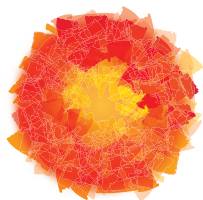


SEPSIS: A GUIDE FOR PATIENTS & RELATIVES



THE UK
SEPSIS
TRUST



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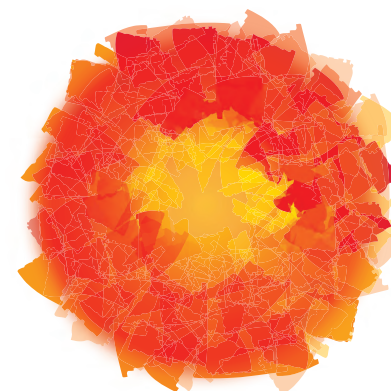
INTRODUCTION

In the UK, at least 150,000* people each year suffer from serious sepsis. Worldwide it is thought that 3 in a 1000 people get sepsis each year, which means that 18 million people are affected.

Sepsis can move from a mild illness to a serious one very quickly, which is very frightening for patients and their relatives.

This booklet is for patients and relatives and it explains sepsis and its causes, the treatment needed and what might help after having sepsis. It has been written by the UK Sepsis Trust, a charity which supports people who have had sepsis and campaigns to raise awareness of the illness, in collaboration with ICU steps.

If a patient cannot read this booklet for him or herself, it may be helpful for relatives to read it. This will help them to understand what the patient is going through and they will be more able to support them as they recover.



WHAT IS SEPSIS?

Sepsis was previously known as septicaemia or blood poisoning. Sepsis is the body's reaction to an infection and means your body attacks its own organs and tissues.

*statistics from the Health and Social Care Information Centre (HSCIC)

WHY DOES SEPSIS HAPPEN?

The condition is caused by the way the body responds to micro-organisms such as bacteria, getting into your body. This infection may have started anywhere in your body. The infection may be only in one part of your body, or it may be widespread. It may have been from:

- a chest infection causing pneumonia
- a urine infection in the bladder
- a problem in the abdomen, such as a burst ulcer or a hole in the bowel
- an infected cut or bite
- a wound.

Sepsis can be caused by a huge variety of different bacteria – some of these you might have heard of, such as streptococcus, E-coli, MRSA, C diff. Most cases of sepsis are caused by common bacteria which we all come into contact with every day without them making us ill.

Sometimes, though, the body responds abnormally to these infections, and causes sepsis.

DIFFERENT TYPES OF SEPSIS

People get infections all the time, which can make them feel ill but they then get better without needing treatment in hospital. Sepsis can develop following chest infection, urine infections and other minor illnesses.

However, other patients develop sepsis, which means they become seriously ill and need hospital treatment straight away.

WHO IS AT RISK OF GETTING SEPSIS?

We do not always know why the body responds in this way and often people who get sepsis are in good health and do not have any long term illness. People are more likely to develop sepsis after a viral illness like a cold, or a minor injury.

However, there are some groups of people who are more likely to get sepsis, such as if you:

- are very young or very old
- are diabetic
- are on long-term steroids or on drugs to treat cancer (chemotherapy)
- have had an organ transplant and are on anti-rejection drugs
- are malnourished (your body hasn't had enough food)
- have serious liver disease
- have a serious illness which affects your immune system (the way your body protects itself from infection), for example leukaemia
- have an infection or a complication after an operation
- are pregnant or have just given birth.

WHAT SEPSIS DOES TO YOUR BODY

To begin with, you may have felt like you were developing a flu-like illness. You may have:

- felt very cold and shivery
- felt very hot and looked flushed
- had a high temperature
- had aching muscles
- felt very tired
- have had sickness and / or diarrhoea (upset stomach)
- not felt like eating
- seemed confused or drunk, or had slurred speech.

As your condition became worse:

- your blood pressure might have dropped because your illness caused your arteries and veins to become larger. Your blood had a bigger space to fill and so your body struggled to keep your blood pressure at a normal level
- your heart tried to help by beating faster
- you might have felt breathless and /or were breathing very quickly
- your skin might have been cold and pale, have had an unusual colour or rash, or it might have been mottled (marked in 'patterns' or patchy in colour)
- your skin might have been hot and flushed.

