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# Post-traumatic Stress Response to Life-Threatening Illnesses in Children and Their Parents

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Post-traumatic stress disorder (PTSD) is a constellation of psychological and physiologic symptoms that are persistent in some individuals who have been exposed to a traumatic event. Similar to most psychiatric disorders defined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) of the American Psychiatric Association [1], the diagnosis depends on a combination of specific symptoms, over a set period of time, severe enough to lead to clinical distress or functional impairment. In this case, to qualify for a formal diagnosis of PTSD, a child or adult must display one or more symptoms from each of three clusters: avoidance of reminders of the stressor (eg, a traumatized soldier who does not want to return to the battlefield), re-experiencing of the event (eg, “flashbacks”), and hyperarousal (eg, hypervigilance, persistent heightened level of anxiety). These symptoms need to persist at least 1 month after the event and to be associated with functional impairments or disability to qualify for a diagnosis of PTSD.

In contrast to most diagnoses in DSM, a diagnosis of PTSD also requires that the symptoms be in response to a specific precipitating event, or trauma. According to the definition in the fourth edition of DSM (DSM-IV), a traumatic event must involve “actual or threatened death or serious injury, or a threat to the physical integrity of self or others,” and the

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39 individual must have experienced “intense fear, helplessness, or horror” at  
40 the time it happened [1]. In the early 1990s, the diagnosis or treatment of  
41 a life-threatening illness first was considered as a possible precipitating event  
42 for PTSD. Field trials done in preparation for DSM-IV evaluated a group  
43 of 24 adolescent cancer survivors and their mothers for PTSD [2,3]. The re-  
44 sults of this field trial and others provided data that prompted the inclusion  
45 of medical illness as a potential precipitating traumatic event for PTSD in  
46 the text of DSM-IV and thereafter DSM-IV-TR [4]. Since that time, studies  
47 of post-traumatic stress symptoms have been published about a variety of  
48 medically ill patient groups, mostly adult but some pediatric studies, includ-  
49 ing cancer, burns, heart disease, diabetes, human immunodeficiency virus,  
50 and organ transplantation. These studies have supported the hypothesis  
51 that post-traumatic stress reactions are seen in medically ill children and  
52 adults and their families during active treatment and long after in survivors.

53 There has been little examination of PTSD in the context of palliative  
54 care settings, where the aim is to alleviate suffering, rather than offer  
55 a cure (see the Preface of this issue for the complexities of this “distinc-  
56 tion”). It could be argued that PTSD should be less common for the chil-  
57 dren and parents in situations at the end of life, in which there are fewer  
58 invasive or painful procedures, and the uncertainty about outcome has  
59 been resolved. The focus on excellent pain management would be predicted  
60 to reduce the likelihood of post-traumatic symptoms [5]. It is also possible,  
61 however, that post-traumatic symptoms could give way to hopelessness and  
62 grief in the less anxious, but more certain, setting of palliative care. This ar-  
63 ticle provides an overview of the literature on post-traumatic stress re-  
64 sponses in children and their parents who are dealing with life-threatening  
65 illness, with a special emphasis on issues that may be encountered in pallia-  
66 tive care settings.

### 67 68 69 **Epidemiology of post-traumatic stress symptoms in pediatric patients** 70 **and their parents** 71

72 Children with cancer are probably the best studied medically ill pediatric  
73 population with regard to post-traumatic stress. Studies of children who are  
74 undergoing active treatment for cancer indicate evidence of post-traumatic  
75 symptoms during and after treatment. In the earliest published research  
76 study, nine children undergoing bone marrow transplant for hematologic  
77 and malignant disorders were followed longitudinally for evidence of  
78 PTSD. Symptoms consistent with PTSD were observed in a clinical inter-  
79 view performed in the hospital immediately before the bone marrow trans-  
80 plant. The children experienced a 4- to 8-week hospitalization in an isolation  
81 room, with intensive chemotherapy and radiation. The number and severity  
82 of the symptoms were increased from the pretransplant level in interviews  
83 held in the children’s homes at the 3-month postdischarge visit after the

84 transplant. The symptoms decreased at the 6-month and 12-month home in-  
85 terviews. The number and severity of symptoms did not return to the pre-  
86 transplant level by the 12-month interview, however, despite the fact that  
87 at this point the child's chance of survival was quite good. Parents were  
88 not assessed formally in this study, but interviews with them about their  
89 children suggested they were distressed, but did not discuss this with their  
90 children [6].

