

Recovery Beyond Survival

A review of the quality of rehabilitation care provided to patients following an admission to an intensive care unit



**What matters to patients and loved ones?
Marginal Gains for 2026**

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#REHAB
LEGEND

What do patients want?



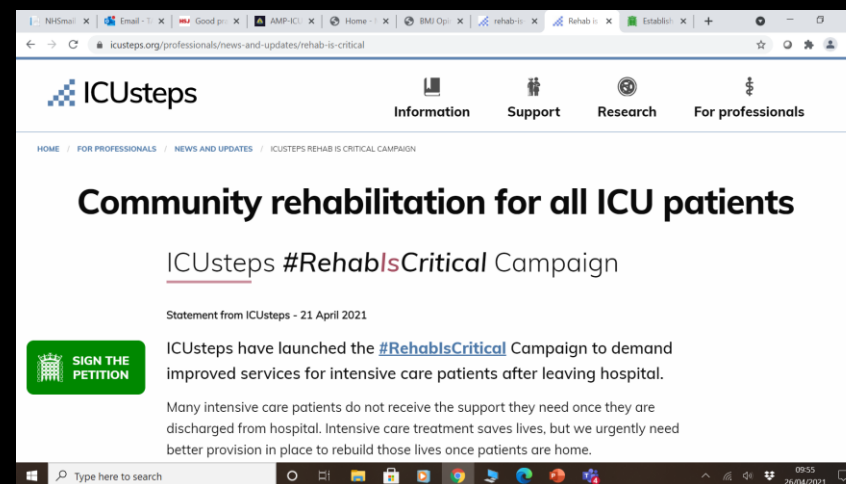
Critical illness and recovery are like travelling through a long tunnel. You start in an intensive care unit (ICU), often a harrowing experience in itself, but that part of the tunnel is well lit. You have a nurse with you 24 hours a day and a skilled multidisciplinary team looking after you.

You move to a ward and the lights in the tunnel can start flickering. There may be little understanding of what you've just been through. There may be no contact with the intensive care unit and their expertise.

Next, you get to go home, but you're in the dark now. You aren't given a map. You have no access to the multidisciplinary team. You have no information. And you don't have access to a healthcare professional who has an in-depth understanding of what you've been through and what can help you.



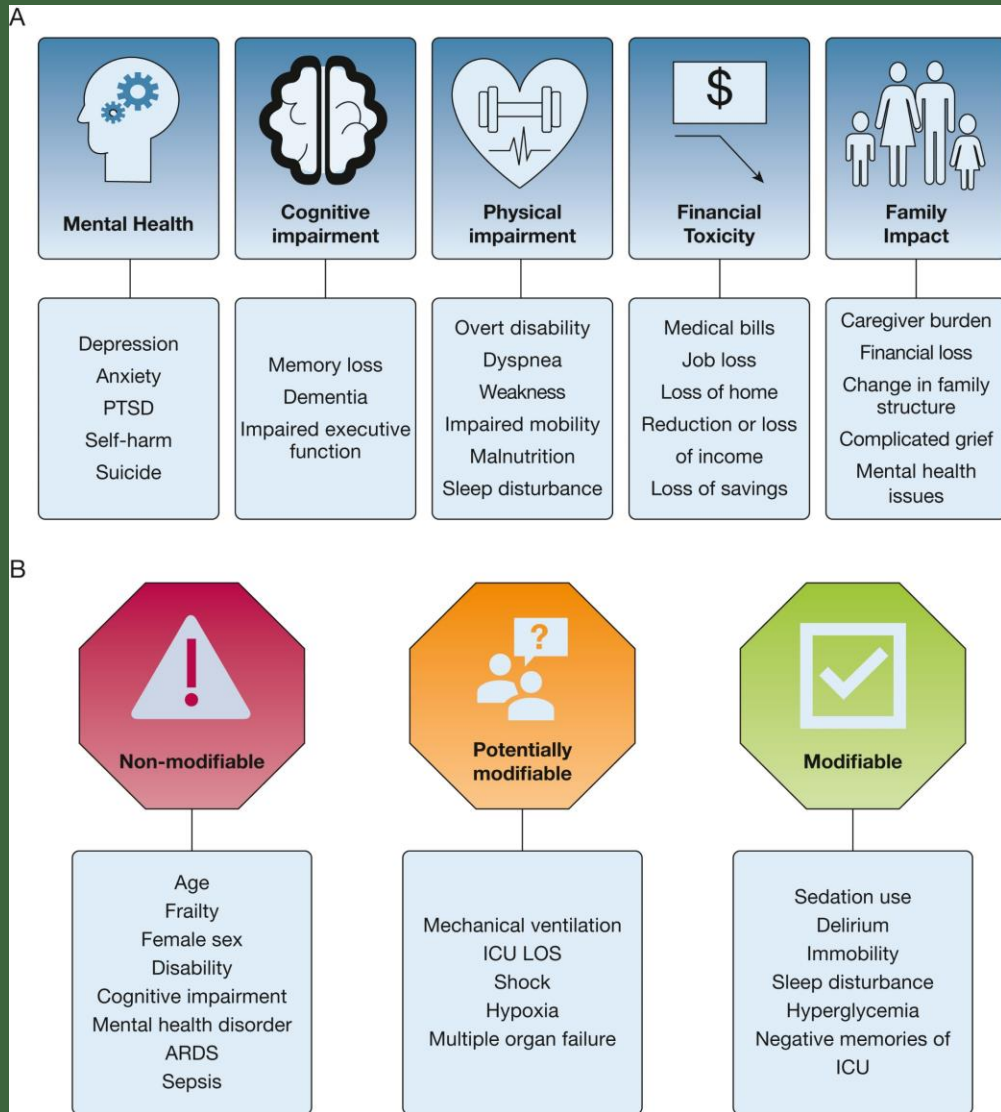
White, C (2021) Surviving critical illness is only the beginning: why patients must be supported in the aftermath. British Medical Journal.



