

# Pediatric Illness, Injury and Traumatic Stress

### Children and families are often distressed by:

- sudden or life-threatening illness or injury
- painful or frightening treatment procedures
- just being in the hospital or ED

Most children and parents are able to cope well, with some extra support and with time. Some will have persistent traumatic stress reactions such as Posttraumatic Stress Disorder (PTSD).

### Prevalence of Traumatic Stress

- Many ill or injured children, and their families (up to 80%) experience some traumatic stress reactions following a lifethreatening illness, injury, or painful medical procedure.
- It has been reported that between 20 30 % of parents and 15 25% of children and siblings experience persistent traumatic stress reactions that impair daily functioning and affect treatment adherence and recovery.

### When they persist, traumatic stress reactions can:

• impair day-to-day functioning

• affect adherence to medical treatment

• impede optimal recovery

By incorporating an awareness of traumatic stress in their encounters with children and families, health care providers can:

- minimize potentially traumatic aspects of medical care
- identify children and families with (or at higher risk for) persistent distress
- provide anticipatory guidance to help prevent long-lasting traumatic stress



### Why A Toolkit?

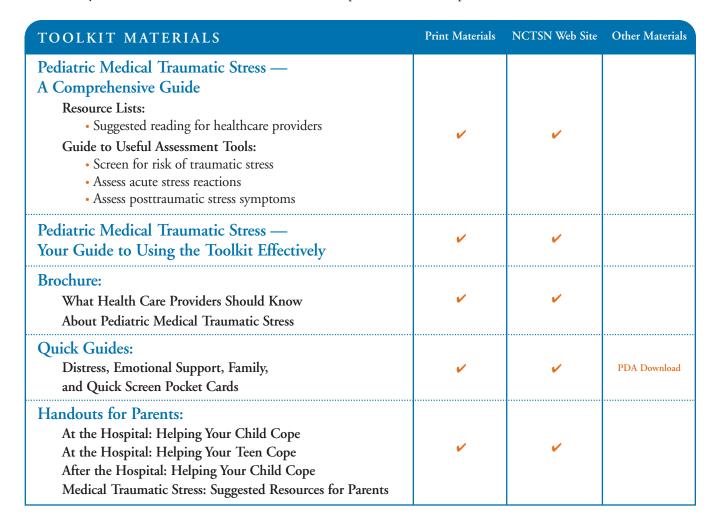
This toolkit was produced by the Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network (NCTSN) to:

- Raise awareness among health care providers about traumatic stress associated with pediatric medical events and medical treatment, as it may affect children and families.
- Promote "trauma-informed practice" of pediatric health care in hospital settings across
  the continuum of care and in a variety of settings within the hospital e.g., from
  emergency care, to specialized inpatient units, to the ICU.

This compendium of materials is designed for hospital-based health care providers (physicians, nurses, and other health care professionals.) The materials may also be of use to mental health professionals who work in health care settings. The materials provide:

- an introduction to traumatic stress as it relates to children facing illness, injury, other medical events
- practical tips and tools for health care providers, and
- handouts that can be given to parents that present evidence-based tips for helping their child cope

The stories of two children (Tommy — a school-age boy struck by a car, and Maria — an adolescent girl newly diagnosed with cancer,) are presented as part of the toolkit. These composite cases are used to help bring these issues to life and to illustrate ways in which toolkit materials could be useful to providers at various points in the continuum of care.





### TRAUMATIC STRESS REACTIONS

### Re-experiencing

- Thinking a lot (unwanted, intrusive thoughts) about the illness, injury, or procedure
- Feeling distressed at thoughts or reminders of it
- Having nightmares and "flashbacks"

#### **Avoidance**

- Avoiding thinking or talking about the illness, injury, or hospital experience, or things associated with it
- Displaying less interest in usual activities
- Feeling emotionally numb or detached from others

### Hyper-arousal

- · Increased irritability
- Trouble concentrating or sleeping
- Exaggerated startle response
- "Hyper-vigilance"—
   always expecting danger

#### Other reactions

- New fears related to the medical event
- New somatic complaints (bellyaches, headaches) not explained by medical condition
- Feeling in a daze or "spacey"



### What Is Traumatic Stress?

Children and parents may have traumatic stress reactions to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. These traumatic stress reactions can include psychological and physiological symptoms of arousal, re-experiencing, and avoidance (see box.) When a constellation of these symptoms persists and causes distress, the individual may have Posttraumatic Stress Disorder (PTSD).

Children may have other kinds of reactions to illness and injury as well, including behavioral changes or symptoms of depression or anxiety. Whenever providers or parents have any serious concerns about a child's ability to cope with illness or injury, or about emotional and behavioral changes that occur in connection with a medical event, careful assessment of the child, in consultation with an experienced mental health professional, is key.

### Persistent Traumatic Stress Reactions

Traumatic stress reactions to medical events are common initially, and not all of these reactions are problematic. For example, in the first few weeks after a difficult or frightening medical event, having frequent intrusive thoughts about what happened may help the individual to process the experience and put it into perspective. For some however, these reactions can be extremely distressing. When they persist, traumatic stress reactions may become disruptive to a child's or parent's everyday functioning and may warrant further attention.

### Who is at Increased Risk?

Studies of ill and injured children and their parents show that the occurrence of traumatic stress reactions is more closely related to the person's subjective experience of the event rather than its objective medical severity. We cannot rely on objective indicators of injury or illness severity to tell us which children or parents are most at risk for psychological sequelae. Research studies suggest a range of risk factors for long-lasting traumatic stress reactions, including: pre-existing vulnerabilities; prior behavioral or emotional concerns; traumatic aspects of the medical event; and the child's or family's early reactions to it.

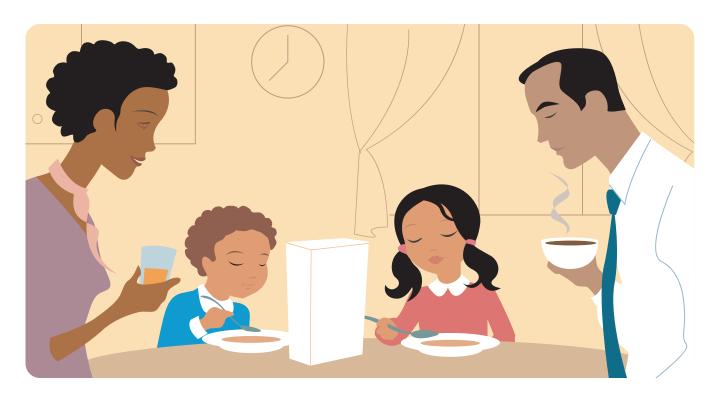
#### Risk Factors For Persistent Traumatic Stress Reactions

An ill or injured child may be at greater risk for persistent traumatic stress reactions if s/he:

- has had severe early traumatic stress reactions
- · has experienced more severe levels of pain
- is exposed to scary sights and sounds in the hospital
- is separated from parents or caregivers
- has had previous traumatic experiences
- has had prior behavioral or emotional problems
- · lacks positive peer support

A parent may be at greater risk for persistent traumatic stress reactions related to his/her child's illness or injury if s/he:

- · has had severe early traumatic stress reactions
- · has had previous traumatic experiences
- · has had prior emotional or mental health problems
- is experiencing other life stressors or disruption
- lacks positive social support



### **Prevention Model:**

Addressing traumatic stress in the pediatric healthcare setting

Persistent distress or risk factors.

Arrange psychosocial and mental health support.

Clinical / Treatment

Acute distress or a few risk factors present.



Provide extra support and anticipatory guidance. Monitor ongoing distress and refer if needed.

**Targeted** 

Most children and families are understandably distressed but coping well.



Universal

Provide general support — help family help themselves.

Provide information regarding common reactions. Screen for indicators of higher risk.

### Preventing and Treating Traumatic Stress

Health care professionals providing optimal care for ill or injured children and families should incorporate an awareness of traumatic stress reactions that may interfere with the children's health and functioning into their routine clinical encounters. In some cases, traumatic stress reactions can have serious implications for medical outcomes. For example, research studies have suggested that avoidance symptoms (e.g., wanting to stay away from reminders of illness) may interfere with optimal adherence to medical regimens post-transplantation.

### It may be useful to think of preventing and treating traumatic stress reactions as a pyramid:

- Universal (at the base): Most children and families need general information and support.
- Targeted (in the middle): A few higher-risk or more distressed children and families need increased support and focused guidance to help them anticipate challenges and to strengthen their coping skills.
- Clinical/Treatment (at the top): Finally, a much smaller group of children and families need more extensive psychosocial support and evaluation or treatment by a mental health professional.

