



THE UK
SEPSIS
TRUST

Information for patients & families

RECOVERY AFTER SEPSIS

This booklet has been compiled by the UK Sepsis Trust, with help from Cardiff and Vale University Hospital Board.

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INTRODUCTION

What is Sepsis?

Sepsis (previously referred to as septicaemia or blood poisoning) 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 250,000 people develop sepsis in the UK each year.

As humans we come into contact with many pathogens, or 'bugs', during our lifetime, some of which cause infections. Our body's natural defense systems and immunity fight these infections.

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 from an infection are not entirely understood and medical research institutions are working to understand this better.

Treatment for sepsis requires intravenous antibiotics. Most people will require hospital admission and some may require treatment in Critical Care. It is not possible to catch sepsis or pass it on to others.

Having sepsis can be frightening, especially if you have never previously heard of this condition that has suddenly made you seriously ill. Being admitted to hospital can be a traumatic experience for you and your close relatives and loved ones.

THIS IS DESIGNED FOR YOU

Sepsis may continue to affect you physically and emotionally after you go home. This booklet provides information on what you may experience during your recovery. It is important to note that it does not matter how old you are, how unwell you were, or how healthy or active you were prior to sepsis - you have had a serious illness and it may take time to recover.

...and for family and friends

People are often shocked and upset by what they have seen someone with sepsis go through. Your family, friends and wider support network will be pleased that you are home, but they may not understand why you feel like you do as you recover.

You will need their support as you recover. During the recovery process, although you may look well you may not feel well. Your family, friends and wider support network need to understand this. Sharing information on how you feel and your recovery with those that are close to you is important and can help them understand.

SEPSIS RECOVERY

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

HOW LONG WILL IT TAKE ME TO RECOVER?

- 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 can take time and be complex, often involving ongoing treatment. If you have suffered organ damage and/or had amputation further specific information will be provided to you by your healthcare providers
- Some people have very few or no problems following sepsis.

COMMON PHYSICAL PROBLEMS DURING RECOVERY

The following list is not exhaustive. Some people have one or two of the problems listed and some may have more.

- 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 sweating
- Joint pains and muscle weakness
- Dizziness
- Headaches
- Nausea
- Breathlessness
- Poor appetite
- Change in taste
- Change in vision
- Reduced kidney function

Your physical recovery is likely to impact on how you're feeling. You may at first feel weak and doing previously simple things may require significantly more effort.

COMMON COGNITIVE PROBLEMS DURING RECOVERY

The following list is not exhaustive. Some people have one or two of the problems listed and some may have more.

- Difficulty with short term memory
- Difficulty with concentration
- Difficulty with speech, for example finding the right words
- Difficulty performing tasks you previously could

“Soon after I was discharged from hospital I tried to return to work. I found this difficult and it was challenging doing some of the tasks I was able to do previously, including answering emails and talking to customers over the phone. This was worrying but after discussing this with the UK Sepsis Trust I realised this can be a normal part of sepsis recovery and I found things did improve over time.”

COMMON PSYCHOLOGICAL & EMOTIONAL PROBLEMS DURING RECOVERY

The following list is not exhaustive. Some people have one or two of the psychological or emotional problems listed and some may have more.

- Mood swings - feeling snappy, irritable, angry or upset
- Low mood
- 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

SEPSIS RECOVERY

During your recovery you may experience some or all of the problems listed, while looking relatively well to the outside world. If it has been some time since you developed sepsis, people may expect you to be fully recovered. This can make those experiencing these problems after sepsis feel very alone and even start to doubt themselves, or wonder if they are imagining all these problems.

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. 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 a Student Wellbeing Officer or academic advisor.

WILL I GET SEPSIS AGAIN?

People who have had sepsis worry about it reccuring.

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.

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.

To remind yourself of these please see the adult symptoms below.

SEPSIS IN ADULTS IS A SERIOUS CONDITION

that can initially look like flu, gastroenteritis or a chest infection. Sepsis affects more than 250,000 people every year in the UK.

The UK Sepsis Trust registered charity number (England & Wales) 1158843

Seek medical help urgently if you develop any or one of the following:

Slurred speech or confusion
Extrême shivering or muscle pain
Passing no urine (in a day)
Severe breathlessness
It feels like you're going to die
Skin mottled or discoloured

JUST ASK

"COULD IT BE SEPSIS?"

IT'S A SIMPLE QUESTION, BUT IT COULD SAVE A LIFE.

WHAT CAN I DO TO HELP MY RECOVERY?

There are many things that you can do to help yourself during your recovery period. These include:

Time: Allow yourself time to recover - there is no standard length of time for this or one size fits all, and recovery time varies greatly.

Pacing: It can take time to recover physically, so try to pace your activity and do not rush yourself. Remember to work on things you enjoy as well as the "to do" list. Try to take time for the things that you would have enjoyed before, even if you do not feel like doing much. Your strength should slowly return as you become more active but this may take longer than you expect it to. 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.

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 support nurses at the UK Sepsis Trust can provide you with some information, support and advice about what has happened and what to expect. The UK Sepsis Trust help to facilitate a number of support groups across the UK, these can be a helpful 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 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 sleep hygiene.

Managing 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 that illness and focusing on how to get better. This can make you feel scared but, with guidance and support, this should become more manageable.

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.

Light 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. 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 exercises are suggested for older people, they are helpful for everyone to build up their strength, slowly. Exercises for strength, balance and flexibility and exercises to do whilst sitting can be found at: www.nhs.uk/Livewell/fitness/

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 which are right for you, and if you're travelling far overseas make sure you are appropriately protected against tropical disease.



WHERE CAN I GET HELP & SUPPORT FROM?

UK Sepsis Trust: We work to raise awareness of sepsis and support those affected. You can visit our support pages for more information about recovering from sepsis. We provide a telephone helpline where you can talk to a trained nurse with experience of sepsis and recovery. We also hold support groups for anyone affected by sepsis. Meeting others who have had sepsis or have had relatives with sepsis can be helpful. To find out more or to attend a support group, visit: sepsistrust.org/support or phone 0808 800 0029

Friends and Family: Loved ones can help with daily household 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.

GP: It is important to update your GP on how your recovery is progressing. Your GP may be able to offer you treatment or refer you to physiotherapy, occupational therapy and/or talking therapy to help you through your recovery.

WHEN SHOULD I SEEK EXPERT HELP?

Most symptoms will improve with time as you make adjustments. You will get aches and pains, just like any other person. This is normal and does not necessarily mean anything bad.

Speak to 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 drinking a lot of alcohol.

FURTHER RESOURCES

For more information regarding the signs and symptoms of sepsis and sepsis recovery please visit sepsistrust.org.

Here are some other useful links and further resources:

Health and Wellbeing

NHS – One you

nhs.uk/oneyou

British Association for Counselling and Psychotherapy (BACP)

itsgoodtotalk.org.uk

Samaritans

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

Mind

mind.org.uk/information-support

Support Following Amputation

Amputation Foundation

amputationfoundation.org

Limbless Association

limbless-association.org

Financial & Practical Advice

Citizens Advice

citizensadvice.org.uk

Turn2us

turn2us.org.uk

visit us at **sepsistrust.org**



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