

# Working with children and families experiencing medical traumatic stress:



## A resource guide for mental health professionals

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## **Purpose of this Resource Guide:**

This resource guide is designed to help psychosocial professionals who are working with children and families impacted by illness or injury, especially in their role as a consultant to or collaborator with hospital-based medical professionals. It is also intended for psychosocial providers who receive referrals from healthcare providers and health care teams. These psychosocial professionals include clinical social workers, mental health counselors, psychologists, psychiatrists, and others. This guide provides: an overview of pediatric medical traumatic stress (PMTS) based on the most recent research; resources and materials to educate medical colleagues (physicians, nurses, physician assistants); and psychosocial screening, assessment, and intervention resources and materials.

We recognize that there are many ongoing stressors that children and families endure after diagnosis of an illness or an injury. The purpose of this guide is to focus specifically on medical traumatic stress and responses that children and families may have.

This guide aims to:

- Increase knowledge of pediatric medical traumatic stress
- Define pediatric trauma-informed care
- Expand resources of materials to support the implementation of trauma-informed care pediatric care
- Support psychosocial providers in collaborating with medical providers about PMTS
- Provide psychosocial professionals with tools to screen, assess, and prevent PMTS, as well as administer interventions to treat PMTS

## Overview: Pediatric Medical Traumatic Stress

In the United States, illness and injury are common among children and adolescents. Each year

- Approximately 20 million children are injured, resulting in 8 million emergency room visits
- Over 11,000 children are diagnosed with cancer
- More than 1,000 children undergo organ transplant
- Approximately 5% of children and adolescents are hospitalized for acute or chronic illness or injury
- Approximately 30% of children newly diagnosed with Type 1 diabetes require hospitalization and intensive care treatment
- Nearly 1 million children and adolescents make emergency room visits for a life-threatening asthma episode
- Between 15,000 and 30,000 children under 15 are hospitalized for burn injuries

Pediatric injury, ambulance transportation, diagnosis of a chronic or acute illness, medical treatment, medical procedures, and hospitalizations may be traumatic for children and their families. However, not all children and families describe contact with the healthcare systems as traumatic. Medical events may be more likely to be experienced as traumatic when they involve:

- Sudden or unexpected onset of the illness or injury
- Painful or frightening treatment procedures
- Sights, sounds, or experiences in the hospital that are upsetting or frightening

Pediatric medical traumatic stress involves exposures to a potentially traumatic medical event and subsequent traumatic stress reactions, such as re-experiencing, avoidance, and hyper-arousal as well as changes in mood, cognitions and behavior. These reactions may persist over time and interfere with recovery from injury or illness and/or with return to normal activities. In addition to the child with illness or injury, parents, siblings, extended family members, and other loved ones are at risk for medical traumatic stress. While many families adapt and cope with the stress related to pediatric injury and illness, all children and families would benefit from medical care that is sensitive to the potentially traumatic nature of medical conditions and treatments and a substantial subset of children and families would benefit from psychosocial support and intervention.

## Potentially Traumatic Medical Events

Traumatic medical experiences are rarely a single event. All along the continuum of health care, ill or injured children and families face multiple traumatic experiences, as well as incidents that will trigger feelings or remind them of those experiences. In addition, traumatic stress doesn't necessarily end with the conclusion of medical treatment.

Factors that contribute to experiencing medical events as traumatic:

- A specific scary or shocking event (injury / initial diagnosis)
- The medical environment (hospital sights / sounds, etc.)
- Pain or painful medical treatment
- Separation from caregivers or family members
- Physical limitations or impairment
- Ongoing uncertainty about prognosis
- Treatment setbacks
- Caregiver helplessness seeing their child in pain, distressed, hooked up to medical equipment, etc.
- Exposure to distress, pain, or death of others (e.g., other patients)
- Exposure to reminders of past traumatic medical experiences
- Sense of life threat (regardless of objective prognosis)

Children, teens, and their adult caregivers can differ significantly in what they perceive as traumatic in the hospital or other medical setting. For children, concrete, immediate consequences – getting needles and painful procedures, scarring and physical changes or disabilities, and pain often lead to distress. For teens, immediate physical consequences, as well as the social consequences of being in the hospital - being isolated from friends and family, missing school, etc. can be the important predictors of distress. For caregivers, thoughts and feelings around the diagnosis and prognosis may be described as traumatic.

What is most traumatic? Kids and parents see things differently.	
Child cancer survivors:	Moms of cancer survivors:
1. Shots	1. Worried about relapse
2. Losing hair	2. Pain
3. Staying in the hospital	3. Scared about death
4. Pain	4. Diagnosis – Finding out
5. Bone marrow procedures	5. Know others that died
6. Know others that died	6. Feeling sad / scared
7. Scared about death	7. Staying in the hospital
8. Worried about relapse	8. Shots
9. Feeling sad / scared	9. Bone marrow procedures
10. Diagnosis – Finding out	10. Losing hair

Research with ill and injured children and families has shown that children and caregivers may find different aspects of the experience traumatic.

## **Pediatric Medical Traumatic Stress Reactions**

As with other types of trauma, emotional and behavioral reactions to potentially traumatic medical events include:

- General anxiety symptoms
- Worry about safety
- Hypervigilance
- Agitation
- Temper tantrums
- Feeling sad or withdrawn
- Problems with sleep; nightmares
- Problems with eating
- Trouble focusing or concentrating
- Feeling numb or seemingly detached
- Behavioral regression (bedwetting, separation anxiety, etc.)
- Difficulty in school / absenteeism

In addition, children and adolescents may have strong emotional reactions to medical reminders, such as: getting upset at going to the doctor for routine check-ups, adverse reactions to pills and needles, reactions to seeing or passing by hospitals and ambulances, etc. Being sick or immune-compromised can lead to serious health problems, thus children may have realistic concerns with exposure to illness. Children who have experienced a potentially traumatic medical event may begin to generalize their experience, possibly manifesting itself in a preoccupation with their own health or the health of others, may avoid others with common illnesses, and may have obsessive thoughts and actions around cleanliness and germs.

