

RCN Competencies: Caring for Infants, Children and Young People Requiring Palliative Care

Second edition

CLINICAL PROFESSIONAL RESOURCE





Acknowledgements

This newly updated competence framework will be helpful for all health care professionals that contribute to the nursing care of infants, children and young people requiring palliative care.

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The working group collaborated to review and restructure the original competencies developed and published in 2012, utilising additional contributions from all members of the RCN CYP Palliative Care nurses community; these members represented NHS and non-statutory children's palliative care services from across all four UK countries.

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This publication is due for review in July 2021. To provide feedback on its contents or on your experience of using the publication, please email publications.feedback@rcn.org.uk

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

This document is a revision of the first RCN competence framework (RCN, 2012) produced for nurses and health care support workers in the UK involved in the care of infants, children and young people requiring palliative care. The newly revised competence framework builds on a number of best practice guidance documents and resources.

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Evaluation

The authors would value any feedback you have about this publication. Please contact publications.feedback@rcn.org.uk clearly stating which publication you are commenting on.

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Introduction

There are a significant number of infants, children and young people across the UK who require palliative care that will begin the moment they receive a diagnosis of a life-limiting or life-threatening condition. Together for Short Lives (www.togetherforshortlives.org.uk) defines palliative care as:

“an active and total approach to care, from the point of diagnosis or recognition throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family.”

Because of the diversity of conditions and individual needs, specialist care provision is required in the home, hospital and hospice. Therefore, specific competences are required for nursing and support staff who work closely with families and other care providers to ensure the best possible quality of life for this group of infants, children and young people and to deliver support for their families.

This document is a revision of the first RCN competence framework (RCN, 2012) produced for nurses and health care support workers in the UK involved in the care of infants, children and young people requiring palliative care. The newly revised competence framework builds on a number of best practice guidance documents and resources, many of which are listed in the contextual factors column of the competence tables.

Readers are also directed to review the resources on the Together for Short Lives website (www.togetherforshortlives.org.uk) and the recently published NICE guideline [NG61] *End of Life Care for Infants, Children and Young People* (2016) (www.nice.org.uk/guidance/ng61) which provides detailed information and resources on palliative care for infants, children and young people, including the age range covered and the scope of palliative care services provided.

Purpose of the competence framework

A competence framework describes the range of knowledge, skills and performance levels required of nurses and supervised health care support workers/assistant practitioners working in a specialty to help them achieve safe, effective and accountable practice. The main purpose of this framework is to support the delivery of high quality, evidence-based care by nurses and health care support workers involved in the care of infants, children and young people requiring palliative care and recognises the workforce delivering from level 1 through to level 4. In this document the use of the term 'child' encompasses the entire span of childhood, from pre-birth to late adolescence.

This competence framework:

- describes roles and responsibilities at different levels to help with workforce development and the specification of role and job descriptions
- supports career progression in the specialist field, allowing staff to demonstrate progress and plan for professional development
- informs the provision of continuing professional development opportunities, such as study days or specialist course development and evaluation
- helps promote the development of leadership roles in infant's, children's and young people's palliative care, specifically strategic leadership roles.

Level 1 Supervised practitioners: student, play worker, health care support worker.

Level 2 Practitioner: registered nurse, play specialist.

Level 3 Advanced practitioner: specialist nurse with theoretical and practical knowledge/training in CYP palliative care.

Level 4 Consultant practitioner: expert with national role and leading research and practice development in CYP palliative care.

Framework development and review

This framework builds on, but does not duplicate, core competence frameworks for nursing staff working with infants, children and young people. It sets out the specific competencies, performance and knowledge/understanding required to provide palliative care to a high quality. The framework draws on the most recent evidence-based standards and guidance, as well as more general evidence-based resources, and these are listed in the contextual factors column of the competence tables as supporting evidence for specific elements of the framework.

Initial drafting and review of the competences was undertaken by members of the RCN children's and young people's (CYP) palliative care community with expertise in this field and who work in a range of care settings across the UK. The contributors then undertook a consensus process to agree the content and level descriptions before RCN staff reviewed the final draft framework to check alignment with other relevant core competences, particularly those related to health care assistants and assistant practitioners.

Using the competence framework for continuing professional development

The detailed competence tables that follow have been structured to enable individuals to locate their current level of expertise in four dimensions.

1. Communicating effectively with children and young people with palliative care needs.
2. Providing multidisciplinary holistic care to children and young people with palliative care needs in any care setting (hospital, hospice, the home, school or other community setting).
3. Working with primary carers and health care professionals to identify and manage symptoms.
4. Sustaining self and the wellbeing of others when caring and supporting children/young people and families with their grief, loss and bereavement.

With the support of supervisors/managers, individuals can use this document to develop a learning and development plan that will provide further experiences and opportunities for learning, and to reflect on learning, to achieve higher levels of competence.

