

## Paediatric medical traumatic stress (PMTS)<sup>1</sup>

The focus of this section is on trauma arising in the context of the medical environment, related to the events that led to medical intervention and/or to distressing aspects of treatments and the contexts in which treatments took place.

This section describes competences for interventions that anticipate and reduce the risk of ongoing traumatic reactions. Descriptions of psychological interventions for the treatment of PTSD in children and young people can be found in the Child and Adolescent Competence Framework ([www.ucl.ac.uk/core/](http://www.ucl.ac.uk/core/))

### Knowledge

An ability to draw on knowledge that paediatric medical traumatic stress (PMTS) is usually defined as a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures and invasive or frightening treatment experiences

an ability to draw on knowledge that these reactions include (but are not limited to): posttraumatic stress symptoms (PTSS), including re-experiencing, avoidance of reminders of the trauma and hyperarousal

An ability to draw on knowledge that most children and families cope effectively and access appropriate support, and that there are a range of normal and understandable reactions to potentially traumatic medical events, such as:

acute stress reactions

intrusive thoughts and re-experiencing

avoidance

hyperarousal

An ability to draw on knowledge that it is the level and persistence of trauma-related distress that signals a need for support

An ability to draw on knowledge of a 'trajectory model' in which subjective appraisals of medical events (such as perception of life-threat or reoccurrence) is a critical predictor of medical traumatic stress across three phases:

the occurrence of potentially traumatic events (peri-trauma) and their immediate aftermath

acute, ongoing and evolving responses to the sequelae of these initial events

longer term traumatic responses when these sequelae have resolved or ended

An ability to draw on knowledge that children and families can follow different trajectories in response to potentially traumatic events:

minimal traumatic reactions that resolve speedily

initial traumatic reactions that remit over time (1-3 months)

chronic traumatic reactions, sustained over a long period

delayed onset, with traumatic reactions emerging some months after the initial events

<sup>1</sup> This section draws extensively on the work of Anne Kazak and colleagues

An ability to draw on knowledge of risk and protective factors that are common across a range of potentially traumatic events (such as illnesses and accidents), for example:	medically related factors
	subjective interpretations (such as a perception of illness as a threat to life)
An ability to draw on knowledge that pre-existing psychological functioning will influence the risk of paediatric medical traumatic stress, including:	prior internalising and externalising difficulties in children
	pre-existing mental health difficulties in significant caregivers, including characterological anxiety
An ability to draw on knowledge that the child's developmental stage may be relevant to:	their risk of post-traumatic stress (for example, through their ability to understand and process their experience)
	how traumatic symptoms manifest e.g. the indicators of trauma in young (preschool) children may include behavioural outburst and / or resignation and lack of resistance
An ability to draw on knowledge of the importance of maintaining a systemic/ contextual perspective when planning interventions (including the parental, familial, social/cultural context, school and community support as well as the medical environment)	
An ability to draw on knowledge that medical traumatic stress can adversely impact on health outcomes (for example, on quality of life or on recurrence)	

### Assessment and formulation

An ability to take a family-centred approach to assessment and intervention that includes the assessment of traumatic reactions in parents and carers and the impact of the medical team	an ability to assess family functioning and parental mental health
An ability to assess the emergence (or re-emergence) of trauma in children, their carers and their families at any point in their contact with medical services, and to identify potential interventions that may ameliorate this	
An ability to draw on the assessment to match the level (intensity) of intervention required to the needs of the child and their family	
An ability to develop a shared understanding of the reason a child is experiencing traumatic reactions with the family and with the medical team	
An ability to undertake repeat screening/assessments over time, so as to detect the emergence or re-emergence of traumatic reactions	

### Interventions to minimise the risk of trauma at different stages of involvement with medical services

An ability to help children and families cope with unexpected admissions, for example by:	providing simple explanations about what is happening and what will happen next.
	providing anticipatory guidance to children and parents regarding normative emotional reactions to injury or interventions (e.g. that feeling worried, confused, or numb is common and to be expected)
	communicating appropriately (for example, slowing down the pace to match the child's or the parent's, asking open-ended questions to check understanding or being willing to repeat important information)
An ability to help children and families cope with diagnosis, for example by:	explaining that feelings of shock, disbelief, or worry are common and expected
	repeating important information and checking understanding (particularly their perceptions of life-threat)
	asking open-ended questions about fears and worries

