

POST SEPSIS SYNDROME INFORMATION SOURCES

Australian Sepsis Network

Post-sepsis syndrome (PSS) is a condition that affects up to 50% of sepsis survivors. It includes physical and/or psychological long-term effects. The risk of having PSS is higher among people admitted to an ICU and for those who have been in the hospital for extended periods of time. While PSS can affect people of any age, older severe sepsis survivors are at higher risk for long-term cognitive impairment and physical problems.

Problems ranged from no longer being able to walk to not being able to participate in everyday activities, such as bathing, toileting, or preparing meals. Changes in mental status can range from no longer being able to perform complicated tasks to not being able to remember everyday things.

For some patients, the cause of their PSS is obvious. Blood clots and poor blood circulation while they were ill may have caused gangrene, resulting in amputations of fingers, toes, or limbs.

Damage to the lungs can affect breathing. Sepsis survivors may be more vulnerable to developing viral respiratory (lung) infections. Other organs may be damaged as well, such as the kidneys or liver.

These lasting physical issues can be explained, but there is more to PSS that cannot yet be explained, such as the disabling fatigue and chronic pain that many survivors experience.

Others report seemingly unrelated problems, like hair loss that may occur weeks after their discharge from hospital. Many sepsis survivors also report symptoms of post-traumatic stress disorder (PTSD). Researchers have already recognised that ICU stays can trigger PTSD, which can last for years.

It is important to note that PSS does not happen only in older patients or in those who were already ill. New deficits can be relatively more severe among patients who were in better health beforehand, possibly because there is less room for further deterioration among patients who already have poor physical or cognitive function prior to the sepsis episode.

In other words, healthy people may be expected to rebound quickly from such a serious illness, but they may actually have the opposite experience.

Emotional and Psychological Affects

Compounding potential complications can be a number of emotional and psychological challenges. These can occur singularly or in combination and often represent the most debilitating factors during recovery and can include:

- Mood swings consisting of irritability, feeling low or becoming angry
- Disinterest in activities, surroundings and possible personal appearance
- Anxiety and a loss of confidence
- Frustration and/or isolation
- Self-doubt about survival and feeling guilty for the burden on others
- Remembering your sepsis episode in flashbacks, dreams or nightmares
- Strain on interpersonal relationships.

What is post sepsis syndrome (PSS)?

Post-sepsis syndrome describes physical and/or long-term effects that affects up to 50% of people who survive sepsis.

Longer term effects of sepsis include:

- Sleep disturbance including insomnia
- Experiencing nightmares, hallucinations, flashbacks and panic attacks
- Muscle and joint pains which can be severe and disabling
- Extreme tiredness and fatigue
- Inability to concentrate
- Impaired mental (cognitive) functioning
- Loss of confidence and self-belief

People who have suffered more severe sepsis and especially those treated in an intensive care unit are at greatest risk of suffering post-sepsis syndrome. Older people who survive severe sepsis are also at greater risk for long-term cognitive impairment and physical problems than people of the same age who were treated for other illnesses.

POST SEPSIS SYNDROME LINKS

1. Global Sepsis Alliance <https://www.global-sepsis-alliance.org/sepsis>

Sepsis does not end at hospital discharge. Many sepsis survivors suffer from the consequences of sepsis for the rest of their lives.

These can include:

- Sadness
- Difficulty swallowing
- Muscle weakness
- Clouded thinking
- Difficulty sleeping
- Poor Memory
- Difficulty Concentrating
- Fatigue
- Anxiety



2. US Sepsis Alliance <https://www.sepsis.org/sepsis-basics/post-sepsis-syndrome/>

Short video on PSS <https://youtu.be/Hlk64wdy44Q>

What is post-sepsis syndrome? Post-sepsis syndrome (PSS) is a condition that affects up to 50% of sepsis survivors. It includes physical and/or psychological long-term effects, such as:

