

Road to recovery

Life following a Intensive illness

Information and advice for patients

Intensive Care Services

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Contact details

The Intensive Care Follow-up Support Service

Due to the type of work we do, most of our time is spent where you need us.

- On Intensive Care
- On the wards
- In the clinic

This means we are not office based. However, we will answer messages as soon as possible.

Email: swbh.swbhicufuss@nhs.net

Contact numbers:

FUSS Direct Line 0121 507 3716

ICU 0121 507 4040

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ICU Clinical Psychologist

Introduction

The aim of this booklet is to help you in your recovery following a Intensive illness. It also has useful information for your relatives/carers. It will give you examples of common problems that may occur and simple suggestions to try and solve them.

During the first few days after leaving Intensive care, you may be unable to concentrate or take in the information in this booklet.

Your relatives/carers can use this booklet to gain an understanding of what you are going through and this can then help them to be actively involved in your recovery.

Message for the patients

You have been very unwell and it is important to know this because it may take a while until you get back to feeling better. The length of time this takes will depend on:

- Your length of illness
- Your weight loss
- Your motivation

You may also find that certain changes in lifestyle are inevitable whilst you are recovering. We will look at these further in this booklet.

Please note that you will probably not experience all of the problems described here but if you do suffer from any of them we hope you will find the relevant advice helpful.

The Intensive Care staff, the Outreach Team and the Follow-up Support Service will all be happy to provide more information and advice during your stay in hospital.

Moving from the Intensive Care Unit to the ward

Leaving Intensive Care is the first big positive step on your road to recovery. Going to the ward means you are getting better and on the way to going home.

The decision for you to leave Intensive Care Unit and go to the ward, will be made by the Intensive Care Consultant. This decision however, is always made in close consultation with the nurses and doctors on the Intensive Care Team and the Specialist team involved in your care.

There is a detailed handover from the Intensive Care Nurses to the ward nurses and between the both medical teams.

Being on the ward

If you have not already had experience being at Midland Metropolitan University Hospital, you will find that the ward environment is quite different from the Intensive Care Unit.

There will be fewer nurses and less equipment on the ward and you will notice you don't have an individual nurse looking after you at all times, although you will still be closely monitored.

You will need to learn to use a 'call bell' for assistance when you need to call a nurse. Please note there may be a delay in responding to the 'call bell' as ward nurses have groups of patients to look after.

As you become stronger, the staff on the ward will encourage you to do more for yourself.

On the ward, the staff, their routines and the various noises will be different to that on the Intensive Care Unit and will take getting used to. This can make moving to the ward a difficult and frightening time for you and your family. Both the staff on the Intensive Care Unit and on the wards do understand this, so please do not hesitate to ask them anything that may concern you.

Visit from the Intensive Care Outreach team

A nurse from our 'Intensive Care Outreach team' will visit you on the ward within the first 24 hours after you move from Intensive care. The Outreach team is made up of highly skilled and experienced Intensive Care Nurses who will work with the ward staff to monitor your physical recovery, helping where necessary, to ensure that your recovery is going well.

Visit from the Follow-up Support Service

A nurse from our 'Follow-up Support Service' (FUSS) may visit you after you leave the Intensive Care Unit and will provide support to help with your ongoing recovery.

The FUSS team is made up of highly experienced Intensive care nurses who will follow your progress from Intensive care to the ward and home.

They will be able to discuss any worries or concerns you or your family have, regarding your physical and psychological rehabilitation.

If at any time during your stay on the ward, you wish to discuss your progress with a member of FUSS, please ask the nurse on the ward to contact the Intensive Care Unit. As part of the service there is also now access to inhouse Psychology, specifically for Intensive Care.

Your discharge

Don't forget, you will need to work with the ward staff to help you get ready for your discharge, as you will be ready to go home soon. Don't be worried about asking questions as we want you to be involved in your discharge and be aware of what is happening.

Some people find it useful to write the questions and answers down. This means you always have the information there to refer back to.

Mobility and exercise

When you first read this, you will probably find that the slightest activity takes a lot of effort and leaves you feeling very tired. This tiredness is normal and will improve with time.

