

YOU HAVE SEPSIS. NOW WHAT?

Your guide to what you may see and feel while in the hospital.



Sepsis, pronounced sep-sis, is a serious illness. Sepsis can make you very sick. You might have to stay in the hospital for a while before you can go back home. It can be scary not knowing what is happening around you, so let's answer some questions you might have.

For the adults:

It can be difficult for a sick child to understand what is happening. To help families as they navigate their child's hospital stay, Sepsis Alliance has put together a guidebook for children hospitalized with sepsis, to help them understand what they might experience while in the hospital and after they go home. We hope that this guide will answer many of the questions your child may have during this challenging time.

While the guide is directed towards your child, we encourage you to read and discuss the contents of this guide with your child. If your child asks something you can't answer or don't feel comfortable answering, ask the nurses or doctors. Together, you are a team.

What is Sepsis?

Sepsis is a serious illness caused by an infection (in-FEK-shun). Infections are caused by germs. Germs are tiny things that you can't see without a microscope, but they can make you sick with illnesses like the flu or an ear infection. Most times, infections go away on their own or with medicines.

Your parents or another adult may have brought you to the hospital because they saw you were sick. Maybe you had a lot of pain or you were very sleepy and couldn't wake up. Now that you're at the hospital, doctors, nurses, and other people will take care of you.

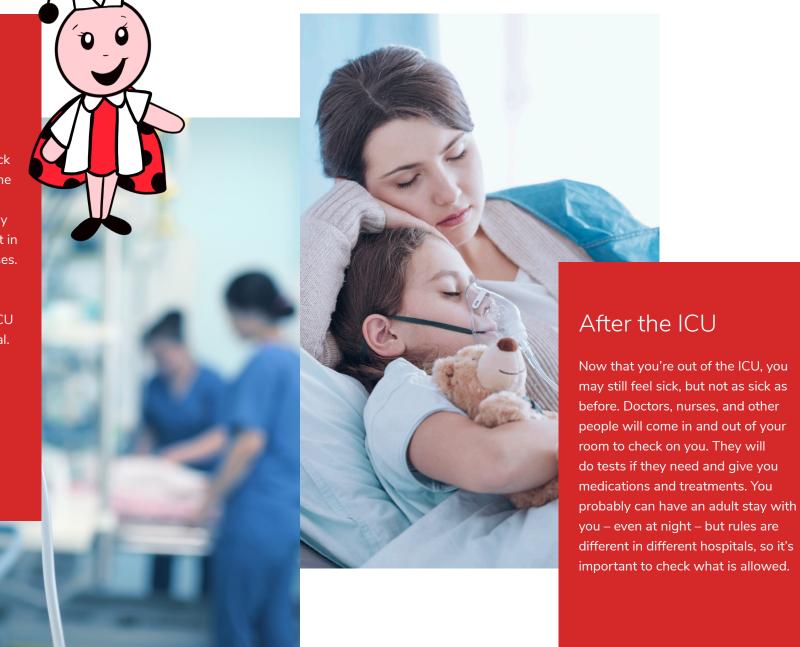
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In the ICU

The ICU, or intensive care unit, is a special place in a hospital. This is where people go if they are very sick and need extra care. When someone leaves the ICU, they are not so seriously sick anymore. They usually still have to stay in the hospital, just in a different room with different nurses.

If you don't remember being in the ICU, that's ok. Most people in the ICU sleep a lot as their body tries to heal. You may get back some memories over time. It might be a good idea to speak to an adult about those memories.



Equipment You May See

Some hospital rooms have a lot of machines. The beeps and alarms on the machines help nurses take care of you. Some beeps are urgent and the nurses come right away. Others aren't urgent, so the nurses may not come right away. You can ask the nurse about the noises if you're curious.

Here are some of the things you might see:









Electric Bed

Buttons on an electric bed can make the top (head) and the bottom (feet) go up and down. Another button can make the whole bed go up and down. Ask your nurse how the bed works so you can move it if you need.

Call Bell

Every patient has a small button attached to their bed. You can push this button to call a nurse. The nurse might be busy at the desk or in another room, so it's important not to play with a call bell in case it goes off when you don't want it to.

Monitors (MON-i-ters)

Monitors are like smoke detectors at home. Instead of warning about smoke, the monitors tell nurses how fast their patients are breathing, how fast their heart is pumping, and more. Sometimes monitors start beeping or making noises.



