



# Palliative care for children and young people





Royal College  
of Nursing

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# RCN Competences:

## *Palliative care for children and young people*

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## Introduction

Across the UK, there are a small number of children and young people (CYP) who require palliative care, beginning at the time of diagnosis of a life-limiting or life-threatening condition. *Together for Short Lives* ([www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)) defines this 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 the nursing and support staff who will work closely with families and other care providers to ensure the best possible quality of life for the child/young person and support for their family.

This is the first competence framework for nurses and health care support workers in the UK involved in the care of children and young people requiring palliative care. It 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. See also *Together for Short Lives* ([www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)) and NHS Scotland ([www.palliativecareguidelines.scot.nhs.uk/paediatric\\_palliative\\_care](http://www.palliativecareguidelines.scot.nhs.uk/paediatric_palliative_care)) for detailed information and resources on palliative care for 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 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 children and young people requiring palliative care. To achieve this goal, the 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 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 children’s and young people’s palliative care, specifically band 8 level.

Levels 2 to 8 of the *Knowledge and Skills Framework* are covered in the competence tables below.

Levels 2-4	Health care support worker working with supervision and support from registered nurses.
Level 5	Registered nurse with good understanding of core principles of CYP palliative care.
Level 6	Experienced nurse with detailed theoretical and practical knowledge of CYP palliative care and responsibility for leadership and management.
Level 7	Specialist expertise and competence in CYP palliative care, leading innovation and quality improvement.
Level 8	Highly expert with a national role, leading research, evidence-based standard development and practice development.

## Development and review

The framework builds on but does not duplicate core competence frameworks for nursing staff working with children and young people. It specifies the particular competences, performance and required knowledge/understanding 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. These are listed in the contextual factors column of the following 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 and young people's (CYP) palliative care community who then carried out a consensus process to agree the content and level descriptions. These members work in various care settings across the UK and have expertise in this field. RCN staff reviewed the final draft framework to check alignment with relevant core competences, particularly those related to health care assistants and assistant practitioners.

The framework will be reviewed and revised in April 2015. If you would like to provide feedback on the framework please contact the co-ordinator for the CYP palliative care community via the RCN Adviser in Children and Young People's Nursing.

## Using the competence framework for continuing professional development

The detailed tables can be used to locate your 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, children's home or other community setting).
3. Sustaining self and others' wellbeing, when caring and supporting children, young people and families with their grief, loss and bereavement.
4. Working with primary carers and health care professionals to identify and manage symptoms.

With the support of your supervisor/manager, you can then create a learning and development plan that will provide more comprehensive experience and opportunities for learning and reflecting on learning to achieve higher levels of competence. RCN members can access materials to support career development at [www.rcn.org.uk/learningzone](http://www.rcn.org.uk/learningzone)

## 1

## Communicating effectively with children and young people with palliative care needs

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
2	Communicates effectively with children and young people requiring palliative care, and their families.	Core 1	<p>Communicates simple information verbally or in writing to other members of the team.</p> <p>Communicates with children and young people of various ages, stages of development and cognitive impairment.</p> <p>Establishes rapport and builds trust with the child or young person and their family.</p> <p>Adheres to organisational policies in relation to accurate reporting.</p> <p>Contributes to multi-professional discussions and communication.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the needs of children/young people at different developmental stages</li> <li>key needs of children and young people requiring palliative care</li> <li>cognitive stages of development and impairment in children</li> <li>the importance of confidentiality</li> <li>local policies relating to appropriate reporting and the identification of risks.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>communicate with children at different developmental stages</li> <li>use verbal and non-verbal approaches effectively when communicating with child, young person and family</li> <li>use open and closed questions appropriately</li> <li>write accurate records</li> <li>use communication aids.</li> </ul>	<p>Sensitivity</p> <p>Empathy 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>Skills for Health (2012) <i>Competencies tools</i>: CS1, CS19.</p> <p>Department of Health (2008b) <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>Department of Health (2004) <i>The NHS Knowledge and Skills Framework (NHS KSF) and the Development Review Process</i>.</p> <p>Nursing and Midwifery Council (2008) <i>The Code: standards of conduct, performance and ethics for nurses and midwives</i>.</p> <p>Local safeguarding policies and procedures.</p> <p>Local confidentiality policies.</p>
3	Communicates effectively with children and young people requiring palliative care, and their families.	Core 1	<p>Uses resources such as communication aids to enable children who may have language difficulties to communicate.</p> <p>Assists with managing barriers to effective communication, eg helping a child to communicate fears or anxieties, simplifying content of information, or using communication aids to enable children to understand treatment or procedures.</p> <p>Consistently adheres to local policies in relation to accurately reporting and recording all communication and activities undertaken.</p> <p>Maintains accurate contemporary records of all communications and activities undertaken.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>common barriers to communication</li> <li>various tools that children may use to communicate eg Makaton or British Sign Language, switches or symbols</li> <li>psychological needs of the child with a palliative care condition and their families</li> <li>the role and value of families and carers as partners in supporting children during the palliative stage of illness.</li> </ul>		