As your body recovers slowly, you will feel very weak and will need to make a lot of effort for the slightest activity. You will find that you feel tired most of the time.

Unfortunately it is difficult to say how long your recovery will take as everybody responds at different rates. It depends on a number of factors such as:

- Your age
- You're previous levels of fitness
- How ill you have been
- How long you have been ill

Please do not be worried if it takes you weeks or even months to start to feel normal again.

Common physical problems for patients who have been in Intensive care for more than a few days are:

- Headaches
- Dizziness
- Widespread muscle wastage
- Stiff joints
- Shaking or tremors
- Loss of taste and nausea leading to a lack of appetite
- Difficulty coughing and swallowing
- Extreme tiredness or fatigue

During your stay on Intensive care you will probably have lost some weight and muscle strength. Your joints may also be very stiff as you have been in bed and immobile for some time.

The physiotherapist will make an assessment of your problems and will work out exercises which are suitable for you.

There are simple exercises you can do for yourself whilst you are sitting out of bed in a chair, which will help you with your recovery.

- Tap with your toes while keeping your heel on the floor
- Bend your knee and then straighten it
- Stretch each arm above your head one at a time

- If you are able, shuffle your bottom to the edge of the chair and then push down with your arms on the arm-rest to lift yourself up

Your appetite

Eating

Since you have been ill, you may have found that you have lost your appetite and your sense of taste may have changed. It is common for foods to:

- Taste saltier than normal
- Taste sweeter than normal
- Have an unusual metallic taste

Many people find that food such as fresh fruit, fruit juices and boiled sweets are refreshing and leave a pleasant taste in the mouth.

If you do find your appetite is poor, it is often easier to take small meals and have snacks in-between. Eating can be made more enjoyable if you take your time.

You should relax for a period of time after eating and avoid eating heavy or fatty foods.

Drinking

During the day you must make sure that you drink enough water, squash and/or hot drinks so you do not become dehydrated.

Dehydration can:

- Dry out your skin
- Make you produce less urine, which can have a bad effect on your kidneys
- Make you feel tired and weak

If you find you are having problems with eating or drinking, it is important to ask your doctor to refer you to a dietician who can advise you nourishing diet for when you go home.

Drinking alcohol - If you enjoy drinking alcohol, check with your doctor that it is safe to drink with the medication you may be taking and that it will not have a bad effect on your condition.

You may well find that a small alcoholic drink before or with your meal may help to stimulate your appetite.

Infections

Sometimes, taking strong antibiotics and steroids can lead to infections such as oral candida (thrush in your mouth), which can give you a thick white substance on the roof of your mouth and tongue, making it painful to swallow. If you think you might have thrush, your GP will be able to treat it easily.

Sleeping

When you are not as physically active, your body does not need as much sleep as usual, so don't be too worried if your normal sleeping pattern has changed. You may find it difficult to fall asleep or find that you keep waking during the night.

As you recover and become more active, you will find that your sleep pattern returns to normal. Go to bed at the same time each evening and most importantly get up at the same time each morning, even if you have not slept well during the night.

For many people, being awake at night can be worrying. Things easily seem to get out of proportion. It is common for a small problem to seem overwhelming in the early hours when you are the only person awake.

Although it is normal to feel like this, when you have been ill it is often much harder to cope with.

Tips to help you relax and sleep

- Reading at bedtime or listening to the radio, can often be a good way of relaxing. Even if you do not fall asleep at least this will help to pass the time.
- Sometimes a warm bath or shower shortly before going to bed helps to relax you making it easier to sleep.
- Using essential oils (Aromatherapy oils) in your bath, or as a massage, is a pleasant way of relaxation.
- Sometimes, a bedtime drink is useful but you should avoid
 - Tea/Coffee
 - Large amounts of alcohol

Your GP can give you advice if you have trouble sleeping but the most important thing is not to worry about lack of sleep, it will do you no harm. Things should return to normal as you become stronger and more active.

Dreams/Hallucinations

Many patients who have had a Intensive illness, experience nightmares and/or hallucinations, which can be very vivid and frightening at the time. You may have had dreams or feelings of being tortured, trapped in bed, or felt as if you were being held captive.

