

Caring for Infants, Babies, Children and Young People Requiring Palliative Care

A career and education framework



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Note: The term 'child' is used to encompass the entire span of childhood, from pre-birth to late adolescence, including babies, children and young people (BCYP).

It is recognised that care may be provided by registered nurses and midwives, health care support workers, assistant practitioners, nursing associates and student nurses and midwives, and trainee nursing associates. For ease of reading, the generic terms 'nurse', 'nursing' and 'nurses' are used throughout this document, unless specified.

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1 Summary

There is an increasing number of babies, infants, children and young people across the UK who require palliative care. Together for Short Lives (togetherforshortlives.org.uk) defines palliative care as:

"Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end-of-life and bereavement support".

Palliative care may be introduced at any point throughout a child's life. Some children may require palliative care from birth; others only as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed at cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-shortening condition or from recognition that curative treatment for a life-threatening condition is not likely to achieve the desired outcome. However, each situation is different and care should be needs-led and tailored to the individual child and their family.

Safe and effective palliative care requires specific competencies for nursing and support staff who work with children and their families in the home, hospital, hospice and in other environments such as school.

This document is a significant revision of the first and second editions (2012/2018). It builds on a number of best practice guidance documents and resources shared in the References section.

Readers are also directed to the following resources:

Together for Short Lives togetherforshortlives.org.uk

NICE guideline [NG61] End of Life Care for Infants, Children and Young People (2016) nice.org.uk/guidance/ng61

Specialist palliative and end of life care services: Children and young people service specification for England (2023) england.nhs.uk/publication/service-specifications-for-palliative-and-end-of-life-care-children-and-young-people-cyp

Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 (2022) england.nhs.uk/publication/service-specifications-for-palliative-and-end-of-life-care-children-and-young-people-cyp.

2 Background to UK BCYP Palliative Care Services

In England, the prevalence of children with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18 (Fraser et al, 2020). It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030.

Palliative care is provided to children with a wide range of life-limiting or life-threatening conditions (in excess of 300 different conditions). Some children will have severe disabilities with multiple and particularly complex health care needs related to their condition, as well as palliative care needs. However, up to 15% of children and young people with palliative care needs do not have a definitive underlying diagnosis (NHS England, 2023) (B1675-specialist-palliative-and-end-of-life-care-services-cyp-service-spec.pdf.pdf (england.nhs.uk)

Access to palliative care should therefore not depend on diagnosis or overall prognosis and can be provided at any stage of a child's illness.

Services which offer palliative care will support and care for children and their families at any point from diagnosis or recognition of palliative care needs, through active treatment, including that aimed at cure, to end-of-life care and into bereavement.

The needs of children and families living with more complex and/or long-term conditions that are life-limiting or life-threatening cannot usually be met by the capabilities of their core team alone. They will need input from a workforce with specialist palliative care skills and expertise.

The NHS England Long Term Plan (2019) sets out children's palliative care as an important priority and has pledged to increase funding.

In Northern Ireland, A Strategy for Children's Palliative and EOL Care (2016) sets out the planned direction for palliative and end-of-life care of ill and dying children and young people for the next ten years. The 2021 review showed much effort has taken place and movement towards the objectives set at the halfway point and outlined areas for ongoing focus.

The Framework for the Delivery of Palliative Care for Children and Young People in Scotland sets out a safe, effective and person centred approach to palliative care for children and young people. There are recognised pathways for palliative care within and between Health Boards, in partnership with Social Work, Education, Children's Hospice Association of Scotland (CHAS) which take into consideration the age, geographical and social needs of their particular population of children and young people from the point of diagnosis of a life-limiting condition or life-threatening condition, through to living with their conditions until the end of their life.

The Welsh Government (October 2022) set out its vision for palliative and end-of-life care in Wales "for all who need it by people working closely together at home when appropriate determined by what matters to the person and underpinned by what works".

"Children and young people with life-shortening conditions and their families should be able to access 'wrap around' care that offers therapeutic services which enable them to live their best lives and reach their full potential" (gov.wales/quality-statement-palliative-and-end-life-care-wales-html).

3 Framework structure

A competency framework describes the range of knowledge, skills and performance levels required of nurses and nursing support workers including nursing associates and assistant practitioners working in a specialty to help them achieve safe, effective and accountable practice.

This framework has a broad range of scope to address the variety and complexity in palliative care but does not aim to replicate competencies that are core to all registered nurses, rather focuses on palliative specific care, or general care where there is the need for particular considerations in the context of children's palliative care.

The framework sets out competencies for knowledge and skills across 5 topic areas in children's palliative care relevant to career stages, highlighting the professional development required by a nursing care workforce spanning 7 levels of role from pre-registration practitioner to nurse consultant. The 5 topic areas are:

- 1. communicating effectively
- 2. multidisciplinary holistic care
- 3. identify and manage symptoms
- 4. grief, loss and bereavement
- 5. leadership and management.

This 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 this specialist field, allowing individuals 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 palliative care, specifically strategic leadership roles
- describes 7 levels of role with descriptors.

The Nurse Level Key (Table 1) provides a guide for levels of practice for individual practitioners. These align with the RCN Levels of Nursing (2024).

These also loosely align with NHS Employers Agenda for Change roles, however due to the lack of protected job titles, standardised job descriptions and often different rates of pay outside the statutory health sector, each organisation providing children's palliative care should adapt this guidance to suit the needs of its own workforce including where these are multiprofessional roles.

Table 1 Nurse level key

The table below identifies roles and descriptors used in the framework:

Preregistration practitioner	Pre-registration nursing student (under supervision) including novice health care support worker
Nursing support workers (supportive)	Unregistered support worker including health care support worker, care assistant, nursery nurse
Registered nursing associate, assistant practitioner and nursing support worker (assistive)	Registered nursing associate and assistant practitioners
Registered nurse	Registered nurse
Enhanced	Example roles: Nurse specialist Nurse practitioner in children's palliative care Children's community nurse Advanced nurse practitioner in children's palliative care (training) Advanced clinical practitioner in children's palliative care (training)
Advanced	Team leader for children's community nursing Team leader for children's palliative care service Advanced clinical practitioner in children's palliative care (qualified) Advanced nurse practitioner in children's palliative care (qualified) Clinical nurse specialist
Consultant	Nurse consultant children's palliative care Lead nurse

Framework development and review

Initial drafting and review of the competencies was undertaken by members of the RCN children's and young people's palliative care community working in a range of care settings across the UK. The contributors then undertook a consensus process to agree the content and level descriptions before review of the final draft framework by the RCN to check alignment with other relevant core competencies.

This competency framework acknowledges that at the time of publication, work is being undertaken by the RCN and The Department of Health across the UK.

4 How to use the framework

The framework is intended as a guide to professional development. It facilitates assessment of an individual's progress and is not intended to be overly prescriptive.

The framework can be used to focus self-directed learning and/or as a tool to support learning and development conversations between a supervisor/manager/coach and their individual supervisees.

Pre-requisite education, skills and knowledge

This framework helps to establish a pathway of development from student (including nursing apprenticeship), unregistered support workers, nursing associates, and registered nurse through to specialist level nursing posts.