91 The presence of post-traumatic stress symptoms in childhood cancer survi-  
92 vors was studied in comparison with other traumatized groups. Pelcovitz  
93 et al [2] compared symptoms of 23 adolescent cancer survivors with 27 ad-  
94 olescents who had been physically abused and 23 healthy, nonabused ad-  
95 olescents. The cancer survivors not only reported more symptoms than the  
96 healthy, nonabused teens, but also more than the physical abuse victims. Us-  
97 ing a measure of lifetime symptoms, 35% of cancer patients versus only 7%  
98 of abused adolescents met PTSD criteria. Cancer survivors reported their  
99 families as being significantly more caring than did the victims of abuse.  
100 The low prevalence of PTSD in the physically abused controls is puzzling  
101 and beyond the scope of this article.

102 Later studies of PTSD prevalence showed mixed outcomes. A large sur-  
103 vey of 309 disease-free childhood cancer survivors, 8 to 20 years old, 6 years  
104 (mean) after the end of cancer treatment represented the following diagnos-  
105 tic groups: 38% acute lymphoblastic leukemia, 10% Wilms' tumor, 9% sar-  
106 coma, 8% acute nonlymphoblastic leukemia, 8% lymphoma, and 6%  
107 Hodgkin's disease. These pediatric cancer survivors were compared with  
108 219 age-matched healthy control children. Both groups completed the  
109 PTSD Reaction Index, a widely used self-report instrument designed for  
110 children and adolescents. Of the cancer survivors, 2.6% reported severe  
111 PTSD symptoms, and 12.1% reported symptoms in the moderate range.  
112 By contrast, in the comparison group, 3.4% reported severe PTSD symp-  
113 toms, and 12.3% reported symptoms in moderate range [7,8], with no statis-  
114 tically significant difference between pediatric cancer survivors and controls.

115 This study was followed by investigations of young adult survivors of  
116 childhood cancer, with different results. Of 78 childhood cancer survivors  
117 age 18 to 40 years, 20.5% met DSM-IV criteria for PTSD at some point af-  
118 ter the end of treatment. As a group, participants reported elevated state  
119 and trait anxiety. Subjects meeting criteria for PTSD reported higher per-  
120 ceived current life threat, more intense treatment histories, and higher levels  
121 of psychological distress than subjects who did not have PTSD [9,10]. A sub-  
122 set of 51 of this sample was assessed with a structured clinical interview to  
123 determine PTSD status and given self-report measures of quality of life  
124 (Rand Short-form 36) and psychological distress (Brief Symptom Inven-  
125 tory). On this more rigorous assessment, 20% of the sample met criteria  
126 for PTSD. On all domains, quality-of-life scores were significantly lower (in-  
127 dicated poorer quality of life) for the PTSD group compared with the non-  
128 PTSD group. The survivors with PTSD also reported clinically significant

129 levels of psychological distress, whereas symptom levels for survivors with-  
130 out PTSD fell well within population norms [11]. Age-specific developmen-  
131 tal challenges were hypothesized to account for this higher level of  
132 symptoms compared with younger cancer survivors. Young adult survivors  
133 faced completion of higher education, career success, search for life part-  
134 ners, and related tasks apt to be affected by cognitive impairment, organ  
135 toxicity, infertility, and other late effects of cancer treatment to a greater de-  
136 gree than younger survivors.

137 Given the findings with PTSD prevalence in these studies of childhood  
138 cancer survivors, it might be concluded that post-traumatic stress symptoms  
139 are experienced primarily during acute illness at the time of initiation of  
140 treatment and after treatment ends by older survivors. Studies of pediatric  
141 solid organ transplant recipients suggest, however, that the level of symp-  
142 toms reported by older cancer survivors in earlier studies may be a better  
143 estimate of the overall impact of life-threatening illness on children at all  
144 ages. A study of 104 pediatric heart, liver, or kidney transplant recipients,  
145 age 12 to 20 years, at least 1 year post-transplant, found that more than  
146 16% of the adolescents reported symptoms meeting criteria for PTSD. An  
147 additional 14.4% met two of the three symptom-cluster criteria. Regression  
148 analysis indicated no effect of gender, ethnicity, age at interview, organ type,  
149 time since transplant, or age at transplant [12].