Depending on where the infection started, you would also have had other symptoms, for example, if you had pneumonia, you would probably have had a bad cough as well.

As the sepsis progressed, your blood pressure might have become very low and this would mean that:

- your organs will not have got enough blood and oxygen. This will have damaged the cells in the organs causing them to fail. The kidneys, lungs, brain and heart are particularly at risk from this
- you won't have needed to urinate (pass water) as much as you normally do
- you may have found it very difficult to breathe
- your skin may have darkened in patches and begun to blister
- you may have become very confused and you might have become unconscious
- you may have swollen up with fluid, which would have made you much bigger than your normal size and meant you looked very different. This might have been frightening for you and your relatives to see. This swelling happens because your blood vessels become leaky and fluid goes into the wrong places, and can leak out of your skin.

By this time, you will have needed urgent medical help and will probably have been taken to a Critical Care Unit (also known as an Intensive Care Unit) in hospital.

WHY DID I NEED TO GO TO THE CRITICAL CARE UNIT?

Critical Care is where the most ill patients in a hospital are treated and nursed.

In Critical Care:

- you can be carefully watched and monitored, including checking your pulse; blood pressure; breathing; oxygen levels; how much liquid you take in and how much you urinate (how much water you pass). These checks are all very important because staff can quickly change your treatment as needed
- staff can give you treatment including support for your major organs, like your heart, kidneys and lungs
- there are highly trained doctors, nurses and physiotherapists who look after you, and support your relatives by explaining what is happening
- nurses look after fewer patients, so there may be one nurse looking after only one or two patients.

WHAT TREATMENT MIGHT I HAVE HAD?

Sepsis is treated by:

- giving you strong drugs to help you beat the infection. These include antibiotics, anti fungal or anti viral drugs depending on what caused the infection. Sometimes it is necessary for the medical team to try different drugs to find the ones that will best treat your illness, and you may have got temporarily worse or better as the new drugs were introduced
- supporting your body's organs until they can begin to recover. This includes helping your blood pressure (with extra fluids or strong drugs) and organs (such as a machine for your kidneys, which is called dialysis or filtration)
- helping you to breathe. Oxygen may have been given using a tight fitting mask, a high flow device inserted into your nostrils, or a hood that looked like a space helmet. If you become very ill, you will have had a breathing tube down your throat. If you needed help breathing for some time, you will have had a tracheostomy. This is where a small hole is made in the front of your neck so that a breathing tube attached to a ventilator (breathing machine) can be put into it
- making sure you have enough food and liquid. This is done by putting a thin tube up your nose and down into your stomach or by putting a tube in your hand or arm called a drip to give food and fluids
- you will have be given painkillers if you needed them and strong drugs to keep you drowsy or asleep, making the treatment more comfortable for you.



WHAT OTHER HELP MIGHT I HAVE RECEIVED IN CRITICAL CARE?

There will have been a whole team of doctors, nurses, physiotherapists and other medical staff who will have treated you, looked after you and tried to make you as comfortable as possible.

The nurses will have spent the most time with you and they will have done things like:

- checking how you were responding to treatment through watching your blood pressure, oxygen levels etc
- giving you the drugs that you needed
- washing you and changing your bed sheets
- turning you often so that you didn't get bedsores and moving your legs and arms so that you didn't get too stiff
- put a catheter in. This tube would have been put in to your bladder to allow urine to be collected
- if you had a breathing tube or tracheostomy, you will have needed the phlegm to be removed from your lungs as you were not able to cough strongly. This would have been done by using a suction tube which was put down the breathing tube. It would have made you cough and retch while it was being done.

HOW MIGHT I HAVE FELT 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.

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 feel so real that it can be very frightening. You may have not 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 had been kidnapped or were being held captive. Experiencing this confusion and hallucinations is called delirium
- 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 many days had gone by
- felt calmer when your friends and family came to see you even if you weren't fully awake.