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	Communicates effectively with children and young people requiring palliative care, and their families, using a range of different aids.	Core 1 HWB2	Facilitates interactions with children and their families, taking into consideration the child's age and abilities.	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the importance of ensuring the child's participation in their care planning, utilising tools/ communication aids as necessary</li> <li>the boundaries when working with the child and their family.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>use various tools to communicate with children eg Makaton or British Sign Language, switches or symbols</li> <li>seek and use interpretation services for children and families from differing ethnic backgrounds.</li> </ul>	Assertive Uses initiative Confident Self aware Advocacy	Skills for Health (2012) <i>Competencies tools</i> . CS2, CS3, CS5, CS6, CS8, CS9 CS13, CS14, CS21.
5	Communicates complex ideas to children, young people and their families and other professionals.	Core 1	<p>Works with multi-agencies and multidisciplinary team members.</p> <p>Facilitates and manages interactions with children and their families, taking into consideration the child's age and abilities.</p> <p>Is aware of own coping strategies.</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 conversation at the appropriate time and pace with understanding and sensitivity.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>skills, interactions and theoretical models that underpin effective communication with children and young people with palliative care needs, and their families</li> <li>the therapeutic nature of nursing and the impact of the nurse and child/carer relationship</li> <li>local geographical area, and awareness of other professional bodies who specialise in supporting children with palliative care needs.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>manage barriers to effective communication, eg helping a child to communicate fear and anxiety of impending treatment and possibility of death, by simplifying content of information using whatever communication tool is necessary, ie verbal, written, communication aids etc.</li> <li>access local support groups, voluntary organisations, and statutory agencies for children, young people and their families.</li> </ul>		Baille (1995) <i>Empathy in the nurse patient relationship</i> . Fallowfield (1993) <i>Giving sad and bad news</i> .

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Meets both comprehensive and specific complex communication needs of children and young people and their families, and other professionals across the continuum of care.	Core 1	<p>Supports children, young people and their families through times of uncertainty, applying their knowledge and communication skills to the child, young person or family.</p> <p>Discusses treatment and care options in an appropriate manner and at an appropriate cognitive level.</p> <p>Communicates with both children and families on a deeper level, including discussion of psychological, emotional or spiritual issues.</p> <p>Contributes to the assessing, planning and documentation of the care of children who have palliative care needs and who have a range of problems or issues.</p> <p>Contributes to multidisciplinary planning and decision-making meetings.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>multidisciplinary care pathways utilised within the clinical setting</li> <li>counselling techniques and how to use them</li> <li>legislation, policies and procedures relating to communication and record keeping</li> <li>for children and families with palliative care needs including psychological issues such as anticipatory grief</li> <li>basic grief theories.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>sensitively break news of diagnosis, and assist child and family with commencing their palliative care journey</li> <li>access resources both statutory and voluntary that support the family</li> <li>hold difficult conversations, ensuring the setting is safe and confidential</li> <li>document important conversations and communicate important facts to appropriate colleagues in confidential format that will contribute to the multidisciplinary planning and decision making.</li> </ul>	<p>Creative</p> <p>Supportive</p> <p>Empowering</p> <p>Advocates</p>	<p>ACT (2004) <i>An integrated care pathway for children and young people with life threatening or life limiting conditions and their families.</i></p> <p>Regional/local care pathways.</p> <p>Local service level agreements between community, acute and voluntary provider.</p> <p>Local and national policies and procedures.</p>



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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
7	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.	Core 1 HWB2	<p>Supports children, young people and their families through times of uncertainty, applying their specialist palliative care knowledge to the child or young person.</p> <p>Communicates confidently and effectively with children and young people.</p> <p>Discusses treatment, care options and coping strategies in an appropriate manner and at an appropriate cognitive level.</p> <p>Supports the child/young person and their family in their choices.</p> <p>Utilises integrated multidisciplinary care pathways to guide child, family and professionals in effective communication and care planning.</p> <p>Provides constructive feedback to other staff or team members on their communication style or delivery at appropriate times.</p> <p>Creates an empowering and affirming environment for families.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the complexity of disease progression</li> <li>the principles underpinning children's palliative care ie the impact of relevant conditions, diseases, treatment effects and the treatment or care options available.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>modify the content, structure and method of communication to meet the needs of the individual child/young person and their family, eg deciding what information/advice to give or not to give as the interaction proceeds</li> <li>explain in depth prognosis and life expectancy and answer difficult questions from children and young people</li> <li>explain death to a child/young person and family</li> <li>formulate or adapt multidisciplinary care pathways and individualise them</li> <li>give constructive feedback</li> <li>use counselling techniques.</li> </ul>	Affirming	<p>Skills for Health (2012) <i>Competencies tools</i>. CS20, CS22, CS30, HSC434.</p> <p>Nursing and Midwifery Council (2009) <i>Record keeping guidance for nurses and midwives</i>.</p>

## 1. Communicating effectively with children and young people with palliative care needs (continued)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
8	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.	Core 1 G1	<p>Analyses complex child/young person/family situations and shares experiences and insights with others.</p> <p>Communicates complex concepts clearly and effectively through the spoken and written word.</p> <p>Guides and supports others to improve communication skills among the team.</p> <p>Teaches communication skills and child specific modes of communication, in formal settings to specialist and non-specialist staff.</p> <p>Debates with clarity and competence, while showing due respect for the perspectives of others.</p> <p>Creates an environment that enables junior staff to share their views of patient/family issues within a multidisciplinary setting.</p> <p>Establishes a therapeutic relationship in which they are able to utilise counselling skills to assist the child, young person or family member to explore their feelings about their illness or care.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the theories and philosophies on palliative care in relation to the experiences of children and families</li> <li>family dynamics and theories/models for supporting families in crisis</li> <li>paediatric palliative care issues at a strategic and national level</li> <li>different models of counselling, their use and application.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>analyse effective communication strategies and the adequacy of theoretical models in respect to complex and diverse practice situations</li> <li>develop strategy collaboratively, and implement an operational plan</li> <li>develop a common vision</li> <li>implement monitoring and evaluation systems and shared governance.</li> </ul>	<p>Influential</p> <p>Enables learning</p> <p>Exercises judgement</p> <p>Analytical</p> <p>Strategic</p> <p>Facilitative</p>	

