

Life after sepsis

A guide for survivors,
carers and bereaved families

Sepsis
Australia



An initiative of

The
George
Institute
for Global Health



Better treatments
Better care
Healthier societies

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The value of the lived experience of sepsis cannot be underestimated. It is crucial that resources are developed appropriately for those who need them most.

Much of the material included in this guide has been obtained from sepsis programs recognised internationally as best practice including the:

- Global Sepsis Alliance
- Sepsis Alliance (US)
- UK Sepsis Trust
- New Zealand Sepsis Trust
- NSW Health - Clinical Excellence Commission - Sepsis Kills
- Queensland Health - Clinical Excellence Queensland - Sepsis

The ASN sincerely appreciates access to this material, which has been customised where required to the Australian context.



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The George Institute and the Australian Sepsis Network acknowledges the Gadigal people of the Eora Nation as the First Custodians of the land on which our Australian office is situated. We pay our respect to Elders past, present and emerging.

Introduction

Sepsis is a life-threatening condition that occurs when the body's response to an infection injures its own tissues and organs. It is estimated that at least 55,000 people develop sepsis and of those there are 8,000 deaths in Australia each year.¹

It is normal for the body's immune system to fight infection from any source, whether it be a throat infection, chest infection, urinary tract or even a minor injury. The inflammation that occurs kills germs and enables repair and recovery. In some people the inflammatory cycle is uncontrolled and disproportionate, leading to the body being damaged and in severe cases organ failure.

The reason some people develop sepsis from an infection is not well understood. Research continues into the cause, early recognition, best treatments and how to provide physical and psychological support following sepsis.

Prevention and early recognition are key to reducing sepsis and achieving the best outcomes for people who develop sepsis.

Treatment of sepsis requires appropriate administration of intravenous antibiotics as soon as possible following blood cultures being obtained. It is not possible to catch sepsis or pass it on to others.

Most people who develop sepsis will require hospital admission and some may require treatment in critical care or intensive care unit (ICU). Survivors may have no memory of their time in critical care, or very confused memories of what happened. This is due to critical illness, strong drugs and other treatments. Many survivors will have:

- Experienced confusion and hallucinations, or delirium
- Felt slightly aware but didn't know where they were or what was happening and could not sleep
- Had nightmares or thought things were happening which were not real and can be very frightening
- Been unable to talk or let people know what they were feeling.

Leaving the critical care unit to transfer to a hospital ward can be frightening especially as the nurse to patient ratio is lower making many patients and their families apprehensive. Increasingly, hospitals have a critical care outreach team of nurses and doctors who will visit the ward to make sure recently transferred patients are ok. They will be able to answer any questions about what happened in critical care, your treatment or any other worries you have. If there isn't an outreach team at the hospital, speak to the ward nurses about any concerns you have.

See frequently asked questions about sepsis:

www.worldsepsisday.org/sepsisfaq

Bereaved Families

Sepsis is a very serious illness that can result in serious injury or death. It can be a terrible shock if your relative dies of sepsis because the illness can move very quickly and they may have been in good health before it happened. It may be difficult for you to remember what happened, so it may help to ask the nurses and doctors about anything you don't understand.

You may find it hard to believe that your relative has died especially if it happened very quickly. Talk to your friends and family and ask for any help that you need. It may help you to talk to a bereavement counsellor because they can offer support and understanding to adults and children who have lost a relative or friend.

Talk to your GP and request a referral to a bereavement counsellor. However, an important first step is to contact sepsis support and advocacy groups who have lived experience with sepsis and with losing loved one's. Please see the resource section of this information package for organisations and contacts.

Damian, father of Maddy (1998-2017)

As an 18-year-old Honours Law student, Maddy was intelligent, beautiful, very independent, wickedly funny with sarcastic undertones (sometimes irreverent) and a great lover of all of God's creatures, in particular dogs. Maddy was larger than life, a high achiever that typically got what she wanted, through sheer dedication and perseverance. Maddy contracted Influenza and just over one week later died from Sepsis. Please educate yourself, your family and friends about Sepsis. Share Maddy's story. Get the flu shot, know the signs of sepsis and if concerned always ask 'Could this be Sepsis?'

Learn more about Maddy's story at

www.maddyjonesfoundation.com.au/maddy

Survivor Recovery After Sepsis

Sepsis affects your whole body, so ongoing symptoms and recovery will involve your whole body. Many people encounter new physical, cognitive, psychological and emotional problems during their recovery from sepsis. It is normal to go through a period of recovery. The majority of patients who survive their encounter with sepsis will eventually make a full recovery.

Recovery time varies for each person. Generally, it can take a few weeks to a few months, but for some people it can take longer. There are contributing factors that can influence recovery from sepsis such as age, medical history and length of hospital stay. For those people who have suffered organ damage and/or have undergone amputations as a result of sepsis, recovery will take time and often involve ongoing treatment. If you have suffered organ damage and/or had amputation further specific information will be provided to you by your healthcare providers and in this support package.