Competencies

1. Communicating effectively with children and young people with palliative care needs

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1	Communicates effectively with children and young people requiring palliative care and their families, using a range of different aids.	<p>Communicates simple information verbally or in writing to other members of the team.</p> <p>Communicates with children of various ages, stages of development and cognitive abilities.</p> <p>Establishes rapport and builds trust with the child and their family at a time of distress.</p> <p>Contributes to multi-professional discussions and communication.</p> <p>Assists with managing barriers to effective communication, for example, helping a child to communicate fears or anxieties, simplifying content of information or using communication aids to enable child to understand treatments, procedures, symptom management plans, pain tools and so forth.</p> <p>Adheres to local policies in relation to accurately reporting and recording all communication and activities undertaken.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> the needs of children at different developmental stages key needs of children requiring palliative care cognitive stages of development and ability in children the importance of confidentiality local policies relating to appropriate identification and reporting of risks common barriers to communication various tools that children may use to communicate (for example, Makaton or British sign language, switches or symbols). psychological needs of the child with a palliative care condition and their families the role and value of families and carers as partners in supporting their child importance of ensuring child's participation in their care planning, utilising appropriate tools/communication aids as necessary maintaining professional boundaries when working with the child and their family. <p>Know how to:</p> <ul style="list-style-type: none"> communicate with children at different developmental stages use verbal and non-verbal approaches and communication aids effectively when communicating with the child and family use open and closed questions appropriately write accurate records. 	<p>Sensitive</p> <p>Empathetic and understanding</p> <p>Integrity</p> <p>Actively listens</p> <p>Confidential</p> <p>Respectful</p> <p>Honest</p> <p>Person-centred</p> <p>Willing to receive feedback</p> <p>Assertive</p> <p>Uses initiative</p> <p>Confident</p> <p>Self aware</p> <p>Advocate</p>	<p>Skills for Health (2012) <i>Competences Tools</i>: CS1, CS19.</p> <p>Department of Health (2015) <i>Mental Capacity Act 2005: Deprivation of Liberty Safeguards: Code of Practice to Supplement the Main Mental Capacity Act 2005 Code of Practice</i>.</p> <p>Nursing and Midwifery Council (2015) <i>The Code: Professional Standards of Practice and Behaviour for Nurses and Midwives</i>.</p> <p>Local safeguarding policies and procedures.</p> <p>Local confidentiality policy.</p> <p>Skills for Health (2012) <i>Competences Tools</i>: CS2, CS3, CS5, CS6, CS8, CS9 CS13, CS14, CS21.</p>

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
2	<p>Meets both comprehensive and specific complex communication needs of children /young people and their families across the continuum of care.</p>	<p>Facilitates and manages interactions with children and their families, taking into consideration the child's age and abilities.</p> <p>Assesses, plans, contributes to, implements, evaluates and documents the care of children with palliative care needs, who have a range of communication problems or issues.</p> <p>Holds conversations at the appropriate time and pace with understanding and sensitivity.</p> <p>Supports children and their families through times of uncertainty, applying their knowledge of communication skills.</p> <p>Discusses treatments, care options and symptom management plans in an appropriate manner and at an appropriate cognitive level.</p> <p>Communicates comprehensively with both children and families, including discussion of psychological, emotional and spiritual issues.</p> <p>Contributes to multidisciplinary planning and decision-making discussions.</p> <p>Leads a discussion with support on specific subjects (such as choice of preferred place of care) associated with children and their families with palliative care needs.</p> <p>Is aware of own needs and coping strategies.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> skills, interactions and theoretical models that underpin effective communication with children who have palliative care needs and their families services in the local geographical area, and awareness of other professional bodies which specialise in supporting children with palliative care needs multidisciplinary care pathways and advance care planning tools available within the clinical setting counselling techniques and how to use them legislation, policies and procedures relating to communication and record keeping psychological issues of children and families with palliative care needs, including issues such as anticipatory grief and continuing bonds <p>Know how to:</p> <ul style="list-style-type: none"> manage barriers to effective communication (helping a child to communicate fear and anxiety of impending treatment and possibility of death, by simplifying content of information given to the child by use of communication aids) access local support groups, voluntary organisations, and statutory agencies for children and their families hold challenging conversations, ensuring the setting is safe and confidential document conversations and communicate significant facts to appropriate colleagues in confidential format that will contribute to multidisciplinary planning and decision making seek and use interpretation services for children and families from different linguistic backgrounds. 	<p>Creative Supportive Empowering Advocates</p>	<p>Mack JW and Liben S (2012) 'Communication', in Goldman A, Hain R and Liben S (editors) <i>Oxford Textbook of Pediatric Palliative Care</i> (2nd Edition), pp.23-34.</p> <p>Levetown M (2008) <i>Communication with Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information, Pediatrics</i> 2008; 121; e 1441.</p> <p>Together for Short Lives (2013) <i>A Core Pathway for Children with Life-Limiting and Life-Threatening Conditions</i> (3rd edition).</p> <p>RCN (2013) <i>Breaking bad news: Supporting parents when they are told of their child's diagnosis</i>. RCN guidance for nurses, midwives and health visitors</p> <p>Regional/local care pathways.</p> <p>Local service level agreements between community, acute and voluntary health and social care providers.</p> <p>Local and national policies and procedures.</p>

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
3	<p>Meets, both directly and indirectly through others, the comprehensive and specific complex communication needs of children /young people and their families, and other professionals across the continuum of care and care pathway.</p>	<p>Supports children and their families through times of uncertainty, applying specialist palliative care knowledge to the care of child and their family members. Communicates confidently and effectively with children and their family members. Discusses treatments, symptom management, care options and coping strategies in an appropriate manner and at an appropriate cognitive level. Communicates choices based on evidence and best practice, such as symptom management advice and care planning. Utilises integrated multidisciplinary care pathways to guide both child, family and professionals in effective communication and care planning. Provides constructive feedback to other staff or team members on their communication style or delivery when communicating with and supporting children and families at times of distress. Creates an empowering and affirming environment for families. Creates an environment that enables all staff to share their views of child/family issues within a multidisciplinary setting. Establishes a therapeutic relationship in which to use counselling skills to assist the child or family member to explore their feelings about their illness, care or dying. Communicates complex concepts clearly and effectively through spoken and written word. Guides and supports others to improve communication skills among the team. Analyses complex child and family situations and shares experiences and insights with others. Demonstrates comprehensive level of clinical reasoning skills.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> the complexity of disease progression the principles underpinning children's palliative care ie, the impact of relevant conditions, diseases, treatment effects and their treatment or care options available. <p>Know how to:</p> <ul style="list-style-type: none"> modify the content, structure and method of communication to meet the needs of the individual child and their family (deciding what information/ advice to give or not to give as the interaction proceeds) sensitively break news of diagnosis and guide the child and family through their palliative care journey explain indepth prognosis, life expectancy and answer challenging questions from child and young person explain death and dying to a child/young person and family explore with the child and young person and family their wishes and choices within advance care planning and symptom management formulate or adapt multidisciplinary care pathways and individualise them ability to give constructive feedback and support to colleagues at all levels. 	<p>Affirming Leading</p>	<p>Skills for Health (2012) <i>Competences Tools</i>; CS20, CS22, CS30, HSC434. Contro N and Scofield S (2012) 'Power of Their Voices: Assessing the Child and Family', in Goldman A, Hain R and Liben S (editors) <i>Oxford Textbook of Palliative Care for Children</i> (2nd edition), pp.58-67. Nursing and Midwifery Council (2015) <i>The Code: Professional Standards of Practice and Behaviour for Nurses and Midwives</i>. Child Bereavement UK information and resources for families.</p>

