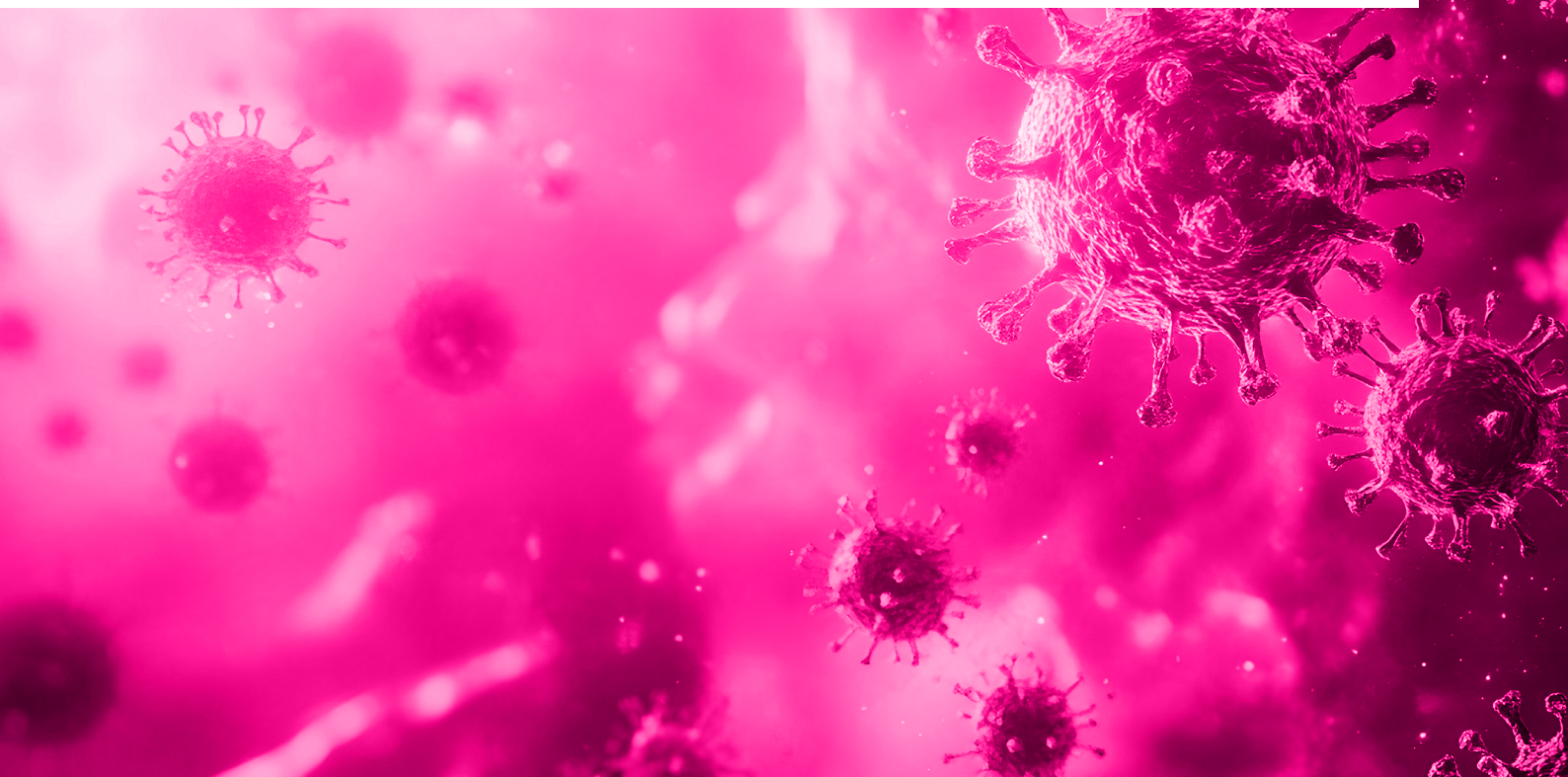


Sepsis
Trust NZ

PATIENT INFORMATION BOOKLET

We are sorry you or your loved ones have been affected by sepsis. We hope this booklet, created by Sepsis Trust NZ, will offer you some helpful advice and support during this difficult time.



