

# The International Journal for Direct Support Professionals

## Sepsis: What is it? How bad is it? What can DSPs do?

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[In 2019, H-CARDD reported that adults with developmental disabilities \(DD\) were almost four times as likely to die prematurely \(before the age of 75\) than other Ontario adults over a six year period. For adults between the ages of 50 and 65, nearly one in six died over the six years studied.](#)

We don't know why these deaths happened, but we know from other countries reporting similar problems that there are a few common causes of death in adults with developmental disabilities that we all need to learn more about: One of these is **sepsis**, a relatively uncommon but serious condition that, if caught on time, can be treated. But if not identified fast enough will surely lead to death.

[In the UK, because of their work showing that sepsis is a major preventable cause of death](#), there has been a lot of attention paid to understanding what sepsis is, and educating health care providers on how to better recognize sepsis in people with DD, and also how to help people with DD and their caregivers to get help faster.

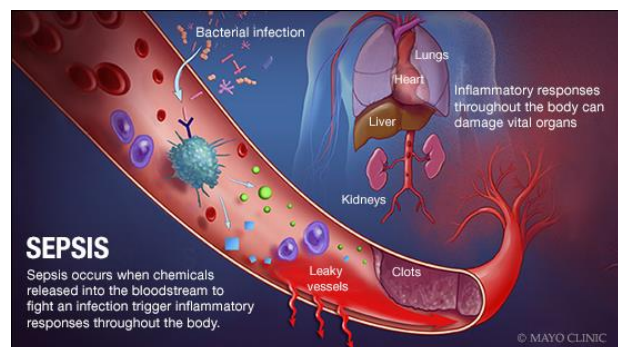
Here in North America, we are starting to do more education about sepsis in health care, but not specifically when it comes to developmental disabilities.

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Never heard of sepsis? That is part of the problem, which we hope this newsletter will correct.

### What is sepsis?

Sepsis is a severe reaction to an infection. Usually, it starts as a bacterial infection, but can also be caused by viruses or other things like parasites. Infection can start from different places in the body, including the blood, urine, the gut, skin, muscle or brain.



During an infection, the body's immune system gets triggered and causes inflammation. When the immune system becomes overactive, this inflammation begins to damage our organs. Sepsis occurs when the damage to these organs stops them from working properly. The most severe form of sepsis is called septic shock, which is when sepsis causes extremely low blood pressure. This means that the major organs like the brain, kidneys, lung, and heart are not getting enough oxygen and is life-threatening. Sepsis is an EMERGENCY, and anyone with sepsis should go to the hospital immediately. It also can get worse quite rapidly, so the faster someone receives medical attention and treatment, the better chance they will have at being able to fight it.

### **Why are people with developmental disabilities more likely to get sepsis?**

Some people are more likely to get sepsis compared to others. People who already have medical problems or those that are frail are most at risk. We know that kids and adults with developmental disabilities have a lot of medical problems, and we also know that they can get frail at a younger age than other people. Earlier H-CARDD work talked about being “80 at 50.” [This is why having regular medical care is so important](#). Also, people who have problems communicating how they are feeling in words may not be able to alert those around them about the early signs of infection which may delay treatment of infection, leading to worsening sepsis. We know this is a huge issue for many people with developmental disabilities. It can also be a problem for some of the people we support who can communicate with words but who are either not very sensitive to what they feel in their bodies or, for whatever reason, don't tend to discuss what they are feeling with other people.

#### ***Example:***

Francine lived in a supported independent living (SIL) apartment with two roommates. She took medication for diabetes and for her heart condition. She went to the doctor a lot, and was often saying she didn't feel so great and didn't like to go to activities. As she was getting older, she was spending more of her day on her own with her cat in the apartment. Because she could speak for herself, and she was often complaining that she didn't feel so well, staff encouraged her to sip tea, or take a rest. As the days went on, Francine began to stop eating, until one of her roommates found her on the floor in her room. She was shivering, her skin was pale, and no one could tell what she was trying to say. An ambulance was called for, and she was admitted to the ICU in the hospital for life support. She spent a total of six weeks in the hospital, including four weeks on the rehabilitation floor, before returning home.

