

# Post Traumatic Stress in Parents of Pediatric Cancer Patients



We were a normal family  
with normal worries....

Then it all changed  
“literally” overnight.



# Common Reactions to Medical Trauma

## (Normalization)

- Thoughts
  - Thoughts of their child dying
  - Intrusive
  - Memories they cannot stop/or control
  - Thinking they are a bad parent
  - Thoughts of hopelessness of the future
- Feelings
  - Worrying about your children
  - Feeling jumpy or on edge
  - Feeling helpless or scared
  - Feeling emotionally numb
  - Overwhelmed with guilt and/or shame
- Actions
  - Being more protective of your child[ren]
  - Avoidance behaviours
  - Not eating, sleeping or taking care of yourself
  - Difficulty maintain relationships
  - Physical symptoms can include: sweating, dizziness and rapid heart rate when reminded of the event.

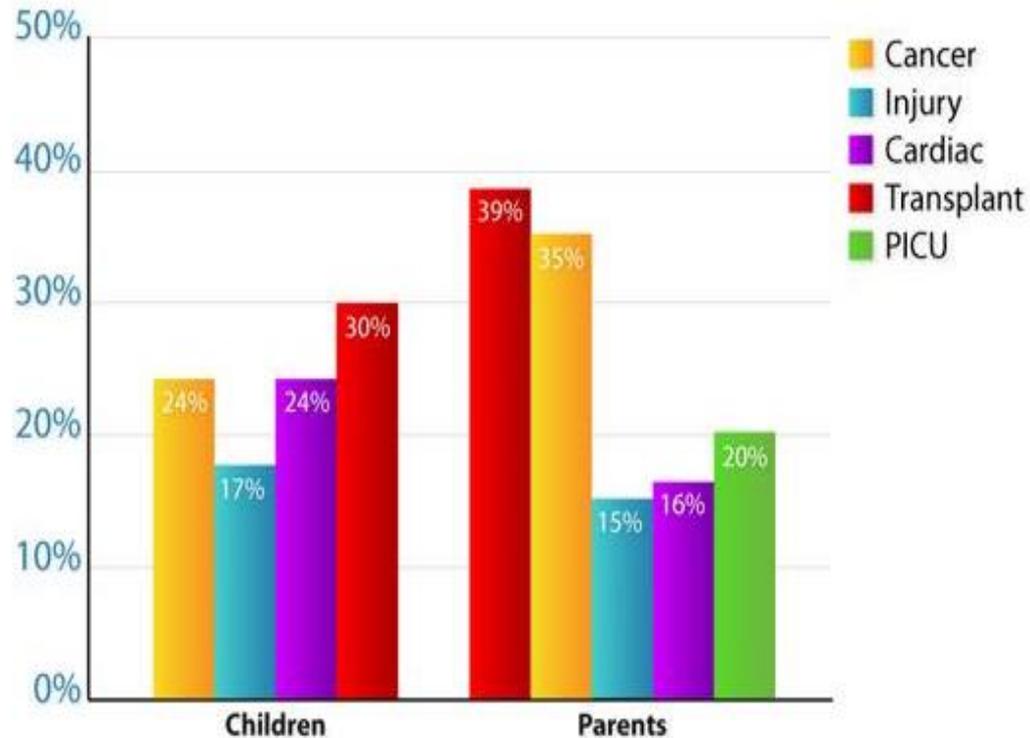


# Traumatic Stress Reactions

- Re-experiencing
- Avoidance
- Hyper-arousal
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# Research Findings

Percent of children & parents with significant traumatic stress symptoms after medical events



Summary of research findings from The Children's Hospital of Philadelphia.

Summarized from peer-reviewed research studies, 1999-2009.

*Note: Traumatic stress levels in children in pediatric intensive care has not yet been well-documented.*

**When should you be  
concerned about PTSD?**

concerned about PTSD?

# DSM-5 Criteria for PTSD

## Criterion A: Stressor (one required)

- Direct exposure.
- Witnessing, in person.
- Indirectly, by learning that a close relative or close friend was exposed to trauma. If the event involved actual or threatened death, it must have been violent or accidental.
- Repeated or extreme indirect exposure to aversive details of the event(s).

