Palliative Care and Bereavement

> This section assumes a good understanding of the competencies required for effective, sensitive communication, pitched at an appropriate developmental level, as outlined in the core competences domain of this framework

PALLIATIVE CARE

Knowledge

- An ability to draw on knowledge that palliative care refers to the management of distressing symptoms from the point of diagnosis throughout the child's life, death and bereavement
  - an ability to draw on knowledge that while end-of-life care is related to palliative care, this specifically refers to management and support offered in the final few weeks of life
- An ability to draw on knowledge that palliative care embraces physical, emotional, social and spiritual factors and focuses on enhancement of quality of life for the child/young person and support for the family
- An ability to draw on knowledge that feelings and the need for information may change over time and/or as circumstances change
- An ability to draw on knowledge that children and their families may be understandably anxious about receiving information about their condition
- An ability to draw on knowledge of communication skills to facilitate and encourage discussion of psychological, emotional or spiritual issues

ENGAGEMENT

Discussing diagnosis / recognition of the need for palliative care

- An ability to draw on knowledge of relevant national and local protocols and best practice standards to discuss diagnosis in a manner that promotes adjustment, for example by ensuring:
  - that disclosure of prognosis takes place face-to-face and in an appropriate setting that assures privacy
  - that the child and their family are ready to hear the information and that there is some prior agreement about who should know what (e.g. by establishing with parents what the child already knows and understands about their condition, and what the parents think their child should be told)
  - that children and young people with life-limiting conditions and their parents or carers should usually be fully informed about the condition and its management
- An ability to help children and families discuss information about prognosis and its implications
- An ability to discuss cultural factors and spiritual beliefs related to death and dying with the child and their family

Discussing Death and Dying

- An ability to draw on knowledge of factors that can affect a child or young person’s understanding of death and their readiness to discuss this, for example:
  - their own or parent’s/carer’s direct experience of illness and death
  - events they may have witnessed in hospital (such as other children dying)
  - facts or ideas about death and dying they have been told or picked up from conversations, or via the media
  - anxiety/denial about death
  - their sense of whether they have ‘permission’ to talk openly about death
- An ability to facilitate conversations about death and dying* with children, young people and their families, where appropriate, holding in mind that:
  - children and families may need support in talking to each other directly about death and dying
  - children and young people may find it difficult to ask directly if they are going to die or are dying
  - carers may have difficulty asking directly if a child or young person is dying
- An ability to explore and discuss concerns in depth and at the child and family’s pace
- An ability to recognise that where more than one child in a family is affected by the same condition, that discussions about death and dying will have multiple meanings for the family

Managing potential barriers to communication

- An ability to manage specific barriers to effective communication in palliative care, such as:
  - societal and cultural perceptions of, or assumptions about palliative care, death and dying
  - the care-worker’s fear of causing distress or destroying hope, resulting in their avoiding important topics
- An ability to manage common dilemmas that arise in discussing palliative care, for example, balancing:
  - hope and realism
  - parental wishes about the child’s life versus the best interest of the child which may involve decisions about child protection
  - differences in the ways in which the clinical team and the family understand the goals of care

CARE PLANNING

- An ability to draw on knowledge that care planning is a supportive process which promotes:
  - co-ordinated care which identifies the roles and responsibilities of professionals’ flexibility and responsiveness to changing needs and choices
  - continuity of services (e.g. to accommodate changes in the professionals involved or in the care setting (such as a hospital admission or transition to adult services)
- An ability to assess the specific needs of the child and their family, ensuring that this:
  - involves the child/young person in the process:
    - if life limiting condition is diagnosed antenatally, involving parents/carers in care planning prior to birth

  - respects cultural and religious differences and identifies beliefs and values relevant to any aspects of care
  - involves a comprehensive and multi-agency approach which avoids the need for multiple assessments

- An ability to help the child or young person and their family:
  - plan their care and express their views
  - understand the life-limiting condition and its management
  - prepare for possible future difficulties or complications

**see communication competency*

Decision Making

- An ability to ensure that children and their families have a central role in decision-making and care planning, and to promote their involvement, for example by:
  - regularly asking children and their families how they wish to be involved in making decisions about their care (recognising that this varies between individuals, at different times, and will depend on what decisions are being made)
  - providing appropriate levels of involvement and availability of the multidisciplinary team to support families in decision making
  - ensuring that when decisions must be made about end of life care children and their families are given enough time to think through and discuss options

