

THE UK
SEPSIS
TRUST

SEPSIS: A GUIDE FOR PATIENTS & RELATIVES

CONTENTS

What is sepsis?	3
How is sepsis diagnosed & treated?	6
Recovery after sepsis & Post Sepsis Syndrome (PSS)	8
Enhancing your recovery	16
Critical Care & sepsis	20
Help & support	22

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. Sepsis can lead to shock, multiple organ failure and death especially if not recognised early and treated promptly. It's estimated that as many as 245,000 people develop this condition each year in the UK.

As humans we come into contact with many pathogens, or 'bugs', during our lifetime, some of which cause infections. Our body's natural defence systems and immunity fight these infections, frequently without any need to visit the GP or hospital.

Sepsis can occur 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 consequence of an infection are not entirely understood – medical research institutions are working to understand this better. It's important to note that it's not possible to catch sepsis or pass it onto others.

Not every infection **will** cause someone to develop sepsis, however almost any infection **can** trigger sepsis – that's why awareness is so important.

Sepsis most commonly develops from a bacterial infection, but it can also develop from both fungal and viral infections. Common infections precipitating sepsis include:

- Chest infections (pneumonia)
- Urinary tract infections
- Abdomen infections (appendicitis, gall bladder infection)
- Skin, soft tissue infections (cellulitis, wound infections)

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. Several factors are likely to play a part in determining whether or not sepsis develops in response to a specific infection:

- Type of 'bug' causing the infection
- Number of 'bugs' present and where they are in the body
- The person's individual factors, such as underlying health conditions and their genetics

We know some groups of people are at a higher risk of developing sepsis. These include:

- Babies (under 1 year old)
- Adults over 75 and/or people who are very frail
- People who have impaired immune systems because of illness or drugs
- Pregnant women

HOW IS SEPSIS DIAGNOSED & TREATED?

Sepsis can be difficult to spot for the individual, for the loved one and for health professionals, particularly 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 the reverse of this booklet.

Sepsis is a medical diagnosis and requires a full clinical assessment. A patient who is unwell and has signs or symptoms of an infection should be evaluated 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 the UK Sepsis Trust) to help often junior health professionals identify people with likely sepsis rapidly. 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).

Antibiotics and control of the source of infection remain the mainstays of treating sepsis as a consequence of bacterial infection – antibiotics will not treat fungal or viral infections. If the source of infection is unknown, then a 'broader spectrum' antibiotic may be used until a source is identified.

If a fungal infection is suspected, antifungal treatment should be started as a matter of urgency initially using broad spectrum drugs. Antiviral therapies are of less proven benefit in patients with viral sepsis, for whom the mainstay of treatment is organ support.

Delivery of prompt antibiotics is part of a bundle of care developed by the UK Sepsis Trust known as the Sepsis Six. This includes:

THE SEPSIS SIX

1. Call for senior clinical help
2. Give oxygen if required
3. Send a full set of blood tests
4. Give IV antibiotics (or antifungals)
5. Give IV fluids
6. Make a clear plan for ongoing monitoring

RECOVERY AFTER SEPSIS & POST SEPSIS SYNDROME

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 with those who are close to you.

Seeing a loved one going through a serious illness such as sepsis can often be traumatic and confusing. People may not have seen quite how ill you were, so it's easy to understand why they might expect you to feel better soon. They, like you, might be shocked by their fear for your safety and the gaps in their knowledge of what you've been through.

...YOUR FAMILY AND FRIENDS

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. However, 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 which may have only hit home after the discharge from hospital.

Don't be afraid to ask for help from friends and family or from your GP. Talk to them about what happened if that helps. If you're finding it difficult to cope, you might want to talk to a professional counsellor – you can find one through the British Association of Counsellors or by asking your GP. You can also get help and advice from the 'Where to go for help' section listed at the end of this booklet'.

HOW LONG WILL IT TAKE TO RECOVER?

Recovery will involve your whole body. Around 40% of people who survive sepsis encounter new physical, cognitive, or psychological 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. Generally, it can take a few weeks to a few months, but for some it can take longer.
- There are contributing factors than can influence recovery such as age, medical history, length of hospital stay and whether or not an admission to Critical Care was required. See section 'Sepsis and Critical Care' for further information.
- For those people who have suffered significant organ damage, recovery can take time and be complex, often involving ongoing treatment requiring input from multiple specialists. If you've suffered organ damage and/or had an amputation, further specific information should be provided to you by your healthcare providers. Do ask them for this if it isn't forthcoming.