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## Providing multidisciplinary holistic care to children and young people with palliative care needs in any care setting (hospital, hospice, children's home or other community setting)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
2	Provides holistic nursing care for children and families under supervision.	HWB5 HWB2 HWB3	<p>Delivers delegated nursing care, within defined guidelines and protocols following the prescribed care plan.</p> <p>Collects reliable information that informs nursing care which contributes to changes in the 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><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the local policy documentation and reporting on care</li> <li>basic principles of the needs of children/young people receiving palliative care, and their families</li> <li>one's own limits of competence.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>contribute to discussions within meetings</li> <li>implement care plans and report significant changes to the senior nurse and, under direction, liaise with appropriate professionals within the team eg dietician for the food plan.</li> </ul>	<p>Communicative</p> <p>Empathetic</p> <p>Team player</p> <p>Listens</p> <p>Responsive</p>	<p>Children's Hospice UK (2004) <i>Are we getting it right? A tool to measure the quality of children's hospice services.</i></p> <p>Local confidentiality policies.</p> <p>ACT (2004) <i>An integrated care pathway for children and young people with life threatening or life limiting conditions and their families.</i></p>
3	Provides holistic nursing care and support for children and families.	HWB5	<p>Assesses child's and family's needs and recognises when to report to supervising nurse.</p> <p>Provides basic palliative care for children in the home, hospice, school or other community setting.</p> <p>Advocates on behalf of the child's and family's needs, reporting to the supervising nurse.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the basic principles of paediatric palliative care practice</li> <li>the importance of promoting a good quality of life</li> <li>the multidisciplinary team and how they contribute to the care pathway for children and young people with palliative care needs</li> <li>various professional roles and responsibilities of the team members</li> <li>choices available to children and their families.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>contribute to discussions within multidisciplinary meetings</li> <li>inform palliative children and their families about choices available to them.</li> </ul>	<p>Enquiring</p> <p>Accountable</p> <p>Self-aware</p> <p>Confident</p>	<p>Skills for Health (2012) <i>Competencies tools.</i> C525, CS22.</p> <p>Craft A. and Killen S. (2007) <i>Palliative care services for children and young people in England: an independent review for the Secretary of State for Health.</i></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>

## 2. Providing multidisciplinary holistic care to children and young people with palliative care needs in any care setting (hospital, hospice, children's home or other community setting)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	Provides holistic nursing care for children and families.	HWB2 HWB5	<p>Assists with assessment and planning of care, guided by protocols and with support from registered practitioners where required.</p> <p>Delivers, evaluates and records care with supervision from an experienced practitioner to address health-related problems/needs.</p> <p>Focuses on achieving optimum quality of life for the child/young person and their family.</p> <p>Is able to initiate a discussion around choice in palliative care.</p> <p>Has a broader understanding of implications of palliative care on the child and family.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the roles and responsibilities of the multidisciplinary care team in children's palliative care</li> <li>own role and responsibilities within the team</li> <li>the varying cognitive stages of development of the child with a palliative care need and the effect this has on decision-making.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>advocate within their knowledge base, to promote a good quality of life for the child, raising concerns and issues, with their senior nurse.</li> </ul>	<p>Understanding</p> <p>Responsive</p> <p>Confident</p> <p>Creative</p>	<p>Skills for Health (2012) <i>Competencies tools</i>. CS25, CS5, CS8.</p> <p>Department of 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>
5	Independently provides holistic nursing care for children and families.	HWB5 HWB2	<p>Monitors the quality of work in own area and alerts others to quality issues.</p> <p>Applies appropriate clinical judgement, in consultation with others, to provide nursing care that meets the complexity of the child/young person's palliative care needs.</p> <p>Partnership working with other agencies including education, social services and voluntary sector.</p> <p>Leads a discussion with support on specific topics associated with children/young people and their families with palliative care needs.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the principles and practice of palliative and specialist nursing care and symptom control</li> <li>support services, voluntary agencies, hospices and charities that families can be signposted to</li> <li>inter professional education pathways.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>utilise resources appropriate to ensure the child/young person attains a good quality of life</li> <li>incorporate end of Life planning as part of the child/young person's daily care.</li> </ul>	<p>Resourceful</p> <p>Adaptable</p> <p>Flexible</p> <p>Reflective</p> <p>Accountable</p> <p>Analytical</p> <p>Judgement</p>	<p>World Health Organization (2008) <i>WHO Definition of Palliative Care for Children.</i></p> <p>Skills for Health (2012) <i>Competencies tools</i>. CS9, CS13, CS14.</p> <p>ACT (2004) <i>An integrated care pathway for children and young people with life threatening or life limiting conditions and their families.</i></p> <p>Department for Education and Skills (2004) <i>Every child matters: change for children.</i></p> <p>Department of Health (2004) <i>The NHS Knowledge and Skills Framework (NHS KSF)</i></p> <p>Department for Education and Skills (2005) <i>Common Core of Skills and Knowledge for the Children's Workforce.</i></p> <p>Nursing and Midwifery Council (2010) <i>Standards for pre-registration nursing education.</i></p>