CONTENTS

What is Sepsis?	02
What causes Sepsis?	02
How is Sepsis treated?	03
What happens in Intensive Care?	04
What happens after Intensive Care?	04
Recovery from Sepsis	05
What can I/we do to help aid the recovery?	07
Signs and symptoms of Sepsis	10

WHAT IS SEPSIS?

Sepsis is a life-threatening condition that arises when the body's response to an infection injures its own tissues and organs.

In other words, sepsis is the body's toxic response to infection.



WHAT CAUSES SEPSIS?

During our lifetime, we come into contact with many pathogens, or 'bugs', some of which cause infections. Our body's natural defence systems and immunity fight these infections, often without any need to visit the GP or hospital. However sometimes, sepsis occurs when the body's immune system – which normally helps us fight infection – overreacts, causing damage to tissues and organs.

The reasons why some people develop sepsis as a result of an infection are not entirely understood – medical researchers are working to understand this better. It's important to note that it's not possible to 'catch' sepsis or pass it onto others.

Sepsis can be caused by any type of infection (bacterial, viral, parasitic or fungal), and the effects can be prevented if it is treated quickly.

Sepsis is indiscriminate: whilst it primarily affects very young children and older adults, and is more common in people with underlying health conditions, it can also be triggered in people who are otherwise fit and healthy.

In Aotearoa New Zealand, some groups of people are at a higher risk of developing sepsis. These include:

- Young people under the age of 12, especially babies and children who are not fully immunised.
- People over the age of 60 years
- Pregnant or recently pregnant wahine (including post-partum, or after an abortion or miscarriage)
- Maori or Pacific ethnicity
- People living in socio-economic deprivation
- People who have had sepsis before
- Recently discharged from hospital
- People with chronic conditions or those who are immunocompromised

HOW IS SEPSIS TREATED?

The earlier sepsis is identified and treated, the better the outcome for the patient. Unfortunately, sepsis can be difficult to spot, especially in the earlier stages. There is no single sign and no single diagnostic test – symptoms can also present differently in adults and children. The most common signs and symptoms for both adults and children can be found on page 10 of this booklet.

A patient who is unwell and has signs or symptoms of an infection should be assessed for the presence of sepsis by looking for one or more organs not working as they should be – this will involve vital signs monitoring and blood tests. Some hospitals use the term Red Flag Sepsis (developed by our friends at the UK Sepsis Trust) to help health professionals identify people with possible sepsis more quickly. This is not an official definition of sepsis but suggests the patient is at high risk and therefore requires prompt medical attention. People who have sepsis require hospital admission (unless they are too frail to be considered for hospitalisation) and some may require treatment in Critical Care. This may include the Intensive Care Unit (ICU) and/or High Dependency Unit (HDU). We know this can be scary for both the patient and their loved ones, but please be reassured all this additional monitoring and treatment is necessary, and it means they are receiving the best possible care for their condition.

Antibiotics and control of the source of infection remain the best way to treat sepsis as a consequence of bacterial infection (antibiotics will not treat fungal, parasitic or viral infections, for which other treatment can be used). If the source of infection is unknown, then a 'broader spectrum' antibiotic may be used until a source is identified. Delivery of prompt antibiotics is part of a bundle of care (developed by the UK Sepsis Trust) known as the Sepsis Six:

THE SEPSIS SIX

01

Call for senior clinical help

02

Give oxygen if required

03

Send a full set of blood tests

04

Give IV antibiotics (or anti-viral medications as appropriate)

05

Give IV fluids

06

Make a plan for ongoing monitoring with senior doctors and nursing staff

WHAT HAPPENS IN INTENSIVE CARE?

During sepsis the immune system attacks body tissue and organs. This can cause them to fail and not work properly, so this then requires specialised organ support in the Intensive Care Unit (ICU).

The ICU is where the sickest patients in the hospital are treated. The nurses and doctors in the ICU can provide organ support by using specialist equipment and medications for failing or damaged organs, for example the heart, lungs and kidneys. Some examples of equipment and medications sometimes used includes respiratory ventilators, kidney dialysis machines, medications to keep the blood pressure up at a safe level for organ function, and sedative medications to induce a coma to allow for treatment to be given and rest for the body to recover.

Typically, in the ICU nurses look after one patient at a time, sometimes two. This means you or your loved one are able to receive high levels of monitoring and treatment 24/7. The ICU team will often include other specialists like dieticians, physiotherapists and pharmacists.

WHAT HAPPENS AFTER INTENSIVE CARE?