These are all common feelings for very ill patients and it can be frightening to not understand what is happening to you. Being in Critical Care and being so ill and confused can be a very upsetting experience and it will take time to understand and deal with it afterwards.

Look at the section on 'How will I feel when I'm home?' and the 'Where to go for help' section at the end of this booklet for more information that might help you.

HOW LONG MIGHT I STAY IN CRITICAL CARE AND HOSPITAL?

The length of time you have to stay in hospital will depend on how ill you are and how long you take to get better. You will only leave Critical Care when you no longer need special drugs and machines to support your body and when you are strong enough to cope on a general ward. It can take weeks of treatment in hospital and once you are home, you will slowly get better but it may take up to 18 months to feel strong and well again.

MOVING TO A GENERAL WARD & THE OUTREACH TEAM / PATIENT AT RISK TEAM

Sometimes it can feel frightening to leave the Critical Care Unit to go to a general ward, or leave the general ward to go home. These changes are happening because you are getting better, but it can be a difficult time for you and your relatives because there is no longer the one-to-one nursing that you had in Critical Care, but you still feel far from being well.

Many hospitals now have a team of Critical Care doctors and nurses who will visit you on the general ward after leaving Critical Care to make sure you are ok. You may have met them when you were very ill before you were sent to the Critical Care Unit. They are called the Outreach Team or the Patient at Risk Team. They will be able to answer any questions you have about what happened to you in Critical Care, your treatment or any other worries you have. If there isn't an Outreach Team at your hospital, speak to the ward nurses about any concerns you have.



REHABILITATION

Rehabilitation means things that will help you get better after having sepsis. 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. You will be working with physiotherapists and they will show you exercises to help you.

WHAT WILL HAPPEN WHEN I GO HOME?

You may be given a rehabilitation plan by your physiotherapist to help you get strong again. If you haven't been given one, look at the 'Where to go for help' section at the back of this booklet for information that can help you.

Generally, when you get home:

- you will be very tired, and will need to sleep and rest a lot. You have been seriously ill and your body and mind need time to get better
- you will be very weak, will have lost a lot of weight and may find it difficult to walk around. You may also find it tiring talking to people. Begin by building up your activity slowly and rest when you are tired
- your skin may be dry, itchy and peel. It may help to put moisturiser on your skin. Your nails may also break easily. Your teeth may feel brittle and becoming damaged.
- you may notice changes to your hair and some may begin to fall out some weeks after your illness. It is unlikely it will all fall out, it usually just gets very thin and then starts to grow again
- it can help to have special nutritional drinks, like Complan® or Build Up® to help you put on weight again. You can get these on prescription by asking your GP or you can buy them from a chemist or supermarket
- you might find it difficult to eat again. Build up slowly by having small meals and healthy snacks when you feel like it.

It can feel very frustrating once you are home, because all the things you could do easily before – walking, eating, even breathing – can suddenly feel very difficult or frightening. You have to remember how ill you have been and try and see that you have made progress, even if it doesn't feel like it sometimes.

HOW WILL I FEEL WHEN I'M HOME?

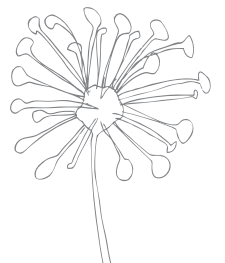
You might feel lots of different things after your illness, for example:

- very upset or crying a lot
- not caring what you look like
- not wanting to see your friends
- getting cross very easily
- scared at how ill you have been or worried that you might get ill again
- have upsetting memories of your time in Critical Care or have flashbacks (sudden powerful memories) of what just happened to you
- have bad dreams or nightmares
- confused about what did happen and what was real and what wasn't
- feeling things will never be ok again
- anxiety – feeling much more worried about things than usual
- depression – feeling miserable, unmotivated or not enjoying the things that you usually do.

There can also be other problems after sepsis, such as:

- chest pain
- pain in the shoulders, back, arms and legs
- breathlessness
- general weakness
- finding it difficult to move around
- finding it difficult to sleep
- not feeling like eating, or food tasting different to normal
- finding it difficult to concentrate or remember things.