The pre-requisite education, skills, and knowledge for each level of practice are set out by the 'standards' listed in the references to gain entry to nursing. Locally derived job descriptions specify entry level for unregistered support worker roles. The framework focuses on competencies that are directly applicable to children's palliative care nursing. It is not the intention to replicate baseline expected nursing standards which are outlined elsewhere.

Standards for nurses - The Nursing and Midwifery Council
Standards for nursing associates - The Nursing and Midwifery Council
Standards for pre-registration nursing programmes - The Nursing and Midwifery Council

The detailed competency tables that follow have been structured to enable individuals to locate their current level of expertise in 5 dimensions with guidance across seven levels of role and responsibility. These are:

- 1. communicating effectively with BCYP with palliative care needs
- 2. providing multidisciplinary holistic care to BCYP 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 BCYP and families with their grief, loss and bereavement
- 5. leadership and management.

Identifying which competencies apply to the nursing care roles

The competencies in each section are separated for:

Learning outcomes: This is the knowledge that nurses need. This also informs higher education institutions (HEI) and course study day leaders on theory content.

Practice competencies: These are the practical skills that should be demonstrable in clinical settings.

There are some practical competencies that are not applicable for some roles.

Identifying what level of competence is needed and in what timeframe

The competency framework uses Benner's (1984) stages of clinical competence as the taxonomy for assessment of achievement, see Table 2 below. While there are benefits with using a stated taxonomy to guide the assessment of levels of achievement, there may be variation in local interpretation and for some competencies. It may also be difficult to distinguish between taxonomy characteristics at higher levels of practice. There may be instances where an assessor/supervisor/manager needs to establish if a practitioner/clinician is competent or not.

The acronyms for each classification are used in the competency work-based record sheets.

Table 2 Benner's (1984) novice to expert classification

Classification	Description of behaviours to apply to job role and responsibilities
Novice (N)	No previous experience of the situation or tasks expected to perform Focus is on the task; follows rules/ guidelines to perform the task If something happens and unable to follow guidelines will be stuck and unable to move on without guidance Unable to prioritise tasks; prefers/ needs to be told what to do Lacks confidence to demonstrate safe practice and requires continual verbal and physical cues, practice is slow (needs lots of support) Unable to use discretionary judgement or predict what might happen in a particular situation.
Advanced beginner (AB)	Demonstrates marginally acceptable performance as a result of prior experience in actual situations Efficient in parts of practice area, requiring occasional supportive cues, may or may not still be slow in practice Knowledge and know-how is developing; experience is needed before being able to apply guidelines to individual patients Still needing support in clinical setting.
Competent (C)	Has experience in field of work, is co-ordinated and has confidence in own actions Has developed good time management and organisational skills Care is completed within a suitable timeframe without supporting cues Sees the patient as a whole and has understanding of what might happen Can recognise patterns and nature of clinical situations more quickly and accurately than an Advanced Beginner Has the ability to cope with and manage contingencies but does not have the speed and flexibility of those at the proficient level.
Proficient (P)	Capable to practice autonomously with high level theoretical knowledge, skills and decision making Demonstrates a systematic application of knowledge and critical awareness (can think further forward and anticipate needs) Works, liaises and communicates effectively within the multidisciplinary team and with other specialities/agencies Demonstrates advanced communication skills. including the ability to have difficult or complex conversations with the child, family and carers Perceives and understands a situation as a whole (has high level holistic understanding and perceives the situation in terms of long-term goals) Understands from experience what to expect in a given situation; recognises when the expected normal changes or goes wrong and can modified plan of care in response.
Expert (E)	Acts autonomously, disseminates knowledge and can supervise learners within the multidisciplinary team Excellent indepth theoretical knowledge and clinical skills Shows intuitive understanding of critical situations and can troubleshoot problems that may arise Has an intuitive grasp of each situation and can focus on the problem without wasteful consideration of alternative diagnoses and solutions Operates from deep understanding of the total situation and performance is fluid, flexible and highly proficient Has highly skilled analytic ability for situations where there is no previous experience Initiates innovative practice and continuously reviews the service and development.

(Competence to Practice Guidelines, EACH, 2022)

Who can assess competence?

Learning outcomes or knowledge-based competencies may be assessed in a variety of ways through completing courses, study days, e-learning or self-directed study. As such this may take the form of marked assignments, reviewing completed workbooks, teacher evaluation from participating in debate during study days, completing e-learning quizzes and tests, writing reflective pieces that are discussed with supervisors, reflective discussions with assessors, or writing for publication.

Competencies may be assessed using locally agreed criteria for those designated as assessors. Guidance on supervision and assessment of practice is also available via the Nursing and Midwifery Council, Standards for student supervision and assessment - The Nursing and Midwifery Council. An assessor does not need to hold the competency themselves as long as they understand the competency statement and any organisational policies or procedures related to it (local, regional, or national). They should be recognised by their organisation or service as an assessor.

5 Recording progress: Work-based record sheets

The competencies section in this guidance is followed by work-based record sheets for that section as recommended in the RCN *Competency Template* (RCN, 2021).

The work-based record sheets are designed to support all steps in the process to record learning and development achievements, plans and progress. They lend themselves to assessment of practice at a local level and may be completed as self-assessment or through more formal assessment by supervisors, and in partnership with members of the wider multi-professional team.

Local educators and/or managers should identify how the framework supports local practice relevant to their setting. Where practitioners have access to support, including preceptorship, appraisal, or practice facilitation, the work-based record sheets may be used to record achievement. Academic course leaders may also determine how the framework can support course development, learning outcomes, how learning may be assessed and recorded, and by whom. Where the workforce does not have access to support and resources to enable competence assessment, the framework may be used to support self-directed learning and/or acquisition of skills, as well as workplace appraisal and NMC revalidation.

Action plans at the bottom of each record sheet, can be used to guide future individual development through the taxonomies, or when a desired taxonomy level has not been met. On each record sheet one of the competencies has been selected to show an example. Each record sheet example uses a different practice level to illustrate how evidence of achievement may vary.

Evidence to demonstrate competence

When providing or reviewing evidence, consider the following points:

- ensure you understand what the competence statement requires
- consider pre-existing evidence, for example earlier competencies/assessments, which may demonstrate knowledge and skills
- does the evidence demonstrate both knowledge and skill? For example, attendance at a study day and supervised practice
- use of a reflective model eg, NMC Revalidation reflective accounts Written reflective accounts - The Nursing and Midwifery Council)
- use of evidence which encompasses multiple competencies eg, a case study demonstrating the application of a range of knowledge and skills
- are there gaps in the evidence and, if so, is there an action plan in place?

Examples of evidence

A wide variety of evidence may be provided to demonstrate attainment of knowledge and skills to fulfil competencies within the framework.

These may include:

- 360° feedback
- formal assessments and appraisals
- audits
- case studies
- certificates of attendance for study sessions/days
- certification for continuing professional development (CPD)
- clinical supervision
- critical incident analysis
- evidence of completing higher education study
- · evidence of group work
- evidence of membership of advisory groups
- evidence of qualification or verification of practice
- locally identified workbooks/e-learning
- policy and protocol development
- posters
- practice developments/changes in practice
- projects
- · publications and presentations
- reflective diaries, including self-appraisal
- research and evidence-based reviews
- service user feedback eg, 'thank you' cards
- signed evidence of supervised practice
- structured reflections eg, NMC Revalidation reflective accounts nmc.org.uk/revalidation/requirements/written-reflective-accounts
- · structured witness statements
- · supervised practice or peer review
- writing for publication.