This preventive intervention model suggests that the health care team provide every ill or injured child and family with basic support and information and regularly screen for acute distress and risk factors to determine which children and families might need more support.

#### Roles for Health Care Providers

Health care providers caring for children in emergency and hospital settings can:

- incorporate an understanding of traumatic stress in their encounters with children and families
- minimize the potential for trauma during medical care
- provide screening, prevention, and anticipatory guidance
- identify children and families in distress, or at risk, and make appropriate referrals

### Assessing and Treating Traumatic Stress Using the D-E-F Protocol:

All health care providers treating children, regardless of discipline, should be "trauma-informed." This means that they should incorporate an understanding of traumatic stress and related responses into their routine encounters with children and families. Trauma-informed health care professionals should be able to provide basic interventions to children and families that will minimize the potential for ongoing trauma and maximize continuity of care. The D-E-F protocol provides a straightforward and reliable method for identifying, preventing, and treating traumatic stress responses at the time of need and within scope of practice. Healthcare 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

### D-E-F PROTOCOL

### for Assessing and Treating Children and Families with Traumatic Stress



**DISTRESS** See pocket card for brief assessment and recommended interventions to address and treat pain, fears and worries, and grief and loss. **Recommendations include:** 

- Actively assess and treat pain, using your hospital's protocol.
- Provide child with information about what is happening and choices regarding treatment decisions when possible.
- Listen carefully for child's understanding and clarify any misconceptions.
- · Ask about fears and worries.
- Provide reassurance and realistic hope.
- E

EMOTIONAL SUPPORT See pocket card for brief assessment and recommended interventions to address child's emotional needs, and barriers to mobilizing existing supports. Recommendations include:

- Encourage parents to be with their child as much as possible and to talk with their child about worries and fears.
- Empower parents to comfort and help their child.
- Encourage child's involvement in age-appropriate activities when possible.



**FAMILY** See pocket card for brief assessment and recommended interventions to address parents' and siblings' distress, family stressors and resources, and needs beyond medical care. **Recommendations include:** 

- Gauge family distress and other life stressors; identify family strengths and coping resources.
- Encourage parents to use own coping resources or support available at the hospital or in the community.





QUICK SCREEN See this pocket card to identify and assist those who have traumatic stress symptoms or who are at greater risk for traumatic stress. Recommendations include:

- Involve psychosocial staff in a team-based approach for those at higher risk.
- Make referrals to hospital or community-based mental health resources when appropriate.

**OTHER** See the charts on pages 7-9 for descriptions and information on useful clinical measures for assessing acute and post-traumatic stress symptoms in children and parents, as well as tools for assessing pain and parent coping assistance.

# Special Considerations in Assessing and Treating Young Children Using the D-E-F Protocol:

Many infants and young children are hospitalized every year with injuries and serious illnesses. Emerging evidence suggests that traumatic stress is a problem for these children as well. The protocols and materials contained in this Toolkit apply to traumatic stress reactions in infants and young children, but a number of special considerations should be noted.



### **Assessing Distress**

The assessment of distress in infants and young children is based more on observing the child's behavior than on the child's direct report. Although young children can sometimes tell us what hurts or that they are scared, the verbal limitations of young children make behavioral observations crucial. Behavioral changes that may be indicators of significant distress include: agitation, uncontrollable crying, becoming quiet or withdrawn, oppositional or aggressive behavior, marked startle response, or changes in previously achieved developmental milestones. It is particularly noteworthy when any of these behavioral changes occur during medical procedures or when parents/caretakers leave or return.

### **Emotional Support and Parent Presence**

An infant or young child who has a secure emotional attachment to his/her parents or caregivers depends on the support of those individuals during stressful or difficult events. Children who are deprived of this support are likely to exhibit even greater distress. Every effort must be made to keep parents and their hospitalized children together and to assist parents in helping their children during the stressful time of hospitalization.





### Young Children's Understanding

Because they are still developing cognitive skills, young children process information differently. For example, many pre-school children associate pain with punishment and may believe they did something wrong when they are in pain, or that they somehow caused their illness or the injury. They can also get mad or frustrated with the medical provider administering a painful procedure. In addition, pre-school children generally do not understand that some losses (such as the death of a family member or a physical disability) are permanent. For any questions about the way that a young patient is processing information or about how to help your patient gain a developmentally-appropriate understanding of what is happening, consult with a developmental specialist (a child psychiatrist or psychologist or a developmental and behavioral pediatrician).

### Health Care Providers' Responses to Medical Traumatic Stress in Their Patients

Working with ill and injured children and families can be professionally meaningful and satisfying. However, health care providers treating children and families with challenging traumatic stress symptoms and circumstances can sometimes feel drained, upset, or frustrated. This may be especially true during times of increased workloads or heightened personal stress. As a result, providers can experience conflicts with these families or other medical team members or find themselves too involved in trying to solve the child's or family's problems in an effort to reduce distress. In working with children and families with complex and challenging illnesses or injuries, it is recommended that health care providers routinely:

- Be aware of their own emotional reactions and distress when dealing with distressed families.
- Talk to another team member or supportive other about their emotional reactions.
- Increase self-care (e.g., relaxation, exercise, stress management, etc.) when they begin to see signs of negative effects.

| DISTRESS: Useful Measures For Pediatric Medical Traumatic Stress   |  |              |                           |   |  |
|--|--|--------------|---------------------------|---|--|
| NAME OF MEASURE  | PURPOSE                                    | DESCRIPTION  | HAS BEEN<br>EVALUATED IN: | CURRENT STATUS<br>OF PSYCHOMETRIC<br>EVIDENCE |  |
|  | SCR  | EENING MEASU | RES                       |   |  |
| Child Stress Disorders Checklist (CSDC) Screening Form  Brief screen for ASD or PSTD in children/teens  4 item screener completed by parent or clinician about child  Children 7 to 18  Evidence for prediction of later PTSD in hospitalized children   |  |              |                           |   |  |
|  | Contact: Glenn Saxe, MD Glenn.Saxe@bmc.org |              |                           |   |  |
| Screening Tool for Early Predictors injured children, and of PTSD their parents, at higher (STEPP)  Screening Tool for Early Predictors injured children, and their parents, at higher risk for later PTSD medical setting  Evidence for prediction of later PTSD in hospitalized injured children and their parents |  |              |                           |   |  |
| References: Winston et al. (2003). Screening for risk of persistent post-traumatic stress in injured children and their parents. JAMA, 290 (5): 643-649.  Contact: Nancy Kassam-Adams, PhD nlkaphd@mail.med.upenn.edu  |  |              |                           |   |  |

| ASSESSMENT OF ACUTE STRESS DISORDER / SYMPTOMS  |   |  |                           |                                    |  |
|---|---|--|---------------------------|------------------------------------|--|
| Child Stress<br>Disorders Checklist<br>(CSDC)   | Assess ASD symptoms in children/teens       | 35 item checklist<br>completed by parent<br>or nurse about child | Children 8 to 17          | Evidence for reliability, validity |  |
| References: Saxe et al. (2003). Child Stress Disorders Checklist: A measure of ASD and PTSD in children.  Journal of the American Academy of Child & Adolescent Psychiatry, 42(8): 972-978.  Contact: Glenn Saxe, MD Glenn.Saxe@bmc.org |   |  |                           |                                    |  |
| Acute Stress<br>Checklist<br>for Children<br>(ASC-Kids)   | Assess ASD<br>symptoms in<br>children/teens | 29 item<br>self-report<br>checklist                              | Children 8 to 17          | Evidence for reliability, validity |  |
| Contact: Nanc   | y Kassam-Adams, PhD 1                       | ılkaphd@mail.med.upenn   | .edu (Has been translated | d into Spanish.)                   |  |
| Acute Stress Disorder Scale (ASDS)  Assess ASD symptoms in older teens  Suitable for older teens  Primarily validated in adults. Suitable for older teens  Suitable for older teens.  |   |  |                           |                                    |  |
| References: Bryant, R., Moulds, M., & Guthrie, R. (2000).  Acute Stress Disorder Scale: A self-report measure of Acute Stress Disorder Psychological Assessment, 12(1), 61-68.  Contact: Richard Bryant, PhD rbryant@psy.unsw.edu.au    |   |  |                           |                                    |  |

