

Sepsis Clinical Care Standard

Information for parents, carers and families of children with sepsis

This leaflet provides information about sepsis and what it means for care and recovery. It is written for families of children who are being treated for sepsis in hospital.

Sepsis is a medical emergency. The best chance of getting better from sepsis is to treat it quickly. Early recognition and rapid treatment help save lives.



What is sepsis?

Sepsis arises when the body responds to an infection by damaging its own organs and tissues. Sepsis can cause:

- Damage to the blood vessels, heart, kidneys, lungs and liver
- Amputation (limb loss)
- Permanent disability
- Death.

Septic shock is the most serious form of sepsis.

Who can get sepsis?

Both adults and children can get sepsis. Any kind of infection can lead to sepsis, including infections with viruses (such as influenza), bacteria and fungi.

Children and newborns have a high risk of sepsis. The risk can be higher in¹:

- Children under 1 year of age
- Aboriginal and Torres Strait Islander children
- Children with complex health conditions
- Children with COVID-19
- Children with poor immune systems
- Children being treated for cancer with chemotherapy
- Children with burns, wounds or injuries
- Children with indwelling devices, lines or catheters
- Children who have just had surgery or another procedure
- Children who have been previously diagnosed with sepsis.

What are the signs and symptoms of sepsis?

Sepsis can develop from common infections. In the beginning, the signs may be mild and similar to the underlying infection. The signs can be vague, without any specific features that stand out from other illnesses. This makes diagnosis challenging, especially in newborn babies. The difference with sepsis is that your child will become more severely ill. The symptoms listed below can be a sign that more severe disease is present.

When a child has sepsis, their parents often feel that their child is very unwell or worried that they are not improving – this is important information. Let a doctor or nurse know if you are worried that your child is very sick or getting worse, especially if you know they have an infection.

Your concern is important and should be considered, as you know your child best.

It's important for you to ask: 'Could it be sepsis?'

Common sepsis signs in children

- Fast breathing or long pauses in breathing
- Blotchy or discoloured skin
- Skin that is abnormally cold to touch
- Rash that doesn't fade when pressed
- Infrequent wet nappies
- Drowsiness – the child is difficult to wake up or confused
- Restlessness or floppy limbs
- Vomiting
- Fits or convulsions
- A lot of unexplained pain

The signs and symptoms may look different in younger children compared with older children. Infants and newborns commonly have non-specific symptoms and signs, such as feeding difficulties or not settling.

What care should you expect while you are in the hospital?

If your child has signs and symptoms of sepsis when they go to see a healthcare provider, or if they develop the signs and symptoms during a hospital stay, the healthcare team will carry out physical checks such as taking temperature and blood pressure, and doing blood tests. These tests can help them understand your child's condition, but there is no single laboratory test for sepsis.

If sepsis is suspected, the clinical team will:

- Immediately place an intravenous cannula in a vein; if this is difficult in a small child or baby, they may put a needle into a bone instead (called an intraosseous needle)
- Immediately take small samples for blood cultures to test for infections in the blood; blood cultures can take 48 hours to give a result
- Start antimicrobials (usually antibiotics) immediately, ideally within one hour, while waiting for blood culture results
- Give intravenous fluids and other medicines to support your child's circulation
- Monitor their response to treatment
- Consult with other clinicians who are experienced in recognising and managing sepsis
- Arrange for transfer or admission to the most appropriate place for your child's care.

Sepsis affects every child differently, and the care required depends on the severity of the illness. Your child may require a hospital stay, or admission to a paediatric intensive care unit.

There may be many different people involved in your child's care. They could include different doctors, the sepsis coordinator (if there is one in your hospital), and a social worker who can support you and direct you towards other sources of support.



Your healthcare team should talk to you throughout your child's admission about:

- What a diagnosis of sepsis means for your child in the short, medium and longer terms; this should be discussed with you over time as the treating team gathers information about your child's infection and response to treatment
- Plans for your child's treatment during the hospital stay and who will provide this care
- What to expect as your child recovers in hospital after the initial critical care for sepsis
- How you can escalate care (that is, increase the level of care) whenever you are concerned
- Support you can receive in hospital.

Remember that you and your family should be informed about your child's treatment options and involved in decisions about their care.

Let your healthcare team know if you need a translator or interpreter; they can help to arrange this. If you identify as Aboriginal or Torres Strait Islander, an Aboriginal and Torres Strait Islander liaison officer can meet with you if you wish.

Dealing with a complex health issue like sepsis can be stressful and challenging. Let your healthcare team know if you or a family member need some support, such as from a social worker.

What care should you expect at discharge from hospital and following discharge?