Somatic complaints, which are often associated with traumatic stress reactions, need to be approached more carefully. Children and adolescents who have experienced illness and injury may experience stomachaches, headaches, and nausea, as well as other sensory reactivity. Teasing apart the extent to which these complaints have an identifiable medical cause is important. Whatever their cause, somatic complaints may be interpreted in a more catastrophic manner by children who have experienced medical traumatic stress.

## Unique Features of Pediatric Medical Traumatic Stress

Many psychosocial professionals are familiar with child trauma and traumatic stress related to child abuse, neglect, and exposure to violence. Medical trauma has some distinct characteristics that may impact the course of traumatic stress symptoms and have implications for medical care and psychosocial intervention, including:

- **Experience of pain / ongoing pain:** Illness and injury often involve acute pain, and may involve chronic pain. Health care systems are paying increasing amounts of attention to pain (as the “fifth vital sign”) and to optimizing pain management. Nonetheless, during and after medical treatment, children may experience pain that is not well controlled.

Children often have little experience with managing pain and may make catastrophic interpretations regarding the meaning of the pain. Children with pain can readily become emotionally and behaviorally dysregulated and frequently do not know how to manage their pain without outside intervention.

- **Painful / distressing procedures:** Children with a serious illness or injury may have to undergo multiple painful or distressing procedures, which can be frightening for them. Anesthesia and other medications often help lessen procedural pain. Health care teams and parents can provide effective distraction to lessen distress during procedures. But often, the child or teen has to endure *some* pain during or after procedures.
- When a child has repeated procedures over time, she or he may develop **anticipatory anxiety**, which can result in behavioral dysregulation or treatment refusal, and can impact overall medical treatment adherence.
- **Sedation and loss of consciousness:** Loss of consciousness – whether due to a traumatic injury or to sedation / anesthesia - can be disorienting or scary to both children and their caregivers. Not being able to place events in time and sequence can maintain traumatic stress symptoms.

Children sedated while in intensive or critical care, or who are coming out of anesthesia, may also experience frightening hallucinations that they believe to be real. These experiences have been linked to increased traumatic stress reactions. In rare instances, children and teens recount hearing people saying things about them while under sedation. In addition, a few children have recalled coming to consciousness during surgery while feeling traumatized at being physically paralyzed by the sedation and unable to talk or communicate.

- **Separation and isolation:** When injury or illness have a sudden onset, children and teens may initially be separated from caregivers during ambulance transport or emergency treatment, which can be very frightening and cause significant distress.

Most parents and caregivers try to maximize time with their hospitalized child. But caregivers often need to work or attend to other children, and children in the hospital often spend considerable time without a parent present. Lengthy hospital stays also mean that children are separated from family, friends, and pets, and can feel isolated from their usual support system.

- **Exposure to sickness, injuries, or death of others:** While hospital personnel and systems do their best to shelter children and families from unnecessary exposure to other frightening events, sometimes these are unavoidable. Children in the emergency room or inpatient hospital may see other seriously injured or ill patients and their families, see and hear frightening sights and sounds (e.g. resuscitations, alarms), and may experience grief and loss when other patients die.

Injured children and teens may be exposed to traumatic elements at the scene of an accident, shooting, or other traumatic event before being brought to the hospital. They may have seen bloodied or broken body parts, witnessed emergency procedures like CPR being performed on others, or noticed faces of those who are upset, scared, or crying. These images can be etched in their memories long after the injuries have healed.

- **Ongoing physical and health consequences:** For some children and families, the potentially traumatic medical events do not have a clear end point. The ongoing possibility of recurrence or life threat is a realistic concern in many conditions. Chronic illnesses, like diabetes and asthma, can have life-threatening episodes and consequences and require ongoing management and vigilance. The course of some cancer treatments may take years to complete and may involve both life-threatening complications and relapse. Some injuries bring permanent scars and physical alterations, disabilities, and loss of prior functioning.

For many children and families, ongoing physical consequences and treatment can serve as both reminders of trauma and loss. Other families may live under heightened threat and hypervigilance, fearing a treatment complication or relapse. Still others might try to avoid these feelings by avoiding needed medical treatment, unfortunately increasing their risk for medical complications.

## Family impact:

Medical events do not just impact children; they impact the entire family system. Many times, medical events create a crisis in the family; as a result, families will naturally reorganize roles and tasks around the trauma event in order to support the ill or injured child or to cope with the impact of the trauma. Family attention, goals, and priorities can suddenly and dramatically shift. Generally, healthier families will make adjustments in balancing medical and non-medical family priorities and return to their prior level of functioning after the immediate medical crisis is over.

