

A Patient's Perspective of Post-Traumatic Stress Disorder (PTSD)

by Nancy Michaels

Post-Traumatic Stress Disorder (PTSD). We've all heard the term. It affects approximately 3.5 percent of U.S. adults, an estimated 1 in 11 people will be diagnosed with it in their lifetime, and women are twice as likely as men to have it. It is a disorder, according to the American Psychiatric Association, that can occur in people who have experienced or witnessed a traumatic event such as a natural disaster, serious accident, terrorist act, war/combat, rape or other violent personal assault. We may even personally know someone who suffers from it.

Sadly, PTSD is alive and well in our modern vernacular and seems almost "normalized" today.

As a former long-term ICU patient, I would also add *serious illness* to the list of PTSD triggers. Extended hospital stays with numerous invasive procedures can most certainly bring on the same types of intense, disturbing symptoms and thoughts that last long after the traumatic events have ended.

In my case, it happened in 2005 when I fell critically ill due to organ failure. Until my hospitalization, I had been extremely healthy. Suddenly, in what seemed like out of nowhere, I became severely ill within a matter of a few weeks. Acute liver failure was the diagnosis, and I was told that I needed an immediate liver transplant. After entering the ICU of a major Boston medical facility, I was put on a list for an organ donor. Within one week of my arrival, I received a non-compatible blood type organ from a 21-year-old donor who had been involved in a tragic car accident a few nights earlier and passed away the day before my transplant, which my surgeon almost elected to not do because he did not think I would survive. That young woman, along with a stellar medical team, literally saved my life.

Although the surgery was a success, it was wrought with complications. I coded twice during the procedure, the second time for more than two minutes due to a blood clot found in my organ. I underwent emergency

brain surgery for a fungal abscess that formed on my brain where a hole had been drilled in my skull prior to the transplant surgery to relieve cranial pressure prior to the transplant. ICU psychosis filled my mind with petrifying thoughts that my nurses were trying to kill me and were stealing my medication. The television was often left on news stations that broadcasted on a loop the horrors of Hurricane Katrina, leaving me to think I was actually in an ICU in New Orleans and could die -- as some critically ill patients tragically did in that city's hospitals at that time. Recently separated from a long-term marriage and concerned about my three small children at home, I was in a constant state of stress and fear.

After three months in ICU, I was transferred to a rehabilitation hospital for six weeks, where I had to learn to do everything again -- stand, brush my teeth, feed myself. After rehab, I was readmitted back to the first hospital with a "failure to thrive" diagnosis typically given to end-of-life patients. I spent another six weeks there before being discharged, only to return eleven more times for multiple days at a time each stay. I experienced two rejection episodes, was unable to keep food down due to an inner ear imbalance that lasted for months, and had high potassium and aspergillum in my lungs. The aspergillum alone could kill me, my surgeon would tell me.

Two months in a coma and the inability to speak for weeks even after I woke up due to a trachea that had been placed was by far the most frightening part of the ordeal. Not being able to communicate my fears to the nurses and doctors -- and therefore never having them addressed -- left me in what could only be described as a state of PTSD.

But my story is not a unique one. I have met many ICU patients through my participation in a local Patient Family Advisory Council (PFAC). I help train and work with patients and family members who do roleplay simulation exercises with ICU interns to help them to better understand the patient and family experience and be more effective communicators. I've had the opportunity to hear first-hand how an ICU stay has impacted people in unique and sometimes terrifying ways.

My personal experience and the experiences of others has led to my helping people understand just what PTSD in ICU patients can look like and how it can manifest itself. Some of the ways include:

- Reliving past unpleasant experiences in flashbacks or nightmares
- Feeling extreme sadness or depression – or fear and anger
- Delaying or avoiding situations or individuals that remind us of the traumatic events we experienced
- Detaching from people
- Overreacting to ordinary scenarios, noises or sounds that remind us of earlier trauma

In myself, I've noticed that my PTSD is most prevalent when needing to undergo certain procedures – both invasive and non-invasive. I typically need medication the night before *and* the morning of the procedure. I've also been treated at a teaching hospital and request for the attending physician or my physician perform procedures, not less experienced medical staff. For others, it might manifest itself in different ways.

In my work as a healthcare consultant, I encourage physicians, nurses, and technicians to show more communication and compassion than they are perhaps used to showing. I help them understand how important it is to not take someone else's feelings of PTSD personally; that it's actually *not* personal and is often something over which a patient has little to no control.

Whether a patient is or is not able to articulate their fears, it is likely to manifest in their behaviors, emotions, and reactions to situations. It's always a good idea to ask them:

- *“Is this conversation making you uncomfortable?”*
- *“Are you afraid of something related to this procedure?”*
- *“Is there something I can do to make you more relaxed or comfortable?”*

From firsthand experience, I can tell you that any and all attempts you make to allow your patients to feel safe with their feelings of post-traumatic stress disorder will be appreciated by them and their family members and can only add to their recovery experience in a positive way.

8/4/19: to be published in EC Emergency Medicine & Critical Care in the next few weeks