Physical –

- Difficulty sleeping, either difficulty getting to sleep or staying asleep
- Fatigue, lethargy
- Shortness of breath, difficulty breathing
- Disabling muscle or joint pain, swelling in the limbs
- Repeat infections, particularly in the first few weeks and months after sepsis
- Poor appetite
- Reduced organ function, e.g. kidney, liver, heart
- Hair loss
- Skin rash

Psychological or emotional –

- Hallucinations
- Panic attacks
- Flashbacks
- Nightmares
- Decreased cognitive (mental) functioning
- Loss of self-esteem, depression, mood swings
- Difficulty concentrating and memory loss
- Post-traumatic stress disorder (PTSD) - the risk of having PSS is higher among people admitted to an intensive care unit (ICU) and for those who have been in the hospital for extended periods of time.

PSS can affect people of any age, but a study from the University of Michigan Health System, published in 2010 the medical journal JAMA, found that older severe sepsis survivors were at higher risk for long-term cognitive impairment and physical problems than others their age who were treated for other illnesses. Their problems ranged from no longer being able to walk to not being able to participate in everyday activities, such as bathing, toileting, or preparing meals. Changes in mental status can range from no longer being able to perform complicated tasks to not being able to remember everyday things. The authors wrote, "...60 percent of hospitalizations for severe sepsis were associated with worsened cognitive and physical function among surviving older adults. The odds of acquiring moderate to severe cognitive impairment were 3.3 times higher following an episode of sepsis than for other hospitalizations."

Children can also live with lasting issues related to sepsis. About 34% of pediatric sepsis survivors are not back to pre-sepsis functioning for at least 28 days after their hospitalization. The numbers could actually be higher as another study that included teachers who evaluated students who had had sepsis. The researchers found that 44% of the children who had been in septic shock had cognitive difficulties compared with healthy children. They are also more likely to have PTSD if they were treated in a pediatric ICU.

Since the risk of infection – and sepsis – is higher after recovery, sepsis survivors should speak to their healthcare provider about infection prevention, including necessary vaccinations.

What causes post-sepsis syndrome?

For some patients, the cause of their PSS is obvious. Blood clots and poor blood circulation while they were ill may have caused gangrene, resulting in amputations of fingers, toes, or limbs. Damage to the lungs can affect breathing. Another study, published in 2012 in the journal *Shock*, researchers found that sepsis survivors may be more vulnerable to developing viral respiratory (lung) infections. Other organs may be damaged as well, such as the kidneys or liver.

These lasting physical issues can be explained, but there is more to PSS that cannot yet be explained, such as the disabling fatigue and chronic pain that many survivors experience. Others complain of seemingly unrelated problems, like hair loss that may occur weeks after their discharge from the hospital.

It is important to note that PSS does not happen only in older patients or in those who were already ill. An editorial published in *JAMA* in October 2010, addressed PSS. In “The Lingering Consequences of Sepsis,” the author wrote, “The new deficits were relatively more severe among patients who were in better health beforehand, possibly because there was less room for further deterioration among patients who already had poor physical or cognitive function prior to the sepsis episode.”

In other words, healthy people may be expected to rebound quickly from such a serious illness, but they may actually have the opposite experience.

What can be done about post-sepsis syndrome?

Doctors and other healthcare professionals must recognize post-sepsis syndrome among sepsis survivors. This way, patients can be directed to the proper resources. Resources may include referrals for:

- Emotional and psychological support (counselling, cognitive behavioural therapy, or neuropsychiatric assessment)
- Physical support such as physical therapy or neurorehabilitation.

FAQ: What is post-ICU syndrome and is it the same thing as PSS?

Post-ICU syndrome (PICS) is a recognized problem that can affect patients who have spent time in an intensive care unit, ICU. It is more likely among patients who have been sedated or placed on a ventilator. It is not unusual for someone in an ICU to become delirious – sometimes called ICU delirium. The longer a patient is in such a unit, the higher the risk of developing delirium or PICS. A study published in the *New England Journal of Medicine* found that some of these patients continued to have cognitive (mental) problems a year after discharge.