Generally all these problems get better in time and are a normal response to what you have been through. Some hospitals have Critical Care Follow Up staff to help patients and families once you leave Critical Care and when you go home. It can really help to talk to someone who knows about the problems you may be having.





WHAT MIGHT HELP ME ONCE I'M HOME?

Once you get home, it may feel strange because even simple things can feel difficult (such as climbing the stairs, talking with friends, getting yourself a drink) and you are likely to feel a lot more tired than when you were in hospital – this is probably because you are doing more now you are at home and your body is using a lot of energy getting better.

It may help to set yourself small, achievable goals each week, like having a bath, dressing yourself, walking up the stairs. It might help to keep a diary so you can see that you are getting better and stronger each week, even if it doesn't feel like it.

It might also help you to:

- talk to family and friends about what you are feeling
- read your patient diary if you have one. Some hospitals help families to keep a diary and you could read this when you feel strong enough
- write down what you remember about your time in Critical Care. You could try to write something for each day and then ask your family to fill in any gaps
- find out about sepsis (by reading the start of this booklet) so you know what happened to your body and find out what treatment you had. Ask your GP if you have questions about it
- speak to a Critical Care Follow Up nurse if there is one at your hospital. Even if there isn't one, you may be able to arrange to go back and see the Critical Care Unit, when you feel strong enough, to understand what happened and where you were.

You should find it easier to cope with your feelings as time goes by and as you begin to get stronger and get back to doing your normal activities. If you feel that you are not getting better or are finding it difficult to cope, go and see your GP for help.



ARE THERE ANY LONG TERM PROBLEMS I MIGHT HAVE AFTER SEPSIS ?

Many people make a good recovery from sepsis and return to their normal, or near normal, state of health within twelve to eighteen months of their illness.

However, sepsis can affect many organs in the body and sometimes they do not work properly afterwards. The most common organs which can be affected are:

- the kidneys. Some people might always need support by a machine (which is called dialysis)
- the heart. This can cause chest pain, problems with your pulse or difficulty when exercising (you might get out of breath easily). These symptoms can normally be improved with medicines such as tablets or a mouth spray
- the brain, if it didn't get enough oxygen. This can make you confused or not think as clearly as you did before and you may find it difficult to concentrate or remember things
- the lungs, leading to breathlessness or aching pains in your chest. You may not be able to walk as far as you did before your illness.

It is normal to feel upset after being in Critical Care, and you may feel anxious or depressed. This should settle down in time but it can help to talk about how you feel and what happened to you to friends, relatives, your GP or to a professional counsellor. Sometimes patients and their relatives can have extreme symptoms of stress - this is called Post Traumatic Stress Disorder (PTSD) and can happen months after your Critical Care stay. If you are struggling to cope, go to your GP for help.

TEENAGERS AND SEPSIS

If you are a teenager who has had sepsis, you may find it difficult when you leave hospital and go home because:

- you may not be used to feeling ill
- it is hard to be so weak and tired when you usually have lots of energy
- your friends can't understand what has happened to you
- you may have extra worries such as having exams to do, or be about to go to university or start a job
- you may find it hard to concentrate or remember things which is difficult if you are about to do exams. Talk this over with your GP or your teachers who may be able to find ways to help.

It is important to realise that recovering from sepsis takes time and patience, which is very hard when you are used to being very active and going out with your friends.

Family, friends, teachers and people at work can help by listening to you when you want to talk and by letting you slowly join in with your normal activities, even if you can't do everything to start with.

Being so ill can be a life changing event and may change your short term plans. Build up your activities slowly and rest as much as you need to in the months after you come out of hospital. Although it may feel like you are only getting better very slowly, remember that you will get well again but it will take time.

