



PEDIATRIC CANCER SURVIVORS MAKE POSITIVE LIFE CHANGES IN THE  
AFTERMATH OF CHILDHOOD TREATMENT AND TRAUMA



## **Pediatric Cancer Survivors Make Positive Life Changes in the Aftermath of Childhood Treatment and Trauma**

Middle school years are difficult for most teens, but add pediatric cancer to a 13-year-old girl's life and everything really gets turned upside down and inside out. Friendships, family time, schoolwork and self-esteem all suffer while this vulnerable adolescent struggles through chemotherapy and other treatments to save her life.

But for Clarissa Schilstra and many others who have survived childhood and adolescent cancer, the traumatic journey of cancer treatment has spawned hope and plans for a good future – and one that gives back to kids facing cancer today. Clarissa, now 21 and a senior at Duke University, has served as a mentor through [The National Children's Cancer Society's](#) (NCCS) pilot mentoring program to two teen girls battling cancer. She also is completing her degree to become a clinical psychologist specializing in helping teen and young adult cancer patients face the challenges of diagnosis and treatment with optimism.

“I wish I'd had someone like a mentor during my own treatment,” admits Clarissa, who was diagnosed at 2 ½ with leukemia and suffered a recurrence at 13, which she remembers being a challenging journey emotionally. “I've gotten really interested in helping young people with illnesses cope and I would love to work with young cancer patients for my career.”

Psychologists and others who study childhood trauma call Clarissa's optimistic outlook in the aftermath of cancer [Post Traumatic Growth](#), or PTG. PTG is defined as a positive change experienced as a result of the struggle with a major life crisis or a traumatic event. The idea that individuals can be changed by those encounters, sometimes in radically positive ways, isn't new. But the study of the phenomena is increasing among psychologists, social workers, counselors and scholars in other traditions of clinical practice and scientific investigation

PTG was first given a name by Lawrence Calhoun and Richard Tedeschi, psychology professors at the University of North Carolina Charlotte (UNCC). The university's [Post Traumatic Growth Research Group](#) is devoted to research and theory on the processes underlying Post Traumatic Growth. The website provides information, links to research articles and opportunities to participate in online studies.

Tedeschi and Calhoun identified five general areas where PTG occurs:

- A sense that new opportunities have emerged from the struggle, opening up possibilities that were not present before.
- Closer relationships with other individuals, and/or an increased sense of connection to others who suffer.

- An increased sense of one's own strength, i.e. *"If I lived through that, I can face anything"*.
- A greater appreciation for life in general.
- A deepening of their spiritual lives.

Calhoun and Tedeschi's [Post Traumatic Growth Inventory](#) breaks these five areas down further, noting characteristics such as, "I'm more likely to try to change things which need changing" under the New Possibilities category and, "A willingness to express emotions" under the Relationship category.

In his book "What Doesn't Kill Us," psychologist [Stephen Joseph](#) describes that after experiencing a distressing or life threatening event, people often report three ways in which their psychological functioning increases:

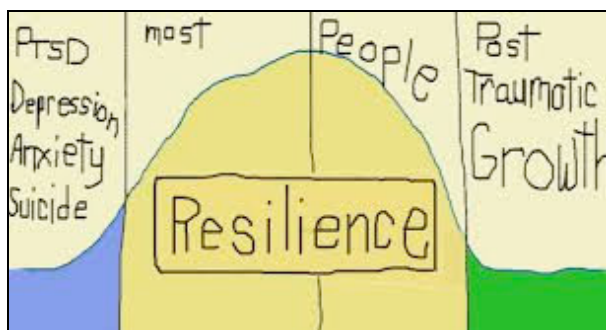
- Relationships are enhanced in some way. For example, people describe that they come to value their friends and family more, feel an increased sense of compassion for others and a longing for more intimate relationships.
- People change their views of themselves in some way. For example, developing in wisdom, personal strength and gratitude, perhaps coupled with a greater acceptance of their vulnerabilities and limitations.
- People describe changes in their life philosophy. For example, finding a fresh appreciation for each new day and re-evaluating their understanding of what really matters in life, becoming less materialistic and more able to live in the present.