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	Facilitates the development of collaborative communication strategies based on continuous review of the communication needs of children /young people and their families, and develops a workplace culture where these needs are met by all, across the continuum of care and patient pathway.	<p>Analyses and synthesises complex child and family situations and shares experiences and insights with others.</p> <p>Takes the lead with teaching of communication skills and child-specific modes of communication, in formal settings to specialist and non-specialist staff.</p> <p>Leads discussions of the multidisciplinary team that draws on members knowledge of the child and their palliative care needs.</p> <p>Debates with clarity and competence, whilst showing due respect for the different perspectives of others.</p> <p>Demonstrates advanced level clinical reasoning skills.</p> <p>Contributes to theory and research in children's palliative care at local and national level.</p> <p>Communicates evidence-based practice and highlights gaps in practice with commissioners or at strategic organisational level.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> the theories and philosophies in palliative care in relation to the experiences of children and families family systems, dynamics and theories/models for supporting families in crisis children's palliative care issues at a strategic and national level different models of counselling, their use and application. <p>Know how to:</p> <ul style="list-style-type: none"> analyse and interpret effective communication strategies and the adequacy of theoretical model in respect of complex and diverse practice situations develop a common vision develop a communication strategy collaboratively and implement an operational plan implement monitoring and evaluation systems and shared governance. 	<p>Influential</p> <p>Enables learning</p> <p>Exercises judgement</p> <p>Analytical</p> <p>Strategic</p> <p>Facilitative</p>	<p>Papadatou D (2009) <i>In the Face of Death: Professionals Who Care for the Dying and the Bereaved.</i></p> <p>Samuel J (2017) <i>Grief Works: Stories of Life, Death and Surviving.</i></p>

2. Providing multidisciplinary holistic care to the child or young person with palliative care needs in any care setting (hospital, hospice, the home, school or other community setting)

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1	Provides holistic nursing care for children/young people and families.	<p>Delivers delegated nursing care, within defined guidelines and protocols following the prescribed care plan.</p> <p>Collects reliable information that informs nursing care, and which contributes to changes in prescribed care or symptom management plan.</p> <p>Maintains activities of daily living for a child with palliative care needs.</p> <p>Relays simple information to other members of the multidisciplinary team.</p> <p>Assists with assessment and planning of care, guided by protocols and with support from registered practitioners.</p> <p>Delivers, evaluates and records care with supervision from a registered practitioner to address health related problems/needs.</p> <p>Focuses on achieving optimum quality of life for the child and their family.</p> <p>Has an understanding of the implications of palliative care for the child and the wider family.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> local policy about documentation and reporting on care basic principles of the needs of children receiving palliative care and their families basic principles of paediatric palliative care practice the importance of promoting a good quality of life the multidisciplinary team and how they contribute to the care pathway for children with palliative care needs various professional roles and responsibilities of team members choices available to children and their families own role and responsibilities within the team and limits of own competence the varying stages of development of the child with a palliative care need and the effect this can have on decision making. <p>Know how to:</p> <ul style="list-style-type: none"> contribute to discussions within multidisciplinary meetings implement the care plans and report significant changes to the registered nurse/practitioner and, under direction, liaise with appropriate professionals within the team (for example, dietician for the food plan) inform children with palliative care needs and their families about choices available to them. 	<p>Communicative</p> <p>Empathetic</p> <p>Team player</p> <p>Listens</p> <p>Responsive</p> <p>Enquiring</p> <p>Accountable</p> <p>Self aware</p> <p>Confident</p> <p>Understanding</p> <p>Creative</p>	<p>Local confidentiality policy.</p> <p><i>Together for Short Lives Core Pathway for Children with Life Limiting, Life Threatening Conditions</i> (3rd edition).</p> <p>Skills for Health (2012) <i>Competencies Tools</i>: CS25, CS5, CS8, CS 22.</p> <p>Department of Health (2011) <i>NHS at Home: Children's Community Nursing Services</i>.</p> <p>Kennedy I (2010) <i>Getting It Right for Children and Young People: Overcoming Cultural Barriers in the NHS so as to Meet Their Needs</i>.</p> <p>Department for Health and Department for Education and Skills (2004) <i>National Service Framework for Children, Young People and Maternity Service. Standard 8: Disabled Children and Young People and Those with Complex Health Needs</i>.</p> <p>RCN (2014) <i>Career, Competence and Education Framework for Neonatal Nursing in the UK</i>. RCN Guidance</p>

