

# WHEN YOUR CHILD HAS SEPSIS:

## INFORMATION ABOUT SEPSIS, CARE AND RECOVERY



THE UNIVERSITY OF BRITISH COLUMBIA  
Action on Sepsis  
Research Excellence Cluster



The CENTRE for  
INTERNATIONAL  
CHILD HEALTH



Provincial Health  
Services Authority



LEAD BENEFACTOR  
save on foods



Sepsis Canada  
Suspect sepsis. Save lives. Support recovery.

Children's Health Queensland  
Hospital and Health Service



Queensland  
Government

Canadian  
Sepsis  
Foundation



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SEPSIS  
ALLIANCE

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## LANGUAGE SERVICES

Your health-care team can provide a translator or interpreter. Please ask.

This booklet is available in the following languages and can be found on the CHBC website.

[Arabic](#)  
[Cantonese](#)  
[Hindi](#)  
[Mandarin](#)  
[Punjabi](#)  
[Tagalog](#)

## WHAT IS SEPSIS?

Sepsis happens when the body is fighting an infection, and attacks its own tissues and organs. Sepsis can happen with any kind of infection (viral, bacterial or fungal). It can damage many parts of the body.

**Sepsis is a medical emergency.** The best chance of getting better from sepsis is to treat it quickly. Without treatment, sepsis can cause:

- Limb and tissue damage (for example, in the arms, legs, fingers, and toes)
- Organ damage and failure (for example, in the heart, kidneys, lungs, or brain)
- Permanent disability
- Death

## WHO CAN GET SEPSIS?

Both adults and children can get sepsis.

- Younger than 1 year old
- With complex health conditions
- With viral or flu like illness
- With poor immune systems
- Having chemotherapy for cancer
- With burns, wounds or injuries
- With indwelling devices (tubes inserted into the body, to deliver or drain fluids) like lines or catheters
- Who have just had surgery or another procedure
- Who have had sepsis in the past

## WHAT ARE THE SYMPTOMS OF SEPSIS?

Sepsis can develop from common infections. At first, sepsis symptoms can be mild. Your child may have the symptoms of a common infection, like a cold or flu. However, sepsis symptoms can change quickly and your child can become very ill in a short time.

Sepsis can look different in younger children. It can be difficult to diagnose sepsis, especially in newborn babies. Infants and newborns may be very fussy or they may have trouble feeding.

**If something feels wrong, get help. You know your child best.**

**ANY ONE OF THE SYMPTOMS MAY MEAN YOUR CHILD IS VERY UNWELL AND COULD HAVE SEPSIS:**



Graphic adapted with permission from resources developed by Children's Health Queensland Hospital and Health Service.

## WHAT WILL HAPPEN IN HOSPITAL OR A HEALTH CARE CENTER?

Your health-care team will ask about your child's medical history and monitor their condition. They will take your child's temperature, check their blood pressure, and do blood tests. There is no single laboratory test for sepsis.

If your health-care team thinks your child could have sepsis, they will:

- Place a thin tube (called an IV cannula) into your child's vein. If this is very difficult, they may put a needle (called an intraosseous needle) into a bone instead.
- Take blood samples and test them for infections. Results may take 48 hours.
- Give your child intravenous (IV) fluids and other medicines to help with blood flow.
- Monitor how your child responds to treatment.

Your health-care team may also:

- Start medicine, like antibiotics right away while they wait for blood test results.
- Speak with other health-care providers.
- Arrange for your child to move to a different area, health-care centre or hospital. This may be a pediatric unit or a Pediatric Intensive Care unit (PICU).

Sepsis affects every child differently. Your child's care needs depend on how sick they are.

### Your health-care team

Your health-care team may include doctors, nurses, social workers and Indigenous or Aboriginal Patient Liaisons. You are your child's most important support and advocate. Please tell your health-care team about your child's condition and any changes you notice.

You will communicate regularly with your health-care team while your child is in the hospital or health-care centre. Your health-care team will share:

- What sepsis means for your child, now and in the future. This can change as the team learns about your child's infection, and how your child responds to treatment.
- What treatment your child will get, and who will provide this care.
- Supports you can access.
- Where to get help if you are concerned.
- What to expect during your child's stay in the hospital or health-care centre.

### Supports available in hospitals and health centers

Serious health issues like sepsis can be stressful for families. If you or another family member need support, tell your health-care team. They can connect you with a social worker or Indigenous or Aboriginal Patient Liaison. They can offer support, and connect you with resources in your community.

## Helping your child cope with medical procedures

Many children struggle with medical procedures. You can help your child feel more comfortable and calm. Let your child know you will support them.

If possible, help your child understand:

- What will happen during the procedure,
- Why the procedure needs to happen, and
- Who will be involved.

Ask your health-care team if a Child-Life Specialist can support your family.



The **BC Children's Hospital Comfort PACT** resource provides information on promoting comfort for your child during medical procedures.

<http://www.cw.bc.ca/library/pdf/pamphlets/BC-Childrens-Comfort-Pact.pdf>



Visit the **BC Children's Hospital Pain Management & Comfort** website to learn more about pain care at this hospital.