Like Clarissa, Jennifer Toth is a pediatric cancer survivor who turned her childhood trauma into a positive focus for her adult life. Diagnosed at 2½ with a rare liver cancer, she and her family subsequently made it a collective goal to give back to kids who followed in Jennifer's footsteps. While she was in middle and high school, they would serve each year at a summer camp for kids with cancer. Jennifer volunteered throughout college with the [NCCS](#). Now, she is a newly graduated nurse specializing in pediatric oncology and planning to work on the same hospital unit where she was treated.

"It's been wonderful," she said of her many opportunities for post-cancer community service. "I've always been really interested in giving back to all the organizations that supported my family and help a lot of other families."

Psychologists studying PTG don't discount that some children who have experienced cancer can suffer from Post Traumatic Stress Disorder (PTSD), with similar emotional struggles as those faced by war and other trauma survivors. In those children, symptoms of PTSD can include nightmares about the cancer, scary thoughts and feelings, emotional numbness, hyperactivity, trouble sleeping and/or concentrating, and ultimately drug or alcohol abuse.

However, a recent [study by St. Jude Children's Research Hospital](#) found that pediatric cancer survivors do not struggle with PTSD any more frequently than children who have *not* experienced cancer. Even more significant, the study found that young cancer patients were also more likely than children who experienced other stressful events to report having benefitted from the experience. The benefits included developing a greater empathy and growing closer to family and friends.



Source: ChildhoodTraumaRecovery.Com

“These results should be very reassuring to childhood cancer patients and their families,” stated the study’s principal author, Sean Phipps, PhD. “This study highlights the impressive capacity of children to adjust to changes in their lives and in most cases do just fine or even thrive emotionally as a result.”

The [NCCS](#) has witnessed PTG firsthand in its Beyond the Cure Ambassador Scholarship recipients, teen and young adult survivors who are tackling college and finding multiple ways to help children now facing cancer. Some do it through support organizations like the NCCS or their treating hospital, and others – like Clarissa and Jennifer – used their childhood experience to shape their careers.

“Many survivors adapt positively to the cancer experience, becoming more resilient to adversity, motivated by hope, and driven to pursue an education and make a difference in the lives of others,” said Julie Komanetsky, vice president of patient and family services for the NCCS.

“For many, cancer has strengthened their character, intensified their love of life, and instilled a sense of duty to truly make a difference in the lives of others.”

### 5 Results of Post Traumatic Growth:

- #1. “A New **Appreciation for Life**”
- #2. “A Changed Sense of **Priorities**”
- #3. “Warmer and More **Intimate Relationships**”
- #4. “A Greater Sense of Personal **Strength**”
- #5. “Recognition of **New Possibilities**”

Source: Laura Jack

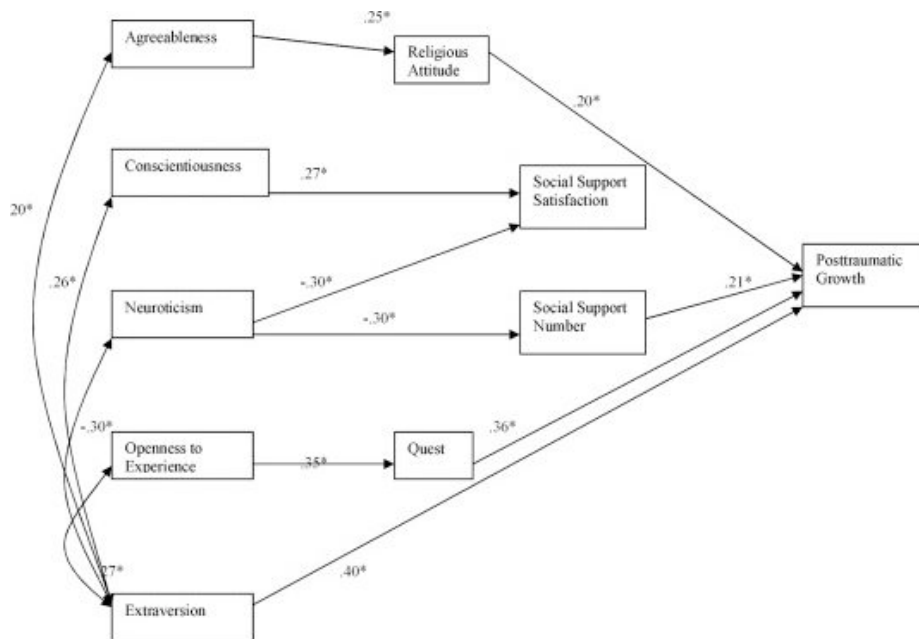
Childhood cancer survivors have served in multiple volunteer roles for the NCCS, not only as mentors but also as public speakers and even contributors to the organization’s publications. Schoolteacher Heather Barger drew illustrations for a children’s activity book for kids in the hospital, and is on the NCCS team that reviews college scholarship applications from childhood cancer survivors. Third-year medical student Hiram Judd serves as an NCCS Ambassador, working to spread cancer awareness, mentoring and networking with cancer patients and their families, and befriending pediatric cancer patients in his area.