involving the child and parents as much as possible in treatment planning
helping to reframe unhelpful (because inaccurate) beliefs about the illness or injury and its outcome or prognosis
An ability to help children and families cope with inpatient stay and medical interventions, for example by:
orienting children and families to the hospital environment, for example by explaining and normalising:
sights (e.g. medical equipment, other sick children)
sounds (e.g. from monitoring instruments)
involving children and families as much as possible in daily care and decision-making
helping families to establish daily routines and appropriate behavioural expectations
recognising parents / caretakers as experts on their child
identifying and incorporating family strengths and coping resources into the treatment plan
helping parents to be present and involved with medical procedures (e.g. by offering support before, during and after procedures)
An ability to help children and families cope with ongoing painful treatment and/or setbacks, for example by:
explaining that feelings of anger, sadness, frustration, and fear are common and expected
being open to expressions of very strong emotions (including anger and grief)
facilitating the expression of worries or fears
being able to hold in mind parents who appear to be "difficult" or angry parents/carers (or children) are often scared or traumatized
helping children and families connect with their coping strengths and spiritual resources
being able to recognise when setbacks trigger a renewal of earlier distress and to help the child and family discuss the reasons for this (for example, because this is seen as indicating failure rather than a temporary event)
being able to recognise that setbacks include re-emergence of a condition and/or being advised of need to undergo a treatment that was previously traumatic
Being able to manage trauma reactions and support children and families in the context of ongoing trauma e.g. ongoing traumatic treatments
An ability to help children and families who are being discharged, for example by:
helping children and families discuss concerns about discharge, such as feelings of loss (e.g. of medical support and a sense of safety), or uncertainty about how they will cope with medical/treatment issues without support
responding to indirect manifestations of concerns around discharge (such as anxiety, agitation and avoidance) by facilitating discussion
helping children and families anticipate the challenges of returning to their home environment, and identifying coping strategies and resources they can draw on
An ability to help the child and family manage the transition from hospital to home, for example, by:
helping families anticipate and plan any appropriate adjustments that will be required
helping parents discuss their worries, identifying and helping to modify unrealistic worries
helping parents to address the reactions and concerns of siblings.
helping children achieve an appropriate level of independence
helping children to reconnect with friends and activities (for example, by discussing worries about feeling different, and preparing answers to questions that friends might ask)

offering the option of follow-up appointments to high-stress' families who appear not to be managing
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**Working with the team**

An ability to help teams to deliver care in a way that reduces the likelihood of trauma by adopting trauma-informed and trauma-sensitive practice
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An ability to recognise the impact of trauma on healthcare staff
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An ability to help to manage burnout/compassion fatigue
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An ability to manage own emotions and reactions to having to witness and/or impose traumatic treatments on babies, children and young people
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## Pain

This set of interventions is suitable for individuals across the spectrum of pain presentations; their application is not restricted to specific manifestations of pain or specific clinical condition

The specific set of techniques employed in pain management interventions can vary, but the selection of techniques should be determined by a clear rationale (based on evidence for the efficacy of any particular combination, and by an appropriate formulation of the problems being addressed)

This intervention can be carried out as an individual or as a group-based intervention

This listing of competences assumes that practitioners are familiar with, and able to deploy, a range of 'generic' CBT techniques. These are referred to briefly in this section, but are fully described and elaborated in the Basic and Specific CBT domains of the CBT competence framework, which can be accessed at [www.ucl.ac.uk/CORE/](http://www.ucl.ac.uk/CORE/)

### Knowledge of biopsychosocial models of chronic pain

An ability to draw on knowledge that the brain plays a dynamic (rather than passive) role in pain perception, and that psychological factors can both amplify and inhibit the experience of pain irrespective of the underlying cause for the pain

An ability to draw on basic knowledge of physiological factors associated with pain and pain response

An ability to draw on knowledge that adjustment to chronic pain is influenced by a number of factors:

characteristics of the child/young person and their parents/family, including:

biological/physiological factors, such as any diagnosis (i.e. the type and likely course of their illness), and the medical interventions that they have received (e.g. surgery, medication)

the social roles occupied by the child (e.g. personal, family, educational roles, role in the healthcare system) and the expectations associated with these roles (which influence the child's beliefs about the appropriate treatment of pain, and in turn the choice of coping options)

dispositional (personality) factors that may increase the risk of disability (e.g. a tendency to negative mood, or emotional vulnerability)

core beliefs about the self as a 'person in pain' (e.g. as a disabled person) that evolve in response to the illness or in family's response to the illness, but may be rooted in early formulations of the self (and which therefore create a cognitive vulnerability)

the child's and family's primary appraisals of pain e.g.:

as a threat or a danger, leading to anticipation of harm and anxiety

as the cause of loss (e.g. loss of activities, education or relationships)

secondary appraisals of pain ('acquired beliefs' and 'automatic thoughts' that arise in response to pain and the child's ability to cope with it) e.g.:

