

Rehabilitation after critical illness in adults

Clinical guideline

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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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This guideline is the basis of QS158.

Overview

This guideline covers rehabilitation strategies for adults who have experienced a critical illness and stayed in critical care. It aims to improve physical, psychological and cognitive outcomes in people who have been discharged from critical care.

Who is it for?

- Health and social care professionals
- Commissioners and providers
- Adults with rehabilitation needs as a result of a critical illness and their families and carers

Introduction

Approximately 110,000 people (estimated from the UK Intensive Care National Audit and Research Centre [ICNARC] Case Mix Programme [CMP] Summary Statistics) spend time in critical care units in England and Wales each year, the majority surviving to be discharged home. The general perception among patients, families and most healthcare professionals is that these people undergo a rapid convalescence and recover to their previous life, in terms of both quantity and quality.

Until relatively recently, there was little understanding of what really happens to all of these people. In the United Kingdom, a handful of hospitals established specialist follow-up clinics, staffed initially by doctors and nurses who also worked in critical care, and who thus understood the context of the patients' clinical stories. Research on the longer-term consequences of critical illness has shown that significant numbers of patients surviving critical illness have important continuing problems. For many, discharge from critical care is the start of an uncertain journey to recovery characterised by, among other problems, weakness, loss of energy and physical difficulties, anxiety, depression, post-traumatic stress (PTS) phenomena and, for some, a loss of mental faculty (termed cognitive function). Family members become informal caregivers, and this itself can exert a secondary toll of ill-health; family relationships can become altered and financial security imperilled. Recovery from illness is highly individual, and few studies have been able to demonstrate a close relationship between features of the acute illness and longer-term impact. Logically, patients who have had prolonged episodes of critical illness are likely to have greater long-term difficulties, however patients with relatively short intensive care stays may also need substantial help.

The optimisation of recovery as a therapeutic objective, rather than mere survival, has developed increasing prominence. Identified as an important area during the creation of [NICE's guideline on acutely ill adults in hospital](#), the Department of Health charged NICE 'To develop a short clinical guideline on rehabilitation after a period of critical illness requiring a stay in an ITU', and this series of documents represents the result of the process.

To the non-specialist, the terminology around critical illness can be confusing. Critical care is now used as a term that encompasses intensive care or intensive therapy; provided in intensive care units (ICUs) or intensive therapy units (ITUs), together with what used to be called high-dependency care provided in high-dependency units (HDUs). Intensive care, or level 3 care, generally involves the support of one or more failing organ system, usually including the lungs, whereas high dependency care, or level 2 care, supports one system. Recently the distinctions have

become blurred, hence the increasing use of the term criticalcare.

For simplicity, we have chosen to divide the potential consequences of critical illness into 'physical', and 'non-physical' domains, the latter to encompass all the non-physical symptoms one might envisage, such as anxiety, depression, post-traumatic stress disorder (PTSD), and cognitive dysfunction.

There is no particular requirement for a specified period of mechanical ventilatory support as an entry criterion for this pathway. Comments from the initial stakeholder meeting drew attention to the numbers of trauma patients, who receive mechanical ventilatory support for brief periods of time and yet who have the potential to benefit greatly.

The Guideline Development Group (GDG) also recognised the strain suffered by many families, and the commitment involved in helping the recovering patient. There is a tension between providing information to help families cope, and recognising that many patients may not wish specific information to be shared; patient autonomy must be respected.

Many families suffer financial strain as well as strain on their health and emotional resources. It was recognised that information around social services and benefits is often difficult to obtain and understand by those who need it, and decisions made around this area occasionally seem arbitrary; however, although there is clear room for improvement, it was difficult to see how this could be incorporated into the guideline beyond generalities, given how often such guidance would need to be changed.

