3 Training

- know the range of patterns of normal development from birth to adulthood
- know and understand the range of children's or young people's psychological and social development, including the normal range and what is outside it
- be able to identify when patterns of development are abnormal and where there may be a risk of abnormality which may only become apparent with time
- know the causes of disability, how disability might affect clinical examination and assessment and be able to contribute to a multi-disciplinary approach to management
- understand the severity of the presentation, taking into account normal development in appropriate domains
- know how to institute further assessment and investigation
- know about different modes of screening and health promotion strategies
- understand the ways in which children's or young person's mental health difficulties may present in infancy, childhood and adolescence
- understand the impact of biological factors, including genetic and cognitive factors, on the mental health of children and young people
- understand the impact of other environmental factors (including violence, trauma, neglect, abuse and disruption, wherever this has occurred) on a child's development, mental health and functioning
- be able to assess the effects of recurrent or chronic illness and its treatment on growth, psycho-social, emotional, physical and sexual development and have strategies to minimize adverse effects

Emotional development

Substantial re-wording or new statements of competence for Level 3 Training

- understand and recognise somatisation disorders and know how to provide initial management and how to access appropriate support
- recognise pointers to fabricated and induced illnesses and know how to provide initial management and how to access available support
- understand the emotional impact of illness and hospitalisation on children, young people and their families and take action to minimize this impact

- understand how a family's, child's or young person's attitude to the problem and services may have a significant impact on the presentation and its management
- recognise the need for specialised input in cases of serious emotional distress or mental illness and ensure their needs are met within local health provision
- understand the emotional dimensions of eating disorders and recognise and initiate treatment
- be able to assess parenting skills and recognise and respond to indications of unsatisfactory or unsafe parenting
- know how to access help in cases where children or young people of different ages might be deprived of opportunities to play and to learn
- know how to manage common behavioural problems

Competences specific to the specialty

- be aware of the need to have close links with relevant support services in the care and support of terminally ill children and young people, and their families, including local child and adult psychiatric services, psychological services, counselling and support groups

Social development

Substantial re-wording or new statements of competence for Level 3 Training

- be able to recognise and understand the impact of autistic spectrum disorders and other organic disorders on social development

Educational development

Substantial re-wording or new statements of competence for Level 3 Training

- demonstrate, in all aspects of their practice, an understanding, of the vulnerability of a child or young person with learning difficulties

Growth and Nutrition

Substantial re-wording or new statements of competence for Level 3 Training

- know the reasons for faltering growth, including emotional factors and how to investigate appropriately
- understand and assess normal and abnormal pubertal development and its relationship to growth

- understand the environmental factors contributing to obesity and how these might be altered
- be able to recognise feeding problems and work with parents directly to offer simple advice and to treat co-morbid conditions
- know about the principles and methods and indications for nutritional support and common problems that may arise from invasive methods or refeeding
- be able to identify nutritional deficiencies and growth failure which may occur in children and young people who undergo unsupervised dietary modification

Adolescence

Substantial re-wording or new statements of competence for Level 3 Training

- understand what the specific needs of young people are, in terms of their emotional, mental and physical health, and how these are different from those of children
- know the epidemiology of the main causes of morbidity and mortality in young people
- ensure that young people have access to ‘in-patient’, ‘outpatient’ and other medical services that best meet their needs
- understand why young people harm themselves and respond appropriately to actual or threatened episodes of self-harm in adolescents
- understand the consequences of self-harm and be able to work as part of a clinical network in the management of the young person who self-harms
- be able to discuss sexual health issues including basic contraceptive advice and know how to help the young person access appropriate sexual health or genetic advice
- know about national policies concerning the health care of young people, including those which help to reduce teenage pregnancy
- understand the processes of adolescence including experimental behaviours, learning by experience, achieving independence from the family, and the consequences of these on health and illness in young people
- be able to discuss comfortably with young people important health behaviours such as the use of tobacco, alcohol or recreational drugs, and intimacy and sexual activities together with the promotion of appropriate strategies for these in relation to specific conditions such as asthma, diabetes, cystic fibrosis, physical disability
- understand the particular needs of adolescents with regard to their independence and autonomy, education and work, body image and sexual identity, concordance with medication and risk-taking and understand how these factors may be affected in young people with chronic conditions

- be able to support young people in self-management of both acute and chronic disease where they want to, and have an understanding as to how to best help when the young person cannot or does not want to manage this
- be able to discuss the implications of chronic illness or disability for career options
- where appropriate and at a negotiated time, be able to raise and agree management of end-of-life issues with young people and their families and record conclusions in medical notes
- understand issues around transition from paediatric to adult care in adolescents with chronic conditions and disabilities, and be able contribute effectively to transitional care services
- understand and value the roles of members of the multidisciplinary team in the delivery of a transitional care programme

Section 4 Specialty-specific Competences in Paediatric Palliative Medicine

This section sets out the competences trainees should acquire in the specialist areas of Paediatrics. They appear in alphabetical order and are grouped in lists and tables. The competences in lists at the beginning of each section apply to all conditions in that specialism. The tables offer detailed reference where specific skills or knowledge may be linked to specific conditions rather than to overall practice in this area.