| DISTRESS: Useful Measures For Pediatric Medical Traumatic Stress  |  |  |  |   |  |
|---|--|--|--|---|--|
| NAME OF MEASURE   | PURPOSE  | DESCRIPTION  | HAS BEEN<br>EVALUATED IN:                                      | CURRENT STATUS<br>OF PSYCHOMETRIC<br>EVIDENCE |  |
| ASSESSME  | NT OF POSTTRA  | AUMATIC STRES  | S DISORDER / S   | YMPTOMS                                       |  |
| Child Stress<br>Disorders Checklist<br>(CSDC)   | Assess PTSD<br>symptoms<br>in children/teens   | 35 item checklist<br>completed by parent<br>or nurse about child | Children 7 to 18   | Evidence for reliability, validity            |  |
| References: Saxe et al. (2003). Child Stress Disorders Checklist: A measure of ASD and PTSD in children.  Journal of the American Academy of Child & Adolescent Psychiatry, 42(8): 972-978.  Contact: Glenn Saxe, MD Glenn.Saxe@bmc.org   |  |  |  |   |  |
| Child PTSD<br>Symptom Scale<br>(CPSS)   | Assess PTSD<br>symptoms in<br>children/teens   | 24 item<br>self-report<br>checklist                              | Children age<br>8 to 15  | Evidence for reliability, validity            |  |
| References: Foa, E., Johnson, K., Feeny, N., & Treadwell, K. (2001).  The Child PTSD Symptom Scale: A preliminary examination of its psychometric properties.  Journal of Clinical Child Psychology, 30(3), 376-384.  Contact: Edna Foa, PhD foa@mail.med.upenn.edu (Has been translated into Spanish, Russian, Armenian, Korean) |  |  |  |   |  |
| PTSD<br>Checklist<br>(PCL)  | Assess PTSD<br>symptoms in<br>older teens  | 17 item<br>self-report<br>checklist                              | Primarily validated<br>in adults. Suitable<br>for older teens. | Well-validated<br>adult PTSD<br>measure       |  |
|   | References: Blanchard, E., Jones-Alexander, J., Buckley, T., & Forneris, C. (1996).  Psychometric properties of the PTSD Checklist (PCL). Behavior Research and Therapy, 34(8), 669-673. |  |  |   |  |

References: Blanchard, E., Jones-Alexander, J., Buckley, T., & Forneris, C. (1996). Psychometric properties of the PTSD Checklist (PCL). *Behavior Research and Therapy*, 34(8), 669-673. Contact: Hitchcock Foundation (603) 653-1230 (Has been translated into Spanish.)

| Faces Pain Scale - Revised  Assess children's pain.  Child chooses from scale of 6 faces scored as 0 to 10.  Children age 4 to 16  Well-validated child pain measure | PAIN ASSESSMENT |  |                  |                         |            |  |
|--|-----------------|--|------------------|-------------------------|------------|--|
|  | 1               |  | scale of 6 faces | Children age<br>4 to 16 | child pain |  |

References: Hicks CL, von Baeyer CL, Spafford P, van Korlaar I & Goodenough B. (2001) The Faces Pain Scale - Revised: Toward a common metric in pediatric pain measurement. *Pain:* 93:173-183. Contact: http://www.dal.ca/~painsrc/docs/pps92.html (Available in English and 15 other languages.)

| EMOTIONAL SUPPORT: Useful Measures For Pediatric Medical Traumatic Stress |  |                          |                           |   |  |
|---|--|--------------------------|---------------------------|---|--|
| NAME OF MEASURE   | PURPOSE  | DESCRIPTION              | HAS BEEN<br>EVALUATED IN: | CURRENT STATUS<br>OF PSYCHOMETRIC<br>EVIDENCE |  |
| SCREENING MEASURES  |  |                          |                           |   |  |
| Hospital Emotional<br>Support Form  | Brief clinical<br>assessment to aid<br>parents in providing<br>coping assistance<br>to child | 12 item<br>questionnaire | Not applicable            | Not applicable                                |  |
| Contact: Glenn Saxe, MD Glenn.Saxe@bmc.org                                |  |                          |                           |   |  |

| FAMILY: Useful Measures For Pediatric Medical Traumatic Stress  |                                     |                                     |                             |   |  |
|---|-------------------------------------|-------------------------------------|-----------------------------|---|--|
| NAME OF MEASURE   | PURPOSE                             | DESCRIPTION                         | HAS BEEN<br>EVALUATED IN:   | CURRENT STATUS<br>OF PSYCHOMETRIC<br>EVIDENCE |  |
| ASSESSME  | NT OF PARENTS                       | S' ACUTE STRES                      | S DISORDER / S              | YMPTOMS                                       |  |
| Acute Stress<br>Disorder Scale<br>(ASDS)  | Assess ASD<br>symptoms<br>in adults | 19 item<br>self-report<br>checklist | Adults<br>(age 17 and over) | Well-validated<br>adult ASD<br>measure        |  |
| References: Bryant, R., Moulds, M., & Guthrie, R. (2000).  Acute Stress Disorder Scale: A self-report measure of Acute Stress Disorder. Psychological Assessment, 12(1), 61 - 68.  Contact: Richard Bryant, PhD rbryant@psy.unsw.edu.au |                                     |                                     |                             |   |  |

|       |                                |                                     | RESS DISSREER               | SYMPTOMS                                |
|-------|--------------------------------|-------------------------------------|-----------------------------|---|
| (PCI) | ess PTSD<br>mptoms<br>1 adults | 17 item<br>self-report<br>checklist | Adults<br>(age 18 and over) | Well-validated<br>adult PTSD<br>measure |

References: Blanchard, E., Jones-Alexander, J., Buckley, T., & Forneris, C. (1996). Psychometric properties of the PTSD Checklist (PCL). Behavior Research and Therapy, 34(8), 669-673. Contact: Hitchcock Foundation (603) 653-1230 (Has been translated into Spanish.)

## Medical Traumatic Stress:

### SUGGESTED READING FOR HEALTH CARE PROVIDERS

#### **Overview Articles**

Bronfman ET, Biron Campis L, Koocher GP. Helping children to cope: Clinical issues for acutely injured and medically traumatized children. *Prof Psychol Res Pr* 1998;29:574-81.

Horowitz L, Kassam-Adams N, Bergstein J. Mental health aspects of emergency medical services for children: Summary of a consensus conference. *J Pediatr Psychol* 2001;26:491-502. (Published concurrently in Acad Emerg Med 2001;8:1187-96.)

Kassam-Adams N, Fein J. Posttraumatic stress disorder and injury. Clinical Pediatric Emergency Medicine 2003;4:148-55.

Kazak A. Comprehensive care for children with cancer and their families: A social ecological framework guiding research, practice and policy. *Children's Services: Social Policy, Research and Practice* 2001;4:217-33.

Landolt MA, Vollrath M, Ribi K, Gnehm HE, Sennhauser FH. Incidence and association of parental and child posttraumatic stress symptoms in pediatric patients. *J Child Psychol Psychiatry* 2003;44:1199-1207.

Saxe G, Vanderbilt D, Zuckerman B. Traumatic stress in injured and ill children. *PTSD Research Quarterly* 2003;14:1-3. Available at www.ncptsd.org/publications/rq/rq\_list.html

Stoddard F, Saxe G. Ten year research review of physical injuries. J Am Acad Child Adolesc Psychiatry 2001;40:1128-45.

Stuber ML, Shemesh E, Saxe GN. Posttraumatic stress responses in children with life-threatening illnesses. *Child Adolesc Psychiatr Clin N Am* 2003;12:195-209.

Zatzick D, Roy-Byrne P. Developing high-quality interventions for posttraumatic stress disorder in the acute care medical setting. *Semin Clin Neuropsychiatry* 2003;8:158-67.

#### Studies: Assessment /Intervention

Kazak, A., Alderfer, M., Streisand, R. SImms, S., Rourke, M., Barakat, L., Gallagher, P. & Cnaan, A. Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families. *J Fam Psychol* 2004; 18(3) 493-504.

Kazak AE, Cant C, Jensen MM, McSherry M, Rourke MT, Hwang W-T et al. Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *J Clin Oncol* 2003;21:3220-5.

Melnyk BM, Alpert-Gillis L, Feinstein NF, Crean HF, Johnson J, Fairbanks E, et al. Creating opportunities for parent empowerment: Program effects on the mental health/coping outcomes of critically ill children and their mothers. *Pediatrics* 2004;113;e597-e607.