The difference between PICS and PSS may seem slight. PICS is ICU related. Patients who are admitted to the ICU are at risk for PICS. PSS, on the other hand, can occur in sepsis patients who were not treated in an ICU, but who had extended hospital stays. The risk increases according to the severity of the illness and how long the hospitalization. Patients with PSS may also have physical issues that aren't usually related to PICS, such as amputations.

FAQ: Are post-COVID syndrome and PSS the same thing?

There have been many articles in the press and online about COVID-19 long-haulers, so named because they experience lasting symptoms long after they recovered from the coronavirus infection. People who have severe COVID-19 have viral sepsis. COVID-19, the infection caused by the SARS-CoV-2 virus, causes sepsis and results in severe illness. Therefore, the symptoms associated with post-COVID syndrome are identical to PSS, except for the loss of taste and smell. However, since sepsis is rarely mentioned in relation to COVID-19, people have started to call the lasting issues post-COVID syndrome instead of PSS.

3. *European Sepsis Alliance*

Sepsis affects your whole body, so recovery also involves your whole body. Most patients who survive sepsis will eventually fully recover. Others may face long-term consequences. It is important to know that recovery may take months or years.

After-sepsis effects, often called Post-Sepsis Syndrome, can present very diverse consequences that sometimes appear even years later.

Mental disorders - sepsis can damage the brain and the nerve tracts. Damage to the brain is usually undetectable on MRI but can manifest itself as the following symptoms:

- Fatigue and tiredness, lack of concentration, reduced reactivity
- Difficulty in multitasking
- Reduced attention span, very limited memory
- Decreased mental capacity
- Other possible disorders:
 - Visual and speech disorders
 - Balance problems, dizziness and headaches
 - Problems with the coordination of movements
 - Chronic nerve pain, or numbness due to nerve damage e.g. in hands or feet
 - Sleep disorders

For the neurocognitive problems, a referral to a cognitive neurologist or a neuropsychologist for examination or treatment is recommended.

Physical problems - sepsis may lead to physical problems which interfere with daily activities:

- Inability to walk
- Problems with swallowing or feeding
- Muscle weakness with paralysis or difficult breathing
- Joint pain and stiffness
- Amputation

Psychological problems - as a result of sepsis and the stay in the intensive care unit, many survivors suffer from:

- Post-traumatic stress symptoms
- Flashbacks or nightmares
- Anxiety
- Depression

It is important to realise that these problems can occur temporarily, can be relieved by specific treatments, and tend to gradually improve with time.

Social consequences - be prepared that life after sepsis may be different than before. Almost all aspects of your daily routine may be affected, forcing you to rearrange and reorganize your life. You may be temporarily dependent on help from family, friends, or professional caretakers. Interpersonal relations with partners and friends may suffer because you are not well, although you have been discharged from the hospital. You may not be able to return to work.

You may find yourself emotionally out of balance and this may last for some time. When problems linger on, don't hesitate to see a doctor. Psychological problems can be treated by a psychotherapist.

Memory gaps about your time in the intensive care unit may occur, too. This can cause a feeling of "missing pieces of your life". An ICU diary, kept by your relatives, can help fill this gap later on.

People around you may not understand the newly occurring problems and this might create frustration and stress. An exchange with other survivors and relatives can be very helpful.

Recovery after sepsis - for survivors - now that your body has successfully recovered from the immediate danger of sepsis, you need to rest, begin to regain your strength, and rebuild your body's reserves. If you continue to be exhausted, there may be other issues going on.

You may want to consider a check-up with your doctor or nurse to be sure that other parts of your body, such as your thyroid, are functioning properly. You can also help rebuild your energy and strength by eating a healthy, balanced diet and getting enough physical exercise.

Exercising when you are already tired may not seem easy. If you start slowly, such as with regular walks around the neighbourhood, you should be able to build up your energy.

When you still feel over-stimulated quickly, or have trouble concentrating, try to find ways to feel more at ease, proceeding more slowly, or, for instance, by practicing mindfulness or listening to music. Seek the necessary peace and don't be afraid to turn people down when you are not up to things yet.

