

Family members of pediatric neurosurgery patients experience high rates of PTSD, says researcher

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When Wendy Beaudoin accepted a job as the nurse practitioner for pediatric neurosurgery and neuro oncology at the Stollery Children's Hospital, she had no idea how thoroughly her personal and professional

lives would intertwine.

That very same day, she learned she was pregnant with her first child, Olivia, who is now 21 years old. Olivia would be born 16 weeks prematurely, weighing just 900 grams, with a neurological condition known as complex hydrocephalus. She has undergone 76 brain and spine surgeries since birth.

While Olivia still experiences headaches and short-term memory loss almost daily, her condition is now stable and she is studying at the University of Alberta to become a teacher. Her mother, meanwhile, is working to turn the family's heart-wrenching medical roller-coaster ride into new knowledge and better services for other families.

Beaudoin is [recruiting eight- to 17-year-old siblings of Stollery patients to participate in a study of post-traumatic stress disorder](#) symptoms such as depression, anxiety and suicidal thoughts. The study builds on Beaudoin's [previous research on the prevalence of PTSD among parents of pediatric neurosurgery patients](#).

In a survey of 168 parents, Beaudoin found 44.6% showed enough symptoms to lead to a clinical diagnosis of PTSD, including disturbing memories, a loss of interest in activities, feeling distant from others and having difficulties with concentration and sleep. For comparison, Beaudoin notes that 24% of military combat members, 11% of first responders and 25% of open heart surgery patients experience PTSD.

Living in a heightened state of fear

It first occurred to Beaudoin that she might have PTSD about 10 years ago. She had just dropped off her son Jake, now 16, at goalie school when she was overcome.

"All of a sudden I couldn't breathe. I pulled over and just cried," she remembers. "It was the realization of, 'My God, this never ends because she'll always have hydrocephalus.'"

Beaudoin describes hydrocephalus as "like a plumbing problem in the brain." A brain bleed Olivia suffered as an infant ruined the drainage pathways that would normally regulate the levels of cerebrospinal fluid in her brain and prevent a buildup and pressure on the organ.

The treatment includes surgically inserting a thin plastic tube called a ventriculoperitoneal shunt in her brain that drains the fluid into the abdomen, where her body can absorb it. As Olivia grew, the shunt had to be replaced frequently with a bigger one, and sometimes it broke or got plugged. The replacement is called a "revision."

"She's had a ton of different operations, and lots of shunt revisions," says Beaudoin. "She's had her skull taken apart and reconstructed to give her brain more room. She's had the back of her brain removed. She's had some operations that took 20 hours and some operations that took 20 minutes."

Beaudoin says she worries every time Olivia sneezes or sleeps in. "With hydrocephalus, there's always a risk—every minute of every day—that the shunt will fail."

From speaking with other parents in the clinic where she works, Beaudoin realized that, like her, they were living with this constant, heightened vigilance and fear. Just knowing they aren't alone helps.

"It is really helpful for parents to know, 'No, you're not crazy. Sure, you're not dealing with this situation very well at this particular moment, but it's not because you're a bad parent or a weak mom or dad. It's because this is a really terrible situation,'" she says.

Getting mental health care for everybody

It was her middle child, Mackenzie, 20, who made Beaudoin realize that it isn't just parents that are affected by this stress, but also siblings. A neuroscience student at Agnes Scott College, Mackenzie read her mother's paper on parental PTSD and started to cry.

"Mom, I think I have this too," she said. Her mother was shocked, but then it clicked: Mackenzie and Jake have been there for every close call, every rush to the hospital, every surgery for Olivia.

"They're great students, they volunteer. I realized they try to be perfect because they've had such an unsettled circumstance and they don't want to add to any more upheaval in the family," Beaudoin says. "It's anxiety-producing for anybody to try to be perfect all the time."

The sibling study starts with contact with the parents to gather demographic information, then the kids fill out randomized, anonymized questionnaires. Preliminary results indicate heightened symptoms of depression, [suicidal ideation](#) and anxiety, but the study is not yet complete, Beaudoin cautions.

Beaudoin presented her family's experiences recently to a nurses' meeting, talking about the parent-focused research she did in 2020. Her current project on siblings involves nurse practitioners from all of the surgical units at the Stollery, including scoliosis, urology, general surgery and ear, nose and throat.

Next she'd like to do a larger randomized trial testing how a mental health intervention could alleviate PTSD before it starts.

She says she finds her own support from family, friends and the close-knit surgical team she works with. She started a closed Facebook support

group for parents of [pediatric neurosurgery](#) patients, and she helped to found the Neurosurgery Kids Fund, which runs an annual kids' camp and year-round family social events like bowling nights.

Beaudoin says the ultimate goal is to get more help for all pediatric surgery patients and their families, similar to what is available through Kids with Cancer Society, which offers support for mental health services and other programs from the time of diagnosis through the entire medical journey.

She believes that level of help would not only alleviate unnecessary pain and suffering, but also save the health care system resources by avoiding the costs of caring for people with entrenched PTSD symptoms.

"What everybody needs is to have access to mental health services right away, up front, and you need consistency," Beaudoin says.

Provided by University of Alberta

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