Confidentiality

- An ability to discuss issues relating to confidentiality, for example:
  - how and with whom information will be shared
  - whether there are significant others who they would like to be involved, and if so how and what information should be shared with these individuals

INTERVENTION IN PALLIATIVE CARE

Psychological distress

- An ability to respond to the distress commonly associated with discussion of care planning and to support children and their families through the process of assessment and care planning and other times of uncertainty
  - an ability for staff to draw on the function of care planning as supportive to help contain their own distress and anxiety

Promoting psychological functioning within palliative care

- An ability to promote psychological functioning by encouraging that the child maintains:
  - secure attachment with at least one adult
  - routines and family rituals
  - participation in activities/hobbies
  - engagement with peers
  - engagement with education

An ability to promote psychological functioning within families by:	
	helping support an understanding of care plans (and so promote adherence)
	enabling families to discuss hospice care and engage in shared decision-making (e.g. to resolve any conflict or confusion about plans for end-of-life care)
	helping to reduce uncertainty and emotional isolation
An ability to respond to psychological distress by adopting and promoting supportive strategies as required e.g. distraction and relaxation	
	an ability to respond to psychological distress due to processes that can be specific to the time period preceding death e.g. respiratory distress, agitation, delirium through use of reassurance, information giving, grounding, promoting a calm environment etc.
An ability to identify and respond to concurrent psychological difficulties and wider stressors that may impact on functioning for which additional support/referral to appropriate services is appropriate	
An ability to revisit discussion of emotional and psychological wellbeing with children and their families, particularly at times of change such as:	
	deterioration of the clinical condition or change of focus to end of life care
	changes in personal circumstances
	changes to support systems (such as nursery care, or school/ college attendance)
An ability to identify when referral onwards for specialist input is required and take appropriate action	

Interaction between physical symptoms and psychological distress

An ability to help optimise symptom control through the use of psychological interventions	
An ability to draw on knowledge of the ways in which physical symptoms may interact with psychological factors, for example:	
	pain may be exacerbated by depression, fear and anxiety
	anxiety may impact on breathing
An ability to apply psychological strategies to where appropriate, for example:	
	distraction, relaxation and controlled breathing to help manage pain
	distraction or problem solving, to help manage anxiety and distress
	graded activity to help manage low mood, isolation and depression
An ability to screen for common mental health conditions in children, young people or their parents/carers, and to recognise when this may need to be addressed by a specific evidence-based psychological intervention	

END OF LIFE CARE, DEATH AND DYING

Knowledge of models of grief

An ability to draw on knowledge of models of grief and the process of coping with loss (such as models that describe the ‘stages’ of grieving and/or ongoing bonds with the deceased)
An ability to draw on knowledge that grief is a cyclical process rather than a linear one
An ability to draw on knowledge that the death of a child is often more traumatic than other bereavements, and impacts not only on parents/carers but also on the wider system (such as siblings, grandparents, friends, school and the community)
An ability to draw on knowledge of children and young people’s developmental understanding of illness and death to inform conversations with children and families and support families and siblings after the death of the child

Normal and complex grief

- An ability to draw on knowledge that grieving is a normal reaction to loss, which may include:
  - difficulty talking about the deceased
  - disturbed appetite/sleep, persistent anger, lack of interest in activities that were previously enjoyed, avoiding work/school/friends
  - an increase in physical ailments, behavioural change and social withdrawal, particularly in children who find it difficult to express their grief verbally
- An ability to draw on knowledge that after the death of a child grief is commonly intense and prolonged and that this alone does not signal a need for intervention
- An ability to draw on knowledge that pathologizing grief early on can be disempowering to children and families
- An ability to draw on knowledge that it is the level and persistence of grief related distress that may indicate a need for support
  - an ability to draw on knowledge of factors that can increase the likelihood of a complicated grief reaction e.g.:
    - previous experience of traumatic losses and bereavements
    - lack of time to prepare for the death
    - pre-existing parental mental health difficulties
- An ability to draw on knowledge that for some parents/cares there may be an elevated risk of harm to self or others in the period immediately following the death, particularly:
  - if acting as a long-term full-time carer has led to social isolation and/or a lack of social support
  - if carers have access to controlled drugs in the home (from providing care for the dying child).
  - if the loss of a caring role and lack of other roles and responsibilities increases the experience of a loss of purpose and meaning to life
- An ability to assess risk and (if necessary) make appropriate management plans