For many patients the recovery after critical illness is relatively straightforward and it is important not to lose sight of this. What is clear is that tens of thousands of patients leave critical care to go home each year, and it is likely that poor-quality recovery represents a substantial problem. Given the individual impact on patients, and ripple effects on families and society in general, poor-quality rehabilitation and impaired recovery from severe illness should be regarded as a major public health issue.

The GDG has made a series of specific research recommendations, which are detailed later in the document. Additionally, of particular strategic importance is the lack of detailed understanding of the pathophysiology of the muscle wasting that is a feature of critical illness, and this area needs to be addressed. Critical illness polyneuropathy and myopathy are related and important problems. Alongside this, a better understanding of the impact of critical illness on the brain, and its relationship to sedation, neuroinflammation, delirium and future cognitive impairment is a priority. There is scope here for interventional trials in the near future. A thorough understanding of the

socioeconomic consequences of critical illness at both individual and society levels is also needed to inform broader policy. As the majority of the recommendations in this guideline are consensus based, this guideline should stimulate, rather than stifle, research, and the impact of the introduction of the recommendations, along with alternative approaches, should be thoroughly evaluated.

From my perspective as GDG Chair, the development process has been a challenge. It is one thing to know that a problem exists, and quite another to translate knowledge of a problem into an evidence-based management guideline, that can be implemented in the NHS for the benefit of patients. The GDG and the technical team have worked extremely hard picking their way through a difficult and somewhat patchy evidence base; I am grateful for their commitment and effort. Our ambition is that this guideline will lead to substantial benefits for recovering patients and their families. We hope that when this guideline is reviewed, the evidence base for specific interventions and service delivery models is more substantial.

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1 Guidance

People have the right to be involved in discussions and make informed decisions about their care, as described in [NICE's information on making decisions about your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

The Guideline Development Group (GDG) used the following definitions in this guideline:

- Short clinical assessment: a brief clinical assessment to identify patients who may be at risk of developing physical and non-physical morbidity.
- Comprehensive clinical assessment: a more detailed assessment to determine the rehabilitation needs of patients who have been identified as being at risk of developing physical and non-physical morbidity.
- Functional assessment: an assessment to examine the patient's daily functional ability.
- Short-term rehabilitation goals: goals for the patient to reach before they are discharged from hospital.
- Medium-term rehabilitation goals: goals to help the patient return to their normal activities of daily living after they are discharged from hospital.
- Physical morbidity: problems such as muscle loss, muscle weakness, musculoskeletal problems including contractures, respiratory problems, sensory problems, pain, and swallowing and communication problems.
- Non-physical morbidity: psychological, emotional and psychiatric problems, and cognitive dysfunction.
- Multidisciplinary team: a team of healthcare professionals with the full spectrum of clinical skills needed to offer holistic care to patients with complex problems. The team may be a group of people who normally work together or who only work together intermittently.

Key principle of care

- 1.1 To ensure continuity of care, healthcare professional(s) with the appropriate competencies should coordinate the patient's rehabilitation care pathway. Key elements of the coordination are as follows.

The healthcare professional(s) may be intensive care professional(s) or, depending on local arrangements, any appropriately trained healthcare professional(s) from a service (including specialist rehabilitation medicine services) with access to referral pathways and medical support (if not medically qualified).

- Ensure the short-term and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient's rehabilitation care pathway.
- Ensure the delivery of the structured and supported self-directed rehabilitation manual, when applicable.
- Liaise with primary/community care for the functional reassessment at 2 to 3 months after the patient's discharge from critical care.
- Ensure information, including documentation, is communicated between hospitals and to other hospital-based or community rehabilitation services and primary care services.
- Give patients the contact details of the healthcare professional(s) on discharge from critical care, and again on discharge from hospital.

See the [NICE guideline on patient experience in adult NHS services](#).

During the critical care stay

- 1.2 During the patient's critical care stay and as early as clinically possible, perform a short clinical assessment to determine the patient's risk of developing physical and non-physical morbidity (see table 1).
- 1.3 For patients at risk of physical and non-physical morbidity, perform a comprehensive clinical assessment to identify their current rehabilitation needs. This should include assessments by healthcare professionals experienced in critical care and rehabilitation.