Robert R, Blakeney P, Villarreal C, Rosenberg L, Meyer WJ. Imipramine treatment in pediatric burn patients with symptoms of Acute Stress Disorder: A pilot study. *J Am Acad Child Adolesc Psychiatry* 1999;38:873-82.

Winston FK, Kassam-Adams N, Garcia-España JF, Ittenbach R, Cnaan A. Screening for risk of persistent posttraumatic stress in injured children and their parents. *JAMA* 2003;290:643-9.

### Studies: Prevalence and Etiology

#### Injury

Daviss W, Mooney D, Racusin R, Ford J, Fleischer A, McHugo G. Predicting posttraumatic stress after hospitalization for pediatric injury. *J Am Acad Child Adolesc Psychiatry* 2000;39:576-83.

Fein J, Kassam-Adams N, Gavin M, Huang R, Blanchard D, Datner E. Persistence of post-traumatic stress in violently injured youth seen in the Emergency Department. *Arch Pediatr Adolesc Med* 2002;156:836-40.

Saxe G, Stoddard F, Courtney D, Cunningham K, Chawla N, Sheridan R, et al. Relationship between acute morphine and the course of PTSD in children with burns. *J Am Acad Child Adolesc Psychiatry* 2001;40:915-21.

Winston FK, Kassam-Adams N, Vivarelli-O'Neill C, Ford J, Newman E, Baxt C, et al. Acute stress disorder symptoms in children and their parents after pediatric traffic injury. *Pediatrics* 2002;109:e90.

Zink KA, McCain GC. Posttraumatic stress disorder in children and adolescents with motor vehicle-related injuries. *J Spec Pediatr Nurs* 2002;8:99-106.

## Medical Traumatic Stress:

### SUGGESTED READING FOR HEALTH CARE PROVIDERS

#### Cancer

Alderfer, M., Labay, L. & Kazak, A. Does posttraumatic stress apply to siblings of childhood cancer survivors? *J Pediatr Psychol* 2003;28, 281-86.

Brown, R., Madan-Swain, A., & Lambert, R. Posttraumatic stress symptoms in adolescent survivors of childhood cancer and their mothers. *J Trauma Stress* 2003;16, 309-18.

Kazak, A., Alderfer, M., Rourke, M., Simms, S., Streisand, R., & Grossman, J. Posttraumatic stress symptoms (PTSS) and Posttraumatic stress disorder (PTSD) in families of adolescent childhood cancer survivors. *J Pediatr Psychol* 2004;29, 211-19.

Langeveld, N., Grootenhuis, M., Voute, P. & DeHann, R. Posttraumatic stress symptoms in adult survivors of childhood cancer. *Pediatric Blood and Cancer* 2004;42, 604-10.

Manne, S., DuHamel, K., Ostroff, J., Parsons, S., Martini, D., WIlliams, S., Mee, L., Sexton, S., Austin, J., Difede, H., Rini, C. & Redd, W. Anxiety, dpressive and posttraumatic stress disorders among mothers of pediatric hematopoietic stem cell transplantation. *Pediatrics* 2004;113, 1700-08

Stuber ML, Kazak AE, Meeske K, Barakat L, Guthrie D, Garnier H, et al. Predictors of posttraumatic stress in childhood cancer survivors. *Pediatrics* 1997;100:958-64.

Stuber ML, Nader KO, Houskamp BM, Pynoos RS. Appraisal of life threat and acute trauma responses in pediatric bone marrow transplant patients. *J Trauma Stress* 1996;9:673-86.

#### Other

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DeMier RL, Hynan MT, Harris HB, & Manniello RL. Perinatal stressors as predictors of symptoms of posttraumatic stress in mothers of infants at high risk. *J Perinatol* 1996;16:276-80.

Landolt, M., Ribi, K., Laimbacher, J., Vollrath, M., Gnehm, H. & Sennhauser, F. Posttraumatic stress disorder in parents of children with newly diagnosed type I diabetes. *J Pediatr Psychol* 2003;27, 647-52.

Levi, R., Drotar, D., Yeates, K., & Taylor, G. Posttraumatic stress symptoms in children following orthopedic or traumatic injury. *J Clin Child Psychol* 1999;28, 232-43.

Noyes, J. (1999). The impact of knowing your child is critically ill: a qualitative study of mothers' experiences. *J Adv Nurs* 29: 427-435.

Shemesh E, Lurie S, Stuber ML, Emre S, Patel Y, Vohra P et al. A pilot study of posttraumatic stress and nonadherence in pediatric liver transplant recipients. *Pediatrics* 2000;105:e29.

Young GS, Mintzer LL, Seacord D, Casteneda M, Mesrkhani V, Stuber M. Symptoms of posttraumatic stress disorder in parents of transplant recipients: Incidence, severity, and related factors. *Pediatrics* 2003;111:e725-31.

#### Procedures and Pain

Gavin L, Roesler T. Posttraumatic distress in children and families after intubation. *Pediatr Emerg Care* 1997;13:222-4. Powers, S. Empirically supported treatments in pediatric psychology: Procedure-related pain. *J Pediatr Psychol* 1999;24, 131-145.

Rennick JE, Johnston CC, Dougherty G, Platt R, Ritchie JA. Children's psychological responses after critical illness and exposure to invasive technology. *J Dev Behav Pediatr* 2002;23:133-44.

Shaw RJ, Robinson TE, Steiner H. Acute stress disorder following ventilation. *Psychosomatics* 2002;43:74-6.



### About the National Child Traumatic Stress Network

The National Child Traumatic Stress Network (NCTSN) works to raise the standard of care and improve access to services for traumatized children, their families, and communities throughout the United States. Under the leadership of the U.S. Department of Health and Human Services, the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Center for Mental Health Services (CMHS), the NCTSN seeks to advance effective interventions and services to address the impact of traumatic stress. The Network is comprised of more than 50 centers across the United States including universities, hospitals, clinics, community-based mental health centers, and other organizations that serve traumatized children and their families.

### The NCTSN Medical Traumatic Stress Working Group

The key to the success of the NCTSN is collaboration among its centers with established areas of expertise. The Medical Traumatic Stress Working Group is comprised of experienced medical and mental health clinicians working to advance the understanding and treatment of traumatic stress associated with medical events and medical treatment as it affects children and families.

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NCTSN

The National Child Traumatic Stress Network

www.NCTSNet.org



### Background: Pediatric Illness, Injury, and Traumatic Stress

Children and families are often distressed by:

- sudden or life-threatening illness or injury
- painful or frightening treatment procedures
- sights, sounds, or experience of being in the hospital or emergency department

Most children and parents are able to cope well, with some extra support and with time. Some will have persistent traumatic stress reactions such as Posttraumatic Stress Disorder (PTSD).

When they persist, traumatic stress reactions can:

- · impair day-to-day functioning
- affect adherence to medical treatment
- impede optimal recovery

By incorporating an awareness of traumatic stress in their encounters with children & families, health care providers can:

- minimize potentially traumatic aspects of medical care
- help identify children and families with (or at higher risk for) persistent distress
- provide anticipatory guidance to help prevent long-lasting traumatic stress

## For More Information and Practical Tools

The Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network (NCTSN) has created a toolkit of materials for health care providers, to raise awareness about traumatic stress associated with pediatric medical events and medical treatment, and to promote "trauma-informed practice" in pediatric health care settings.

#### The toolkit includes:

- Specific information about the D-E-F protocol, developed for health care providers to guide assessment and intervention
- Practical tips and tools for health care providers
- Handouts that can be given to parents that present evidence-based tips for helping their child cope

The NCTSN Website (www.NCTSNet.org) has information for health care providers and parents about medical traumatic stress, as well as links to this toolkit of materials.



## Medical Traumatic Stress: What Health Care Providers Need To Know





#### TRAUMATIC STRESS REACTIONS

#### Re-experiencing

- Thinking a lot (unwanted, intrusive thoughts) about the illness, injury, or procedure
- · Feeling distressed at thoughts or reminders of it
- · Having nightmares and "flashbacks"

#### Avoidance

- Avoiding thinking or talking about the illness, injury, hospital, or things associated with it
- · Displaying less interest in usual activities
- · Feeling emotionally numb or detached from others



### Hyper-arousal

- · Increased irritability
- Trouble concentrating or sleeping
- · Exaggerated startle response
- · "Hyper-vigilance"— always expecting danger

#### Other reactions

- New fears related to the medical event
- New somatic complaints (bellyaches, headaches) not explained by the medical condition
- Feeling in a daze or "spacey"

### What Is Traumatic Stress?

Children and parents may have traumatic stress reactions to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. These reactions can include psychological and physiological symptoms of arousal, re-experiencing, and avoidance (see box at left.) When a constellation of these symptoms persists and causes distress, the individual may have Posttraumatic Stress Disorder (PTSD). Children may have other kinds of reactions to illness and injury, including behavioral changes or symptoms of depression or anxiety. Whenever providers or parents have any serious concerns about a child, careful assessment, in consultation with an experienced mental health professional, is key.