These dreams / hallucinations can be caused by:

- The medication used for pain relief & sedation
- The severity of your illness
- Intensive care delirium

These dreams can sometimes continue following your discharge to the ward, but be reassured that they are unfortunately a normal part of the Intensive care experience and they will usually go away after a few days.

It can help to talk to about this with someone you trust and remember it is nothing to feel ashamed or embarrassed about.

Low Mood

Many patients complain of feeling 'really good' one day and 'really down' the next. You may find that you feel low in mood or depressed for a while.

Sometimes, it may seem to you that your recovery progress is slow and that you may never get back to feeling normal again. It often feels that you take three steps forward and two steps back in the struggle to recover your physical strength. These feelings are normal reactions to illness and will get better with time.

It can be discouraging at times and therefore it is very important that you are realistic about what you will be able to do for yourself. Gradually take on the activities you did before you became ill and do not set yourself targets you will find too difficult to reach, as this may make you feel you have failed.

Discuss with the nurses, doctors and physiotherapists about what you can reasonably expect to do.

Remember:

- It is normal to have setbacks in the recovery process
- Try to be patient and give yourself time
- When you are home, it is also important to involve family and friends in setting the targets or goals, because they will often be the people who are best able to monitor your progress and encourage you

Anxiety

When have suffered a Intensive illness, it is understandable that that we will experience heightened emotions and racing thoughts. When we are facing things that are out of our control such as illness our emotion system can become overwhelmed leaving us feeling anxious.

A lot of our usual coping strategies may have also been taken away from us. This might be things like going to work, spending time with loved ones and other activities we enjoy.

When we become unwell our mind will produce lots of different thoughts. We might start to think why me? What if I have to go to hospital again? What if I die? These thoughts can leave us feeling anxious and low in mood because we are focusing on what has happened and may happen in the future.

We may also feel anxious and low after we have had an illness because we may worry about becoming unwell again, what our lives will be like going forwards, how it made our loved ones feel and how to get the care we need. These are normal thoughts and feelings to have but sometimes they might feel uncomfortable.

Our thoughts and emotions may affect what we do or how we act. If we are anxious we may avoid doing things and spend time worrying about lots of different things. Sometimes we may withdraw from others, or not reach out for help. This is a natural response but it is not always helpful if we are struggling.

Remember:

- What we think and feel is natural. We just need to decide whether it is helpful to focus on these thoughts and feelings or if they are making us feel worse.

- Talking to others can help if you are struggling; either loved ones or professionals such as your GP or local talking therapies service (please see Mental Health section in back of booklet).
- General relaxation exercises may be helpful such as relaxed breathing.
- There are lots of apps available that have guided mindfulness and relaxation exercises (please see Resources section).

Your family and friends

Your family and friends will be delighted that you are now getting better. It will have been an extremely worrying time for them. The experience of having a family member or close friend in the Intensive Care unit can be frightening and stressful.

You may find they are over-protective and will not let you do as much as you think you able to do.

Talking over what has happened and sharing worries will help you to work together towards your recovery.

You and your partner

Your illness may have reduced your sex drive however it may help you feel better.

It is possible that either you or your partner are concerned that sex could be harmful to you. This rarely is the case but as with other forms of exercise you should only do as much as feels comfortable.

You will be able to return to your normal relationship but again this may take some time and patience from you both.

Changes in your voice or appearance

Your appearance may have changed as a result of being ill but these changes are usually temporary. You may suffer hair loss or a change in the quality of your hair, or find that the texture of your skin has changed and has become much drier than before.

You may also have lost a lot of weight but, exercise and a sensible diet will all help to get you back to normal over time. You may also have some scars that are unsightly. These will fade in time and as your skin returns to normal they will not seem so obvious.

You may find that your voice has changed. It may have become husky or may be so weak that you are unable to raise your voice or shout.

This is probably the result of being intubated or of having a tracheostomy. This should return to normal over time.