COMMON PROBLEMS FOLLOWING SEPSIS

The following lists are not exhaustive. Some people have one or two of the problems listed, some may have more.

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 and 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

RECOVERY FROM SEPSIS

During your recovery you may experience some of the problems listed, while looking relatively well to the outside world. If it's been some time since you had sepsis, people close to you are likely to expect you to be fully recovered. This can make you feel very alone and even start to doubt yourself or wonder if you're imagining all these things. Be reassured that it's normal to experience physical, cognitive and psychological problems after any serious illness, not just sepsis. Give it time and seek support as you need it – remember you're not alone in your recovery.

It's important to take your time getting back to work, study or other activities. It may be advisable to discuss a phased return with your GP or Occupational Health Team at work to assist with the recovery process. For further information, access our Return To Work resource [here](#). If you're currently in higher education, you may find it useful to talk to a Student Wellbeing Officer or academic advisor.

“I didn't like to tell my family and friends that I was putting on a brave show. They thought I was much better than I was and I didn't want to disappoint them. Once I'd spoken to my GP I felt much better – she was really reassuring and said that everything was quite normal and to be expected.”

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 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 a helpful Recovery Diary [here](#).

WHY DO I FEEL THE WAY I DO?

Sepsis can cause widespread inflammation and changes in blood flow in the smallest of our blood vessels. This can affect the function of organs and body tissues in different parts of our body. Other problems faced can be due to:

- A prolonged hospital stay resulting in periods of immobility
- Some medications used whilst in hospital including sedatives
- Delirium, which is common during critical illness
- Loss of appetite or malnourishment
- The psychological trauma of being in hospital and being seriously unwell

WILL I GET SEPSIS AGAIN?

People who've had sepsis understandably worry about it recurring. Evidence suggests that for a period of time during recovery some people can be more prone to getting further infections, and therefore are at increased risk of sepsis. If it does recur, it would normally be a consequence of a new infection. This may develop in a similar part of the body that caused the first episode of sepsis – this can be 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 the reverse of this booklet.

ENHANCING YOUR RECOVERY

Time: 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 that they’re 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 opportunity to share your thoughts and feelings about what happened in a way that feels comforting to you, the better your recovery. The nurses at the UK Sepsis Trust (UKST) can provide you with support and information about what’s happened and what to expect. UKST also runs a number of support groups, which can be a useful tool on the road to recovery.

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.

“I found it quite frustrating how difficult everything was. I felt depressed, tired and lacked energy. Even small tasks were hard and took much longer than I expected! The diary was really helpful in reminding me of the progress I'd made.”

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. The NHS Choices website has some gentle exercises to get you started for improving strength, balance and flexibility. Some of these can be done sitting or standing. Although these are suggested for older people, they are helpful for anyone needing to build their strength slowly. Exercises for strength, balance and flexibility and exercises to do whilst sitting can be found at:

<https://www.nhs.uk/live-well/exercise/sitting-exercises/>

<https://www.nhs.uk/live-well/exercise/strength-exercises/>

<https://www.nhs.uk/live-well/exercise/flexibility-exercises/>

<https://www.nhs.uk/live-well/exercise/balance-exercises/>

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 disease.

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 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
- Relying on drugs which are not prescribed or drinking a lot of alcohol

CRITICAL CARE & SEPSIS

As a result of sepsis, people may require an admission to Critical Care. This includes both the Intensive Care Unit (ICU) and High Dependency Unit (HDU). Critical Care is where the most unwell patients in a hospital are treated.

Your care would have involved treatment to support one or more organs which were beginning to fail. This could have been the lungs (perhaps using a ventilator), heart and circulation (drugs to support the blood pressure and heart rate) or kidneys (using a machine to take over your kidney function if you were not passing urine).

In Critical Care you can be carefully watched and monitored, including continually checking your pulse; blood pressure; breathing rate; oxygen levels; how much liquid you take in and how much you urinate. These checks are all very important because staff can quickly identify any deterioration in your condition and change your treatment as needed.

