SEPSIS:
Survivors' Information
A life beyond Sepsis

Many people experience sepsis each year as a response to an infection which may have started anywhere within their body. The majority recover with a course of antibiotics and possibly a short stay in hospital. Unfortunately, some individuals develop sepsis so severe that they can become desperately ill very quickly and might need treatment in an ITU / HDU (Intensive Care Unit or High Dependency Unit, together known as a Critical Care Unit). To learn more about sepsis please see our booklet ‘Sepsis: a guide for patients and relatives’, which you can find on our website.

Up to 80% of patients survive sepsis. Most patients who experience this critical illness will return to a normal or a ‘near normal’ life within 18 months of being ill. However, some survivors will have long term problems, occasionally having life changing effects which might impact on both them and their family. This leaflet is designed to briefly outline what to expect as you start to recover from sepsis and to guide you through the next few months of your recovery. It starts from the time you’re ready to leave Critical Care.

These long term problems can be divided into physical and psychological, and often start during the acute phase of your illness. Collectively, they are known as Post Sepsis Syndrome (PSS). Post Sepsis Syndrome is more common in people who have needed to be cared for in a Critical Care Unit, particularly if their stay was over four days. Be reassured, these symptoms, especially in the first few months, are normal and in most people gradually improve with time on their own.

You may find that it helps to share this leaflet with your family and friends, or even your GP and community or practice nurse. PSS is not widely known and it’s important that you are able to talk to people who understand that your symptoms are real.

In this document are the most common problems experienced by survivors. This is not intended as an exhaustive list.
PHYSICAL LONG TERM PROBLEMS

• Poor mobility
• Breathlessness / chest pain
• Fatigue
• Loss of appetite
• Taste changes
• Dry skin
• Brittle nails
• Brittle teeth
• Hair loss
• Oedema (excessive fluid in the tissues, which look swollen)
• Joint stiffness or pain
• Muscle wasting
• Changes of sensation in limbs (tingling, numbness, pain)
• Reduced libido (loss of sex drive)
• Poor kidney function (which may need dialysis)
• Repeated infections

PSYCHOLOGICAL LONG TERM PROBLEMS

• Anxiety
• Insomnia (difficulty sleeping which can also be a result of pain or breathlessness)
• Flashbacks, panic attacks and nightmares
• Depression
• PTSD (Post Traumatic Stress Disorder)
• Poor concentration
• Short term memory loss
Time to transfer to the ward

This is good news! You are now well enough to go to a ward and no longer need such a high level of care. However, this may be quite frightening for both you and your family. You may still be very weak and have drips and drainage tubes and may be worried about how you’ll cope without a nurse close by to help you. You have probably come to trust the nurses looking after you in Critical Care and might know some of them quite well. Emotionally, you may feel really low and anxious. So moving to the ward may be extremely worrying. You will be leaving the staff and routine you know and it will all be strange initially on the ward.

“Be reassured the ward doctors and nurses will be fully aware of your condition and how much you are able to do”

Be reassured the ward doctors and nurses will be fully aware of your condition and how much you are able to do, as a detailed handover of each patient is given on transfer. They will, however, encourage you to be more independent as you become able, to prepare you for going home. Do remember there are fewer nurses on the ward, so be prepared to wait a little longer for them to help you with washing, bedpans etc.

Many hospitals have a Critical Care Outreach Team and, if so, one of their team is likely to visit you daily in the early days to review your progress. So if you have any questions about your illness or concerns about your recovery, do ask them.

At this stage you may still be experiencing strange dreams, nightmares or flashbacks and your memory and concentration could be poor. This is quite normal for patients after Critical Care, just try to accept that it may take a while for you to feel like your old self again and allow yourself time to heal.

Your limbs may still be very swollen with excess fluid which will make it quite difficult for you to move about or even feed yourself. This excessive fluid (which we call oedema) is not dangerous and in the vast majority of cases will gradually disappear as your mobility improves and your body begins to recover. You may be finding it very hard to sleep, the ward is likely to be very noisy and busy and each day can seem extremely long. There is no harm in having a short sleep after lunch to refresh yourself but try to stop yourself from napping all day as this will interfere with regaining your normal sleep pattern.