## 2. Providing multidisciplinary holistic care to children and young people with palliative care needs in any care setting (hospital, hospice, children's home or other community setting)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Provides comprehensive holistic and evidence-based nursing care to children and young people with complex palliative care needs across the care pathway.	Core 2 Core 5 Core 4 Core 2	<p>Develops therapeutic relationships with children, young people and their families to assist their informed choices for care and treatment.</p> <p>Leads discussions of the multidisciplinary team that draws on members' knowledge and understanding of the child/young person and their palliative care needs, participating actively and collaboratively as a member of the team.</p> <p>Provides the child/young person choice where possible, recognising the impact these choices can have on quality of life ie remaining at home at end of life.</p> <p>Interprets basic clinical data to inform decision making.</p> <p>Supports junior 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>Participates in the unit's recognised role in providing specialist advice and support.</p> <p>Develops individual learning outcomes for clinicians.</p> <p>Provides specialist learning and development around children's palliative care issues, nursing and care staff and also educational establishments.</p> <p>Is able to support others in discussions and can act as an advocate to children, young people, and families with palliative care needs.</p> <p>Is able to be a 'key worker'.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>palliative care conditions and the effect of its progressive nature, and plan ahead working with resources available to promote a good quality of life</li> <li>theories and principles of children's palliative care and how this can be applied for other non-medical/nursing staff, eg teachers who are also involved in the lives of children and young people with palliative care needs</li> <li>psychological issues and family dynamics affecting children/young people and their carers when they are at the end of life stage and integrating this into practice</li> <li>change management and decision-making processes</li> <li>advocacy</li> <li>Mental Capacity Act</li> <li>accountability.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>discuss with the child/young person what their wishes are</li> <li>recognise that choices made may conflict with carers' personal feelings, but respecting these feelings without influencing them</li> <li>manage diverse religious and cultural beliefs of families, particularly when making quality of life decisions for the child/young person.</li> </ul>	Sensitive Confident Knowledgeable Self-assured Reflective innovative	Skills for Health (2012) <i>Competencies tools</i> . CS23. Royal College of Nursing (2010b) <i>Principles of Nursing Practice: The Principles</i> .

## 2. Providing multidisciplinary holistic care to children and young people with palliative care needs in any care setting (hospital, hospice, children's home or other community setting)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
7	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	HWB2 G6	<p>Recognises the impact of advanced disease or deterioration in a child's condition when interpreting the clinical situation, applying judgement and evaluating the outcomes of care and interventions.</p> <p>Advises and liaises with others, acting as a resource to support others to achieve effective clinical outcomes.</p> <p>Utilises resources effectively, organising appropriate nursing cover for a clinical area that recognises the needs of specialist palliative care.</p> <p>Organises appropriately skilled nurses to provide 24-hour support packages to children at the end of life in the home care setting.</p> <p>Takes the lead professional role.</p> <p>Manages resources effectively to ensure that quality of life is optimised for a child/young person with a palliative care need.</p> <p>At local and national level, recognises that parents are part of the team.</p> <p>Recognises that goals sometimes have to be negotiated with children and young people and their families.</p> <p>Ensures that children and young people and their families maintain ownership of their care.</p> <p>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 young people and their families in relation to palliative care needs, modelling a collaboratively and inclusive approach as an active member of the team.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>managerial and organisational theory, in order to provide leadership that is sensitive to the specialist palliative care environment</li> <li>wide-ranging implications of the decision making of care and treatment on the child/young person and carer</li> <li>the need to manage resources, within budgetary constraints</li> <li>continuing care process for children and young people</li> <li>the team around the child</li> <li>the complexity of disease progression and the effect this will have on the child/young person's quality of life.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>utilise resources (both people and equipment) to support the child/young person to achieve the best quality of life</li> <li>develop a culture of effectiveness in the workplace</li> <li>facilitate a common vision</li> <li>evaluate service provision</li> <li>develop strategic intent</li> <li>be collaborative and inclusive.</li> </ul>	<p>Influential Leader Agent of change Researcher Empowering Visionary Assertive Demonstrates clarity Innovative</p>	<p>Department of Health (2010) <i>National Framework for Children and Young People's Continuing Care</i>.</p> <p>Children's Workforce Development Council (2009) <i>Coordinating and delivering integrated services for children and young people: the Team Around the Child (TAC) and the lead professional: a guide for managers</i>.</p> <p>Skills for Health (2012) <i>Competencies tools</i>. CS23, CS4.</p>

## 2. Providing multidisciplinary holistic care to children and young people with palliative care needs in any care setting (hospital, hospice, children's home or other community setting)