- 1.4 For patients at risk, agree short-term and medium-term rehabilitation goals, based on the comprehensive clinical assessment. The patient's family and/or carer should also be involved.

During the critical care stay, the patient may not gain full consciousness or may not have full capacity to give formal consent. Therefore, the involvement of the family and/or carer is important at this stage.

- 1.5 The comprehensive clinical assessment and the rehabilitation goals should be collated and documented in the patient's clinical records.

- 1.6 For patients at risk, start rehabilitation as early as clinically possible, based on the comprehensive clinical assessment and the rehabilitation goals.

Rehabilitation should include:

- measures to prevent avoidable physical and non-physical morbidity, including a review of previous and current medication
- nutrition support, based on the recommendations in the [NICE guideline on nutrition support for adults](#).
- an individualised, structured rehabilitation programme with frequent follow-up reviews. The details of the structured rehabilitation programme and the reviews should be collated and documented in the patient's clinical records.

- 1.7 Give patients the following information during their critical care stay. Also give the information to their family and/or carer, unless the patient disagrees.

During the critical care stay, the patient may not gain full consciousness or may not have full capacity to give formal consent. Therefore, the involvement of the family and/or carer is important at this stage.

- Information about the patient's critical illness, interventions and treatments.
- Information about the equipment used during the patient's critical care stay.
- If applicable, information about any possible short-term and/or long-term physical and non-physical problems which may require rehabilitation.

Deliver all the above information more than once during the patient's critical care stay.

Before discharge from critical care

- 1.8 For patients who were previously identified as being at low risk, perform a short clinical assessment before their discharge from critical care to determine their risk of developing physical and non-physical morbidity (see table 1).
- 1.9 For patients at risk, and patients who started the individualised, structured rehabilitation programme in critical care, perform a comprehensive clinical reassessment to identify their current rehabilitation needs. The comprehensive reassessment should pay particular attention to:
- physical, sensory and communication problems (see table 2)
 - underlying factors, such as pre-existing psychological or psychiatric distress
 - symptoms that have developed during the critical care stay, such as delusions, intrusive memories, anxiety, panic episodes, nightmares, flashback episodes or depression (see the [NICE guideline on the prevention, diagnosis and management of delirium](#)).
- 1.10 For patients who were previously identified as being at risk during critical care, the outcomes of the comprehensive reassessment should inform the individualised, structured rehabilitation programme (recommendation 1.6).
- 1.11 For patients at risk, agree or review and update the rehabilitation goals, based on the comprehensive reassessment. The family and/or carer should also be involved, unless the patient disagrees.
- 1.12 Ensure that the transfer of patients and the formal structured handover of their care are in line with the [NICE guideline on acutely ill patients in hospital](#). This should include the formal handover of the individualised, structured rehabilitation programme.
- 1.13 Give patients the following information before, or as soon as possible after, their discharge from critical care. Also give the information to their family and/or carer, unless the patient disagrees.
- Information about the rehabilitation care pathway.

- Information about the differences between critical care and ward-based care. This should include information about the differences in the environment, and staffing and monitoring levels.
- Information about the transfer of clinical responsibility to a different medical team (this includes information about the formal structured handover of care recommended in the [NICE guideline on acutely ill patients in hospital](#)).
- If applicable, emphasise the information about possible short-term and/or long-term physical and non-physical problems that may require rehabilitation.
- If applicable, information about sleeping problems, nightmares and hallucinations and the readjustment to ward-based care.