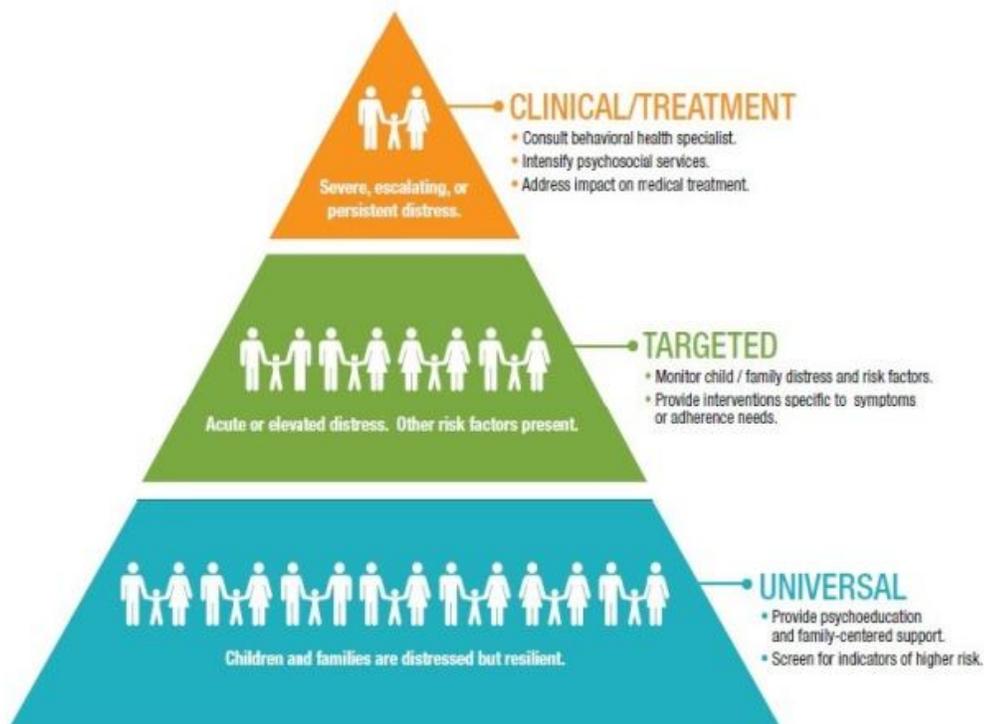
Some families, however, have a difficult time re-stabilizing due to ongoing worries, concerns, or consequences from the medical event. Even when the crisis is over and the child has returned to prior functioning, some caregivers remain on guard and hypervigilant and often describe themselves as “waiting for the other shoe to drop.”

Siblings, in particular, can suffer during this time of medical crisis. When family priorities shift, siblings often feel they have been relegated to the lowest priority. They may have to parent themselves, or be parented by friends or extended family members. This loss of parental attention can be very distressing for them, which they sometimes translate as being unloved. They may also have very conflicting feelings – feeling worried and sympathetic for their ill or injured sibling, yet also feeling very jealous.

Care giving roles also change during a medical event. Many caregivers feel unprepared and unskilled at caring for or even parenting their ill and injured child, relying a great deal on the medical team for help, support, and guidance. Parents can feel both helpless and guilty at not being able to adequately care for their child. They may also tend to relax the disciplinary rules for the ill or injured child, due to feelings of sadness or guilt. Some caregivers also feel guilty about not being able to be in multiple places at once and often have to choose

between competing priorities. They also may have to make decisions under duress, and feel uncertain regarding whether they were making the right decision.

## Pediatric Psychosocial Preventive Health Model



Later in this guide we describe the use of the Pediatric Psychosocial Preventive Health Model (PPPHM; see image) will be discussed as a helpful guide for mental health clinicians to support clinical decision making. When working with families coping with an ill or injured child the PPPHM may be useful in conceptualizing families and their psychosocial risk level:

## Prevalence of Pediatric Medical Traumatic Stress

The chart below shows the estimated prevalence of reported posttraumatic stress symptoms in children and their caregivers. A caveat: There is variation across studies, and some injury or illness groups have received more research attention than others.

Sample / Setting	Prevalence	
	Patients	Caregivers
<b>Illness:</b>		
Cancer In-Treatment	10%	50%
Cancer Survivors	30%	30%
Cardiac Surgery	25%	15%
Organ Transplantation	20%	35%
HIV	30%	Not studied
Asthma	15%	25%
Diabetes	5%	35%
<b>Injury:</b>		
Various injuries (falls, sports injuries, violently injured)	20%	20%
Burns	30%	30%
Motor Vehicle/Pedestrian	30%	15%
TBI	40%	Not studied
Spinal Cord	40%	40%
Disfigurement	20%	Not studied
<b>Intensive Care:</b>		
PICU	35%	25%

## Who is at higher risk for medical trauma?

Research has identified a number of factors that are associated with higher risk for pediatric medical traumatic stress among children and caregivers.

	Children / Patients	Caregivers
Perceived risk of life threat	√	√
Experienced early traumatic stress symptoms	√	√
Experienced more severe levels of pain	√	
Exposed to scary sights and sounds in the hospital	√	
Separated from parents or caregivers during / after trauma	√	
History of previous traumatic experiences	√	√
History of behavioral, emotional, or other mental health problems	√	√
Lack peer support	√	√
Have experienced other life stressors or disruptions		√

## **Developmental Impact of Medical Traumatic Stress:**

The way that children respond to potentially traumatic medical events is influenced by their age and development.

**Younger children's** responses are often behavioral and somatic; they will SHOW you that they are upset, rather than tell you. Younger children:

- Do not recognize or anticipate danger until it happens.
- Can experience separation from caregivers, siblings, and/or pets as traumatic.
- Do not have the cognitive and regulatory capacity to calm their own fears, and so they may have strong startle responses, night terrors, or aggressive outbursts as a result.
- Depend on caregiver presence and support to soothe and calm them more than any other age group.
- Think in images and are more likely to process trauma through play, drawing, and storytelling, rather than talking.
- Can regress behaviorally (bed-wetting, thumb-sucking, etc.) in response to distress.
- May not understand that some losses and/or illnesses are permanent.
- Need routine, predictability, and behavioral limits to reestablish feelings of safety and security.