The main goal of treatment in the ICU is to get you or your loved one well enough to be safely transferred to either the High Dependency Unit (HDU), or to a ward for ongoing care and rehabilitation. This move and the change in environment from the ICU can be a big change.

On the ward, the focus of treatment is ongoing medical management and rehabilitation. The input from staff may change, as nurses in the wards look after more than one or two patients, and doctors see patients less frequently than in the ICU. Also, patients are generally not attached to continuous monitoring on the wards. It is important that staff in the ICU prepare patients for the transfer out, discuss what that might be like and what they can expect in terms of care planning.

This is important for a lot of reasons. Patients often still feel uncertain about what to expect or scared about 'what if things go wrong?' The patient might still be confused or not thinking clearly because of the sepsis and/or treatments received in the ICU. Sepsis survivors often will have cognitive changes and trouble with healthy sleep patterns after a sepsis event and being in the ICU, so this transition should not be underestimated.

Moving from the ICU to either the HDU or ward can be a big change for sepsis survivors and their loved ones. It is important to remember that from a medical and nursing perspective this move is a good thing as it is a sign of improvement. But if you are uncertain or have any concerns, speak to the staff involved.

RECOVERY FROM SEPSIS

From the patient's perspective:

Your experience of sepsis is likely to continue to affect you physically and emotionally after you go home. It doesn't matter how old you are, how unwell you were or how healthy or active you were prior to your illness. The fact is that you've been very ill and it may take some time for you to recover.

Having sepsis can be frightening, especially if you've never previously heard of it and are rarely sick. Being admitted to hospital can be a traumatic experience for you, your close relatives and loved ones. Your family, friends and wider support network will be pleased that you're back home, but they may not understand what you went through or why you feel like you do. You will undoubtedly need their support as you recover. However, it's important for everyone to realise that during this process you may look well, but you may not feel well.

Your family, friends and wider support network need to understand this, which is why it's so important to share information on how you're getting on to those closest to you.

From your loved one's perspective:

Watching someone you know and/or love become seriously ill will have been an upsetting experience and it will take time to get over this. Once your relative is home, you might feel relieved that they're out of hospital but a bit anxious about the responsibility of caring for them.

Now that your relative is out of danger, you may have your own reaction to the stress you've been under. This is quite normal and to be expected. You may feel upset, tearful, anxious, depressed or just very tired. Your relative might look and seem different to normal, and you may have to juggle things to find time to look after them. You might begin to realise that this upheaval to your own lifestyle could last for many months - a realisation that may only hit home after discharge. Don't be afraid to ask for help from friends, family, or a health professional. It can also help to talk through what happened, if you feel ready.

If you're finding it difficult to cope, you may find it helpful to speak with a professional counsellor. You're also welcome to join the [Sepsis Support NZ](#) Facebook group, moderated by people with lived experience of sepsis, for support and shared insights.

Online support meetings and workshops run throughout the year - sign up for updates at www.sepsis.org.nz/support. For more information and resources (including videos and podcasts), visit www.sepsis.org.nz.

How long is the recovery?

Recovery will involve your whole body. Around 50% of people who survive sepsis encounter new physical, cognitive, psychological or medical problems during their recovery. A large percentage of these people will go on to make a full recovery, but for some it can be about adapting to a new way of life.

Recovery time varies for each person. It may take a few weeks to a few months, and sometimes longer, depending on factors like age, medical history, and how long you were in hospital. If you've had significant organ damage or an amputation, recovery can be more complex and may involve ongoing care from multiple specialists - your healthcare team can provide specific guidance, so please ask. Further support is available at www.sepsis.org.nz.

COMMON PROBLEMS FOLLOWING SEPSIS

You may encounter one or more of the symptoms listed below as you begin your recovery.