Rehabilitation starts when you are in hospital by slowly beginning to move around and look after yourself again. For example, washing yourself, sitting up, standing and then walking, taking yourself to the toilet etc. Nurses, physiotherapists and occupational therapists will work with you to improve your mobility and strength.

Discharge planning should commence early during your hospital stay to ensure a coordinated and smooth transition to rehabilitation and community health services. Support is also available through support organisations and peer groups. Details on some of these is provided in this information pack.

For a short information video on post sepsis recovery see:

www.youtube.com/watch?v=Hlk64wdy44Q²

#sepsis
survivors
may suffer
life-long
disability & health
problems

Post Sepsis Syndrome

Post-sepsis syndrome (PSS) is a condition that affects up to 50% of sepsis survivors. It includes physical and/or psychological long-term effects. The risk of having PSS is higher among people admitted to an ICU and for those who have been in the hospital for extended periods of time. While PSS can affect people of any age, older severe sepsis survivors are at higher risk for long-term cognitive impairment and physical problems.

Problems ranged from no longer being able to walk to not being able to participate in everyday activities, such as bathing, toileting, or preparing meals. Changes in mental status can range from no longer being able to perform complicated tasks to not being able to remember everyday things.

For some patients, the cause of their PSS is obvious. Blood clots and poor blood circulation while they were ill may have caused gangrene, resulting in amputations of fingers, toes, or limbs. Damage to the lungs can affect breathing. Sepsis survivors may be more vulnerable to developing viral respiratory (lung) infections. Other organs may be damaged as well, such as the kidneys or liver.

These lasting physical issues can be explained, but there is more to PSS that cannot yet be explained, such as the disabling fatigue and chronic pain that many survivors experience. Others report seemingly unrelated problems, like hair loss that may occur weeks after their discharge from hospital.

Many sepsis survivors also report symptoms of post-traumatic stress disorder (PTSD). Researchers have already recognised that ICU stays can trigger PTSD, which can last for years. It is important to note that PSS does not happen only in older patients or in those who were already ill.

New deficits can be relatively more severe among patients who were in better health beforehand, possibly because there is less room for further deterioration among patients who already have poor physical or cognitive function prior to the sepsis episode. In other words, healthy people may be expected to rebound quickly from such a serious illness, but they may actually have the opposite experience.

Common Problems in Recovery

Sepsis survivors can experience cognitive, emotional and/or physical complications.³ Initially survivors are likely to feel weak and find doing simple tasks more difficult, but this should improve over time. The list provided below represents a range of potential complications but is not exhaustive:

- Fatigue
- Difficult concentration
- Short term memory loss
- Speech, e.g. finding the right words
- Dizziness
- Headaches
- Nausea
- Poor appetite
- Change in taste
- Change in vision
- Trouble sleeping
- Intolerance of bright, noisy or crowded spaces
- Breathlessness
- Temperature sensitivities, often feeling cold or sweating
- New allergies and sensitivities
- Repeated infections
- Itchy and dry skin
- Brittle hair and hair loss
- Brittle teeth and nails
- Joint pains and muscle weakness
- Reduced kidney function

Post-ICU syndrome (PICS) is a recognised problem that can affect patients who have spent time in an ICU. It is more likely among patients who have been sedated or placed on a ventilator. It is not unusual for someone in an ICU to become delirious – sometimes called ICU delirium. The longer a patient is in such a unit, the higher the risk of developing delirium or PICS. The difference between PICS and PSS rests in the other issues that a sepsis survivor may experience, as PSS is not just a change in cognitive function.

Survivors have described that after discharge from hospital, during their sepsis recovery, they tried returning to work but encountered difficulty completing task that were previously quite simple. Through talking with support groups and health professionals they realised that this is part of the normal recovery and will improve over time though the time taken for each person varied.

Emotional and Psychological Affects

Compounding potential complications can be a number of emotional and psychological challenges. These can occur singularly or in combination and often represent the most debilitating factors during recovery and can include.⁴

- Mood swings consisting of irritability, feeling low or becoming angry
- Disinterest in activities, surroundings and possible personal appearance
- Anxiety and a loss of confidence
- Frustration and/or isolation
- Self-doubt about survival and feeling guilty for the burden on others
- Remembering your sepsis episode in flashbacks, dreams or nightmares
- Strain on interpersonal relationships.

Fiona Gray – Sepsis survivor

I had been suffering a recurring sore throat for months and thought I was just run down being a new mum. In the early hours of 12 July 2015, I was settling my daughter after she'd woken and as I left her room I banged my elbow quite hard. I developed a golf ball size swelling on my elbow, extreme pain and within two hours I was shivering uncontrollably and rocking back and forth screaming for my husband to take me to hospital. I went to surgery and ended up on life support. It took me a good 3 months to feel remotely normal but I have recovered with some ongoing side effects like memory loss and brain fog, weakened immune system, fever and chills but I am slowly improving.



