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WHAT YOUR PATIENT IS THINKING

The treatment terrifies me more than the diagnosis

Brenda Denzler describes how earlier traumatic experiences of medical treatment continue to have an impact to this day

Brenda Denzler

I was only 5 years old when I had my first big encounter with the medical profession. I always had clear, though fragmented, memories of what happened, but none of how I felt about it. I remember being forcibly restrained for a lifesaving procedure and being isolated for six weeks in a hospital room.

As an adult, I had recurring nightmares and experienced hypervigilance in all medical settings. I never knew why. Then, when I was diagnosed with an aggressive form of cancer, all the medical demons from my past came roaring out of my unconscious, where they'd been doing their quiet work for decades. I found that I had lots of emotional memories from my earliest medical encounters. Cancer scared me a lot, but the idea that I was going to have to submit myself to strangers who would do hurtful things to me in the name of treating me was beyond terrifying. I considered rejecting conventional treatment and trying holistic methods instead.

Fighting the panic

I accepted conventional treatment, but only with great difficulty. A decade later and the cancer is gone, but I still struggle with my medical demons. I've made progress via talk therapy, but I doubt I will ever be able to totally overcome them. My stomach still knots up when I get a message in my patient portal. Sometimes the smallest medical interaction will trigger a full blown panic attack. Having to take on a new doctor fills me with intense dread. Coping with treatment trauma is exhausting.

People who have experienced treatment trauma may be some of your most difficult patients. But it is not because we want to be. It is because in a healthcare setting, we are transformed by fear. Neuroscience says this is because the neural pathways created by the original events have become hardwired in us. Being with health professionals awakens those fears, and we find ourselves reliving the trauma. I find it hard to trust you implicitly. I can get extremely weepy and emotional, or maybe a little too shrill or loud and come across as a bit threatening. Sometimes I can seem dissociated or blank. It's because I am fighting a quickly rising tide of panic that could totally overwhelm me. No matter how much I may need your help, I want to run away.

When you encounter someone like me, consider asking open-ended questions about their earlier experiences receiving medical treatment. The patient may not yet be aware of how deeply they've been affected by such things, but their behaviour and their

answers may help you understand how best to help them.

Help me feel involved

I am the co-moderator of a support group for people who, like me, have been traumatised by their medical treatments. The reasons for our trauma vary a lot, and include being forcibly restrained, being subject to medical mistakes, anaesthesia snafus, or being ignored or disbelieved. Sometimes it is just the fact that medical treatment can be traumatic. Medicine is often not a gentle discipline.

You can help by making me feel empowered and in control. First, be willing to take the time I need. Don't rush through the visit. Second, listen to me without preconceptions based on what may be in my chart; believe what I tell you about my medical situation, not just what someone else wrote about it. Third, include me as an active partner in diagnosis and treatment decisions. Feeling like I am the passive recipient of decision making scares me. Fourth, don't take it personally. Know that as my positive experiences with you accumulate, my treatment trauma will be less likely to be an active issue when we meet.

Finally, remember who I really am: a survivor of a very specific kind of trauma who's doing the best she can. When I'm not on your turf, I'm actually a very different person.

What you need to know

- Medical treatment can create lasting trauma in patients that may affect their future ability to seek out and receive healthcare
- People with treatment related trauma need informed, sensitive, and supportive care in all healthcare settings
- Help patients with treatment trauma feel involved and empowered during decision making

Education into practice

- How could you establish whether your patient has experienced any treatment trauma?
- What support could you offer a patient who has experienced treatment trauma?
- How and when could you explore your patient's concerns about treatments and any potential side effects?

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