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WHAT YOUR PATIENT IS THINKING

Let's find a way to work together

Myrian describes how an acquired brain injury has affected her, and the challenges she now faces when engaging in healthcare consultations

In 2015 I experienced varicella zoster virus meningoencephalitis and was left with an acquired brain injury. The fallout has affected every area of my life, and is impossible to predict. I was unprepared for the downward spiral that my brain and body would enter. I have had more than 30 MRI, PET, and CT scans, as well as x ray imaging, multiple biopsies, a lifesaving ileostomy, and more than 400 vials of blood taken.

Managing day-to-day living with a brain injury and all my other conditions affects me in ways that medical professionals are often unable to comprehend. Daily, my injured brain is trying to juggle too many balls. Ask too much of it and it drops a few. Things like bright light, noise, or asking me questions while putting an intravenous line into my arm can often reduce my cognitive functions. I manage to adapt and compensate with a respectful nod here and there, cracking a joke, or asking the odd question. But inside, my brain is empty, numb, and zombie-like. Comprehension and communication go into basic survival mode. This can last for days.

Masking the challenges

Trying to navigate a healthcare appointment or interaction is particularly challenging. I am unable to engage in discussions as fully as I would like. Unable to ask for clarification or the right questions in the moment as my brain tries to process the information, it can take days to cognitively process what has been happening and the meaning of what a medical professional has said. As a person who seeks out facts and enjoys research, I like to know what I am dealing with, which makes being unable to engage fully in consultations frustrating.

I know medical professionals are busy; however, I wish they could record our interactions in writing and share it with me immediately. This would allow me to process and review the discussion in the days following. I wish I had the option to reach out to my health professional if I need clarity on what was said, or query something soon after discharge or an appointment.

Beyond the notes

If a healthcare professional looks at my medical record, they may see some of my history. What they won't see are the effects on my body and on my life. The record doesn't show that I have been solely responsible for managing my own complex care, day to day, as well as my illness and symptoms, or how draining and emotionally exhausting all this can be.

Nor does it show how incredibly resilient and courageous I am.

Given my complex medical history, I wish healthcare professionals would ask me how I best communicate and try to know more about me to help them care more effectively. Beyond my medical condition, I am a person who loves losing herself in research, enjoys art and theatre, misses travelling and having the freedom of choice of goals and dreams that make me thrive, not just survive. My hope is that, in every interaction with a patient, healthcare professionals see that they are dealing with their human equal. I am someone who is actively trying to work with them to find out as much as I can to get better, manage better, and in some way become a whole human again.

What you need to know

- A person with brain injury may experience episodes of reduced cognitive function. Ask them how you can ensure you are not overwhelming them in appointments
- Writing and sharing notes from the consultation may help a patient to process and understand the discussions you have had
- Seeing the patient as a whole person, beyond just their health, will help you work together

Education in practice

- Think of a time when you met with a patient who had experienced brain injury. How did you feel the discussion went? What might you have done to improve their experience of the consultation?
- What might you ask a patient to try to understand them as a person, beyond their condition?

Read more about Myrian: www.agapyearforthesoul.com

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