For more information and to talk to someone see my Australia and NZ Sepsis Support Group at www.facebook.com/groups/1282752471763476

Be reassured that it is normal and common to experience physical, cognitive and psychological problems after any serious illness, not just sepsis. Give it time and seek support as you need it – you are not alone in your recovery.

WORLD SEPSIS DAY INFOGRAPHICS

POST-SEPSIS SYMPTOMS
Sepsis Does Not End at Hospital Discharge

- Sadness
- Difficulty Swallowing
- Muscle Weakness
- Clouded Thinking
- Difficulty Sleeping
- Poor Memory
- Difficulty Concentrating
- Fatigue
- Anxiety

Global Sepsis Alliance | www.worldsepsisday.org | September 13, 2020
www.global-sepsis-alliance.org | World Sepsis Day

It is important to take your time getting back to work, study or other activities. It may be advisable to discuss a phased return to work with your GP or Occupational Health Team at work to assist with the recovery process. If you are currently in higher education, you may find it useful to talk to student services or academic advisor.

Sepsis:

Post-sepsis symptoms

Possible post-sepsis symptoms are:

- Neuromuscular weakness
- Chronic pain
- Post-traumatic stress disorder
- Cognitive impairment
- Depression

Incidence of post-traumatic stress disorder¹

Event	Incidence (%)
Rape	55.5%
War	38.8%
Intensive care unit survivors	22%
Physical violence	11.5%
Fire/Natural disasters	4.6%

Sepsis accounts for 50–60 % of ICU cases.¹

Sepsis and Amputations

Sepsis can do a lot of harm to the body, from shutting down the body's organs to causing blood clots that block the flow of your blood. When someone has sepsis, the blood clotting mechanism begins to work overtime. While blood is supposed to clot when it's exposed outside the body, like a cut finger, it's not supposed to do this inside blood vessels. With sepsis, tiny blood clots can form throughout blood vessels, making it difficult for blood to pass and bring vital oxygen and nutrients to the organs and tissues. As the small blood clots build up, they can block the blood vessels completely.

When oxygen and nutrients can't get to the tissues in the fingers, hands, arms, toes, feet, and legs, the tissues begin to die and develop gangrene. At first, the skin may look mottled, bluish purple, and then finally black as the tissue dies. Dead tissue must be removed because it can cause infection to spread. If the gangrenous area is small enough, the surgeon may be able to remove just enough to stop further spreading. However, if the damage is extensive, an amputation may be needed.

When the decision is made to perform an amputation, the surgeon must decide at what level it needs to be done. The decision is based on ensuring that enough tissue is removed to make certain that all damaged tissue is gone, while trying to preserve the patient's independence and mobility as much as possible.

After the surgery has begun, the surgeon may have to do a larger amputation than originally planned. Much of the procedure depends on the condition of the muscles and the skin and sometimes this isn't obvious before the surgery. Once the amputation is complete, the surgeon has two options: leave the site open or close it up right away. An open site, where the incision is not sewn or stapled closed, allows the doctors and nurses to monitor for and remove any infected tissue that might have been left behind. If this procedure is chosen, the surgeon will close up the flap once he or she is sure that the site is completely clean and infection-free.

Limbs 4 Life is a peer group organisation that aims to empower amputees with knowledge and support, provide information and support to amputees and their families while promoting an inclusive community. For more information see www.limbs4life.org.au.

Sepsis and Antibiotic Resistance

Antibiotic resistance refers to infections caused by bacteria that cannot be treated with traditional antibiotics. According to the World Health Organization (WHO), antibiotic resistance is an increasingly serious threat to global public health.

Most bacteria that we are exposed to every day are harmless. They are everywhere, including on our skin, in our mouth, and in our gut. However, some bacteria are harmful if they get inside the body, where they cause an infection that can lead to death if left untreated.

Antibiotics treat or stop infections in one of two ways: they either kill the bacteria outright or they stop their ability to reproduce, so that they stop spreading and causing further harm. If an illness is caused by a virus or a fungus, antibiotics have no effect. However, anti-viral and anti-fungal drugs are available that may be appropriate. As a group, these are referred to as anti-microbial agents or drugs.

Not all types of antibiotics can kill all types of bacteria, so researchers continue to look for newer and better antibiotics to try to treat all types of infections. The most commonly known “superbug,” or antibiotic-resistant bacteria is Methicillin-Resistant Staphylococcus Aureus (MRSA), first found in 1961. As the years passed, MRSA became resistant to the most commonly used antibiotics: penicillin, methicillin, tetracycline, and erythromycin. A newer drug, vancomycin, did treat MRSA, but it was expensive and doctors tried to use vancomycin sparingly to reduce the risk of MRSA mutating again. In 2002, Vancomycin-Resistant Staphylococcus Aureus (VRSA) was found. Enterococcus, a common cause of urinary tract infections, often becomes resistant to vancomycin and is called Vancomycin-Resistant Enterococcus (VRE).

