

In 2005 I was losing my eyesight, I was very sick, and there were major changes in my appearance, morphing me into someone that I didn't recognize in the mirror. I didn't know it yet, but I had major endocrine issues.

I went to my family doctor and got an MRI, which showed I had a tumor. I was put on the waiting lists to see specialists, but they told me the wait was months long.

I went to the Mayo Clinic in Arizona, where I was able to get a diagnosis. The MRI I received at Mayo confirmed a tumor, and again they couldn't tell for sure what kind it was until surgery. The one that seems to be the most consistent in my medical files is a craniopharyngiomas, a tumor that forms in the Rathke cleft.

For the first time, they found that I also had Cushing's, which is a rare condition. This is why it was imperative for me to have both a neurosurgeon and an endocrinologist. My case was so complex – the tumor was not only compromising my optic chiasm but was also damaging my pituitary gland, and it was uncertain whether I had a pituitary tumor on the gland itself. I was not producing ACTH, which is fatal, and I had gone into adrenal crisis on 4 different occasions.

They also felt that I had an adrenal tumor, but because I had a window of 4 to 6 weeks to save my vision, and to try to reduce the brutally high cortisol levels in my body, we focused on the brain surgery, and I returned to Canada to have the adrenal issues treated here. That surgery was also needed, and it took me three years to get it done. It has just been one nightmare after another.

All experts who have reviewed my case, both before and after, made it very clear that I needed surgery within hours to days. I wish I could release my medical files, but unfortunately I am in litigation trying to recoup my financial loss from the government.

My husband was told in no uncertain terms that if I waited the time scheduled to see specialists back in Canada I would be dead. Mayo recommended surgery immediately, and when we asked the definition of immediately they said they would have me on the table by Monday (this was Friday). I came back to Canada with those reports and I was refused surgery and put back on the wait list. My family doctor applied to the government to cover my return to the U.S., and we were denied and told to wait. That is how I ended up getting treatment in the United States, which was never my intention.

Shona Holmes