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.

The RCN and the working group drawn from the Children and Young People’s (CYP) Forum for Palliative Care would like to thank everyone involved with the development of this document, especially Fiona Smith, RCN Professional Lead for Children’s and Young People’s Nursing, for her leadership and support of this project.

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 document draws on the framework and content contained in the previous RCN Competences: Palliative Care for Children and Young People (2012) document and we are most grateful to the original authors of that publication: Rachel Cooke, Helen Jordan, Liz Lyles, Bernadette O’Gorman, Julia Shirtliffe, Jan Sutherland and Brenda Yorsten.

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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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.

Purpose of the competence framework
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.
### 1. Communicating effectively with children and young people with palliative care needs

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<th>Level</th>
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</table>
| 1     | Communicates effectively with children and young people requiring palliative care and their families, using a range of different aids. | Communicates simple information verbally or in writing to other members of the team. Communicates with children of various ages, stages of development and cognitive abilities. Establishes rapport and builds trust with the child and their family at a time of distress. Contributes to multi-professional discussions and communication. 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. Adheres to local policies in relation to accurately reporting and recording all communication and activities undertaken. | **Knowledge and understanding of:**  
- 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. | Sensitive  
Empathetic and understanding  
Integrity  
Actively listens  
Confidential  
Respectful  
Honest  
Person-centred  
Willing to receive feedback  
Assertive  
Uses initiative  
Confident  
Self aware  
Local safeguarding policies and procedures.  
Local confidentiality policy.  
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<td>2</td>
<td>Meets both comprehensive and specific complex communication needs of children /young people and their families across the continuum of care.</td>
<td>Facilitates and manages interactions with children and their families, taking into consideration the child’s age and abilities. 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. Holds conversations at the appropriate time and pace with understanding and sensitivity. Supports children and their families through times of uncertainty, applying their knowledge of communication skills. Discusses treatments, care options and symptom management plans in an appropriate manner and at an appropriate cognitive level. Communicates comprehensively with both children and families, including discussion of psychological, emotional and spiritual issues. Contributes to multidisciplinary planning and decision-making discussions. 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. Is aware of own needs and coping strategies.</td>
<td><strong>Knowledge and understanding of:</strong>  • 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  • basic level of grief theories.  <strong>Know how to:</strong>  • 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.</td>
<td>Creative Supportive Empowering Advocates</td>
<td>Mack JW and Liben S (2012) ‘Communication’, in Goldman A, Hain R and Liben S (editors) Oxford Textbook of Pediatric Palliative Care (2nd Edition), pp.23-34. Levetown M (2008) Communication with Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information, Pediatrics 2008; 121; e1441. Together for Short Lives (2013) A Core Pathway for Children with Life Limiting and Life-Threatening Conditions (3rd edition). RCN (2013) Breaking bad news: Supporting parents when they are told of their child’s diagnosis. RCN guidance for nurses, midwives and health visitors. Regional/local care pathways. Local service level agreements between community, acute and voluntary health and social care providers. Local and national policies and procedures.</td>
</tr>
<tr>
<td>Level</td>
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| 3     | Must meet, 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. | 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. | Knowledge and understanding of:  
- 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.  
**Know how to:**  
- 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 in-depth 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. | Affirming Leading | Skills for Health (2012) Competences Tools; CS20, CS22, CS30, HSC434.  
Child Bereavement UK information and resources for families. |
<table>
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<td>4</td>
<td>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.</td>
<td>Analyses and synthesises complex child and family situations and shares experiences and insights with others. Takes the lead with teaching of communication skills and child-specific modes of communication, in formal settings to specialist and non-specialist staff. Leads discussions of the multidisciplinary team that draws on members knowledge of the child and their palliative care needs. Debates with clarity and competence, whilst showing due respect for the different perspectives of others. Demonstrates advanced level clinical reasoning skills. Contributes to theory and research in children's palliative care at local and national level. Communicates evidence-based practice and highlights gaps in practice with commissioners or at strategic organisational level.</td>
<td>Knowledge and understanding of: • 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. <strong>Know how to:</strong> • 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.</td>
<td>Influential Enables learning Exercises judgement Analytical Strategic Facilitative</td>
<td>Papadatou D (2009) <em>In the Face of Death: Professionals Who Care for the Dying and the Bereaved.</em> Samuel J (2017) <em>Grief Works: Stories of Life, Death and Surviving.</em></td>
</tr>
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</table>
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)