The race for new antibiotics continues, but there is a real concern that bacteria will mutate and we will not yet have an effective treatment. It is essential to educate people about the proper use of antibiotics. Using too little or too short a course of antibiotics for a specific infection may result in bacteria mutating and becoming resistant. The reverse can happen as well – resistance can result from antibiotics being used for longer than necessary or not taking a prescription as instructed.

Supporting Your Recovery

Many things can be done to support yourself during your recovery period, including:

- **Time:** allow yourself time to recover. There is no standard length of time for this or a one size fits all, and recovery time varies greatly.
- **Pacing:** physical recovery is gradual so pace your activity and do not rush yourself. Work on things you enjoy as well as a “to do” list, even if you do not feel like doing much.
- **Strength:** this will slowly return as you become more active but this may take longer than you expect. Conserve your energy and don't overdo it too quickly.
- **Talk:** taking the opportunity to share your thoughts, feelings and concerns will benefit your recovery. Participation in a sepsis support group is highly recommended particularly where other members have experienced similar consequences from sepsis.
- **Self-care:** look after yourself by eating 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 have little appetite when you leave hospital, try eating little but more often if you struggle with bigger meals.
- **Sleep:** you need regular sleep to keep your body healthy. It can take time to get back into a normal sleep routine. You may find it harder to fall asleep, or you may wake more frequently during the night. Sleep should eventually improve but, if it doesn't, contact your GP for advice about improving sleep.
- **Stress and anxiety:** as you get better and start doing more, you may face new challenges. One common challenge is accepting that you were ill, understanding the illness and focusing on how to get better. Manage this through your immediate support people and through survivor support groups.

- **Diary:** keeping a daily diary documenting your physical symptoms and feelings, sleep and activity can be both therapeutic and useful. A diary can chart your progress and can help you to monitor any symptoms that you may want to discuss with your GP. It is important to celebrate your achievements, regardless of how small you feel they may be.
- **Exercises:** it is important to keep mobile if possible, but you may not have energy to do the same amount of exercise that you were doing before you were ill and may have lost muscle tone. Do light exercise to improve strength, balance, and flexibility.
- **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 the vaccinations that are right for you, and if you're travelling overseas make sure you are appropriately protected against tropical disease.
- **Antibiotic resistance:**⁵ During recovery you may experience a number of infections that need to be assessed quickly by a health professional. To avoid development resistance:
 - Refrain from insisting on an antibiotic for illnesses not caused by bacteria such as influenza, cold or sore throat (unless confirmed as a Strep throat).
 - Do not take an antibiotic prescription that was not prescribed for you. In other words, don't take a relative's or friend's antibiotic because you think you may have the same infection.
 - Complete the full prescription as directed, including number of times of day, the correct dosage, in the correct way, for the full length of time, regardless of how well you may feel, unless otherwise directed by your doctor.
 - Practicing infection prevention by thorough and frequent hand washing, avoiding people who have infections, and getting recommended vaccinations.

Getting Sepsis Again

People who have had sepsis worry about it recurring, which is to be expected. Evidence suggests that for a period of time during recovery, people can be more prone to getting infections and therefore be at increased risk of sepsis.

Compared to non-sepsis admissions, sepsis survivors have a greater risk of readmission, usually for treatment of unresolved, recurrent or new infection. The reasons for recurring infections post sepsis are poorly understood – it may be a result of immunosuppression from a persistent compensatory anti-inflammatory response to the initial pro-inflammatory storm. These recurring infections can be particularly distressing for survivors and wearing both physically and emotionally; each time impacting on the small improvements that have been made. Many survivors live in constant fear and anxiety about the prospect of acquiring another infection and become preoccupied with the prospect that they may develop sepsis again. If sepsis does recur, it could have been caused by the original infection or by a new infection.

The most important thing is to be aware of the symptoms of sepsis and seek medical help urgently if you suspect it.

#StopSepsis
the **Symptoms:**
fever, rapid heart rate,
rapid breathing &
confusion

Mary, mother of Preston

In 2003, Preston, was diagnosed with pneumonia, which caused an acute lung injury. This injury allowed a secondary infection to take hold which lead to sepsis. Within hours, her brave little boy passed away. Mary believes that you know your child better than anyone so it is critical that you tell health professionals any concerns you have and don't be afraid to ask "Could this be sepsis?"



Getting Help and Advice

Everyone's response to sepsis is specific to the individual. Subsequently, some survivors will experience mild short-term cognitive, emotional and/or physical complications. A discharge referral letter from the hospital that treated your sepsis should be obtained and a copy provided to your GP during a post sepsis consultation to pre-empt potential symptoms and complications.

Most symptoms, such as general aches and pains, will improve with time as you recover and make adjustments. However, consult your GP if you are still experiencing the following problems more than a month after discharge from hospital:

- Frequent anxiety or worries that interfere with ability to face day-to-day life
- Low mood or depression, impacting on 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
- Using drugs (prescription/non-prescription/recreational) or heavy alcohol use.