150 Comparable prevalence is found in other pediatric studies. A group of 35  
151 children, and their parents, who had been hospitalized in a pediatric ICU  
152 were compared with 33 children/parent pairs who had been hospitalized  
153 on general pediatric wards; 21% of pediatric ICU–discharged children de-  
154 veloped PTSD compared with none of the ward admissions. Pediatric  
155 ICU children had significantly more PTSD features of irritability and persis-  
156 tent avoidance of reminders of the admission [13]. In another study, 22% of  
157 143 children 7 to 15 years old who experienced motor vehicle injury met cri-  
158 teria for PTSD. There were no associations for presence or absence of PTSD  
159 with age, gender, race, injury, or cause of injury [14].

#### 161 *Parents of children with serious medical illness*

162  
163 The largest study of post-traumatic stress symptoms in parents of children  
164 with life-threatening illness compared 309 mothers and 213 fathers of child-  
165 hood cancer survivors with 211 mothers and 114 fathers of a healthy control  
166 group. Of the survivors' mothers, 10.1% reported severe levels of current  
167 post-traumatic stress symptoms, and 27% reported moderate levels of symp-  
168 toms. The mothers in the comparison group reported 3% severe and 18.2%  
169 moderate levels of symptoms ( $P = .001$ ). Of the fathers, 7.1% reported severe  
170 and 28.3% reported moderate symptoms of PTSD compared with 0% severe  
171 and 17.3% moderate in the fathers in the comparison group ( $P < .001$ ) [7].

172 Another large but uncontrolled study of parents included 170 caregivers  
173 (mostly mothers) of pediatric transplant recipients 10 to 38 months after

174 their child's most recent transplant. Although the parents did not report el-  
175 levated levels of depression or anxiety, they did report elevated levels of post-  
176 traumatic stress symptoms, with 27.1% of the parents meeting diagnostic  
177 criteria for PTSD. The rate of post-traumatic stress symptoms did not  
178 vary by type of transplant or by ethnic group [15].

179 A similar prevalence is found in populations of parents dealing with  
180 a more acute life threat to their children. A study of 272 parents of children  
181 in the pediatric ICU for more than 48 hours found that 32% met symptom  
182 criteria for acute stress disorder. At follow-up 2 months later with 161 of the  
183 parents, 21% met symptom criteria for PTSD [16]. A British study found  
184 that parents of children hospitalized in the ICU were more likely to screen  
185 positive for PTSD (27%) compared with parents of children admitted to the  
186 ward (7%) [13]. In another study of mothers of children experiencing acute  
187 life-threatening illness, 111 mothers of children who survived hematopoietic  
188 stem cell transplantation completed self-report measures of psychological  
189 functioning at the time of hematopoietic stem cell transplantation and  
190 self-report measures and a structured psychiatric interview 18 months later.  
191 Approximately 20% of mothers had clinically significant PTSD spectrum  
192 symptoms. This prevalence increased to nearly one third when subthreshold  
193 PTSD was included [17].

### 194 195 **Predictors for the development of post-traumatic stress disorder** 196 **in medically ill children and their parents**

#### 197 *Children*

198  
199 Studies examining predictors of post-traumatic stress symptoms in chil-  
200 dren with life-threatening illness have found consistent factors similar to  
201 those found for other types of traumatic exposure. In a report from the larg-  
202 est study to date of childhood cancer survivors, 186 survivors age 8 through  
203 20 years, off treatment for more than 1 year, significant, independent predic-  
204 tors of persistent post-traumatic stress symptoms included (1) the survivor's  
205 retrospective subjective appraisal of life threat at the time of treatment,  
206 and the degree to which the survivor experienced the treatment as "hard"  
207 or "scary"; (2) the child's level of trait anxiety; (3) history of other stressful  
208 experiences; (4) time since the termination of treatment (negative associa-  
209 tion); (5) female gender; and (6) family and social support (negative associa-  
210 tion). The survivor's anxiety and current appraisal of life threat, but not  
211 post-traumatic stress symptoms, were related to the mother's perception  
212 of stress of treatment and current life threat. The assessment of prognosis  
213 and treatment intensity made by the oncologist was not significantly related  
214 to the appraisals of life threat or treatment intensity by the survivor and did  
215 not predict post-traumatic stress symptoms in the survivor [18].

