



Recovering from critical illness

Information for patients



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INTRODUCTION

You have been given this booklet because you have had a prolonged stay in a critical care unit. We know that there are many common issues that may affect people recovering from critical illness. You may have experienced physical problems such as weakness, pain or breathlessness and psychological symptoms that might include anxiety, stress or difficulty sleeping. Some people experience strange thoughts or nightmares and memory loss has also been reported.

Everyone's experience is different. As you recover from your illness, we want to help you to manage these issues as best you can to enhance your recovery and ultimately get you back home.

This can also be a stressful time for your loved ones. We hope that the information in this book will help you and your family with your transition as you leave the critical care unit and prepare to leave hospital..

HOW TO USE THIS BOOK

Use this book with your family as a source of information; record your thoughts, feelings and any questions you may have. Record your goals and progress in the rehabilitation and goal setting sections. There are parts to fill in about issues that are of particular concern to you. The physiotherapists will help you complete some of the exercise sections. You can also fill in any goals that you wish to set yourself and note the achievements you make along the way.

We have included a list of very useful websites and contacts that cover many of the issues that you may be dealing with.

There's also information about the InS:PIRE programme. This is a five week outpatient programme which continues to focus on rehabilitation after critical illness once you have left hospital.

WHAT MATTERS TO YOU?

When you have been critically ill you may have been unable to communicate effectively for some time. This may have been because you were asleep on a ventilator, you may have had a tube (tracheostomy) in your neck, or you may have been too unwell to talk.

During this time the staff looking after you will focus on doing things to try and make you better and as comfortable as possible. We hope that as you start to feel better you can tell us some of the things that are important to you, so that we can use the information to work together to support your recovery and rehabilitation. We hope that your family and friends will also get involved and we're happy to include them with your agreement.

Please use the boxes below to record some of these things; you can use this to start a conversation with staff on the wards.

What do you like to be called?

Do you have any visual or hearing impairment? Please give details

What are your interests/ hobbies?

It is important to let us know if you have any long term conditions or problems that you feel are particularly important for us to be aware of as you begin your recovery (such as a painful shoulder)

“SAY 2 YOU”

As you begin your recovery you will notice that the different specialists in the hospital will have certain things that they want to organise for you, like tests, scans, or goals they want you to achieve such as improved strength or movement. All of these things are to try and get you better and ultimately get you home. We also want you to tell us what the most important issues are for you at this time. These might be physical problems like weakness, pain, poor balance that you feel need to be addressed. It can help if you take one or two important issues and write them down. A family member or staff member can help you complete this if needed.

Issue 1

Issue 2

Other important issues

PREPARING FOR THE WARD.....

LEAVING CRITICAL CARE

The time will come when you are well enough to be moved out of the critical care unit to another ward in the hospital. This can bring mixed emotions. On one hand you are getting better and don't need the intensity of medical and nursing input that you received when you were most unwell. This is good news! On the other hand it is normal to feel apprehensive and worried about what might happen to you. You have built up relationships with the team in critical care and they understand what you have been through while you were there. In addition to different healthcare staff looking after you, the staffing levels on general wards are different to critical care areas. For example, you may be used to having one-to-one nursing care and be anxious that you won't receive the same level of attention. This is where communication becomes very important. The staff on the wards will be given a clear handover of the important medical and nursing information relating to your stay in hospital. The physiotherapists will also inform the ward physiotherapists about how you are getting on and what you can and can't do and what you might need a little extra help with. It is important that if possible you also let staff know how you feel about things and ask for assistance where required.

Part of recovering from a serious illness is about starting to do more for yourself. This can be very frustrating and extremely exhausting, particularly if you have had issues with muscle weakness and pain. Sometimes you may feel that people are pushing you too hard and other times you may feel that you are being held back and that you want to do more. It is important that you listen to your body and make small steps to do more and more by yourself. Make sure you communicate with the team and let them know your thoughts.

You may also be worrying about other things such as finances, employment, your role as a carer, or your pets while you are in hospital. Your relatives may also be struggling to come to terms with what has happened to you, and there may be a lot of uncertainty about what is going to happen when you leave hospital. There are many organisations and resources that can provide advice and support about these things, we've included some in the "Useful Resource" section of this booklet.