General principles of Palliative Medicine in Children

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

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

Practice of Paediatric Palliative Medicine – Symptom Control

In general

- know how to access current knowledge and expertise (for example major textbooks, current research and reviews in journals and on-line), dealing with adult as well as paediatric pain
- have detailed knowledge of new developments in pain assessment in normal and developmentally disordered children and young people
- know the indications for, range and mechanism and adverse effects of all major non-opioid or mixed opioid analgesics
- know the range of neurolytic procedures available and what they entail for the patient (especially intrathecal, epidural, coeliac axis block and regional nerve blocks)
- be able to recognise and manage specific pain syndromes, particularly neuropathic pain, bone pain, muscle spasm and cerebral irritation
- be able to identify the causes for anxiety-related nausea and vomiting, and possess basic counselling skills to explore these
- understand the mechanism of all major non-pharmacological approaches to pain management

Opioids

- be able to prescribe opioids safely in disease (particularly renal failure, liver failure or delirium)
- understand the concept of oral morphine equivalence
- understand opioid substitution, including issues of incomplete tolerance
- be able to recognize and manage adverse effects of opioid therapy
- be able to rotate or substitute opioids
- know about alternative major opioids to morphine, their potency and about their advantages and disadvantages compared to morphine
- know the conversion ratios for enteral and parenteral administration of alternative opioids to morphine
- understand urgent opioid titration intravenously, including calculation of regular dose

Nausea and Vomiting

- understand the mechanism and the role of unusual medications such as steroids and octreotide in managing nausea and vomiting
- know the mechanism of emesis in liver damage, metabolic derangement, gastrointestinal damage and intracranial causes, irrespective of the underlying life-limiting condition

- be able to formulate a rational approach to anti-emesis when the first and second lines fail, based on an understanding of the likely mechanism
- recognise the holistic nature of nausea and vomiting in children with life-limiting conditions
- understand and know how to manage psychological aspects of nausea and vomiting using psycho-active medications and the potential use of non-pharmacological measures such as counselling, hypnosis, acupuncture and other complementary therapies
- be able to identify and explore the causes for specifically anxiety-related nausea and vomiting

Constipation, Anorexia, Cachexia, Hiccough

- know current and evolving theories of anorexia, cachexia and hiccough in children with life-limiting conditions
- be able to devise and implement a rational, patient-specific evidence-based approach to the management of constipation, anorexia, cachexia and hiccough
- be able to work with the multi-disciplinary team in managing constipation and faecal impaction by dietary measures, medications and lifestyle modification
- be able to identify and modify other symptom control measures which may contribute to constipation, for example, the use of non-constipating opioids or baclofen
- be able to manage complications of constipation, for example, bowel obstruction, pain, nausea and vomiting
- understand the theoretical mechanisms that link anorexia, cachexia and fatigue in both malignant and non-malignant conditions

Mouthcare, Feeding, Hydration

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

Dyspnoea

- know the current evidence base for the management of dyspnoea
- be able to provide support for professionals in other specialities, for example, respiratory or neurological teams, in the management of dyspnoea in terminally ill children (including in cases of rapid home discharge planning), irrespective of the underlying condition limiting life

- be able to anticipate and plan the management of children at risk of sudden, acute episodes of dyspnoea, for example airway obstruction, panic attacks, haemoptysis or cough
- know when to seek specialist help in the management children with life-limiting conditions on artificial ventilation
- know about multi-disciplinary team approach to the management of dyspnoea, involving, for example psychologists and play leaders
- know about the pathophysiology of dyspnoea in children with malignant and non-malignant life-limiting conditions.
- understand when investigation is necessary and when it is inappropriate
- recognise when oxygen therapy is inappropriate
- recognise and know how to treat causes for dyspnoea including panic, anxiety, painful breathing, breathlessness, cough, haemoptysis and excessive secretions in cases of dyspnoea
- understand that dyspnoea is a subjective experience which does not necessarily correlate with related objective observations such as tachypnoea