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
8	Leads strategic development to create a culture where children and young people consistently experience quality palliative care that is person-centred, safe and effective across the care pathway and in any care setting.	IK2 Core 4 Core 5 G2 Core 4 Core 5 G7	<p>Practises independently, seeking to determine positive outcomes for children and young people and their families.</p> <p>Promotes and maintains quality of life for children/young people who have a palliative care need.</p> <p>Reviews and manages symptom control interventions.</p> <p>Critically analyses complex clinical data and information to inform diagnosis and decision making.</p> <p>Develops detailed standards, protocols and care strategies in specialist palliative care.</p> <p>Influences others through dissemination of knowledge and information.</p> <p>Facilitates change and development and systematic evaluation.</p> <p>Demonstrates leadership in influencing specialist nursing practice.</p> <p>Uses research and audit to determine evidence of best practice as a rationale for prescribed care.</p> <p>Actively seeks new knowledge innovations and creates appropriate change.</p> <p>Provides clinical supervision to junior staff around issues of quality of life for a child/young person with a palliative care need.</p> <p>Debates with clarity and competence around issues of quality of life ensuring best quality of care for the child/young person is central to those discussions.</p> <p>Facilitates a common vision for developing, providing and evaluating services to children/young people 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><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the principles and practices of specialist nursing practice</li> <li>the immediate and long-term impact and outcomes of care and treatment decisions for parents and young people</li> <li>national policies and strategies that compliment health led guidance around children with either complex health or palliative care needs, eg education and schools policies</li> <li>forming, norming, performing, reforming</li> <li>accountability</li> <li>advanced communication</li> <li>peer support</li> <li>supervision.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>critically appraise new developments/evidence to identify appropriate changes to be implemented</li> <li>use the audit process to improve care</li> <li>develop a culture of effectiveness and learning</li> <li>develop multi agency polices and care pathways for children and young people requiring palliative care</li> <li>follow guidance on the professional and ethical issues surrounding decision making in both general terms and related specifically to paediatric palliative care</li> <li>use reflection as a valuable tool to maintain standards and to develop professionally.</li> </ul>		Local supervision policies.



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## Sustaining self and others' wellbeing, when caring and supporting children, young people and families with their grief, loss and bereavement

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
2	Recognise signs of distress in the child/young person and families and access appropriate support.	Core 1 Level 1(a) Core 6 level 1 Core 1 level 1 (d) & (e) Core 3	Listens to the child/young person talk about their anticipatory grief. Alerts registered nurse of distress in child and young person or family members. Adheres to organisational policies related to appropriately supporting people in the work environment of palliative care.	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>when self support is required</li> <li>key aspects of grief, loss and bereavement</li> <li>delivery of significant news</li> <li>performance and therapeutic boundaries.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>refer to another appropriate senior member of the team</li> <li>follow the local guidance on the practicalities of when a child dies within the acute or community setting</li> <li>maintain self respect and (mutual) respect for others and confidentiality.</li> </ul>	Sensitive Honest Genuine Self-aware Communicative Interested Compliant Listens	<p>Chowns G (2009) <i>Swampy ground: brief interventions with families before bereavement</i>.</p> <p>Local policies and documentation related to spiritual care.</p> <p>Local HR policies and guidelines which address support and wellbeing in the workplace.</p> <p>Royal College of Nursing (2010a) <i>A Dignity charter for RCN members</i>.</p> <p>Bereavement Services Association and Primary Care Commissioning (2011) <i>When a person dies: guidance for professionals on developing bereavement services</i>.</p> <p>Grief Encounter: Helping Bereaved Children <a href="http://www.griefencounter.org.uk">www.griefencounter.org.uk</a></p> <p>Child Bereavement UK <a href="http://www.childbereavement.org.uk">www.childbereavement.org.uk</a></p> <p>Winstons Wish: the Charity for Bereaved Children <a href="http://www.winstonswish.org.uk">www.winstonswish.org.uk</a></p>
3	Recognise signs of distress in the child/young person and families and access appropriate support.	Core 1 Level 2(b)	Reports accurately to senior staff. Supports and listens to grieving family members and carers. Respects an individual's beliefs, community, culture and religion. Assists with age appropriate play to assist in conversation.	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>grief and the grieving process</li> <li>the uniqueness of how grief is experienced by each individual</li> <li>belief systems, culture and religion</li> <li>using play to express feeling and emotions.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>allow children and young people to express their feelings and tell their story without passing judgement</li> <li>acknowledge the family's loss</li> <li>carry out procedure with respect of their belief and religious wishes</li> <li>acknowledge and seek support when family members present anger which is loss-related</li> <li>answer the questions and refer to the most appropriate staff member if not able to answer.</li> </ul>	Patient Non-judgemental Caring Flexible Compassionate	<p>Clinical supervision local policies</p> <p>Reflection tools.</p> <p>Worden J W (2009) <i>Grief counselling and grief therapy: a handbook for the mental health practitioner</i>.</p> <p>Stroebe M and Schut H (1999) <i>The Dual Process Model of Coping with Bereavement: rationale and description</i>.</p> <p>Klass D, Silverman S, Nickman S (editors) (1996) <i>Continuing bonds: new understandings of grief</i>.</p> <p>West Midlands Children and Young People's Palliative Care Toolkit (2012a) <i>ACT Family Support Sheet – Spiritual Matters</i>.</p>



### 3. Sustaining self and others' wellbeing, when caring and supporting children, young people and families with their grief, loss and bereavement