beliefs about the causes of pain and how best to manage it (for example, believing that activity will result in more pain and/or more physical damage leading to avoidance of activities)

beliefs about the ability to control pain (e.g. whether variations in pain are perceived as being under the person's control, or are attributed to external factors that are beyond their control)
a tendency to react to pain by magnifying the threat value of pain sensations (catastrophizing)
unhelpful cognitions (e.g. "I am useless, it's my own fault that I am like this)
behavioural strategies (which may or may not be adaptive) adopted by the child and/or parents in order to cope with pain and/or stressors associate with pain
An ability to draw on knowledge that because parents/carers have an important role in influencing the child's adjustment to chronic pain their attitudes beliefs and behaviours should be taken into account e.g.:
parental catastrophisation leading to the maintenance of unhelpful cognitive and behavioural responses to pain
parental beliefs that there is a need for further medical assessment/medical intervention in the context of chronic pain
unhelpful behavioural responses (such as sitting up through the night with the child, sanctioning school absences, adapting family life around the experience of pain)
An ability to draw on knowledge of the potential influence of the child's school in the management of the child's adjustment to pain (e.g. being over- or under-reactive to the child's pain)

### **Knowledge of the rationale for pain-management interventions**

An ability to draw on knowledge of models commonly applied in pain management, and their differing (though often overlapping) assumptions e.g.:
stress-appraisal-coping models, which assume that the experience of pain is mediated by cognitive and emotional factors, with a weak (or no) relationship with the level of physical injury or damage
'contextual' models, which distinguish between psychological experiences (such as thoughts and feelings) and the context that lends these experiences their influence over behaviour, and which therefore:
place an emphasis on changing the function of experience rather than the experience itself
focus on altering the influence exerted by an experience (e.g. where anxiety about pain restricts a person's movements, focusing on the contingencies that will help them carry out the behaviour, rather than focusing on reducing their pain or anxiety about exacerbating pain)
An ability to draw on knowledge that children who can focus on positive goals and changing behaviour (rather than predominantly on pain reduction) tend to have lower perceived levels of pain, less pain-related distress and depression, less disability and lower level of avoidance of activities
An ability to draw on knowledge that interventions aim to engage the child as an active collaborator in developing self-management strategies (intended not to remove pain but to increase functioning in spite of pain) by helping them consider the thoughts, beliefs and schemas that shape their current coping strategies
an ability to draw on knowledge of the important role that parents can play as co-therapists/collaborators in supporting this process
An ability to draw on knowledge that children's understanding of pain and ability to manage it will change as they develop and are able to understand more cognitively complex models of pain

## Assessment

An ability to draw on knowledge of standardised measures that are commonly used to assess functioning in relation to pain, and to assess experience and cognitive appraisals of pain
An ability to work with the child and their family in order to use measures collaboratively, making use of their responses as the basis for discussion and further evaluation
An ability to help the child and their family discuss their medical history, the medical interventions that they have received that relate to their pain (including surgery, medication and investigatory procedures) and the impact of these interventions on their beliefs and behaviour
an ability to help the child and their family discuss their experience of the healthcare system and to identify any implications of these experiences for the intervention
An ability to work with the child and their family to develop a detailed account of pain-related problems, including:
the onset and duration of their pain
impact of pain on:
activities of daily living
personal, family and social functioning
capacity for maintaining schooling / study
major stressful life events that occurred prior to the onset of pain and/or that are associated with a worsening of pain
daily stressors associated with worsening of pain (e.g. lack of sleep, difficulty in relaxing)
reactions of the family to the child's pain and the limitations arising from this
An ability to help the child and their family discuss their pain-related beliefs (e.g. their understanding of its aetiology, likely prognosis, likely timescale for improvement)
An ability to discuss with the child and their family the strategies that they have adopted to manage their pain (including the effectiveness of these strategies and any adverse impacts) e.g.:
activities that are avoided because of anxiety that they believe will cause further harm
activities that are maintained in spite of pain
An ability to gauge the child's adjustment in relation to:
physical functioning (e.g. pain severity, pain behaviours, activity level, physical strength and mobility)
psychological functioning (e.g. beliefs, distress, depression, anxiety or behavioural responses (e.g. fear-avoidance behaviours, or psychological difficulties (such as anxiety or depression) that predate the onset of pain)
social functioning (e.g. difficulty maintaining school, relationships and social isolation)
An ability to help the child identify their goals for any intervention

## Engagement

An ability to validate the reality of the child's experience of pain
An ability to discuss the treatment rationale, conveying a sense that:
their pain is real, and is a bodily and emotional experience
pain triggers a range of cognitive and emotional reactions which can make the experience of pain worse
learning different ways to manage these reactions can reduce the experience of pain

