



# WHEN A LOVED ONE HAS SEPSIS:

## A CAREGIVER'S GUIDE



When Carl Flatley, DDS founded Sepsis Alliance after the death of his daughter Erin to sepsis, his dream was to have an organization that would help prevent any other parent from experiencing the same loss.

Since its founding, the Sepsis Alliance team has put together many different types of resources to help educate both the public and the healthcare community about sepsis, how to recognize it, how it should be managed, and how it may be prevented in the first place.

When the Faces of Sepsis section of the site was established, sepsis survivors and loved ones were encouraged to share their stories, so others could learn from their experiences. Hundreds of stories were from family members who were unexpectedly placed in the position of giving care to a survivor who was left with long-lasting and life-altering complications from sepsis or septic shock. It became increasingly clear that these caregivers felt alone, without support. To address this, the Sepsis Alliance team has put together this caregiver guidebook, *When a Loved One Has Sepsis: A Caregiver's Guide*.

It is our hope that this guidebook will help answer many of the questions that may come up when a loved one is admitted to the hospital for sepsis or septic shock through to their discharge and adjusting to life after sepsis.

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*Please note that information in this guide about intensive care units (ICU) and their practices is of general nature, and all ICUs have their own policies and procedures regarding issues such as visiting hours, speaking with staff, and more. If your family member has been admitted to an ICU, ask if a staff member if unit has an ICU orientation or information sheet, which may list all pertinent information.*



# For Caregivers

The ICU is a specialized unit in a hospital where staff cares for people who are seriously ill.

Depending on the size of the hospital, there can be one general ICU or more specialized ICUs:

- **Medical ICU:** For medical issues like sepsis, organ failure, and respiratory failure
- **Surgical ICU:** For patients who are seriously ill after surgery
- **Neurological ICU:** For issues such as strokes or other neurological conditions
- **Pediatric ICU (PICU):** For children
- **Neonatal ICU (NICU):** For babies just after birth who are seriously ill or who were born premature

The staff in these units treat the sickest people in the hospital. Their stays are kept as short as possible while they are treated and stabilized, so they can be transferred to a step-down or regular unit or ward. However, for people who are extremely ill, ICU stays can run into weeks, sometimes months.



# When your family member is admitted to an ICU

**A patient can be admitted to an ICU directly from the emergency room or from another floor or unit in the hospital.**

As patients are transferred to the ICU, stress levels can run high among family members. As much as we don't want a loved one to be in an ICU, if they are ill enough to be admitted, this is the place they need to be.

When your loved one is admitted into the ICU, it is important that one family member be designated as the contact person, and perhaps a second one as back up. The nurses and other staff members are taking care of your loved one. Receiving calls from multiple people for information takes them away from that care. By having one contact person, the staff can relay the information one time, and that contact person can then be responsible for ensuring the rest of the family is informed.



## Family Ties

Unfortunately, in times of crisis, cracks may occur in a family. How a partner or spouse reacts to the illness of a loved one may differ from how a parent, sibling, or child does. This can result in misunderstandings, frustration, and anger. If this occurs, it's important to recognize that everyone perceives things in different ways but the goal is the same: returning your loved one to full health. If your family is experiencing difficulties, seeking help from a support group, or a counselor or therapist, may help ease the stress for all involved. Emotions can run high during these times of crisis, but it's important that the end goal, the well-being of your loved one, is kept in mind.

## Legal Authority

The staff also needs to know who in the family has legal authority to make decisions on behalf of the patient, as well as which family members should be included in team meetings.

## Visiting

Visiting hours in ICUs may be restricted and visitors may be limited to two people at a time. There are also times when no visitors are permitted to be at the bedside, usually for confidentiality purposes. This is generally at change of shift, when nurses are exchanging information about the patients, and during daily rounds, when the ICU team goes to each patient's bedside to discuss the progress, treatment, and any other issues related to their ICU stay.

Most ICUs have a dedicated lounge or waiting room for ICU visitors where you can wait until you are allowed back into the unit.

# The ICU Team

Healthcare professionals who work in an ICU setting have advanced training to care for seriously ill patients. The multidisciplinary team (members from many areas of care) in your hospital may include physicians, nurses, respiratory therapists, pharmacists, physical therapists, nutritionists, patient care managers, and pastoral care workers.