Your appetite may still be poor and you may experience taste changes which could put you off eating. Some patients may still be tube or drip fed and not allowed to eat normally at this time. When you are able, try to eat something every meal time and take the supplement drinks
like Fortisips offered in between. Diabetics can also take these drinks provided they sip them slowly. This will help you to build up your strength and recover quicker. Many hospitals will allow you to ask your relatives to bring snacks or even meals in for you (though please check first with your nurse). Your body is crying out for nutrients to rebuild itself, and at this stage a little bit of what you fancy (within reason) is likely to do you more good than harm.

“You’re unlikely to notice your improvement day by day, but try not to become frustrated. Slowly but surely, you should become stronger and gain more confidence”

Usually, the physios will still be helping you to move around at this stage as your muscles may still be quite weak compared to normal. So listen to their advice and practice the exercises as suggested. They will continue your exercise programme on the wards and normally provide an exercise plan for when you go home.

You’re unlikely to notice your improvement day by day, but try not to become frustrated. Slowly but surely, you should become stronger and gain more confidence. The number of drips and tubes in your body should gradually reduce and you should begin to feel normal. If, however, you feel you’re not making any progress, ask the medical, physiotherapy and nursing teams looking after you. They may surprise you when they compare your present state with how you were a week ago!

Of course, your body remains vulnerable at this stage and a small number of patients can go on to develop further infections or other problems. The team will be watching you closely to pick up on any early signs.
Going home —
What to expect

How long you were critically ill for and how severe your sepsis was, will influence when you are able to go home. Generally, the more severe and prolonged the illness the longer the rehabilitation in hospital will be. The hospital staff will want to ensure that you can cope at home with the support available to you once you leave, so if you have an able-bodied family around you it’s likely that you’ll go home sooner than if you live alone.

Once home, you and your family will find yourselves trying to cope with every day activities with far less support than when you were in hospital. You may have many questions about how you should be feeling and how hard you should try and push yourself physically to do things you would normally be able to do. This can be a very frustrating and often anxious time. Remember, everyone is an individual and will have different needs and abilities at this stage. Listen to your body and if you become tired, then stop and rest for a while and try again later. Pushing yourself too hard will only delay your progress.

Set yourself small, achievable goals each day, e.g. taking a bath unaided for the first time or having a walk in the garden. You will be weak initially, that is perfectly normal. Keeping a diary of your progress can help you see how
much you are improving each week. If deemed necessary, a physio or nurse will be asked to visit you at home or see you in clinic.

Your emotions may be very changeable. You may feel like crying for no obvious reason or your mood may be really low. This is also normal. You’ve been through a life changing experience and it will take time for you and your family to come to terms with it. Try talking to a relative or someone else close to you about it. This often helps them as well. Remember that your rehabilitation will be a difficult time for your relatives too. They may be worried about you and have probably had to change their lives considerably to help care for you. Relationships can be strained and talking openly about this together is the best way to ensure that you all get back to normal as quickly as possible.

Some Critical Care Units provide a ‘Follow Up’ service which you can contact for advice and help. They may send you an appointment to review your progress. Your GP should also be able to provide information and support during your rehabilitation, so don’t be afraid to ask them. They may not have heard of PSS but they will have a lot of experience in dealing with people with emotional, psychological and physical problems.

The UK Sepsis Trust can be contacted if you have any queries about recovering after sepsis or should you need some advice. Our contact details are listed at the end of this leaflet.
Returning to Work

Going back to work can be a really daunting prospect! Most employers will be happy to allow you to start back on reduced hours until you are feeling fit enough to work your normal shifts. You may have lost your confidence and feel unprepared for these added stresses. You may still have outpatient appointments for physiotherapy, to see the doctors who looked after you or for dialysis sessions which will dictate how much you can work.