PREGNANCY AND SEPSIS

It is possible to get sepsis if you are pregnant or if you have just had a baby. This may happen because your immune system (the way your body fights infections) is not as strong during pregnancy. There are also other risk factors such as if:

- you have a 'strep' throat or a close relative has a strep infection. For pregnant women or women who have just given birth, the bacteria can get transferred from your hands to your genital area and cause genital tract sepsis
- you have swine flu – this is a particular risk in pregnant women, who seem to become very ill more quickly than women who are not pregnant
- you are diabetic
- you have had a caesarean section
- you needed forceps or ventouse for your baby to be born
- you had heavy blood loss after your baby was born
- your waters broke and took over 24 hours to stop
- you needed help for the placenta to come away after the birth
- you had a lot of genital tearing after the birth (3rd or 4th degree tears).

If you develop serious sepsis during pregnancy, you will need emergency hospital treatment straight away and you and your baby will be closely watched.

Sadly, sometimes you may be so ill with sepsis that your body is unable to carry on with the pregnancy and you may have a miscarriage. You and your partner may need a lot of help and support afterwards to come to terms with your illness and treatment in Critical Care as well as the loss of your baby. Accept the help offered by friends and family, especially if they can help with practical things such as cooking or childcare. Talk to friends and family about your feelings. There are charities which can provide support for women who have had a miscarriage. They may be able to arrange for you to talk to someone who has also had a miscarriage. See 'Where to go for help' for websites that might be useful.

NECROTISING FASCIITIS

Necrotising fasciitis (NF) is a serious infection which is caused by a number of different bacteria. It affects the soft tissue under the skin, and can happen on any part of the body but it is most common in the legs.

If you have NF, you may previously have been in good health. You may have cut or grazed yourself, but in a small way so that you didn't notice it. Sometimes it may come from having an operation. However it happens, bacteria then spreads very rapidly in the tissues below the skin, before there is any sign on the skin that there is a problem.

The first signs are flu-like symptoms, followed by excessive pain within 24 hours. By this stage, urgent treatment will be essential and this can include surgery. If you do not receive help:

- the skin over the infected area becomes dusky and purple with a flaky appearance
- blisters may form
- the infection will have penetrated deep into the underlying tissues and will cause sepsis. This means low blood pressure and failure of vital organs such as your liver, kidneys etc
- it will be necessary to remove the infected flesh, and you may need an amputation (part of your arm, leg or fingers removed) in order to save your life.

For further information and help, please see the details for the Lee Spark NF Foundation and you can gain help from our friends at Findingyourfeet for limb loss in the 'Where to go for help' section at the end of this booklet.

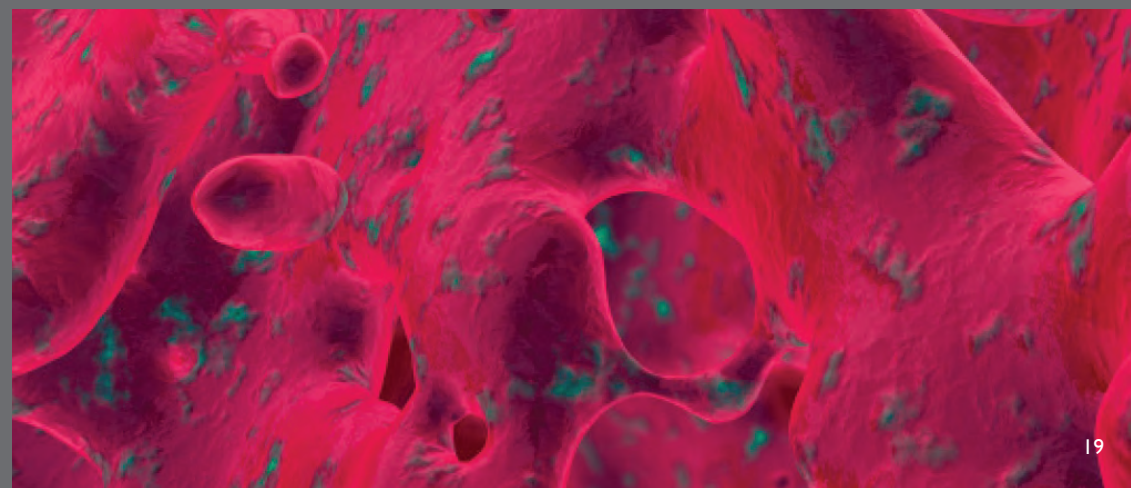
LOSS OF LIMBS

You may have been so ill with sepsis that you may have needed to have an amputation – this means that a part of your body had to be removed to stop the infection or because the sepsis caused it to lose its blood supply. This may be parts of your arm or fingers, or parts of your leg or toes.