These are examples and the list is not exhaustive.

6 Competencies

Please refer to Nurse level colour key on page 8

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Co	mmunicating effectively							
Com	municating effectively with children with pa	lliative care needs	S.					
Lear	ning outcomes - practitioners will be able to:	Preregistration practitioner (under supervision)	Unregistered support worker	Registered nursing associate & assistant practitioners	Registered nurse	Enhanced level	Advanced level	Consultant level
1.1	Discuss the importance of effective person-centred communication in children's palliative care							
1.2	Demonstrate knowledge of communication theories and how they are applied in practice, including barriers and facilitators of effective communication in children's palliative care							
1.3	Explore the importance of multi- professional communication in children's palliative care and how this can be enhanced							
1.4	Identify supportive strategies which will help those providing palliative care to develop emotional resilience							
	ctice competencies with children/far titioners will be able to demonstrate an abilit							
1.5	Select and adopt an effective communication approach, from a range of core communication skills, to assess the information, education and supportive care needs of the child, family and carers throughout their palliative care journey							

1.6	Enable child/family to communicate fears and concerns supporting them through times of uncertainty				
1.7	Build rapport and trust with families displaying sensitivity and empathy at times of distress				
1.8	Assist with managing barriers to effective communication, and adapt to manage fears or anxieties, simplifying content and using communication aids as needed to enable children's understanding				
1.9	Adhere to local care policies ensuring written communication is factual and concise				
1.10	Maintain accurate contemporaneous records across all aspects of palliative care and multi-professional interactions				
1.11	Show awareness of psychological, emotional and spiritual needs when communicating with children and their families				
1.12	Adapt communication to meet the needs of families and children dependent on age and abilities referring to specialist colleagues if required eg, SALT				
1.13	Demonstrate advanced communication skills with children and families				
1.14	Empower families to make informed decisions in conjunction with the multidisciplinary team				
1.15	Assess, plan, document and evaluate the communication needs of children and their family members				
1.16	Discuss treatments, care plans, symptom assessment and management tools (eg, pain) according to role				

1.17	Lead a discussion with the child/family on key issues such as choice of preferred place of care				
1.18	Listen and reflect with families regarding uncertainties in issues such as diagnosis, decision making, advance care planning, dying, and talk through with sensitivity symptom and advance care planning and options for specialist service delivery				
1.19	Communicate effectively outcomes from multidisciplinary team/meeting to support choices based on evidence and best practice for symptom and/or advance care plans or plans for the provision of service/care to children and their family members				
	etice competencies as part of the tea citioners will be able to demonstrate an ability	he team			
1.20	Communicate information verbally or in writing to other member of the team, by adapting communication to ensure information is shared well				
1.21	Effective communication in pre-brief/ de-brief				
1.22	Recognise and communicate own emotional needs seeking help as appropriate				
1.23	Provide constructive feedback to others on style/delivery				
1.24	Deliver an accurate account of history taking and clinical decision making and evidence of a physical/advanced/health assessment skills module				
1.25	Generate high quality written communication from visits/deaths/ transition including discharge summaries. Demonstrate high quality verbal communication, preparing: advance care plan, ambulance directive, symptom management plan				

1.26	Demonstrate completion of advanced communication training, and ability to apply these skills in practice navigating complex situations with advanced level clinical reasoning skills				
1.27	Appropriately utilise communication in order to promote clear and unambiguous information exchanges with other members of the multidisciplinary team and wider networks				
1.28	Lead the specialist paediatric palliative care multidisciplinary team meeting, including debating with clarity and confidence and sensitivity, creating an environment that enables the sharing of views and opinions				
1.29	Analyse and synthesise complex child information and present experiences and insights with others. Communicate complex concepts clearly and effectively				
1.30	Teach communication skills to others in specialist and non-specialist roles using a variety of delivery methods to accommodate different learning styles				
1.31	Demonstrate ability to communicate and collaborate with commissioners and funders at a strategic organisational/ regional/national level				
1.32	Utilise child and family feedback, compliments and complaints to advance service development and improvement				

Multidisciplinary holistic care

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

. 101	iding mutualsciptinary notistic care to borr with pathative care needs in any care setting (nospitat, nospice, the nome, school of other community setting).								
Lear	ning outcomes - practitioners will be able to:	Preregistration practitioner (under supervision)	Unregistered support worker	Registered nursing associate & assistant practitioners	Registered nurse	Enhanced level	Advanced level	Consultant level	
2.1	Identify the impact of having palliative care needs on the physical, psychological, emotional, social and spiritual wellbeing of the child, family and carers								
2.2	Understand the complex and changing information, educational and supportive care needs of the child, family and carers								
2.3	Discuss what can optimise activities of daily living and quality of life for the child and their family								
2.4	Explain the function of the multidisciplinary team and importance of the key worker/case manager/co-ordinator role								
	essment and care planning practice titioners will be able to demonstrate an ability								
2.5	Provide holistic and evidence-based nursing care that meets the child's palliative care needs across the care pathway								
2.6	Deliver delegated nursing care, within defined guidelines and protocols following a prescribed care plan								
2.7	Gather accurate information that assists with assessment and planning of nursing care, and which contributes to changes in prescribed care or symptom management planning								
2.8	Practice independent nursing care which promotes positive outcomes for children and their families								

2.9	Share a common vision for developing, providing and evaluating holistic multidisciplinary services to children and their families that are person centred, safe and effective as well as promoting a team culture that can sustain this across the continuum of care and pathways				
2.10	Utilise integrated multidisciplinary care pathways to guide both child, family and professionals in effective care planning				
2.11	Recognise the impact of advanced disease or deterioration in child's condition when analysing and interpreting the clinical situation, and apply judgement to evaluate the outcomes of care and interventions				
2.12	Critically analyse complex clinical data and information to inform diagnosis and decision making				
	lity of life practice competencies itioners will be able to demonstrate an ability	y to:			
2.13	Promote quality of life and best interests for children with palliative care needs				
2.14	Advocate, hold others to account, and challenge with clarity and competence regarding issues of holistic care and quality of life, and ensure best quality of care for the child is central to these discussions				
	ordinating care practice competenci itioners will be able to demonstrate an ability				
2.15	Work in partnership with other sectors and agencies including health, education, social services and voluntary sector				
2.16	Seek opportunities and promote ways of collaborative working across care settings and sectors to facilitate seamless care				
2.17	Adopt a lead professional role in co-ordinating complex care when required				

2.18	Lead multidisciplinary team meetings, and draw on the expertise, knowledge and understanding of multidisciplinary team members to develop and evaluate care for and with children and their families, modelling a collaborative and inclusive approach as an active member of the team								
2.19	Write and implement standards, protocols, policies and care strategies in specialist palliative care and promote their use in practice across agencies								
	rmation and education practice com itioners will be able to demonstrate an ability	-							
2.20	Provide child and family with choices where possible, and recognise the impact these choices can have on quality of life, for example, remaining in hospital or staying at home at end-of-life								
_	Empowerment practice competencies Practitioners will be able to demonstrate an ability to:								
2.21	Build therapeutic relationships with children and their family to enable their informed choices for care and treatment								