“It may be more realistic to reduce your hours permanently, to take a sabbatical or change your job altogether. Only you will know how much you can cope with.”

Finances may be stretched while you are recovering. Many employers will continue paying your salary for several months and then ask for your situation to be reviewed. Others will only pay for a few weeks. Some people will have to rely on statutory sick pay. The government now provides a benefit called ‘Personal Independence Payment (PIP)’ which is designed for people who have experienced a life changing illness or disability. However, you can only claim after a three month period from the start of your illness. Your employer and the Department for Work and Pensions GOV.UK (DWP) will be able to advise you. Contact details are also listed at the end of this leaflet.
Sometimes there will be a role reversal in your relationship with your partner or spouse, especially if you were the bread winner and are likely to be off work for some time. It may be necessary for them to work extra hours and take on more of the household duties until you are feeling well again.

Your physical relationship with your partner or spouse may change after your illness. Major surgery or injury may mean you look different, sometimes leaving you with scars or a stoma (when the bowel is brought out onto the surface of your abdomen). The loss of digits or a limb occasionally results because of sepsis. You may lose a great deal of weight or most of your hair temporarily. You may feel extremely tired all the time and not interested in the physical side of your relationship or worried you may not be physically fit enough. Just holding hands or having a cuddle and being close is a good start. When you can climb a flight of stairs without stopping or becoming too breathless, it’s a good indication you are reasonably fit.

The majority of couples do manage to work through these changes. Get to know each other again. Visible scars on your face, neck or legs can often be disguised using make up and concealer or dressing cleverly. You and your partner may grow to embrace these features in time. Remember the fact you’ve survived and you are still together with the rest of your life ahead of you is the important thing.

“Remember the fact you’ve survived and you are still together with the rest of your life ahead of you is the important thing.”
What happens if you don’t improve as expected?

The majority of patients make a good recovery from sepsis but what happens if you are one of the few that don’t seem to improve as expected? What should you and your family look for during your rehabilitation period in hospital?

Signs of Deterioration or Lack of Improvement Physically

- Persistent fever – when your temperature remains high longer than expected or after you’ve finished the antibiotics. You may feel very hot or cold and shiver
- Your pulse is permanently higher than normal (over 90 at rest)
- Your blood pressure may be low
- You may have trouble passing urine or it causes pain or the amount is very small
- You have a great deal of pain in one area of your body. The area may be red and angry to look at and feel very warm
- You develop a cough and you start to cough up phlegm
- You may develop diarrhoea and vomit and/or become dehydrated

The doctors and nurses looking after you will be constantly checking for any of these signs and if they are concerned will take the appropriate action eg. send a specimen of your urine, blood or phlegm to see if there is any signs of infection, possibly start some antibiotics or give you some extra fluid via a drip. Some patients can develop a small collection of fluid in an area after abdominal surgery or in their chest. The consultant looking after you would then decide if it needed draining away or not. Usually, these physical problems can be sorted out quite easily and quickly and only delay your recovery for a short period.
Many patients who are cared for in a Critical Care Unit experience some mild emotional or psychological problems for a short time. For example, you can have vivid nightmares or panic attacks either on the unit, ward or when you return home. These are very frightening. You may feel very low in mood and be tearful for no apparent reason. These are all perfectly normal reactions following sepsis.

However, if these feelings continue for several months after you return home and you can’t seem to ‘shake them off’ it’s time to discuss them with your GP or Follow Up nurse if your hospital provides one. Sometimes you need to talk your experiences through with a professional in order to recover properly.

More Critical Care Units are now providing formal Follow Up clinics so you can discuss any concerns you have with Critical Care staff, or informal support groups where you can talk to other survivors, their relatives and support staff. The UK Sepsis Trust is now starting to set up informal support groups, so do ask or look on our website if you would like to come along. Alternatively, you can just phone up to arrange to speak to one of our support staff.