Intravenous (in-TRA-vee-nus) Pumps

You might have a thin clear tube going into your arm. This is called an intravenous or IV. IV tubes are attached to bags of fluid and medications that hang from a pole. The IV lets fluids and medicines go straight into your body instead of you swallowing them. The tubes are also attached to IV pumps or machines. These pumps control how fast the fluids and medicines move through the tubes. The pumps make noises to alert nurses when the bags are empty or a tube is blocked.



Oxygen (OK-si-jen) Meter

A tiny device on the tip of your finger measures how much oxygen is in your blood. Oxygen is part of the air we breathe. The meter doesn't hurt. It sits on the end of your finger or sometimes the ear lobe. The full name of the device is a pulse oximeter (OK-sime-ter).



Temperature

Your body has a body temperature – how warm or cool it is – all the time. If your body temperature is higher than normal, this could mean you have an infection. To check if your infection is going away, a nurse will take your temperature a few times during the day and maybe at night.

Blood Pressure

Nurses use a band wrapped around your arm to help measure your blood pressure. This tells them how well your blood is moving around in your body. The band (or cuff) will tighten around your arm for a few seconds as the machine takes its measurement, and then get looser.

Blood Tests

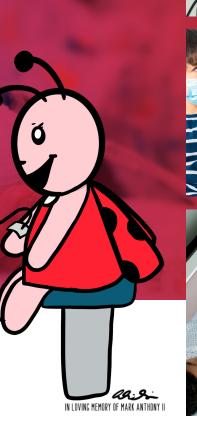
Blood tests may sound scary, but your blood can tell the doctors a lot about how you are doing. They can tell how well you are breathing, how your body is working, and a lot more. When nurses take your blood for a test, it may look like a lot, but it's not. And your body creates new blood to replace it.

X-rays and Similar Tests

X-rays and other similar tests can show doctors what is going on inside your body. They can show your bones and organs, like your kidneys or your heart. You don't need to do anything but lie or sit quietly for a few minutes as the machines take the pictures. If you think you might be uncomfortable or scared, you could ask if you could hold a special treasure, like a stuffed animal or toy.

Tests You May Have

One way for doctors and nurses to see if you're getting better is by doing tests.



Talking to Nurses, Doctors, and Others

If you have a question when someone is taking care of you, ask it. Sometimes they may be too busy to answer right away, but you can ask again later if that happens. Or you can ask the adult in your life to ask.







Going Home

Yay! You are well enough to go home from the hospital!

You may still not feel completely well, but your doctor decided that you can go home and get better there.

Before going home, your nurse will speak to your parents or guardians about what they can do to help you get better. Here are some things that might happen. You might:

- Need special medicines like you were getting in the hospital. If they are given by IV, the adult in your life might learn how to do it, or a nurse might visit you at home every day to give the medicine.
- Need to come back to the hospital or go see your doctor every once in a while for check-ups or tests.
- Have to stay home from school for a while.
- See a physical therapist (PT) or occupational therapist (OT) to help you get stronger. They show you exercises and other movements to help your body recover and get stronger. They also may give you some special equipment, like a walker or crutches, if you need it.

It Takes Time to Get Better

It can take a long time to get better after having a serious illness like sepsis. You might find it harder to remember things, do homework, or even do things like run as fast as you did before. This is called post-sepsis syndrome - or PSS for short.

It's important to know that your body is working hard to heal and it can take time.

If you find school harder than it used to be, ask the adult in your life to speak with your teacher about what happened to you. Ask them to explain to your teacher that you are trying, but it can take time for you to get back to the student you were before.

Your other activities might also be harder. If you like to play a sport but don't play as well as before, ask your adult to speak with your coach. They can even print out letters from the Sepsis Alliance website to give to teachers and coaches to explain PSS to them.



Getting Back to Normal

Going back to school and your activities helps your life get back to normal. You can see your friends and catch up on what you missed while you were sick. It's important to take your time and pay attention to how you feel. If you're worried, speak with your parent, a teacher, or some other adult in your life.

> When it comes to sepsis, remember **IT'S ABOUT TIME**^{*} Watch for:

TEMPERATURE





higher or lower than normal

INFECTION may have signs and symptoms of an infection

MENTAL DECLINE confused, sleepy, difficult to rouse

EXTREMELY ILL severe pain, discomfort. shortness of breath

Can You Get Sick Again?

If someone was seriously ill, they might be scared of getting sick again. This is normal. You don't want that to happen and it's scary that it could. Some people who had sepsis do have to go back to the hospital a few weeks or months later. If you start to feel sick again, or you are worried, speak to your parents or guardian. Don't hide it and hope it goes away. They may bring you back to your doctor or the hospital so they can check you.

Bug is a friendly ladybug who loves to help children learn about sepsis. You can learn more from Bug at sepsis.org.



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