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</table>
| 1     | Provides holistic nursing care for children/young people and families. | Delivers delegated nursing care, within defined guidelines and protocols following the prescribed care plan. Collects reliable information that informs nursing care, and which contributes to changes in prescribed care or symptom management plan. Maintains activities of daily living for a child with palliative care needs. Relays simple information to other members of the multidisciplinary team. Assists with assessment and planning of care, guided by protocols and with support from registered practitioners. Delivers, evaluates and records care with supervision from a registered practitioner to address health related problems/needs. Focuses on achieving optimum quality of life for the child and their family. Has an understanding of the implications of palliative care for the child and the wider family. | Knowledge and understanding of:  
- 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.  
Know how to:  
- 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. | Communicative  
Empathetic  
Team player  
Listens  
Responsive  
Enquiring  
Accountable  
Self aware  
Confident  
Understanding  
Creative | Local confidentiality policy.  
Skills for Health (2012) Competencies Tools; CS25, CS5, CS8, CS 22.  
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<tr>
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<th>Knowledge and understanding of:</th>
<th>Performance criteria</th>
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<tr>
<td>Resourceful</td>
<td>- the principles and practice of palliative care and symptom control</td>
<td>2 Provides comprehensive holistic and evidence-based nursing care to children and young people with complex palliative care needs across the care pathway.</td>
</tr>
<tr>
<td>Adaptable</td>
<td>- support services, voluntary agencies, hospices and charities that provide a range of palliative care services and voluntary sector.</td>
<td>Monitors the quality of work in own area and alerts others to quality issues.</td>
</tr>
<tr>
<td>Flexible</td>
<td>- the nature of a variety of palliative care conditions</td>
<td>Applies appropriate clinical judgment, in consultation with others, to provide nursing care that meets the complexity of the child’s palliative care needs.</td>
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<tr>
<td>Reflective</td>
<td>- how to plan ahead utilising resources available to promote a good quality of life</td>
<td>Works in partnership with other health and social care professionals and agencies including:</td>
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<tr>
<td>Accountable</td>
<td>- theories and principles of palliative care and how these can be applied to other members of the multidisciplinary team, for example, teachers who are also allowed in the child’s school.</td>
<td>Develops therapeutic relationships with children and their families to assist their informed choices for care and treatment.</td>
</tr>
<tr>
<td>Analytical</td>
<td>- psychosocial issues and family needs</td>
<td>Provides the child and family with choices where possible, recognising the impact these choices can have on quality of life.</td>
</tr>
<tr>
<td>Judgment</td>
<td>- the 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 allowed in the child’s school.</td>
<td>Assists the child and family in their decision making.</td>
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<td>Sensitive</td>
<td>- how to plan ahead utilising resources available to promote a good quality of life</td>
<td>Know how to:</td>
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<tr>
<td>Confident</td>
<td>- how to plan ahead utilising resources available to promote a good quality of life</td>
<td>2 Provides comprehensive holistic and evidence-based nursing care to children and young people with complex palliative care needs across the care pathway.</td>
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<tr>
<td>Knowledgeable</td>
<td>- how to plan ahead utilising resources available to promote a good quality of life</td>
<td>Evaluates outcomes of care and makes alterations appropriate to the ever-changing clinical situation.</td>
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<td>Self assured</td>
<td>- how to plan ahead utilising resources available to promote a good quality of life</td>
<td>Acts as a key worker when required.</td>
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<tr>
<td>Innovative</td>
<td>- how to plan ahead utilising resources available to promote a good quality of life</td>
<td>Know how to:</td>
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<tr>
<td>3</td>
<td>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.</td>
<td>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.</td>
<td>• 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 complexity of disease progression and the effect this will have on child's quality of life and the immediate and long-term impact and outcomes of care and treatment decisions for the child and their family • Principles and practices of specialist nursing practice • The principles and practices of specialist palliative care • The immediate and long-term impact of care and treatment decisions for children and their families.</td>
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<tr>
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<tr>
<td>Influential Leader</td>
<td>Knowledge and understanding of:</td>
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<td>Visionary Advocate</td>
<td>Knowledge and understanding of:</td>
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<tr>
<td>Action Researcher</td>
<td>Knowledge and understanding of:</td>
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<th>Attitudes and behaviours</th>
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<tr>
<td>Skilled Supporter</td>
<td>Knowledge and understanding of:</td>
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<td>Skilled Supervisor</td>
<td>Knowledge and understanding of:</td>
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<tr>
<td>Skilled Peers</td>
<td>Knowledge and understanding of:</td>
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<tr>
<td>Innovative Communicator</td>
<td>Knowledge and understanding of:</td>
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<tr>
<td>Accountable Manager</td>
<td>Knowledge and understanding of:</td>
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<tr>
<td>Advanced Clinical Practitioner</td>
<td>Knowledge and understanding of:</td>
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<tr>
<td>Skilled Supporter</td>
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</table>
| 4     | 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. | 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. | Knowledge and understanding of:  
• 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.  