### Preventing and Treating Traumatic Stress

Health care professionals providing optimal medical care for ill or injured children and families should incorporate an awareness of traumatic stress reactions, especially those that can interfere with the child's health and functioning. In some cases, traumatic stress reactions can have serious implications for medical outcomes.

### Health care providers caring for children in emergency and hospital settings can:

- incorporate an understanding of traumatic stress in their encounters with children & families
- minimize the potential for trauma during medical care
- provide screening, prevention, and anticipatory guidance
- · identify children and families in distress or at risk

After attending to the basics of children's physical health (the ABC's,) health care providers can promote recovery by paying attention to the DEF's: Reduce DISTRESS, Promote EMOTIONAL SUPPORT; and Remember the FAMILY. (See protocol at right)

### D DISTRESS

- Actively assess and treat pain, using your hospital's protocol.
- Provide child with information about what is happening and choices regarding treatment decisions when possible.
- Listen carefully for child's understanding and clarify any misconceptions.
- Ask about fears and worries.
- Provide reassurance and realistic hope.

### E EMOTIONAL SUPPORT

- Encourage parents to be with their child as much as possible and to talk with their child about worries and fears.
- Empower parents to comfort and help their child.
- Encourage child's involvement in age-appropriate activities when possible.

### F FAMILY

- Gauge family distress and other life stressors;
   identify family strengths and coping resources.
- Encourage parents to use own coping resources or support available at the hospital or in the community.



## Traumatic Stress in Ill or Injured Children AFTER THE ABC'S CONSIDER THE DEF'S

 Assess and manage pain. Ask about fears and worries. Distress

Consider grief and loss.

• Who and what does the patient need now? Barriers to mobilizing existing supports? Support

Family

Emotional

Assess parents' or siblings' and others' distress.

• Gauge family stressors and resources.

Address other needs (beyond medical.)

### QUICK SCREEN

Is this child at risk for ongoing traumatic stress reactions?

ASK PARENT: Since this has happened, does your child...

- get Physical symptoms if reminded of the illness or injury?
- try not to Talk about it?
- Startle easily (for example, jump at sudden noises?)
- get very Distressed if reminded of the illness or injury?

#### **ASK CHILD:**

- Have you been really scared or thought you might die?
- Does a sudden noise really make you jump?
- Do you feel very upset when something reminds you of being sick or hurt?
- Do you have people who care about you and pay attention to what you say?

#### REMEMBER RISK FACTORS:

- Severe pain at any time?
- Exposed to scary sights and sounds?
- · Separated from parents or caretakers?
- · Loved ones ill or injured? Did anyone die?
- Other losses such as, home, pet, belongings?
- · Is child mourning loss of ability, body image, or future?
- Prior scary experiences?
- Prior behavior problems?

If multiple concerns or risk factors present, arrange follow-up and consider referral for further assessment.

## D Distress



### How to Assess: Distress

### TRAUMATIC STRESS IN ILL OR INJURED CHILDREN

### Pain: Use your hospital's pediatric pain assessment. Ask:

- Current pain: "How is your pain right now?"
- Worst pain: "What was the worst pain you have had since this happened?"

#### Fears and Worries:

- "Sometimes children are scared or upset when something like this happens. Is there anything that has been scary or upsetting for you?"
- "What worries you most?"

#### Grief or Loss:

- Anyone else hurt or ill?
- Other recent losses? (loss/damage to home, pet, etc.)



### How to help: Distress

#### Tips to help families of injured or ill children

- Provide the child with as much control as possible over the clinical encounter. The child should:
  - · understand what is about to happen
  - · have a say in what is about to happen
  - · have some control over pain management
- 2 Actively assess and treat pain.
  - · Use your hospital's pain management protocol
- 3 Listen carefully to hear how the child understands what is happening.
  - After explaining diagnosis or procedure, ask the child to say it back to you.
  - Remember that the child's understanding may be incomplete or in error.
- 4 Clarify any misconceptions.
  - Provide accurate information.
  - · Use words and ideas the child can understand.
- 5 Provide reassurance and realistic hope.
  - Describe what is being done to help the child get better.
  - State that there are many people working together to help the child.
- 6 Pay attention to grief and loss.
  - Mobilize your hospital's bereavement service and/or grief protocols.
  - Encourage parents to listen to their child's concerns and be open to talking about their child's experience.

E

### Emotional Support

### How to Assess: Emotional Support

#### TRAUMATIC STRESS IN ILL OR INJURED CHILDREN



#### What Does The Child Need Now?

- Ask parents: "What helps your child cope with upsetting or scary things?"
- Ask child: "What has been the best thing so far that helps you feel better?"

### Who Is Available To Help The Child?

- Do the parents understand the illness or injury and treatment plan?
- Are they able to help calm their child?
- Are they able to be with their child for procedures?

### How Can Existing Supports Be Mobilized?

 Ask parents: "Who can you or your child usually turn to for help or support? Are they aware of what's happened?"



### How to help: Emotional Support

### Tips to help families of injured or ill children

- 1 Encourage parent presence.
  - Encourage parents to be with their child as much as possible during hospital stay.
  - Encourage parents to talk with their child about worries, hopes, etc.
  - Parents know their child better than anyone, and can help staff understand their child's needs and coping strengths.
- 2 Empower parents to comfort and help their child.
  - Help parents understand the illness or injury and treatment plan — so that they can give age-appropriate explanations to their child.
  - Encourage parents to use the ways they have learned to soothe and calm their child at home.
  - Parents may welcome specific suggestions from staff about how to help their child during procedures — e.g., "You can hold his hand and talk to him while we do this."
- Encourage social support & involvement in "normal" activities.
  - Suggest age-appropriate positive activities that fit the child's medical status (play, family time, videos.)
  - Promote the child's appropriate contact with friends, classmates, teachers (letters, calls, email.)

## Family

### How to Assess: Family

TRAUMATIC STRESS IN ILL OR INJURED CHILDREN



### Assess Parents' or Siblings' and Others' Distress

- "Have you or other family members been very upset since this happened?"
- "Who is having an especially difficult time?"

### Gauge Family Stressors & Resources

- "Are there other stresses for your family right now?"
- "Have you been able to get some sleep? To eat regularly?"

### Address Other Needs (Beyond Medical)

 "Are there other worries (money, housing, etc.) that make it especially hard to deal with this right now?"



### How to help: Family

#### Tips to help families of injured or ill children

- 1 Encourage parents' basic self-care.
  - Encourage parents to take care of themselves.
     They need sleep, nutrition, and breaks from the hospital.
- 2 Remember family members' emotional needs.
  - Help them to enlist support systems (friends, family, faith community)
  - If parents or other family members are having difficulty coping,
    - use hospital services (chaplain, family support services)
    - consider referral of parent to mental health professional.
- 3 Be sensitive to resource needs of the family.
  - These issues can significantly interfere with the child's recovery. If problems are identified, utilize psychosocial resources (e.g., social work services) to address them.
  - Housing
  - Finances
  - Insurance
  - Language/Translation
  - Immigration
  - · Care of other children

## Medical Traumatic Stress:

### SUGGESTED RESOURCES FOR PARENTS

#### Selected Books & Articles:

#### Children and Trauma: A Guide For Parents and Professionals

Cynthia Monahon, Jossey-Bass Publishers; San Francisco; 1997.

An informative book for parents and professionals about the impact of traumatic events on children, warning signs for ongoing problems, and ways of helping children cope with the experience.

#### Your Child in the Hospital: A Practical Guide for Parents

Nancy Keene, Rachel Prentice, & Linda Lamb, O'Reilly & Associates, Inc.; Cambridge, MA; 1999.

A pocket-sized guide describing what it is like for parents and children to go through a hospitalization from the point of view of those who've already been through the experience.