**Physicians:** Physicians (doctors) working in an ICU are intensivists or critical care attending doctors. They coordinate patient care, which often involves consulting physicians from other specialties, such as surgery, hematology, or infectious disease.



**Nurses:** Critical care nurses have advanced training and certifications to manage the complex needs of seriously ill patients. In the ICU, the nurse-to-patient ratio may be one-to-one, although the ratio can be two patients to one nurse, depending on the patients' acuity, or how ill they are. The nurses provide round-the-clock monitoring and care, and they are the patient's first-line resource with the healthcare team. When nurses take breaks or leave the unit, another nurse in the unit receives report about the patient and then covers for that period.



**Respiratory Therapists:** Respiratory therapists play a vital role in monitoring the patients' respiratory system, administering respiratory treatments, and maintaining the equipment used to help patients breathe, from the oxygen masks to ventilators. Depending on the size of the ICU, a respiratory therapist may be assigned full-time to the unit or may come and go as needed.



**Pharmacists:** Critical care pharmacists are usually behind the scenes in the ICU, although they may have contact with the patients as well. They may advise physicians on the best medications or medication combinations for a particular patient, and are responsible for ensuring that the patients receive the right medications and monitoring their progress.



**Physical Therapists:** Physical therapists help ICU patients move about as much as possible, despite their illness and limited mobility. They assess how much the patient can move, what type of movements and exercises are needed, and they draw up a plan for the team to follow. Regular movement may help reduce risk such as developing a deep vein thrombosis (DVT) or pneumonia.



**Nutritionists:** ICU patients require a special balance of nutrients to help them fight their illness and to heal. Nutritionists help calculate how many calories the patients need and how best for them to be consumed. If a patient is on artificial feeding, such as total parenteral nutrition or tube feedings, the nutritionist manages this aspect of care.



**Patient Care Managers:** Patient care managers are often social workers who work with families to help them navigate through the complexities of the hospital stay. They may also help with post-discharge planning.



**Pastoral Care Worker:** Depending on the denomination, there may be faith-specific workers or general pastoral care workers who provide patients and families with spiritual and emotional support.

# Machinery & Equipment

There many pieces of equipment used in an ICU setting that are not usually seen in other parts of the hospital. Here are a few of the most common types of equipment you may see.



## Monitors

Monitors help the nurses watch a patient's vital signs: pulse (heart beat), respirations, and blood pressure. Monitors can also keep track of the blood's oxygen saturation, which indicates how much oxygen the blood is transporting to the blood tissues and organs. More advanced monitors can measure the body's internal temperature, the pressure in the brain (intracranial pressure), and the body's fluid status.



## Pulse Oximetry

A pulse oximetry monitor, often called a pulse ox, is a small piece of equipment that is fit over the tip of a finger or toe, or on the ear lobe. It measures the amount of oxygen in the blood.



## Intravenous (IV) Pump

IV pumps control how quickly an IV fluid or infusion flows into the body. The pumps are programmable and the flow can change according to the type of fluid and if there is medication in the IV fluid.



## Ventilator

Ventilators, sometimes called respirators, help patients to breathe. The machines can either do all the work for the patient by pushing the air into the lungs at a preprogrammed speed, or they may only help when needed. The machine is programmed to record how often the patient breathes and if there are not enough breaths within a certain period, the machine will assist by taking over as needed.



### Arterial Line

Arterial lines look like IV lines but they go directly into an artery, usually the wrist or groin. These lines allow nurses to monitor blood pressure and to take frequent samples of blood without inserting a needle in a vein each time one is needed. The line is protected with a special cap that allows for the blood to be drawn and it must be monitored closely because the pressure of the blood pumping from the heart can cause serious bleeding if the line becomes undone.

### Intracranial Pressure Monitor

An intracranial pressure (ICP) monitor measures the fluid pressure in the brain. A sensor that has been placed directly below the skull is attached to the monitor.



### Central Lines

Central lines are large IV catheters most often inserted into a large vein near the shoulder, although they can be inserted in any large vein, such as the neck or groin. Central lines have larger catheters than IVs and are used to give fluids more quickly and easily. They also don't need to be changed as often as an IV, which may be more comfortable for the patient.