Before discharge from hospital, your healthcare team should give you information about:

- What your child's recovery will be like and how long it will take
- Potential long-lasting effects of sepsis, and treatment your child will need after leaving hospital
- The need to prevent infection, and simple ways to prevent infection or sepsis coming back
- The signs that your child's condition is getting worse and what to do if you are concerned
- What you can do to best support your child's health after discharge
- The medicines your child needs to use after discharge, including
 - why your child needs medicines
 - how to use the medicines correctly
 - how long your child needs to take the medicines
 - potential side effects
- Recovery goals and clear instructions about follow-up with health professionals after discharge from hospital.

Leaving hospital is not the end of the journey. Depending on the situation, your child may need support from several clinicians to get back to the level of physical and mental wellness they had before the sepsis diagnosis. These can include:

- Paediatricians
- Physiotherapists
- Occupational therapists
- Neuropsychologists or cognitive behavioural therapists
- Speech pathologists
- Dietitians
- One or more specialist doctors.

When your child is discharged from hospital, the healthcare team will give you a discharge summary that gives important information about the care your child received in hospital and the care they will need afterwards, including their medicines and required appointments. The hospital will usually send a copy to your general practitioner (GP). Make an appointment to see your GP soon after you leave the hospital and take a copy of your child's discharge summary with you, just in case they haven't received it. You will also receive a discharge referral letter to give to your GP.

Post-sepsis health complications

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

Many sepsis survivors fully recover and return to their usual selves. However, recovery and returning to day care, school or sport activities may take time. Patients and families may need additional support to make a full recovery.

Some sepsis survivors experience long-lasting physical, cognitive and psychological effects. This is called 'post-sepsis syndrome'. We are still learning how children are affected by post-sepsis syndrome. Your role as the expert in your child and their behaviour is crucial to recognising symptoms and monitoring progress to recovery.

Some children experience physical symptoms such as headaches and other pain, tiredness, difficulties sleeping, changes in appetite, and changes in muscle tone or weakness. Children can also suffer cognitive and psychosocial symptoms, including changes in behaviour, changes in concentration and fear of medical treatments.

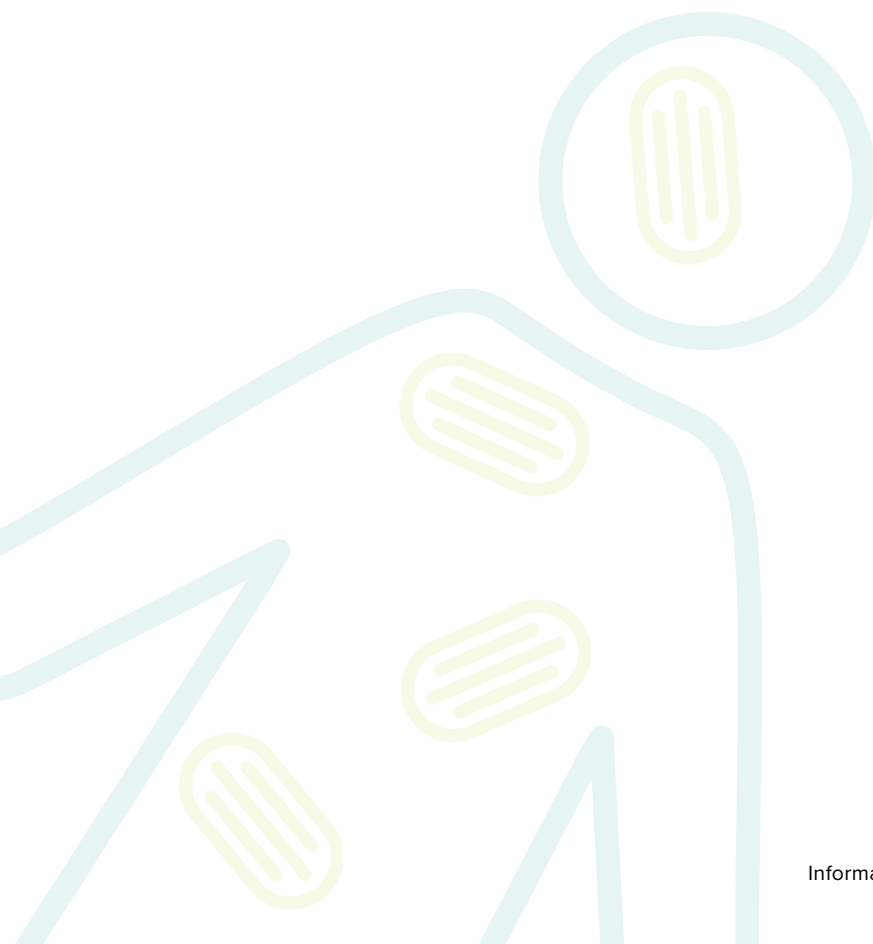
Your GP or paediatrician can help you to manage any ongoing effects of sepsis and can refer you to other medical specialists or healthcare providers if necessary.

Preventing sepsis in the future

Sepsis survivors have an increased risk of having sepsis again in the short term. This is thought to be due to changes in the immune system caused by sepsis. Infections cannot always be avoided, so if your child does develop an infection, monitor them for signs of sepsis and go to your GP or to hospital if you are concerned.