If you are finding it really difficult to cope with these long term problems, your GP or specialist may refer you to a psychologist for support. Please don’t be worried or upset about seeing them. They are trained professionals who can help you through this bad patch. Most of us are happy to see a doctor if we are feeling physically ill. These specialists are just there to help when we are feeling down emotionally. Then you can get on and live your life feeling much better.
Useful Exercises
Often ex-patients suffer from stiff joints, lack of energy and overall weakness for many weeks after they have recovered from their acute illness. Listed below are several exercises that should help improve your strength and mobility:

1. Sit comfortably on a chair and look forward. Slowly tilt your head to the right and then the left. Repeat several times. Then slowly bend your head backwards and forwards. Repeat several times.

2. Sitting on a chair, clasp your hands together in front of you and raise your arms upwards and back over your head as far as you can. Repeat several times.

3. Stand up – circle your left arm in a forward movement past your ear several times and then change direction and circle backwards. Repeat with the right arm.

4. Lie down on the floor on your back. Bend both your knees up, keeping your legs together and your feet touching the floor. Move your knees slowly from side to side, aiming to touch the floor each side. Repeat several times.

5. Lie on the floor – bend the right knee up to a right angle position and hold for 5 seconds, then lower it to the ground and straighten your leg. Repeat with the left leg. Do this several times. Be careful if you suffer with a bad back.

6. Sit on a chair and lift one leg a few inches off the ground. Make a circle with your foot by rotating your ankle and then change to the other foot. Repeat several times.

7. Sit on a chair with your back well supported and your knees together. Then straighten your right leg and bend your toes towards you. Repeat on the left side. Take care if you suffer from cramp.
Some recent words of inspiration from two Sepsis survivors...

“We were told I was finally well enough to come home after nearly three months in hospital, complete with butterfly bags in both of my lungs. I had lost approximately 6 stone in weight and was understandably very weak. Climbing the stairs was a mammoth task, which could only be achieved on all fours at first. Having a bath was exhilarating after all that time but I needed help to get in and out at first and wringing out the flannel was just one step too far!

The recovery process took time; things like stepping up a curb, getting dressed and having a shave presented all sorts of hurdles. Achieving small steps along the way but trying to do a little more each day. It was useful to have a diary to read, to understand what my family had gone through and also to help sort out what had been dreams or reality.

Slowly, slowly we got through the first few weeks and we had a very emotional Christmas. I returned to work in the New Year but I took it easy at first as it was very tiring!

I am incredibly blessed to have made a full recovery and feel very lucky to have had the support of the amazing health care professionals, my family and friends, who have all helped me along the way.

It is great there is now a support group for sepsis survivors; knowing there is help out there and knowing that whatever you are feeling is ‘normal.’”

— Mark and Diane Sollis, 2014
When I came out of hospital, it had all seemed like a bad dream and I was left with unimaginable fatigue. Then I found out it was sepsis, something I had never heard of before. I couldn’t even walk to the end of the driveway, let alone down the aisle in the church in six weeks time to get married. However, with a lot of rest and determination, I achieved my dream and something I had not envisaged myself being able to do.

After sepsis, anything is possible and in time you will feel yourself again. There is life after sepsis, you just need to remember that on your road to recovery, never lose hope. If I can do it, anyone can.

—— Anna Coles, 2014
Helpful Contacts

www.sepsistrust.org / phone: 0800 389 6255
UK Sepsis Forum

ICU Steps
www.icusteps.org
Voicemail 0300 30 20 121

Department for Work and Pensions GOV.UK (DWP)
www.gov.uk/pip/overview

GOV.UK (DWP) you need to go to Carers and Disability Benefit section and PIP is there.

The UK Sepsis Trust now have support groups in various areas. Details are available on our website.

‘A Guide for Patients and Relatives’ 2012, a booklet produced by the UKST giving a detailed account of sepsis.
Available to download from the website or phone 0800 389 6255 for a copy.

The UK Sepsis Trust Ltd (UKST). Registered charity number: 1158843. Registered company number: 8644039.
Sepsis Enterprises Ltd; trading company of UKST. Company number: 9583335. VAT Registration number: 225570222