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For Parents of Ill Children, a Growing Recognition of PTSD

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Post-traumatic stress diagnoses have long focused on combat soldiers. Now, doctors are increasingly aware of those symptoms in another group: parents of children with life-threatening medical conditions.

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By Amy Dockser Marcus

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Shelly Miller still has flashbacks to a summer day more than five years ago when her son Dylan, who can't walk or talk due to a rare genetic disorder, suddenly began vomiting and seizing.

Post-traumatic stress disorder in combat soldiers is receiving greater attention and wider societal recognition. Now doctors and researchers are trying to do the same for a group that has similar symptoms: parents of children with life-threatening medical conditions.

Shelly Miller of Bridgetown, Ohio, has a teenage son named Dylan who can't walk or talk due to a rare genetic disorder. One day more than five years ago, after her husband picked him up at a summer camp, Dylan suddenly began vomiting and seizing. They raced to the emergency room, where doctors told them Dylan had suffered a concussion; the parents didn't know how it had happened.

Although years have passed, Ms. Miller says she still has flashbacks to that summer afternoon. She replays the memory of her husband running in from the car with their child in his arms, shouting, "something is not right!" She avoids going past the camp.

It is only in recent months that Ms. Miller, after reading online about the high incidence of post-traumatic stress symptoms among parents of medically fragile children, suddenly had a name for her experiences. "I recognized myself," she says. "It felt like an awakening."

Ms. Miller recognized her own symptoms while reading online about the high incidence of post-traumatic stress among parents of medically fragile children.

Medically traumatic stress is a growing area of research in the field of post-traumatic stress disorder, or PTSD. For parents, a child's single medical event or an ongoing medical condition—such as cancer, severe injuries, Type 1 diabetes, epilepsy, or other neurological disorders—can cause post-traumatic stress. Symptoms may include reliving the experience, avoiding reminders of the event or condition, feeling numb or detached from others, anxiety, difficulty concentrating and being constantly on the lookout for danger.

Studies have found in cases of children with life-threatening illness and conditions, "rates of PTSD are at least as high among parents as kids," says Nancy Kassam-Adams, director of the

Center for Pediatric Traumatic Stress at The Children's Hospital of Philadelphia. Even so, when it comes to identifying and treating PTSD, "parents are often an afterthought," she says.

Where to Get Help

Here are some resources for people seeking information about PTSD and its symptoms in parents.

- * www.nctsn.org: The National Child Traumatic Stress Network focuses on different types of child trauma and offers resources for many groups, including parents
- * www.healthcaretoolbox.org: A site developed by the Center for Pediatric Traumatic Stress with information about trauma related to pediatric illness and injury and includes some resources for parents
- * www.aftertheinjury.org: A site sponsored by the Center for Injury Research and Prevention at [Children's Hospital of Philadelphia](http://www.childrenshospital.org) that offers resources for children and adolescents with injuries and also their caregivers, including videos and other tools
- * www.copingspace.org: Started by parents of a child who died of cancer, the site offers resources and support for parents and families, including information about PTSD

Historically, psychiatrists didn't consider medical diseases traumatic events. In 2000, the profession's official handbook of diagnoses—the [American Psychiatric Association's](http://www.psychiatry.org) Diagnostic and Statistical Manual of Mental Disorders—explicitly added "life-threatening illness" as something that might trigger PTSD in patients and their loved ones. But discussion and diagnoses still focused mainly on survivors of violence and other better-understood traumas.

More recently, there is a growing awareness of the condition in parents of ill children, with increased attention from doctors and support groups. That's partly a result of people being more willing to share traumatic experiences. Greater realization about the need to address PTSD in soldiers has also led to recognition of the experience of trauma in other areas.

In a paper published in 2009 in the journal *Health Psychology*, a group of researchers analyzed 16 studies reporting on the prevalence of PTSD in parents of children with chronic illness. In the pooled data, 22.8% of parents had PTSD.

Richard Shaw, professor of psychiatry and pediatrics at Stanford University School of Medicine, said he and his colleagues study PTSD in parents whose children were born prematurely and are in the neonatal intensive care unit at Lucile Packard Children's Hospital in Palo Alto, Calif. Their research found that 30% of the parents went on to receive a diagnosis of PTSD, and another 30% to 40% experienced significant symptoms that impaired their functioning.

