

# The circus of life

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## MORE ONLINE

### Audio

Listen to Dr. Vyas read this story.

[NPub.org/a3o111](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6111111/)

She was the first patient in neuro-ophthalmology clinic that morning. She had called the week before reporting that she was having headaches again and seeing dark spots in her vision. She got the appointment on an urgent basis. I introduced myself as a resident and invited them to the small exam room. She introduced her husband to me and sat in the familiar examination chair.

I had read in her chart that she had been diagnosed with idiopathic intracranial hypertension (IIH) 2 years before. After treatment with acetazolamide, topiramate, and vigorous weight loss, her symptoms had resolved over the next year. She had cautiously come off the drugs under supervision of her neuro-ophthalmologist. She and her husband had been trying to get pregnant for over 4 years without success. She was in her late 30s and was undergoing hormonal treatment through a fertility clinic who knew about her IIH diagnosis.

“What brings you back?” I asked her.

She said, “My symptoms are back.”

I said, “Tell me more.”

She recounted the last few months of her life. After coming off the drugs 9 months before, she finally got pregnant 3 months later. The initial months of pregnancy were rough because of morning sickness, but she had toughed it out. She was gaining weight as expected for her pregnancy, though not desired due to her diagnosis. At the start of her third month, she started having the same headaches and transient loss of vision with position change. She paused for a second, looked at me, and said, “I knew it was coming back, but I was too excited about carrying a baby,” as if making a plea not to judge her decision to avoid seeing her neuro-ophthalmologist at that time.

Unfortunately, a few weeks later she had a spontaneous miscarriage. It was not her fault. It was no one’s fault.

As if the pain of losing a much desired child wasn’t enough, she was above her target BMI again, and she knew that her headaches were a sign that she could lose her vision. She was still young, had a great career ahead of her, and to lose her vision would change her life completely. No wonder she was worried and scared.

After listening to her story, I could not respond to her for about half a minute. She broke the silence, looked at me, and said, “I guess this is life.” Her husband’s nonverbal gesture revealed the pain they both were going through. She had tears in her eyes. I gave her a tissue and held her hand. I told her that I was extremely sorry for her loss and felt extremely sad to hear that her disease had come back.

Her exam showed what she knew it would when she had walked in the room. She had grade II–III papilledema, normal visual acuities, and enlarged blind spots on formal visual field testing.

“What now?” she asked.

I said, “It is a tough road ahead.” She would have to put the fertility plans on hold as hormone treatment could also increase weight gain irrespective of her becoming pregnant. In addition, the medications for treatment of IIH are not safe in the first trimester of pregnancy.

Her husband, understanding the complexity of the situation, asked how long before they could try to get pregnant again.

Gently, I explained the need for patience and the risk of her losing vision in both eyes. First, she had go back on the medications, get the disease under control, and lose weight. Then, if her symptoms resolved and her exam returned to normal, she could gradually come off of the medications. If she had no symptoms and her exam remained stable for a few months, they could try again. The process could take up to a year, if not more.

I returned to the exam room few minutes later with the staff neuro-ophthalmologist. He re-reviewed the history with her and her husband and discussed the prognosis of her condition if left untreated. He also empathized with her situation and her current state, the patient now in tears, sobbing, and laid out a plan to tackle the road ahead. He tried his best to console her, and her husband chimed in as well to comfort the patient. His efforts succeeded to some degree and they left the appointment a bit more hopeful, confident that she would get the right treatment in time. I thought to myself how difficult it is to comfort a patient in such situations.

She seemed to me like a trapeze artist, slowly swinging away from her destination, the pedestal board, hoping to come close enough to it at the next swing and attempt the leap.

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