Consider involving your friends and family in your recovery and get them to understand your needs and support you. Be aware of your limitations and take your moments of rest in time before you become exhausted.

During your recovery, you may experience that there is a thin line between "I'm doing alright" and "I can't go any further". Learn to recognize and communicate what your body is telling you, so the people surrounding you can also pay attention.

FAQ: How to prevent sepsis recurrence?

Sepsis survivors have an increased risk of sepsis recurrence. We do not yet know why, but possibly this is due to some pre-existing or resulting immune damage. Because sepsis results from infections, preventing infections will reduce the risk of sepsis.

Measures to reduce the risk of infections and thus sepsis:

- Vaccinate against preventable infections such as pneumonia, meningitis, or measles
- Take your yearly flu shots
- Be aware of the early symptoms of sepsis and do not hesitate to call an ambulance – early treatment saves lives
- Have a healthy lifestyle and respect basic hygiene measures
- Regularly and thoroughly wash hands with soap, e.g. after using the toilet, after cleaning your nose, after contact with animals or raw meat
- Pay attention to insect bites and skin injuries
- In case of infections, have sepsis in mind

Ask for help - knowledge about sepsis is spreading, but still many doctors and therapists do not recognize the early symptoms or the problems after sepsis. That is why you have to specifically ask about it. Bring along information about sepsis to your healthcare provider so you have back-up and can discuss your problems more easily. If necessary, ask for a reference to a specialist and for advice.

Early rehabilitation measures can help you get better, such as:

- Physical therapy
- Occupational therapy
- Psychotherapy
- Cognitive neurology
- Orthoptics (for visual impairment)
- Speech therapy (for speech disorders)
- Combined inpatient treatment with therapeutic measures

So far, there are no sepsis-specific rehabilitation measures for sepsis survivors, so look for a facility that covers all or as many of the existing consequences as possible.

Post-ICU clinics - some institutions have set up clinics to follow up with patients after discharge from the ICU. You might want to check with your local hospital if there is an outpatient clinic for survivors of sepsis or of intensive care treatment.

Self-help groups or initiatives - search and contact other sepsis survivors, local sepsis organizations, or patient groups which can be very active and provide valuable support.

4. **UK Sepsis Trust**

<https://sepsistrust.org/get-support/support/support-for-survivors/post-sepsis-syndrome/>

Some sepsis survivors experience a variety of physical, psychological and emotional problems while recovering. This is known as Post Sepsis Syndrome (PSS) and usually lasts between 6 and 18 months, sometimes longer.

Because you may look well, others (including your employer, doctor, or family) may be unaware of the problems and expect you to be better now. Don't suffer in silence. Tell them about PSS and how it's affecting you.

Physical symptoms of PSS:

- Lethargy/excessive tiredness

- Poor mobility / muscle weakness
- Breathlessness / chest pains
- Swollen limbs (excessive fluid in the tissues)
- Joint and muscle pains
- Insomnia
- Hair loss
- Dry / flaking skin and nails
- Taste changes
- Poor appetite
- Changes in vision
- Changes in sensation in limbs
- Repeated infections from the original site or a new infection
- Reduced kidney function
- Feeling cold
- Excessive sweating

Psychological and emotional symptoms of PSS:

- Anxiety / fear of sepsis recurring
- Depression
- Flashbacks
- Nightmares
- Insomnia (due to stress or anxiety)
- PTSD (Post Traumatic Stress Disorder)
- Poor concentration
- Short term memory loss
- Mood swings

What treatment is available?

There is no specific treatment for PSS, but most people will get better with time. In the meantime, it's a case of managing the individual problems and looking after yourself while you are recovering. Tell your family and friends about PSS, explain how you feel and give them information to read so they can understand what you're going through. It will help you all get through this difficult time.

Not all doctors know about PSS, so it may be helpful to take one of our booklets with you or to print out this information. It is important that your doctor assesses your symptoms and excludes any other causes of the problems. Your doctor may refer you to a different professional to help manage individual PSS problems, such as a pain specialist to manage your pain, a counsellor or psychiatrist to manage mental health and emotional problems, or a physio or occupational therapist to manage fatigue.

