THE UK
SEPSIS
TRUST

SEPSIS RECOVERY AFTER CRITICAL CARE

CONTENTS

INTRODUCTION

Your experience of sepsis and Critical Care may 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. You have been very poorly and it may take some time for you to recover.

THIS IS FOR YOU, YOUR FAMILY AND YOUR FRIENDS

People are often shocked and upset by what someone in Critical Care has gone through. These feelings might have been made worse if your loved ones were not able to spend much time with you loved whilst you were in hospital. As a result people might not have seen quite how ill you were, so it's easy to understand why they might expect you to feel better very soon.

Your family, friends and wider support network will be pleased you are back home, but they may not understand what you went through or why you feel like you do.

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, so it's important to share information on how you're getting on with those that are close to you.

HOW LONG WILL IT TAKE YOU TO RECOVER?

Recovery will commonly involve your whole body. Many people encounter new physical, cognitive and psychological problems, with a number of these new challenges being expected considering how poorly you have been.

- 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. Some people have very few or no ongoing problems following critical illness
- There are contributing factors that can influence recovery such as age, genetics, medical history and length of hospital stay
- For those people who have suffered significant organ damage, recovery can take time and be complex, often involving ongoing treatment. If you have suffered organ damage and/or had an amputation, specific information will be given to you by your healthcare providers

WHAT IS CRITICAL CARE?

You may be reading this because you, a relative or friend have recently received Critical Care in a High Dependency Unit (HDU) or Intensive Care Unit (ICU) as a result of sepsis.

This care is likely to have involved treatment to support one or more organs which were beginning to fail. This could have been the lungs (breathing), heart and circulation (blood pressure or heart rate) or kidneys (not passing urine).

WHY DID YOU NEED CRITICAL CARE?

Critical Care is where the most unwell patients in a hospital are treated.

Some patients with sepsis become more unwell because of the overwhelming response by the immune system and develop something called septic shock. This is when the blood pressure drops to dangerously low levels and organs stop working properly or fail completely. Septic shock means that further organs, in particular the heart and circulation system, and often the kidneys, require support.

In Critical Care:

- you can be carefully watched and monitored, including 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

- staff can give you treatment including support for your major organs, like your heart, kidneys and lungs

- there are highly trained doctors, nurses, physiotherapists, pharmacists and dietitians who look after you, and support your relatives by explaining what is happening

- nurses look after fewer patients. There may be one nurse looking after only one or two patients

THE HELP YOU MAY HAVE RECEIVED IN CRITICAL CARE

A team of doctors, nurses, physiotherapists and other health professionals 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
- putting a catheter in. This tube would have been put into your bladder to allow urine to be collected
- Removing phlegm from the lungs if you had a breathing tube or a tracheostomy, as you wouldn't have been able to cough strongly. This would have been done using a suction tube which was put down the breathing tube. It might have made you cough and retch while it was being done, which you may remember

EQUIPMENT AND TREATMENT IN CRITICAL CARE

There is a range of equipment used in Critical Care that's different from the rest of the hospital. Here are descriptions of some of the equipment and treatments used in Critical Care:

Alarms: Critical Care is noisier than a general hospital ward because of the sounds of equipment and alarms. If you heard an alarm it didn't necessarily mean something was wrong, there may have just been something the staff needed to be aware of - for example a drug infusion which was nearing empty and needed to be changed.

Breathing tubes: Many patients in Critical Care need support with their breathing. In the most severely ill, this involves passing a plastic breathing tube (endotracheal tube) into the mouth and down the windpipe. Most patients will need sedation to keep them comfortable while this breathing tube is in place, though the staff will try to use as little sedation as possible to help the patient's recovery- the aim is to keep patients as relaxed and calm as possible.

Ventilator or breathing machine: The ventilator is also sometimes called a breathing machine. This helps the patient to breathe while they are very ill, or too sleepy or weak to breathe by themselves. It is connected to the patient via a tubing system and a breathing tube (endotracheal tube) that is inserted into the patient's mouth and windpipe. The tubing allows the ventilator to push air and oxygen (under varying amounts of pressure) into the patient's lungs. Sometimes a tracheostomy or 'trache' tube is required. This is connected to the ventilator via a tube that is inserted through the neck and into the windpipe.

EQUIPMENT AND TREATMENT IN CRITICAL CARE

Blood pressure monitoring: Blood pressure is measured in Critical Care using either a blood pressure cuff (like the one at your GP) or using a cannula inserted directly into an artery, usually in the wrist or groin. This is called an arterial line.