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
2	Provides comprehensive holistic and evidence-based nursing care to children and young people with complex palliative care needs across the care pathway.	<p>Monitors the quality of work in own area and alerts others to quality issues.</p> <p>Applies appropriate clinical judgment, in consultation with others, to provide nursing care that meets the complexity of the child's palliative care needs.</p> <p>Works in partnership with other sectors and agencies including: health, education, social services and voluntary sector.</p> <p>Develops therapeutic relationships with children and their family to assist their informed choices for care and treatment.</p> <p>Provides the child and family with choices where possible, recognising the impact these choices can have on quality of life, for example, remaining in hospital or staying at home at end of life.</p> <p>Interprets basic clinical data to inform decision making.</p> <p>Supports inexperienced staff to develop skills in organising, prioritising and delegating.</p> <p>Ensures an appropriate induction or development programme is in place.</p> <p>Evaluates outcomes of care and makes alterations appropriate to the ever-changing clinical situation.</p> <p>Supports others in discussions and acts as an advocate to children and families with palliative care needs.</p> <p>Acts as a 'key worker' when required.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> the principles and practice of palliative and specialist nursing care and symptom control support services, voluntary agencies, hospices and charities that provide a range of support for families the nature of a variety of palliative care conditions how to plan ahead utilising resources available to promote a good quality of life theories and principles of children's palliative care and how these can be applied to other members of the multidisciplinary team, for example, teachers who are also involved in the lives of children with palliative care needs psychological issues and family dynamics affecting children and their carers from the point of diagnosis to the end-of-life stage and how to integrate this into practice. <p>Know how to:</p> <ul style="list-style-type: none"> incorporate end-of-life planning as part of the child's daily care discuss with the child and family members what their wishes are recognise that choices made may conflict with the personal feelings of others, and respect these feelings without influencing manage diverse religious and cultural beliefs of families, particularly when making quality of life decisions for the child. 	Resourceful Adaptable Flexible Reflective Accountable Analytical Judgment Sensitive Confident Knowledgeable Self assured Innovative	World Health Organization (2008) <i>WHO Definition of Palliative Care for Children</i> . Nursing and Midwifery Council (2014) <i>Standards for Competence for Registered Nurses</i> .

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
3	<p>Provides comprehensive holistic and evidence-based nursing care to children and young people with complex palliative care needs across the care pathway and in a range of settings.</p>	<p>Promotes and maintains quality-of-life for children who have a palliative care need. Reviews and manages symptom control interventions. Provides clinical supervision to inexperienced staff around issues of quality of life for a child with a palliative care need. Provides specialist level learning and development around children's palliative care issues for nursing and multidisciplinary team as part of university programmes. Recognises the impact of advanced disease or deterioration in child's condition when analysing and interpreting the clinical situation, applying judgement and evaluating the outcomes of care and interventions. Advises and liaises with others, acting as a resource to support others to achieve effective clinical outcomes. Utilises resources effectively, organising appropriate nursing cover for a clinical area that recognises the needs of specialist palliative care. Organises appropriately skilled nurses to provide 24-hour support packages to children at the end of life in the home care setting. Takes the lead professional role as required. Manages resources effectively to ensure that quality of life is optimised for a child with a palliative care need. Chairs discussions of the multidisciplinary team, drawing on the expertise, knowledge and understanding of multidisciplinary team members to develop and evaluate care for and with children and their families in relation to palliative care needs, modelling a collaborative and inclusive approach as an active member of the team.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> managerial and organisational theory to provide leadership that is sensitive to the specialist palliative care environment wide-ranging implications of the decision making of palliative care and treatment on the child, and family members the team around the child with a condition which may require palliative care the complexity of disease progression and the effect this will have on child's quality of life the principles and practices of specialist nursing practice the immediate and long-term impact and outcomes of care and treatment decisions for children and their family members. <p>Know how to:</p> <ul style="list-style-type: none"> use the audit process to improve care develop a culture of effectiveness and learning develop multi-agency policies and care pathways for children and young people requiring palliative care follow guidance on the professional and ethical issues surrounding decision making in both general terms and related specifically to children's palliative care use reflection as a tool to maintain and develop professional standards. 	<p>Influential Leader Agent of change Researcher Empowering Visionary Assertive Visionary Demonstrates clarity Innovative Accountable Advanced communicator Skilled peer support Skilled supervisor</p>	<p>Department of Health (2016) <i>National Framework for Children and Young People's Continuing Care</i>. Skills for Health (2012) <i>Competences Tools: CS 23, CS 4</i>.</p>

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	<p>Leads strategic development to create a culture where children and young people consistently experience quality palliative care that is person-centred, and effective across the care pathway and in any care setting.</p>	<p>Practices independently seeking to determine positive outcomes for children and their families. Critically analyses and synthesises complex clinical data and information to inform diagnosis and decision making. Develops detailed standards, protocols and care strategies in specialist palliative care. Influences others through dissemination of knowledge and information. Facilitates change and development and systematic evaluation. Demonstrates leadership in influencing specialist nursing practice within children's palliative care. Uses research and audit to determine evidence of best practice as a rationale for prescribed care. Actively seeks new knowledge and innovations and creates appropriate change. Debates with clarity and competence around issues of quality of life, ensuring best quality of care for the child is central to these discussions. Facilitates a common vision for developing, providing and evaluating services to children and their families that are person-centred, safe and effective as well as a team culture that can sustain this across the continuum of care and pathways.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> national policies and strategies that compliment health led guidance around children with either complex health or palliative care needs, such as education and social care policies. <p>Know how to:</p> <ul style="list-style-type: none"> critically appraise new developments/evidence to identify appropriate changes to be implemented. 	<p>Influential Leader Agent of Change Researcher Empowering Visionary Assertive Demonstrates clarity Innovative</p>	<p>Local supervision policies.</p>