This means that as well as the other emotional and physical effects of the illness, life after sepsis may feel very different because you have to learn how to cope with a disability as well. You may have

to learn new ways of doing everyday things such as washing and dressing, change the way get about, and modify the exercise, sports and hobbies you enjoy.

Most people who have had amputations return to a full and productive life after a period of adjustment, but at first you may not see this and you will need a lot of support.



WHAT CAN I DO TO HELP MY RELATIVE?

It can be very frightening to watch your relative or friend get ill so quickly and then need so much medical help. The nurses and doctors are doing everything they can to help the patient. If there is something you don't understand or are worried about, speak to one of the nurses.

You have a very important role helping the patient. You can:

- talk to the patient, tell them where they are and what is happening – it may really help them to hear a voice they know. Even if the patient is sedated (put in a deep sleep with strong drugs), they may still be able to hear you, even if they show no sign of it. So keep talking to them, say comforting things, and hold their hand. If you find it difficult to know what to say, you could try reading something like a favourite book or newspaper to them so they can hear your voice
- help nurses if they have questions about how the patient was before they came into Critical Care
- help look after the patient by doing things like brushing their hair or keeping their mouth moist by using a special damp sponge. If the patient is sedated, talk to them while you do this because they may feel these things but not understand what is happening
- massage your relative's hands and feet. This can be very comforting whilst they are in bed and it can also help swollen limbs that have too much fluid trapped in them. If you do massage the patient, please check with the nurse first so you do not affect any drips or monitors
- keep a diary of a relative's progress throughout their illness. This can be very helpful for when the patient is recovering, as they often find it difficult to remember much of their time in Critical Care. Many units provide diaries for relatives and staff to complete whilst the patient is sedated or drowsy. Do ask a nurse to see if they provide patient /relative diaries, but if they don't, you can write one yourself. Just make a few notes each day about how the patient is and any important changes to their treatment etc.



Just by being there, by letting the patient hear a voice they know and by giving them encouragement, reassurance and support means that you can help speed their recovery. Do be positive when talking to them about getting better but don't tell them everything is fine if it isn't. Instead reassure them that the doctors and nurses are doing everything they can to make them better.

It is very distressing to have a relative or friend so ill and you must remember to look after yourself at this time as well. You may have friends and family who really want to do something to help you, so take up their offers of help if you can. You shouldn't feel guilty for not being at the patient's bedside 24 hours a day – it means they have time to rest as well as you, and the hospital will call you if there is any serious change to their condition.

HOW DO YOU KNOW IF THE PATIENT IS IN PAIN?

Nurses check patients for pain every hour when they are doing other checks such as blood pressure and oxygen level etc. They will check more often than that during treatment that might cause the patient pain. Even if the patient is sedated, there will be physical signs of pain such as a raised blood pressure and pulse, sweating, crying and they can become restless and agitated. The nurses will do all they can to try and make the patient comfortable. It may help for you to talk to your relative, hold their hand and reassure them if they seem upset.

CAN THEY HEAR ME?

Unless there has been any damage to the patient's hearing, they will be able to hear you even when sedated. However, patients rarely remember conversations, but they can hear sounds like the machines making noises or someone's voice. This is one of the reasons why the nurses will talk to him or her before they touch or move them, and why it is helpful for you to talk to them too, even if it looks as if they can't hear you.

CAN I TAKE A PICTURE OF MY RELATIVE WHILST THEY ARE SEDATED IN CRITICAL CARE?