To reduce the risk of infections (and sepsis):

- Keep up to date with your child's vaccinations (including COVID-19 and influenza, if applicable) to prevent infections
- Support your child to take care with basic hygiene measures such as washing hands regularly with soap and water
- Pay close attention to insect bites and skin injuries; see a doctor if they are not healing, or become red, hot or inflamed
- If an infection occurs, visit your GP; ensure that your child takes any medicines prescribed as directed
- Let healthcare providers know of your child's past sepsis diagnosis if you go to hospital or to see a doctor
- Be aware of the early symptoms of sepsis, and do not hesitate to call an ambulance if you are concerned about sepsis. Just ask: 'Could it be sepsis?' Early treatment saves lives.



Resources to support you following discharge

Leaving hospital after sepsis is a big step. The healthcare service should give you information about accessing emotional and psychological support, including social work services and counselling.

Participation in peer support or advocacy groups may help support recovery following sepsis. In these groups, members share their experiences, relate to others who have been through a similar experience and provide practical help to each other. Peer support groups include:

- [Australian Sepsis Network](#)
- [Australia & NZ Sepsis Support Group](#)
- [Children's Health Queensland Hospital and Health Service Peer Mentor Program](#)
- [Maddy Jones Foundation](#) (Queensland)
- [Mandy and Rod McCracken](#) (Victoria)
- [Movement for Mia](#) (Queensland – children)
- [Renovating Matthew](#) (Queensland)
- [Reaching 4 Korina](#) (New South Wales)
- [Sepsis Awareness Tasmania](#)
- [T 4 Thomas](#) (Northern Territory).

In case of limb amputation:

- [Amputees NSW](#)
- [Amputee & Families Support Group Queensland](#)
- [Amputees in Touch South Australia](#)
- [Limbs4kids](#).

Please note that no specific group is being recommended, and choice is at the discretion of parents, carers or families.

More information about sepsis

- [Australian Sepsis Network](#)
- [Children's Health Queensland Hospital and Health Service](#)
- [Global Sepsis Alliance](#)
- [National Sepsis Program](#)
- [New South Wales Clinical Excellence Commission – SEPSIS KILLS Program](#).

The *Sepsis Clinical Care Standard* provides guidance to clinicians and healthcare services, and information for patients about the care they can expect to receive if they have sepsis.

Questions?



Find out more about the *Sepsis Clinical Care Standard* and other resources. Scan the QR code or use the link safetyandquality.gov.au/sepsis-consumer.

Sepsis discharge checklist and discussion guide – for parents, carers and families

When you are discharged from hospital after treatment for sepsis, it is important that you and your family receive information about sepsis and

your ongoing needs. The list below can help you have discussions with your healthcare team and ask questions if you need to.

Item	Yes	Note
You and your healthcare team should discuss		
The diagnosis of sepsis, and the nature and length of sepsis recovery	<input type="checkbox"/>	<input type="text"/>
Specific follow-up appointments and referrals	<input type="checkbox"/>	<input type="text"/>
Post-sepsis syndrome, including its signs and symptoms	<input type="checkbox"/>	<input type="text"/>
Possible complications to watch out for and what to do if they occur	<input type="checkbox"/>	<input type="text"/>
Current restrictions (for example, physical, diet)	<input type="checkbox"/>	<input type="text"/>
Ways to reduce the risk of infection and future sepsis episodes, including necessary vaccinations	<input type="checkbox"/>	<input type="text"/>
Introduction and referral to social work services	<input type="checkbox"/>	<input type="text"/>
Introduction and referral to peer sepsis support groups	<input type="checkbox"/>	<input type="text"/>
Communicating your care to your GP, clinic or paediatrician		
<ul style="list-style-type: none"> The healthcare team should contact your GP, clinic or paediatrician If you do not have a regular GP, clinic or paediatrician, your healthcare team should have identified a GP, clinic or paediatrician for you. Their name and contact details should be provided to you 	<input type="checkbox"/>	<input type="text"/>
You should receive		
Information on the medicines you need to take, including changes to medications taken before admission: <ul style="list-style-type: none"> Type, dose, frequency and how to use How to manage pain, including medicines required 	<input type="checkbox"/>	<input type="text"/>
Discharge summary, including the following sections: <ul style="list-style-type: none"> Diagnosis of sepsis and type of infection Management plan Medicines list Follow-up appointments and referrals Name and contact details of someone you can contact at the hospital about your sepsis care (that is, the lead doctor or nurse who organised the care that was provided in hospital) 	<input type="checkbox"/>	<input type="text"/>
Discharge letter to your GP about your child's sepsis diagnosis and potential post-sepsis health problems	<input type="checkbox"/>	<input type="text"/>

Adapted from the Post Sepsis Discharge Checklist in *Life after sepsis: a guide for survivors, carers and bereaved families* (Australian Sepsis Network).