“You relearn how to sign your name, to understand your history, to remember those that you love and who have loved you. It all takes time.”
The journey begins the day that you awake in the ICU. As you struggle to breathe, to take assessment of your body, your sense of self and of time—it becomes apparent that your life is forever changed. You can choose to succumb or you can take on this new journey, where your every move will be tested each and every day. The new path requires identifying your limitations and adapting. Finding resources is key, including physicians who understand what happens after the body reboots during septic shock. It takes the balance of 22 prescription medications, a wound vac, home administered IV medications, and nothing can remedy the chronic feeling of weakness, disorientation, and overwhelming loss.

My septic shock experience arose from a post-operative infection. Upon my return to the ED, providers managed endless symptoms with focused responses: a transfusion for the anemia, oxygen for the shortness of breath, a CT scan for the disorientation, a return to the OR in a search for the infection. While they addressed the symptoms, they missed the big picture: that I was quickly going into septic shock and would ultimately lose consciousness and begin organ failure. Eight days later I awoke in ICU to encounter physicians who were astounded at my survival, and together we began to learn what really happened.

Sepsis does not end when the patient leaves the hospital.

Six years later, I am fully functioning—I am working, can enjoy my hobbies, have rediscovered my passion for life. But during the six years I struggled with extensive memory loss, chronic fatigue, waves of disorientation, reactions to medication, and PTSD. It has taken a strategic physician to wean me from prescriptions, a nurturing psychologist to heal the emotional impact, and my own fierce determination to get this far.

SEPSIS

The word sepsis comes from the Greek meaning “decay” or “to putrefy.” In medical terms, sepsis is defined as either “the presence of pathogenic organisms or their toxins in the blood and tissues” or “the poisoned condition resulting from the presence of pathogens or their toxins as in septicemia.” Patients are given a diagnosis of sepsis when they develop clinical signs of infections or systemic inflammation; sepsis is not diagnosed based on the location of the infection or by the name of the causative microbe. Signs and symptoms include abnormalities of:

- Body temperature
- Heart rate
- Respiratory rate
- White blood cell count

Forty percent of patients diagnosed with severe sepsis do not survive. Until a cure for sepsis is found, early detection is the surest hope for survival.

Source: Sepsis Alliance. “Definition of Sepsis.” sepsisalliance.org
You don’t forget the nightmares, the memory of struggling to breathe, the feeling of isolation, panic, and pain. You relearn how to sign your name, to understand your history, to remember those that you love and who have loved you. It all takes time.

Post-sepsis syndrome does not share the recognition of other catastrophic conditions. There are no ribbons, no fundraisers, no resources to address the psychological devastation, hair loss, memory loss, and financial strain of hundreds of thousands in medical bills.

Post-sepsis patients find themselves, and their families, struggling every day to understand what happened, why it happened, and most importantly, when things will get better. For a lot of patients, that last question can overtake them on their weakest of days, when the will to survive comes into jeopardy.

Sometimes the sense that nothing will return to normal, that an identity is lost, that they have failed somewhere in life and are now paying for it, is overwhelming. According to the CDC, there are 1.4 million sepsis survivors in the U.S.—all of whom trudge through the journey alone, looking for hope even as they stagger forward.

I am grateful that clarity has been provided in my own treatment, and I wish the same for fellow survivors.