Above all, remind yourself that, horrible as PSS is, you're not alone, and these problems are part of the recovery process. Sometimes you have to look back to where you started to see how far you have come.

Recurring infections

Some survivors find that their immune system is not as effective in the year following their sepsis. As a result, they get one infection after another, whether it's coughs and colds, repeated water infections or a recurring wound infection.

This can be worrying, as many people fear that they may get sepsis again. In most cases, early medical consultation and treatment with antibiotics treat the infection and it doesn't progress to anything worse. But it's important not to neglect any infections. Always make sure you, and those close to you, know the signs of sepsis and seek urgent medical attention if concerned.

Additional UK resources here: <https://sepsistrust.org/get-support/support/resources/>

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Research Paper

Prescott HC, Girard TD. Recovery From Severe COVID-19: Leveraging the Lessons of Survival From Sepsis. *JAMA*. 2020;324(8):739–740. doi:10.1001/jama.2020.14103

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NICE Sepsis Guidelines

<https://www.nice.org.uk/guidance/NG51/chapter/Recommendations#managing-suspected-sepsis-outside-acute-hospital-settings>

Extract:

1.11 Information and support for people with sepsis and their families and carers

People who have sepsis and their families and carers

- 1.11.1 Ensure a care team member is nominated to give information to families and carers, particularly in emergency situations such as in the emergency department. This should include:
 - an explanation that the person has sepsis, and what this means
 - an explanation of any investigations and the management plan
 - regular and timely updates on treatment, care and progress.
- 1.11.2 Ensure information is given without using medical jargon. Check regularly that people understand the information and explanations they are given.
- 1.11.3 Give people with sepsis and their family members and carers opportunities to ask questions about diagnosis, treatment options, prognosis and complications. Be willing to repeat any information as needed.
- 1.11.4 Give people with sepsis and their families and carers information about national charities and support groups that provide information about sepsis and the causes of sepsis.

Information at discharge for people assessed for suspected sepsis, but not diagnosed with sepsis

- 1.11.5 Give people who have been assessed for sepsis but have been discharged without a diagnosis of sepsis (and their family or carers, if appropriate) verbal and written information about:
 - what sepsis is, and why it was suspected
 - what tests and investigations have been done
 - instructions about which symptoms to monitor
 - when to get medical attention if their illness continues
 - how to get medical attention if they need to seek help urgently.

- 1.11.6 Confirm that people understand the information they have been given, and what actions they should take to get help if they need it.

Information at discharge for people at increased risk of sepsis

- 1.11.7 Ensure people who are at increased risk of sepsis (for example after surgery) are told before discharge about symptoms that should prompt them to get medical attention and how to get it.

See NICE's guideline on neutropenic sepsis for information for people with neutropenic sepsis (recommendation 1.1.1.1).

Information at discharge for people who have had sepsis

- 1.11.8 Ensure people and their families and carers if appropriate have been informed that they have had sepsis.
- 1.11.9 Ensure discharge notifications to GPs include the diagnosis of sepsis.
- 1.11.10 Give people who have had sepsis (and their families and carers, when appropriate) opportunities to discuss their concerns. These may include:
 - why they developed sepsis
 - whether they are likely to develop sepsis again
 - if more investigations are necessary
 - details of any community care needed, for example, related to peripherally inserted central venous catheters (PICC) lines or other intravenous catheters
 - what they should expect during recovery
 - arrangements for follow-up, including specific critical care follow up if relevant
 - possible short-term and long-term problems.
- 1.11.11 Give people who have had sepsis and their families and carers information about national charities and support groups that provide information about sepsis and causes of sepsis.
- 1.11.12 Advise carers they have a legal right to have a carer's assessment of their needs and give them information on how they can get this.

See NICE's guideline on rehabilitation after critical illness in adults for recommendations on rehabilitation and follow up after critical illness.

See NICE's guideline on meningitis (bacterial) and meningococcal septicaemia in under 16s for follow up of people who have had meningococcal septicaemia.