Physical

- Fatigue
- Repeated infections
- Trouble sleeping
- New allergies and sensitivities
- Itchy and dry skin
- Brittle hair and hair loss
- Brittle nails and teeth
- Intolerance of very bright, noisy or crowded spaces
- Temperature sensitivities, often feeling very cold or sweaty
- Joint pains and muscle weakness
- Dizziness
- Headaches
- Nausea
- Breathlessness
- Poor appetite
- Change in taste
- Change in vision
- Reduced kidney function

Cognitive

- Difficulty with short term memory
- Difficulty with concentration
- Problems with speech, for example finding the right words
- Ability to perform tasks you previously found easy

Psychological

- Low mood, mood swings - feeling snappy, irritable, angry or upset
- Lack of interest in things that you previously enjoyed doing & possibly in your personal appearance
- Anxiety about becoming unwell again
- Loss of confidence
- Wondering "what if I hadn't survived?"
- Feeling guilty for the worry everyone experienced, or that you survived
- Remembering some or all parts of your hospital stay, with these thoughts recurring as dreams, nightmares, or "flashbacks"
- Feeling frustrated, isolated or that nobody understands how you may be feeling
- Strain on your relationships
- The development of new medical conditions, or a change in pre-existing conditions

WHEN SHOULD I SEEK EXPERT HELP?

Most symptoms will improve with time as you make adjustments. You will get aches and pains and have good days and bad, just like any other person. This is normal and does not necessarily mean that anything untoward is happening. However, you should speak to your GP if you're still experiencing the following problems more than a month after discharge from hospital:

- Frequent anxiety or worries that interfere with your ability to face day-to-day life
- Low mood or depression impacting your motivation, your opinion of yourself, or your thoughts about the future
- Continued poor sleep, ongoing nightmares or flashbacks
- Change in behaviour
- Difficulty doing previously 'normal' tasks, or looking after the home and family
- Relying on drugs which are not prescribed or drinking a lot of alcohol
- Generally feeling unwell, not improving, or have new concerns about your health

WHAT HELPS WITH RECOVERY?

Time. It's important to take your time getting back to work, study or other activities. Allow yourself time to recover and manage your expectations - there is no standard length of time for this or 'one size fits all' - everyone is different. Whilst it can be helpful to have longer term goals, focus more on your short-term ones and ensure they are realistic.

Plan, pace & prioritise: It can take time to recover physically, so try to pace your activity and don't rush yourself. Remember to work on things you enjoy as well as the "to do" list. Your strength should slowly return as you become more active, but this may take longer than you expect. Try not to overdo it and try to think of your energy a bit like your household budget: don't spend it all on day one, spread it out over the days. It can be helpful to plan and prioritise your activities to further manage your fatigue. Using a diary or planner can be a good way of doing this as it can help you identify any patterns. A diary can also chart your progress and help you to monitor any symptoms that you may want to discuss with your GP. It's important to celebrate your achievements, regardless of how small you feel they may be.

Space to talk: The more often you have the chance to share your thoughts and feelings about what happened in a way that feels comforting to you, the better your recovery. The team at the NZ Sepsis Trust can provide you with support and information about what's happened and what to expect, or reach out to your GP.

Self-care: Look after yourself. Try to eat healthy, nutritious food including fresh fruit and vegetables and drink plenty of water. Preparing meals can be tiring, especially when living on your own. If you struggle with bigger meals, try eating little but more often.

Sleep: You need regular sleep to keep your body healthy. It can take time to get back into a normal routine. You may find it harder to fall asleep, or you may wake more frequently during the night. Your routine should eventually improve but, if it doesn't, contact your GP for advice.

Managing stress & anxiety: As you get better and start doing more, you may face new challenges. One common challenge is accepting that you were ill, understanding what you've been through and focusing on how to get better. This can make you feel scared but, with guidance and support, this should become more manageable.

Light exercise: It's important to keep mobile if possible, but it's quite likely that you won't have the energy to return to normal, and you may have lost muscle tone. There are lots of light exercises you can do, some even seated, that will help you to keep moving, so reach out for physio support from your GP if you need it.

Vaccination: In addition to paying attention to the basics of infection prevention such as washing your hands and keeping cuts clean, it's important to prevent infections through vaccination. Speak to your GP or pharmacist about which vaccinations are right for you, and if you're travelling far overseas make sure you are appropriately protected against tropical diseases.

POST SEPSIS SYNDROME

As we've said, some people find their recovery is longer and more problematic than expected and can encounter all or a variety of the symptoms listed above for many months.

Post Sepsis Syndrome (PSS) describes a variable set of ongoing issues that people encounter for a prolonged period of time. There is no specific treatment for PSS, and whilst most people will get better with time, it's commonly a case of managing the individual problems and looking after yourself while you are recovering.

You can access some further information on PSS here www.sepsis.org.nz

WILL I GET SEPSIS AGAIN?