216  
217 Even injuries that are not life-threatening seem to result in post-traumatic  
218 stress symptoms in some cases. In one study, 400 pediatric orthopedic

219 trauma patients with an average age of 11 years were assessed an average  
220 of 36 days after injury. Of the children, 33% reported high levels of post-  
221 traumatic stress symptoms. Levels of symptoms were not related to the mean  
222 Injury Severity Score or summed Extremity Abbreviated Injury Score.  
223 The only identified predictor was that patients admitted to the hospital after  
224 injuries were significantly more likely to develop high levels of post-traumatic  
225 stress symptoms compared with patients not admitted [19].

226 The subjective appraisal of the traumatic event, rather than an objective  
227 measure of actual risk or exposure, is particularly significant for the pallia-  
228 tive care setting. Although it could be argued that the prognosis is grim for  
229 all of the children in a palliative care setting, not all experience it as trau-  
230 matic, and not all children receiving palliative care services die (see Preface).  
231 There are many stressful events in the course of a serious illness, however,  
232 which may have been experienced as traumatic by a child or parent. This  
233 appraisal is highly individual and is shaped significantly by developmental  
234 level and by the parent's, usually the mother's, appraisal of risk. Younger  
235 children are less likely to interpret the diagnosis or life threat as the most  
236 traumatic aspect of the illness because they are less likely to understand fully  
237 the potential implications. Younger children are more likely than older chil-  
238 dren and parents to find separation from friends and family to be a major  
239 traumatic event, however [20]. Exposure to traumatic events at different de-  
240 velopmental stages is likely to result in different psychological outcomes and  
241 disorder profiles, but interpretation of studies published to date are limited  
242 by failure to stratify by age or stage of development. Studies are needed with  
243 the sample sizes necessary to examine this question by age and developmen-  
244 tal level stratification.

245 Often the intrusive or painful medical procedures and treatments, such as  
246 transplantation and chemotherapy, are cited later as traumatic events by chil-  
247 dren of all ages who report medically related post-traumatic stress symptoms.  
248 Medical professionals may be perceived as "inflictors" of trauma, with par-  
249 ents as collaborators. Clinical experience suggests some children may experi-  
250 ence medical treatment as akin to interpersonal violence, despite sensitive,  
251 well-intentioned caregivers. Studies of children exposed to repeated, interper-  
252 sonal traumatic events suggest these events are more likely to lead to blunting  
253 and dissociation, whereas an acute, noninterpersonal event, such as a natural  
254 disaster, are more likely to lead to hypervigilance and avoidance of re-  
255 minders. Although this distinction has not been firmly established for medi-  
256 cally related traumatic stress responses, it should be considered for seriously  
257 ill children in intensive medical settings whose withdrawal and "depression"  
258 may reflect traumatic dissociation, rather than a mood disorder.

### 259 260 *Parents*

261  
262 Predictors for post-traumatic stress responses in parents resemble the pre-  
263 dictors seen in childhood cancer survivors. Mothers and fathers of 331

264 survivors of childhood cancer age 8 to 20 years were surveyed using the  
265 Posttraumatic Stress Disorder Reaction Index, a validated instrument  
266 used for self-report of traumatic stress symptoms in adults and adolescents.  
267 Trait anxiety as reported at 5 years after the end of treatment was the stron-  
268 gest predictor of post-traumatic stress symptoms for mothers and for fa-  
269 thers. Other significant contributors were the parent's perception of the  
270 life threat to the child, the parent's perception of the intensity of the child's  
271 treatment, and the parent's social support. Similar to the children, the on-  
272 cologist's rating of life threat and treatment intensity did not contribute  
273 to post-traumatic stress symptoms in the parent. In contrast to the child sur-  
274 vivors, there was a small but statistically significant correlation between the  
275 parent's and oncologist's rating of life threat and treatment intensity [21].

