



SPINA BIFIDA
ASSOCIATION

Community Information Session: Parent Perspectives for Coping with Medical Trauma

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To build a better and brighter future for all those impacted by Spina Bifida

Overview of Today's Talk

This talk is directed towards caregivers of youth with spina bifida.



What is a medical traumatic event?

Any medical event that makes someone **feel intensely threatened**

- Experiencing pain
- Experiencing an injury
- Experiencing serious illness
- Receiving a new diagnosis
- Receiving an undesirable prognosis
- Undergoing surgery
- Undergoing medical tests
- Receiving medical treatments
- Other medical interactions



The caregiver(s) and child may perceive the same medical event differently

What is medical traumatic stress?

The **negative psychological** and **physical** response that someone can experience following a medical event

Re-experiencing
memories, dreams,
flashbacks...

Increased Arousal
feeling irritable, reckless
behavior, hypervigilant, hard
to focus, poor sleep

Avoidance
of thoughts, places, people...

**Negative
Mood/Thoughts**
feeling anxious, depressed,
detached; having distorted
thoughts; dissociation

What else is important to know about medical traumatic stress?



Medical traumatic stress is related to a person's *subjective experience* of the medical event, not its *objective severity*

You may...

- Experience the traumatic event
- Witness the traumatic event occurring to others
- Learn the traumatic event occurred to a close family member/friend

What else is important to know about medical traumatic stress?

It is **different from everyday stress** because it interferes with functioning
Such as receiving medical care, taking care of yourself

Some may be at greater risk for experiencing it

For example, those who have existing anxiety and depression, or those with few social supports

Details of the medical event can impact IF or HOW someone experiences it

*Did it happen suddenly or gradually?
Were there unexpected complications?*

A medical or mental health provider **can evaluate for it**

Sometimes it may be diagnosed as Acute Stress Disorder or Post-traumatic Stress Disorder

How common is medical traumatic stress in caregivers of youth with spina bifida?

We don't have a lot of research...

**In a sample of
parents of
23 newborns and
58 school-aged
kids**

- 75% experienced medical traumatic stress when first learning about their child's diagnosis; in many cases it resolved within 4 years
- 30% of mothers and 20% of fathers still experienced some symptoms when their child was 5-11 years old

**For all kids, parents' experience of medical traumatic stress
can predict their child's symptoms over the next year**

*What can we
do to manage
medical traumatic stress?*

How can caregivers help their kids?

- ✓ Gently encourage your child to talk about the medical event and their reactions to it
- ✓ Answer your child's questions honestly, and listen for unspoken worries or fears
- ✓ Support your child in participating in normal activities (school, friends) as much as possible
- ✓ Get professional help if you are concerned about your child
- ✓ If talking about it makes you tense or upset, get support for yourself, so you can help your child



How can caregivers help their kids?

Creating a “social story” or plan can help!

The reason I went to the hospital was because _____.
(reason)

When I think about what happened to me now, I feel _____.
(how you feel when you think about it)

Some of the things that remind me of what happened to me are _____ and
(something that reminds you of what happened)

_____. If I think about what happened and get upset, one way I can calm down is by
(something else that reminds you of what happened)

_____. I could also talk to _____ about how I feel. The next time
(something you can do to calm down) (name of person)

I get upset about what happened, I plan to: _____.
(your plan)

What can professional help look like?

**Trauma-focused
Cognitive Behavior
Therapy (TF-CBT) is
for all ages**

- ✓ Learning relaxation strategies to reduce anxiety/stress
- ✓ Building awareness of our thoughts and how to think in realistic, adaptive ways
- ✓ Creating a trauma narrative to help us process the event
- ✓ Learning how family members can be supportive



Caregiver Experiences

Comments & Questions

Resources

- [NCTSN Resources | The National Child Traumatic Stress Network](#)
- [At the Hospital: Helping My Teen Cope - What Parents Can Do | The National Child Traumatic Stress Network \(nctsn.org\)](#)
- [At the Hospital: Helping My Child Cope - What Parents Can Do | The National Child Traumatic Stress Network \(nctsn.org\)](#)
- [Aftertheinjury.org](#)
- [Healthcaretoolbox.org/patient-education-parents](#)
- [Find a TF-CBT Certified Therapist - TF-CBT Certification Program \(tfcbt.org\)](#)

Are there mental health professionals who work in your medical setting or primary care practice?

Select References Cited

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Thank you!



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