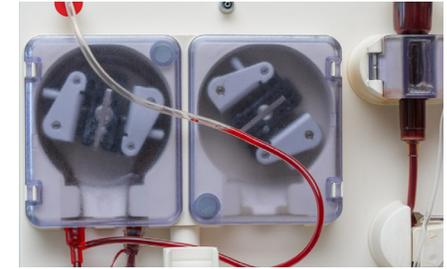
### Nasogastric Tube

A nasogastric (NG) tube is inserted through the nose and goes down into the stomach. If it is inserted through the mouth, it is called an oral-gastric tube, but through the nose is the most common approach. This tube may be connected to a suction bottle, which draws out stomach contents to help reduce nausea and vomiting.



### Endotracheal Tube

An endotracheal tube, or ET tube, is inserted through the mouth into the trachea (windpipe) and is attached to a ventilator. When a patient has an ET tube, he or she is intubated. When the tube comes out, this is called extubation. Patients with ET tubes cannot speak as the tube passes through the vocal cords. If there is damage in the mouth but intubation is necessary, a nasotracheal tube is inserted through the nose. Patients who are intubated may be restrained, their hands fastened down, if there is a danger of them unknowingly pulling the tube out. If a patient must be on a ventilator for an extended time or there is too much damage to the mouth or throat to allow for intubation, the physicians may opt to perform a tracheostomy. This procedure makes an opening in the throat for direct access to the trachea. A tube is then inserted through the opening and fastened down, and connected to the ventilator.



### Dialysis

A portable dialysis machine allows patients to undergo dialysis in the ICU if their kidneys fail. A special catheter is inserted into a large vein and attached to the dialysis machine. Blood flows through the machine, which filters out toxins in the blood, which is what the kidneys normally do. Once the blood has been filtered, it flows back into the body.

### Urinary Catheter

Often referred to as a Foley catheter or indwelling catheter, a urinary catheter is a tube that is inserted through the urethra to the bladder to help drain urine into a bag attached to the side of the bed. Patients may need a urinary catheter for a few hours or indefinitely, depending on the situation. If the catheter is to remain in for an extended period, it needs to be changed according to the facility's protocol.

# What nurses are checking when they assess their patients

**Nurses monitor ICU patients around the clock. By watching the monitors and observing the patients, nurses can assess if their patients are stable, improving, or deteriorating. All the observations are meticulously recorded in the patient charts so everyone on the team can be kept up-to-date on the progress.**

At shift change, the nurses leaving the unit speak directly to the nurses coming to work the next shift. This report hands off the patient care from one nurse to another. In many ICUs, visitors are asked to leave the unit during this time for privacy purposes because the nurses will be discussing each patient's case in detail at the bedside.

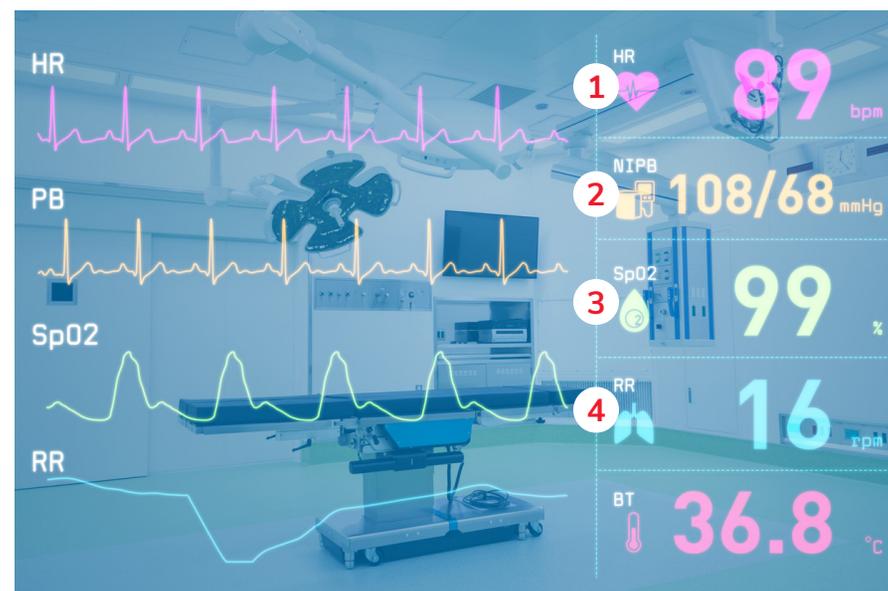
At the start of each shift, the nurses check their patients' vital signs, as well as any other measurement being monitored, and their overall wellbeing. A nurse new to your family member's care may ask you questions you have been asked many times already. Although this may seem repetitive, this allows the nurse to understand the situation and see things through their own observations.