## Criterion B: Intrusion symptoms: (one required)

*The traumatic event is persistently re-experienced in the following way(s):*

- Recurrent, involuntary, and intrusive memories.
  - Traumatic nightmares.
  - Dissociative reactions (e.g., flashbacks) which may occur on a continuum from brief episodes to complete loss of consciousness.
  - Intense or prolonged distress after exposure to traumatic reminders.
  - Marked physiologic reactivity after exposure to trauma-related stimuli.
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# DSM-5: PTSD Criteria

## Criterion C: Avoidance (one required)

- Persistent effortful avoidance of distressing trauma-related stimuli after the event:
- Trauma-related thoughts or feelings.
- Trauma-related external reminders (e.g., people, places, conversations, activities, objects, or situations).

## Criterion D: Negative Alterations in Cognitions and Mood (Two Required)

- Negative alterations in cognitions and mood that began or worsened after the traumatic event:
- Inability to recall key features of the traumatic event (usually dissociative amnesia; not due to head injury, alcohol, or drugs).
- Persistent (and often distorted) negative beliefs and expectations about oneself or the world (e.g., "I am bad," "The world is completely dangerous").
- Persistent distorted blame of self or others for causing the traumatic event or for resulting consequences.
- Persistent negative trauma-related emotions (e.g., fear, horror, anger, guilt, or shame).
- Markedly diminished interest in (pre-traumatic) significant activities.
- Feeling alienated from others (e.g., detachment or estrangement).
- Constricted affect: persistent inability to experience positive emotions.

# DSM-5 Criteria

## Criterion E: Alterations in Arousal and Reactivity (Two Required)

- Irritable or aggressive behavior
- Self-destructive or reckless behavior
- Hyper vigilance
- Exaggerated startle response
- Problems in concentration
- Sleep disturbance

## Criterion F: Duration

- Persistence of symptoms (in Criteria B, C, D, and E) for more than one month.

## Criterion G: functional significance

- Significant symptom-related distress or functional impairment (e.g., social, occupational).

# Increased Risk for PTSD for Parents

- Financial Strain as a result of a family needing to reorganize their entire life.
- Limited Social Support and coping tools.
- Sudden shock of your child's life-threatening illness.
- Prolonged exposure to social, emotional, financial, and medical stress.
- Similar to others who struggle with PTSD, parents of children with cancer may face a lifelong fear of the return of cancer and/or devastating treatment outcomes.
- Early unresolved developmental trauma/previous trauma as an adult.



# What can Happen?



- Parents often put their own needs aside to care for their child, which can result in increased symptoms and decreased coping with diagnosis and treatment.
- A parent may become overwhelmed with symptoms and may have trouble complying with their child's caregiving needs (medications), and may respond inappropriately to health care providers. May also lead to missed appointments and/or difficulty attending to and understanding information presented during visits.
- It is often not until after the therapy is finished that parents begin to 'fall apart.' This is when parents finally allow themselves to begin to look at everything they have been dealing with, but it could be two or three years later.
- Maladaptive coping, such as excessive drinking.

# How to Take Care of yourself

- ***Five Areas of Therapeutic Care***

- Physical Self-Care
- Lifestyle Self-care
- Mental and Emotional Self-care
- Social Support
- Spiritual Connection



# When to Seek Professional Mental Health Assistance

- When your symptoms increase, continue for months/years and cannot function. Make an appointment with your family doctor/psychiatrist.
- It is always recommended to speak to a mental health professional to assist with early symptoms.



# Treatment Options

- The World Health Organization has recommended two types of therapy for the treatment of PTSD.
  - Eye Movement Desensitization and Reprocessing (EMDR) [www.emdria.org](http://www.emdria.org)
  - Cognitive Behavioural Therapy (CBT)

# Post-Traumatic Stress Support and Interventions: Future Change is Needed

- Continued research about survivors, parents and siblings responses pertaining to the trauma of a cancer diagnosis.
- Assessment in-hospital through questionnaires, such as The Children's Hospital of Philadelphia's Psychosocial Assessment Tool (PAT) that identifies those at higher-risk for managing the stress of childhood cancer. Once identified implement strategies to support areas of concern for families to increase their resources/strengths to manage the journey of the cancer journey.
- Develop treatment approaches and psychosocial services in-hospital to reduce the experience of trauma at diagnosis and treatment.
- Normalize the experience of PTS for both parents and their children.
- Provide additional support to those with cancer-related PTSD.