Seizures and other neurological problems

- know symptoms likely to be associated with common neurological or neuromuscular conditions, particularly Duchenne muscular dystrophy, spinal muscular atrophy and cerebral palsy.
- know about and be able to treat and manage common complex symptoms associated with all common life-limiting neurological and neuromuscular disorders
- be able to manage terminal status epilepticus
- understand the limitations and benefits of therapies and the side-effects that therapies themselves can manifest
- be familiar with range, benefits and burdens of anaesthetic and neurological procedures that may help neurological symptoms, for example the intrathecal baclofen pump, nerve blocks
- recognise that some neurological symptoms are more distressing to watch than to experience, and to negotiate treatment goals that are appropriate
- recognise that neurological symptoms may not be fully controllable or that some treatment may sometimes impose more of a burden to the child than can be justified by its benefit
- have developed communication skills to be able to explore this with the family and, where appropriate, the child

Psychological symptoms

- be able to diagnose depression, adjustment disorder, anxiety and delirium in children
- be familiar with the distinctive presentation, differential diagnosis and management of these conditions in palliative medicine, particularly with respect to available tools for diagnosis and evaluation
- understand, recognise and respect the distinction between a coping strategy and psychopathology
- be able to devise and implement a rational initial management plan for psychological symptoms, including pharmacological and non-pharmacological approaches
- be able to work, where necessary, with adult, child and adolescent psychiatry and psychology services in managing psychopathology in children with life-limiting conditions

Skin symptoms

- maintain up-to-date knowledge and skills of the causes and management of all types of skin disorder in children and young people with life-limiting conditions
- know about epidermolysis and other life-limiting skin conditions, including restrictive dermopathy, ichthyoses and Neu-Laxova
- be aware of the unique nature of pain syndromes associated with certain specific life-limiting skin conditions such as epidermolysis bullosa
- understand the causes of pruritus and be able to manage it
- know about the different types of dressing available and how and when they should be used
- be able to facilitate and participate in a multi-disciplinary team approach to the management of skin symptoms and disorders associated with systemic life-limiting conditions.
- be aware of the limitations of the management of some skin symptoms and disorders
- be able to accept and inform the family, the child and the team that symptoms may not be fully controllable or may progress
- understand the need to address emotional, psychological, social and spiritual needs as well as physical ones in managing children with life-limiting skin conditions
- be familiar with the mechanism, evidence-base and practical use for topical analgesics such as non-steroidal anti-inflammatory drugs and opioids

Emergencies

- be able to identify likely emergencies early in the palliative course of life-limiting conditions
- have the skills and up-to-date knowledge to teach, advise and support effectively and sensitively colleagues in a difficult situation caring for a child or young person in an emergency, if necessary by telephone
- be able to prepare a detailed management plan for all five palliative medicine emergencies (cord compression, haemorrhage, SVC obstruction, uncontrolled pain and seizures), including correct drug, dose and route for specific situation and child
- know the ethical considerations of managing palliative medicine emergencies at the end of life, particularly those relating to euthanasia, the principle of double effect and terminal sedation, and if necessary to contribute to clinical ethics committee debates on these subjects

Ethics and the Law

- be able to apply basic medical ethical principles to complex decision-making in children with life-limiting conditions
- be familiar with principle of ‘attention to scope’
- understand principles of double effect and ‘unintended consequences’
- be familiar with ethical and legal debates surrounding euthanasia and physician-assisted suicide
- be aware of global differences in legislation on euthanasia and physician-assisted suicide

Malignant diseases

- know the symptoms that are likely in acute lymphoblastic leukaemia, acute myeloid leukaemia and all major tumours
- understand the distinction between chemotherapy that is palliative, experimental, potentially curative or futile
- understand the mechanism of common oncology modalities used for palliation, particularly radiotherapy, antimetabolites and steroids
- know how the main types of tumour are likely to spread
- understand the mechanism of palliative chemotherapy agents
- be familiar with the extent and the limitations of oncology outreach, inpatient and children’s hospice models for providing palliative medicine for children with cancer
- understand the need for close liaison with medical and nursing oncology colleagues throughout the course of a child’s illness