Identify and manage symptoms

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

*****	king with primary carers and health care professionals to identify and manage symptoms.								
Leari	ning outcomes - practitioners will be able to:	Preregistration practitioner (under supervision)	Unregistered Support Worker	Registered nursing associate & assistant practitioners	Registered nurse	Enhanced level	Advanced level	Consultant level	
3.1	Explain the core principles of effective symptom management								
3.2	Describe the holistic and multidisciplinary approach to symptom assessment, management and evaluation. Recognise the benefits of symptom assessment and evaluation tools								
3.3	Identify how anticipatory symptom management planning and prescribing is essential for effective end-of-life care								
3.4	Define the range of physical, psychological and spiritual symptoms which may be experienced at end-of-life								
3.5	Evidence appropriate non-medical prescribing qualification competency as required								
	ctice competencies with children/far								
3.6	Enable children to voice and or demonstrate experiencing pain/discomfort								
3.7	Recognise and report changes in child's behaviour and condition								
3.8	Follow organisational policy and individualised care plans including related to medicines management to support effective symptom management								
3.9	Follow individualised care plan for equipment use, moving and handling and positioning to support effective symptom management								

3.10	Provide non-pharmacological symptom management such as massage, music therapy and positioning				
3.11	Facilitate individualised therapeutic strategies to reduce psychological symptoms				
3.12	Collaborate with the team around the child to manage symptoms				
3.13	Use standard symptom assessment tools eg, pain, dystonia, agitation to assist carers to identify and manage symptoms				
3.14	Follow local policy for documenting and sharing symptom management treatment information including consultation and evaluation				
3.15	Recognise when treatment plans need review and adjustment				
3.16	Follow individualised emergency protocols and administer medication such as for seizure management				
3.17	Assess, plan, deliver, evaluate and record individualised care and symptom management for the child				
3.18	Identify and mitigate risks associated with symptom management for example when identifying preferred place of care and death				
3.19	Assess and take urgent action for distressing and complex symptoms and situations				
3.20	Recognise the risks and burdens of treatment options				
3.21	Prescribe safely and effectively in line with the competency framework for all prescribers (Royal Pharmaceutical Society, 2021) and according to sphere of practice				

3.22	Negotiate treatment goals, end-of-life decisions and ceilings of care							
3.23	Develop and use individualised symptom management plans to assist carers and other professionals to identify and manage symptoms							
	Practice competencies as leaders and managers Practitioners will be able to demonstrate an ability to:							
3.24	Provide clinical leadership in the management of physical, psychological and spiritual symptoms, involving family members and the multidisciplinary team around the child							
3.25	Teach a range of symptom management techniques to professionals and carers							
3.26	Participate in the development of system- wide symptom management guidelines and protocols							

Grief, loss and bereavement

Sustaining self and the wellbeing of others when caring and supporting BCYP and families with their grief, loss and bereavement

Oust	Sustaining sett and the wettbeing of others when caring and supporting Bott and families with their girel, toss and believement							
Lear	ning outcomes - practitioners will be able to:	Preregistration practitioner (under supervision)	Unregistered support worker	Registered nursing associate & assistant practitioners	Registered nurse	Enhanced level	Advanced level	Consultant level
4.1	Explore theories of loss, grief and bereavement and describe how these are applied in clinical practice							
4.2	Consider own beliefs, attitudes and values to death, dying and bereavement and how these may impact on care delivery							
4.3	Define the goals of care when a child is dying, encompassing their own goals in the context of their family and carers eg, preferences for location of care, child comfort and dignity, symptom management, family and caregiver support							
4.4	Describe the signs of dying and distinguish between reversible treatable symptoms, those that could be minimised by treatment, and those which may indicate the final phase of life							
	ctice competencies with children and titioners will be able to demonstrate an ability							
4.5	Recognise signs of distress in the child and family members and enable access to appropriate support							
4.6	Support and actively listen to the child, grieving family members and carers about their worries or concerns							
4.7	Assist in age-appropriate play to engage children in conversation to encourage them to express their feelings and emotions with regards to loss							

4.8	Follow local organisational guidelines related to supporting children, families and colleagues before, at the time of, and after death				
4.9	Respect an individual's beliefs, community, culture, spirituality and religion				
4.10	Give advice to families and carers on practical issues following death, and seek support from more experienced team members where necessary				
4.11	Support children, families, carers and work colleagues through the grief process				
4.12	Deliver honest and accurate information about death and provide opportunities for child and family to ask questions (cognitive and developmentally appropriate)				
4.13	Provide a range of supportive and practical interventions for children at the end-of-life, and their families as part of advance care planning, referring to other sources of support as required				
4.14	Implement the advance care plan, and review in partnership with the child and their family with support of an experienced palliative care nurse/practitioner where necessary. Include the child in discussions and decision making, including their specific wishes (where appropriate, depending on cognitive ability)				
4.15	Assess, plan, provide and evaluate a comprehensive plan of care for a child at the end-of-life and their families when grieving				
4.16	Assess any risks associated with the individual needs of the bereaved advising on continuing support services as required				
4.17	Care for a dying child and provide care for the body after death				
4.18	Performing verification of death				

	cal leadership practice competencie itioners will be able to demonstrate an ability				
4.19	Collect relevant data to monitor outcomes of bereavement care				
4.20	Encourage the organisation to be open and accountable in their response to death and dying in children				
4.21	Proactively seek out bereavement support, assess current provision and identify areas for improvement within own work setting				
4.22	Enable colleagues to develop coping strategies to support children and families affected by loss through education and professional development				
4.23	Act as a facilitator for colleagues who require bereavement support				
4.24	Act as a resource for those providing bereavement support and how to care for themselves				
4.25	Influence culture within the organisation and society's attitudes to death and dying of children by using strong evidence-based knowledge of grief and loss				
4.26	Lead and develop local and system wide education initiative in relation to bereavement				
4.27	Be accountable for service delivery of bereavement support				
4.28	Take overall responsibility for implementation of research and development programmes related to grief, loss and bereavement				

		Preregistration		Registered nursing				
Learn	ning outcomes - practitioners will be able to:	practitioner (under supervision)	Unregistered support worker	associate & assistant practitioners	Registered nurse	Enhanced level	Advanced level	Consultant level
5.1	Differentiate between leadership and management and consider how different models of leadership may impact on the care provided to children, families and carers							
5.2	Describe the importance of the legal, ethical and professional issues in relation to the care of children, families and carers							
5.3	Describe the principles of risk assessment and risk management in relation to the care of children, families and carers							
	tice competencies itioners will be able to demonstrate an ability	y to:			'			
5.4	Practice in accordance with legal, ethical and professional principals, national and local policies and standards, in order to provide safe, effective, timely, costeffective care to children, families and carers							
5.5	Participate in clinical supervision							
5.6	Contribute to national data collections and audits							
5.7	Evidence of continuing professional development							
5.8	Recognise own limitations and seek appropriate emotional and developmental guidance and support when required							
5.9	Recognise own supervision needs and access clinical supervision acting as a role model to support self and others with the multidisciplinary team							