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	Provide simple supportive interventions and signpost information for the child/young person and their families who are dealing with grief and loss.	Core 1 Level 3(b) Core 6 level 2	Behaves with appropriate sensitivity and professionalism in a reassured way. Uses listening skills to support individuals in their grief. Accesses appropriate support and refers to others. Maintains a healthy work/lifestyle balance thereby enabling one to support others as well as oneself.	<b>Knowledge and understanding of:</b> <ul style="list-style-type: none"> <li>cognitive development of a grieving child</li> <li>how to maintain therapeutic boundaries.</li> </ul> <b>Knows how to:</b> <ul style="list-style-type: none"> <li>refer to another member of the team and when this is appropriate</li> <li>signpost family to relevant support services within or without the organisation</li> <li>self reflect and describe feeling and emotions in a reflective diary</li> <li>work with and accept own personal strengths and limitations when faced with grief.</li> </ul>	Confident Reassured Creative Empathetic Facilitative Assertive Reflective	Crossley D (2000) <i>Muddles, puddles and sunshine: your activity book to help when someone has died.</i>  Connected: National Communication Skills Training (2012) <i>Communication skills in cancer.</i>
5	Assess, plan and provide a range of supportive and practical interventions for a child or young person at the end of life, and their families, under the supervision of an experienced palliative care nurse as part of advanced care planning.	Core 1&4 HWB5 (3) HWB2 (3)	Implements an advanced care plan, evaluating this in partnership with the child/young person and their family with support of an experienced palliative care nurse. Uses listening skills to support individual family members/carers. Reports accurately to senior staff and is aware of the boundaries of support offered. 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.	<b>Knowledge and understanding of:</b> <ul style="list-style-type: none"> <li>basic theories about bereavement, including physical, psychological, social and spiritual dimensions of grief and anticipatory grief</li> <li>development stages including cognitive development</li> <li>local and national policies relating to self support and supporting others well-being in the work environment</li> <li>the family's experience of grief and loss prior to the death of their child.</li> </ul> <b>Knows how to:</b> <ul style="list-style-type: none"> <li>use support mechanisms for self and other team members</li> <li>use advanced listening skills</li> <li>carry out the practicalities of dealing with death.</li> <li>support the bereaved family's carers</li> <li>access clinical supervision</li> <li>practically support others effectively</li> <li>manage anger and handle conflict which is related to loss</li> <li>process the impact of loss and grief.</li> </ul>	Assured Respectful Knowledgeable Intuitive Professional integrity Proactive Self-aware Realistic	NHS National End of Life Care Programme (2012) <i>National End of Life Care Programme [for adults].</i>  West Midlands Children and Young People's Palliative Care Toolkit (2012b) <i>Guide to using the Child and Young Person's Advance Care Plan.</i>  Skills for Health (2012) <i>Competencies tools.</i> CS22, CS5, CS955.

### 3. Sustaining self and others' wellbeing, when caring and supporting children, young people and families with their grief, loss and bereavement

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Assess, plan and provide a range of supportive and practical interventions for a child or young person at the end of life appropriate to their cognitive level, and their families.	HWB1 Level 3(d) Core 4 Level 3(b) & Core 1 Level 4 (d)	<p>Assesses any risks associated with the individual needs of the bereaved.</p> <p>Supports young person, families, carers and work colleagues through the bereavement process.</p> <p>Where appropriate (depending cognitive ability) includes the child/young person in discussion and decision making as wished by them.</p> <p>Delivers honest and accurate information about death and an opportunity for the child/young person/family to ask informative questions (cognitive developmentally appropriate).</p> <p>Refers appropriately to other agencies and services as required.</p> <p>Encourages and promotes reflective practice among staff when there has been a death.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>children's attitudes and responses at different developmental and cognitive stages</li> <li>the impact of cultural and religious beliefs on the bereavement process, eg meaning, existential, transcendental, values, beliefs, practices, spiritual advisors, rites rituals symbols, icons</li> <li>the determinants of grief that can influence the grieving process (ie age, gender, religion, ethnicity, culture, and relationship)</li> <li>ethical decision making in the child/young person's palliative care including withdrawing and withholding treatment.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>distinguish between normal and complicated grief</li> <li>recognise and act on staff distress</li> <li>co-ordinate reflective sessions for staff</li> <li>recognise the need for emotional support for colleagues and provide this where appropriate in a trusting, confidential manner.</li> </ul>	Encourager Responsive Passionate Articulate Supportive	Victoria Hospice Society (2006) <i>Developmental perspectives on the experience of grieving children: their understanding and reactions and supportive interventions.</i>
7	Assess, plan and provide a comprehensive plan of care for a child or young person at the end of life and their families in complex grieving situations and at the same time developing the health care team with implementing and evaluating the care plan.	Core 1 level 4	<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 that a death of a child places on staff.</p> <p>Through education, enables staff to develop coping strategies to support children and families affected by loss.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>theories of grief, loss and bereavement</li> <li>family characteristics such as demographics, culture, personal values and how this impacts on the grief process</li> <li>the manifestations of grief which might be physical, cognitive, emotional and/or behavioural</li> <li>the importance of providing support mechanisms for staff.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>access external bereavement support services available</li> <li>demonstrate effective non-verbal communication skills for clinical practice when caring for a dying child</li> <li>demonstrate reflective, open, probing and analytical questioning as a therapeutic tool.</li> </ul>	Facilitative Responsive Charismatic	Child Bereavement Trust professional articles and leaflets.

### 3. Sustaining self and others' wellbeing, when caring and supporting children, young people and families with their grief, loss and bereavement