Assessing these symptoms in association with a recent sepsis episode will better inform the most appropriate intervention and support required. Other survivors experience more severe long term cognitive, emotional and/or physical complications that require a comprehensive, proactive management plan to maximise comfort, functionality and quality of life.

Key to facilitating this approach is actually confirming that you had sepsis and conveying this information to your GP and primary carers so that symptoms are assessed within the context of sepsis. This may vary and broaden the recovery and rehabilitation management plan. A sepsis fact sheet can also be provided if required (see example Appendix 1).

A significant challenge reported by survivors and their families is knowing how to explain their concerns to health professionals and describing the signs and symptoms of sepsis or ongoing complications. Language and terminology are important to not only ensure early recognition of sepsis or potential problems but to also assess each person comprehensively and not just by discreet symptoms. Remember to always ask “Could this be sepsis?”, especially when the seeking help for children or adults than cannot verbalise how they feel (see Appendix 2).

As sepsis survivor’s progress through their recovery, there should be regular and ongoing physical and psycho-social reassessments and adjustments to management plans, rehabilitation goals and the type of services accessed for support. This process should commence prior to discharge from hospital after sepsis with referrals and notifications to community and primary care providers having been made on behalf of the survivor and their family. An example of a post sepsis discharge checklist is provided at Appendix 3. An additional reference is the guidance provided by the Australian Commission on Safety and Quality in Health Care on the structure and content of a comprehensive discharge plan (see link in footnote⁶).

Matt Ames – Sepsis survivor

Matt was 39 years old when what started as a sore throat resulted in the loss of all four of his limbs. He had contracted streptococcal resulting in septic shock and was never expected to survive. Since his limbs were removed, Matt has been faced with incredible challenges but has focused on his rehabilitation and sharing his story of resilience with others. Matt has beaten the odds, spurred on by the fact that he is the father of four young children nine and husband to Diane, who is determined to grow old with him.



For more on Matts story see www.australiansepsisnetwork.net.au/sepsis-stories/matt

The US based Sepsis Alliance⁷ provides valuable information on a series of factors that may increase the likelihood of sepsis and alter the course of detection, treatment and recovery.

See www.sepsis.org/sepsis-basics/sepsis-and for more information on:

- Aging
- Amputations
- Animal Bites
- Antibiotic Resistance
- Autoimmune Diseases
- Bacterial Infections
- Burns
- Clostridium Difficile (C. diff)
- Cancer
- Cellulitis
- Children
- Chronic Obstructive Pulmonary Disease
- Coronavirus (COVID-19)
- Dementia
- Diabetes
- Fungal Infections
- Group A Streptococcus
- Group B Streptococcus
- Healthcare-Acquired Infections
- HIV/AIDS
- Influenza
- Intestinal E. Coli Infections
- IV Drug Use
- Joint Replacements
- Kidney Failure & Transplants
- Liver Disease
- Long-Term Care
- Nutrition (Post Sepsis)
- Pneumonia
- Post-Traumatic Stress Disorder
- Pregnancy & Childbirth
- Pressure Ulcers
- Surgery
- Urinary Tract Infections
- Viral Infections
- Plus more subjects

Some practical considerations:⁸

Physical mobility and independent living:

- During discharge planning and ongoing through recovery, physical mobility aid requirements and modifications to the patient's home environment should be assessed and organised to support access and ensure safety.
- Disability support - engage the Social Worker to provide guidance and to advocate for access to care and social support services in the short and long term.

Work & employment

- Sepsis survivors may find it difficult to cope with their previous workload and stressful to return to work. Most employers will be supportive but as the term sepsis and its potential consequences are not well understood, relevant information should be provided to all employers before returning to work. Employers have a duty to make reasonable adjustments to working practices to accommodate their employees. This includes:
 - Not refusing employment due to disability or illness
 - Providing time for medical appointments
 - Disregard any disability-related absences
 - Reasonable workplace adjustments such as working hours, workstations and physical access
- Legal considerations - decision making when someone is no longer able to make decisions. In some situations, family members may no longer be able to take care of their own finances, health, or welfare, as a result of suffering from sepsis. If a loved one has lost the capacity to do this, you may need to seek legal support ensuring their financial affairs including establishing a lasting power of attorney and creating a Statutory Will on behalf of the loved one. Speak to the social worker in the first instance for guidance on the correct processes and requirements.

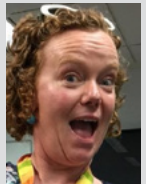
Resources

The Australian Sepsis Network (ASN) is a national collaborative of experts and consumer advocates for sepsis survivors and bereaved families. These groups and individuals lead the fight against sepsis through state based programs on clinical care and research, and local action to raise awareness and improve support. The ASN website provides a comprehensive range of resources and links to clinical experts and consumer advocacy and support groups, to improve your understanding of sepsis and post sepsis recovery.