PHYSICAL RECOVERY

This is your personal rehabilitation record. Many people who have been on a ventilator experience muscle fatigue, weakness and poor stamina during their recovery period. Some studies have found that patients can lose up to 2% of muscle mass per day whilst in a critical care unit. So, the length of time you were in the Unit can affect how you feel. It is really important for you to try and get as active as possible as quickly as possible and start using those muscles again, with guidance from the healthcare staff, even though it may be the last thing you feel like doing.

This booklet will allow you to record your future goals, track your exercise and document any questions that you may have. Healthcare staff on the ward will help you to complete this along with your family/carers.

WHY IS EXERCISE IMPORTANT?

Exercise Helps:

- ❖ Reduce stress and make you feel happier
- ❖ Reduce your blood pressure
- ❖ Reduce aches and pains from joints and muscles
- ❖ Rebuild strength and power
- ❖ Improve stamina

Important things to remember about exercise:

Listen to your body! Although it's important to begin exercising as soon as you are able, trying to do too much too soon may slow your recovery down. You will probably find that you have good and bad days, on your good days don't be tempted to do more than is on your plan. On your bad days try not to be put off.

Exercise should make you breathe a little harder and make you feel warm. This is normal and should be a guide as to how much your fitness is improving. You are working too hard if you are so breathless that you are unable to speak. If you feel any discomfort during exercise it is ok to stop and take a rest.

The next few pages of this booklet will provide you with a space to record your daily exercise and how you felt during and after.

EXERCISE RECORD

Filling in your exercise records is really important in helping you to make a good physical recovery. This will help guide you so that you can increase the amount you are doing in a safe way. Trying to remember what you were able to do a week ago can be difficult, by looking at the sheets you and your family/friends will be able to see your progress.

Date:	I found this....				Walking Aid I Used and Distance I Achieved
Walk 1					
	Too Easy	Fairly Easy	Fairly Hard	Too Hard	
Walk 2					
	Too Easy	Fairly Easy	Fairly Hard	Too Hard	
Exercise					
	Too Easy	Fairly Easy	Fairly Hard	Too Hard	

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ROAD TO HOME

It is important to reflect back on your time in hospital. Think about what you have already achieved but also what may have made this more challenging.

My Achievements	Challenges That I've Overcome
●	●
●	●
●	●
●	●
●	●
●	●
●	●

Home checklist:

- Grip strength: _____Kg
- Personalised exercise plan provided
- Referral made to community
-
-
-

NUTRITION TO SUPPORT RECOVERY

It is normal to experience some muscle loss and subsequent weight loss during your time in a Critical Care Unit. This is because during critical illness your body uses any available energy sources to focus on getting you well and this will in part come from your muscle and fat stores, regardless of how much nutrition you receive. A Dietitian will have been reviewing you regularly to monitor your nutritional needs and to minimise these losses whilst you were in the Critical Care Unit. If you were unable to eat for yourself you may have been fed with liquid nutrition via a feeding tube (into the stomach or small bowel) or intravenously (into a vein).

The good news is that now you are recovering your body can start to re-build muscle and get you back to a healthy weight with adequate nutrition. Adequate nutrition is important for your physical rehabilitation in order to provide you with the energy for therapy and also the protein to re-build muscle stores and help your body heal.

You may find it difficult as you begin to eat normally and this can be due to:

- ❖ Taste changes
- ❖ Poor appetite
- ❖ Sore mouth or throat
- ❖ Feeling nauseous
- ❖ Feeling tired

These symptoms are common and could be a result of having been unwell, medications, weight loss, having been on a ventilator, or just simply from having not eaten in a long time. These symptoms will resolve as you recover, but in the meantime you may find it helpful to stick to softer food options, smaller meals with snacks in between and to have high energy/high protein snacks and/or supplement drinks provided by your Dietitian. A high protein diet is important following a

period of critical illness or surgery and may be required for some weeks or months as you increase your mobility and exercise levels and your body shape returns to normal. If you have a chronic kidney condition please speak to a Dietitian before increasing your intake of protein.

If you feel you are struggling with your nutritional intakes and are not already seeing a Dietitian, please speak to one of the healthcare team and ask to be referred, or if you are an outpatient please ask to be referred via your GP.