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
8	Act as a facilitator for staff who require bereavement support. Mentor staff through case management and review influencing change in practice of children and young people who have palliative care needs.	Core 2 level 4 (e)	Acts as a resource for those providing bereavement support, including how to care for themselves. Collects relevant data to monitor outcomes of bereavement care. Encourages the organisation to be open and accountable to their response to bereavement and loss in children. Influences culture within the organisation and society's attitudes to death and children dying by utilising a strong, evidence-based knowledge of grief and loss in development of palliative care. Leads and develops local and national education initiatives in relation to bereavement. Builds capacity across the palliative care workforce by analysing skill gaps specific to end of life care.	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>• how to differentiate between complicated grief reactions and depression</li> <li>• the importance of debriefing staff and provision of clinical supervision</li> <li>• complicated grief reactions and the cost of emotional labour within the workforce</li> <li>• end of life management including physiological changes, rites and rituals.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>• direct the bereaved through to the appropriate bereavement support services available</li> <li>• 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</li> <li>• collect data to monitor and evaluate outcomes leading to effective change, this is to include feedback from families, staff and referral agencies and supervisors in line with end of life strategy/guidelines</li> <li>• understand self as an advanced practitioner and seek appropriate clinical supervision.</li> </ul>	Facilitative Accountable Influential Enquiring Motivating Empowering Innovative Analytical	Cox K, James V (2008) <i>Professional boundaries in palliative care nursing.</i>  Davies B, Oberle K (1990) <i>Dimensions of the supportive role of the nurse in palliative care.</i>

## 4

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
2	Recognise signs of pain/discomfort in the child/young person and access appropriate support.		<p>Adheres to organisational policy related to medicine management.</p> <p>Adheres to individual child/young person's care plan re: use of equipment and positioning of child/young person.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>signs and symptoms of pain/discomfort in an individual child/young person</li> <li>distraction methods that may help to alleviate symptoms</li> <li>local policies relating to medicine management</li> <li>correct use of equipment to support position changes.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>seek advice and support in the management of symptoms</li> <li>provide distraction methods to help alleviate symptoms.</li> </ul>	<p>Sensitive</p> <p>Empathetic and understanding</p> <p>Demonstrates integrity</p> <p>Confidential</p> <p>Respectful</p> <p>Honest</p> <p>Person-centred.</p>	
3	Identify symptoms in children and measure severity, then use this knowledge to inform senior staff and contribute to symptom management.		<p>Assesses child's physical wellbeing and looks for signs of distress.</p> <p>Uses pain and other symptom assessment tools.</p> <p>Recognises the need to accurately report findings to senior staff.</p> <p>Assists in providing non-pharmacological symptom management, eg massage, music therapy and positioning.</p> <p>Follows individualised emergency protocols for seizure management.</p> <p>Administers emergency medications for seizure management in community settings.</p> <p>Contributes to multidisciplinary team discussions by reporting observations of child behaviour related to symptoms.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the range of symptoms that may be experienced by children receiving palliative care</li> <li>various children's symptom assessment tools</li> <li>non-pharmacological methods to help relieve symptoms</li> <li>types of seizures, and how to recognise them, and use of rescue medications and possible side effects</li> <li>the importance of early recognition and reporting of symptoms in children.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>use observational skills when assessing children with palliative care needs</li> <li>recognise non verbal signs of pain and distress</li> <li>recognise and act when child is displaying symptoms</li> <li>administer rescue medications correctly to individual children in emergency situations.</li> </ul>	<p>Observant</p> <p>Problem solving</p> <p>Uses initiative</p> <p>Accountable</p>	<p>Collins J et al (2000) <i>The measurement of symptoms in children with cancer.</i></p> <p>Together for Short Lives (2011) <i>Basic symptom control in paediatric palliative care.</i></p> <p>Institute of Child Health, University College London and Royal College of Nursing Institute (2012) <i>Paediatric Pain Profile (PPP).</i></p> <p>Wong- Baker Faces Foundation (2012) <i>Wong- Baker Faces Foundation.</i></p> <p>Local policies for seizure management.</p>

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
4	Participate effectively in discussion as an active member of the team with primary carers to identify a range of symptoms.		<p>Works with multiple agencies and multidisciplinary team members to manage symptoms.</p> <p>Follows symptom management care plan.</p> <p>Assesses and records symptoms and plans symptom management collaboratively.</p> <p>Delivers, evaluates and records care with supervision from an experienced practitioner.</p> <p>Initiates discussion about symptom management.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>the varying symptoms that may cause distress to a child/young person</li> <li>how symptoms may affect a child/young person's wellbeing</li> <li>how signs and symptoms relate to the disease process.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>follow care plans to treat symptoms</li> <li>evaluate effectiveness of treatments</li> <li>report effectiveness of treatment to specialists</li> <li>record observations of symptoms.</li> </ul>	<p>Understanding</p> <p>Responsive</p> <p>Observant</p> <p>Communicates</p> <p>Actively listens</p> <p>Team worker</p>	
5	Lead effective discussion as a member of the team with primary carers to identify a range of symptoms. Involved in formulating the symptom control plans.		<p>Actively seeks and participates in peer review of own practice.</p> <p>Assesses the child's needs and ensures they are pain free, adequately hydrated and symptoms are well managed.</p> <p>Recognises fluctuating signs and symptoms.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>pathophysiology of common symptoms</li> <li>effective symptom management.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>undertake a comprehensive nursing assessment</li> <li>evaluate clinical outcomes and symptom control</li> <li>work sensitively with the family to offer support and information to inform decision making about symptom management, contributing to interventions related to family dynamics.</li> </ul>	<p>Leader</p> <p>Compassionate</p>	<p>Nursing and Midwifery Council (2012) <i>Working with Young People</i>.</p> <p>Department of Health (2008a) <i>Better care: better lives: improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions</i>.</p>