5.10	Use reflective practice to validate and, where possible, improve upon current practice and be aware of the emotional vulnerability of staff following the death of a child				
5.11	Facilitate new and inexperienced staff to develop skills in organising, prioritising and delegating care to achieve effective clinical outcomes				
5.12	Evidence a specialist qualification at (Level 4 PGCert or 5 Diploma – England, N. Ireland & Wales) (Level 7 HNC/Cert HC or 8 HND/DipHE – Scotland)				
5.13	Plan, allocate, co-ordinate and evaluate the use of health care resources in a safe and effective manner when providing care to children, families and carers on a day- to-day basis				
5.14	Build sustainable professional relationships within and across organisational boundaries and agencies				
5.15	Participate in peer review				
5.16	Evidence of promoting the professional development of others				
5.17	Evidence a specialist qualification at (Level 6 Degree, England, N. Ireland & Wales) (Level 9 Graduate diploma/degree or 10 degree with honours – Scotland)				
5.18	Develop, initiate, evaluate and report child and family experience measures during palliative and end-of-life care				
5.19	Understand and analyse clinical data to inform advanced level decision making				
5.20	Influence specialist nursing practice within children's palliative care				
5.21	Lead and utilise research and audit to determine evidence of best practice as a rationale for prescribed care				

5.22	Deliver universal level children's palliative care training and education one-to-one or to small groups				
5.23	Use specialist knowledge to evaluate new and complex clinical ideas that are emerging in the most advanced arenas in children's palliative care				
5.24	Plan, allocate, co-ordinate and evaluate the use of health care resources for delivering services at local and system- wide level				
5.25	Mentor staff through case management and review influencing change in practice as required				
5.26	Lead local practice innovations and service redesign				
5.27	Influence system-wide/regional network initiatives in the development of palliative and end-of-life care pathways				
5.28	Develop palliative and end-of-life care teaching programmes and deliver learning and development for the multidisciplinary team				
5.29	Organise appropriately skilled nurses to provide 24-hour support to children at end-of-life in the home care setting				
5.30	Manage resources to ensure that safe and effective children's palliative care is delivered across the 24-hour period				
5.31	Demonstrate influence of others through dissemination of knowledge and information				
5.32	Facilitate change and development and systematic evaluation				
5.33	Demonstrate the acquisition of new knowledge and opportunities for innovation and lead appropriate change				

5.34	Evidence advanced knowledge of national and international innovations that contribute to children's palliative care				
5.35	Evidence a specialist qualification at advanced level (Level 7 Masters or 8 Doctoral – England, N. Ireland & Wales) (Level 11 Masters or 12 Doctoral – Scotland)				
5.36	Deliver targeted/specialist level training and education to medium and large groups at local, system-wide and national events				
5.37	Lead education strategy in children's palliative care ensuring there is provision of education for those encountering children with palliative care needs				
5.38	Manage budget setting and monitoring needs including funding sources for developing services				
5.39	Influence the quality improvement cycle for continuous review and development of children's services				
5.40	Contribute to business and budget planning though preparation of children's palliative care business cases and report writing				
5.41	Influence national policy concerning symptom management as part of the wider provision of palliative and end-of-life care for children				
5.42	Influence children's palliative care policy as a national resource, expert, adviser, researcher and author				
5.43	Inform the strategic direction and lead changes to children's palliative care service delivery at local and systemwide level demonstrating innovation and solution focussed approaches				

5.44	Provide consultancy to initiating and participating in research in children's palliative care				
5.45	Develop strategies with system-wide commissioning bodies to address shortfalls in children's palliative and end-of-life care				
5.46	Collaborate with Health Education England, HEIs and FE providers to meet the learning and development needs and build capacity in the health care workforce				

7 Competencies evidence base

Competency subject area	Evidence base
Communicating effectively	Skills for Health (2015). National Occupational Standards: CS1 Communicate with children and young people, and those involved in their care. CS19 Develop relationships with children, young people and those involved in their care. Mental Capacity Act Code of Practice (2005). Mental Capacity Amendment Act (2019). Liberty Protection Safeguards (LPS). Gov.UK. Nursing and Midwifery Council (updated 2018). The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates. Skills for Health (2015) National Occupational Standards: CS2 Work with children and young people to agree the nature and purpose of assessment of their health and wellbeing CS3 Work with children and young people to assess their health and wellbeing CS5 Develop care plans with children and young people CS6 Implement care plans to meet the needs of children and young people CS13 Deliver interventions for children and young people, and those involved in their care CS14 Evaluate interventions with children and young people
	Mack JW, and Sisk B, (2021) Communication. In: Hain R, Goldman A, Rapoport A and Meiring M (eds). Oxford Textbook of Palliative Care for Children. 3rd edition. Oxford University Press. pp 17-24. Levetown M and Committee on Bioethics (2008). Communicating with children and families: from everyday interactions to skill in conveying distressing information. Pediatrics, 121 (5), pp.e1441-e1460. Together for Short Lives (2013) A Core Pathway for Children with Life Limiting and Life-Threatening Conditions (3rd edition).
	Skills for Health (2021). National Occupational Standards: CS20 Enable children and young people to understand their health and wellbeing. Skills for Health (2015) National Occupational Standards: CS22 Support children and young people to cope with changes that impact on their health and wellbeing. CS30 Provide advice and information to children and young people and those involved in their care on how to manage their own health and wellbeing. Contro N and Zimmerman J (2021) Assessment of the child and family. In: Hain R, Goldman A, Rapoport A and Meiring M (eds). Oxford Textbook of Palliative Care for Children. 3rd edition. Oxford University Press. pp 59-65. Nursing and Midwifery Council (updated 2018). The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates. Papadatou D (2009) In the Face of Death: Professionals Who Care for the Dying and the Bereaved. Springer Publishers. Samuel J (2018) Grief works: Stories of life, death, and surviving. Penguin.

Multidisciplinary holistic care

Together for Short Lives (2013) A Core Pathway for Children with Life Limiting and Life-Threatening Conditions (3rd edition). Skills for Health (2015). National Occupational Standards: CS25 Recognise and manage adverse signs and symptoms in babies, children and young people

CS5 Develop care plans with children and young people

CS22 Support children and young people to cope with changes that impact on their health and wellbeing.

RCN (2020) Future proofing community children's nursing.

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Nursing and Midwifery Council (2014) Standards for Competence for Registered Nurses.

Department of Health (2016) National Framework for Children and Young People's Continuing Care.

Skills for Health (2015) Occupational Standards: CS23 Work with others to improve health care services for children, young people and those involved in their care

CS4 Plan multidisciplinary assessment of the health and well-being of children and young people.

Identify and manage symptoms

Together for Short Lives (2022) Basic Symptom Control in Paediatric Palliative Care. 10th edition.

Wong-Baker Faces Pain Rating Scale. Wong-Baker Foundation wongbakerfaces.org

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Carter B and Simons J (2014) Stories of children's pain: Linking Experience to Evidence and Practice. SAGE Publishing. WHO (2012) WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses.

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WHO (2012) WHO guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses.