Please see: www.australiansepsisnetwork.net.au



Mandy Mccracken – Sepsis survivor

In 2013, Mandy lost her hands and feet to sepsis. It began with a fever, vomiting and diarrhoea and led to a ten month long hospital stay. Now with the aid of prosthetic hands and legs, Mandy has returned to driving, gardening, cooking and she has even gone back to occasionally rock climbing. With the help of her husband and their three daughters, Mandy is continuing to live a vibrant and fun filled life. After meeting other quadruple amputees, Mandy and fellow amputee, Korrin Barrett began the Quad Squad. The worlds only support group for people specifically missing all four limbs, the Quad Squad now has over 230 members and is a place to connect and support one another. Meeting biannually in Australia, Mandy facilitates the Quad Squad Muster, where quadruple amputees share tips and ideas as well as hear from industry experts.



To learn more see: www.australiansepsisnetwork.net.au/sepsis-stories/mandy-mccracken

Sepsis Support Groups

Who		Contact
	ANZ Sepsis Support Group (National/ SA)	www.facebook.com/groups/1282752471763476
	T for Thomas (NT)	www.tforthomas.com
	Maddy Jones Foundation for Sepsis Prevention (QLD)	www.maddyjonesfoundation.com.au
	Renovating Matthew (QLD)	www.renovatingmatthew.com
	Movement for Mia (QLD)	www.movementformia.org
	Reaching for Korina (NSW)	www.reaching4korina.com.au
	Mandy & Rod McCracken (VIC)	www.mandyandrodmccracken.com
	Sepsis Awareness Tasmania	www.facebook.com/Sepsis-Awareness-Tasmania-348691578989266

Bereavement Support

Health services can refer you to their linked bereavement services. If that does not occur or you wish to use another, see the following options (please note that no specific service is being recommended and choice is at the discretion of the bereaved):

- Australian Centre for Grief and Bereavement (National)

253 Wellington Road
MULGRAVE VIC 3170
Australia.

Phone: (03) 9265 2100 OR Free call: 1800 642 066

Email: info@grief.org.au Web: www.grief.org.au

- Associated Counsellors & Psychologists Sydney PTY LTD

35 locations across NSW

Phone: (02) 8205 0566

www.counsellingsydney.com.au/grief-bereavement

- Queensland Government, Grief Counselling and Support

www.qld.gov.au/health/support/loss/coping

- Children's Health Queensland Hospital and Health Service

Directory of support services for bereaved families

www.childrens.health.qld.gov.au/service-bereavement-support-directory

- Grief Link, South Australia Health and University of Adelaide

www.grieflink.org.au

National, State and Territory Programs

- Health Direct – Sepsis

www.healthdirect.gov.au/sepsis-septicaemia

- New South Wales: Clinical Excellence Commission – Sepsis Kills Program

www.cec.health.nsw.gov.au/keep-patients-safe/Sepsis

- Northern Territory: NT Health Sepsis Management Plan

www.digitallibrary.health.nt.gov.au/prodjsui/bitstream/10137/7775/1/NT%20Health%20Sepsis%20Management%20Plan.pdf

- Queensland: Clinical excellence Queensland – Sepsis

www.clinicalexcellence.qld.gov.au/priority-areas/safety-and-quality/sepsis

- South Australia: SA Health Sepsis

www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/clinical+resources+a+--+z/sepsis+for+health+professionals

- Victoria: Better Care – Think Sepsis Act Fast

www.bettercare.vic.gov.au/our-work/innovation-fund/scaling-projects/sepsis-scaling

Queensland Paediatric Sepsis Program - Family Support Network

<https://www.childrens.health.qld.gov.au/chq/information-for-families/sepsis/support/>

Queensland Paediatric Sepsis Program - Peer Mentor Program

<https://www.childrens.health.qld.gov.au/chq/information-for-families/sepsis/support/>

International Programs

- Global Sepsis Alliance has a mission to provide global leadership to reduce the worldwide burden of sepsis. The GSA was founded in 2010 with the aim to raise awareness and reduce the burden of sepsis worldwide. More than 100 organisations have joined the Global Sepsis Alliance.

www.global-sepsis-alliance.org/sepsis

- Centres for Disease Control and Prevention – I survived sepsis, what's next?

www.cdc.gov/sepsis/life-after-sepsis/index.html

- Sepsis Alliance (US) has produced a library of Sepsis Information Guides on dozens of topics including topics such as Life After Sepsis, Aging, Amputations, Dental Infections, Diabetes, Influenza, and more.

www.sepsis.org/education/resources/sepsis-information-guides

- UK Sepsis Trust exists to fight this life-threatening condition, stop preventable deaths and support those affected by sepsis.

www.sepsistrust.org/get-support/support-for-survivors/post-sepsis-syndrome

- New Zealand Sepsis Trust aims to champion research, awareness and advocacy by promoting clinical tools, providing education and fundraising to build awareness and sepsis research capability.

www.bpac.org.nz/guidelines/4

Appendix 1 Sepsis Fact Sheet



SEPSIS INFORMATION GUIDES



Life *after* Sepsis

ABOUT SEPSIS

What is sepsis?