During ward-based care

- 1.14 For patients who were previously identified as being at low risk before discharge from critical care, perform a short clinical assessment to determine their risk of physical and non-physical morbidity (see table 1).
- 1.15 For patients at risk, perform a comprehensive clinical reassessment (see recommendation 1.9) to identify their current rehabilitation needs.
- 1.16 For patients at risk, offer an individualised, structured rehabilitation programme, based on the comprehensive clinical reassessment and the agreed or updated rehabilitation goals set before the patient was discharged from critical care. Comprehensive reassessments apply to both those before discharge from critical care and during ward-based care.
- 1.17 The individualised, structured rehabilitation programme should be developed and delivered by members of a multidisciplinary team, and should include appropriate referrals, if applicable.
- 1.18 Based on clinical judgement and the individual patient's rehabilitation needs, consider offering a structured and supported self-directed rehabilitation manual for at least 6 weeks after discharge from critical care, as part of the individualised, structured rehabilitation programme.

The structured and supported self-directed rehabilitation manual (based on

Jones et al. 2003) should be coordinated by an appropriately skilled healthcare professional throughout its duration. The optimal time for starting the structured and supported self-directed rehabilitation manual should be based on individual patients' physical and cognitive capacity at different stages of their illness and recovery.

- 1.19 For patients with symptoms of stress related to traumatic incidents and/or memories, refer to the [NICE guideline on the management of post-traumatic stress disorder](#) (PTSD) and initiate appropriate preventative strategies.

Before discharge to home or community care

- 1.20 Before discharging patients who were receiving the individualised structured rehabilitation programme during ward-based care (recommendation 1.15):

- perform a functional assessment which should include the following physical and non-physical dimensions (also see table 2 for possible examples):
 - physical problems (physical dimension)
 - sensory problems (physical dimension)
 - communication problems (physical dimension)
 - social care or equipment needs (physical dimension)
 - anxiety (non-physical dimension)
 - depression (non-physical dimension)
 - post-traumatic stress-related symptoms (non-physical dimension)
 - behavioural and cognitive problems (non-physical dimension)
 - psychosocial problems (non-physical dimension).
- assess the impact of the outcomes from the functional assessment on the patient's activities of daily living and participation

- based on the functional assessment, review, update and agree the rehabilitation goals with the patient. The family and/or carer should be involved if the patient agrees.

See also, the [NICE guideline on the transition between inpatient hospital settings and community or care home settings for adults with social care needs](#).

1.21 If continuing rehabilitation needs are identified from the functional assessment, ensure that before the patient is discharged:

- discharge arrangements, including appropriate referrals for the necessary ongoing care, are in place before completing the discharge
- all discharge documents are completed and forwarded to the appropriate post-discharge services and the patient
- the patient, and/or the family and/or carer as appropriate, is aware of the discharge arrangements and understands them (see the [NICE guideline on intermediate care including reablement](#)).

1.22 Give patients the following information before their discharge to home or community care. Also give the information to their family and/or carer, if the patient agrees.

- Information about their physical recovery, based on the goals set during ward-based care if applicable.
- If applicable, information about diet and any other continuing treatments.
- Information about how to manage activities of daily living including self-care and re-engaging with everyday life.
- If applicable, information about driving, returning to work, housing and benefits.
- Information about local statutory and non-statutory support services, such as support groups.
- General guidance, especially for the family and/or carer, on what to expect and how to support the patient at home. This should take into account both the patient's needs and the family's/carer's needs.
- Give the patient their own copy of the critical care discharge summary.

2–3 months after discharge from critical care

- 1.23 Review patients with rehabilitation needs 2 to 3 months after their discharge from critical care. Carry out a functional reassessment of their health and social care needs, using the dimensions in recommendation 1.20. If appropriate, also enquire about sexual dysfunction.
- 1.24 The functional reassessment should be face to face in the community or in hospital, performed by an appropriately-skilled healthcare professional(s) who is familiar with the patient's critical care problems and rehabilitation care pathway.
- 1.25 Based on the functional reassessment.
- Refer the patient to the appropriate rehabilitation or specialist services if:
 - the patient appears to be recovering at a slower rate than anticipated, according to their rehabilitation goals, or
 - the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
 - Give support if the patient is not recovering as quickly as they anticipated.
 - If anxiety or depression is suspected, follow the stepped care models recommended in the [NICE guidelines on generalised anxiety disorder and panic disorder in adults and depression in adults](#).
 - If PTSD is suspected or the patient has significant symptoms of PTS, refer to the [NICE guideline on post-traumatic stress disorder](#).