Non-malignant diseases

- know how to access information on current management strategies for rare disorders
- demonstrate an empirical approach to symptom management of rare disorders where there is little published evidence-base
- demonstrate knowledge of symptom patterns in specific groups of life-limiting conditions and be able to anticipate these, even when they are not evident in the child
- understand the specific needs of families whose children have non-malignant life-limiting conditions, with relation to interactions with professionals, such as dealing with loss and bereavement and perceptions of quality of life issues
- demonstrate detailed knowledge of common specific non-malignant life-limiting conditions
- be able to ensure that an appropriate management plan is formulated, with the involvement of the multi-disciplinary team and other specialists
- be able to manage specific symptoms common in non-malignant LLC, especially pain, nausea and vomiting and constipation
- know about the role of rehabilitation specialists and services and be able to facilitate access to them
- be able to manage situations of clinical uncertainty, especially with respect to prognosis and the likelihood of death
- understand the specific needs of families whose children have non-malignant life-limiting conditions with regard to disease trajectory and uncertain prognosis, interaction with other professionals, support in loss and bereavement, and perception of quality of life

The period immediately before death

- recognize that home is the preferred place of death for most children in most families
- be familiar with services in the locality and know how to make and implement a referral
- understand the need to develop services to support the child and family in dying at home, where this is preferred and in other locations, particularly in a hospice, hospital or school
- know how to access relevant funding to support care at home and know how to advocate for the family in terms of completing appropriate administrative requirements
- understand the need to visit patients in different locations in order to facilitate care
- be able to teach effectively the diagnosis of dying in children
- know about the final pathway of disease processes, prognostic indices and their application and limitations and be able to make a diagnosis of imminent death
- be able to support colleagues, sometimes at a distance, in recognizing that a child's death is imminent
- be able to prescribe a subcutaneous syringe driver confidently and accurately

- be able to work with a wide variety of models delivering care to the child whose death is imminent, including specialist outreach teams, community paediatric teams, primary care teams and children's hospices as well as acute paediatric wards
- be able to anticipate specific likely symptoms in the period immediately before death, and ensure that appropriate medication is available by the appropriate route in good time

Practicalities after death

- know distinction between verification and certification of death
- know who can issue a death certificate
- know who can complete the different parts of a cremation form
- understand the role and powers of the coroner, when to refer and be able to advise on the procedures they will follow
- know the practicalities relating to organ donation.
- understand and be able to advise on the legal implications of moving a child after death
- be able to organise a post-mortem
- understand and be able to advise on procedures for post-mortem biopsy and retained tissue
- be able to explore, record and communicate effectively to other professionals (especially ambulance and out-of-hours services in the community) the wishes of families regarding resuscitation of their child

Section 5 **Practical Procedures and Investigations**

By the end of Level 3 Training, trainees will:

- know the appropriate indications for practical procedures and investigations
- know the contraindications and complications of procedures
- know the local and national guidelines for obtaining informed consent
- know the local and national guidelines for undertaking investigations or procedures
- know the local guidelines for providing sedation and pain relief for practical procedures
- know the relevant anatomical markers for invasive procedures
- know and practise scrupulous aseptic techniques
- be aware of safety issues for patients and staff in relation to investigations of body fluids and radiation
- understand the importance of post-mortem investigations
- know the national and local guidance for obtaining consent for post-mortem
- be able to interpret results of investigations requested and respond appropriately
- be able to record results and document procedures legibly and accurately
- be able to give appropriate medical information when requesting investigations
- know that results should be requested clearly and retrieved promptly
- understand common age-appropriate normal ranges or appearances
- be able to use all equipment required to undertake common procedures and investigations
- be able to explain the investigation results to parents and/or the child
- be aware of the factors that are likely to influence the anxiety of the child, parent and doctor and know how to enlist effectively the help of play-leaders, nursing staff and more senior paediatric staff when necessary
- be receptive to feedback from patients and parents/carers on the effects of medication/treatment
- know about the role of complex investigations eg CT and MRI scans and their diagnostic potential and complications
- recognise when the results of commonly-used radiological investigations are abnormal
- have developed confidence in independent performance of practical procedures
- be able to supervise and teach others
- recognise complications of procedures and be able to respond appropriately
- understand and follow the local guidelines for the prevention and management of needle-stick injury

- be able to recognise the importance of universal precautions as well as the disposal of sharps within the department
- have experience of speaking to parents when complications have occurred
- know about processes for critical incident reporting
- obtain informed consent appropriately
- supervise handover of results that still need to be obtained at the end of shifts

Diagnostic Procedures

By the end of Level 3 Training, trainees will be able to perform the following diagnostic procedures independently:

- collection of blood from central lines
- umbilical artery and venous cannulation and sampling
- peripheral arterial cannulation
- venesection
- capillary blood sampling
- suprapubic aspiration of urine
- urethral catheterisation
- routine testing of urine
- perform basic lung function tests
- electrocardiogram
- lumbar puncture
- non-invasive blood pressure measurement