An ability to discuss with the child and their family the collaborative nature of the intervention, and the expectation that they will be active participants who put learning from sessions into practice

An ability to use the engagement process to introduce psychoeducation about chronic pain and its management from a biopsychosocial perspective

## Intervention

### Setting goals

An ability to help the child and their family identify what they would like to be different, to identify short and longer-term goals that they would like to achieve, ensuring that these are:

meaningful and important for the CYP and their family

“SMART” (Specific, measureable, achievable, realistic and testable)

achievable in the short or long-term (e.g. not dependent on the actions of others for the goal to be reached)

described in behavioural terms (i.e. what would be seen to be different)

An ability to help children break-down goals into smaller incremental steps so as to minimise anxiety about harm

An ability to help the child and their family identify factors that have made it difficult to achieve these goals (e.g. because they involve walking further than is currently possible)

An ability to help the child and their family identify strategies they have successfully used to achieve goals in the past, and to think about how these might be applied currently

## Working on cognitions

An ability to integrate and apply work with cognitions alongside behavioural components of pain management interventions

### Making the connection between stressors and pain

An ability to discuss links between pain and negative emotions, and help the child identify biological, emotional and cognitive reactions to pain

An ability to help the child and their family identify situations that they find difficult and that are associated with pain flare-ups

An ability to help the child identify the ways in which they appraise or interpret these situations, for example:

as a challenge (e.g. as something that they can manage),

as a threat (e.g. as something that they are unable to cope with)

as a loss (e.g. as a situation that has caused lasting damage)

An ability to help the child consider how their appraisal of the situation might impact on the ways they focus attention, on their thoughts and feelings, and on subsequent behaviour

an ability to help the child and their family complete diaries that set-out links between these factors, and to use these as practice assignments

### **Identifying unhelpful automatic thoughts**

An ability to discuss the stress-appraisal-coping model of pain, making links between thoughts about pain and pain-related stressors, and how these influence adjustment to chronic pain

An ability to introduce the idea of unhelpful automatic thoughts using examples from the experiences of the child to demonstrate their influence on the experience and management of pain-related stressful events

An ability to describe common unhelpful automatic thoughts (such as all-or-nothing thinking or overgeneralising), and to help the child discuss how these might apply to themselves

an ability to help the child complete diaries that set-out links between stressful events, automatic thoughts and the level of belief in these thoughts

### **Evaluating unhelpful automatic thoughts**

An ability to help the child review practice assignment in order to clarify and specify automatic thoughts

An ability to help the child evaluate automatic thoughts, for example by weighing evidence for and against the thought and rating their belief in the thought

an ability to help the child and their family complete diaries that help them evaluate automatic thoughts and the level of belief in these thoughts

### **Challenging unhelpful automatic thoughts**

An ability to help the child and their family review practice assignments in order to review the authenticity of automatic thoughts and identify any ways in which they are unhelpful and/or based on cognitive distortions

An ability to help the child construct an alternative thought that is more realistic and to rate their belief in this new thought

an ability to help the child complete diaries that help them evaluate, challenge and reconstruct automatic thoughts

### **Working with pain-specific beliefs**

An ability to help the child identify unhelpful beliefs about their pain, and to challenge these beliefs and construct alternative (more adaptive beliefs) e.g.: beliefs about:

the cause of pain

the meaning of pain

the amount of control they have over the pain

the appropriate ways of treating the pain

An ability to help the child consider their reactions to negative pain-related experiences such as an exacerbation of pain (e.g. feeling less competent or worthwhile)

An ability to help the child identify automatic thoughts in response to pain-related situations and to underpinning beliefs

An ability to help the child challenge beliefs and to construct alternatives

## Using pacing to regulate activity levels

An ability to help the child and their family identify unhelpful patterns of activity in response to pain, including:	
	avoidance of activities (leading to underactivity and/or excessive rest)
	unhelpful patterns of behaviour (e.g. 'boom or bust' cycles - repeated periods of strenuous activity leading to enforced rest and more pain)
	unhelpful task persistence (e.g. comparing themselves to peers who are pain-free and forcing themselves to complete a task without taking a break, resulting in pain flare-ups)
An ability to help the child identify factors that maintain unhelpful patterns of activity	
An ability to discuss the rationale for pacing e.g.:	
	the adverse physical impact of underactivity (e.g. 'deconditioning' leading to reduced exercise tolerance and greater experience of pain)
	the advantages of maintaining an even level of activity
	the advantages of activity levels being guided by an agreed target rather than by pain
An ability to work with the child to identify activities or exercises that they would like to build up and the order in which this will be attempted (usually starting with activities that are easier)	
An ability to help the child pace a specific activity:	
	specifying the activity (including agreeing when an activity is best managed by being broken up into smaller units)
	agreeing on a 'baseline' (identifying what can be managed without incurring too much extra pain or exhaustion, usually based on trying out the activity a few times)
	setting an initial starting point just below baseline (in order to ensure success)
	carrying out the activity and taking frequent short breaks
	helping the child to maintain a record of the plan and to use this to monitor progress
	agreeing the rate at which activity will be built up, guided by progress being achieved
	identifying and problem-solving any barriers to maintaining progress
	an ability to maintain motivation by including 'fun' activities alongside those which are useful and/or necessary