Psychological Recovery

Leaving the Critical Care Unit following critical illness can be a stressful and daunting time, and can lead you to feeling a variety of different emotions. You may feel tense or low, or have difficulties adjusting to the changes that have come to your life following your illness. Your friends and family may experience these feelings too.

This section will focus on common challenges people face after leaving a Critical Care Unit, such as difficult thoughts and feelings, difficulties with memory and concentration, and difficulties sleeping. It will provide some helpful strategies to help manage such difficulties as they arise.

Common Thoughts and Feelings

We all worry and have negative thoughts from time to time. It is natural to worry following care in the ICU.

You may have thoughts such as:

‘What’s the point?’

‘My life is as good as over’

‘I’ll never be the same again’

‘What if I end up in intensive care again?’

‘What if things don’t get better?’

Our thoughts and worries can cause unpleasant feelings. Common feelings following care in the ICU include:

- ❖ Frustration
- ❖ Anger
- ❖ Denial
- ❖ Vulnerability
- ❖ Guilt
- ❖ Loss of confidence
- ❖ Grief
- ❖ Tearful
- ❖ Worried
- ❖ Acceptance

Feelings of anxiety, depression and traumatic stress are common responses following illness. As well as affecting the way we think, when we are worried, scared or feeling a lot of stress, our bodies respond by changing our body chemicals to try and help us cope. This can lead to us feeling different physical symptoms that may feel similar to those experienced during illness, and can lead us to worrying more.

Below is a list of symptoms experienced when we are affected by anxiety, depression or traumatic stress.

Anxiety

- A feeling of worry, unease or nervousness
- Physical symptoms: ‘butterflies’ or stomach tightness, tight chest, palpitations, dry mouth, sweating, muscle tension
- Psychological symptoms: irritable, restless, poor concentration, ‘what ifs...’, racing thoughts.

Depression

- Low mood and periods of sadness
- Physical symptoms: poor appetite, difficulty sleeping, tiredness/lack of energy
- Psychological symptoms: feelings of hopelessness, sadness, loss of interest/enjoyment from activities

Traumatic Stress

- Stress reaction following a traumatic event or threat of a traumatic event
- Symptoms: Re-living experiences (flashbacks/nightmares), avoidance (people, places, activities), hypersensitivity/over-alert, numbing, amnesia (memory)

Helpful Coping Strategies

Sometimes our symptoms, thoughts and feelings about illness can get in the way of us doing what is important to us.

There are several strategies that you can put in place to help manage feelings of anxiety, depression and stress. These can include:

- ❖ Recognising tension
- ❖ Identifying and noticing your thoughts/worries
- ❖ Mindfulness and relaxation techniques:
 - o Controlled Breathing
 - o Progressive Muscle Relaxation
 - o 5-5-5 technique: Notice 5 things you can: hear, see, feel - right now
- ❖ Gradually facing your fears
- ❖ Maintaining social support
- ❖ Problem-solving
- ❖ Increase your activity levels

MINDFULNESS TASTER EXERCISE

Leaves on a Stream

Find a comfortable position. Close your eyes.

Imagine a stream, with leaves floating down

As thoughts appear, place them on the leaves and let them float past

Whenever you get hooked by thoughts, gently unhook yourself and carry on.

Do this once or twice a day for 3 to 5 minutes.

- o Pacing – increasing or decreasing activity levels to suit your needs
- o Involvement in treatment/making decisions about your treatment

If your thoughts and feelings become too difficult to manage, it may be helpful to reach out to your friends or family, or contact a free helpline such as Samaritans (116 123). If feelings persist, it may be helpful to contact your GP for further support. The “Useful Resources” section provides details of other organisations.

Cognitive Difficulties

You may experience ‘cognitive difficulties’ following your illness, which are difficulties with memory, attention and concentration. These difficulties can be caused by medications, being ventilated, fatigue, physical health problems and mood changes.

The following techniques can help with difficulties with memory:

- ❖ Adapt your environment:
 - o Use a notepad or notice-board
 - o Have a special place for objects
 - o Memory aids (e.g. diary/calendar, lists, watches/alarm, pill boxes)
- ❖ Follow a routine
- ❖ Prioritise information
- ❖ Improve general well-being
 - o Identify activities you find enjoyable and relaxing
 - o Share your feelings with others

Sleep Difficulties

Poor, fragmented sleep is one of the most frequent complaints among people who have been in Critical Care Units.

