

When an 8-Year-Old's Brain Tumor Returned a Third Time, Proton Therapy Was Tried

After two surgeries, Fred Hutch Cancer Center doctors aimed to finish the tumor once and for all with radiation.

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In 2019, at age four, Hedley Elliot got extreme head- and earaches. For his parents, it was an emotional time, and they urgently sought a diagnosis and treatment for his pain. Fortunately, they live close to Stanford University in northern California, where they were sent immediately from an urgent care clinic. While doctors were able to control his pain, the diagnosis was serious: Hedley had craniopharyngioma, a rare type of noncancerous brain tumor. It's generally slow-growing and is in the middle of the head, near nerves from the eyes to the brain and the pituitary gland, which controls most of the body's hormones. Patients with these tumors can have vision loss and problems making the hormones their bodies need.

Surgeons at Stanford removed the entire tumor through a minimally invasive transsphenoidal procedure, where they access the tumor through the nose. Hedley did well with the procedure and recovered from surgery, had his 5th birthday and started kindergarten all in the same month. Every six months, he received MRIs to monitor any changes in the area. After a year, Hedley's tumor returned. He had another surgery followed by an 18-month respite.

Unfortunately, the tumor returned a third time. This time, his brain tumor team and radiation oncologist at Stanford decided radiation might be able to destroy any lingering tumor cells, and recommended proton therapy after discussing Hedley's case with [Ralph Ermoian, MD](#), a pediatric radiation oncologist at Fred Hutch Cancer Center - Proton Therapy.

"Hedley was a terrific candidate for proton radiation," Ermoian said. "Compared to conventional radiation, protons would be just as likely to cure him of the tumor. However, they would expose the healthy parts of Hedley's brain to less radiation, resulting in fewer or less-intense side effects in the years and decades to come."

"We looked up what exactly proton therapy was and what it would mean," said Hedley's mom Alayna Elliot. "I also went to various medical journals, articles and Facebook groups that were

very hopeful about the treatment. Since his initial diagnosis, when everything was so chaotic, we've gotten better at asking questions of his care team to understand the approach from all different angles."

Hedley's care team at Fred Hutch were able to schedule treatment during the summer of 2023, when Hedley didn't have school. His grandparents came over from Australia to watch his two younger sisters while Hedley and his parents traveled to Seattle for treatment.

"Most treatments were OK," said Alaynna. "Some days he was stuck in the mask for a bit longer, but the therapists had a cool playlist of Hedley's favorite music at the time — early 2000s rock, like Offspring, Blink 182 and Sum 41. Also, one radiation therapist, Trang, painted Hedley's mask to look like Deadpool. That was wonderful."

Afterward, Hedley would get his [Hope for Henry](#) bucks. Hope for Henry is a program the proton therapy facility uses to help kids feel in charge of their treatment. They receive pretend money for tasks they achieve, such as daily treatment. Hedley's advice for other kids treated at the facility is: "Save up until you have at least 20 Hope for Henry bucks so you can pick Legos or the other really cool toys."

"The staff made it special, their personal touches really helped," said Alaynna. "They didn't treat him like a sick kid. They were patient and answered any questions Hedley had. They also had great recommendations on what to do in Seattle. He usually came out of treatments smiling and goofing off."

"Sometimes patients have a hard time with treatment, but many, like Hedley, sail through," said Ermoian. "It was great but not surprising to see how well Hedley fared during proton therapy."

Hedley's family was able to develop a routine that created a predictability that helped everyone. His middle sister Willa was old enough to travel, and missing her brother, she came to visit. They made the trip about more than just Hedley's tumor. Before treatment, they played Go Fish together, and for the 15 minutes or so that Hedley received treatment, Willa colored. After Hedley's treatment, the family explored Seattle.

Hedley only experienced slight fatigue from treatment, which usually didn't impact the rest of his day.

To get his mind off treatment, Hedley and his family explored all there is to see in Seattle during the summer. His favorite place to visit was Seattle Center with the Space Needle, fountain and playground. They also went glamping, kayaking and spent the Fourth of July with friends on Lake Sammamish.

"I think being able to make his life as normal as possible — during treatment and after — is important," said Alaynna. "My advice to others is that having support from family and friends is such a big part of normalcy. I think the chance to have some sort of family life while we were in Seattle and including his sister was good."

Hedley finished proton therapy towards the end of that summer and was able to start fourth grade as usual in the fall. In fact, he felt so good that he played soccer, flag football, baseball and basketball that year. He had one “bump in the road,” a brief period of nausea, headaches and profound tiredness called “somnolence syndrome,” but otherwise is doing well and getting routine follow ups at Stanford.

Recently, he had his one-year MRI and everything looked clear. He’ll see an endocrinologist about his growth because his hormones have been impacted in ways that were expected, and he’ll see an ophthalmologist to make sure his vision remains good.

Hedley just turned 10 and is going into 5th grade. His mom says this year he has to pick one sport! He’ll probably choose flag football — and maybe talk Alaynna into tae kwon do, as well.

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<http://beta.docker.cancerhealth.com/article/8yearolds-brain-tumor-returned-third-time-proton-therapy-tried>