Royal Pharmaceutical Society and Royal College of Nursing (2019) Professional guidance on the administration of medicines in health care settings.

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Grief, loss and bereavement

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8 Work-based record sheets

Communicating effectively Communicating effectively with children with palliative care needs.		itioner level See key)	Level of achievement required (Benner Taxonomy)	Self assessment		Level achi (assesse		Evidence of achievement
Learning outcomes - practitioners will be able to:					L	Date	Sig.	
Example 1.1 Discuss the importance of effective personcentred communication in children's palliative care	V		Competent	Novice	АВ	11.09.2023	Manager	 Group discussion as part of mandatory induction session to workplace (hospice) related to admission process and care plan preparation (Add to action plan: buddy with registered practitioner in workplace as part of super-numerary induction)
1.13 Demonstrate advanced communication skills with children and families		V	Competent	Competent	С	11.09.2023	Supervisor	Service user feedback received following conversations between parent and registered nurse about changes made within ACPlan
1.1 Discuss the importance of effective person- centred communication in children's palliative care								
1.2 Demonstrate knowledge of communication theories and how they are applied in practice, including barriers and facilitators of effective communication in children's palliative care		П						
Explore the importance of multi- professional communication in children's palliative care and how this can be enhanced								
1.4 Identify supportive strategies which will help those providing palliative care to develop emotional resilience								

Practice competencies with children/far Practitioners will be able to demonstrate an ability	es									
1.5 Select and adopt an effective communication approach, from a range of core communication skills, to assess the information, education and supportive care needs of the child, family and carers throughout their palliative care journey										
1.6 Enable child/family to communicate fears and concerns supporting them through times of uncertainty										
1.7 Build rapport and trust with families displaying sensitivity and empathy at times of distress										
1.8 Assist with managing barriers to effective communication, and adapt to manage fears or anxieties, simplifying content and using communication aids as needed to enable children's understanding										
1.9 Adhere to local care policies ensuring written communication is factual and concise										
1.10 Maintain accurate contemporaneous records across all aspects of palliative care and multi-professional interactions										
1.11 Show awareness of psychological, emotional and spiritual needs when communicating with children and their families										
1.12 Adapt communication to meet the needs of families and children dependent on age and abilities referring to specialist colleagues if required eg, SALT										
1.13 Demonstrate advanced communication skills with children and families										
1.14 Empower families to make informed decisions in conjunction with the multidisciplinary team										

1.15	Assess, plan, document and evaluate the communication needs of children and their family members							
1.16	Discuss treatments, care plans, symptom assessment and management tools (eg, pain) according to role							
1.17	Lead a discussion with the child/family on key issues such as choice of preferred place of care							
1.18	Listen and reflect with families regarding uncertainties in issues such as diagnosis, decision making, advance care planning, dying, and talk through with sensitivity symptom and advance care planning and options for specialist service delivery							
1.19	Communicate effectively outcomes from multidisciplinary team/meeting to support choices based on evidence and best practice for symptom and/or advance care plans or plans for the provision of service/care to children and their family members							
	ctice competencies as part of the tea	leadi	ng th	e te	am	ı		
1.20	Communicate information verbally or in writing to other member of the team, by adapting communication to ensure information is shared well							
1.21	Effective communication in pre-brief/ de-brief							
1.22	Recognise and communicate own emotional needs seeking help as appropriate							
1.23	Provide constructive feedback to others on style/delivery							
1.24	Deliver an accurate account of history taking and clinical decision making and evidence of a physical/advanced/health assessment skills module							

1.25 Generate high quality written communication from visits/deaths/ transition including discharge summaries. Demonstrate high quality verbal communication, preparing: advance care plan, ambulance directive, symptom management plan				
1.26 Demonstrate completion of advanced communication training, and ability to apply these skills in practice navigating complex situations with advanced level clinical reasoning skills				
1.27 Appropriately utilise communication in order to promote clear and unambiguous information exchanges with other members of the multidisciplinary team and wider networks				
1.28 Lead the specialist paediatric palliative care multidisciplinary team meeting, including debating with clarity and confidence and sensitivity, creating an environment that enables the sharing of views and opinions				
1.29 Analyse and synthesise complex child information and present experiences and insights with others. Communicate complex concepts clearly and effectively				
1.30 Teach communication skills to others in specialist and non-specialist roles using a variety of delivery methods to accommodate different learning styles				
1.31 Demonstrate ability to communicate and collaborate with commissioners and funders at a strategic organisational/regional/national level				
1.32 Utilise child and family feedback, compliments and complaints to advance service development and improvement.				

Action plan to achieve req	uired competency level:	
Reviewed by (signature and role)	Comments	Date
,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		

Prov with (hos	Itidisciplinary holistic care iding multidisciplinary holistic care to BCYP palliative care needs in any care setting pital, hospice, the home, school or other munity setting).	Practitioner levo (See key)	el	Level of chievement required (Benner Faxonomy)	Self assessment		Level achi		Evidence of achievement
Lear	ning outcomes - practitioners will be able to:					L	Date	Sig.	
Exam 2.8	nple Practice independent nursing care which promotes positive outcomes for children and their families	√	Co	ompetent	Advanced beginner	C	11.09.23	Line manager	Mid-way preceptorship feedback able to demonstrate independent nursing care by creating a care plan for child with neurodegenerative condition in ward environment
2.18	Lead multidisciplinary team meetings, and draw on the expertise, knowledge and understanding of multidisciplinary team members to develop and evaluate care for and with children and their families, modelling a collaborative and inclusive approach as an active member of the team		Pr	roficient	Proficient	P	11.09.23	Supervisor	Reflective case study highlighting challenging scenario bringing together health, social care, and education to support a CYP in transition from primary to secondary education
2.1	Identify the impact of having palliative care needs on the physical, psychological, emotional, social and spiritual wellbeing of the child, family and carers								
2.2	Understand the complex and changing information, educational and supportive care needs of the child, family and carers								
2.3	Discuss what can optimise activities of daily living and quality of life for the child and their family								
2.4	Explain the function of the multidisciplinary team and importance of the key worker/ case manager/co-ordinator role								
	essment and care planning practice of titioners will be able to demonstrate an ability	•							
2.5	Provide holistic and evidence-based nursing care that meets the child's palliative care needs across the care pathway								

2.6	Deliver delegated nursing care, within defined guidelines and protocols following a prescribed care plan							
2.7	Gather accurate information that assists with assessment and planning of nursing care, and which contributes to changes in prescribed care or symptom management planning							
2.8	Practice independent nursing care which promotes positive outcomes for children and their families							
2.9	Share a common vision for developing, providing and evaluating holistic multidisciplinary services to children and their families that are person-centred, safe and effective as well as promoting a team culture that can sustain this across the continuum of care and pathways							
2.10	Utilise integrated multidisciplinary care pathways to guide both child, family and professionals in effective care planning							
2.11	Recognise the impact of advanced disease or deterioration in child's condition when analysing and interpreting the clinical situation, and apply judgement to evaluate the outcomes of care and interventions							
2.12	Critically analyse complex clinical data and information to inform diagnosis and decision making							
	lity of life practice competencies itioners will be able to demonstrate an ability	to:						
2.13	Promote quality of life and best interests for children with palliative care needs							
2.14	Advocate, hold others to account, and challenge with clarity and competence regarding issues of holistic care and quality of life, and ensure best quality of care for the child is central to these discussions							