## Relaxation

An ability to discuss the rationale for relaxation with the child (e.g. its role in reducing tension, helping them to feel more in control of pain, helping with sleep)	
An ability to help the child learn and make use of applied relaxation techniques	
An ability to help the child select from a range of relaxation techniques including progressive muscle relaxation, visualisation and controlled breathing	

## Attentional techniques

An ability to describe the rationale underpinning attentional techniques	
An ability to help the child desensitise themselves by focus on the pain itself (with the aim of reducing central reactivity to pain signals)	
An ability to help the child accept that desensitisation requires them to desist from avoiding or escaping the pain, and to:	
	accept that the pain is not harmful, and is not a cue to stop an activity
	try not to protect themselves from the pain
	acknowledge that the pain is present, but not react to it

An ability to help the child identify opportunities for practicing desensitising (e.g. by scheduling practice sessions and/or by practising in response to pain)
An ability to help the child complete diaries in order to monitor changes in their level of distress
Based on the child's experience of their efficacy, an ability to work with them to identify which attentional techniques, in which situations, are most suitable for them

### **Problem solving**

An ability to discuss the rationale for problem-solving with the child and their family (as a systematic method for managing problems and improving their confidence that they can cope)
An ability to help the child and their family apply problem-solving techniques to specific problem areas

### **Managing interpersonal problems, peer relationships and educational challenges associated with pain**

An ability to help the child and their family identify interpersonal difficulties that arise in relation to living with chronic pain (e.g. feeling more irritable or withdrawn, difficulty managing the demands of others, tensions in close relationships)
An ability to help the child identify and practice communicating their needs more clearly and/or assertively
An ability to help the child maintain relationships with peers when their pain may impact both the amount and type of contact (e.g. reduced school attendance or being unable to participate in sports)
An ability to help the child and family maintain education and school attendance (e.g. by identifying appropriate adaptations and liaising with the school to help implement these)

### **Managing setbacks**

An ability to help the child and their family develop an explicit plan to manage flare-ups and setbacks that includes:
acting early
reviewing factors that may have resulted in the flare-up
making use of coping strategies

### **Acceptance and Commitment Therapy (ACT) as applied to chronic pain**

This listing focuses on the competences specifically associated with implementing ACT. As such it needs to be read in the context of the foregoing competences, which describe the knowledge and skills associated with cognitive and behavioural interventions, as well as outlining the usual structure of these interventions.

### Knowledge of ACT as applied to chronic pain

An ability to draw on knowledge that ACT assumes that problems with chronic pain arise because children or young people have become avoidant and problem-focused, and their behaviour has become over-regulated by their thoughts and feelings	
An ability to draw on knowledge that ACT aims to help children and young people move to a position where their behaviour is determined by the values and goals they wish to achieve, so that they are:	
	more open to experience and willing to accept their experience of discomfort and pain in the service of pursuing values and goals (holding in mind that with younger children it may be more appropriate to focus on goals rather than values)
	in contact with direct (positively reinforcing) contingencies (e.g. experiencing the reward contingent on maintaining social contact rather than avoiding contact because this might involve exposure to pain)
	aware of (but not engaged with) their thoughts and feelings, such that their actions are not over-determined by them
An ability to draw on knowledge that (from an ACT perspective) problems with chronic pain arise because the child's behaviour lacks 'psychological flexibility':	
	because behaviour patterns are largely guided by negative reinforcement and avoidance rather than being guided by goals and values (e.g. avoiding a valued activity in order not to experience pain, but at the cost of achieving goals)
	because their behaviour patterns are dominated by the literal content of thoughts, images, evaluations, or judgements (e.g. pain is unquestioningly experienced as a signal that something is wrong and responded to accordingly)
	because there is an over-identification with thoughts and feelings ("thoughts and feelings are me, and there is no distance between me and them")
	because there is a loss of openness to experience, and so a loss of contact with the present moment and direct behavioural contingencies (i.e. potential immediate opportunities/ rewards in the child's environment)
	because across a range of situations, behaviour is dominated by patterns that do not contribute to the achievement of goals (e.g. repeatedly breaking or avoiding commitments, or consistently acting impulsively in ways that repeat failure)

