

My pathway to recovery

Critical Care Recovery Service

Information for patients

Welcome to your recovery journey

Recovering from a critical illness is a significant and often challenging process. It's a unique journey that requires patience and support from an expert team. You've been through a lot, and you need time to heal and adjust. Understanding what to expect and how to manage your recovery can make this journey smoother and more manageable.

Understanding your recovery

The path to recovery from a critical illness involves not just physical healing but also psychological and cognitive adjustment. It's natural to experience a range of feelings and symptoms as you move from the intensive care unit to the process of rehabilitation and recovery. Each person's experience is unique, and recovery can vary greatly depending on the nature of the illness, the treatments received, and your own individual health background.

We know that patients who survive their critical illness often describe a range of physical, cognitive, and psychological symptoms which can affect the way they live their lives. We call this condition **Post Intensive Care Syndrome (PICS)**. There is a lot of research ongoing about what the factors are which cause post intensive care syndrome, and how we can best help patients recover from this. The information below describes the key components of the Post intensive care syndrome and describes how we might help you recover from this.

During your recovery, it's important to be gentle with yourself and acknowledge that recovery is a gradual process. Recovering from critical illness involves multiple aspects of your wellbeing:

- **Physical recovery:** Your body needs to heal from the illness it has endured. This includes regaining strength, mobility, and normal daily activities. You may face challenges such as fatigue, muscle weakness, and reduced mobility, but with time and appropriate interventions, these can improve. During your recovery you may work with physiotherapists and occupational therapists to regain your physical function.
- **Emotional and psychological adjustment:** Facing a critical illness can impact your mood and mental health. Feelings of anxiety, depression, and low mood are common. Understanding that these feelings are a normal part of recovery can help you address them more effectively. Seeking support from mental health professionals and peer support groups can be beneficial.
- **Cognitive recovery:** Cognitive challenges, such as difficulty concentrating or memory issues, are also very common following critical illness. Engaging in cognitive exercises and mental stimulation can aid in cognitive recovery.
- **Nutritional recovery:** Your body's nutritional needs might have changed due to your illness. Eating a balanced diet that supports healing and provides the energy you need is crucial. Working with a dietitian can help you address issues like appetite changes and weight loss.

While recovery may present challenges, many people find that with time they overcome these obstacles. It's important to set realistic goals, celebrate small victories, and be patient with yourself. Recovery is not necessarily about getting back to where you were before the illness but about moving forward with a new perspective.

Your recovery journey is unique to you and taking it one day at a time can help you manage the process more effectively.

Your recovery team

Throughout your recovery journey, you will be supported by a dedicated team of healthcare professionals called the NHS Lothian Critical Care Recovery Service. This team includes consultants in critical care who oversee your overall medical recovery, and critical care recovery nurses who provide specialised care and monitor your progress. Physiotherapists and occupational therapists will help you regain strength and mobility, and speech and language therapists will assist with any communication or swallowing difficulties. Dietitians will ensure you have a balanced diet to support your healing, while mental health nurses and consultant psychiatrists will provide essential support for your emotional and psychological wellbeing. Pharmacists will manage your medications to ensure their effectiveness and safety. Together, this multidisciplinary team is committed to helping you achieve the best possible recovery.

Common symptoms following critical illness

After a critical illness, it's common to experience a range of symptoms as your body recovers, such as:

Fatigue

Feeling unusually tired is common. It's important to rest, but also try to gradually increase your activity level under the supervision of the recovery team. This gradual increase in the amount of activity you are doing is called pacing.

Weight loss

During your illness, you might have lost weight due to a reduced appetite or other factors. To help regain weight, focus on a balanced diet rich in protein and calories. The dietician involved in your care can help create a nutrition plan that meets your needs.

Loss of appetite

Many people experience a reduced appetite after a critical illness. Eating smaller, frequent meals and incorporating snacks can help. It's also helpful to eat foods that you enjoy and that are nutritious.

Change in voice

Some people notice changes in their voice, such as hoarseness or weakness. This can be due to the breathing tube used during your illness. Speech therapists can offer exercises and strategies to improve your voice. If the changes in your voice persist for some months after your illness, you may benefit from being referred to an ear, nose, and throat (ENT) specialist.

