



MY GUIDE TO SEPSIS AND THE INTENSIVE CARE UNIT

Adult Companion Guide to the Children's
Guide for a Loved One with Sepsis

For parents or guardians.

Speaking to children about serious illnesses can be difficult. To help families during these hard times, Sepsis Alliance has put together a guidebook for children to help them understand what they may see, hear, or feel when a loved one is hospitalized with sepsis, or any other type of serious illness.

We hope that this handbook will answer many questions children may have when sepsis strikes a family.

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How to use this guide:

Please read through the child's guide before sitting down with your child so you know what to expect. There are blank lines throughout the text where you can add the personal information, such as: *Will _____ be okay?* and *The hospital is where _____ will get medicine and treatment for sepsis.*

This is where you can add names like Grandma or a sibling's name, and then later, he/she/they/her/him/their, whichever is appropriate.

We recommend you read through the book along with your child the first time. There are likely words that your child has never seen written or heard before.

Explaining a serious illness to a child can be difficult and stressful for a parent or guardian, and the situation should be handled delicately. Adults must consider what information to tell the child, what language to use, and how they may react to the news. We have to take into account the child's age, the illness, how the loved one appears, and if the child wants to visit his or her loved one. Here are some tips to help you in this journey and ideas for how to help a child understand this stressful time.

Anticipate and respond to changes in the child's behavior.

The illness and hospitalization of a loved one is frightening and stressful for a child. Children respond to and express the experience of stress in different ways. They may be unable to say what they're feeling or thinking. So, it's important to notice and respond to their behaviors. Very often in reaction to a stressful situation a youngster's behavior may go backwards, or regress. They may act like a younger child, needing more reassurance. Some children might withdraw. There could be nightmares and difficulty concentrating in school. They might misbehave or they might act as if nothing unusual is going on. A noticeable change in behavior may be a clue that the child is struggling.

Children need the caring adults around them to help them understand that their own behaviors are a result of all the emotions they're experiencing. The adult can suggest to the child that they might be feeling frightened, worried, angry, or sad, and that whatever emotions they feel are valid. Together you might discuss ways to help support your child. Reminding them that they are loved and will be cared for is essential.





Get help.

If you're not sure how to speak with your child or you need help, many hospitals have social workers, psychologists, therapists, or child specialists who can guide you. In addition to this guide, they may have other books or toys that help explain the loved one's illness. You may even speak with your child's teacher or school nurse, as they might have had children in the class who went through similar experiences and could give suggestions on how to handle the situation.

Be honest.

Children are smart. They often know there is something going on before anyone tells them. The problem is, if the adults in their life don't tell them the truth, the children may incorrectly pick up on signals and imagine scenarios that aren't true. They may even blame themselves for the loved one's illness, or they may imagine the worst. You can be hopeful, but stay honest.

Find out what the child wants to know.

Sometimes we read too much into a question. The question may be very basic and not need an in-depth response. In other words, sometimes simple answers are all that are needed.

Name the illness.

Whether the illness is sepsis or some other disease like cancer, it's important to use the right language. This way if your child asks someone else a question, they will use the correct language and hopefully prevent misunderstandings.

Don't downplay things by using overly simplistic language or euphemisms.

For example, if someone has died, don't tell your child that he or she has gone into a long sleep. Your child may then fear sleeping.

Allow the child to choose whether he or she wants to visit the hospital.

It may be a good idea to take a photo of the hospital room from a child's eye level (with permission from the loved one and/or staff) before the visit so your child can be prepared. This guide has photos of some of the more common things you may see in an intensive care unit (ICU). If your child decides not to visit, leave the door open so they can reconsider visiting at another time. Another option is to use FaceTime or Skype, so the communication is real time, but less scary. You could also offer to take a video of your child to bring to their loved one, and vice versa.

If you bring the child to visit, be prepared for a change in behavior.

Children can be overwhelmed when they visit a hospital and unsure of how to behave. Or they may act out once they've returned home or gone to school. This isn't unexpected. Bring small toys, books, or videos that would give your child something to do while sitting at the bedside and engage the loved one. If the child has a special blanket or stuffed animal, they may want to bring it. This may help them feel more secure. Give your child a journal to write or draw in. The journal could be for things that happen at home to share with the loved one, or for what they see or hear in the hospital. There are a few pages in the guide to help your child get started.

With sepsis, remember:

IT'S ABOUT TIME™



TEMPERATURE
that's abnormal

Signs of an
INFECTION

MENTAL
DECLINE

Feeling
EXTREMELY ILL

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[**sepsis.org**](https://sepsis.org)

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 the unit has an ICU orientation or information sheet, which may list all pertinent information.

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