

Catherine's Proton Experience

A few days short of our daughter's fifth birthday, and awaiting a check-up appointment with our pediatrician, my husband and I convinced ourselves that no doctor was going to be able to explain Catherine's severe dawn headaches without performing an MRI scan of her brain. The headaches were her only symptoms, and over the months, we had cleared every possible cause we could think of (eyesight, diet, and environment). So with our pediatrician's approval we decided to attempt an MRI without anesthesia at our local radiology clinic.

I remember feeling embarrassed - we must have appeared like a pair of completely overwrought parents as we waited anxiously beside the radiographer. And Catherine behaved as she would for the next difficult months to come – like a trooper. She lay still enough for 15 minutes, the 15 minutes that would confirm that she had a brain tumor lodged up against her pituitary gland.

My husband called me with the devastating news as I drove Catherine to a café for a reward milkshake. I remember seeing the bitumen on the road ahead tear open and our car plunged head first down into the dark ravine. At least, that is the most vivid emotional memory I have of our experience – the deep shock of the news. Because up to that point, Catherine had appeared to be a bright and healthy four year-old.

Catherine's surgeon was the non-heroic type, for which we are eternally grateful. After manipulating the tumor during his operation, he observed temporary diabetes in Catherine's urine output, a sure sign that the tumor was entangled around her pituitary stalk. So he sliced the top of the tumor away like a boiled egg and drained it, leaving the cyst slightly deflated.

The subsequent biopsy revealed Catherine had a Craniopharyngioma, a benign tumor that develops near the pituitary gland. We were spared the threat of secondary cancer, but the tumor would certainly take Catherine's life if left untreated.

Although the surgeon had dramatically relieved the pressure inside Catherine's brain, he believed that the tumor would re-grow rapidly, and radiation would be our next best option to eradicate the tumor. Our endocrinologist concurred.

However, we were shocked to discover the bleak side-effects of radiation to the brain when we met with the local oncologist. So damaging were these effects that he advised us to wait until Catherine was older, to allow her brain to create more of the networks she would require later in life. Our hand seemed forced – should we go home and wait for the inevitable regrowth of the tumor, then engage in another surgical drainage and expose Catherine to the myriad of associated risks, hoping we could hold out until Catherine turned, say, seven? Or should we expose her to radiation immediately and be faced with a lowering of her IQ, possible hearing and vision loss, adverse bone development effects and hypothalamus damage (your appetite control centre).

We were vaguely aware that there were many options available around Australia regarding radiation machines. Perhaps there was a form that could limit the side effects.

Even before our oncology appointment, we had discovered (through Google of all things) that there are two main forms of radiotherapy – photon (X-ray) and proton. Photon radiotherapy treats a tumor with a consistent beam of radiation that passes through its target and back out the other side. The trouble is, it damages healthy brain tissue and structures on the way in, and on the way out. Proton radiotherapy works a little differently. The dose of the radiation can be designed to be at its weakest when entering the body, peak when it hits the target, then dramatically drop off again as it exits. Theoretically, this is an effective way of preserving the healthy areas of the brain. And studies have shown that on average, less than half the radiation dose to healthy tissue results as compared to photon treatment therapy.

Photons are widely available in Australia, protons are not. Protons are used to treat childhood brain tumors regularly overseas (there are at least 40 proton centers worldwide, from USA to Switzerland, South Korea to Japan). In the UK for example, the National Health System (equivalent to our own Medicare) routinely sends pediatric patients for proton treatment in the USA. We picked up the phone and started calling.

It seemed obvious to focus on larger hospitals which had broad experience with Craniopharyngiomas. Massachusetts General Hospital is the original teaching hospital of Harvard Medical School. We got a direct line through to their leading pediatric oncologist who generously gave us time to talk and explained the process of their weekly Pediatric Brain Tumor Board & Brain Conference. We were asked to collate all of Catherine's records, and mail them over as soon as possible. In return for a nominal fee, their team of specialists reviewed Catherine's case notes, and advised that if she were a patient at their hospital, with access to both photon and proton radiotherapy, they would highly recommend proton radiotherapy immediately to eradicate the tumor. Failing to do so would most certainly lead to a full recurrence of the tumor to its original size in the short term, and risk Catherine's life.

We left for Boston soon after. Catherine received six weeks of daily proton radiotherapy treatment (Monday to Friday) under anesthesia. We saw no serious side effects during the treatment apart from the day to day recovery from her anesthetic. And then we returned home, praying that over the next 12 months, Catherine's tumor would slowly shrink to a hint of scar tissue. It only took three months, and Catherine remains tumor free two years later.

But just as importantly, all her critical brain structures have remained intact. Her eyesight has returned to normal, her hearing shows no signs of damage, her hypothalamus is working normally. The tumor irreversibly damaged her pituitary gland before surgery, but that is nothing that supplementary hormones can't correct. And a beautiful moment came when we returned to Boston for a voluntary check-up last Christmas – her IQ had increased since her last test.

Catherine is a happy, well-adjusted little girl who is in great health. We are not naive to the fact that Craniopharyngiomas can re-occur in patients, but at this stage, she has the chance of living a full life.

We hope that her story inspires you to ask your oncologist whether proton might be appropriate for you.