3. Working with primary carers and health care professionals to identify and manage symptoms

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1	Identify and describe severity of symptoms in child or young person including recognition of pain and/or discomfort. Use this knowledge to access appropriate support from senior staff and contribute to symptom management.	Provides opportunities for children to voice and or demonstrate experiencing pain/discomfort. Alert to changes in child's behaviour. Adheres to organisational policy related to medicine management. Adheres to individual, child's care plan in relation to use of equipment and positioning of the child and administration of medicines in the community setting. Assesses child's physical wellbeing and looks for signs of distress. Uses pain and other symptom assessment tools. Recognises the need to report findings accurately to senior staff. Assists in providing non-pharmacological symptom management such as massage, music therapy and positioning. Follows individualised emergency protocols for seizure management. Administers emergency medications for seizure management in community settings. Contributes to multidisciplinary team discussions by reporting observations of child behaviour related to symptoms.	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> signs and symptoms of pain/discomfort in an individual child changes in child's behaviour distraction methods that may help to alleviate symptoms local policies relating to medicine management correct use of equipment to support position changes. the range of symptoms that may be experienced by children receiving palliative care the importance of early recognition and reporting of symptoms in children various children's symptom assessment tools non-pharmacological methods to help relieve symptoms types of seizures and how to recognise them, and use of emergency medications and possible side effects local policy and procedures relating to seizure management. <p>Know how to:</p> <ul style="list-style-type: none"> seek advice and support in the management of symptoms provide distraction methods to help alleviate symptoms use observational skills when assessing child with palliative care needs recognise non-verbal signs of pain and distress recognise and act when child is displaying symptoms administer emergency medications correctly to individual children when required. 	Sensitive Empathetic and understanding Demonstrates integrity Confidential Respectful Honest Person-centred Observant Problem solving Uses initiative Accountable	Local safeguarding policies. NHS Choices guideline: <i>Birth-to-Five Development Timeline</i> . Local policies for safe moving and handling. Together for Short Lives (2016) <i>Basic Symptom Control in Paediatric Palliative Care</i> (edition 9.5). Wong-Baker FACES Foundation (2012) <i>Wong-Baker Faces Pain Rating Scale</i> .

Level	Competence	Performance criteria	Knowledge and understanding of:	Attitudes and behaviours	Contextual factors
2	Participate effectively in discussion as an active member of the team with primary carers to identify a range of symptoms. Be involved as part of the team in planning the symptom management plans.	Works with agencies and multidisciplinary team members to manage symptoms. Follows symptom management/care plan. Assesses and records symptoms; plans symptom management collaboratively. Delivers, evaluates and records care under the direction of an experienced practitioner. Initiates discussion about symptom management. Assesses the child's needs and ensures that symptoms (including pain and thirst) are well managed. Recognises fluctuating signs and symptoms. Actively seeks and participates in peer review of own practice.	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> pathophysiology of common symptoms effective symptom management the varying symptoms that may cause distress to a child how symptoms may affect a child's wellbeing how signs and symptoms relate to the disease process. <p>Know how to:</p> <ul style="list-style-type: none"> follow care plans to treat symptoms evaluate effectiveness of treatments report effectiveness of treatment to specialist record observations of symptoms undertake a comprehensive nursing assessment evaluate clinical effectiveness of interventions and symptom control work sensitively with the family to offer support and information to inform decision making about symptom management, contributing to interventions related to family dynamics. 	Understanding Responsive Observant Communicates Actively listens Team worker Leader Compassionate	Carter B. (2015) Parents' and Children's Beliefs and Concerns About Taking Medicines, <i>Journal of Child Health Care</i> , 19(1), pp.3-5. Together for Short Lives (2016) <i>Basic Symptom Control in Paediatric Palliative Care</i> (edition 9.5). Institute of Child Health, University College London and Royal College of Nursing Institute (2012) <i>Paediatric Pain Profile (PPP)</i> . Carter B and Simons J (2014) <i>Stories of Children's Pain: Linking Experience to Evidence and Practice</i> . WHO (2012) <i>WHO guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses</i> .

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
3	Leads effective discussion on symptom management planning as a member of the team. Takes responsibility for teaching and training carers, both family and professional in managing child/young person's palliative care symptoms.	Leads in developing appropriate tools and devising action plans to help facilitate carers to identify symptoms and take appropriate steps in reducing or eliminating those symptoms. Acts as a lead resource in regard to clinical management of symptoms, involving both family and other professionals such as a GP. Evaluates environmental risk factors that may influence place of care in relation to symptom management and appropriate outcome for child. Adheres to local and national prescribing guidance but discusses with family when need arises to exceed licensed boundaries; assessing the risks and benefits with the child and carers if appropriate. Ensures all symptom management measures are documented and shared according to local policy. Recognises when treatments need to be adjusted. Assesses and rapidly synthesises complex and urgent or distressing situations. Plans therapeutic approaches to reduce symptoms with parents and other carers. Works outside licence of medications within the context of safe prescribing to help reduce child's symptoms if required.	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> counselling parents in understanding how ethical dilemmas have to be managed within the law, such as parental requests for euthanasia managing uncertainty and acute situations utilising leadership and compassionate skills within the context of complex palliative symptom management pharmacological and non-pharmacological strategies and interventions generally used within the field of children's palliative care care emergencies and appropriate responses within the context of the individual situation evidence based strategies, acknowledging further responses, including application of the use of medications off licence advance care planning and individual complex symptom management, leading the team around the child broad based evidence for the risks and benefits of symptom management approaches emerging skills and knowledge and interpreting safely their application in symptom management. <p>Know how to:</p> <ul style="list-style-type: none"> use research, prescribing formularies and multi-agency approach in ensuring appropriate, effective and timely symptom control teach others to help identify, manage and support complex symptoms teach others in a parent friendly approach how to support their child safely and effectively in managing symptoms. 	<p>Creative thinker</p> <p>Enabler</p> <p>Analytical</p> <p>Innovator</p> <p>Provides strategic direction</p> <p>Consultative</p> <p>Predictor</p> <p>Activist</p> <p>Dynamic</p>	<p>British National Formulary (2016) BNF for Children 2016-2017.</p> <p>Together for Short Lives (2016) <i>Basic Symptom Control in Paediatric Palliative Care</i> (edition 9.5).</p> <p>Regional/local care symptom management pathways.</p> <p>The Association for Paediatric Palliative Care Medicine (2017) <i>APPM Master Formulary</i> (4th edition).</p> <p>World Health Organization (2012) <i>WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illness</i>.</p> <p>Nursing and Midwifery Council (2007) <i>Standards for Medicine Management</i>.</p> <p>Twycross R and Wilcock A (editors) (2011) <i>Palliative Care Formulary</i> (5th revised edition).</p> <p>Department for Education (2015) <i>Working Together to Safeguard Children</i>.</p> <p>Together for Short Lives (2016) <i>Basic Symptom Control in Paediatric Palliative Care</i> (edition 9.5).</p> <p>Goldman A, Hain R & Liben S [Eds.] Section III Symptom Care <i>Oxford Textbook of Palliative Care for Children</i> (2nd edition), pp.167-374.</p>