Sepsis is the body's overwhelming and life-threatening response to an infection, which can lead to tissue damage, organ failure, and death.

What causes sepsis?

Any type of infection that is anywhere in your body can cause sepsis, including infections of the skin, lungs (such as pneumonia), urinary tract, abdomen (such as appendicitis), or other part of the body. An infection occurs when germs enter a person's body and multiply, causing illness, organ and tissue damage.

Are there different types of sepsis?

Severe sepsis occurs when sepsis progresses, causing organ dysfunction. This is the stage before septic shock. Septic shock develops when the blood pressure drops to dangerously low levels.

WHAT COMES NEXT?

What are the first steps in recovery?

After you have had sepsis, rehabilitation usually starts in the hospital by slowly helping you to move around and look after yourself: bathing, sitting up, standing, walking, taking yourself to the restroom, etc. The purpose of rehabilitation is to restore you back to your previous level of health or as close to it as possible. Begin your rehabilitation by building up your activities slowly, and resting when you are tired.

How will I feel when I get home?

You have been seriously ill, and your body and mind need time to get better. You may experience the following physical symptoms upon returning home:

- General to extreme weakness and fatigue
- Breathlessness
- General body pains or aches
- Difficulty moving around or sleeping
- Weight loss, lack of appetite, food not tasting normal
- Dry and itchy skin that may peel
- Brittle nails
- Hair loss

It is also not unusual to have the following feelings once home:

- Unsure of yourself
- Not caring about your appearance
- Wanting to be alone, avoiding friends and family
- Flashbacks, bad memories
- Confusing reality (e.g., not sure what is real and what isn't)
- Feeling anxious, more worried than usual
- Poor concentration
- Depressed, angry, unmotivated
- Frustration at not being able to do everyday tasks

What can I do to help myself recover at home?

- Set small, achievable goals for yourself each week, such as taking a bath, dressing yourself, or walking up the stairs
- Rest and rebuild your strength
- Talk about what you are feeling to family and friends
- Record your thoughts, struggles, and milestones in a journal
- Learn about sepsis to understand what happened
- Ask your family to fill in any gaps you may have in your memory about what happened to you
- Eat a balanced diet
- Exercise if you feel up to it
- Make a list of questions to ask your healthcare provider when you go for a check up

Are there any long-term effects of sepsis?

Many people who survive sepsis recover completely and their lives return to normal. However, older people, people who have suffered more severe sepsis and those treated in an intensive care unit are at greatest risk of long-term problems, including suffering from post-sepsis syndrome.

What is post-sepsis syndrome (PSS)?

Post-sepsis syndrome is the term used to describe the group of long-term problems that some people with severe sepsis experience. These problems may not become apparent for several weeks (post-sepsis), and may include such long-term consequences as:

- Insomnia, difficulty getting to or staying asleep
- Nightmares, vivid hallucinations, panic attacks
- Disabling muscle and joint pains
- Decreased mental (cognitive) functioning
- Loss of self-esteem and self-belief
- Organ dysfunction (kidney failure, respiratory problems, etc.)
- Amputations



What's normal and when should I be concerned?

Generally, the problems described in this fact sheet do improve with time. They are a normal response to what you have been through. Some hospitals have follow-up clinics or staff to help patients and families once they have been discharged. Find out if yours does or if there are local resources available to help you while you get better. However, if you feel that you are not getting better, finding it difficult to cope, or continue to be exhausted call your healthcare provider.

Where can I get more information?

Sepsis Alliance was created to raise sepsis awareness among the general public and healthcare professionals. Sepsis Alliance offers information on a variety of sepsis-related topics. Please visit sepsis.org/library to view the full series of Sepsis Information Guides. You can also check postsepsissyndrome.com for information on post-sepsis syndrome.

To learn more about sepsis,
visit us online at Sepsis.org



SEPSIS ALLIANCE

Suspect Sepsis. Save Lives.

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Appendix 2 Could this be sepsis?

Queensland Health

Could this be sepsis?

Sepsis is a medical emergency and needs immediate treatment.

It happens when the body is fighting an infection but it starts to attack itself. Sepsis can damage the heart, blood vessels, lungs, kidneys and blood clotting systems, and can even cause death. The best chance of getting better from sepsis is to treat it quickly.

Knowing if your child has sepsis is tricky because many of the initial symptoms of sepsis are like those we see in common mild infections. 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.

Sepsis is rare but any child can develop sepsis and we all need to know what to look for. You know your child best and we need you in our team.

Trust your gut feeling

If you feel your child is **more unwell than ever before** or **this illness is different from other times** - just ask your doctor or nurse "Could this be sepsis?"

Knowing the signs of sepsis

Any **ONE** of these may mean your child is **critically unwell**.

Come to hospital straight away - DON'T DELAY.



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Queensland
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Signs and symptoms of serious illness in children who may have sepsis:

Any infection can cause sepsis. Most infections in children are caused by viruses and they will get better in a few days with care at home. Some infections need treatment with antibiotics to get better. The list below has some of the signs and symptoms in children who are sick. These may also mean a child is sick with sepsis.

