



Dear Doctor:

Sepsis, your body's toxic response to infection, is a little known, but frighteningly common condition in the United States. This major healthcare issue involves over 1.7 million hospitalizations and each year claims over 270,000 lives in the U.S. alone<sup>1</sup>. Up to one-half of sepsis survivors who were admitted to the hospital are left with long-term and frequently life-altering effects. These are particularly common among patients who were treated in intensive care units (ICU), as well as with those who have spent a long period of time in the hospital.

Sepsis Alliance is a not-for-profit organization dedicated to raising awareness of sepsis as a medical emergency and supporting those affected by sepsis. We frequently receive messages from people living with long-term effects after surviving sepsis. We call this post-sepsis syndrome (PSS). Many of these survivors were discharged from the hospital with no warning that they may not "bounce back" once the initial crisis was over. However, many survivors continue to experience problems that can affect their ability to return to their previous quality of life.

For some patients, these lasting problems are obvious: amputations required because of tissue death caused by changes in the blood vessels and blood clots that interrupted blood flow to the limbs; breathing difficulties because of damage to the lungs; or kidney damage that made dialysis necessary.

There are often "invisible" lasting effects, such as chronic fatigue, pain, and memory loss, as well as those that affect the peripheral nervous system. We don't yet know the specific causes of these issues, but they may have something to do with changes in the blood circulation, along with sepsis-associated changes in the brain, muscles, and peripheral nerves. According to the Society of Critical Care Medicine<sup>2</sup>, ICU-acquired muscle weakness (weakness that develops while a patient is in an ICU) affects 33% of all patients on ventilators, 50% of all patients admitted with sepsis, and up to 50% of patients who stay in the unit for at least one week.

Post-traumatic stress disorder (PTSD) is another problem that affects many survivors. In 22% of cases<sup>3</sup> where patients are admitted to an ICU, the

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<sup>1</sup> <https://jamanetwork.com/journals/jama/fullarticle/2654187>

<sup>2</sup> <https://www.sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome>

<sup>3</sup> <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2572638/?report=classic>

psychological changes are severe enough to warrant a diagnosis of PTSD and 16% of these cases may be classified as moderate to severe. People with sepsis who were treated in an ICU are also more likely to develop PTSD than other ICU survivors.<sup>4</sup>

Sepsis survivors of all ages are presenting with these problems. One issue that is frequently brought to our attention at Sepsis Alliance is that survivors who have PSS feel that their concerns are not taken seriously by the general public (family, friends, employers) and their concerns may not be addressed by some healthcare professionals. Many survivors are desperate for assistance.

We in the healthcare community need to work together to ensure that healthcare professionals respect the needs of patients discharged from the hospital after treatment for sepsis and provide access to rehabilitation services. The World Sepsis Declaration<sup>4</sup>, promoted by the Global Sepsis Alliance, has set this need for follow-up care as a key target: "*Access to appropriate rehabilitation services will have improved for all patients worldwide - By 2020, all member countries will have set standards and established resources for the provision of follow up care following discharge from hospitals of patients who have suffered sepsis.*" The declaration has been signed by over 2,500 hospitals worldwide and three governments to date.

To this end, we have made this letter available to those who are seeking help for what they believe to be post-sepsis syndrome. We ask that you consider referring sepsis survivors who may need follow-up care to the appropriate services, dependent on their needs. This may mean referrals for emotional and psychological support (counseling, cognitive behavior therapy, or neuropsychiatric assessment), or for physical support such as physical therapy or neurorehabilitation.

If you would like more information about sepsis or Sepsis Alliance, I invite you to visit our website at [Sepsis.org](http://Sepsis.org), call us at 619-232-0300, or email us at [info@sepsis.org](mailto:info@sepsis.org). We would be pleased to offer our assistance as we all work together to provide a better future to sepsis survivors and their loved ones.

Sincerely,

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[https://www.hopkinsmedicine.org/news/media/releases/ptsd\\_symptoms\\_common\\_among\\_icu\\_survivors](https://www.hopkinsmedicine.org/news/media/releases/ptsd_symptoms_common_among_icu_survivors)