Know how to:  
• critically appraise new developments/evidence to identify appropriate changes to be implemented. | Influential Leader  
Agent of Change  
Researcher  
Empowering  
Visionary  
Assertive  
Demonstrates clarity  
Innovative | Local supervision policies. |
3. Working with primary carers and health care professionals to identify and manage symptoms

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| 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. | **Knowledge and understanding of:**  
- 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.  
**Know how to:**  
- 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: *Birth-to-Five Development Timeline*.  
Local policies for safe moving and handling.  
<table>
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| 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. | **Knowledge and understanding of:**  
- 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.  
**Know how to:**  
- 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  
Institute of Child Health, University College London and Royal College of Nursing Institute (2012) *Paediatric Pain Profile (PPP)*.  
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<td>Leads effective discussion on symptom planning and management as a member of the team. Takes responsibility for clinical management of symptoms involving both family and other professionals such as a GP, pharmacist and the specialist palliative care service.</td>
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<td>Creative thinker</td>
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<td>Enabler</td>
<td>Know how to:</td>
<td>- Teach others to help identify, manage and support complex symptoms and their impact on child safety and effective and effective in managing symptoms.</td>
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</table>
## 3 cont.

| Provides teaching opportunities for professionals and carers at appropriate cognitive levels in regard to learning recognised techniques for symptom management. | • 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. |
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<tr>
<td>Works with stakeholders to develop and implement local guidance for symptom management; promoting evidence-based practice and cost effectiveness.</td>
<td>NICE Guideline Chapter 9 (NG61) Managing Distressing Symptoms. End of Life Care for Infants, Children and Young People: Planning and Management.</td>
</tr>
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<td>Leads new practice and service redesign solutions to better meet the needs of the child at the end of life.</td>
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<td>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.</td>
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| 4     | Utilise highly developed clinical skills and skills in teaching, research, practice development, quality improvement and service evaluation. | Provides teaching opportunities for professionals and carers at appropriate cognitive levels with regards to novel techniques and practices. Contributes to national data collections and audits. Provides leadership and consultancy to initiate research in symptom management at the end of life. Develops strategies with local and national commissioning bodies to address shortfalls in appropriate symptom management provision. 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. Influences national policy concerning appropriate symptom management provision. 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. | **Knowledge and understanding of:**  
- 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.  
**Know how to:**  
- participate in activities that contribute to improved services across tertiary, secondary, primary and hospice settings  
- carry out and disseminate research. | Facilitative  
Accountable  
Influential  
Enquiring  
Motivating  
Empowering  
Innovative  
NICE Guideline Chapter 9 Managing distressing symptoms [NG61]. End of Life Care for Infants, Children and Young People: Planning and Management.  
4. Sustaining self and the wellbeing of others when caring and supporting children, young people and families with their grief, loss and bereavement