#### People like that are the only people here. (short story)

Lorrie Moore, The New Yorker, Jan 27, 1997; Volume 72, Number 44, Page 58 (14).

A first-person account of one family's experience of having their child diagnosed with cancer, subsequent treatment, and their interactions with the healthcare environment.

#### It won't hurt forever: Guiding your child through trauma.

Peter Levine, Mothering, January / February 2002.

Describes the experiences of children going through trauma and ways of helping them and their parents cope with their thoughts and feelings.

#### Childhood cancer survivorship: Posttraumatic stress can affect both children and parents.

Anne E. Kazak, *Coping*, January / February 2002.

Contains information on post-traumatic stress research and symptoms that parents and children may experience after cancer diagnosis and treatment.

#### Selected Internet (web) Resources:

#### Information for parents on traumatic stress during cancer treatment:

http://www.pbtfus.org/InformedParent7.html

#### Helping kids prepare for and cope with medical tests or procedures:

http://www.vh.org/pediatric/patient/pediatrics/cqqa/procedure.html

http://www.chop.edu/childlife/stress\_coping.shtml

#### Helping brothers and sisters of an ill or injured child:

http://www.chop.edu/childlife/sibs\_cando.shtml

#### Traumatic Stress Resources for Parents and Professionals:

The National Child Traumatic Stress Network: http://www.NCTSNet.org

Contact your local librarian (or the social worker from your child's hospital) for storybooks on illness and injury appropriate for your child's age and medical condition.



## At the Hospital: Helping My Child Cope

### WHAT PARENTS CAN DO

Traumatic stress symptoms are common after a serious illness, injury, or hospitalization. Even though it is your child who is ill or injured, your whole family can be affected. It's normal for you, as a parent, to feel overwhelmed or unprepared to help your child (or yourself) cope.

### Traumatic stress symptoms can include:

- · Being easily upset or angry
- · Feeling anxious, jumpy, or confused
- · Being irritable or uncooperative
- · Feeling empty or numb

## Things in the hospital that can be traumatic for children:

- · Being left alone
- Being in pain or going through painful procedures, like shots
- Seeing an injury to their body
- Being exposed to medical equipment that looks or sounds scary
- Thinking that being in the hospital is a punishment
- Seeing other hurt or sick kids
- Being afraid of dying



### The hospital can be traumatic for parents too:

Having a sick, injured, or hospitalized child often results in feelings of frustration, sadness, worry, or helplessness.

- It is a stressful time when relationships with medical staff take priority, and other important relationships and activities get interrupted or put on hold.
- Having a sick or injured child often challenges parents' innermost beliefs about the safety of their children.

### Many parents and caregivers of hospitalized children tell us that:

- They worry about what will happen to their child, even though they don't always show it.
- They feel unprepared to talk with their sick or injured child (or their other children) about feelings, fears, and questions.

**Special information for parents and caregivers:** There are professionals at the hospital who have experience helping other parents and caregivers in your situation. If you are upset, have questions about how to help your child, or just need to talk, please seek out someone at the hospital who is available to assist you and your family — this might be a social worker, a chaplain, or another mental health professional.

Also, read the tips on the other side of this handout to help your child cope while at the hospital.



## Eight Ways You Can Help Your Child Cope While At The Hospital



- You are the best person to help your child. Although it may be difficult at times, try to be calm and reassuring. Give frequent hugs and praise. Hold your child's hand during tests and procedures, and distract your child with stories and pictures.
- Be patient with your child. Children's reactions can include crying, temper tantrums, whining, clinging, and acting out in frustration. These feelings and behaviors are common but temporary. If your child's behavior is becoming unmanageable, it's okay to set rules and limits like you would at home.
- Help your child understand what is happening. Use simple words that he or she can understand. If your child needs to go through a painful procedure, be honest about the fact that it may hurt but also explain its purpose is to help him or her feel better.
- Allow your child to talk about worries or feelings about being in the hospital. Remind your child that it's okay to be scared or cry, but also help them talk about their feelings. Younger children are often better at expressing their feelings through play, drawing, or story-telling. Listen to your child, and help your child understand that these feelings are normal.
- Talk about your feelings together. Children often know more than they admit, but they can easily misinterpret information or other people's feelings. Ask questions to figure out what they know and what they imagine. Reassure your child that he or she has not done anything wrong.
- Help your child see the hospital staff as helpers. Remind your child that the staff has a lot of experience helping children feel better. Encourage your child to participate by asking his or her own questions to the doctors or nurses. It's important for you as a parent to have accurate information, so ask your own questions too.
- Young children are often more affected by being left alone. Have a family member or familiar adult stay with your child as much as possible. Always tell your child when you are leaving, why, and when you will be back.
- Take care of yourself. If you are worried, upset, or not getting sleep, it will be harder to help your child. Don't be afraid to ask friends or family for help. Talk about your worries with other adults, such as family, friends, a counselor, a member of the clergy, or your doctor.



Developed by the Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network.

## After the Hospital: Helping My Child Cope

### WHAT PARENTS CAN DO

When children are seriously ill or injured, and have to stay in the hospital, they and their families may feel upset or worried. These feelings are common and can continue after they return home. In addition, children and parents may wonder how they will cope without the support of hospital staff. Some families may also have difficulty readjusting to daily routines.

What should I expect in the days and weeks after the hospital? After being in the hospital, it is also common for some children to have minor changes in behavior. A few children and parents keep thinking about the experience and get upset frequently. Sometimes they also try to avoid places (such as the hospital) and things that remind them of it. These reactions usually get better with time, understanding, and support.

### Other common (temporary) reactions after coming home from the hospital:

### In younger children:

- · Clinging to parents or other adults
- Bed wetting or thumb sucking
- Being afraid of the dark

#### In older children and teens:

- Changes in sleeping and eating
- Being easily startled or jumpy
- Complaints of headaches or bellyaches, or other minor illnesses

#### In parents:

- Worrying a lot more about their child being safe
- Being overprotective or "on guard," even when there's no need
- Getting upset at reminders of what happened, especially if their children are in pain or discomfort
- Feeling anxious about caring for their child's medical needs on their own

### Signs that your child may need extra help:

- Watching out for danger all the time
- Having new fears
- Not wanting to go to school, or doing a lot worse in school
- Not wanting to be with friends or go back to usual activities
- Arguing a lot with friends or family

When and where should I get extra help for my child? Most children and families feel better within a few days or weeks. (See tips for parents on other side.) Some injuries and illnesses have behavior changes associated with them, so it's important to talk to your doctor as well. If your child's reactions last longer, seem to get worse, or get in the way of day-to-day activities, see your doctor or a school counselor.

The National Child Traumatic Stress Network



www.NCTSNet.org

## Eight Ways You Can Help Your Child Cope After Being in The Hospital



- Go back to everyday routines. Normal routines help children feel safe. Help your child go back to doing his/her usual activities—as much as the injury or illness allows.
- Be patient and give everyone time to readjust. Keep in mind that people in the same family can react in different ways. Brothers and sisters can feel upset too. Most family members just need time and reassurance that things are returning to normal.
- Set normal limits. You may be tempted to relax the rules in order to help your child feel special, or to make up for the hard times that he or she is experiencing. However it is often better for your child if you set normal limits on behavior and keep most of your family rules and expectations the same.
- Allow your children to talk about feelings and worries, if they want to. For younger children, encourage play, drawing, and story-telling. Ask your child (and brothers and sisters) what they are thinking, feeling, and imagining. Be a good listener—and share the facts, as well as your feelings and reactions.
- Encourage your child to spend time with friends. After a serious illness or injury, some children feel a little "different." They may also wonder how their friends will react. Invite a few of your child's friends to visit, and help your child plan a few fun activities. It may be helpful to assist your child in answering questions his or her friends may have about the illness or injury (Is it contagious? How long will the bandages be on? etc.)
- Help your child do some things on his or her own. It is often tempting to do things for your child after he or she is injured or ill. But it is more helpful for children to do things again on their own. As much as the injury or illness allows, encourage your child to do the things (including chores) he or she used to do.
- Take time to deal with your own feelings. It will be harder to help your child if you are feeling really worried, upset, or overwhelmed. Talk about your feelings with another adult, such as a friend, your doctor, a counselor, or a member of the clergy.



Follow up with the doctor. Even if your child is getting better, the doctor needs to know how your child is coping, especially since some injuries and illnesses have behavior changes associated with them. For children and families who need extra help dealing with their reactions, helpful treatments are available. Your doctor will be able to help you figure out what's best for you and your family.