People who've had sepsis understandably worry about it recurring. Evidence suggests that after an episode of sepsis, people can be more prone to getting further infections, and are therefore at increased risk of sepsis.

If it does recur, it can be from any type of infection, not necessarily the same one the patient experienced originally. This may develop in a similar part of the body that caused the first episode of sepsis - this can be a coincidence but might be due to an underlying health condition. Occasionally, it might be a reactivation of the initial infection if this was undertreated.

The most important thing is to be aware of the symptoms of sepsis, and to seek medical help urgently if you suspect it. The most common signs of sepsis in adults and children are listed on page 10 of this booklet.

HELP AND SUPPORT

The NZ Sepsis Trust: We work to raise awareness of sepsis and support those affected. You can join the [Sepsis Support NZ](#) Facebook group, sign up for our online support groups here: www.sepsis.org.nz/support, or visit our website www.sepsis.org.nz for more information.

Family & friends: Loved ones can help with daily chores like laundry and shopping. They are also there to listen to what you have been through and will need to understand that it may take some time for you to feel better again and back to your old self.

GP: It is important to update your GP with your progress, especially if you had a long Critical Care stay. Your GP can also review your medicines and may be able to offer treatment or refer you to physiotherapy, dietician services, occupational therapy and/or talking therapy.

All or some of these will help you on your recovery journey.



SIGNS & SYMPTOMS OF SEPSIS

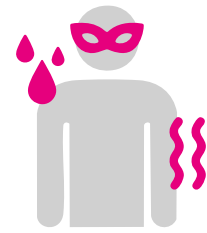
In Adults



RAPID BREATHING
or HEART RATE



CONFUSION,
SLURRED SPEECH or
DISORIENTATION



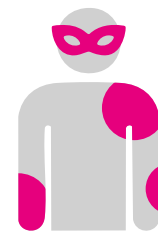
FEVER or
SHIVERING



MUSCLE
PAIN



NOT PASSING
URINE



DISCOLOURED
SKIN

SIGNS & SYMPTOMS OF SEPSIS

In Children



RAPID
BREATHING



SEIZURES, FITS, OR
PERSISTENT VOMITING



FEVER OR COLD
TO TOUCH



SLEEPY, HARD TO
WAKE, OR UNUSUALLY
RESTLESS



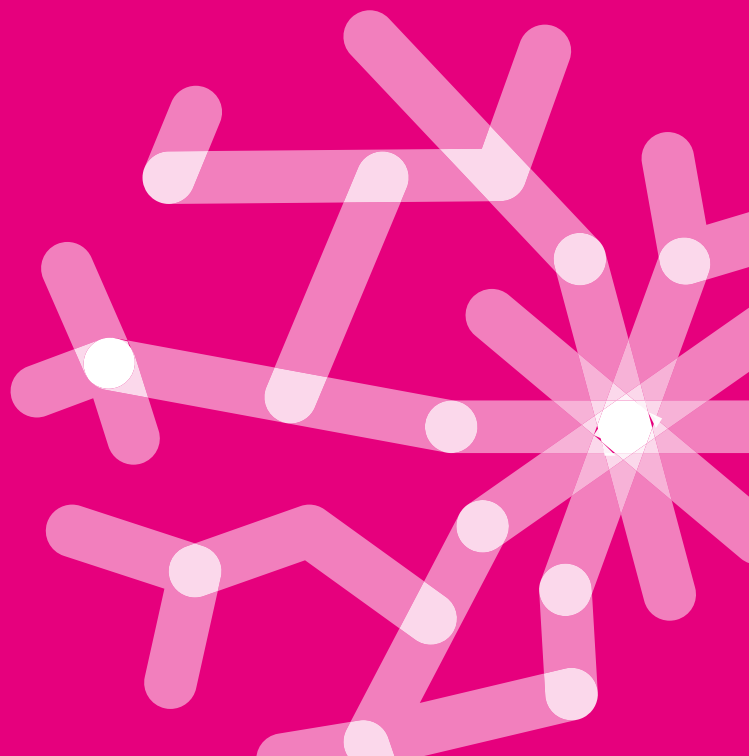
NOT PASSING URINE
OR DRY NAPPY



PALE, BLUE,
OR BLOTCHY
SKIN/RASH



Sepsis
Trust NZ



Scan this QR code to visit our website
and learn more about Sepsis.

  www.sepsis.org.nz