Swallowing difficulties

Swallowing difficulties, or 'dysphagia', can occur after a critical illness due to muscle weakness and difficulties in co-ordinating the muscles which control your swallow. If you have difficulties with your swallowing, you'll work with and be closely reviewed by our speech and language therapists to ensure you are safe in your transition back to eating a normal diet.

Reduced mobility

You may find it difficult to move around as easily as before. Gentle physiotherapy with your physiotherapists and regular exercise, tailored to your ability, can help you regain strength and mobility.

Reduced muscle strength

Muscle weakness is common and can affect daily activities. Gradual strength training and physiotherapy can help in rebuilding muscle strength and endurance.

Pain

Some patients who have been critically ill develop issues with pain affecting various parts of the body, which can sometimes be due to nerve sensitivities and joint discomfort. There are several non-medication interventions in addition to medications that can help with pain, so let us know if you are experiencing persistent pain.

Low mood

Feeling down or low in mood is a natural response to a major illness. It's important to talk to us if you are experiencing persistent low mood or depression. Mental health support via our mental health team can be beneficial.

Difficulty concentrating

Some individuals find it hard to focus or concentrate. This can be due to the stress of illness or medications. Cognitive exercises and mental stimulation can help improve concentration over time and can be provided by our occupational therapists.

Poor sleep

Sleep patterns may be disrupted following a critical illness. Maintaining a regular sleep schedule, creating a restful environment, and discussing any persistent sleep issues with the critical care recovery team can help improve your sleep quality.

Memories of delirium

You might have memories of confusion or delirium from your illness – these are memories of strange or unusual events that often felt very real at the time. These memories can be distressing for some people, but they gradually reduce with time. Discussing them with the recovery team can help you understand and manage these experiences better.

Hair loss

Some individuals experience hair loss following a critical illness, which can be a result of the stress on your body, medications, or changes in nutrition. This condition is typically temporary, and hair growth often resumes as your health improves (within 12 months). There are some treatments which we offer for this, so please let us know if hair loss is affecting you.

My recovery goals

Setting clear, achievable goals can be a helpful way to navigate your recovery journey. These goals are designed to provide direction, motivate you, and track your progress. While every person's recovery is unique, the following goals can serve as a starting point.

Setting goals is about creating a roadmap for your recovery, but it is important to remain flexible. Your healthcare team is here to help you adjust these goals as needed and support you in achieving them. Celebrate your progress, no matter how small, and stay focused on your path to recovery.

My recovery goals and what's important to me
Physical health goals
Emotional and psychological goals
Cognitive goals
Social and daily living goals
Long-term goals

Further information and support

NHS Critical Care Recovery Service

For further information please visit our website or scan the QR code below:

www.criticalcarerecovery.com



The “getting home” section of the website has several articles and videos which may be helpful as you think about going home from hospital. In addition to information about your recovery, there are stories from previous patients about their journey home after intensive care.

ICU Steps

ICU Steps is a patient support group with lots of resources on their website:

<https://icusteps.org>



They offer local meetings with other survivors of critical illness in addition they support the families of those recovering from critical illness.

VOCAL

VOCAL is an organisation that provides help and support to carers. If you feel like you or someone who helps care for you would appreciate someone to talk with, please visit their website for more information:

www.vocal.org.uk



Remember you are not alone

Your recovery from a critical illness is a journey that encompasses physical, emotional, and cognitive recovery. Understanding the common symptoms, you may experience can help you better manage your recovery. Setting realistic and achievable goals, while remaining flexible and patient with yourself, is key to navigating this process. Remember, you are not alone—your recovery team and support networks are here to guide you through this process and are wishing you a smooth and steady recovery.

Some people find it helpful to visit ICU once they are feeling better. If you wish to visit, please contact us on 07811711330 to discuss this.

Authors

Gilly Fleming, Elizabeth Wilson, Nadine Cosette, Thomas Jones, Raegan Robertson, Emma Forbes, Sophie Hobson, Leanne Dow, Louise Elliott, Alasdair Fitzgerald, Jo Thompson, Laura Richards, Mhairi Johnston

