

# I'm clawing my way back from a brain injury, so please be patient

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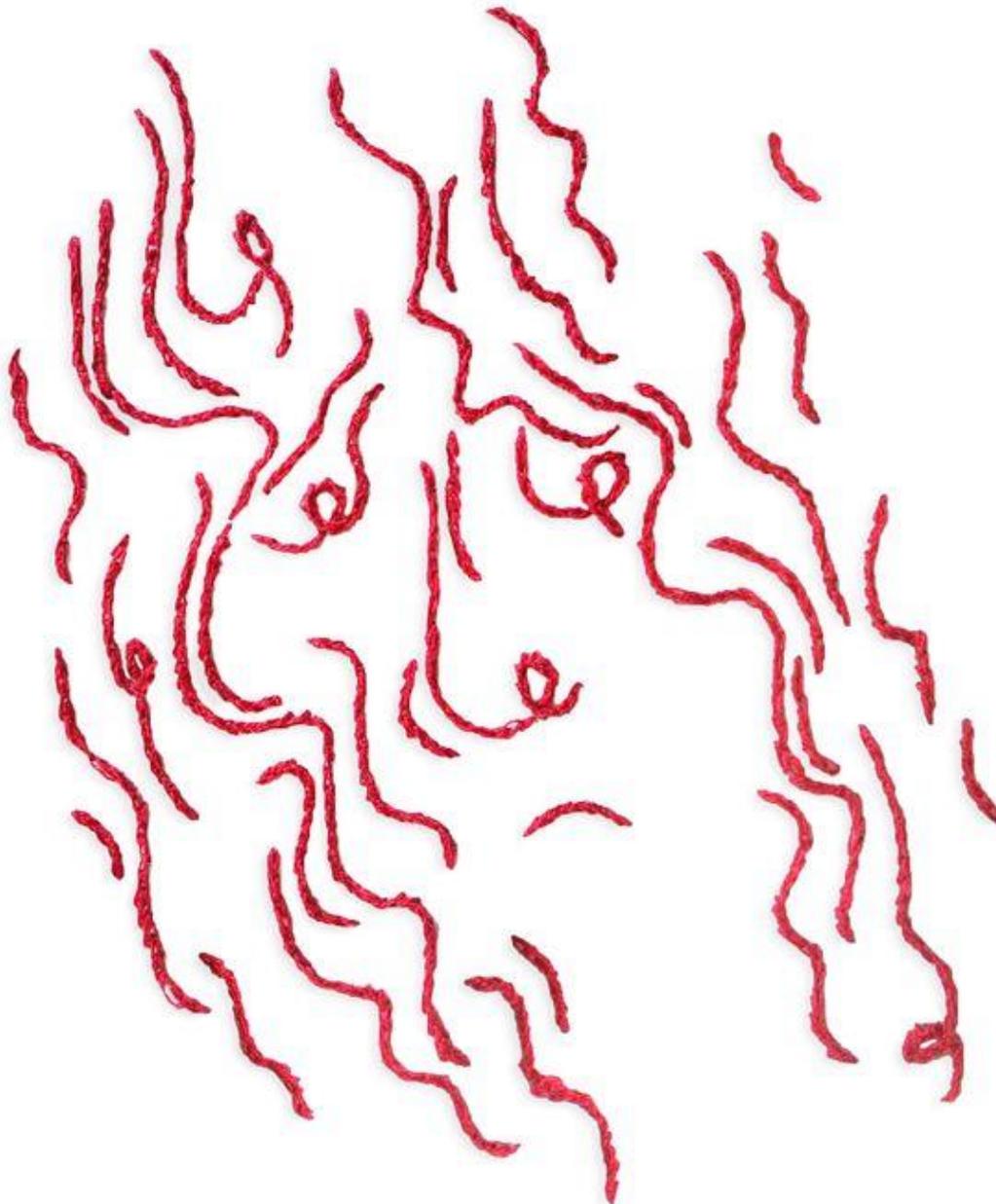


ILLUSTRATION BY ASHLEY WONG

First Person is a daily personal piece submitted by readers.