While you are visiting your family member, you may hear alarms sounding. These alarms may be stressful to you, especially if it appears that the staff may not be responding quickly to them. Some of the alarms are notifications for the staff and do not require immediate action. If you are concerned about an alarm, ask your family member's nurse what the alarms are for and what actions might be taken if they go off.

You may be curious as to what numbers you should pay attention to. It's important to keep in mind that every patient is different, so the numbers that you are watching for may not be the same as what the nurses are looking for.

**1. Pulse (Heart Rate):** The average resting heart rate for a healthy adult is between 60 and 80 beats per minute, although women generally have a more rapid heartbeat than men. Athletes tend to have lower heart rates. Children generally have a more rapid pulse. A higher than average heart rate indicates the heart is pumping harder than normal. A patient who is in shock generally has a more rapid than usual heartbeat as the heart tries to compensate.

**2. Blood Pressure:** Normal blood pressure is on average about 110 or 120 over 70 or 80. If a patient is in shock, these numbers will be quite a bit lower.



**3. Oxygenation Level:** Normal blood oxygenation levels are between 95% and 100% for a healthy adult. If a patient is receiving oxygen, by mask for example, these numbers may drop when the oxygen source is removed. When nurses record a patient's oxygenation level, they mention if the patient is receiving oxygen at the time it was measured.

**4. Respiratory Rate (breaths per minute):** Respiratory rate (breaths per minute): The average respiratory rate for an adult at rest is between 12 to 20 breaths per minute.

## Situations where you may be asked to leave the ICU

If you are visiting a loved one, you may be asked to leave for a short while in some situations. These include:

- Your loved one needs **hands-on care**, such as bathing or toileting.
- Your loved one needs a **procedure**, such as insertion of a urinary catheter, changing a dressing, etc.
- **A neighboring patient** may be undergoing a sensitive procedure that requires confidentiality.



## Keeping your family member safe from infection

One of the biggest concerns in healthcare facilities is the spread of infection. Patients are at higher risk of contracting an infection because they are already ill and less able to fight the germs. They also have passages through which bacteria can enter, such as an ET tube for the ventilator, a recent surgical incision, central lines, and urinary catheters. When visiting the ICU, you must wash your hands before entering, with soap and water or an alcohol-based waterless solution), and before and after any time you touch your family member.

If your family member is in isolation, the nurses will explain to you the procedures involved in keeping everyone safe from infection. It is vital that you follow these instructions every time you visit the ICU.

# Discharge From ICU

**The primary goal of the staff in the ICU is to get your loved one well enough to be discharged to a lower acuity unit. In some hospitals, this is a special “step down” unit, in other facilities, it is to a general ward.**

Sometimes the transfer from an ICU seems very fast to the family. One moment, their loved one needs this high level of care and then they don't. The staff ensures that the patients are ready to leave before they are transferred. However, sometimes patients who were ready to be moved from the ICU do deteriorate after the move and they must be transferred back to the ICU for specialized care again. This does not mean the patients were not ready to be discharged from the ICU though. Unfortunately, some patients do relapse or develop other health problems that require a second or subsequent ICU admission.

Once your family member has been moved to a less acute unit or floor, you will see that the patient/nurse ratio changes. Since patients not in the ICU are generally not as sick, they don't require the same one-on-one nursing care as they did before. This change may seem disconcerting at first, so if you are concerned, speak with your loved one's nurse and ask about the routines on the floor and any issues that may worry you.



# My loved one is in the hospital, what can I do to help?

There are few feelings worse than the helplessness that comes with watching a loved one in the hospital. You feel there is nothing you can do to help. While it's true you may not be able to actively help your loved one with treatment, there are things you can do to be helpful overall, even if it doesn't seem so at the time. Many of the things you do now, during the hospitalization, will only become obviously helpful later on.