The NCCS also has witnessed Post Traumatic Growth in younger children, like 12-year-old Sam Fleming. Sam was diagnosed with neuroblastoma at age four and still gets periodic treatment, but is in school and active in sports. His experience having an NCCS mentor spurred him to start planning for college and thinking about ways he can give back to younger children with cancer. “It’s amazing to see how he’s setting goals for his future and talking about becoming an NCCS mentor when he’s older,” said his mom, Linda Fleming. “Even now he takes the opportunity to engage with younger children when he goes to the clinic for his quarterly treatments.”

Post Traumatic Growth theory does not suggest that there is an absence of suffering among survivors. Many struggle with late effects, which are health and developmental issues that occur months or even years after remission as a result of their treatment. These can include everything from cognitive problems and infertility caused by chemotherapy drugs, to physical disabilities stemming from surgeries.

What PTG does suggest, according to Calhoun and Tedeschi, is that appreciable growth occurs within the context of pain and loss and may even build resilience, essentially preparing survivors for future events that may otherwise be traumatic.

Personality also contributes to how a childhood cancer survivor will approach life later on. Traits such as extraversion, optimism, positive affect and openness to experience have been positively associated with PTG, while personality traits such as neuroticism have been negatively associated with PTG, according to [multiple studies](#). Tedeschi & Calhoun also asserted that other demographic variables, including gender and socioeconomic status might play a role in how an individual manages the interruption of one’s life goals or plans through a personal crisis or a trauma.



Source: Massey University of New Zealand

John Chibnall, a professor of neurology and psychology at the St. Louis University School of Medicine, recently shared findings about PTG at the NCCS's annual survivorship conference. He noted a number of factors that promote Post Traumatic Growth:

- Greater parent participation in medical decision-making
- Higher levels of parent resilience in response to stress
- Greater processing and awareness by the child of the cancer experience and its role in her/his life: in other words, they are not in denial about their situation.

Chibnall also stressed that PTG is not related to the child's age, gender or race; intensity of cancer treatment; family income; or number of siblings or parents in the home.

Pam Gabris, director of NCCS's Beyond the Cure survivorship program, said parent and survivors' comments during and after the event were very positive.

"What Dr. Chibnall shared about Post Traumatic Growth was very upbeat and encouraging to families who worry about the impact of cancer treatment on their child," Gabris said. "One mom wrote on the follow-up survey that because of the information we shared, she now has hope for her daughter's future."

#### **About the NCCS**

The mission of The National Children's Cancer Society is to provide emotional, financial and educational support to children with cancer, their families and survivors. To learn more about the NCCS and its support services, visit [thenccs.org](http://thenccs.org). The National Children's Cancer Society is a 501C(3) organization that has provided more than \$61 million in direct financial assistance to more than 36,000 children with cancer. To contact the NCCS, call (314) 241-1600. You can also visit the NCCS on Facebook at <https://www.facebook.com/thenccs>.