Table 1 Examples from the short clinical assessment that may indicate the patient is at risk of developing physical and non-physical morbidity

Physical	<ul style="list-style-type: none"> • Unable to get out of bed independently. • Anticipated long duration of critical care stay. • Obvious significant physical or neurological injury. • Lack of cognitive functioning to continue exercise independently. • Unable to self ventilate on 35% of oxygen or less. • Presence of premorbid respiratory or mobility problems. • Unable to mobilise independently over short distances.
Non-physical	<ul style="list-style-type: none"> • Recurrent nightmares, particularly where patients report trying to stay awake to avoid nightmares. • Intrusive memories of traumatic events which have occurred prior to admission (for example, road traffic accidents) or during their critical care stay (for example, delusion experiences or flashbacks). • New and recurrent anxiety or panic attacks. • Expressing the wish not to talk about their illness or changing the subject quickly off the topic.

Note: this list is not exhaustive and healthcare professionals should use their clinical judgement

Table 2 Symptoms from the functional assessment that may indicate the presence of physical and non-physical morbidity

Physical dimensions	-
Physical problems	Weakness, inability/partial ability to sit, rise to standing, or to walk, fatigue, pain, breathlessness, swallowing difficulties, incontinence, inability/partial ability to self-care.

Physical dimensions	-
Sensory problems	Changes in vision or hearing, pain, altered sensation.
Communication problems	Difficulties in speaking or using language to communicate, difficulties in writing.
Social care or equipment needs	Mobility aids, transport, housing, benefits, employment and leisure needs.
Non-physical dimensions	-
Anxiety, depression and PTSD-related symptoms	New or recurrent somatic symptoms including palpitations, irritability and sweating; symptoms of derealisation and depersonalisation; avoidance behaviour; depressive symptoms including tearfulness and withdrawal; nightmares, delusions, hallucinations and flashbacks.
Behavioural and cognitive problems	Loss of memory, attention deficits, sequencing problems, deficits in organisational skills, confusion, apathy, disinhibition, compromised insight.
Other psychological or psychosocial problems	Low-self-esteem, poor or low self-image and/or body image issues, relationship difficulties, including those with the family and/or carer.

2 Research recommendations

- What is the most effective way of identifying patients at risk of critical illness-associated physical morbidity, psychological morbidity and cognitive dysfunction and how can the disease progress and response to interventions monitored?
- In patients at high risk, which therapeutic strategies are the most clinically and cost effective at reducing the prevalence and severity of critical illness-associated physical morbidity, psychological morbidity and cognitive dysfunction?
- In patients with established morbidity, which **specific** therapeutic strategies are the most clinically and cost effective at reducing the magnitude of critical illness-associated physical morbidity, psychological morbidity and cognitive dysfunction?
- For patients at high risk of critical illness-associated morbidity, what is the clinical effectiveness and cost effectiveness of organised critical care rehabilitation versus usual care on physical and psychological functioning, participation and quality of life?
- For those patients **not** identified as at high risk of critical illness-associated morbidity, what is the clinical effectiveness and cost effectiveness of organised critical care rehabilitation versus usual care on physical, psychological functioning, participation and quality of life?

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE webpages on acute and critical care](#).

For full details of the evidence and the guideline committee's discussions, see the [evidence reviews](#). You can also find information about [how the guideline was developed](#), including details of the committee.

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

Update information

Minor changes since publication

July 2018: Cross-references to other NICE guidelines were added.

October 2015: Title changed from 'Rehabilitation after critical illness' to 'Rehabilitation after critical illness in adults' for clarity and consistency with other guidance on this topic.

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Accreditation