Stress

The period of getting better/recovery after a Intensive illness can be a stressful experience. The level of stress and how long it lasts varies. In previous sections, we have described some of the symptoms which may be caused by stress such as:

- Disturbed sleep
- Lack of physical energy

- Lack of appetite
- Moods or depressions
- Problems with family relationships

Recovering from a stressful event takes time. If at the end of each week you can look back and say that overall things were better than the week before, you will know that you are making progress.

It may be useful to keep a diary of your recovery progress so you do not forget how well you are doing.

If you feel that you are making no progress, you may wish to speak to our Intensive Care Follow-up Support Service, your GP, or one of the support groups listed in the back of this booklet for help, support and advice.

Post Traumatic Stress

In a few cases, there are some patients who do have more severe symptoms of stress following a Intensive illness. This is known as Post Traumatic Stress Disorder (PTSD).

This does get better over time and most people have found that psychological therapy can be really helpful.

PTSD occurs after a traumatic event such as Intensive illness and is made up of a set of symptoms:

1. Re-experiencing memories of a traumatic event through flashbacks or nightmares. These memories for people who have had an illness are often delusional such as hallucinations or feeling that people were trying to hurt them when they are ill.
2. Avoiding reminders of the time they were ill, such as not wanting to go back to hospital to an out-patient appointment or not being able to watch medical programmes on the television.
3. Being unable to settle, feeling restless, being easily startled and not being able to sleep.
4. Loss of confidence.

Patients may have some of these symptoms when they first go home but on the whole these should settle down over a month after leaving hospital.

Intensive Care Follow-up Service

A Intensive Care Outpatient clinic is offered 6-8 weeks following your discharge home. At Outpatient clinic, we will

- Review your progress and recovery.
- Give you the chance to ask any questions and/or discuss any problems, issues or worries you or your family may have.
- Give advice and if necessary assist in referring you for further specialist treatment.
- Arrange for you to re-visit the Intensive care unit if wished.

We may have kept a diary for you on Intensive care. If this is the case, you will be given the opportunity to take this home with you following the clinic visit. The diary is intended to help 'fill in the gaps' and contains information about your stay in Intensive care and also messages from your family.

We will also invite you to our Patient and Carer Support group meetings, which are held 4 times a year. These meetings provide the opportunity for patients and families to discuss their memories and experiences together with members of the Intensive care team.

Many patients and their families find the meetings a great comfort, as, even after discharge from hospital, there is someone who cares and is willing to discuss any problems that affect your recovery from Intensive illness.

Useful contacts

Alcoholics Anonymous

Tel: 0845 769 7555

Website: www.alcoholics-anonymous.org.uk

Asthma UK

A charity dedicated to improving the health and wellbeing of people in the UK whose lives are affected by asthma.

Helpline: 0800 121 6244

Website: www.asthma.org.uk

Sandwell Healthy Minds (NHS)

Tel: 0303 033 9903

Email: bcpft.sandwellhealthyminds@nhs.net

Website: www.sandwellhealthyminds.nhs.uk

Birmingham Healthy Minds (NHS)

Tel: 0121 301 2525

Website: www.bsmhft.nhs.uk/our-services/birmingham-healthy-minds

British Heart Foundation

A charity that gives information and support on the health of your heart.

Helpline: 0300 330 3311

Website: www.bhf.org.uk

Citizens Advice Bureau (Including debt support advice)

Birmingham Centre

Gazette Buildings

168 Corporation Street.

B4 6TF

Tel: 0844 477 1010

Website: www.adviceguide.org.uk

The Colostomy Association

Providing support and information to anyone who has a colostomy.

Helpline: 0800 328 4257

Website: www.colostomyassociation.org.uk

Diabetes

The largest charity in the UK for the care and treatment of people with diabetes.

Helpline: 0345 123 2399

Website: www.diabetes.org.uk

Disabilities

Disability Rights UK

For independent living advice

Helpline: 0300 555 1525

Website: www.disabilityrightsuk.org

Elderly Care

Age UK

Helpline: 0800 169 6565

Website: www.ageuk.org.uk

Epilepsy

Epilepsy

Helpline: 0808 800 5050

Website: www.epilepsy.org

Guillain-Barre and Associated Inflammatory Neuropathies

Guillain-Barre Syndrome and Associated Inflammatory Neuropathies Support Group

Helpline: 0800 374 803

Website: www.gaincharity.org.uk

Headway

A charity that supports people with brain injuries and the people who care for them.