Therapeutic Procedures

By the end of Level 3 Training, trainees will be able to perform the following therapeutic procedures independently:

- administer intradermal, subcutaneous, intramuscular, intravenous injections
- percutaneous long-line insertion
- bag, valve and mask ventilation
- needle thoracocentesis for pleural effusion or pneumothorax
- tracheal intubation
- intubation of newborn infants of most gestations
- administration of surfactant
- external chest compression
- insertion of intraosseous needle

- They will be able to perform the following procedures if involved in the provision of neonatal care
- intubation of extremely immature babies or those with congenital malformation of head and neck
- drain a pneumothorax in babies and older children
- neonatal chest drain insertion
- exchange transfusion (full and partial)
- cranial ultrasound scanning
- cerebral ventricular tap
- abdominal paracentesis

Competencies specific to the specialty

By the end of level 3 training in paediatric palliative medicine, trainees will:

- be able to set up and maintain subcutaneous syringe driver infusions
- have a working knowledge of indications for and practical management of gastrostomies and jejunostomies, in particular common practical problems (tube blockage etc) and solutions
- know about indications for and practical management of tracheostomies
- know about indications for and practical management of nerve blocks, and intrathecal pumps, including complications
- have a working knowledge of the indications for, and day-to-day management of, invasive and non-invasive ventilation, assisted cough machines and suction apparatus

Pharmacology and Therapeutics

By the end of Level 3 Training, trainees will:

- know and understand the pharmacological basis for treatments
- know the approved indications and justification for prescribing drugs in common paediatric problems
- know the pharmacokinetics and pharmacodynamics of commonly prescribed drugs
- be able to calculate drugs accurately according to specific dose for weight, or age/weight range or on a specific dose/surface area basis
- know the risks of prescribing in the child-bearing years, in pregnancy and in breast-feeding mothers
- know about the roles of the regulatory agencies involved in drug use, monitoring and licensing (for example the National Institute of Health and Health and Clinical Excellence, the Committee on Safety of Medicines, the Medicines and Healthcare products Regulatory Agency and Hospital Formulary Committees)

- be able to find out information necessary for safe prescribing through use of paediatric formularies and pharmacy liaison
- know about drug interactions of commonly used drugs
- know about procedures for obtaining consent in children and young people for the administration of drugs
- be able to use the local and national guidelines for the relief of pain in children
- know and follow local policies for intrathecal cytotoxic therapy
- respond appropriately to errors of prescription or administration and be able to talk to parents about this
- be able to prescribe safely and supervise prescription for the newborn, and for children of all ages
- know about the licensing of medicines for paediatric patients and unlicensed and off-label use and the implications of extemporaneous products
- know how to explain relevant potential adverse side-effects
- be able to advise and supervise safe prescription of intravenous fluids to medical and surgical patients
- be able to prescribe in a manner that enhances adherence and provide information and explanation that enhances concordance

Competences specific to the specialty

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

- know the pharmacokinetics of morphine and diamorphine in health and disease
- know the symptoms, signs and causes of narcotisation
- understand the reluctance of family members and professionals to use medications with respiratory depressant side-effects in the treatment of children and young people with life-limiting conditions and respiratory symptoms
- know the receptor interaction of all common anti-emetics
- understand the concept of receptor complementarity and use of first- and second-line anti-emetics based on an understanding of their mechanism
- know how some anti-emetics may interact with each other
- be able to prescribe the appropriate anti-emetic by the appropriate route and at the appropriate dose depending on the cause of the nausea and vomiting
- be able to prescribe empirically and appropriately in the face of incomplete clinical data
- know about the correct practical set-up and use of a syringe driver
- know which medications can be mixed in the same syringe driver
- be aware of recent evidence regarding the use of a syringe driver and alternative methods for the administration of drugs
- be able to calculate syringe doses subcutaneously or intravenously

- be able to calculate equianalgesic doses of major opioids taking into account the drug and route
- anticipate, recognise and appropriately manage complications of syringe driver use, including precipitation and irritation.
- be able to prescribe adjuvant therapy appropriate to the nature of pain
- understand the nature of total pain and the limitations of pharmacological therapy alone
- have a detailed knowledge of the classification and mechanisms of action of laxatives and rectal measures
- understand the types of medication used for appetite stimulation in anorexia, and their use, limitations and risks
- be able to titrate laxative medications according to the degree of constipation

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