Knowledge of impact of death on siblings

- An ability to draw on knowledge that prior to a bereavement, siblings will have been exposed to challenging experiences, for example:
  - living with the knowledge that their sibling is going to die
  - experiencing and/or being exposed to a range of powerful emotions (such as rejection, guilt, anger, protectiveness)
  - long periods of separation from their sibling and parents (due to hospitalisation)
  - acting as carers
  - high levels of parental stress and a family focus on the needs of their sibling
  - daily life being disrupted and unpredictable
- An ability to draw on knowledge of factors that impact on the ability of siblings to manage their grief including:
  - how adults are coping
  - how information about their siblings’ death is shared and whether the ongoing experience of grief is managed
  - grieving parents trying to protect siblings from distressing facts (and so withholding information that is needed to understand the bereavement)
- An ability to draw on knowledge of the importance of maintaining routines (e.g. school attendance and maintaining supportive social relationships)
- An ability to draw on knowledge that for siblings who have the same life-limiting condition, the impact of their sibling’s death may have a different meaning for them than for siblings who do not share the same condition

Knowledge of impact of loss of pregnancy or baby

An ability to draw on knowledge that grieving for the loss of a pregnancy or baby can be complicated by the absence of evidence of the baby’s existence or any shared memories

An ability to draw on knowledge that most parents are unprepared for the death of their baby which can further complicate the grieving process

INTERVENTION

An ability to ‘sit with’ and facilitate expressions of grief, and to convey a sense that this as an appropriate reaction to death rather than something that requires ‘fixing’

Supporting children and families to prepare for end of life

An ability to support children and families to prepare for end of life and to help identify actions that may be supportive, for example:

- religious or spiritual ceremonies
- recording or preserving memories in a manner that is coherent with cultural beliefs (e.g. through photographs or hand prints)
- helping them to talk to professionals involved to discuss memories or events and/or answer any concerns or questions
- offering information about local services and bereavement support

Recognising and Responding to Grief

Children and Young People

An ability to recognise and respond to signs of grief in children, young people and their parents/carers across different domains of functioning, for example:

- physical (e.g. aches, headache, abdominal pain, tight chest, fatigue)
- cognitions (e.g. disbelief, confusion, preoccupation, sense of the presence of the deceased)
- social (e.g. withdrawing from social interaction, poor school attendance)
- behavioural (e.g. sleep difficulty, loss of appetite, crying, regression to behaviours from an earlier developmental stage)
- feelings (e.g. sadness, anger, guilt, loneliness, anxiety, numbness, helplessness, anxiety, depression)
- spiritual (e.g. searching for a sense of meaning, hostility towards God/higher being)

Parents / Carers

An ability to help bereaved parents, for example by:

- providing opportunities to talk about events leading up to their child’s death
- constructing conversation around remembering the child who has died
- encouraging parents to honour and remember their child, for example by:
  - writing their child’s biography
  - establishing memorials
  - remembering their child with others in their social world

- advising them of opportunities for bereavement support and (if appropriate) putting them in contact with other parents who have experienced the death of a child

Siblings

- An ability to support siblings, for example by:
  - giving siblings choice about how much they want to be involved
  - acknowledging the things they do to support their dying sibling
  - addressing any misconceptions they may have about being to blame or responsible for their siblings' illness being contagious
  - helping parents to support siblings by:
    - encouraging them to continue with normal routines as far as possible, and addressing guilt about continuing with their own lives
      - helping them to recognise that siblings who share the same condition may have their own needs and questions
    - helping them to express their feelings and recognise their need for support
    - ensuring that key people in their life are aware of events (particularly nursery/school)
    - checking their understanding of the information they have been given
    - supporting them to attend funerals (if they wish to)
    - helping them create memories of their sibling (e.g. memory boxes/books, photos, drawings, stories) and acknowledging continuing bonds they may have with their sibling who has died

Ending contact with the service

- An ability to negotiate the ending of contact in a manner that recognises that this can represent a further loss
  - an ability to help the family to discuss the meaning and impact of ending contact with the service

STAFF WELLBEING AND SUPPORT

- An ability to draw on knowledge that personal experience of death may impact on how staff interact with and support children, young people and families
- An ability to draw on knowledge that because working with children and families with life limiting conditions is distressing it is important to utilise strategies to protect staff's own psychological functioning, for example:
  - accessing professional support and supervision, including debriefing and psychosocial meetings
  - accessing general strategies to support self-care/resilience, including exercise, social supports, maintaining a good work-life balance
- An ability to draw on knowledge of factors that might make it more difficult to manage stress within the workplace (such as feeling isolated/not part of a team; frequent exposure to child death and suffering; high workloads and staff shortages)