Helpline: 0808 800 2244

Website: www.headway.org.uk

HealthTalk

A helpful website covering a wide variety of personal experiences of health and illness. It includes video interviews of people who have been through different illnesses and includes sections for intensive care patients and their relatives.

Website: www.healthtalk.org/intensive-care

ICUsteps

A charity set up by former intensive care patients and their family members. It aims to promote better support and rehabilitation after a Intensive illness. They hold regular, informal drop-in sessions in Milton Keynes. They also offer support to former patients and their family members who want to set up similar groups in other areas. The website includes information about the experiences of former patients and family members, a bulletin board and more contact details.

Website: www.icusteps.com

Narcotics Anonymous

Tel: 0300 999 1212

Website: www.ukna.org

Meningitis

Meningitis Now provides support and information on identifying, and recovering from meningitis.

Helpline: 0800 028 18 28

Website: www.meningitisnow.org

Macmillan Cancer Support

Macmillan Cancer Support improves the lives of people affected by cancer. They provide practical, medical, emotional and financial support and campaign for better cancer treatment.

Helpline: 0808 808 2020

Youthline: 0808 808 0800

Website: www.macmillan.org.uk

Mental Health

Mind

Helpline: 020 8519 2122

Website: www.mind.org.uk

Pain

Pain Concern/ Support

Helpline: 0300 123 0789

Website: www.painconcern.org.uk

Princess Royal Trust for Carers

The Princess Royal Trust for Carers is the largest provider of support services for carers in the UK.

Tel: 0844 800 4361

Website: www.carers.org

Samaritans

Samaritans provides confidential, unbiased emotional support, 24 hours a day, for people who feel distressed, desperate or suicidal.

Helpline: 08457 90 90 90

Website: www.samaritans.org

Spinal Injuries Association

A support charity for people suffering from spinal-cord injuries.

Helpline: 0800 980 0501

Website: www.spinal.co.uk

The Stroke Association

An organisation that provides support and information on strokes and guidance on coping with life after a stroke.

Helpline: 0845 3033 100

Website: www.stroke.org.uk

Smoking

NHS Smoking Helpline

Tel: 0300 123 1044

Website: www.nhs.uk/smokefree

The Lee Spark NF Foundation

The Lee Spark NF Foundation is a charity aimed at preventing streptococcal infections from leading to necrotising fasciitis (a rare and serious infection that causes skin and the tissues beneath it to die). They offer information and support to families affected by necrotising fasciitis, and raise awareness among health professionals working with families affected by this infection.

Tel: 01254 878701

Website: www.nfsuk.org.uk

Resources

Apps available for download:

Insight Timer

iPhone rating: 5 stars

Android rating: 5 stars

Price: Free with optional in-app purchases

More meditation is practiced on Insight Timer than anywhere else, and the app has 10 or more free guided meditations added every day. Browse thousands of guided meditations to begin building a simple daily habit, jump into discussion groups and the community features, and use the music tracks and ambient sounds to calm the mind and promote sleep.

Calm

iPhone rating: 5 stars

Android rating: 5 stars

Price: Some basic free content with optional in-app purchases and subscription

This award-winning app has calming exercises, breathing techniques to help you relax, and even a Calm Kids section with meditations for kids between 3 and 17. The new Sleep Stories section features a great mix of voice talent - you may recognize actors Matthew McConaughey or Jerome Flynn - to lull you to sleep.

Headspace

iPhone rating: 5 stars

Android rating: 4 stars

Price: Some free content with optional in-app purchases and subscription

Find calmness, wellness, and balance in your life with this app's guided meditation and mindfulness techniques for daytime use. Before bed, try any of its 10 new sleep music tracks or 16 nature soundscapes. The app builds personalized plans based on a little input from you, so you can learn the essentials of meditation and build from there.

Helpful Websites:

<https://www.nhs.uk/nhs-services/mental-health-services/>

<https://www.nhs.uk/every-mind-matters/>



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