276 Similar predictors were found in the pediatric ICU study previously cited.  
277 Symptoms of PTSD and acute stress disorder at 2-month follow-up were as-  
278 sociated with the parents' *perception* of life threat rather than *actual* life  
279 threat as measured by the Pediatric Risk of Mortality Scale. Other predic-  
280 tors of PTSD at 2 months were the symptoms of acute stress disorder as-  
281 sessed in the pediatric ICU, an unexpected admission, and the occurrence  
282 of another hospital admission or other traumatic event after the index ad-  
283 mission [16].

284 The relationship between post-traumatic stress symptoms in children and  
285 their parents was studied in 209 children, age 6.5 to 14.5 years, interviewed 5  
286 to 6 weeks after an accident or a new diagnosis of cancer or diabetes mellitus  
287 type 1. Of the children, 11.5% reported post-traumatic stress symptom  
288 levels in the clinical range of PTSD; 16% of the 175 fathers and 23.9% of  
289 the 180 mothers met full DSM-IV diagnostic criteria for current PTSD. Pre-  
290 dictors of the development of PTSD in the children included accident-  
291 related injury (rather than cancer or diabetes) and the functional status of  
292 the child. The development of PTSD in the parents was associated with  
293 the diagnosis of cancer in their child (more commonly than injury). PTSD  
294 symptom scores of mothers and fathers were significantly correlated with  
295 each other. The children's PTSD symptoms were not significantly related  
296 to the symptoms of the mothers and fathers, however [22].

297  
298  
299

## 300 **Implications for care**

### 301 *Children*

302  
303 Given the focus on quality of life and comfort care in a palliative care set-  
304 ting, what are the implications of PTSD in this setting? The study of Meeske  
305 et al [11] of 51 young adult survivors of childhood cancer, 20% of whom met  
306 symptom criteria for PTSD, lends support to PTSD as an indicator of dis-  
307 tress, finding that the summative score for psychological distress was in the  
308 upper 97th percentile compared with a normative population. Of importance



309 to children in palliative care, in this study subjects with moderate and severe  
310 “late effects” of treatment (eg, cardiovascular or pulmonary complications)  
311 were more likely to have PTSD. This finding suggests that a more severe  
312 medical outcome might act to sustain chronic symptoms of PTSD and be  
313 an indicator of more traumatic exposure over time [11]. In the pediatric on-  
314 cology setting and by implication with other life-limiting illnesses, a substan-  
315 tial proportion of children sick enough to reach the point of palliative care  
316 are likely to have experienced multiple risk factors for PTSD and associated  
317 distress. These patients also are likely to experience functional impairment  
318 and reduced quality of life, which may be improved if PTSD symptoms  
319 are addressed.

320 Post-traumatic stress symptoms also seem to be related to nonadherence  
321 to treatment. A study of 19 pediatric liver transplant recipients found that 6  
322 reported symptoms consistent with a diagnosis of PTSD. Three of these,  
323 and none of the others, had been rated as significantly nonadherent by their  
324 medical care team. The children with PTSD had significant fluctuations in  
325 their blood levels of immunosuppressive drugs. In this study, no significant  
326 differences were found in perception of disease threat or demographic vari-  
327 ables between the subjects reporting PTSD and the subjects who did not.  
328 Most importantly, the three children who had been nonadherent became  
329 adherent to their medications when they were treated successfully for  
330 PTSD, using a cognitive-behavioral therapy (CBT) approach with an imagi-  
331 nal exposure component. Nonadherence to medications seemed to be re-  
332 lated to the avoidance dimension of PTSD (patients avoid taking the  
333 medication because it is a traumatic reminder of the illness), as the avoid-  
334 ance dimension of PTSD accounted for much of the association with non-  
335 adherence [25].