Poor sleep can cause us to feel mentally and physically exhausted, and can make us feel irritable, anxious and low.

Poor sleep can also lead to difficulties with memory and concentration, and increase the risk of other physical health conditions.

What causes poor sleep?

Several factors can cause poor sleep, including:

- ❖ Stress and strain
- ❖ Depression and anxiety
- ❖ Life changes
- ❖ Shift work
- ❖ Diet
- ❖ Sleeping pills
- ❖ Pain, discomfort

HOW CAN I IMPROVE MY SLEEP?

‘Sleep hygiene’ is a term for habits and practices that can be used to help improve our sleep. Restoring good sleep hygiene takes time and practice:

Before Bed

- Establish a bedtime routine, such as light reading before going to bed to help you relax.
- Try to avoid eating late but ensure you are not hungry at bedtime.
- Avoid caffeine and alcohol in the evening

Sleep Pattern

- Try to fix a time for going to bed and waking up. Going to bed early can also result in a disturbed sleep.
- If you do not fall asleep within 30 minutes, go to another room and do some quiet activity.
- Regular exercise - avoid strenuous exercise 2 hours before bed.
- Avoid napping throughout the day. if you must, try early afternoon for 30-40 minutes.

Sleep Environment

- Ensure that your bedroom is as restful as possible (temperature and lighting).
- Make sure your mattress and bedding are comfortable.
- Only use your bed for sleep and intimacy.
- Avoid watching television or using smart technology in bed - this can keep you awake.

Waking up overnight

- If you cannot get back to sleep within 20 minutes, get up and go to another room.
- Do some quiet activity and try to keep the light dim.
- When you feel sleepy, go back to bed.

Your Medications

During your time in hospital the doctors looking after you may have started you on new medications. You may or may not have been taking long term medicines at the time you were brought into hospital. Either way, they may have changed a bit and it can be quite confusing knowing what you are supposed to be taking and why.

Some of the medications you receive on the ward will be stopped by the time you leave hospital. There will be others that you'll need to continue after leaving hospital. The doctor or pharmacist can write these down for you in the box below with an explanation about what each one is for.

Name of Drug	What is this for?

GOING HOME

It is normal to have mixed emotions when the time comes to leave hospital. On one hand you are really happy to be getting away from the hospital environment and back to your own surroundings. On the other hand you may be anxious about how you will cope without the help and support you have had in hospital. This is a normal part of the recovery process.

The physiotherapy and occupational therapy teams will have been assessing you while in hospital. It might be that a period of supported care has been organised for you when you first go home. Depending on your needs this may mean that a community team will visit you at home to help with certain aspects of your care.

However, it may be that there is no additional support arranged for you.

If you are getting support from healthcare teams in the community then please use this book to show them the progress you have already made.

Although leaving hospital can feel great at first, it can become more difficult. Some people may feel a bit lost without the support they had in hospital or feel daunted at the challenge they face to get back to “normal”.

Please remember that there is a lot of support out there to help with your recovery, some included in the “Useful Resources” section. In addition you may be invited to the InS:PIRE programme.

InS:PIRE



We know that leaving hospital can be extremely challenging for you and those around you. You will have much less support than you did in the hospital and this can be physically very tiring as well as emotionally draining.



You may feel pressured to get back to doing all the things you did at home before you were unwell. You may also feel you have to “keep up appearances” and meet up with friends and visitors. This can be daunting and it is important that you pace yourself physically and mentally. Working towards small targets will be much more achievable and rewarding than doing too much too soon. Those around you will understand.

You may be contacted following your discharge about attending InS:PIRE. This is a five week programme to help you and your carers/ family continue on your road to recovery. The team is made up of different health professionals who all specialise in recovery from critical illness. They will be able to assist with any challenges that you may be facing. These challenges may not just be physical, they may be about: medications; ongoing medical questions; difficulties with sleep, memory or other emotional factors.

You can find more information at: www.nhsggc.org.uk/inspire or please ask one of the critical care staff members for more information.

WHY....? HOW....? WHEN....?