Co-ordinating care practice competenci Practitioners will be able to demonstrate an ability						
2.15 Work in partnership with other sectors and agencies including health, education, social services and voluntary sector						
2.16 Seek opportunities and promote ways of collaborative working across care settings and sectors to facilitate seamless care						
2.17 Adopt a lead professional role in co-ordinating complex care when required						
2.18 Lead multidisciplinary team meetings, and draw on the expertise, knowledge and understanding of multidisciplinary team members to develop and evaluate care for and with children and their families, modelling a collaborative and inclusive approach as an active member of the team						
2.19 Write and implement standards, protocols, policies and care strategies in specialist palliative care and promote their use in practice across agencies						
Information and education practice com Practitioners will be able to demonstrate an ability		es		,		
2.20 Provide child and family with choices where possible, and recognise the impact these choices can have on quality of life, for example, remaining in hospital or staying at home at end-of-life						
Empowerment practice competencies Practitioners will be able to demonstrate an ability	to:					
2.21 Build therapeutic relationships with children and their family to enable their informed choices for care and treatment						

Action plan to achieve req	uired competency level:	
Reviewed by (signature and role)	Comments	Date

Working with primary ca	nage symptoms arers and health care y and manage symptoms.	Pra	actiti (Se	ionei ee ke		el	Level of achievement required (Benner Taxonomy)	chievement required (Benner Self		Level ach		Evidence of achievement
Learning outcomes – pra	actitioners will be able to:								L	Date	Sig.	• Completion of a learning
Example 3.7 Recognise and rep behaviour and con	ort changes in child's dition	√ V					Competent	Competent	С	21.02.23	Clinical manager	 Completion of e-learning module in managing challenging behaviour Reflective diary discussion case example given of working with a child at home
prescribers (Royal	nd effectively in line icy framework for all Pharmaceutical Society, g to sphere of practice				V		Proficient	Competent	P	11.09.23	NMP lead	 Evidence of completion of independent study day focusing on prescribing in children's palliative care Audit of prescribing practice (last five occasions) verbal and written report to quality group
3.1 Explain the core p symptom manage	rinciples of effective ment											
approach to symp management and	tic and multidisciplinary tom assessment, evaluation. Recognise nptom assessment and											
	ipatory symptom ning and prescribing is tive end-of-life care											
	of physical, psychological otoms which may be d-of-life											
3.5 Evidence appropri prescribing qualifi required	ate non-medical cation competency as											

	ctice competencies with children and titioners will be able to demonstrate an ability	mi	lies						
3.6	Enable children to voice and or demonstrate experiencing pain/discomfort								
3.7	Recognise and report changes in child's behaviour and condition								
3.8	Follow organisational policy and individualised care plans including related to medicines management to support effective symptom management								
3.9	Follow individualised care plan for equipment use, moving and handling and positioning to support effective symptom management								
3.10	Provide non-pharmacological symptom management such as massage, music therapy and positioning								
3.11	Facilitate individualised therapeutic strategies to reduce psychological symptoms								
3.12	Collaborate with the team around the child to manage symptoms								
3.13	Use standard symptom assessment tools e.g. pain, dystonia, agitation to assist carers to identify and manage symptoms								
3.14	Follow local policy for documenting and sharing symptom management treatment information including consultation and evaluation								
3.15	Recognise when treatment plans need review and adjustment								
3.16	Follow individualised emergency protocols and administer medication such as for seizure management								

3.17	Assess, plan, deliver, evaluate and record individualised care and symptom management for the child							
3.18	Identify and mitigate risks associated with symptom management for example when identifying preferred place of care and death							
3.19	Assess and take urgent action for distressing and complex symptoms and situations							
3.20	Recognise the risks and burdens of treatment options							
3.21	Prescribe safely and effectively in line with the competency framework for all prescribers (Royal Pharmaceutical Society, 2011) and according to sphere of practice							
3.22	Negotiate treatment goals, end-of-life decisions and ceilings of care							
3.23	Develop and use individualised symptom management plans to assist carers and other professionals to identify and manage symptoms							
	ctice competencies as leaders and maitioners will be able to demonstrate an ability	_	rs	·				
3.24	Provide clinical leadership in the management of physical, psychological and spiritual symptoms, involving family members and the multidisciplinary team around the child							
3.25	Teach a range of symptom management techniques to professionals and carers							
3.26	Participate in the development of system- wide symptom management guidelines and protocols							

Action plan to achieve required competency level:											
Reviewed by (signature and role)	Comments	Date									

Sust	Grief, loss and bereavement Sustaining self and the wellbeing of others wher caring and supporting BCYP and families with their grief, loss and bereavement.		actitioner le (See key)	vel	Level of achievement required (Benner Taxonomy)	Self assessment		Level ach		Evidence of achievement
Lear	ning outcomes - practitioners will be able to:						L	Date	Sig.	
E xan 4.2	nple Consider own beliefs, attitudes and values to death, dying and bereavement and how these may impact on care delivery	√			Competent	Novice	AB	11.09.23	Manager	 Mandatory training for new hospice team members session led by Spiritual Care Lead Reflective group work with peers (Add to action plan: further reading and reflection with peers, feedback to manager in one month)
4.25	Influence culture within the organisation and society's attitudes to death and dying of children by using strong evidence-based knowledge of grief and loss			√	Proficient	Proficient	Р	11.09.23	Manager	Presentation to senior leadership team on research in to staff wellbeing strategies from Compassionate Managers level 1 course
4.1	Explore theories of loss, grief and bereavement and describe how these are applied in clinical practice									
4.2	Consider own beliefs, attitudes and values to death, dying and bereavement and how these may impact on care delivery									
4.3	Define the goals of care when a child is dying, encompassing their own goals in the context of their family and carers eg, preferences for location of care, child comfort and dignity, symptom management, family and caregiver support									
4.4	Describe the signs of dying and distinguish between reversible treatable symptoms, those that could be minimised by treatment, and those which may indicate the final phase of life									

	ctice competencies with children and titioners will be able to demonstrate an ability	ilies					
4.5	Recognise signs of distress in the child and family members and enable access to appropriate support						
4.6	Support and actively listen to the child, grieving family members and carers about their worries or concerns						
4.7	Assist in age-appropriate play to engage children in conversation to encourage them to express their feelings and emotions with regards to loss						
4.8	Follow local organisational guidelines related to supporting children, families and colleagues before, at the time of, and after death						
4.9	Respect an individual's beliefs, community, culture, spirituality and religion						
4.10	Give advice to families and carers on practical issues following death, and seek support from more experienced team members where necessary						
4.11	Support children, families, carers and work colleagues through the grief process						
4.12	Deliver honest and accurate information about death and provide opportunities for child and family to ask questions (cognitive and developmentally appropriate)						
4.13	Provide a range of supportive and practical interventions for children at the end-of-life, and their families as part of advance care planning, referring to other sources of support as required						