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</table>
| 1     | Recognise signs of distress in the child/young person and family members and enable access to appropriate support. | Listens to the child talking about their anticipatory grief. Alerts registered nurse/practitioner of distress in child or family members. Adheres to local organisational guidelines related to appropriately supporting children, families and colleagues before, at the time of and after death. Supports and listens to grieving family members and carers. Respects an individual’s beliefs, community, culture and religion. Assists with age-appropriate play to engage children in conversation to encourage them to express their feelings and emotions with regards to loss. | **Knowledge and understanding of:**  
- 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.  
**Know how to:**  
- 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. | Sensitive  
Honesty  
Genuine  
Self-aware  
Communicative  
Interested  
Compliant  
Listens  
Patient  
Non-judgmental  
Caring  
Flexible  
Local policy and documentation related to spiritual care.  
Local HR policies guidelines which address support and wellbeing in the workplace.  
Grief Encounter: Helping Bereaved Children, Child Bereavement UK resource.  
Winston’s Wish: The Charity for Bereaved Children.  
Child Death Helpline; anybody effected by a death of a child at any age.  
Clinical supervision local policy.  
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| 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. | Behaves with appropriate sensitivity and professionalism consistently. Uses listening skills to support individuals in their grief. Accesses relevant support for children and families and refers appropriately. Manages workload, effectively enabling support for others as well as self. Implements advance care plan, evaluating this in partnership with the child and their family with support of an experienced palliative care nurse/practitioner. Gives advice to families and carers on practical issues following death, seeking support from more senior staff where necessary. Recognises own supervision needs and accesses clinical supervision. Uses reflection to develop practice and shares knowledge with peers and others. | **Knowledge and understanding of:**
  - 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.
  **Know how to:**
  - 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. | Confident
  Reassured
  Creative
  Empathetic
  Facilitative
  Assertive
  Reflective
  Professional integrity
  Proactive
  Self aware
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. At the same time, enabling the multidisciplinary team with implementing and evaluating the care plan.

- Assesses any risks associated with the individual needs of the bereaved.
- Supports children, families, carers and work colleagues through the grief process. Where appropriate (depending on cognitive ability), includes the child in discussions and decision making, including their specific wishes.
- Delivers honest and accurate information about death and an opportunity for child and family, to ask informative questions (cognitively appropriate).
- Refers appropriately to other agencies and services as required.

Assess any factors that can influence the grief process (such as age, gender, culture, personal values and how this impacts on the grief process).

- Theory 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 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

Know how to:

- Distinguish between normal and complicated grief
- Recognize the need for emotional support from colleagues and provide this where appropriate in a trusting, confidential manner
- Recognize 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 to families specific to their geographical area, including non-statutory organizations

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.

Through education, enables staff to develop coping strategies to support children and families affected by loss.
| 3 cont. | • 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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<td>- Encourage the organisation to develop local and national education initiatives in relation to bereavement care.</td>
<td>- Empowering</td>
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</table>
References


Child Bereavement UK information and resources for families including guidance for different age-groups. Available at: [https://childbereavementuk.org/for-families/infosheets](https://childbereavementuk.org/for-families/infosheets) (accessed 10 April 2018).


Institute of Child Health, University College London and Royal College of Nursing Institute (2012) *Paediatric Pain Profile (PPP)*. Available at: www.ppprofile.org.uk (accessed 10 April 2018).


NHS Choices, Birth-to-Five Development Timeline, online resource. Available at: www.nhs.uk/Tools/Pages/birthtofive.aspx (accessed 11 April 2018).


Royal College of Nursing (2012) *Competences: Palliative Care for Children and Young People*, London: RCN.


West Midlands Children and Young People’s Palliative Care Toolkit (2017) *Advanced Care Planning*. Available at: www.togetherforshortlives.org.uk/professionals/external_resources/2918_west_midlands_toolkit.


**Useful websites**

Child Bereavement UK  
[www.childbereavementuk.org](http://www.childbereavementuk.org)

Child death helpline – for anybody effected by a death of a child at any age  
[http://childdeathhelpline.org.uk](http://childdeathhelpline.org.uk)

Grief Encounter: Helping Bereaved Children  
[www.griefencounter.org.uk](http://www.griefencounter.org.uk)

Source of learning about child development  
[www.sirenfilms.co.uk](http://www.sirenfilms.co.uk)

Together for Short Lives  
[www.togetherforshortlives.org.uk/professionals/resources](http://www.togetherforshortlives.org.uk/professionals/resources)

Winston’s Wish (the childhood bereavement charity)  
[www.winstonswish.org.uk](http://www.winstonswish.org.uk)