

Life After Sepsis Guide





Issued in April 2020 by the Global Sepsis Alliance

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SHOULD I BE CONCERNED ABOUT SEPSIS?

Every 2.8 seconds, someone in the world dies of sepsis. This amounts to an estimated total of at least 11 million deaths worldwide annually.

Sepsis can occur to anyone regardless of age, gender, and geographical location. However, some people are at greater risk: infants, elderly, chronically ill patients, and people with immune suppression, e.g. undergoing chemotherapy or steroid treatment, people suffering from diabetes, or those without a spleen.

Around 40% of sepsis survivors suffer severe and lasting effects. Sepsis is life-threatening, but if detected early it can be easily treated.

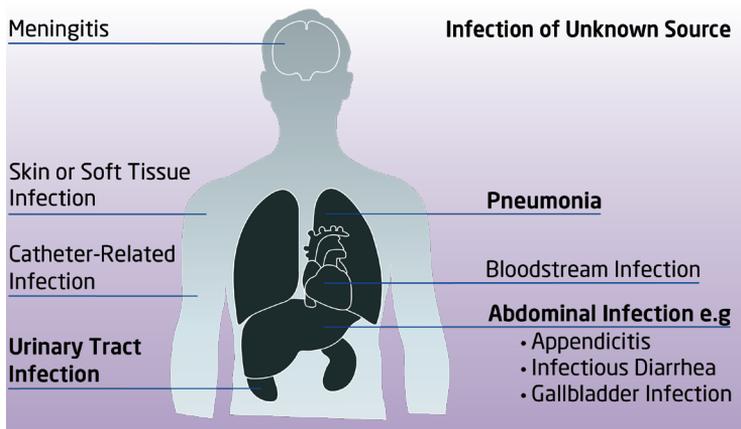
This brochure was issued by the Global Sepsis Alliance, with a lot of help from the Patient and Family Support Working Group of the European Sepsis Alliance. The GSA's mission is to provide global leadership to reduce the worldwide burden of sepsis. This brochure aims at guiding survivors and their families, who are the most vulnerable when sepsis occurs. It also wants to inform the general public, patients, their relatives, and healthcare professionals about sepsis. It explains that there is a need for an urgent response due to the consequences of sepsis, including lifelong disabilities. This document is not intended to be a substitute for medical advice, but rather to ensure that more people are better equipped to recognize sepsis, prevent it, and cope with its long-lasting effects.

We thank the following organisations and platforms for their contribution:

- *Members of the ESA Working Group "Patient and Family Support" - that includes sepsis survivors and their relatives*
- *UK Sepsis Trust*
- *Aktionsbündnis Patientensicherheit e.V., Handlungsempfehlung Sepsis Berlin 2020*
- *Sepsis en daarna*

What Causes Sepsis?

Sepsis - sometimes called blood-poisoning - is a life-threatening condition. It occurs when the body's response to an infection gets out of control. Normally, our immune system fights infections, but sometimes, for reasons we do not yet understand, it attacks our body's own organs and tissues. The most common sources of sepsis are lung or abdominal infections, but sepsis can also result from the flu, a skin lesion, or an indwelling catheter.



What Happens When You Have Sepsis?

Sepsis is the body's dysregulated response to an infection. A number of very serious symptoms develop, and every organ can be affected. These include the blood pressure dropping, breathing and heart rates increase, the brain may have difficulty functioning, and blood clotting may be disturbed.

The body suffers from the inflammation and lack of oxygen. If left untreated, the lungs may fill up with fluid, and organs may start to fail.

WHAT IS SEPSIS?

When to Suspect Sepsis

Sepsis can initially look like flu, gastroenteritis, or a chest infection. There is no specific sign, and symptoms appear differently amongst adults, children, and the elderly. In the latter, for instance, the most common early symptoms like fever can be absent, while later symptoms may be severe with rapid progression to septic shock. Sepsis is always an emergency and requires immediate hospital treatment. Seek medical help urgently, if you have or suspect an infection and develop one of these symptoms or if you spot them in a person close to you.

When at the hospital just ask: "Could it be sepsis?"
Early recognition of sepsis saves lives!



Slurred Speech
or Confusion



Extrême Shivering
or Muscle Pain/Fever



Passing No
Urine All Day



Severe
Breathlessness



It Feels Like
You're Going to Die



Skin Mottled or
Discolored

How to Spot Sepsis in Children and Newborn

Any child with a diagnosed or suspected infection who...