<p>3 cont.</p>	<p>Provides teaching opportunities for professionals and carers at appropriate cognitive levels in regard to learning recognised techniques for symptom management.</p> <p>Participates in the development of symptom management guidelines and protocols related to children's palliative care.</p> <p>Works with stakeholders to develop and implement local guidance for symptom management; promoting evidence-based practice and cost effectiveness.</p> <p>Leads development, auditing and reporting of child-related experience of symptoms.</p> <p>Measures outcomes to produce information on the quality of the end of life care episode.</p> <p>Identifies shortfalls in appropriate symptom management.</p> <p>Identifies the need for change, proactively generating practice innovations.</p> <p>Leads new practice and service redesign solutions to better meet the needs of the child at the end of life.</p> <p>Leads on liaising with local and regional children's palliative care networks in terms of symptom management in the development of end of life care pathways.</p>	<ul style="list-style-type: none"> • prescribe pharmacological and non-pharmacological interventions • independently direct and plan the care in situations that are complex and unpredictable, both within local and national guidance, demonstrating leadership approaches when the unpredictable occurs. 	<p>Mancini A et al., (2014) <i>Practical Guidance for the Management of Palliative Care on Neonatal Units.</i></p> <p>NICE Guideline Chapter 9 [NG61] <i>Managing Distressing Symptoms. End of Life Care for Infants, Children and Young People: Planning and Management.</i></p> <p>Siden H et al., (2012) <i>Longitudinal Assessment of Symptoms in the Charting the Territory Study: When a Child has a Progressive, Metabolic, Neurological, or Chromosomal Condition, Journal of Palliative Care, 28(3), pp.230-230.</i></p> <p>Chang J et al., (2015) <i>Pain Assessment in Children: Validity of Facial Expression Items in Observational Pain Scales, Clinical Journal of Pain, 31(3), pp.189-197.</i></p> <p>Craig F, Henderson EM and Bluebond-Langner M (2015) <i>Management of Respiratory Symptoms in Paediatric Palliative care, Current Opinion in Support Palliative Care, 9(3), pp.217-226.</i></p> <p>Rosen AR and Wolfe J (2017) <i>Approaching the Third Decade of Paediatric Palliative Oncology Investigation: Historical Progress and Future Directions, Lancet Child and Adolescent Health 1:56-67.</i></p>
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Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	Utilise highly developed clinical skills and skills in teaching, research, practice development, quality improvement and service evaluation.	<p>Provides teaching opportunities for professionals and carers at appropriate cognitive levels with regards to novel techniques and practices.</p> <p>Contributes to national data collections and audits.</p> <p>Provides leadership and consultancy to initiate research in symptom management at the end of life.</p> <p>Develops strategies with local and national commissioning bodies to address shortfalls in appropriate symptom management provision.</p> <p>Leads on liaison with national children's palliative care networks in terms of symptom management and in the development of end of life care pathways.</p> <p>Influences national policy concerning appropriate symptom management provision.</p> <p>Collaborates with higher educational institutions and other education providers to meet the educational needs of health care professionals with regards to symptom management and end of life care planning.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> national and local trends in children's palliative care health and support services and community resources in developing and implementing care plans for children and their families research methods. <p>Know how to:</p> <ul style="list-style-type: none"> participate in activities that contribute to improved services across tertiary, secondary, primary and hospice settings carry out and disseminate research. 	<p>Facilitative</p> <p>Accountable</p> <p>Influential</p> <p>Enquiring</p> <p>Motivating</p> <p>Empowering</p> <p>Innovative</p> <p>Analytical</p>	<p>Royal Pharmaceutical Society (2016) <i>A Single Competency Framework For All Prescribers</i>.</p> <p>NICE Guideline Chapter 9 Managing distressing symptoms [NG61], <i>End of Life Care for Infants, Children and Young People: Planning and Management</i>.</p> <p>Widger K et al., (2014) A Scoping Review on Pain Assessment and Management in Pediatric Palliative Care, <i>Journal of Palliative Care</i>, 30(3), pp.195-195.</p>

4. Sustaining self and the wellbeing of others when caring and supporting children, young people and families with their grief, loss and bereavement