<http://www.bcchildrens.ca/health-info/pain-management-comfort>

## Resources for Indigenous, Aboriginal, Metis, or Inuit families

If you identify as Indigenous, Aboriginal, Metis, or Inuit, you can request an Indigenous or Aboriginal Patient Liaison. They can advocate for you and guide you through the health-care system.

## WHAT CARE WILL MY CHILD NEED AT HOME?

Before discharge to home, your health-care team will give you information about:

- Ongoing medical treatment your child will need
- What your child's recovery will be like
- Recovery goals and timelines
- Possible long-term effects of sepsis on your child
- How to prevent new infections
- How you can help your child recover
- Medicines your child needs to take, including:
  - Why your child needs those medicines
  - How to give medicines, and how long your child needs to take the medicines
  - Potential side effects
- Health professionals your child must see in your community
- When to get help

### Your community health-care team

Your child's care will continue after you leave the hospital or health-care center. As your child recovers, they may need support from health-care providers. These may include:

- Pediatrician
- Family Doctor (GP)
- Nurse Practitioner
- Physiotherapists
- Occupational therapists
- Neuropsychologists or cognitive behavioural therapists
- Speech pathologists
- Dietitians
- Other specialist health-care providers

## POST-SEPSIS HEALTH COMPLICATIONS

Sepsis can affect many organs in the body. It affects everyone differently.

Many sepsis survivors make a full recovery. However, it may take time for your child to return to daycare, school, sports or other activities. You and your family may need additional supports as your child recovers.

Some sepsis survivors experience long-lasting physical, mental and emotional effects. This is called post-sepsis syndrome.

Some children experience symptoms like:

- Behaviour changes
- Difficulty concentrating
- Headaches and other pain
- Tiredness
- Trouble sleeping
- Changes in appetite
- Changes in muscle tone
- Weakness
- Fear of medical treatments

## HOW CAN YOU SUPPORT YOUR CHILD'S RECOVERY?

Your health-care team will refer you to health-care providers in your community. These providers can assess and support your child's recovery. Regular check-ups can help your child recover.

It is also important to see a health-care provider if you notice that:

- Your child's development is delayed, or
- Your child is progressing more slowly than their siblings.

## WHERE CAN YOU SEEK CARE IN YOUR COMMUNITY?

The Infant & Child Development Association of BC's Infant Development Program and Supported Child Development Program can connect you with professionals to support your child's development. Professionals include occupational therapists, speech pathologists, physiotherapists and social workers. You can self-refer or ask your health-care provider for a referral to these programs.

The Aboriginal Infant Development Program and Aboriginal Supported Child Development Program ensure culturally safe and sensitive care for First Nations, Métis, and Inuit children and families. You can self-refer or ask your health-care provider for a referral to these programs.



Learn more about these programs through the **Infant & Child Development Association of BC** webpage.

<https://icdabc.ca/programs>

## HOW CAN I EXPLAIN SEPSIS?

Not all health-care providers know about sepsis and post-sepsis syndrome. It may be helpful to print out this booklet and bring it to your health-care provider.



**Sepsis Alliance** has letters explaining sepsis and post-sepsis syndrome. You can share these letters with:

- Doctors
- Teachers
- Coaches
- Daycare workers, and
- Employers

<https://www.sepsis.org/education/patients-family/sepsis-survivors>

## WHERE CAN I GET SUPPORT FOR MY FAMILY AND MYSELF?

Often families need mental health or wellness support after a child has sepsis. If you need support, please ask your discharge nurse, your primary-care provider, or pediatrician.

You can also check these resources:



**Foundry BC** offers free, confidential support for young people ages 12-24. Supports are available online and in-person across BC.

<https://foundrybc.ca>



**Canadian Sepsis Foundation** supports sepsis survivors and families through advocacy and networking.

Facebook profile:  
<https://m.facebook.com/sepsiscanada>

<https://www.canadiansepsisfoundation.ca/>



**Sepsis Alliance Connect** is a virtual community that connects people affected by sepsis. Members can take part in live and pre-recorded programs, share resources, and find encouragement about sepsis and recovery.

<https://www.sepsis.org/sepsis-alliance-connect/>

## HOW CAN I PREVENT A NEW SEPSIS INFECTION?

In the months after your child has sepsis, they are at higher risk of a new sepsis infection. This is because sepsis changes the immune system.

To reduce your child's risk of infection:

- Keep up to date with your child's vaccinations (including COVID-19 and influenza vaccines).
- Help your child with basic hygiene, like washing their hands regularly with soap and water.
- Monitor insect bites, cuts, burns and other skin wounds. If they become red, hot or swollen, or do not heal, contact your health-care provider.
- If you see a health-care provider, tell them that your child has had sepsis in the past.

If your child develops any new infection, visit your health-care provider. Follow instructions for any medications they prescribe.

Monitor your child for signs of sepsis. If you are worried, contact your health-care provider right away or, go to the hospital or health-care center and ask, "**Could it be Sepsis**"?