Developed by the Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network.

## At the Hospital: Helping My Teen Cope

### WHAT PARENTS CAN DO

Traumatic stress symptoms are common after a serious illness, injury, or hospitalization. Even though it is your teen who is ill or injured, your whole family can be affected. At first, as a parent, you might not feel prepared to help your teen (or yourself) cope.

### Traumatic stress symptoms can include:

- Being easily upset or angry
- · Feeling anxious, jumpy, or confused
- Being irritable or uncooperative
- Feeling empty or numb

## Things in the hospital that can be traumatic for teens:

- Uncertainty about what might happen next
- Being in pain or going through painful procedures
- Having a noticeable injury or being permanently injured
- Fear about what others will think of them being sick or in the hospital
- Fear of dying



### The hospital can be traumatic for parents too:

Having a sick, injured or hospitalized teen often results in feelings of frustration, sadness, worry, or helplessness.

- For parents, it is a stressful time when relationships with medical staff take priority, and other important relationships and activities get interrupted or put on hold.
- For both parents and teens, the hospital experience often challenges innermost beliefs about safety, vulnerability, and fairness.

In addition, many parents feel unprepared to talk with their sick or injured teens (or their other children) about feelings, fears, and questions.



### Special information for parents and caregivers of teens:

There are professionals at the hospital who have experience helping other parents and teens in your situation. If you are upset, have questions about how to help your teen, or just need to talk, please seek out one of the family resources available at the hospital: this might be a social worker, a chaplain, or another mental health professional. It might be helpful to encourage your teen to talk to someone as well. Also, read the other side of this handout for tips on helping your teen cope while at the hospital.



## Eight Ways You Can Help Your Teen Cope While At The Hospital



- You are the best person to help your teen.
  Although it may be difficult at times, try to be calm and reassuring. Give frequent hugs and praise. Remind your teen that the medical staff has a lot of experience helping other sick and injured teens.
- Be patient with your teen. Intense feelings are common but temporary reactions to the hospital experience. Remind your teen that it's okay to be confused, angry, or scared and to talk about his or her feelings. Recognize that your teen may want to appear "grown up," while also feeling afraid and in need of your comfort and support.
- Be honest with your teen. Teens want information, even if they don't ask. If your teen needs to go through a painful procedure, be honest about the fact that it may hurt, but also explain that its purpose is to help them feel better. The more your teen knows what to expect, the more comfortable he or she will be.
- Include your teen in medical discussions when possible. Encourage your teen to ask his or her own questions of the doctors and nurses. Help your teen participate in decision-making by planning how to cope with pain and stressful procedures in advance.
- Talk about your feelings together. Teens often know more than they admit, but can sometimes misinterpret information or other people's feelings. Gently ask questions to learn what your teen thinks and believes, and share your thoughts, feelings, and reactions.
- Teens are self-conscious and will especially worry about how they will look and fit in with others, and about their privacy. Reassure your teen, but be honest. Find ways of respecting and supporting your teen's privacy. Allow your teen to do some things on his or her own with regard to care.
- Help your teen stay connected with old friends, as well as make new friends. Ask the medical staff to help you introduce your teen to others on the floor with similar experiences.



Take care of yourself. Your teen can tell if you are worried, upset, or not sleeping, which will make it harder on everyone. Don't be afraid to ask family or friends for help. Talk about your worries with other adults, such as family, friends, a counselor, a member of the clergy, or your doctor.

Developed by the Medical Traumatic Stress Working Group of the National Child Traumatic Stress Network.

### After the Hospital: Getting Back to a Schedule

After coming home from the hospital, Tracy couldn't go back to school yet. In this story, Tracy found a way of doing some normal things each day. Hercules the dog would like to hear your story too.

When I was sick and in the hospital, someone from my family was always with me. Even though I didn't feel well, having someone around made me feel safe. It helped me think about things other than being sick.

When I came home, my doctor said I couldn't go back to school yet. For the first few days, I stayed upstairs in bed, watching cartoons while mom worked on the computer downstairs. Being in bed all day was like being in the hospital! Mom brought me some homework from my teachers at school, but I didn't want to do it. Then she pulled out my favorite card game, but I didn't feel like doing that either. My mom asked: "Other than feeling sick, is there anything else bothering you?" Mom and I talked and figured out that being at home and missing out on stuff with my friends made me feel bored and sad. Mom said, "maybe you'd feel better if your day was more like it usually is." "How can I do that?" I asked. "I can't even go to school." "But there are lots of things you can do to get back to your regular schedule," Mom said.

That was true. Mom helped me get dressed every morning. Instead of staying in bed, I came downstairs. I started to get caught up on my schoolwork, sitting at the desk where mom was working. I wasn't so lonely, and she was right there to help when I had a question. Mom and I even played cards each day after lunch. I got

back to doing my chores again, too — feeding the dog and clearing the table after dinner. When I was well enough to go out, my family and I went to see a movie. That was really fun because I got to choose the movie. Mom let me call my friends on the phone and invite one over to visit. I was worried that none of my friends would want to visit since I was still sick. But Jamie came over one day and we watched movies and played cards. I'm not back to school yet, but I'm doing a lot more things now and seeing more friends.

## Share with Tracy and me how you are trying to get back into a schedule. Fill in the blanks to tell your story.

Some of the things I really miss being able to do since I went to the hospital are

|   | and                                     | When I think about the things                      |
|---|---|--|
| (something you miss doing)              | (something else you m                   |  |
| I still can't do, I feel                |   | Someone that I can talk to about my feelings is    |
|   | (how you feel)                          | ,  |
|   | . Even though I can't do everything I u | sed to do, I can do some things that would help me |
| (name of person)                        |   |  |
| feel like the old me again, like        | and                                     |  |
| <u> </u>                                | (something you can do)                  | (something else you can do)                        |
| If I could spend some special time with | someone now that I'm home, I would ask  | to   |
| 1                                       | ,                                       | (name of person)                                   |
|   |   | with me.   |



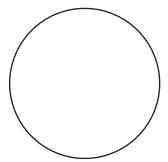
Many doctors write prescriptions for patients with things to help them feel better. What would *your* prescription say?

Write or draw a prescription to help you feel better.

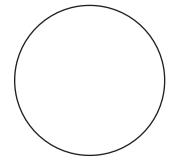
# 

When kids come home from the hospital, they sometimes forget how much better they are feeling. In the blank faces below, draw a face of how you felt when you first went to the hospital, how you felt (or will feel) when you go home, and how you felt (or will feel) when you go back to school. Do your three faces look different from each other?

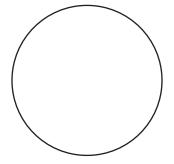
NO SUBSTITUTIONS



Draw a face of how you felt when you first went to the hospital.



Draw a face of how you felt (or will feel) when you come home from the hospital.



Draw a face of how you felt (or will feel) when you go back to school and see your friends.





SIGNATURE

WITHOUT RESTRICTIONS

**REPEAT** 



### What Do I Say? Talking About What Happened With Others

After being injured, Jesse was worried about what others would think. With help, Jesse figured out what to say to others. After the story, can you tell Hercules the dog about what happened to you?

I don't remember my accident, but it hurt a lot when I woke up in the hospital. I remember getting X-rays and that I had two operations! The doctors told me they could fix the parts of my body that were broken. But they said that I might walk funny and look different for awhile, because of my injuries. I was worried about what I would tell my friends when they saw me.

After my operations, I went to PT: physical therapy. That's a place where kids and adults work to make their bodies strong enough to go home. I kept to myself at PT. I didn't know what people would say about the weird way I walked and the cuts from my accident.

In the gym, I saw a girl — Kim — who walked funny too. She was using crutches. Kim came over to talk to me: "I'm getting better. Soon I won't need my crutches. What happened to you?" I felt weird because I didn't know what to say. Later, my therapist said to me: "You looked worried when Kim asked what happened." "I guess so." I said. My therapist said: "Lots of people have a hard time talking about what happened to them. But it gets easier with

practice. Maybe we can figure out what you want to say to other people about your accident."

My therapist got me started, and then I practiced telling my doctor and my family. When I saw Kim again, I told her and the other kids about my accident, just as I practiced it. Kim said she felt better because she was worried she had hurt my feelings when she asked me what happened. My therapist was right — knowing what to say and being able to talk about my accident got easier with practice and I feel better!