WHAT YOU MAY HAVE EXPERIENCED IN CRITICAL CARE

You may have no memory of your time in Critical Care, or you may have very confused memories of what happened to you there. The strong drugs and your treatment will have affected your body and mind. Not remembering what happened is extremely common. Some people remember the end of their admission, whilst others remember almost nothing. You may have:

- felt slightly aware but didn't know where you were or what was happening

- had nightmares or thought things were happening which were not real – these can, again, be very frightening. You may not have realised you were in hospital and your mind may have tried to make sense of what was happening, by making you think things like you'd been kidnapped or were being held captive. Experiencing confusion and hallucinations is called delirium and is extremely common.
- been unable to talk or let people know what you were feeling
- have found it very difficult to sleep or have had strange dreams when you did sleep
- not known what time of day it was, or how long you had been in hospital

Some hospitals provide an opportunity to revisit the Critical Care Unit and people often find this incredibly beneficial. It's completely up to you, some people are never ready or don't wish to think about what happened. Alternatively it may take some weeks, months or years to feel like you would like to learn more.

EQUIPMENT & TREATMENT IN CRITICAL CARE

There is a range of equipment used in Critical Care that is different from the rest of the hospital. Understanding what some of the machines or noises were can sometimes help to put the missing pieces of the jigsaw back together. Further information about Critical Care can be found in our [Recovery After Critical Illness Booklet](#) and you can also speak with our Support Nurses, who have a wealth of experience working in Critical Care.

HELP & SUPPORT

The UK Sepsis Trust: We work to raise awareness of sepsis and support those affected. You can talk to our support nurses for free by calling our helpline 0808 800 0029 or visiting: <https://sepsistrust.org/get-support/>

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.

Critical Care follow up: Some Critical Care units provide a follow up service. This does vary but will often include an outpatient appointment to see the doctors and nurses who may have been involved with your care. This may also be an opportunity to re-visit the unit. Although this can be unnerving, some patients find it helpful in the long term as it can help fill in some of the blank.

FURTHER RESOURCES

The UK Sepsis Trust

For more information and support relating to sepsis, severe infection and critical illness visit:

sepsistrust.org/get-support/, or phone our support team on 0808 800 0029 (UK number).

Critical Care

Critical Care Recovery

www.criticalcarerecovery.com

ICU Steps

www.icusteps.com

Health & Wellbeing

NHS – One You

www.nhs.uk/oneyou

British Association for counselling and Psychotherapy (BACP)

www.itsgoodtotalk.org.uk

Samaritans

www.samaritans.org/how-we-can-help-you/contact-us

Mind

www.mind.org.uk/information-support

Financial & Practical Advice

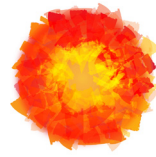
Citizens Advice

www.citizensadvice.org.uk

Following Amputation

Amputation Foundation

www.amputationfoundation.org



SEPSIS IS THE BODY'S RESPONSE TO AN INFECTION.

If you think you have an infection and develop any of the following symptoms you may have sepsis.

Dial 999 and Just Ask:
"Could it be Sepsis?"

ADULT SYMPTOMS:

- S**lurred speech or confusion
- E**xtrême shivering or muscle pain
- P**assing no urine (in a day)
- S**evere breathlessness
- I**t feels like you're going to die
- S**kin mottled or discoloured

JUST ASK

"COULD IT BE SEPSIS?"
IT'S A SIMPLE QUESTION BUT IT COULD SAVE A LIFE.

ANY CHILD WHO:

- 1 Is breathing very fast
- 2 Has a fit or convulsion
- 3 Looks mottled, bluish or very pale
- 4 Has a rash that doesn't fade when you press it
- 5 Is very lethargic or difficult to wake
- 6 Feels abnormally cold to touch

MIGHT HAVE SEPSIS

Dial 999 and Just Ask:
"Could it be Sepsis?"

ANY CHILD UNDER 5 WHO:

- 1 Is not feeding
- 2 Is vomiting repeatedly
- 3 Hasn't had a wee or wet nappy for 12 hours

MIGHT HAVE SEPSIS

If you're worried they're deteriorating call 111 or make an appointment to see your GP

Visit us at sepsistrust.org
Email info@sepsistrust.org or call
0800 389 6255 for more information