If you think your child is not getting better, or they are getting sicker, **trust your gut feeling**. Tick the boxes of the signs and symptoms your child has, and ask your doctor or nurse **“Could this be sepsis?”**.



Temperature

- Shivering or shaking with a fever
- Low temperature (less than 36°C)
- High temperature (more than 38°C) for 5 days or more
- High temperature (more than 38°C) in a baby 3 months or younger



Pain

- Headache, neck, muscle, chest, bone or joint pain for no obvious reason
- Pain relief is not working



Breathing

- Grunting noises when breathing
- Working harder to breathe – sucking under the ribs or caving in of the breast bone
- Nostrils that move in and out (flare) with each breath
- Crackly noises from the chest



Skin

- Cold hands and feet
- Skin painful to touch
- Bright red skin all over
- Rash



Activity and movement

- Can't concentrate
- Can't stay awake
- No interest in playing
- Not interested in what is happening around them
- Irritable and won't settle
- Restlessness
- Unable to walk or refusing to walk
- Not using an arm, leg, hand or foot for no obvious reason
- Feeling more unwell than they have before



Toileting

- No urine (wee) or wet nappies for 12 hours or more
- Fewer nappies and not as heavy as usual
- Blood in the faeces (poo)
- More than 5 watery diarrhoea (poo) episodes in 24 hours



Eating and drinking

- Unable to keep any fluids down because of vomiting
- Vomit that is green or black or has blood in it
- Not interested in drinking or feeding
- Very thirsty
- Dry mouth, lips and tongue

We know that illnesses can change. Trust your gut feeling. Even if your child has recently been seen by a doctor, if you think your child may have sepsis come back to the hospital and just ask

“Could this be sepsis?”

Appendix 3 Post Sepsis Discharge Checklist

Planning	Notes/Contacts
1. Discharge letter to GP confirming a sepsis diagnosis, mechanism and type of infection, and potential post sepsis issues. Uploaded to My health record?	
2. Discharge plan provided with relevant referrals and follow up appointments made, and introduction to peer sepsis support group confirmed. Uploaded to My health record?	
3. Name and contact details of hospital-based coordinator for post sepsis care.	
4. Name and contact details of community-based coordinator for post sepsis care.	
5. Post discharge follow up appointment made with confirmation of who should attend and are there any test results required for the appointment?	
6. Sepsis fact sheet for health professionals	
7. Medications prescribed and dispensed with accompanying information on: <ul style="list-style-type: none"> - Whether the medications have changed to those taken before admission? - Type, dose, frequency and how to administer - How often should I take pain relief if required? - How to assess if effective? - When should I call my doctor about my pain? 	
8. Do I require a special diet or other specific nutritional supplements?	
9. Do I have any physical restrictions such as driving or certain types of activities?	
10. When can I return to work/school and are there any restrictions or conditions?	
11. If required, has home care/services been arranged such as Nursing, Physiotherapy, occupational therapy and Transport	
12. If required, have physical aids been organised?	
13. If wound care is required, what is the procedure and where do I get supplies?	
14. What complications should I watch for and who do I contact if concerned?	

References

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- 2 Sepsis Alliance: www.sepsis.org/sepsis-basics/post-sepsis-syndrome
- 3 UK Sepsis Trust www.sepsistrust.org/about
- 4 Global Sepsis Alliance www.global-sepsis-alliance.org
- 5 Sepsis Alliance – Sepsis and Antibiotic Resistance: <file:///C:/Users/bab-benbroek/Downloads/Sepsis-AntibioticResistance-v2.pdf>
- 6 The Australian Commission on Safety and Quality in Health Care. National guidelines for on-screen presentation of discharge summaries. Sydney: ACSQHC; 2017.
www.safetyandquality.gov.au/sites/default/files/2019-06/National-guidelines-for-on-screen-presentation-of-discharge-summaries-Sep-2017.pdf
- 7 Sepsis Alliance – Sepsis and series
www.sepsis.org/sepsis-basics/sepsis-and
- 8 UK Sepsis Trust Practical and Legal Information
www.sepsistrust.org/get-support/resources

About The George Institute for Global Health

The George Institute for Global Health is an independent medical research institute aiming to improve the health of millions of people worldwide by generating effective, evidence-based and affordable solutions to the world's biggest health challenges. Headquartered in Sydney, with major centres in China, India and the UK, it has projects in more than 50 countries and affiliations with world-class universities. In 2018, The George Institute was ranked the number-one independent research institute in Australia by Times Higher Education.

The George thought leadership program seeks to challenge the status quo and foster the kind of debates and discussions that lead to positive changes in health outcomes in a range of strategic focus areas, such as promoting healthy environments. By providing different perspectives and driving new thought we can rethink how to create healthy environments where healthy eating is facilitated.

Life after sepsis

A guide for survivors,
carers and bereaved families



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Better treatments
Better care
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