At the moment, hospital policies do not normally allow for relatives to take photographs while they are visiting in Critical Care because the patient is unable to agree to the photo (give their consent). Some units will routinely take one photograph of each patient but these are kept in a locked cabinet until the patients themselves are able to give consent for them to be seen. If consent is not given the photograph will be destroyed.

WHO CAN I SPEAK TO WHEN I HAVE QUESTIONS?

The nurses who look after your relative will have very detailed, up to date information about the patient but they can also arrange for you to speak to the Critical Care doctors or other specialists, such as surgeons when they have been involved in your relative's care. However, this may take a short time to arrange as doctors do not often have time set aside for such discussions.

MY RELATIVE SEEMS UPSET AND SAYS THEY ARE HAVING STRANGE DREAMS. IS THIS NORMAL? WHY DOES IT HAPPEN?

Over two thirds of sedated patients who are having help with their breathing can experience strange, vivid dreams and hallucinations. This is called delirium. This can be very frightening for them because it seems so real, and it can be upsetting for you if the patient is unhappy.

This delirium happens because:

- the strong drugs (such as Morphine and Valium type drugs) which are needed to help the patient cope with their treatment are very powerful and can cause delirium as a side effect. These drugs can also make it difficult for the patient to understand or remember what happened in Critical Care
- when a patient is very ill, they produce chemicals to fight the illness or infection, which can cause confusion. This can also lead to delirium
- patients cannot clearly understand what is happening to them and this leads to gaps in their memory, which can sometimes last for weeks. Patients try to make sense of what is happening and fill in these gaps in the form of dreams. These dreams can be very strange and frightening because the patient thinks they are real.
- Some Critical Care Units have a Follow Up nurse to talk to patients when they leave Critical Care about such experiences or you can look at the 'Where to go for help' section for more information.

WILL A NURSE BE WITH MY RELATIVE ALL THE TIME?

A nurse will stay with the patient all of the time if they are sedated and on a breathing machine. Should that nurse need to leave the bed space for a short time then another nurse will look after the patient for them. Patients who are awake and stable will share a nurse with another patient. They are provided with a call bell and will remain closely watched until they are ready to leave Critical Care and go to a general ward.

HOW MIGHT I FEEL ONCE MY RELATIVE IS HOME?

You have been through a very upsetting experience and it will take time to get over it. Once your relative is home, you might feel very relieved that they are out of hospital or anxious about the responsibility of caring for them. However, now that your relative is out of danger, you may have a reaction to the stress you have been under. 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.

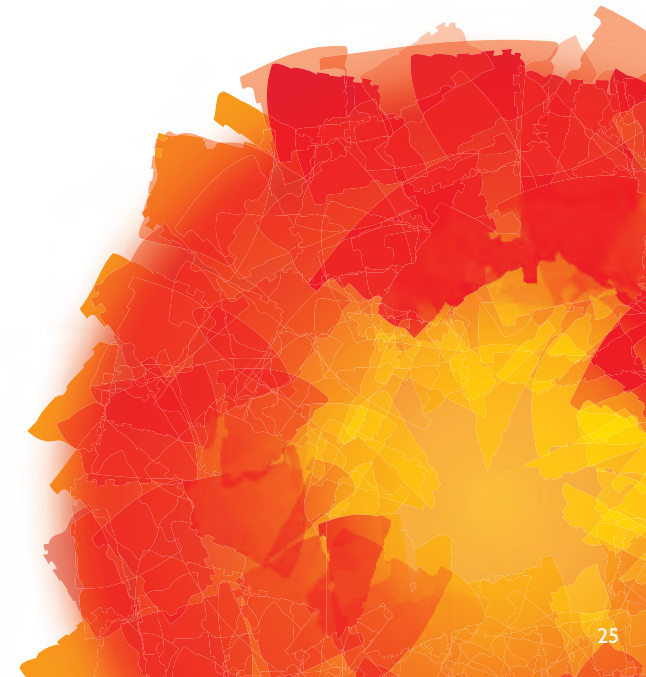
Don't be afraid to ask for help, either from friends and family or from your GP. Talk to family and friends about what happened if that helps you. If you are finding it difficult to cope, you might want to talk to a professional counsellor - you can find one yourself through the British Association of 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.