4.14	Implement the advance care plan, and review in partnership with the child and their family with support of an experienced palliative care nurse/practitioner where necessary. Include the child in discussions and decision making, including their specific wishes (where appropriate, depending on cognitive ability)					
4.15	Assess, plan, provide and evaluate a comprehensive plan of care for a child at the end-of-life and their families when grieving					
4.16	Assess any risks associated with the individual needs of the bereaved advising on continuing support services as required					
4.17	Care for a dying child and provide care for the body after death					
4.18	Performing verification of death					
	cal leadership practice competencie itioners will be able to demonstrate an ability					
4.19	Collect relevant data to monitor outcomes of bereavement care					
4.20	Encourage the organisation to be open and accountable in their response to death and dying in children					
4.21	Proactively seek out bereavement support, assess current provision and identify areas for improvement within own work setting					
4.22	Enable colleagues to develop coping strategies to support children and families affected by loss through education and professional development					
4.23	Act as a facilitator for colleagues who require bereavement support					
4.24	Act as a resource for those providing bereavement support and how to care for themselves					

4.25	Influence culture within the organisation and society's attitudes to death and dying of children by using strong evidence-based knowledge of grief and loss						
4.26	Lead and develop local and system wide education initiative in relation to bereavement						
4.27	Be accountable for service delivery of bereavement support						
4.28	Take overall responsibility for implementation of research and development programmes related to grief, loss and bereavement						

Action plan to achieve required competency level:												
Reviewed by (signature and role)	Comments	Date										

Lea	Leadership and management		Practitioner level (See key)				Level of achievement required (Benner Taxonomy)	Self assessment		Level achi (Assess		Evidence of achievement
Learr	ning outcomes - practitioners will be able to:								L	Date	Sig.	
Exam 5.7	nple Evidence of continuing professional evelopment		√				Competent	Competent	С	11.09.23	Clinical manager	Certificate of attendance and reflective account about study day on communicating with children who are non-verbal (including barriers and facilitators of effective communication in the outpatient department)
5.42	Influence children's palliative care policy as a national resource, expert, adviser, researcher and author	_		31	1	V	Proficient	Proficient	Р	11.09.23	Supervisor	 Contribution to national working party on definitions and needs of children requiring children's palliative care Critique and feedback policy documentation to national team
5.1	Differentiate between leadership and management and consider how different models of leadership may impact on the care provided to children, families and carers											
5.2	Describe the importance of the legal, ethical and professional issues in relation to the care of children, families and carers											
5.3	Describe the principles of risk assessment and risk management in relation to the care of children, families and carers											

	Practice competencies Practitioners will be able to demonstrate an ability to:													
5.4	Practice in accordance with legal, ethical and professional principals, national and local policies and standards, in order to provide safe, effective, timely, cost-effective care to children, families and carers													
5.5	Participate in clinical supervision													
5.6	Contribute to national data collections and audits													
5.7	Evidence of continuing professional development													
5.8	Recognise own limitations and seek appropriate emotional and developmental guidance and support when required													
5.9	Recognise own supervision needs and access clinical supervision acting as a role model to support self and others with the multidisciplinary team													
5.10	Use reflective practice to validate and, where possible, improve upon current practice and be aware of the emotional vulnerability of staff following the death of a child													
5.11	Facilitate new and inexperienced staff to develop skills in organising, prioritising and delegating care to achieve effective clinical outcomes													
5.12	Evidence a specialist qualification at (Level 4 PGCert or 5 Diploma – England, N.Ireland & Wales) (Level 7 HNC/Cert HC or 8 HND/ DipHE – Scotland)													
5.13	Plan, allocate, co-ordinate and evaluate the use of health care resources in a safe and effective manner when providing care to children, families and carers on a day-to-day basis													

	T					
relationsh	ainable professional ips within and across onal boundaries and agencies					
5.15 Participate	e in peer review					
	of promoting the professional ent of others					
6 Degree, (Level 9 G	a specialist qualification at (Level England, N. Ireland & Wales) raduate diploma/degree or 10 th honours – Scotland)					
and family	nitiate, evaluate and report child v experience measures during and end-of-life care					
	nd and analyse clinical data to vanced level decision making					
	specialist nursing practice within palliative care					
determine	utilise research and audit to evidence of best practice as a for prescribed care					
	iversal level children's palliative ng and education one-to-one or roups					
new and c emerging	alist knowledge to evaluate omplex clinical ideas that are in the most advanced arenas in palliative care					
use of hea	cate, co-ordinate and evaluate the lth care resources for delivering t local and system-wide level					
	aff through case management v influencing change in practice d					
5.26 Lead local redesign	practice innovations and service					

			·		
5.27 Influence system-wide/regional network initiatives in the development of palliar and end-of-life care pathways					
5.28 Develop palliative and end-of-life care teaching programmes and deliver lear and development for the multidisciplin team					
5.29 Organise appropriately skilled nurses provide 24-hour support to children at of-life in the home care setting					
5.30 Manage resources to ensure that safe and effective children's palliative care delivered across the 24-hour period	is				
5.31 Demonstrate influence of others through dissemination of knowledge a information	nd				
5.32 Facilitate change and development an systematic evaluation	d				
5.33 Demonstrate the acquisition of new knowledge and opportunities for innovand lead appropriate change	ation				
5.34 Evidence advanced knowledge of national and international innovations that contribute to children's palliative care	onal				
5.35 Evidence a specialist qualification at advanced level (Level 7 Masters or 8 Doctoral – England, N. Ireland & Wales (Level 11 Masters or 12 Doctoral – Scot) land)				
5.36 Deliver targeted/specialist level training and education to medium and large grat local, system-wide and national eve	oups				
5.37 Lead education strategy in children's palliative care ensuring there is provis education for those encountering child with palliative care needs					
5.38 Manage budget setting and monitoring needs including funding sources for developing services	g				

f	nfluence the quality improvement cycle for continuous review and development of children's services					
r F	Contribute to business and budget blanning though preparation of children's balliative care business cases and report writing					
s F	onfluence national policy concerning symptom management as part of the wider provision of palliative and end-of-life care for children					
a	nfluence children's palliative care policy as a national resource, expert, adviser, researcher and author					
	nform the strategic direction and lead changes to children's palliative care service delivery at local and system-wide level demonstrating innovation and solution focussed approaches					
ŗ	Provide consultancy to initiating and participating in research in children's palliative care					
C	Develop strategies with system-wide commissioning bodies to address shortfalls n children's palliative and end-of-life care					
E	Collaborate with Health Education England, HEIs and FE providers to meet the earning and development needs and build capacity in the health care workforce					

Action plan to achieve req	uired competency level:	
Reviewed by (signature and role)	Comments	Date

9 References

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RCN quality assurance

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

Safe and effective palliative care requires specific competencies for nursing and support staff who work with children and their families in a range of settings.

This framework sets out competencies for knowledge and skills across 5 topic areas in children's palliative care relevant to career stages, highlighting the professional development required by a nursing care workforce spanning 7 levels of role from pre-registration practitioner to nurse consultant.

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The Nine Quality Standards

This publication has met the nine quality standards of the quality framework for RCN professional publications. For more information, or to request further details on how the nine quality standards have been met in relation to this particular professional publication, please contact publications.feedback@rcn.org.uk

Evaluation

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

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