### Intervention

An ability to describe and to discuss with the child an individualised conceptualisation of their difficulties	
An ability to describe the rationale for ACT and the likely focus and structure of the intervention, in terms of:	
	openness (e.g. helping the child to consider thoughts or feelings that they find difficult to experience or focus on, and the ways in which integrating these into patterns of behaviour might increase their choices regarding what they can achieve)
	awareness (e.g. helping the child to become aware of and move on from preoccupations (often based in the past or anticipating the future) that bind them to particular set of behaviours that do not help them achieve their goals)
	engagement (helping the child to focus on controlling behaviour rather than thoughts and feelings, and on starting to initiate goal-directed actions)
An ability to draw on knowledge that a primary vehicle for promoting psychological flexibility resides within the therapeutic relationship	
An ability to draw on knowledge that the intervention focuses on helping the child to achieve greater psychological flexibility	

An ability to draw on knowledge that the main techniques employed in ACT are exposure, experiential exercises, and the manipulation of direct operant contingencies, rather than didactic methods, such as lecturing or instruction
An ability to identify moments in therapy where the child demonstrates behaviour that is psychologically inflexible or flexible and employ appropriate ACT interventions to decrease the former and enhance the latter
An ability to draw on knowledge of the importance of the therapist and child working together as equal collaborators (and hence for the child to choose their goals, and be able to decide the level of their participation in any ACT intervention)
An ability to work with the child to identify in-session behavioural patterns in order to help them achieve behaviour change
An ability to help the child to connect with their experiences by developing their skills in observation and awareness (for example, using techniques such as exposure, skills training and mindfulness)
An ability to help the child allow experiences to be present without attempts to avoid, control or change them, when this serves goals and related behaviour change
An ability to help the child 'let go' of words, thoughts and the meanings attached to them in favour of greater openness to experience and being able to 'live in the moment'
An ability to help the child accept but not engage with thoughts feelings and 'stories' about the self (e.g. "because my pain stopped me from doing sport I am a failure")
An ability to help children adopt a sense of self that is experienced as separate from (and not threatened or overwhelmed by) thoughts and feelings (for example dis-identifying with "stories" about who they are and that act to restrict what they can achieve, or being able to connect with experience as an observer of thoughts and feelings)
An ability to help the child or young person identify and discuss their values and goals, helping them to:
align their behaviour with these values and goals
initiate changes in behaviour
build changes in behaviour into persistent, generalized, and integrated patterns

## 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 is 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)	

## Procedural Distress

### Knowledge

An ability to draw on knowledge that some procedures contain inherently aversive elements and, as such, a distress response may be adaptive and appropriate	
An ability to draw on knowledge that a most people experience some degree of fear in response to medical procedures; as such normative fear response should be differentiated from a response that warrants intervention because it is disproportionate or obstructs the successful completion of the procedure	
An ability to draw on knowledge of the procedure and the medical context in which it occurs in order to understand the potential triggers for the young person's fearful responses	
An ability to draw on knowledge of policy and practice in relation to safeguarding capacity and consent procedures that may apply if medical needs are judged to take precedence over the child's own wishes and/or those of their family	
An ability to draw on knowledge that interventions for procedural fear focus on enabling the young person to tolerate the procedure (e.g. utilising rather than deconstructing safety behaviours if this is the most efficient route)	
An ability to draw on knowledge that if the procedure is not medical necessary or urgent, then an intervention may include halting the procedure until the young person is ready and/or agreeable to undertaking it	
An ability to draw on knowledge that the term "procedural fear" relates to a range of distress responses to medical procedures including fear, phobia and anxiety, and that:	
	because fear is a primary emotion that occurs in direct short-term response to the stimulus with little cognitive mediation, intervention should focus on emotional regulation and coping strategies, such as increasing control and predictability
	that anxiety is more usually associated with long-standing cognitive attributions
	that phobia is an anxiety associated with a specific trigger and characterized by a high level of avoidance of that trigger
	that a small proportion of the population experience vasovagal syncope in response to the sight or thought of blood and related triggers
	that in a small proportion of the population, medical procedures can trigger post-traumatic symptoms such as dissociation, flashbacks or extreme fear and avoidance relating to previous medical experiences
An ability to draw on knowledge that there are a number of social and environmental factors that can contribute to a fearful response, e.g.:	
	the way in which the procedure is conducted (e.g. a healthcare professional attempting to conduct the procedure in a brusque and impatient manner)
	the physical environment (e.g. an overstimulating or unconfined environment, such as an area with bright lights, loud noises and lots of people)
	parents/carers who are themselves fearful of medical procedures and who may elicit a fearful response from the young person
	the young person's exposure to accounts of frightening medical procedures (e.g. from friends, siblings or parents)
	failure to let the child know in advance about the medical procedure
	multiple prior experience of medical procedures, particularly if these have been aversive or traumatic