I was 35 years old when the inoperable arteriovenous malformation (AVM) in my brain was first diagnosed.

After years of headaches and cervical pain (which I later found out were small cerebral hemorrhages), and after years of being told by doctors that I suffered from stress headaches, migraines and poor coping skills, the undiagnosed vascular grenade in my head finally blew.

I lost the feeling and movement on the left side of my body, and the vision in my left eye doubled – I saw two of everything. I lost my balance and my co-ordination. It was a hard thing for a previously healthy young woman – a mother, nurse, wife and go-getter – to deal with.

Time, rehabilitation, physiotherapy, a lot of sweat and tears ... those losses all came back – maybe not as good as they had once been, but they came back.

That was 18 years ago. A lot has happened since then.

Over the years, as I experienced repeat bleeding, endured radiation and battled brain swelling, I lost and rebuilt many many things.

I lost my career (I was a military nursing officer), my husband to divorce, my confidence – and more than just a little bit of who I was.

Brain injury is a thief. A silent and invisible thief.

When the brain is first injured, little thought is given, in those first crisis stages, to feelings. There is just no time to worry about the emotional when the fight is on to save brain function.

However, in my all-too-informed opinion, the emotional fallout of brain injury can be just as important as the physical in the long run.

I don't presume to speak for everyone. More than any other organ, the brain remains a mystery; it's unique to each person. Some brain-injury survivors suffer no deficits at all, others simply never come back. And some, like me, get stuck somewhere between who we once were and who we are eventually going to be.

The first thing I want people to know is that I am still here. No, I am not the same. I have lost pieces of myself. I may never again be exactly who I was and who you knew, but I am still here.

I am still me.

I am, I have to admit, a little slower than I was. My processing speed is seriously messed up. I will no longer be the nurse who can juggle multiple patients or the mother who can hike and bike and keep up with her two busy sons. But I will always have that deep need to help others that all nurses have, and I will always love my sons and family as I always have.

Those parts of me remain. So, have patience with the slower me. And have patience with the tired me.

Of all the things that have proven unbeatable and intractable on this long journey is the fatigue. It is pathological and relentless and well ... embarrassing. If you catch me napping in the afternoon (and I now must do so almost every afternoon), please do not go out of your way to make me feel lazy or indulgent. My brain – energy suck that it is – is simply working overtime, rewiring and rerouting signals; doing whatever a brain must do when its normal pathways have been obliterated.

I also ask that you forgive the new unpredictable me.

I will have good days and I will have bad days. There are days when I won't answer the phone and days that an unexpected headache will send me into hiding. I will inevitably cancel plans. I will skip an appointment or bail on lunch or refuse an invitation.

Please, don't take it personally.

I now have a hair-trigger head. Sometimes, it seems that any little thing can set it off. The weather can be my enemy, a certain type of food, too much activity.

With all that my poor brain went through, I now have to deal with this thing called “flooding” – which I've since learned is a common brain injury outcome for those like me. My normal brain filters are all but fried and can no longer muffle or regulate incoming (or outgoing, unfortunately) information as it once did. Too much noise, too many lights, too many people, too much anything is all amplified in my head. Too much unregulated input can all too quickly turn into a roar, a buzz that will shut me down, make me stutter and become so overwhelming that I can't find words, I mess up and I lose things.

So please, don't rush me.

Sit down and join me in my quiet, now slower world. I am good in the quiet – deserted beaches are my happy place – and still quite social when there are only one or a few people to interact with.

I may not always be able to join you in your world, but I do hope that you will choose to join me in mine every once in a while. For, while it may not be as exciting or as busy as yours, this is where you will find me – a little broken, perhaps, and with a few pieces missing – but you will find me.

I'm still here.