**School-age children** will take cues from adults' non-verbal behaviors regarding how serious the illness or injury is, and how to respond. School-age children:

- May discount verbal explanations if what they observe does not match up with what adults are telling them.
- Can overestimate life-threat or severity of condition based on sights, sounds, or past experiences.
- Will use their imagination to “fill in the blanks” (e.g. magical thinking) in the absence of realistic information or explanations (especially about diagnosis, prognosis, etc.)
- Sometimes imagine that an illness or injury is punishment for something they did wrong.
- Often react out of frustration and helplessness; as a result, responses can be impulsive, but are not necessarily intentional.
- Can experience significant grief and loss reactions, even if the loss was expected.
- Need routine, predictability, and behavioral limits to reestablish feelings of safety and security.

**Adolescents** can be more concerned about the “here and now” issues rather than the future.

Adolescents:

- Can be unrealistic in their expectations or beliefs about prognosis, recovery, etc.
- Will sometimes act “grown up” and try to protect others from their more distressing thoughts and feelings.
- Are sensitive to being excluded from discussions of their condition, treatment, etc.
- Are self-conscious about looking different or being isolated from peers.
- Can experience significant pain, anger, or frustration when challenged to do something that was once routine.
- Responses can include withdrawing or acting out (intense anger, emotional outbursts, increased aggression, etc.) in response to stressors and feeling dependent on others.

## **Role of beliefs:**

Beliefs play an important role in the immediate response of children and families to a potentially traumatic medical event, as some beliefs may interfere with medical care and long-term coping.

Take for example, a 4 year old girl with no family history of cancer, who is suddenly diagnosed with leukemia and has to undergo three years of chemotherapy. Or, an 8 year old boy who is gravely injured when the limb of the tree holding his swing suddenly breaks and falls on top of him.

It is human nature to seek explanations and understanding for why traumatic events occur, especially when they seem out of the blue and without justification. Pediatric illnesses and injuries are no different. Many caregivers struggle with explanations when their child suddenly becomes ill or injured, and sometimes end up blaming themselves, even if, logically, they were not to blame.

Children will “fill in the blanks” with their own explanations, and, like adults, sometimes they will blame themselves or view the illness or injury as punishment for something they did wrong before the illness or injury occurred.

Having no explanations or no one to blame can increase a child’s or caregiver’s sense of helplessness, which can also amplify traumatic stress responses. Asking children and caregivers about their beliefs about the cause of the illness or injury is important, as this information can help to identify the level of psychosocial needs and type of intervention needed (e.g., psychoeducation, more formal evidence-based preventive intervention). For example, some children and families would benefit from basic education about medical treatment and typical emotional reactions to pediatric injury and illness. By “filling in the blanks” in a developmentally appropriate manner, unhelpful beliefs about self-blame and punishment may also be dispelled. The families’ focus may then shift to more adaptive beliefs about their coping strengths and abilities.

# Trauma-Informed Care

## Trauma-Informed Care and Family-Centered Care

Medical providers treating children should be knowledgeable about pediatric medical traumatic stress and the variability in the ways in which children and families may respond to contact with the health care system. Pediatric physicians, nurses, physician assistants, and other medical providers should aim to deliver family-centered care to optimize outcomes for children and families. Psychosocial professionals can collaborate with health care teams to promote and support patient- and family-centered and trauma-informed care.

**Patient-Centered Care:** Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions. Patient-centered care is a partnership among practitioners, patients, and their families ensuring that decisions respect patients' wants, needs, and preferences, and that patients have the education and support they need to make decisions and participate in their own care (Institute of Medicine [IOM]; American Academy of Pediatrics [AAP]).

**Family-Centered Care:** Incorporating aspects of patient-centered care, family-centered care is based on the understanding that the family is the child's primary source of strength and support. Further, this approach to care recognizes that the perspectives and information provided by families, children, and young adults are important in clinical decision making (AAP).

**Trauma-Informed Care:** An organizational structure and treatment framework that involves understanding, recognizing, and responding to the effects of all types of trauma, and seeking to employ practices that do not traumatize or re-traumatize. Trauma-Informed Care also emphasizes physical, psychological and emotional safety, trustworthiness and transparency, collaboration and mutuality, empowerment, and cultural sensitivity and responsiveness (National Child Traumatic Stress Network [NCTSN]; Substance Abuse and Mental Health Services Administration [SAMHSA]).

Psychosocial professionals who work directly within a health care setting, or who form collaborative working relationships with health care professionals, can help to educate medical providers about trauma-informed care. In this role, it is critical to not *add* to a medical professional's routine, but support the integration of trauma-informed principles with current family-centered principles. Trauma-informed care means that medical providers' treatment of children and families minimize the potential for ongoing trauma and optimizes both emotional and physical health outcomes.

## **A Training Model: D-E-F**

In their role as (internal or external) collaborators and consultants, psychosocial professionals can offer a simple framework to support medical professionals in providing trauma-informed care to children and families. The D-E-F protocol provides a straightforward method to educate and support medical providers in specific strategies they can employ to help prevent and address traumatic stress responses in children and families. Strategies suggested by the D-E-F protocol are within the scope of practice of the physician, nurse, or other health care professional.

Health care providers are experts in treating illness, restoring functioning, and saving lives. After attending to the basics of children's physical health (the A-B-C's), providers can promote their patients' health and recovery by paying attention to the next steps — "D-E-F"

- Reduce DISTRESS
- Promote EMOTIONAL SUPPORT
- Remember the FAMILY

Some simple tips to help medical providers provide trauma-informed care (i.e., D-E-F) are below. More formal training in D-E-F for health care professionals can be found at [www.healthcaretoolbox.org](http://www.healthcaretoolbox.org), including brief online courses that offer free nursing continuing education credits. Other D-E-F resources can also be found on the website.