Fill in the blanks in the story below. It can help you figure out how to talk about what happened to you.



Since I came to the hospital, I have talked about what happened to me with

| (                                      | _ and                                 |                                  | talking with others about what  |
|--|---------------------------------------|----------------------------------|---------------------------------|
| (name of person)                       | (name of another person               | )                                |                                 |
| happened to me is                      |                                       | 🗖 I do / 🗇 I do not feel wo      | orried about talking with other |
|  | (why it is hard)                      | (check one)                      |                                 |
| people about what happened to          | o me. One of the reasons 🗖 I do / 🗖   | I do not feel nervous is because |                                 |
|  | (check                                | one)                             | (reason)                        |
| Some of the important things I         | d like to tell others about what happ | ened include                     | and                             |
|  |                                       | (something I                     | 'd like to tell others)         |
|  | One person that I can practi          | ice talking with is              |                                 |
| (something else I'd like to tell other | ers)                                  | (                                | name of person)                 |



Draw a picture or write about what happened to you.

Practice talking about what happened by explaining your drawing or by reading what you wrote to someone you trust.



Jesse was worried about what other people would say.
Write what you think the people below are wondering about your illness or injury.
Talk to your parents or another adult about what you would say to them.









### When it Hurts: Dealing with Pain

Jordan had some painful treatment at the hospital. But Anita helped Jordan learn new ways to cope with the pain. After the story, Hercules the dog wants to hear about how you've coped with pain too.

I sometimes have pain from my illness, but never this bad. I was afraid something really bad was wrong with me. I was crying hard when my Grandma and I got to the ER. This lady from the hospital, Anita, asked if I wanted to blow bubbles while waiting for the doctor. She said it would be fun. It did help me forget about my pain for awhile.

When I finally saw the doctor, he told me that I'd have to stay in the hospital and that I'd have to get medicine through a needle. I told Grandma I was scared. She said I'd be okay, but we should ask the doctor to explain what they were going to do. Dr. Blum talked to me about how the medicine would help my pain and my illness. He said that because of my illness I might have pain like this again sometimes. He told me Anita knew some games that would help me cope with the pain.

Anita and I came up with a pretend story about one of my favorites things — swimming in the pool on a hot day. She taught me to think about that whenever I had to get the medicine through the needle. She also taught me a relaxation game where I made my arms and my legs go floppy and took deep breaths. We talked about other things I've done before to help with my pain — like playing games, watching cartoons, or listening to music. We made a list of them so that I could remember how to cope with the pain. Grandma also came up with the idea of an "ice cream coupon." She'd give me a coupon every time I tried to do one of the things on the list when getting my medication through the needle.

The first time I got the medicine through the needle, I started to cry and forgot about all the things Anita taught me. But Grandma pulled out the list and we went through my pretend story about the swimming pool. It helped! The next time I got the needle, we did the story again and I didn't think about my pain as much. I can't say I liked being at the hospital, but I learned a lot about how to deal with my pain. And now that I'm home, I have three

ice cream coupons from Grandma that I'm going to use!

Everyone feels pain sometimes. What are the ways you have coped with your pain? Fill in the blanks to complete the story.

| In the hospital, the things that were painful | were                                  |        |  |
|---|---------------------------------------|--------|--|
|   | (something that was pair              | nful)  |  |
| and   | Being in pain made me feel            |        | Some of                                    |
| (something else that was painful)             |                                       |        | (how you felt)                             |
| the things that helped me feel better were _  |                                       | and    |  |
|   | (something that made you feel better) |        | (something else that made you feel better) |
| The people who helped me feel better when     | I was in pain were                    |        |  |
|   |                                       | (names | of people)                                 |
| The next time I feel pain, I can do           |                                       |        | to help feel better.                       |
| •   | (what you can do)                     |        | •  |



A team of people at the hospital helped Jordan deal with pain.

Choose the people below you would ask to be on your team and use the squares to write the things that you and they can do together to help you cope with pain.

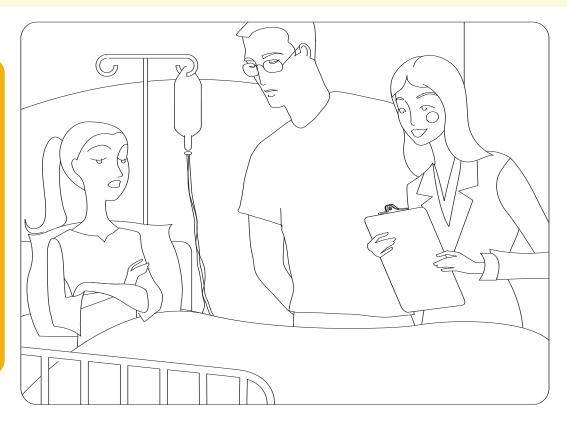








Being in
the hospital and
feeling pain can
make you feel a lot
of different feelings.
Use different colors
in the picture
on the right to show
how this girl feels
about being in
the hospital and
coping with pain.









### Making a Plan: Dealing with Things that Remind You of What Happened

After a bike accident, Angel was nervous about riding bikes again. With help, Angel came up with a plan to cope with being scared. After the story, will you share your plan with Hercules the dog?



My step-dad and I were riding bikes when a car came around the corner and hit my back tire.

I heard a screech as the car tried to stop. I fell to the ground and couldn't move my arm. Even though my step-dad was with me, I remember being scared as I rode in the ambulance. The sirens were so loud. At the hospital, I had to have 2 operations on my arm and stay there until I could move it better.

I went home and when my doctor said I could ride bikes again, my step-dad really wanted me to get back on my bike. I was scared at first, but my step-dad came with me. For the first few times, we rode near our house. When I got scared, my step-dad helped me calm down by having me stop my bike and telling me I was safe.

Two days later, when we were riding, I heard a car tire screech. My heart started beating fast, I felt dizzy and like I couldn't breathe. It felt like my accident all over again! I felt so shaky that I couldn't ride my bike anymore that day. My step-dad said it was okay to take a break but that we should try it again soon. Later that night, he helped me work out a plan to feel safe again when I get scared like that. Here's the plan: we can ride bikes just in the neighborhood. When I get scared, I can stop, get off my bike, and wait a few minutes till I calm down or we can walk it home. My step-dad

also taught me how to take deep breaths to help me calm down when I'm having a hard time.

A few days later, we started riding on our street again. My heart pounded when some cars went by, but I remembered the plan and calmed myself down. The first time it happened, I had to stop and walk the bike to a safe place. The next time, I just stopped, calmed myself down, and then rode a little more. Now I'm riding by myself sometimes – still staying near the house – but I'm getting a little less scared each time.

### Tell your story like Angel did by filling in the blanks below.

| Γhe 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(something that reminds y         | ou of what happened)                |
| (something else that reminds you of what happened) | . If I think about what happened and get u | pset, one way I can calm down is by |
| I constraints (something you can do to calm down)  | ould also talk to(name of person)          | about how I feel. The next time     |
| get upset about what happened, I plan to:          | (vour plan)                                |                                     |



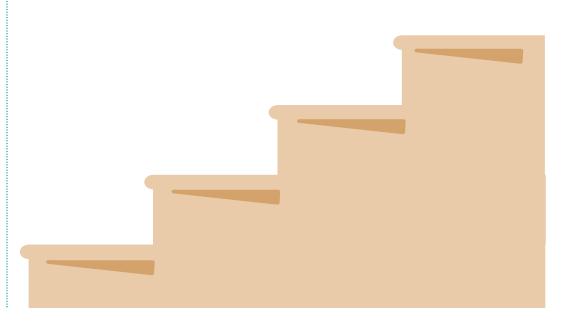
Suggested Goals:

- Ride my bike again
- Play with my friends
- · Go back to school

Steps you can take to get you there:

- Ask someone for help
- Make a plan
- Talk about a feeling or problem.
- Ask someone in my family to help me the first few times.
- Try it out for a few minutes the first time.
- Do something you enjoy.

Dealing with things that remind you of what happened can be hard, but it helps if you break it down into smaller steps. What do you want to try to do again? On the top step, write down (or draw) your goal – the thing you want to do again. On the other steps, write (or draw) things you can do to help reach your goal. If you can't think of anything, you can use some of the ideas on the side, or you can ask someone in your family to help you with this.



Sometimes, after an illness or an injury, we think about all the things that we can't do, and we don't remember all the good things we can still do. On each of the notes below, write yourself a reminder of all the good things you like to do AND can still do now!