## Journaling

When a loved one is recovering from a serious illness, there may be gaps in her memory. If your loved one was in a coma, there will be days when events occurred that she won't know anything about. You and other visitors can help shed light on the gaps by maintaining a record of those days.

You don't need to be a good writer to keep a journal. Simple notes to prod your memory are all you need so you can tell your loved one about events. Some hospitals provide journals for their patients' families because they have recognized how important this can be. Ask the staff if they have this. If you prefer to use an electronic device, there are journaling apps, some of which are specific to journaling while ill.



What should you include in a journal? Some people like to keep detailed notes about treatments and progress, as well as conversations with staff. Others prefer to keep their journals more general, discussing family events, who visited the hospital, and other things that come to mind. There is no right or wrong approach. However, if you want to take photos of your loved one, check with the staff to ensure this is allowed. Some have strict privacy rules which don't allow for photographs or recordings. As well, consider how your loved one would react to seeing photos of herself in a vulnerable position. Also, be sure that no one else is in the photo unless they grant permission, either staff or visitors.

## Speak to Your Loved One

Even if your loved one is unconscious, speak to him, assuming you can be heard. Speak normally and discuss everyday things, as well as issues that you're addressing while there. Let him know what day it is, what the weather is like are examples. Some people like to read to their loved one, either from a newspaper or magazine, or chapters from a book. This interaction keeps you in touch with your loved one and if he can hear you, there is a connection. If someone enters the room,



acknowledge that person and tell your loved one who is with you. And when you leave, be sure to say good-bye and say when you'll be back.

If your loved one is awake, don't ask questions that can't be answered. If he is intubated and on a ventilator, he will only be able to answer yes or no questions, unless he has a board with words to point to or paper to write on. Medications and illness may make their coordination and understanding difficult. Be patient. Keep in mind that he may become frustrated, so keep your questions simple and easy to answer.

If it's not too awkward, be sure to touch your loved one. Hold his hand, wipe her face, make skin contact. This connection is important. You may want to play music for your loved one. Check with the nurses to make sure you may. If so, playing his favorite music can help mask the unit noises.

# Caring for Yourself While Your Loved One Is Ill

**Although it is your family member who is ill, possibly fighting for his life, it is vital that you take care of yourself as well during this time. Some ICUs view visiting hours as not only necessary for their patients, but for their loved ones as well. This time away from your family member allows you time to yourself to eat a meal, make phone calls, or get rest, without feeling guilty.**

Your mental and physical health are crucial when you want to help a family member through a serious illness. Here are some tips to help you help yourself:

**Ask for or accept help.** Most times when a family is going through a crisis, friends and family will ask what they can do to help or say, “Call me if there’s something I can do.” Take that help. Whether it’s to ferry your children to and from activities, making meals, shoveling your driveway, or helping clean your house, take advantage of these offers. The less of the everyday stuff you don’t have to do, the more you can focus on the things you want. There are apps and websites that allow friends and family to schedule things like provide meals or transportation. These types of tools are helpful in relieving the burden on you.

**Eat real food.** It’s easy to fall into the trap of eating fast food or snacks when you spend a lot of time in a hospital. When you can’t be with your loved one, take that time to go eat a proper meal, either in the facility cafeteria, a local restaurant, or with a friend who brings you something. This nutrition is important to keeping you functioning.

**Go home for a break.** When your loved one is in an ICU, she is being monitored by a nurse 24 hours a day. Take comfort in this knowledge and allow yourself a break at home to take a shower, eat a meal, get some sleep, or just sit in front of the television. This allows you to recharge. The hospital will call you if there are any changes you need to know about. And if you are really uncomfortable about leaving your loved one without a family member, remember those who offered to help you. Ask someone to take your place for a while.

**Don’t take things personally.** You may see personality changes in your loved one the longer he is in the ICU. A normally quiet, calm man may become loud and impatient. Or he may strike out, even become agitated or violent. Some patients lash out at their family members, saying things they would normally never say. While it may be hard, it’s important that you don’t take these actions personally. Your loved one is fighting a serious illness and receiving medications that can affect his thinking. He may not remember what he said or did when it comes time to leave the unit. If your family member is displaying behaviors that upset you, speak to his nurse about ways to handle the situation. And don’t forget that you can always leave to take a break and regroup.