	Assess Distress	Help with Distress
<b>DISTRESS</b>	<b>Use hospital's pain assessment</b> <ul style="list-style-type: none"> <li>How is your pain right now?</li> <li>What was your worst pain since this happened?</li> </ul>	<b>Provide child with as much control as possible</b> <ul style="list-style-type: none"> <li>Help child understand what is happening</li> <li>Allow child to have a say in what will happen next</li> </ul>
	<b>Fears and worries</b> <ul style="list-style-type: none"> <li>What has been scary or upsetting for you?</li> <li>What worries you the most?</li> </ul>	<b>Provide accurate information, using basic words</b> <ul style="list-style-type: none"> <li>Ask child to repeat back explanations</li> <li>Listen carefully and clarify misconceptions</li> </ul>
	<b>Grief and loss</b> <ul style="list-style-type: none"> <li>Was anyone else hurt or ill?</li> <li>Other recent losses? (home, pet, etc.)</li> </ul>	<b>Provide reassurance and realistic hope</b> <ul style="list-style-type: none"> <li>Describe what is being done to help child feel better</li> <li>Address child's concerns or worries</li> </ul>

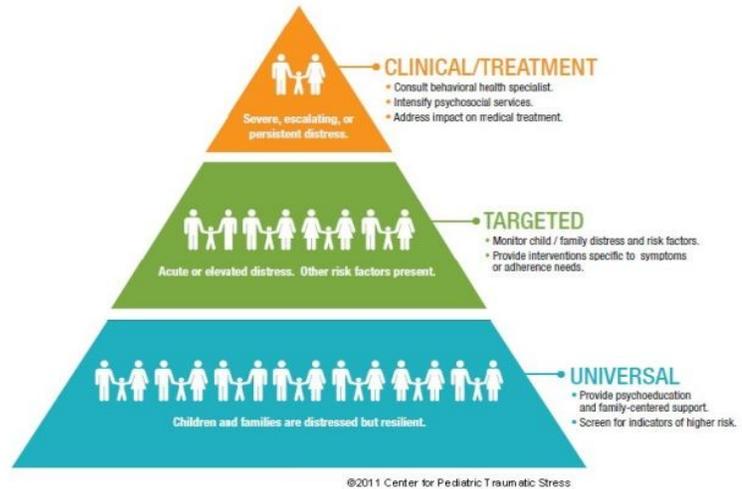
	Assess Emotional Support	Help with Emotional Support
<b>EMOTIONAL SUPPORT</b>	<b>What does the child need now?</b> <ul style="list-style-type: none"> <li>Parents: What helps your child cope when upset/scared?</li> <li>Child: What helps you feel better when you are upset/scared?</li> </ul>	<b>Listen to parents and encourage their presence</b> <ul style="list-style-type: none"> <li>Ask parents for their expertise about their child</li> <li>Ask parents about their concerns</li> <li>Encourage them to be with their child</li> </ul>
	<b>Who is available to help the child?</b> <ul style="list-style-type: none"> <li>Do parents understand the illness/injury or treatment?</li> <li>Can they be with their child during procedures?</li> <li>Can they help calm/soothe their child?</li> </ul>	<b>Empower parents to help their child</b> <ul style="list-style-type: none"> <li>Suggest ways they can help their child</li> <li>Involve them in physical care, as appropriate</li> <li>Help them seek out support if upset/anxious</li> </ul>
	<b>What are the barriers to mobilizing parent support?</b> <ul style="list-style-type: none"> <li>Do parents' responses make it harder for them to help?</li> <li>How confident is the parent in caring for their child?</li> </ul>	<b>Encourage child/parent involvement in "normal" activities</b> <ul style="list-style-type: none"> <li>Suggest activities that fit child's medical status</li> <li>Find activities they can do together</li> <li>Promote contact with child's friends and teachers</li> </ul>

	Assess Family	Help with Family
<b>FAMILY</b>	<b>Assess distress of parents/family members</b> <ul style="list-style-type: none"> <li>How is your family coping right now?</li> <li>Who is having an especially difficult time?</li> </ul>	<b>Encourage parents' basic self-care</b> <ul style="list-style-type: none"> <li>Support problem-solving for caregivers to find ways to eat, sleep, and take breaks – taking care of themselves so that they can continue to be a support to their child – taking care of themselves so that they can continue to be a support to their child</li> <li>Help them enlist support of family, friends, and community</li> </ul>
	<b>Gauge family stressor and resources</b> <ul style="list-style-type: none"> <li>Are you eating, getting sleep, and taking breaks?</li> <li>Do you have friends who can help out at home?</li> </ul>	<b>Remember other family members' needs</b> <ul style="list-style-type: none"> <li>Involve siblings and explain treatment to them when possible</li> <li>Enlist hospital resources such as chaplain and social work as needed</li> </ul>
	<b>Address other needs (beyond medical)</b> <ul style="list-style-type: none"> <li>Are there other stressors going on (such as money, job, transportation) that make it particularly difficult right now?</li> </ul>	<b>Be sensitive to the cultural and resource needs of the family</b> <ul style="list-style-type: none"> <li>Remember that outside issues can impact recovery</li> <li>Be open to involving other healing professionals and customs</li> </ul>

# Conceptualizing psychosocial care decision making

The Pediatric Psychosocial Preventive Health Model (PPPHM) can be used to guide assessment of psychosocial risks and inform clinical decision making (e.g., referrals for varying levels of psychosocial support). This preventive model suggests that the health care team provide every ill or injured child and family with basic support and information (i.e., trauma-informed care for the Universal group) and regularly screen for acute distress and risk factors to determine which children and families might need more support (i.e., Targeted or Clinical/Treatment).