The team created an intervention combining techniques used successfully with combat veterans, such as muscle relaxation and developing a trauma narrative that participants read aloud and work through with a therapist, along with parent education and coping skills in the neonatal

intensive care unit. Parents who received the six-session intervention reported a reduction in trauma symptoms, anxiety and depression, he said.

This year, the hospital is going to run pilot studies of a similar intervention for parents experiencing post-traumatic stress symptoms whose children have illnesses including cancer.

Parents say such programs can help. Isabelle Delmas of Newark, Calif., said she suffered depression throughout the pregnancy of her second child, a son, who was born prematurely at 27 weeks. When the baby was born through caesarean section, she feared "I would not come out of the hospital with a baby." The baby remained in neonatal intensive care and then infant intensive care for three months at Lucile Packard, she said. A psychologist met her at the NICU and told her about a support group for parents with post-traumatic stress symptoms. She talked about the aspects of the birth that made it a traumatic event. The exercises and sharing, she said, "validated my feelings, and made sense."

Anne E. Kazak, director of the Center for Healthcare Delivery Science at Nemours Children's Health Systems in Wilmington, Del., says at children's hospitals where parents bring their very ill children for treatment, "we do a good job of making the experience as child-friendly as possible"—doctors wear neck ties with cartoon characters and there are colorful play areas. "Parents are not fooled by any of this. They feel the helplessness, perhaps even more so than the kids because they feel it is their job to protect their children," said Dr. Kazak, whose research has focused on PTSD in children with cancer and their families. "Parents understand that they are fighting for their child's life, they are seeing children on the unit dying, and seeing kids in pain and that's trauma."

Cindy and Gavin Kerr, whose son, Ryan, died from cancer at age 17 in 2008, say that more than 10 years after his death, post-traumatic stress reverberates in their lives. "You go through life with this naive belief that nothing bad is going to happen to your child," said Mr. Kerr. "Once it happens to you, you can never put it back in the bottle."

The couple describes themselves as "high-functioning and resilient." Nonetheless, if Mr. Kerr is late from work, "I am sure something happened," says Ms. Kerr. "If there is a phone call at a weird hour, I get intense anxiety," adds Mr. Kerr. Last year, they created a website, CopingSpace.org, with resources for parents and families coping with PTSD and symptoms of medical traumatic stress.

Hillary Savoie's 8-year-old daughter, Esmé, is medically fragile, developmentally delayed and has seizures. Ms. Savoie says she still has flashbacks of one episode, walking into the emergency room with Esmé blue in her arms a few months after the child's birth. "I can smell the air in the room," she said. "It is very vivid."

More than five years after Dylan's concussion, "my son is happy," says Ms. Miller, pictured with her husband. Now, she added, it's time "to think about what this did to me and my husband."

Esmé remains at risk for medical emergencies like falling and choking that require Ms. Savoie to act quickly. One challenge, she says, is constant hypervigilance keeps the child she loves safe but

can harm Ms. Savoie's own mental health and relationship with friends and family. "If your child's health status is unchanged for the duration of their life or your own, how do you reorient yourself to regular life while remaining in anticipation of the repeat of a traumatic event? The thing that is harming you is also helping you protect your child," she said.

Ms. Savoie, who chronicled her own experiences and those of other mothers with symptoms of PTSD for the [online site Romper](#), said she reached out to Katherine Junger, a clinical psychologist at Cincinnati Children's Hospital, to speak to parents attending a meeting of the foundation she set up. Dr. Junger said she has made changes in her own practice recently, specifically assessing the parents' mental health rather than more broadly asking about the family's adjustment. She not only talks about the experience as stressful but also notes that seeing one's child have a seizure can be "experienced as traumatic," and she assesses them for trauma symptoms. While she does not diagnose parents with any mental health disorder, she says, the assessments let her refer parents on that might need targeted intervention and offer better support for those who are experiencing the events as traumatic.

In the case of Ms. Miller, she said her son, Dylan, was treated at the hospital for a concussion the day of the incident and sent home. Over five years later, she said, "My son is happy." Now, she added, it's time "to think about what this did to me and my husband."

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2015 Research

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4495936/>

2009 Meta analysis

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