336  
337  
338

### *Parents*

339 The impact of post-traumatic stress on the parents is at least as serious  
340 a problem, given the higher prevalence of post-traumatic stress symptoms  
341 in parents than in their ill children and the added impact of grief and loss  
342 if the child dies. A small study found potentially adverse physiologic corre-  
343 lates of chronic PTSD in mothers of childhood cancer patients, even when  
344 the child survived. Participants included 21 mothers of pediatric cancer sur-  
345 vivors with ( $n = 14$ ) and without ( $n = 7$ ) PTSD and control mothers of  
346 healthy children ( $n = 8$ ). The PTSD group showed higher total urinary cor-  
347 tisol and a trend for higher total urinary norepinephrine than the non-PTSD  
348 group, who were no different from controls. This finding is consistent with  
349 findings in other populations of PTSD patients and suggests these mothers  
350 have a chronic stress response [26]. These findings are of even greater con-  
351 cern with the speculation that the parent’s PTSD symptoms may affect  
352 the child’s perception of threat and influence his or her risk for PTSD  
353 and other psychological symptoms. Parental functioning is unquestionably

354 important for medically ill children, who might be dependent on their par-  
355 ents to administer medical treatments, make and transport to medical ap-  
356 pointments, and perform related essential practical and psychological  
357 support functions.  
358

359  
360  
361

## Interventions

362 In the palliative care setting, some of the known contributors to psycholo-  
363 gical trauma and PTSD already have been reduced or eliminated, includ-  
364 ing painful medical interventions and the side effects of curative  
365 chemotherapy. Life threat is, by definition, always present. As noted else-  
366 where in this issue, adequate pain management, psychopharmacotherapy,  
367 CBT, and psychodynamic psychotherapy, with varying and emerging evi-  
368 dence bases, are cornerstones in the treatment of children with life-limiting  
369 illness. PTSD and acute stress disorder can be conceptualized as major  
370 symptom clusters with which children with life-limiting illness may present.  
371 Although controlled clinical intervention trials of PTSD treatment options  
372 in the unique setting of life-limiting pediatric illness have not been per-  
373 formed, other pediatric (and adult) research offers guidance until more de-  
374 finitive studies are conducted. The only rigorously investigated approach for  
375 the treatment of PTSD in children to date [27] used a manual to deliver an  
376 imaginal exposure-based CBT treatment in nonmedical PTSD. This was  
377 a randomized, multicenter, controlled trial of 229 children, age 8 to 14 years,  
378 all of whom had a history of sexual abuse. The trauma-focused CBT was  
379 superior to a form of “child-centered therapy” on all outcome measures, in-  
380 cluding depression, PTSD, and behavior. No other forms of treatment have  
381 been evaluated in large randomized trials. In adults, the best studied ap-  
382 proaches include trauma-focused CBT (see later) and selective serotonin re-  
383 uptake inhibitors (SSRIs). Paroxetine and sertraline are approved by the US  
384 Food and Drug Administration (FDA) for the treatment of PTSD in adults.  
385 A cautionary note is that for children, the use of SSRIs, as described in the  
386 FDA’s “black box” warning, may be associated with an increase in suicidal  
387 ideation. An open trial [28] suggested the safety and efficacy of the SSRI flu-  
388 voxamine when given to children with cancer; fluvoxamine is the only SSRI  
389 studied in depressed children with cancer. At present, trauma-specific CBT  
390 techniques and, in selected cases, SSRIs are the best justified interventions  
391 for medically ill children who experience significant distress or impairment  
392 related to PTSD based on a growing, if incomplete, evidence base and  
393 with appropriate FDA-mandated precautions.

394 A different set of interventions may hold promise for PTSD prevention in  
395 medically ill children by addressing presymptomatic risk factors. Intervен-  
396 tions can be made to decrease the fear and helplessness associated with ill-  
397 ness and treatment. Although there has been limited formal study of family  
398 interventions in such settings [29], principles of humane family-centered care

399 mandate psychosocial child and family support in pediatric palliative care,  
400 as exemplified by novel multidisciplinary team approaches such as the Help-  
401 ing Hands Service at the Cleveland Clinic Children's Hospital.