**Pediatric Psychosocial Preventive Health Model**



Subsequent sections of this guide include key considerations when screening and assessing for distress and risk factors associated with PMTS, and intervention considerations for impacted children and families.

RISK LEVEL (PPPHM)	Who are these families?	Professional(s) involved
<b>UNIVERSAL</b>	Children and families are distressed, but resilient.	Physicians, Nursing, Child Life, Social Work, Care Coordinators
<b>TARGETED</b>	Children and families may have acute or elevated distress and other risk factors may be present in the individual(s) and family as a whole.	Physicians, Nursing, Psychology, Social Work, Professional Mental Health Counselors
<b>CLINICAL</b>	Severe, escalating, and persistent distress is ongoing in children and families.	Psychology, Psychiatry, Clinical Social Work, Professional Mental Health Counselors

## Screening, Assessment, and Intervention

All family members are at risk for medical traumatic stress and level of distress is often not apparent during interactions focused on medical treatment. Regular screening for pediatric medical traumatic stress is a critical step to identifying families who would benefit from additional psychosocial support beyond trauma-informed care.

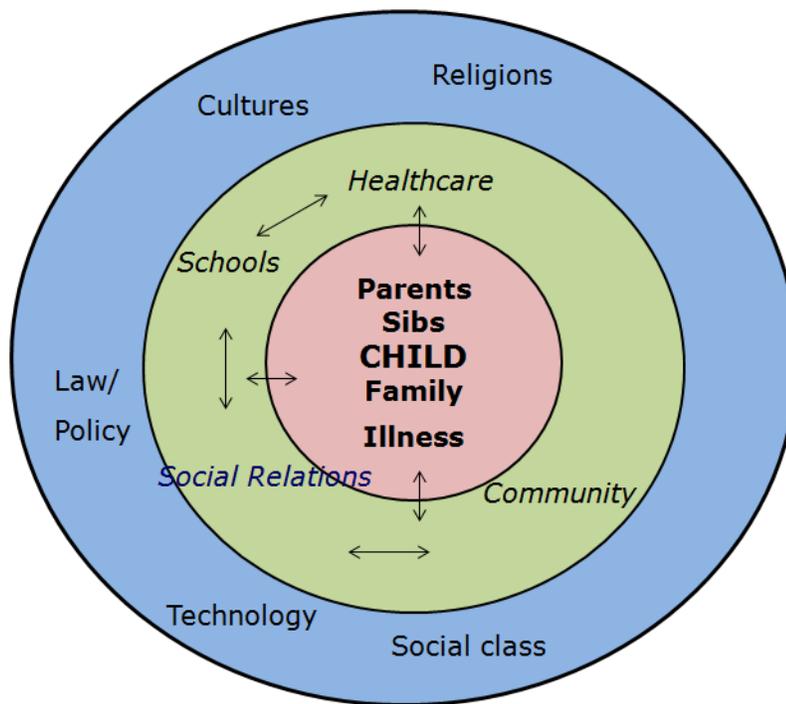
### Screening and Assessment

Screening and assessment practices facilitate triaging families to the appropriate and needed level of psychosocial care. It is important to understand the difference between screening and assessing for psychosocial risk and pediatric medical traumatic stress.

Screening or Assessment	Similarities	Differences	Professional(s) involved
<b>Screening</b>	<ul style="list-style-type: none"> <li>Identifies risk factors</li> <li>Supports psychosocial intervention decision-making (general)</li> </ul>	<ul style="list-style-type: none"> <li>Administration and scoring are brief (5 to 10 minutes)</li> <li>Determines the need for more in-depth assessment</li> <li>Examines broad socio-ecological family risk factors</li> </ul>	Physicians, Nurses, Social Work, Child Life, Psychology
<b>Assessment</b>	<ul style="list-style-type: none"> <li>Builds rapport between professional and child/family</li> <li>Supports inter-disciplinary collaboration</li> </ul>	<ul style="list-style-type: none"> <li>Provides in-depth understanding of specified risk factor and current symptom presentation</li> <li>Informs evidence-based intervention so that approach is tailored to child/family</li> <li>Defines nature of problem</li> <li>Provides evidence and support for diagnostic impressions</li> </ul>	Psychology, Psychiatry, Clinical Social Work, Professional Counselors

## Screening Considerations

### Social ecological context for screening



Screening generally involves a brief initial determination of risk status or distress / symptoms. Screening results are used to guide next steps. Depending on the context, the purpose of screening may be to provide an initial determination of socio-ecological family risk, protective, and promotive factors, and/or to estimate individual-level risk and protective factors or traumatic stress symptoms. The PPPHM model helps guide interpretation of screening results (see below). Ideally, screening is done universally with all ill or injured children and their families. Many screening measures are designed to be administered by frontline providers, or for self-administration by children or parents.

RISK LEVEL (PPPHM)	Screening Risk Level	Next Steps dependent upon Risk Level	Professional(s) involved
<b>CLINICAL</b>	HIGH	<ul style="list-style-type: none"> <li>Refer for further Assessment and Evaluation</li> </ul>	Psychology, Psychiatry, Clinical Social Work, Professional Counselors
<b>TARGETED</b>	MODERATE	Dependent upon specific child / family needs or risk factors: <ul style="list-style-type: none"> <li>Refer to for further Assessment and Evaluation <i>OR</i></li> <li>Provide interventions specific to symptoms and adherence needs <i>AND</i></li> <li>Monitor ongoing distress</li> </ul>	Physicians, Nursing, Psychology, Social Work, Professional Counselors
<b>UNIVERSAL</b>	LOW	<ul style="list-style-type: none"> <li>Provide psycho-education and trauma-informed / family-centered support <i>AND</i></li> <li>Further screen for specific higher risk domains</li> </ul>	Physicians, Nursing, Child Life, Social Work, Care Coordinators

## **Assessment Considerations**

Elevated levels of psychosocial risk may indicate the need for a more in-depth, domain specific assessment to be conducted by psychology, psychiatry, or other another clinical mental health provider. There are specific considerations to be aware of when working with ill or injured children and families. It is important to find ways to meet with each family member individually, as this format allows space for more open emotional reactions to the medical and other potentially traumatic experiences. Some caregivers and children may be hesitant to separate from each other, particularly soon after the medical event. Being flexible and creative in ways to obtain privacy while considering the family members' preferences are key.