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
1	Recognise signs of distress in the child/young person and family members and enable access to appropriate support.	<p>Listens to the child talking about their anticipatory grief.</p> <p>Alerts registered nurse/practitioner of distress in child or family members.</p> <p>Adheres to local organisational guidelines related to children, families and colleagues appropriately supporting before, at the time of and after death.</p> <p>Supports and listens to grieving family members and carers.</p> <p>Respects an individual's beliefs, community, culture and religion.</p> <p>Assists with age-appropriate play to engage children in conversation to encourage them to express their feelings and emotions with regards to loss.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> key aspects of grief, loss and bereavement; impact of delivery of significant news; belief systems, culture and religion using play to express feeling and emotions own performance and own therapeutic boundaries when self support is required. <p>Know how to:</p> <ul style="list-style-type: none"> refer to another appropriate experienced member of the team follow local guidance on the practicalities of when a child dies within the acute or community setting maintain self respect and (mutual) respect for others and confidentiality allow children to express their feelings and tell their story without passing judgment acknowledge the family's loss carry out procedures with respect of their belief and religious wishes acknowledge and seek support when family members express displaced anger which is related to loss answer questions and refer to the most appropriate staff member if not able to answer. 	<p>Sensitive</p> <p>Honesty</p> <p>Genuine</p> <p>Self-aware</p> <p>Communicative</p> <p>Interested</p> <p>Compliant</p> <p>Listens</p> <p>Patient</p> <p>Non-judgmental</p> <p>Caring</p> <p>Flexible</p> <p>Compassionate</p>	<p>Chowns G (2009) <i>Swampy Ground: Brief Interventions With Families Before Bereavement</i>, in Monroe B and Kraus F (eds) <i>Brief Interventions with Bereaved Children</i> (2nd edition), pp.37-54.</p> <p>Local policy and documentation related to spiritual care.</p> <p>Local HR policies guidelines which address support and wellbeing in the workplace.</p> <p><i>Grief Encounter: Helping Bereaved Children</i>, Child Bereavement UK resource.</p> <p>Winston's Wish: The Charity for Bereaved Children.</p> <p>Child Death Helpline; anybody effected by a death of a child at any age.</p> <p>Clinical supervision local policy.</p> <p>Worden JW (2009) <i>Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner</i> (4th edition).</p> <p>Bonanno GA (2010) <i>The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life After Loss</i>. Basic Books. New York.</p> <p>Together for Short Lives (2018) <i>Spiritual, Religious and Cultural Wishes</i>.</p> <p>Crossley D (2000) <i>Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone has Died</i>.</p>

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
2	Assess, plan and provide a range of supportive and practical interventions for children and young people at the end of life, and their families, under the supervision of an experienced palliative care nurse as part of advance care planning.	<p>Behaves with appropriate sensitivity and professionalism consistently.</p> <p>Uses listening skills to support individuals in their grief.</p> <p>Accesses relevant support for children and families and refers appropriately.</p> <p>Manages workload, effectively enabling support for others as well as self.</p> <p>Implements advance care plan, evaluating this in partnership with the child and their family with support of an experienced palliative care nurse/practitioner.</p> <p>Gives advice to families and carers on practical issues following death, seeking support from more senior staff where necessary.</p> <p>Recognises own supervision needs and accesses clinical supervision.</p> <p>Uses reflection to develop practice and shares knowledge with peers and others.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> cognitive development of a grieving child how to maintain therapeutic boundaries basic theories about bereavement, including physical, psychological, social and spiritual dimensions of grief including anticipatory grief the family's experience of grief and loss prior to the death of their child local and national policies relating to self support and supporting others wellbeing in the work environment. <p>Know how to:</p> <ul style="list-style-type: none"> decide when it is appropriate to refer to another member of the team signpost family to relevant support services within or outside the organisation self reflect and describe feelings and emotions in a reflective diary identify own strengths and limitations when confronted with grief use coping mechanisms for self and other team members use advanced listening skills carry out the practicalities of dealing with death support the bereaved family's carers access clinical/restorative supervision practically support others effectively manage anger and handle conflict which is related to loss process the impact of loss and grief. 	<p>Confident</p> <p>Reassured</p> <p>Creative</p> <p>Empathetic</p> <p>Facilitative</p> <p>Assertive</p> <p>Reflective</p> <p>Professional integrity</p> <p>Proactive</p> <p>Self aware</p> <p>Realistic</p>	<p>West Midlands Children and Young People's Palliative Care Toolkit (2017) <i>Advanced Care Plan and Policy</i>.</p> <p>Together for Short Lives (2012) <i>A Guide to End-of-life Care – Care of Children and Young People Before Death, At The Time of Death and After Death</i>.</p>

Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
3	<p>Assess, plan and provide a comprehensive plan of care for a child or young person at the end of life and their families when grieving.</p> <p>At the same time, enabling the multidisciplinary team with implementing and evaluating the care plan.</p>	<p>Assesses any risks associated with the individual needs of the bereaved.</p> <p>Supports children, families, carers and work colleagues through the grief process.</p> <p>Where appropriate (depending on cognitive ability), includes the child in discussions and decision making, including their specific wishes.</p> <p>Delivers honest and accurate information about death and an opportunity for child and family, to ask informative questions (cognitive developmentally appropriate).</p> <p>Refers appropriately to other agencies and services as required.</p> <p>Advises the grieving family member on continuing support services.</p> <p>Proactively seeks out different bereavement support, assessing current provision and identifying areas for improvement within own work setting.</p> <p>Encourages reflective practice to validate and, where possible, improve upon current practice and is aware of the emotional vulnerability of staff following the death of a child.</p> <p>Through education, enables staff to develop coping strategies to support children and families affected by loss.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> children's attitudes and responses at different developmental and cognitive stages the impact cultural and religious beliefs have on the bereavement process; for example, meaning, existential, transcendental, values, beliefs, practices, spiritual advisors, rites rituals symbols, icons the determinants of grief that can influence the grieving process (such as age, gender, religion, ethnicity, culture, and relationship) ethical decision making in childrens palliative care including withdrawing/withholding life sustaining treatment theories of grief, loss and bereavement family characteristics such as demographics, culture, personal values and how this impacts on the grief process the manifestations of grief which might be physical, cognitive, emotional and or behavioral the importance of providing support mechanisms for staff the importance of understanding self as an advanced practitioner and seeking appropriate clinical/restorative supervision. <p>Know how to:</p> <ul style="list-style-type: none"> distinguish between normal and complicated grief recognise the need for emotional support with colleagues and provide this where appropriate in a trusting, confidential manner recognise and act on staff distress coordinate and lead reflective sessions for staff debriefs following the death of a child identify and refer appropriately additional support for families specific to their geographical area, including non-statutory organisations 	<p>Encourager</p> <p>Responsive</p> <p>Passionate</p> <p>Articulate</p> <p>Supportive</p> <p>Facilitative</p> <p>Responsive</p> <p>Charisma</p> <p>Resilience</p> <p>Emotional intelligence</p>	<p>Relf M, Machin L and Archer N (2010) <i>Guidance for Bereavement Needs Assessment in Palliative Care</i> (2nd edition).</p> <p>Fredman G (1997) <i>Death Talk: Conversations With Children and Families</i>.</p> <p>Hefferman M, Griffin M, McNulty R and Fitzpatrick J (2010) Self Compassion and Emotional Intelligence in Nurses, <i>International Journal of Nursing Practice</i>, 16, pp.366-373.</p> <p>Portnoy S and Stubbs D (2012) 'Bereavement', in Goldman A, Hain R and Liben S [editors] (2012) <i>Oxford Textbook of Palliative Care for Children</i> (2nd edition), pp.155-164.</p> <p>McQueen A (2004) Emotional Intelligence in Nursing Work. <i>Journal of Advanced Nursing</i>, 47(1), pp.101-108.</p> <p>Wilson J (2014) The Awareness of Emotional Intelligence by Nurses and Support Workers in an Acute Hospital Setting, <i>Journal of Health Sciences</i>, 2(9), pp.458-464.</p>

<p>3 cont.</p>			<ul style="list-style-type: none"> • role model and demonstrate the skills of effective non-verbal communication for clinical practice when caring for a dying child • role model and demonstrate the skills of reflective, open, probing and analytical questioning as a therapeutic tool • liaise with coroners, mortuary/pathology team, funeral directors • refer to local children's hospice for use of their bereavement suites (cool rooms where available) • organise transportation of the child after death according to local guidelines. 		
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Level	Competence	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	<p>Act as a facilitator for staff who require bereavement support.</p> <p>Mentor staff through case management and review influencing change in practice of children and young people with a condition which may require palliative care.</p>	<p>Acts as a resource for those providing bereavement support and how to care for themselves.</p> <p>Collects relevant data to monitor outcomes of bereavement care.</p> <p>Encourages the organisation to be open and accountable for their response to death and dying in children.</p> <p>Influences culture within the organisation and society's attitudes to death and dying of children by utilising strong evidence-based knowledge of grief and loss; in development of palliative care.</p> <p>Leads and develops local and national education initiatives in relation to bereavement.</p> <p>Builds capacity across the palliative care workforce by analysing skill gaps specific to end of life care.</p> <p>Accountable for service delivery of bereavement support.</p> <p>Takes overall responsibility for coordination of research and development programmes related to grief, loss and bereavement.</p>	<p>Knowledge and understanding of:</p> <ul style="list-style-type: none"> • how to differentiate between complicated grief reactions and depression • the importance of debriefing staff and provision of clinical supervision • complicated grief reactions and the cost of emotional labour within the workforce • end of life management including physiological changes, rites and rituals. <p>Know how to:</p> <ul style="list-style-type: none"> • direct the bereaved through to the appropriate bereavement support services available • role model and demonstrate the skills of paraphrasing, reflecting, clarifying, summarising and the use of empathy to illustrate techniques appropriate in the delivery of significant news to both the child and family • collect data to monitor and evaluate outcomes leading to effective change; this should include feedback from families, staff and referral agencies and supervisors in line with end of life strategy/ guidelines. 	<p>Facilitative</p> <p>Accountable</p> <p>Influential</p> <p>Enquiring</p> <p>Motivating</p> <p>Empowering</p> <p>Innovative</p> <p>Analytical</p>	<p>Cox K and James V (2008) Professional Boundaries in Palliative Care, in Payne S, Seymour J and Ingelton C (editors) <i>Palliative Care Nursing: Principles and Evidence in Practice</i>, pp.554-571.</p> <p>Wallbank S (2013) Reflecting on Leadership and the Model of Restorative Supervision, <i>Journal of Health Visiting</i>, 1, pp.173-176.</p> <p>Goodrich J (2011) <i>Schwartz Centre Rounds: An Evaluation of the UK Pilots</i>.</p> <p>Mastracci SH, Newman MA and Guy ME (2010) Emotional Labor: Why and How to Teach It, <i>Journal of Public Affairs Education</i>, 16(2), pp.123-41.</p> <p>Hefferman M et al., (2010) Self Compassion and Emotional Intelligence in nurses, <i>International Journal of Nursing Practice</i>, 16, pp.366-373.</p>

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Useful websites

Child Bereavement UK
www.childbereavementuk.org

Child death helpline – for anybody effected by a death of a child at any age
<http://childdeathhelpline.org.uk>

Grief Encounter: Helping Bereaved Children
www.griefencounter.org.uk

Source of learning about child development
www.sirenfilm.co.uk

Together for Short Lives
www.togetherforshortlives.org.uk/professionals/resources

Winston's Wish (the childhood bereavement charity)
www.winstonswish.org.uk

The RCN represents nurses and nursing, promotes
excellence in practice and shapes health policies

RCN Online
www.rcn.org.uk

RCN Direct
www.rcn.org.uk/direct
0345 772 6100

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