- is very drowsy, won't wake up, or does not show interest in anything
- feels abnormally cold to the touch
- has pale, clammy, or mottled skin
- has convulsions or seizures
- has not been drinking for more than 8 hours
- is not feeding (if under 6 months of age)
- has been persistently vomiting for 24 hours
- has passed no water or had a wet diaper all day

...might have sepsis.

Any Newborn - up to 1 month of age - with a diagnosed or suspected infection who...

- is very drowsy or won't wake up
- is feeble or not crying
- is breathing very fast (more than 1 breath a second) or has labored breathing
- feels abnormally cold to the touch
- has pale, clammy, or mottled skin
- has convulsions or seizures
- shows poor or no sucking, or poor feeding
- has been persistently vomiting for 24 hours
- has passed no water or had a wet diaper all day

...might have sepsis.

What Happens at the Hospital?

Having sepsis can be frightening for you and your loved ones. This is especially true if you have never heard of this condition and it has suddenly made you seriously ill. Being admitted to the hospital can be a traumatic experience and may involve the following:

- **Intensive care:** many sepsis patients are admitted to an intensive care unit, where their vital functions can be closely monitored and failing organs can be supported. In other cases, treatment happens in the general ward.
- **Sepsis treatment:** there is no single medication against sepsis. Sepsis treatment consists of intravenous antibiotics and fluids.
- **Septic shock:** it is the most severe form of sepsis. Many sepsis patients will be in a coma temporarily and will receive mechanical ventilation with a breathing tube.
- **Source control:** the source of the infection needs to be identified and treated. This may involve, for instance, surgical interventions to drain an abscess.
- **Hospitalization:** the total hospital stay can last from a few days to months.

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 and dizziness
- 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 realize that these problems can occur temporarily, can be relieved by specific treatments, and tend to gradually improve with time.



Sadness



Difficulty Swallowing



Muscle Weakness



Clouded Thinking



Difficulty Sleeping



Poor Memory



Difficulty Concentrating



Fatigue



Anxiety

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 neighborhood, 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.

For Families and Close Ones

You might be shocked by what you have seen your loved one go through. You have been through ups and downs during the sepsis episode. You have experienced major interruptions of daily life as your relative struggled for survival.

Now, you will be relieved that your loved one can return home. You may expect a swift recovery and a return to normal. However, don't be disappointed if this takes longer than expected or if some effects remain.

Children

They can struggle to accept the new reality and that the sepsis survivor is not the exact same person they were used to before. Make sure that they receive the appropriate support and respect their sensitiveness.

Spouses and Partners

They might misinterpret the different behaviors, e.g. a lower libido. Therefore it is important to share the struggles, feelings, progress, and join or support rehabilitation therapies.

Friends and Relatives

They might not understand why a person who survived sepsis is not able to have the same social life as before. Offer help, do not voice disappointment, and respect the pace of recovery.

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 preexisting 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

Further measures include

- 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.

Share Your Story

Sepsis can be a traumatic experience, but continued awareness raising and education can help prevent it and mitigate its effects on others. Share your story with your family, your friends, and your community. Awareness is the most important tool to fight sepsis.

If you would like to share your story publicly via the World Sepsis Day website, please get in touch with us at worldsepsisday.org/contact.

Useful Websites

Global Sepsis Alliance
global-sepsis-alliance.org

Learn more about sepsis
global-sepsis-alliance.org/sepsis

World Sepsis Day
worldsepsisday.org

UK Sepsis Trust
sepsistrust.org

Contact

For any query about this brochure, please contact the Global Sepsis Alliance at info@worldsepsisday.org

Donate to Our Cause

The Global Sepsis Alliance is an international non-profit charity organization. Please consider donating to support our cause.

global-sepsis-alliance.org/donate

Glossary

Pneumonia

a lung infection

Meningitis

an infection affecting the membranes of the brain or of the spinal cord

Appendicitis

an inflammation of the appendix (abdomen)

Septic shock

cardio-circulatory failure leading to a sudden drop in blood pressure

Post-traumatic stress symptoms

the effects of a traumatic event that can vary in time and frequency. They can include flashbacks, nightmares, physical sensations, sleeping disorders, irritability, depression, anxiety, and others

Cognitive Neurology

the science studying the biological aspects of brain and mental processes

Orthoptics

the study of irregularities of the functioning of the eyes