### **Why are people with developmental disabilities more likely to die if they have sepsis?**

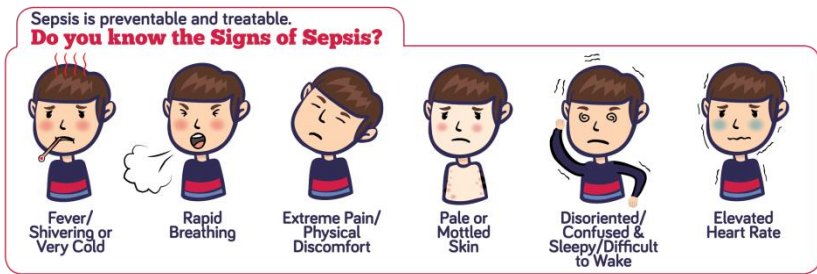
We are not completely sure but this may be due to sepsis not being recognized early enough as a result of communication issues. They may not be able to explain why they are feeling unwell, and other people only notice it when it is quite severe. Sometimes, in people with developmental disabilities a medical diagnosis may be missed because of something called diagnostic overshadowing – when symptoms of illness are considered to “just be the person's developmental disability.” Despite lots of research in the field, there is still lots about sepsis we don't understand.

## How do you recognize sepsis?

One of the toughest parts of sepsis is that it can be very difficult to recognize.

Symptoms of sepsis are usually not specific and,

therefore, they are high risk for being missed as important. The most common symptoms of sepsis are fever, fatigue, feeling unwell, lightheadedness, shivering, nausea, vomiting, and reduced urination. However, some patients, especially those with developmental disabilities, may present in different ways. Most important is to know what sepsis is, think about sepsis, and consider it as a possibility when someone is not feeling well.



In the Autism community, they have used an expression called [“know your normal.”](#) What might be normal or typical for one person can be quite different for someone else. It is very important to notice when a person is behaving very differently from their usual selves, especially if this change has been fairly rapid.

## What can a family caregiver or direct support professional do if they think someone they are supporting might have sepsis?

As mentioned earlier, sepsis is an **EMERGENCY**. Anyone suspected of having sepsis should go to a hospital immediately for assessment by a doctor or nurse. This could involve driving to the hospital or even calling an ambulance.

## How do doctors treat sepsis?

The two main treatments for sepsis are antibiotics (usually intravenous) and intravenous fluids. The antibiotics kill the bacteria causing the infection, while the fluids help to keep blood pressure up and ensure good blood supply to the organs of the body. Sometimes, depending on where the infection started, patients with sepsis may need surgery, for example, if there is a problem with the intestines leading to sepsis from the belly. Other than this, treatment is supportive, giving the body time to fight off the bugs. Researchers are always looking for new treatments in sepsis including a number of Canadian studies.

## What happens if someone I am supporting gets admitted to hospital with sepsis? What can I expect?

As sepsis is an EMERGENCY, doctors and nurses at the hospital will treat patients with suspected sepsis seriously. They will start treatments, like intravenous antibiotics and fluids, quickly and will watch the patient quite closely to determine next steps. Sometimes patients with sepsis, and especially those with septic shock, may need to be admitted to the intensive care unit in order to help treat their sepsis. This may mean using life support, such as putting patients on a ventilator, in order to support their organs in doing their job.

## What can we do to prevent sepsis?

There are a number of steps you can take to reduce the chance that the person with disabilities that you are caring for has a lesser chance of getting sepsis:

- Encourage a healthy diet and drinking plenty of fluids
- Ensure their vaccinations are up-to-date (including annual flu shots)
- Practice good hygiene, including regular hand washing
- Stay away from people with coughs and colds
- Keep wounds clean and monitor them regularly for redness, pain, or pus
- Seek medical advice if you are concerned about a worsening infection or suspect sepsis

### **What do you wish that caregivers who work with people with developmental disabilities understood about sepsis?**

If you're concerned someone has sepsis, specifically, if they are not acting like themselves, have a change in how awake they are, or feel unwell, make sure they get evaluated immediately by a health professional. It is crucial to act quickly and take it seriously.

### **About the Authors**

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## References and Resources

LeDeR Briefings for Carers: Infection/Sepsis:

[https://www.bristol.ac.uk/media-library/sites/sps/leder/Infection%20\(sepsis\)%20poster.pdf](https://www.bristol.ac.uk/media-library/sites/sps/leder/Infection%20(sepsis)%20poster.pdf)

LeDeR Briefings for Carers: Signs that a person is becoming unwell

<https://www.bristol.ac.uk/media-library/sites/sps/leder/recognising%20deterioration%20poster%20FINAL.pdf>

CDC, Sepsis Fact Sheet

<https://www.sepsis.org/files/sepsis-fact-sheet.pdf>

STOP AND WATCH, a tool to help spot warning signs for worsening condition:

<http://www.northcumbriaccg.nhs.uk/about-us/safeguarding/stop-and-watch.aspx>

RESTORE2, soft signs to assess risk of deterioration:

<https://www.westhampshireccg.nhs.uk/restore2-training-and-resources>

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