You probably have many more questions that you would like to ask. It can help to write them down here and ask them the next time you see the doctor or appropriate health professional. There is no such thing as a “silly” question. It is really important to get questions cleared up so that you don’t dwell on them. Trust me we will have heard it before..

Questions	Answers
•	•
•	•
•	•
•	•
•	•
•	•
•	•

USEFUL RESOURCES

Critical Illness Recovery Websites:

- ❖ www.criticalcarerecovery.com
- ❖ www.icusteps.org
- ❖ www.nhsggc.org.uk/inspire

Specific Issues:

Benefits, Welfare and Debt advice:

- ❖ Money Matters Advice Service
Tel. 0303 123 1008
Citizens Advice Scotland
www.citizensadvice.org.uk/scotland
- ❖ My Life My Money App
(Available on Google Play and Apple for download)
Support/Advice for Carers: www.lanarkshirecarerscentre.org.uk
Stopping Smoking: Tel. 0300 303 0242
www.canstopsmoking.org

Health and Wellbeing Support

- ❖ <https://www.nhsinform.scot/scotlands-service-directory>
Local Groups, Services and Events
Taking part in leisure activities can help improve well-being
- ❖ North Lanarkshire:
www.locatornl.org.uk
- ❖ South Lanarkshire
www.vaslan.org.uk
www.locator.org.uk

Mental Well-being

- ❖ Multiple Resources available through Well Connected Programme (North and South Lanarkshire). www.elament.org.uk

Stress Control

Stress control classes will help us deliver skills and techniques to manage common issues caused by modern day living such as stress, anxiety or low confidence, which can affect well-being. Classes are community-based and consist of six sessions lasting 90 minutes each. At Stress Control you do not speak, just sit back and listen about helpful stress control techniques.

To find out your nearest class and book a free place:

Telephone 0300 303 0447 or

Email: stresscontrol@lanarkshire.scot.nhs.uk

Alternatively just go along to the class of your choice.

For the most up to date timetable and location of classes, please see www.elament.org

In a crisis, support is available from:

- ❖ Samaritans - Tel: 116 123 (UK) free to call 24 hour support or online at www.samaritans.org
- ❖ Breathing Space - Telephone 0800 83 85 87
Opening hours:
Weekdays: Monday-Thursday 6pm to 2am
Weekend: Friday 6pm-Monday 6am
- ❖ Contact your GP, or ring NHS 24 by dialling 111 - medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
- ❖ MIND – www.mind.org.uk

Making Life Easier

- ❖ MLE (North Lanarkshire residents only) www.makinglifeeasier.org.uk – Information, professional advice and direct access to services and support

Outdoor Activities

- ❖ www.bit.do/lan-greenspace

Volunteering

South Lanarkshire

- ❖ Voluntary Action South Lanarkshire. Tel. 01698 300 390
- ❖ www.vaslan.org.uk

North Lanarkshire

- ❖ Voluntary action North Lanarkshire. Tel. 01698 358 866
- ❖ Email: dutyofficer@vanl.co.uk

Employment

- ❖ North Lanarkshire's Working Tel. 0800 073 0226

Healthy Reading

All Lanarkshire Libraries now have a Healthy Reading Section, with a wide range of mental health and well-being self-help leaflets, books, CDs, DVDs and web-based support. You will also find a wide range of information for mental health and well-being at the elament (eLanarkshire Mental Health Resources) website: <http://www.elament.org.uk>

List of Contributors

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CONFIDENTIALITY AND THE USE OF PATIENT INFORMATION

NHS Lanarkshire take care to ensure your personal information is only accessible to authorised people. Our staff have a legal and contractual duty to keep personal health information secure, and confidential. In order to find out more about current data protection legislation and how we process your information, please visit the Data Protection Notice on our website at www.nhslanarkshire.scot.nhs.uk or ask a member of staff for a copy of our Data Protection Notice.

NHS Lanarkshire - for local services and the latest health news visit www.nhslanarkshire.scot.nhs.uk
NHS Lanarkshire General
Enquiry Line: 0300 30 30 243

NHS inform - The national health information service for Scotland.
www.nhsinform.co.uk
Tel No: 0800 22 44 88

If you need this information in another language or format, please e-mail: Translation.
Services@lanarkshire.scot.nhs.uk



www.careopinion.org.uk

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