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
6	Take responsibility for teaching and training carers, both family and professional in managing children's palliative care symptoms.		<p>Leads in developing appropriate tools and devising action plans to help facilitate carers to both identify symptoms and take appropriate steps in reducing or eliminating those symptoms.</p> <p>Acts as a lead resource in regard to clinically managing palliative symptoms, involving both family and other professionals, eg general practitioner.</p> <p>Consistently evaluates environmental risk assessment factors that may influence place of care in regard to symptom management and appropriate outcome for the child.</p> <p>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.</p> <p>Ensures all symptom management measures are documented and shared according to local policy.</p> <p>Recognises when treatments need to be adjusted.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>counselling parents in how ethical dilemmas have to be managed with the law, eg parental requests for euthanasia</li> <li>managing uncertainty and acute situations utilising leadership and compassionate skills within the context of complex palliative symptom management</li> <li>all drugs generally used within the field of children's palliative care as well as non-pharmalogical interventions</li> <li>palliative care emergencies and appropriate responses within the context of the individual situation.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>use research, prescribing formularies and multi agency approach in ensuring appropriate, effective and timely symptom control</li> <li>teach others in a parent friendly approach how to support the child safely and effectively in managing symptoms</li> <li>teach others to help identify, manage and support complex symptoms.</li> </ul>	<p>Creative thinker</p> <p>Enabler</p> <p>Analytical</p>	<p>British National Formulary (2012) <i>BNF for children 2012-2013</i>.</p> <p>Together for Short Lives (2011) <i>Basic symptom control in paediatric palliative care</i>.</p> <p>Regional and local care symptom management pathways.</p> <p>Association for Paediatric Palliative Medicine (2012) <i>APPM master formulary</i>.</p> <p>World Health Organization (2012) <i>WHO guidelines on pharmacological treatment of persisting pain in children with medical illness</i>.</p> <p>Twycross R and Wilcock A (editors) (2011) <i>Palliative Care Formulary</i>.</p> <p>Parliament <i>Mental Capacity Act 2005</i>.</p> <p>Parliament <i>Children Act 1989</i>.</p> <p>Department for Children, Schools and Families (2010) <i>Working Together to Safeguard Children: a guide to inter-agency working to safeguard and promote the welfare of children</i>.</p>

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
7	Utilise highly developed specialist skills underpinned with advanced theoretical and practical knowledge of the sphere of children's palliative care symptom management.		<p>Assesses and rapidly synthesises complex, urgent or distressing situations.</p> <p>Plans therapeutic approaches to reduce symptoms with parents and other carers.</p> <p>Utilises innovative and pioneering techniques or pharmacological approaches in reducing child's severe complex symptoms and empowering others through problem solving approaches.</p> <p>Works outside licence of medications within the context of safe prescribing to help reduce child's symptoms if required.</p> <p>Provides teaching opportunities for professionals and carers at appropriate cognitive levels in regard to learning recognised and revolutionary techniques for symptom management.</p> <p>Participates in the development of symptom management guidelines and protocols related to children and young people's palliative care.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>evidence-based strategies, acknowledging further responses including application of the use of medications off licence</li> <li>advance care planning and individual complex symptom management, leading the team around the child</li> <li>broad-based evidence for the risks and benefits of symptom management approaches</li> <li>emerging skills and knowledge and interpreting safely their application in symptom management.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>prescribe non-medical interventions</li> <li>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.</li> </ul>	<p>Innovator</p> <p>Provides strategic direction</p> <p>Consultative</p> <p>Predictor</p> <p>Activist</p> <p>Dynamic</p>	<p>National Prescribing Centre (2012) <i>A single competency framework for all prescribers.</i></p>

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

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviours	Contextual factors
8	Utilise a strong evidence-based knowledge across the range of symptom control interventions pertinent to palliative care needs of the child.		<p>Works with stakeholders to develop and implement local guidance for symptom management, promoting evidence-based practice and cost-effectiveness.</p> <p>Leads on developing, auditing and reporting on child-related experience.</p> <p>Measures outcomes to produce information on the end of life care episode, including contributing to national data collections and audits.</p> <p>Initiates research in symptom management at the end of life through leadership and consultancy.</p> <p>Identifies shortfalls in appropriate symptom management and develops strategies with local commissioning bodies to address them.</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 and the end of life.</p> <p>Leads on liaising with local, regional and national children's palliative care networks in terms of symptom management in the development of end of life care pathways.</p> <p>Influences national policy concerning appropriate symptom management.</p> <p>Collaborates with higher educational institutions and other education providers to meet the educational needs of health care professionals in regards to symptom management and end of life care planning.</p>	<p><b>Knowledge and understanding of:</b></p> <ul style="list-style-type: none"> <li>national and local trends in children's palliative care</li> <li>health and support services and community resources in developing and implementing care plans for children and their families</li> <li>research methods.</li> </ul> <p><b>Knows how to:</b></p> <ul style="list-style-type: none"> <li>participate in activities that contribute to improved services across tertiary, primary and hospice settings</li> <li>carry out and disseminate research.</li> </ul>	<p>Facilitative</p> <p>Accountable</p> <p>Influential</p> <p>Enquiring</p> <p>Motivating</p> <p>Empowering</p> <p>Innovative</p> <p>Analytical</p>	



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## Useful websites:

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### Connected: National Communication Skills Training.

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### Grief Encounter: Helping Bereaved Children.

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Available at: [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk) (Accessed 8 October 2012) (Web).

### Winston's Wish: the Charity for Bereaved Children.

Available at: [www.winstonswish.org.uk](http://www.winstonswish.org.uk) (Accessed 8 October 2012) (Web).

### Wong-Baker Faces Foundation.

Available at: [www.wongbakerfaces.org](http://www.wongbakerfaces.org) (Accessed 8 October 2012) (Web).



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