## **Assessment Domains**

An assessment for pediatric medical traumatic stress can be conducted in much the same way that you would assess for posttraumatic stress symptoms related to other types of potentially traumatic events. Ideally, all family members at elevated risk should be assessed. A multi-domain assessment may include:

- behavioral, emotional, and social functioning
- social/attachment history
- physiological arousal
- cognitive and academic functioning
- beliefs
- trauma symptoms and impact on daily functioning
- trauma history and exposure

## **Standardized Questionnaires**

Standardized questionnaires should be used to assess symptoms and/or functioning across the above mentioned domains. Assessments for pediatric medical traumatic stress may be inclusive of related and/or frequently co-occurring, which may also have implications for health outcomes, such as:

- Trauma or stress-related difficulties (e.g., Acute Stress Disorder / Posttraumatic Stress Disorder)
- Anxiety (e.g., Generalized Anxiety Disorder, Obsessive Compulsive Disorder)
- Mood difficulties (e.g., Major Depressive Disorder)
- Behavioral problems (e.g., Oppositional Defiant Disorder, Attention Deficit Hyperactivity Disorder)
- Substance use problems

Click the link below for some information on assessment instruments:

<https://www.healthcaretoolbox.org/tools-and-resources/tools-you-can-use-assessment.html>

## Clinical Interview Considerations

It is important to gather information about current emotional reactions, perceptions of the medical event, treatment, hospitalization, and prognosis, and about current and past coping strategies and other relevant psychosocial history. In this context, clinical interviewing is not intended to result in a typical/formal psychological assessment report.

Understanding the child's and family's experiences with regard to the following elements should be prioritized in psychosocial history-taking for children facing illness, injury and other medical events:

Aspects of current/most recent medical event(s):

- Was alone / without caregiver for initial or lengthy parts of treatment
- Illness / injury was sudden and scary
- Treatment is painful or scary
- Was unprepared for / did not understand treatment
- Experienced scary sights and sounds in hospital / during treatment
- Felt isolated from friends and family during hospital / treatment
- Missed school for lengthy periods of time due to injury / illness
- Has strong emotional or fear reactions towards going to doctor / dentist, getting shots, seeing ambulances, and being in or near hospitals
- Overreacts to minor injuries / illnesses
- Is hypervigilant regarding illness or injury in self / others
- Is preoccupied with one's health or avoiding germs, contamination
- Has had to change or see different medical providers frequently

Health history:

- Chronic or serious illnesses
- Serious injuries (accidents, dog bites, violence)
- Life-threatening allergies / allergic reactions
- Current medication use for health conditions
- Current pain level
- Scars, handicaps, or physical disabilities
- History of substance use (particularly in adolescents)
- Family psychiatric history

Prior Potentially Traumatic Medical Events, including:

- Surgeries
- Emergency room visits
- Ambulance transports
- Lengthy hospital stays
- Prolonged or painful treatments (blood transfusions, surgical pinning / casting, spinal taps, invasive procedures)
- Knows someone else in family with serious illness, injury, or prolonged hospitalization
- Knew other sick or injured children in the hospital / knew someone who died
- Family member was also injured or ill as a result of the trauma

\*And any other potentially traumatic events, such as a history of child abuse, exposure to domestic violence, traumatic grief, etc.

The goal of the assessment process is to provide both the health care team and the psychosocial professionals involved with a clearer picture of the needs and strengths of children and families at the **Targeted and Clinical\*** levels. Most importantly, the assessment process supports professionals in selecting and facilitating appropriate evidence-based interventions with ill or injured children and their families. The next section will discuss special intervention considerations for the ill or injured child and their family.

RISK LEVEL (PPPHM)	Assessment Risk Level	Next Steps dependent upon Risk Level	Professional(s) involved
<b>CLINICAL</b>	MODERATE-HIGH	<ul style="list-style-type: none"> <li>• Intensify psychosocial services</li> <li>• Address impact on medical treatment</li> <li>• Provide trauma-specific interventions</li> </ul>	Psychology, Psychiatry, Clinical Social Work, Professional Counselors
<b>TARGETED</b>	LOW-MODERATE	<ul style="list-style-type: none"> <li>• Monitor child/family distress and risk factors</li> <li>• Provide interventions specific to symptoms and adherence needs</li> </ul>	Physicians, Nursing, Psychology, Social Work, Professional Counselors
<b>UNIVERSAL*</b>	LOW	<ul style="list-style-type: none"> <li>• Provide psycho-education and trauma-informed / family-centered support</li> </ul>	Physicians, Nursing, Child Life, Social Work, Care Coordinators

*\*Note: Typically **screening** will inform you (and other professionals) on next steps for **low-risk** families and more in-depth assessments and evaluations may not be necessary. If a child is targeted for assessment, but your assessment determines that a child/family is at **Low Risk**, Universal interventions are likely to meet their needs.*

## Intervention Considerations

Interventions should be tailored to the individual dependent upon developmental stage and psychosocial risk level, as well as the needs and strengths of siblings and caregivers involved. Below are specific elements to consider with regard to the ill or injured child's developmental stage, as well as to siblings and caregivers, when developing an intervention plan.