An ability to draw on knowledge that not all distress or resistance in response to medical procedures is related to fear
preexisting psychosocial difficulties can contribute to the appearance of procedural fear (e.g. a generalized pattern of oppositional behavior)
An ability to draw on knowledge of the role of a developmental stage in understanding and responding to fearful responses and/or resistance to medical procedures
extreme emotional reactions may be more common in pre-school aged children and interventions for children in this age range are more effectively aimed at modifying parental behaviours
An ability to draw on knowledge that, there is a broad range of intervention options, including direct work with the child but also focused on changing the practice of the professionals conducting the procedure, parental behavior or the environment in which the procedure occurs

### Assessment

An ability to undertake an assessment which accurately identifies the factors leading to procedure fear, and hence identifies the most appropriate set of interventions
an ability to identify 'alternative' aetiologies that may account for apparent procedural fear such as prior medical trauma, ongoing family conflict or significant ambivalence about having the procedure

### Intervention

An ability to maintain a primary focus on helping the young person undertake the procedure
An ability to engage the young person in psychological intervention for procedural fear even when they are unwilling or unmotivated to address this
An ability to work collaboratively with the child to identify 'compromises' that they find acceptable (e.g. accepting sedation before the procedure)
An ability to use motivational enhancement techniques (such as Motivational Interviewing or solution focused approaches) to help the young person to engage in interventions that address their procedural fear (i.e. not focusing on problems but on what needs to happen in order to proceed)
An ability to work closely with the healthcare team and service delivering the procedure:
to assess the specific demand characteristics and extent of flexibility in the procedure in order to accommodate the young person's individual needs
to identify other factors that may directly contribute to fearfulness in the young person such as pain
to help healthcare professionals modify their behavior in order to reduce fear in the young person
to advocate on behalf of the young person in order that (where possible) their needs and wants are taken into consideration where possible
to negotiate halting the procedure if it ceases to be in the best interests of the child (e.g. if it is conducted in a way that leads to significant levels of agitation and/or risks becoming a traumatising experience)

## Fear

An ability to decrease the fear response to the medical procedure by:	
	managing the expression of emotional distress in the client (and where appropriate their parents and the healthcare professionals)
	identifying strategies that parents/carers identify as 'emotionally regulating' (e.g. cuddling by carer, relaxation, bringing a favourite toy, distracting activities such as listening to music)
	employing strategies for reducing fear that increase the young person's sense of control and certainty in relation to the procedure:
	identifying and rehearsing what is involved in the procedure
	where possible offering choices in how the procedure is conducted
	helping the young person ask questions in order to more fully understand what happens in the procedure
	ensuring that healthcare professionals are advised of any changes to procedure agreed and rehearsed with the young person, and ensuring that they conduct it in this way
	discussing the experience of the procedure once it has been completed in order to help the young person process their emotional experience
	establishing an appropriate reinforcement schedule:
	establishing positive associations and/or positive reinforcements for the procedure
	ensuring that the child is not punished for failing to successfully tolerate the procedure
	giving praise and/or rewards for attempts at the procedure as well as for undertaking the procedure successfully

## Anxiety

An ability to identify the specific triggers of fearfulness where the developmental stage of the child makes this possible (i.e. where the child is old enough to articulate this information)	
An ability to conduct behavioural interventions for anxiety (such as graded exposure)	
An ability to teach the young person and their parents anxiety management strategies (such as relaxation, distraction)	
	particularly with younger children, an ability to help reduce parental anxiety and (in turn, and indirectly) that of the child