Early treatment saves lives.

## WHERE CAN I LEARN MORE ABOUT SEPSIS?



**Sepsis Alliance** provides information, education materials and advocacy. They have colouring books, videos, and guides for children explaining sepsis. You will also find text-based and visual guides for children with IDD.

<https://www.sepsis.org/sepsisand/children/>



**Canadian Sepsis Foundation** raises awareness about sepsis, prevention, and recovery.

<https://www.canadiansepsisfoundation.ca/>



**Global Sepsis Alliance** is a charity that aims to reduce sepsis worldwide. Features sepsis information in many languages.

<https://www.global-sepsis-alliance.org/sepsis>

### Sepsis research

Researchers are still learning how post-sepsis syndrome affects children. Visit the sites below to learn about sepsis research in Canada.



**Sepsis Canada**  
<https://www.sepsiscanada.ca>



**The University of British Columbia  
Action on Sepsis Research Cluster**  
<https://sepsis.ubc.ca>

## GOING HOME AFTER SEPSIS: A CHECKLIST

Before your child leaves the hospital or health care center after having sepsis, your health-care team will share information about your child's care.

This checklist includes things that you may want to discuss with your health-care team.

ITEM	YES	NOTE
<b>Your child's health-care team will ensure you understand:</b>		
Your child's sepsis diagnosis, the kind of sepsis they had, and how long they will need to recover at home	<input type="checkbox"/>	
What follow-up appointments and referrals your child needs	<input type="checkbox"/>	
Signs and symptoms of post-sepsis syndrome to watch for, and what to do if they occur	<input type="checkbox"/>	
Complications to watch for, and what to do if they occur	<input type="checkbox"/>	
Any restrictions while your child recovers (like activity or diet restrictions)	<input type="checkbox"/>	
How to reduce the risk of infections and sepsis, including any vaccines your child needs	<input type="checkbox"/>	
If requested, refer you to Social Work services or an Indigenous or Aboriginal Patient Liaison	<input type="checkbox"/>	
<b>Your health care team will contact your primary-care provider or pediatrician and share:</b>		
<ul style="list-style-type: none"> <li>Your child's sepsis diagnosis</li> <li>Potential post-sepsis complications</li> </ul>	<input type="checkbox"/>	
<b>Your health-care team will give you:</b>		
Information on your child's medicines, including: <ul style="list-style-type: none"> <li>Type of medicines, how to use, dose, and schedule</li> <li>Any changes to your child's regular medicines</li> <li>How to manage pain</li> </ul>	<input type="checkbox"/>	
Your child's discharge summary, including information on: <ul style="list-style-type: none"> <li>Your child's sepsis diagnosis, and type of infection</li> <li>Managing pain</li> <li>Medicines to take</li> <li>Follow-up appointments and referrals</li> <li>Name and contact details of someone you can contact about your child's sepsis care</li> </ul>	<input type="checkbox"/>	

Adapted with permission from: Australian Commission on Safety and Quality in Health Care. Sepsis Clinical Care Standard Information for parents, carers and families of children with sepsis. Sydney: ACSQHC; 2022 & Children's Health Queensland Hospital and Health Service & Action on Sepsis Research Excellence Cluster & Hamilton Health Sciences Sepsis Education Package for Patients and Families



## PATIENT EXPERIENCE & QUALITY OF CARE

You and your family are a part of your child's care team. Health-care providers will inform you about your child's treatment options. You will be involved in decisions about your child's care.

If you have concerns about your child's illness, talk to your health-care team.

If you have concerns about the quality of care your child and family receives:

- Talk to your health-care team first. If possible, express your concerns at the time and place they arise. Your health-care team can resolve most concerns this way.
- If you still have concerns after speaking with your health-care team, contact your local Patient Care Quality Office (PCQO).

The PCQO takes concerns about your family's care seriously. They cannot intervene or advocate for your child in hospital, but they can:

- Accept and record your feedback,
- Help to resolve concerns about quality of care that your health-care team provided, and
- Improve patient services in future.

The PCQO also accepts your compliments and will pass on those comments to the programs and ensure staff are recognized for the care they provided.

Each health authority has their own PCQO. Please contact the office in your area. The websites below also give more information on what to expect when you contact the PCQO.

### HEALTH AUTHORITY WEBSITES WITH CONTACT INFORMATION

[Patient Care Quality Office Fraser Health Authority](#)

[Patient Care Quality Office Interior Health](#)

[Patient Care Quality Office Island Health](#)

[Patient Care Quality Office Northern Health](#)

[Patient Care Quality Office Provincial Health Services Authority \(PHSA\) BC Children's Hospital](#)

[Patient Care Quality Office Vancouver Coastal Health](#)

### MÉTIS NATION BRITISH COLUMBIA

[The Métis Nation British Columbia Health Experience Program](#) assists Métis individuals, families and communities across BC navigate the healthcare feedback process. The program provides a safe space for Métis-led conversations around all types of health experiences and advocates for change, through story sharing and ensuring Métis are being represented in health.