Below are two resources (HealthCareToolbox.org and National Child Traumatic Stress Network) that provide information on evidence-based practices you can use for trauma-exposed children and families. It is important to note that there is not currently an evidence-based practices specifically for PMTS, but there are evidence-based practices (e.g., [TF-CBT](#), [SCCIP-ND](#), [CFTSI](#)) that have shown efficacy in supporting children with an injury or illness and their family in improving family-centered promotive factors and reducing symptoms (e.g., PTSS, depression, anxiety):

<https://www.healthcaretoolbox.org/tools-and-resources/tools-you-can-use-intervention.html>

<http://nctsn.org/resources/topics/treatments-that-work/promising-practices#q4>

**Note:** *The elements below apply to the index child (patient), and to siblings.*

### Intervention considerations with younger children:

As noted above, younger children greatly benefit from routine, both during admissions or outpatient medical visits and at home. Younger children also will respond more readily to behavioral interventions than talk therapy. Be sure to rely on observed behavior, not just verbal report, to understand how a child is feeling and to assess for response to treatment.

- Remember that you are the main source of comfort for the child.
- Provide concrete explanations for treatment interventions and what to expect in sessions.
- Help identify and label what they may be thinking and feeling; remind them that other children often feel the same way.
- Encourage expression of thoughts and feelings through play, drawing, or storytelling.
- Tolerate regressive symptoms in a time-limited manner.
- Address distortions and magical thinking about the illness, injury, or prognosis, and help them “fill in the blanks” with realistic information.

### Intervention considerations with school-age children:

School-age children formulate their responses based on their own perceptions and on cues provided by adults. Younger school-age children often demonstrate more concrete thinking, but the capacity for abstract thinking and self-reflection develops steadily across this age range. Ask open-ended questions to school-age children to learn what they know and, especially, what they are imagining.

- Address distortions and magical thinking about the illness, injury, or prognosis, and help them “fill in the blanks” with realistic information.
- Help them create a coherent story to tell others about what happened or will happen.
- Tell them that it is normal and expected for kids to feel afraid, angry, or sad.
- Help them acknowledge the bad things that have happened, and balance these with the good.
- Reassure the child that she or he has done nothing wrong to cause the illness, injury, or pain.
- Support activities that offer predictability, routine, and clear behavioral limits and expectations.

### Intervention considerations with adolescents:

Since adolescents are often concerned with “here and now” issues, be sure to address these first.

- Address their expectations regarding the illness or injury, and what could have been done to prevent or lessen the trauma.
- Help them understand that it’s common to react to extremely stressful situations by feeling angry, numb, or acting out.
- Be open to their expression of strong emotions.
- Discuss the expected strain the injury or illness might have on their relationships with family and friends, as well as potential feelings of isolation.
- Make sure they are actively involved in discussions and decisions that will impact them, and in their daily care, whenever possible.
- Help them anticipate the challenges the illness or injury will cause to their academic and social lives and problem-solve ways to overcome these challenges.
- Allow them time to acknowledge and to grieve the loss of things they can no longer do, while helping them explore and discover things they can do.
- Address distortions and magical thinking about the illness, injury, or prognosis, and help them “fill in the blanks” with realistic information.

### Additional intervention considerations with parents / caregivers:

- Address communication with child, partner, and others in the parent’s support system about the illness or injury and its treatment.
- Help parent help child with emotional regulation and with specific traumatic stress reactions.
- Help anticipate adherence concerns with medical and psychosocial treatment.
- Provide education about developmental stages and other factors that impact the child’s (and siblings) psychosocial outcomes.
- Address caregiver’s perceptions of their own behaviors and coping strategies, their beliefs and appraisals of their child’s illness, injury, treatment, and prognosis, and the consequences of their behaviors, beliefs and perceptions for themselves and their family.
- Teach intervention skills to coincide with child interventions (ensure caregivers can support child in-home with possible emotional and behavioral concerns specific to medical traumatic stress)

RISK LEVEL (PPPHM)	Who are these families?	Intervention needs	Professional(s) involved
<b>CLINICAL</b>	Severe, escalating, and persistent distress is ongoing in children and families.	<ul style="list-style-type: none"> <li>• Intensify psychosocial services</li> <li>• Address impact on medical treatment</li> <li>• Provide trauma-specific interventions</li> </ul>	Psychology, Psychiatry, Clinical Social Work, Professional Counselors
<b>TARGETED</b>	Children and families may have acute or elevated distress and other risk factors may be present in the individual(s) and family as a whole.	<ul style="list-style-type: none"> <li>• Monitor child/family distress and risk factors</li> <li>• Provide interventions specific to symptoms and adherence needs</li> </ul>	Physicians, Nursing, Psychology, Social Work, Professional Counselors
<b>UNIVERSAL</b>	Children and families are distressed, but resilient.	<ul style="list-style-type: none"> <li>• Trauma-informed care</li> <li>• Provide psycho-education and family-centered support</li> <li>• Screen for indicators of higher risk</li> </ul>	Physicians, Nursing, Child Life, Social Work, Care Coordinators

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*This guidebook was developed by the Center for Pediatric Traumatic Stress (CPTS) and funded through the National Child Traumatic Stress Network (NCTSN) by the Substance Abuse and Mental Health Administration (SAMHSA). The views, opinions, and content are those of the authors, and do not necessarily reflect those of NCTSN or SAMHSA.*

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*See [www.HealthCareToolbox.org](http://www.HealthCareToolbox.org) for more resources, screening and assessment tools, interventions, and patient handouts.*

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