An arterial line can measure blood pressure accurately and continuously, helping to identify problems quickly. It can also be used to take blood samples which show how much oxygen and carbon dioxide is in the blood. This helps make sure that the patient is getting the right support from the ventilator.

Feeding in Critical Care: It's very important for patients in Critical Care to maintain adequate nutrition and a good calorie intake in order to fight infection and enhance recovery, so while patients are unable to eat normally, feeding tubes are commonly used. A nasogastric tube (NG tube) is the most common type of feeding tube used. These are long thin tubes, placed by a nurse or the doctor, which goes into the nose, down the oesophagus (food pipe) until it reaches the stomach.

Some patients whose symptoms are severe may be unable to absorb food through their gut. In this case, the nutrition team will support the doctors in designing intravenous nutrition, otherwise known as TPN.

Kidney machine or 'filter': A kidney machine or 'filter' is a form of kidney support. This is a machine that can temporarily take over the work of the kidneys when they are struggling to work normally. Health professionals can monitor how well the patients kidneys are working by recording the amount of urine they pass and by doing simple blood tests.

WHAT YOU MAY HAVE EXPERIENCED IN CRITICAL CARE

Patients might have no memory of their time in Critical Care or may have very confused memories of what happened to them there. The strong drugs and treatments will have affected their body and mind.

They may have:

- felt slightly aware but didn't know where they were or what was happening
- had nightmares or thought things were happening which were not real – and these can be frightening. They may not have realised they were in hospital, and their mind may have tried to make sense of what was happening, for example by making them think things such as they had been kidnapped or were being held captive. Experiencing this confusion and hallucinations is called delirium and is very common
- been unable to talk or let people know what they were feeling have found it very difficult to sleep or have had strange dreams when they did sleep
- not known what time of day it was, or how long they had been in hospital

Not remembering what happened is extremely common and can make moving forward difficult. Memories can often be hazy or 'jumbled'. It can be difficult to piece together what happened before being admitted, and what took place while they were there. Some people remember the end of their admission, whilst others remember almost nothing.

Some people are happy not to remember very much, but for others, this can be upsetting. It may be that they are only ready to find out more in the weeks, months and sometimes years after getting home. It may be that they just want to put it behind them.

HOW YOU MAY BE FEELING

Here are some common physical and cognitive problems you may experience during recovery. Some are as a result of sepsis, and some a result of time spent in Critical Care.

- Fatigue
- Problems sleeping
- Brittle hair and hair loss
- Joint pains and muscle weakness
- Nausea
- Breathlessness
- Poor appetite
- Change in vision and hearing
- Reduced kidney function
- Short term memory loss
- Judgement and decision-making
- Speech, for example finding the right words
- Loss of concentration
- Difficulty performing tasks that were previously simple

WHAT YOU MAY BE THINKING

Here are some of the most common psychological and emotional problems experienced during recovery:

- Low mood and/or mood swings
- Lack of interest in things that you previously enjoyed, and possibly your personal appearance
- Anxiety about becoming unwell again
- Loss of confidence
- Wondering 'what if I hadn't survived?', as well as feeling guilty that you did
- Feeling guilty about what you have put your friends and family through
- Flashbacks and nightmares
- Frustrated that nobody understands
- Strain on personal relationships

During your recovery you may experience some of all of the problems listed, while looking relatively well to the outside world. Be reassured that it is normal and common to experience physical, cognitive and psychological problems after any critical illness. 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.

WHAT TO DO TO HELP WITH YOUR RECOVERY

There are a number of ways to help yourself during your recovery period. These include:

Time: Allow yourself time to recover - there is no standard pattern for this and recovery times vary 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 things you know you ought to do. Try to take time for the things that you would have enjoyed before, even if you don't 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 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 information, support and advice about what has happened and what to expect.

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. In the early recovery phase, it is normal to find yourself eating more and craving things like protein. Listen to your body- it needs these vital ingredients to rebuild itself.

WHAT TO DO TO HELP WITH YOUR RECOVERY

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, look to the further resources page or 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 Exercise: 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 as well as exercises to do whilst sitting can be found at: nhs.uk/live-well/exercise/easy-low-impact-exercises/

WHEN TO 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 is wrong.

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 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
- Significant change in behaviour and real difficulty in doing simple tasks and looking after self and home.
- Using drugs (prescription/non-prescription/recreational) or drinking a lot of alcohol

FURTHER HELP AND RESOURCES

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).

Here are some other useful links:

Critical Care

Critical Care Recovery
criticalcarerecovery.com

ICU Steps
icusteps.com

Health and Wellbeing

NHS Every Mind Matters
nhs.uk/every-mind-matters/

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

Financial and Practical Advice

Citizens Advice
citizensadvice.org.uk

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