**Ask for support.** Ask the ICU staff or patient coordinator if there is a support group for family members of seriously ill patients. If there isn’t, Facebook offers support through various Facebook pages, dedicated to sepsis and sepsis support. You may also consider speaking to a pastoral support person, therapist, or psychologist to help you organize your thoughts and concerns.



# For The Caregiver

## **What happened during the hospital stay.**

Patients may stay in acute care hospitals for varying lengths of time. Some are discharged home or to a rehabilitation facility after only a few days, while others may be hospitalized for weeks or longer. Some patients and loved ones are anxious when it's time for discharge, while others are concerned or fearful. Whichever is the case, being prepared will help ease the transition from patient to survivor.



# Understanding discharge instructions

Before patients are discharged from the hospital, they should receive and understand these discharge instructions. These instructions include information about the type of follow-up care needed, medication prescriptions, a summary of the hospital stay, and any instructions regarding follow-up or continued treatment.

The information may be overwhelming; however, understanding the instructions and information is essential. If you have any questions, ask for clarification or more details. Here are some examples and a checklist you can use to help during the discharge process.



- Have any **follow-up appointments** been already made? Which ones do I need to make? What is the contact information to make these appointments?
  - What if my loved one does **not feel ready to go home**? Is there an alternative, such as a rehabilitation or skilled nursing facility?
  - How do I help my loved one **manage medications**?
  - How do I help my loved one **care for wounds/incisions**?
  - What should I do if he/she starts to feel sick again? Are there any **red flags** to watch out for?
  - Are there any **activities he/she should avoid**?
  - When can he/she **expect to go back to work/school**?
- Also, talk to the team prior to discharge if additional help is needed at home. Things to consider are:
- How can I get **help with transportation** to follow-up appointments, nursing care such as dressing changes, meals, etc.?
  - Will **additional equipment be needed**, such as a raised toilet seat, walker, cane, or hand-rails?

# Post-Sepsis Syndrome

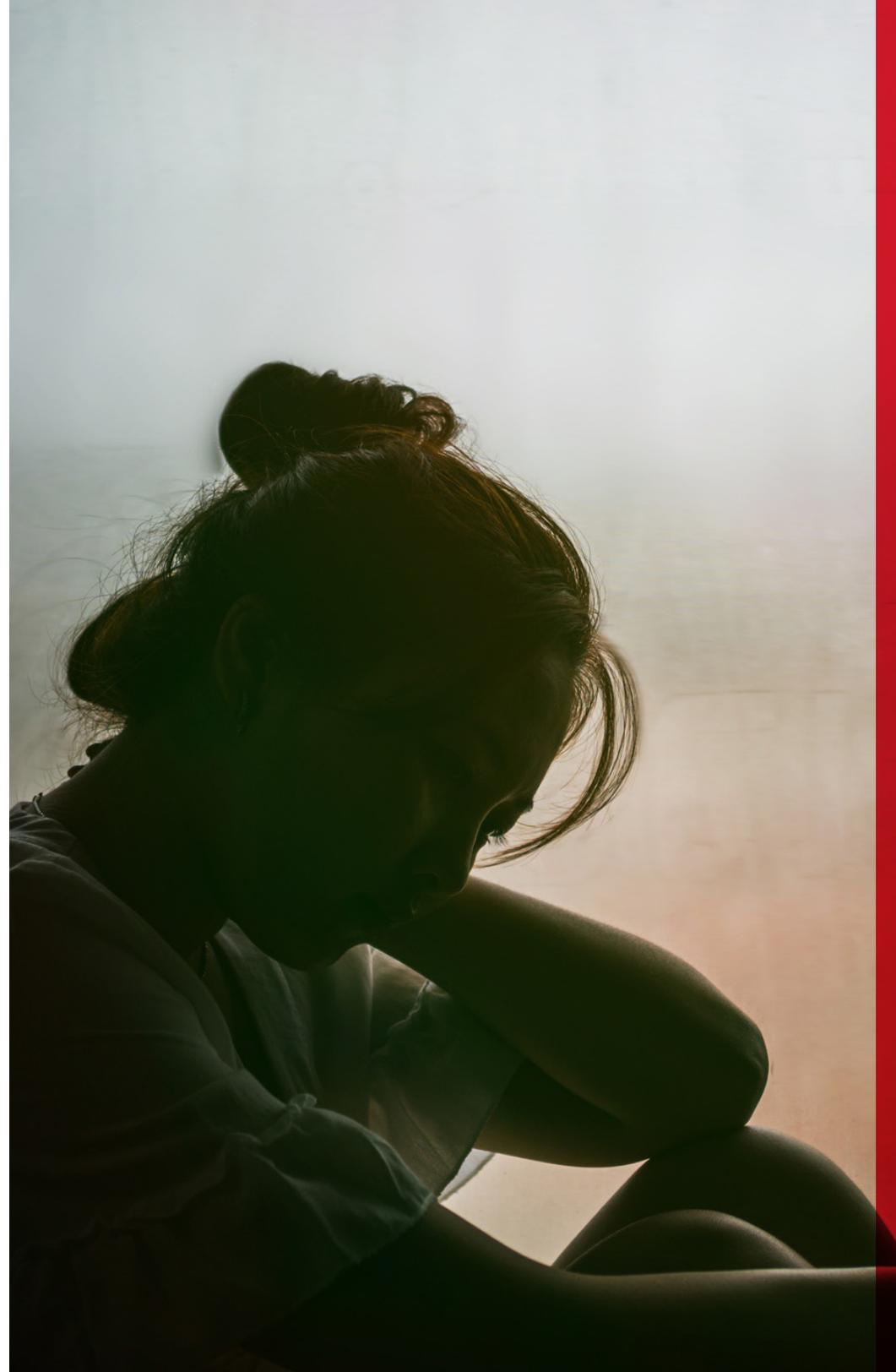
Up to half of people who survive sepsis are left with long-term physical and/or psychological effects. This condition is called post-sepsis syndrome. The risks of developing post-sepsis syndrome are higher among patients who required ICU care, especially if they were on a ventilator. The most common effects include:

- **Difficulty sleeping, either difficulty getting to sleep or staying asleep**
- **Nightmares**
- **Hallucinations**
- **Panic attacks**
- **Disabling muscle or joint pain**
- **Difficulty concentrating**
- **Decreased cognitive (mental) functioning**
- **Loss of self-esteem**
- **Depression**

Other issues that may affect survivors include living with wounds that haven't healed yet, a colostomy, amputations, or organ dysfunction, such as reduced kidney function. Recovery from sepsis can take months, even longer for some people. Whether it's fatigue, mood swings, or any other issue caused by sepsis, it's important to recognize that every person recovers at a different pace.

The cognitive problems associated with post-sepsis syndrome may not be obvious right away, but may occur as time passes and the shock of being so ill passes.

Post-sepsis syndrome is not yet widely understood or known within the medical community. Keeping records of problems and any challenges you and your loved one experience can help explain the situation to healthcare providers. Finding a mental health professional who has expertise in post-traumatic stress disorder, particularly among those who have been seriously ill, may also be helpful.



# Life After Sepsis

Once the initial hospitalization and recovery is past, you may still be concerned about your loved one's health. It's not unusual to think that even minor health problems may make your loved one sick again. She may also get very anxious when she becomes ill or must undergo a medical procedure. Hopefully, this will ease with time.

Any new healthcare professionals, including dentists, should know about the history of sepsis. People who survived sepsis are at higher risk of developing it again.



# Post-Sepsis Syndrome

How much support a survivor and loved ones need varies from person to person. If you are struggling to cope or just have questions, there are some resources available:

- Ask at your local hospital if there are any support groups for survivors or for caregivers.
- Ask your doctor's office about support groups.
- Look online for support groups.
- Join Facebook and **follow Sepsis Alliance**.
- Submit your story to Faces of Sepsis (**FacesOfSepsis.org**).
- See a **mental health practitioner**, preferably someone with experience working with survivors of serious or chronic illnesses.

Most importantly – ask for help. It's not easy for many people to ask for help but it's important to do so. Whether it's to help with a few meals or housework, transportation, or an ear to listen, this help can make a big difference in your life.



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[sepsis.org](http://sepsis.org)

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