[Q3]

402 The following guidelines are offered to help clinicians develop a sensible  
403 approach to intervention for children in palliative care and their parents as  
404 a broader base of empirical evidence is awaited:

- 405 1. Given that perceptions of life threat and treatment intensity are a major  
406 contributor to symptoms, and that these perceptions vary greatly among  
407 child, parent, and physician, open and careful communication among  
408 the child, parents, and medical team about the child's medical condition  
409 is essential. This is not primarily to ensure the child has "the truth" so  
410 much as for the parents and medical care team to understand the child's  
411 perspective. It is often difficult for the medical team to comprehend that  
412 treatments that are aimed at palliation of symptoms (eg, placement of  
413 an intravenous catheter for administration of opiate analgesics) could  
414 be perceived as traumatic by the pediatric patient and his or her family,  
415 as reminders of past traumatic events.
- 416 2. When it is clear which specific reminders or treatments are distressing to  
417 a given child, interventions can be designed to help minimize this dis-  
418 tress. Such an intervention may be improved pain control, but more of-  
419 ten it is a matter of decreasing a sense of helplessness. Interventions  
420 often can be set up that restore more control and choice for the child  
421 or parents even with seriously or terminally ill children. Not every med-  
422 ical intervention can be eliminated or postponed, but some can, and  
423 such small changes as moments of privacy for child and family unen-  
424 cumbered by medical intervention can make a great difference.
- 425 3. Pretreatment with medications that decrease pain without causing con-  
426 fusion or perceived loss of control may be helpful in decreasing trauma  
427 symptoms. Pain and anxiety seem to amplify the imprinting of traumatic  
428 reminders and the conditioning of specific reactions. Increasing the mor-  
429 phine given to a burn-injured child while in the hospital diminishes the  
430 risk of PTSD 6 months after discharge [5]. As discussed elsewhere in this  
431 issue, desensitizing interventions, based on established behavioral prin-  
432 ciples, also can be useful.
- 433 4. Identification of traumatic reminders can help minimize avoidance by  
434 directly addressing the symptoms associated with re-experiencing. The  
435 child, family, and medical team can be helped by the psychiatric consul-  
436 tant to recognize traumatic reminders and develop ways of dealing with  
437 and minimizing these.

439 The staff can be trained to recognize and help with symptoms of PTSD.  
440 A toolkit has been created by the National Child Traumatic Stress Network  
441 (NCTSN), with support from the Substance Abuse and Mental Health Ser-  
442 vices Administration of the National Institute of Mental Health. These ma-  
443 terials were designed to be useful for hospital-based health care providers,

444 including physicians, nurses, and emergency care providers, and for parents.  
445 The toolkit includes the following:

- 446 1. An introduction to traumatic stress as it relates to children facing illness,  
447 injury, and other medical events.
- 448 2. Practical tips and tools for health care providers.
- 449 3. Handouts that can be given to parents with evidence-based tips for help-  
450 ing their child cope.  
451

452 These materials can be downloaded free of charge from the NCTSN web-  
453 site, [www.nctsn.org](http://www.nctsn.org).

### 454 455 **Summary**

456 Symptoms of PTSD have been reported in response to a variety of life-  
457 threatening medical illnesses and injuries in adults and children. Emerging  
458 data suggest that children often experience medical treatment and hospital-  
459 ization as traumatic, putting caregivers and medical personnel in the role of  
460 the unintended accomplice. Adequate pain control by pharmacologic and  
461 behavioral means; child and family psychological support using evidence-  
462 based CBT, dynamic psychotherapy, and other techniques; and meticulous  
463 attention to communication via a team-based approach are the cornerstones  
464 of pediatric palliative care in general and PTSD prevention and treatment in  
465 particular. Emerging evidence suggests that PTSD in life-limiting pediatric  
466 illness can be ameliorated, if not prevented, and treated when it occurs, con-  
467 tributing materially to the quality of life of a child and family. A landmark  
468 finding of PTSD research with medically ill children and their families is that  
469 parents are at least as symptomatic, or more so, as their children, underlin-  
470 ing the importance of a family-directed approach addressing every family  
471 member. Pediatric caregivers increasingly recognize their therapeutic role  
472 when curative therapy is no longer possible is as pivotal as in the setting  
473 of acute illness.  
474  
475

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