What do patients want

- Patients want an MDT
- Patients want a plan and someone to call

Patients need and want support across the trajectory



Domain	Cognitive	Physical	Psychological		
Assessment	 MoCA MMSE Barthel Index	 Respiratory Spirometry 6MWT mMRC	 General Review ICU course Assess symptoms Evaluate for new conditions Medication reconciliation Health maintenance screening	 ICU-AW BBS FTSST EQ-5D MMT HGD	 HADS IES-R Evaluation for financial instability Evaluation for housing instability
Management	Cognitive retraining Compensatory strategies Exercise therapy Occupational therapy	Oxygen titration Breathing retraining Pulmonary rehabilitation	Address reversible causes of PICS Manage symptoms & new medical conditions Subspecialty referral	Mobility aides Environmental adjustments Graded exercise programs Physical therapy	Support groups Psychotherapy Psychiatric referral Social work referral

“How are you going to make it count?”

“**CHANGE WILL
NOT COME IF
WE WAIT FOR
SOME OTHER
PERSON OR
SOME OTHER
TIME. WE ARE
THE ONES
WE’VE BEEN
WAITING FOR.**”

– Barack Obama

“Without the data... we have no capacity to challenge”

A rectangular inset image with a dark, textured background, possibly representing a close-up of a surface like gravel or a similar material. The text is centered and written in a clean, white, sans-serif font.

**The ultimate purpose of collecting
the data is to provide
a basis for action or
a recommendation.**

Patients want goals.... - #MyRehabGoals26



Patients want help to speak up

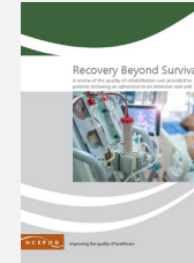
The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is a charity that works to make healthcare services better for the people who use them. We do this by collecting information from people who have used healthcare services. Our work has led to lots of positive changes in how healthcare is provided.

We collected information from hospitals, doctors, GPs and patients to see how rehabilitation care for people who were admitted to an intensive care unit (ICU) and were discharged from hospital could be made better.

For information about ICU and your recovery visit:

[ICUsteps](#)
[Faculty of Intensive Care Medicine](#)
[ICU Delirium](#)

www.ncepod.org.uk



WHAT WE FOUND

Rehabilitation care was not well coordinated throughout the pathway; on admission to an ICU, at step-down to the ward and in the community.

Initial and subsequent assessments of rehabilitation need to set/update goals were not always undertaken.

Full multidisciplinary team (MDT) input was rarely available to meet all the rehabilitation needs of patients.

Ongoing rehabilitation needs/goals were often not shared between healthcare providers as the patient moved through the pathway.

Information for the patient or their family about the ICU admission and any lasting impact it may have was limited.

WHAT HEALTH SERVICES CAN DO

Assign a rehabilitation lead with oversight and responsibility for the provision of holistic rehabilitation.

Assessments should be repeated and documented at key stages along the patient's pathway from admission to community services and GP follow-up.

Make pathways clearer, to ensure the patient sees the correct specialist at the correct time for their rehabilitation needs.

Provide patients with access to support services, physiotherapy, occupational therapy, and psychology services for their rehabilitation as needed.

Provide a service which is appropriate for patients at different stages of rehabilitation throughout the pathway.

WHAT YOU AS A PATIENT/CARER CAN DO

Ask your hospital team for contact details of your rehabilitation coordinator.

Ask your rehabilitation care team about your specific rehabilitation goals and how your progress will be monitored.

Ask your care team when will your rehabilitation needs be reassessed.

Ask your care team about which follow up appointments you have scheduled. Find out which specialists will be involved in your rehabilitation care.

Ask your care team whether there is a peer support group that you can join.

Be involved in decisions regarding your rehabilitation care following admission to critical care. Share your rehabilitation goals with your family and carers.

Remember: No question is too small or unimportant. Your healthcare team wants to help you understand your recovery and feel confident about your care. If you don't understand something, keep asking until you do.

#REHAB
LEGEND

Patient
Stories



Economics

Data



Decision
Makers

NCEPOD

World Health Organisation Film Festival



We created a short film about the campaign with the patients and their stories



The 'Patient Firsts' Project

Campaigning for
everyone's right to
rehabilitation

PetitionForRehab.com



“After today how are you going to make it count?”

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Do something...

- Think Green - Move your electricity provider to 100% renewable

Get 7 of your friends to do it too

- Be proud to work in ICU

We have forgotten Covid too quickly

- Take time to care for yourself and others

Protect the asset (it's you)

- Keep pushing and use the scaffolding

GPICS NCEPOD

Take time to reflect

Success
CONSISTS OF GOING
FROM FAILURE TO FAILURE
WITHOUT LOSS OF
ENTHUSIASM

We Want You!



“CHANGE WILL NOT COME IF WE WAIT FOR SOME OTHER PERSON OR SOME OTHER TIME. WE ARE THE ONES WE’VE BEEN WAITING FOR.”

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 Right to Rehab Campaign

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