## Visible difference/body image issues

### Knowledge

An ability to draw on knowledge of the role of appearance in an evolutionary and social context:	
	physical appearance is often (unconsciously) used by individuals and groups to distinguish between desirable and undesirable potential group members
	attractiveness is a consistent construct across cultures and nationalities
	attractive individuals are typically imbued with positive attributes while unattractive individuals are imbued with negative attributes
	attractive individuals are typically treated more positively by others than individuals who are unattractive
	attractive individuals are often more successful in a range of social spheres (e.g. in education, employment and in establishing marital relationships)
An ability to draw on knowledge that a specific disfigurement does not necessarily lead to an individual being perceived as unattractive (the disfigurement will be seen in the context of their "background attractiveness")	
An ability to draw on knowledge of psychological and social functioning in young people with disfigured appearance:	
	that there is limited evidence of a significantly increased likelihood of psychological morbidity in childhood
	that where difficulties arise these are most likely to be in the areas of self-esteem and social relationships
	that physical co-morbidities or symptoms associated with the condition causing the disfigurement are more likely to contribute to psychological morbidity than the disfigurement alone
	that other aspects of the young person's psychological functioning, social context and life experience will have an equally powerful effect on their development and should be taken into account when understanding (formulating) the presenting difficulties
An ability to draw on knowledge of social development, social functioning and social difficulties associated with disfigured appearance, and so consider:	
	how social victimization and isolation can be the result of the disfigured individual's beliefs and behavior as well as those of the individuals and systems around them
	the impact of implicit and explicit societal messages about appearance on social motivation, social engagement, social skills development and developing sense of self of a young person with a disfigured appearance
An ability to draw on knowledge of the role that family functioning can play in moderating or exacerbating distress over appearance	
An ability to draw on knowledge that distress over appearance reflects the subjective appraisal of the child and their family, and may or may not be congruent with the level of visible difference as perceived by health professionals	
An ability to draw on knowledge of cultural differences in attitudes towards appearance, especially in relation to cultural or religious beliefs that may lead to stigma or rejection in relation to visible difference	

An ability to draw on knowledge of the medical condition that is the cause of the disfigurement in order to understand the cause, course and prognosis as well as the impact and side-effects of treatment, and so:	
	judge if the level of difficulty and distress is proportionate to the disfigurement and/or other symptoms experienced by the young person
	identify whether the young person's or their carers' understanding of medical treatments and their likely effects is congruent with those of the treating medical team
An ability to draw on knowledge that (as well as the disfigurement) other symptoms, treatment requirements and individual meanings related to the condition can also be impacting on the young person and their family	

**Assessment**

An ability to help young people to discuss their appearance, their sense of self-worth and their experiences of social rejection and isolation	
	an ability to help parents and carers discuss their feelings around appearance and their sense of (and reactions to) their child's experiences
An ability to help key people in the young person's system discuss their perception of the challenges arising from the young person's disfigurement	
An ability to maintain a development focus when working with young people and their families affected by disfigured appearance, and that:	
	disfigured appearance is likely to elicit different challenges at different developmental and transitional stages
	social context will play an important role in contributing to the young person's developing understanding of their appearance
An ability to identify emotional, psychological, social and behavioural difficulties that are present and troubling to young people and their families	
An ability to draw on information from young people, their families and their wider social contexts to understand the emotional, cognitive, relational and behavioural elements of the young person's difficulties and how they relate to their disfigured appearance	
An ability to work with systems in the young person's life (such as medical, educational and social services) in order to identify any 'systemic' factors that contribute to psychological difficulties	
An ability to hold in mind that there may be multiple factors in addition to disfigurement that may contribute to the young person's difficulties	
An ability to identify when help-seeking for disfigurement-related difficulties reflects a disproportionate concern about body-image (e.g. body dysmorphic disorder)	

**Interventions**

**Developing social skills**

An ability to help the CYP develop social skills to deal with challenging social experiences related to looking different (such as being stared at in public places, being victimised and or bullied by other young people)	
An ability to identify and utilise appropriate techniques for working with a young person's developing sense of self (e.g. narrative approach to help them 'situate' their disfigurements in context of sense of self and so try to achieve a more balanced sense of self, or behavioural experiments to test out the reactions of others)	

An ability to work with families and with wider social systems (such as schools) to support adaptive social skills development and development of an adaptive self-concept (and so generalize adaptive skills outside the therapy room)

an ability to intervene where systems around the young person have adopted unhelpful strategies to support them (e.g. withdrawing a child from a class and so marginalizing them)

### **Working with 'disproportionate' reactions/ misunderstanding of the condition**

An ability to work with the young person, their family and the wider system, where there appears to be a disproportionate reaction to the experience of having a disfigured appearance

An ability to work with the young person and their families where their understanding of the disfiguring condition and potential treatment is at marked variance with medical opinion

an ability to help the young person and their families to discuss their outlook and the mechanisms supporting this viewpoint

### **Effecting change in the wider social context**

An ability to work with relevant systems (such as healthcare, education and social services) in order to engage organisational support for the disfigured young person (e.g. to establish procedures for reporting and responding to experiences of victimization)

An ability to effect organisational/systemic change to establish a more supportive, less marginalising environment around the young person, e.g.:

by providing training to educational or healthcare professionals

by helping to modify unhelpful organisational responses (e.g. a school which blames the disfigured young person for their social victimization by schoolmates)