

Study helps parents build resilience to navigate child's cancer

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Tatum Fettig remembers when her family's lives changed forever. In 2016, her daughter Teagan began vomiting and struggling with balance. At Seattle Children's, Teagan, then 2, was diagnosed with a pediatric

brain tumor, medulloblastoma. Through the grueling process of chemotherapy treatment and radiation, Fettig and her husband were by Teagan's side, trying to cope with the uncertainty of whether they would see their youngest child grow up. They mourned the loss of their former life.

"Having a child with cancer is traumatizing," Fettig said. "It doesn't mean you're broken, but it affects the whole family. People tell parents to take care of themselves, but when your kid is sick, you can't think of anything else."

Fettig's experience is not uncommon. Research shows that parents of children with cancer experience [psychological stress](#) during the child's treatment. After treatment is complete, parents report higher anxiety, depression and posttraumatic stress than the average population. However, formal mental, emotional and social support for parents is not typical after a child's cancer diagnosis.

In a study published in *JAMA Network Open*, Seattle Children's researchers addressed this need, adapting an intervention previously used for teens and young adults with cancer. They found that one-on-one sessions teaching skills through a tool called [Promoting Resilience in Stress Management for Parents](#) (PRISM-P) improved resilience and benefit finding, or personal growth, among parents of children with cancer.

"This tells me we are doing what is perhaps most important for parents: helping them to know they can come back again tomorrow and that they can find some good in the bad. These two things will help both them and their families," said [Dr. Abby Rosenberg](#), a researcher at Seattle Children's Research Institute and lead author of the study. "We know that parent well-being transfers to kid well-being and vice versa, so it is important to help parents to help their kids. In fact, that is what we heard

a lot in the PRISM-P trial: 'This helps me take better care of my kid.'"

The need for more support

Parents of children undergoing cancer treatment face unique demands and challenges that significantly impact their lives. This can include changes in employment status, possibly leading to new financial stressors, or changes to the family dynamic and structure if treatment is sought out far from home.

Parents must also learn various caregiving roles, which can be overwhelming.

"Being a parent of a child with cancer is necessarily hard," Rosenberg said. "Caregivers might experience sadness, anger, angst, terror, and stress, as well as profound love, patience, and sacrifice."

Each family in Seattle Children's Cancer Care Unit has an assigned social worker who assists with diverse needs ranging from concrete, including assistance with insurance and transportation, to psychosocial, such as counseling and friendly, compassionate support. However, Rosenberg says nearly every family says they would like more help.

"The child's needs come first and parent needs, especially when it comes to dedicated time to bolster coping skills, are often unmet," Rosenberg said.

Promoting resilience to help parents cope

PRISM-P—which can be taught by volunteers—aims to help caregivers cope with life changes and stresses.

"The program is easy to learn, with simple skills we learned from other families were necessary for coping at its foundation," Rosenberg said. "It also says: 'we see you.' In other words, it acknowledges that there is more to cancer than biology."

To help build resilience, the ability to use resources to sustain psychological or physical well-being in the face of stress, PRISM teaches four skills. These include stress management and relaxation, setting measurable goals with clear steps, cognitive restructuring (recognizing negative self-talk and reframing experiences) and meaning making (finding purpose and identifying gratitude despite adversity). Each skill has been associated with positive emotional outcomes and better coping, and people can pick the ones that work for them, Rosenberg said.

"While we identified the resources by listening to patients and families, we also know they have been used in human experiences as diverse as natural disaster, poverty, war, and illness," Rosenberg said. "What we are really doing is targeting the resources people either figure out or don't, and deliberately providing them so people don't have to learn on their own."

The study included 94 parents whose children recently received a cancer diagnosis at Seattle

Children's from December 2016 through December 2018. The randomized clinical trial explored whether PRISM-P delivered in either four one-on-one sessions or one-day group sessions improved parent-reported resilience compared with usual care.

In between sessions, worksheets and the [PRISM digital app](#) provided parents opportunities to put what they learned into practice. For example, parents had access to deep breathing guidance and journals that helped set goals, stop negative self-talk and record moments of gratitude.

While one-on-one sessions were effective in building parent-reported resilience, the group setting sessions did not lead to any significant improvement. This was likely because they were difficult for parents to get to, with few [parents](#) participating in each group.

All study participants reported that the program was valuable.

Helping both parents and children

Fettig participated in the study's one-on-one PRISM-P sessions while her daughter received cancer treatment. Before becoming Teagan's caretaker, Fettig was a high school counselor. Despite knowing the importance of resilience skills, Fettig remembers feeling overwhelmed and unable to relax during Teagan's treatment, until she began using tools taught through PRISM.

"When you're under such acute stress and in fight-or-flight mode, all you can think about is your kid surviving," Fettig said. "PRISM is simple, useful and accessible. It helped me organize time for my mental health and reminded me of the resources I knew already existed but was not tapping into. I feel lucky that I got access to PRISM."

Fettig specifically used the stress management tool of mindfulness, which involves taking a breath, quieting the mind and identifying emotions and stressors without judgment. After participating in the PRISM sessions, Fettig began using meditation phone apps in the hospital room each day while Teagan was inpatient.

"It's a real challenge to calm yourself when your kid's undergoing chemotherapy," Fettig said. "I learned that if I could calm my body down, I could sometimes calm my mind down. Nothing could fix our problems at the time, but I realized that if mindfulness helped me be calmer just for a moment, I was grateful for that one moment that I got."

Fettig discovered that mindfulness helped her be more present with her daughter.

"PRISM helped me start thinking about being calm—whether that's through meditating or playing music in the hospital room," Fettig said.

"Making this connection that the more present I was, the more available I was to help Teagan motivated me—the idea that if I calmed down, she would enjoy the days she got more."

Expanding PRISM

After proton radiation treatment, Teagan suffered from a side effect that prevented her from walking, talking and sitting up, requiring several additional treatments. Today, Teagan is a happy, social 4-year-old who loves her older brother, horse therapy, dancing, singing and art projects. She is walking more and more in her walker, progressing in therapies and recently began her second year of preschool. Fettig said she continues to rely on the mindfulness skills she learned in PRISM.

"For us, post-treatment is a much bigger part of our journey. It's a full-time job to manage the side effects from cancer treatment and Teagan's different therapies," Fettig said. "You realize when you have a kid with [cancer](#) that you have very little control over anything. The one thing I can put my energy into is getting her the best care to make the best out of this situation that no parent wants to be in."

Rosenberg and her colleagues are working to expand PRISM beyond the Cancer Care Unit through a pilot program in various Seattle Children's clinics. They are hoping to find out whether the tool will help patients, families and staff.

"This next phase is so important because it will tell us how to get PRISM into as many hands as possible, and that is my goal," Rosenberg said.

More information: Abby R. Rosenberg et al, Effect of the Promoting Resilience in Stress Management Intervention for Parents of Children With Cancer (PRISM-P), *JAMA Network Open* (2019). [DOI: 10.1001/jamanetworkopen.2019.11578](https://doi.org/10.1001/jamanetworkopen.2019.11578)

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