

Vishma's story: a mystery solved

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Vishma was born in Toronto to parents who had immigrated from Trinidad and Tobago. Her childhood was filled with family, friends and fun. When she was 19 years old, she had a daughter and graduated from high school. She subsequently got her undergraduate degree and began her career in sales and advertising.

Things were going well until she was 27 years old. After a trip to Trinidad, she developed fatigue, fever and unexplained weight loss. For more than a month, she sought help in many hospital emergency departments. A week-long admission to investigate the fever of unknown origin did not yield a diagnosis. It was only when she was in kidney failure that a diagnosis of antineutrophil cytoplasmic autoantibody (ANCA)-associated vasculitis was made. Vishma was treated with plasmapheresis, high-dose pulse corticosteroids, rituximab, cyclophosphamide and azathioprine. Her clinical course was complicated by an intracerebral hemorrhage and methicillin-resistant *Staphylococcus aureus* discitis. During the year after diagnosis, she had many admissions to hospital, an admission to the intensive care unit and inpatient rehabilitation.

Eventually Vishma's disease went into remission. Presently, she has no symptoms or signs of vasculitis, has stable stage 2 chronic kidney disease and takes maintenance azathioprine and antihypertensive medications.

Patient's perspective

Like many people my age, I was building my career by working and studying. I was a strong person and strived to do things for the people I loved.

It was roughly 5 months from the start of my symptoms to the time of diagnosis. I had fever, cough and weakness and was unable to keep food down. I lost around 60 pounds and was afraid of my own reflection. I was in agony. I felt hopeless, weak and ashamed that I needed help to bathe and get to the toilet. Visits to walk-in clinics, emergency departments, churches, priests, astrologers and spiritual healers did not help. I felt like a burden to those around me. I was terrified that I would be swept under the rug and forgotten, and that my daughter would grow up and not remember me. I knew that if they didn't figure it out, I would die. I was afraid to die — maybe because I thought of myself as the strong one.

I went to one last hospital and that was where I met Dr. Etchells and his team. He told me that my kidneys were failing. I was sure he was mistaken, but he wasn't. Thankfully, the results of one of the tests from 2 weeks before became available and gave the

doctors some indication of how to treat me. I was transferred to another hospital to have plasmapheresis. I ended up having a stroke, which affected my vision, and then developed a spine infection and had to relearn to walk. I was discharged home with a walker and a physiotherapy routine. My mother stayed with me for a month to help me bathe safely; bathing was tricky because of the PICC line. I would get lightheaded and dizzy when I got out of the bath. I graduated to 2 walking poles after about 1 month and was able to walk independently about a month later. Dr. Reich has adjusted my medications to keep my vasculitis in remission.

This experience has humbled me, yet it's given me so much wisdom. Before I got sick, I was focused on my career ambitions and a fast-paced life. It was sobering to learn that life can be taken away. Now I am focused on my health and the present. Most of my 32-year-old peers don't see the world the way I do, so sometimes I feel a little alienated. I'm thankful that I survived, and I hope to be able to enjoy a long, full, happy and healthy life — one where I don't let the small stuff bother me because life can be so fragile. — Vishma Sookdeo

General internist's perspective

I printed my list of inpatients. One of my former teachers called it his "cast of characters."

There was a new cast member. Vishma.

Act I

Vishma had endured several visits to emergency departments and a long inpatient stay at another hospital, which had yielded no diagnosis. Her condition had worsened at home, so she brought herself to our hospital.

Vishma looked ... dreadful.

She was pale, sweaty and too weak to get out of bed. She was wearing the standard hospital gown, already wet and twisted in uncomfortable immodesty.

Vishma had an acute kidney injury with hematuria and proteinuria, suggesting a glomerulonephritis. She also had new neurologic signs that my resident wanted me to review. Vishma did her best to participate but she was exhausted. I like neurology. Vishma had ulnar, median and peroneal nerve lesions, suggesting a mononeuritis multiplex. I admit that I enjoyed being the centre of my resident's attention. I was the star of the show! I asked Vishma if she might join us for morning rounds so that others might learn from her condition. She was willing but simply too ill at the time. A few days later, she was transferred downtown for plasmapheresis.