# Pediatric Psychosocial Preventive Health Model

Addressing traumatic stress in the pediatric healthcare setting

## CLINICAL/TREATMENT

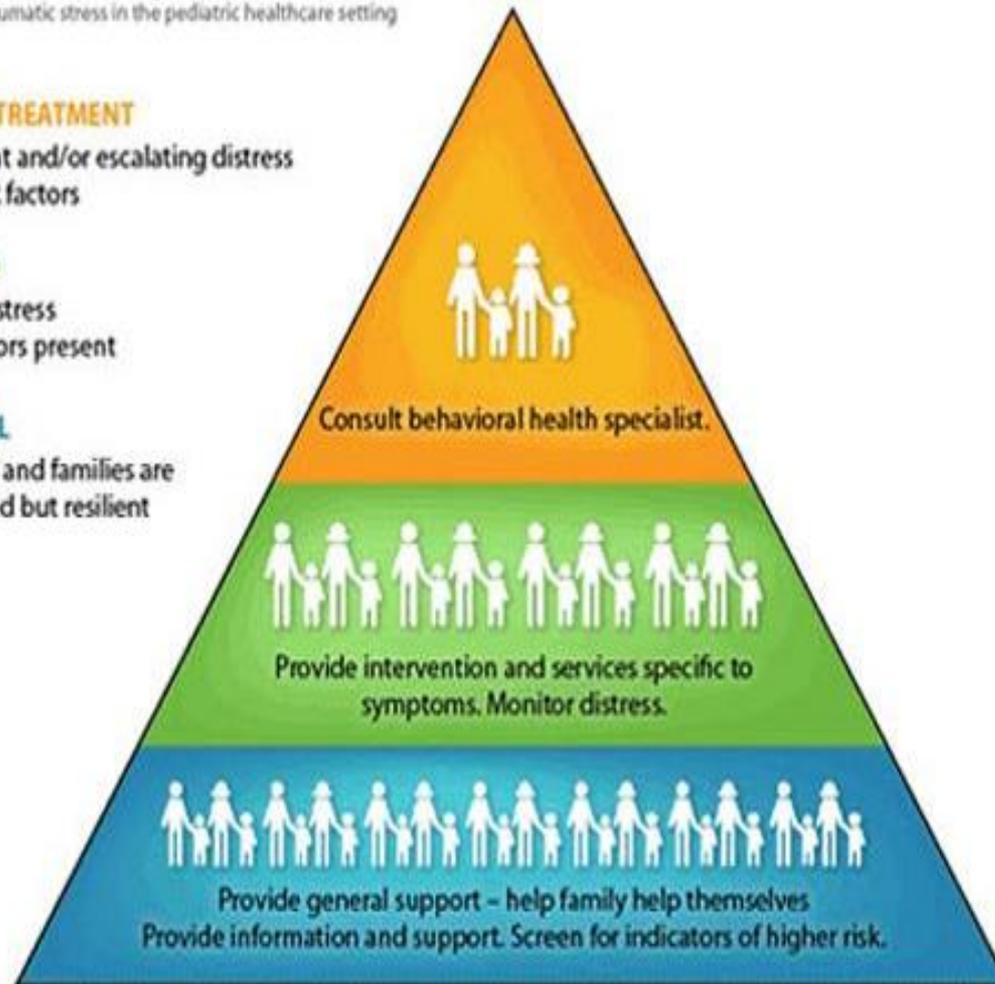
- Persistent and/or escalating distress
- High risk factors

## TARGETED

- Acute distress
- Risk factors present

## UNIVERSAL

- Children and families are distressed but resilient



“As a parent we want the best of & for our children. If they are hurt, we hurt even more. If they have achieved something that they are proud of, we are even more proud. Childhood cancer takes our ability to parent, knocks it to the ground & stomps on it.

It's not like a cut that we can bandage  
nor like a cold or broken bone where  
you can take your child to a doctor to fix.

Cancer renders us helpless.”

~ Ellyn Miller, mom to Gabriella Miller

"When something bad happens you have three choices you can either let it define you, let it destroy you or you can let it strengthen you."

~ Compassionate Friends

Thank you!

Questions...

# References

"Posttraumatic stress symptoms during treatment in parents of children with cancer." Published in the Oct. 20, 2005, *Journal of Clinical Oncology* (Vol. 23, No. 30: 7405-7410). First author: Anne E. Kazak, PhD, ABPP, the Children's Hospital of Philadelphia.

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Eye Movement Desensitization and Reprocessing (EMDR). <http://www.emdria.org/>

The Children's Hospital of Philadelphia: <http://www.chop.edu/centers-programs/cancer-center/posttraumatic-stress-pediatric-cancer#.VSx7I5TF83A>