IF YOUR FRIEND OR RELATIVE DIES

Sepsis is a very serious illness, and sadly sometimes patients can die because they don't get treatment in time or their body is not able to fight the infection. 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 you 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 afterwards because they can offer support and understanding to adults and children who have lost a relative or friend. You can ask your GP to refer you or see 'Where to go for help' at the end of this booklet for more information.



There are support services and websites which can provide information and help for people who have been in Critical Care, and for survivors of sepsis and their families. These include:

THE UK SEPSIS TRUST

www.sepsistrust.org

info@sepsistrust.org

Tel: 0800 389 6255

Our charity provides support and information to patients and relatives affected by sepsis, including those whose relatives have died from sepsis. We are developing support groups across the country. We support projects that improve spotting the early signs and treatment of sepsis in the community and hospitals, and promote public and professional awareness of this condition. We have additional leaflets on our website; such as our post-op sepsis booklet.

ICUSTEPS

www.icusteps.org

Voicemail 0300 30 20 121

This charity supports intensive care patients and their relatives. They have support groups around the country, where you can talk about your experience with other patients and relatives. They have published a booklet called 'Intensive Care: a guide for patients and relatives' (which your hospital may give you, or you can find it on their website).

They also have information sheets on the website on subjects such as Physiotherapy & rehabilitation (containing exercises to help you get strong again) and Delirium.

INTENSIVE CARE FOUNDATION

<http://www.ics.ac.uk/icf/patients-and-relatives/>

Tel: +44 (0)20 7280 4350

Critical Care Patient Liaison Committee is part of the Intensive Care Foundation and covers subjects in Critical Care from a patients, relatives, friends and carers perspective. They provide information for patients and relatives in a booklet which you can download from their website.

CRUSE BEREAVEMENT CARE

<http://www.cruse.org.uk/bereavement-services>

Tel: 0844 4779400

Cruse Bereavement Care provides counselling, support, information, advice, education and training services to anyone who has been bereaved. They help you understand your grief and cope with your loss.

FINDING YOUR FEET

<http://findingyourfeet.net>

They offer practical, emotional and financial support for those who have suffered limb loss or loss of limb function. We support individuals and their families, helping people find their feet in life again.

BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY (BACP)

<http://www.bacp.co.uk/>

Tel: 01455 883300

For details of counsellors and therapists in your area.

LEE SPARK NECROTISING FASCIITIS FOUNDATION

www.nfsuk.org.uk

Tel: 01254 878701

The Foundation is the United Kingdom's only support group for people who have been affected by necrotising fasciitis and has helped thousands of sufferers, relatives and medical staff from organisations around the world.

The charity aims to support NF patients and their families; educate the medical profession and the general public; promote recognition of the early signs and symptoms of necrotising fasciitis and severe streptococcal infection; highlight the causes, effects, treatment and management of this disease and promote research into prevention and treatment.

MISCARRIAGE ASSOCIATION

www.miscarriageassociation.org.uk

Tel: 01924 200799

A charity set up to provide information and support after miscarriage. They have a website, a telephone helpline, support groups and volunteers who have been through miscarriage who can talk with you.

SAYING GOODBYE

<http://www.sayinggoodbye.org/>

Tel: 0845 293 8027

Saying Goodbye is run by a couple who have lost babies themselves. They work in partnership with the Miscarriage Association to hold remembrance events for people who have suffered the loss of a baby at any stage.

'GROUP B STREP SUPPORT' (PREVENTING GBS INFECTIONS IN NEWBORN BABIES).

Tel: 01444 416176

Email: info@gbss.org.uk

They offer information and support to families affected by group B strep infections; inform health professionals and individuals how these infections can be prevented in newborns and they endeavour to generate support for research to prevent GBS infections in newborn babies.



This booklet was written by Dr Ron Daniels Consultant Intensivist & CEO at UKST Libby Kain Executive Lead for Support at UKST and Catherine White (former sepsis patient) from ICUsteps.

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