Vishma was off my list. I heard she had a stroke and hoped she would recover.

Act II

About a year later, Vishma sent me a very kind email, offering to come to morning rounds. She had remembered my request and was interested in joining our morning teaching rounds to share her story.

I arrived at our meeting place before rounds. Vishma was not there. But she was.

Vishma was now a ... different person!

Now, she was upright! Now, she was dressed in civilian clothing! Now, she commanded the full attention of 30 medical students, residents and staff physicians! She told us that, before her diagnosis, when she was sent home from another hospital with no diagnosis and no treatment, she felt she had been sent home to die. She felt disregarded. No one to call. No one who cared. She made me reflect on my own feelings when I cannot establish a diagnosis. Maybe I feel frustration and perhaps even a sense of failure. She taught me that when I discharge a patient without a firm diagnosis, I must offer the same care and support as for a patient with an established diagnosis.

Vishma had had a difficult part and a shabby costume in Act I. Act II reminded me that Vishma was always the star of the show, always the centre of patient-centred care. I am so glad that she allowed me to be in her cast of characters. — Ed Etchells

Nephrologist's perspective

As someone who treats autoimmune kidney diseases such as vasculitis, I am accustomed to cautiously wielding the double-edged sword of life-saving immunosuppressing medications that carry with them the risk of toxicity. However, Vishma's illness terrified me.

I vividly remember accepting her in transfer to offer her the "best" therapies that were available at our hospital. Within 72 hours of her nighttime arrival, she had a stroke. We did not know if this was due to her disease or the treatments, but I shared the devastation of this event with Vishma.

This shocking occurrence was only the start of months of watching both the disease and our treatments wreak havoc on

Vishma's body. For many months she encountered one terrible complication after another: sequelae of the stroke, severe otitis requiring tympanostomy tubes, *S. aureus* discitis, all punctuated by the body-ravaging effects of prednisone. Vasculitis can affect almost all organs of the body — as can complications of treatment. My rational physician mind remained focused on the goal: saving her life and avoiding dialysis. Nonetheless, contributing to serious treatment-related complications brought inescapable feelings of guilt and fear, despite my years of clinical experience. The guilt of contributing to treatment complications weighs heavily on me, but I have to be mindful not to let this fear paralyze me and prevent necessary treatment decisions.

Vishma possessed an air of incredible steady stoicism. During those scary times, I found that inspiring but also a little unsettling. I was fully prepared for tears, anger and frustration, but Vishma faced each setback with a calm and level acceptance; this was yet another obstacle that just needed to be overcome. I believe that despite her external demeanour, she was fighting fiercely to live. She attacked rehabilitation with the determination of a warrior.

All these years later, I tell my fellows about Vishma as a lesson on the humility and vigilance required when treating vasculitis. We cause great harm to patients while doing our best to save them. Vishma has the dubious distinction of demonstrating nearly all of the potential complications of the disease and its treatment. Her experience highlights why the early mortality of vasculitis rivals that of many cancers. I want trainees to understand that treating these diseases requires tremendous respect for both the ruthlessness of autoimmune conditions and the potential toxicity of our treatments. I remind them to approach vasculitis with humility but also to muster Vishma's courage and help patients fight for the best possible outcome.

Vishma's battle was so difficult — it was inspiring and rewarding to see her emerge from the fight and enjoy health. The personal, emotional and physical struggles of patients with rare and life-threatening immune diseases are unappreciated. By generously sharing her experience, Vishma is helping to change that. — Heather Reich

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on advisory boards for Chinook, Travere, Novartis and Pfizer regarding immunoglobulin A nephropathy. Dr. Reich was national coordinating investigator for trials by Calliditas and Chinook; investigator for glomerulonephropathy clinical trials by Calliditas, Pfizer, Omeros, Chemocentryx and Alnylam; director, Glomerulonephritis Fellowship funded by the Louise Fast Foundation; and advisor for the Canadian Agency for Drugs and Technologies in Health. No other competing interests were declared.

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