

Rehabilitation after critical illness

Information for the public

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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about the rehabilitation of adults who have stayed in critical care that is set out in NICE clinical guideline 83.

Does this information apply to me?

Yes, if you are an adult who, as a result of critical illness, has stayed in critical care and need rehabilitation.

No, if you are:

- an adult who is having treatment for symptoms and pain in the final stages of a terminal illness
- an adult whose rehabilitation needs are already routinely assessed and delivered as part of your care, for example, if you have a brief stay in a critical care unit for immediate postoperative care after major elective surgery, or if you have a condition for which published guidelines already exist – such as head injury, heart attack and stroke.

Your care

If you think that your care does not match what is described in this information, please talk to a member of your healthcare team in the first instance.

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain your critical illness and rehabilitation simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on

consent (www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.nhs.uk/CarersDirect/moneyandlegal/legal. In Wales healthcare professionals should follow advice on consent from the Welsh Government (www.wales.nhs.uk/consent).

What 'critical care' means

'Critical care' is now used as the term that encompasses 'intensive care', 'intensive therapy' and 'high dependency' units.

Critical care is needed if a patient needs specialised monitoring, treatment and attention, for example, after routine complex surgery, a life-threatening illness or an injury.

If someone needs critical care, they can be said to have a 'critical illness'.

What 'rehabilitation' means

After a critical illness, many patients can experience other problems, such as weakness, loss of energy, physical difficulties, anxiety, depression, post-traumatic stress and, for some, problems with thinking, remembering and planning (known as cognitive function). The patient's critical illness can also affect their family members, with many families experiencing financial, health and emotional worries, and psychological difficulties.

'Rehabilitation' is designed to help the process of physical and psychological recovery and help people cope with the physical, psychological and emotional effects associated with critical illness and with being a patient in critical care. Rehabilitation can help you get physically and psychologically stronger after your experience through the use of gentle exercise programmes, advice and support.

Your 'rehabilitation goals' are what you and your healthcare team agree will help you recover your ability to take part in your usual daily activities as much and as rapidly as possible.

What should happen during your critical

care stay

Following a critical illness, some people will have a rapid recovery. For others, recovery may be longer and they will need more structured support. Sometimes this is obvious early on, but occasionally this only becomes apparent later. Your healthcare team will perform regular health checks (called assessments) to check your progress.

While you are in critical care, you should have a health check (called a short clinical assessment) to identify:

- any physical or psychological problems
- the likelihood of any problems developing in the future, and
- your current rehabilitation needs.

If the health check shows that you could benefit from more structured support, you should have a more detailed health check (called a comprehensive clinical assessment) to identify your rehabilitation needs. Your healthcare team should talk to you about your rehabilitation goals and they should involve your family and/or carer if you are unconscious or unable to give formal consent.

If you need more structured support, your rehabilitation should start while you are in critical care. You should be offered a structured rehabilitation programme that is tailored to your needs and has regular reviews to check your progress. The rehabilitation programme should include:

- measures to prevent avoidable physical and psychological problems (for example, preventing stiffness in muscles and joints and minimising pain and discomfort)
- a review of your previous and current medicines, and
- measures to improve or maintain the levels of nutrients in your body. NICE has produced information for the public about nutrition support in adults. See www.nice.org.uk/Guidance/CG32

The details of your rehabilitation programme and reviews should be recorded in your clinical records.

Information and support

You, your family and/or carer should be given information on the following more than once during your critical care stay.

- Your critical illness, tests, investigations or operations, and the treatment you received. In some hospitals this may include a diary of your stay in critical care offered to you later on in your recovery; this may include photographs.
- The equipment used while you were in critical care.
- Possible short-term and/or long-term physical or psychological problems which may need rehabilitation.
- Contact details of the key people looking after you.

What should happen before you are discharged from critical care

When you are discharged from critical care, you are likely to be cared for on another ward in the hospital. Before you are discharged from critical care you should have another health check (short clinical assessment) to identify any physical or psychological problems.

If the health check shows that you could benefit from more structured support, you should then have a more detailed health check (comprehensive clinical assessment) to identify your current rehabilitation needs.

Your healthcare team should talk to you about your rehabilitation goals and your rehabilitation programme, both of which should take into account the results of your health checks and be tailored to your individual needs. Your family and/or carer should be involved unless you disagree.

Information and support

You should be given the following information before, or soon after, your discharge from critical care. Your family and/or carer should also be given the information, unless you disagree.

- Your rehabilitation programme.
- How the care you receive in critical care and on the general ward will differ, how you might adjust to this and ways to cope with possible problems, for example sleeping problems, nightmares and hallucinations.
- Your transfer from critical care to a different team of doctors and nurses.
- Any possible short-term and/or long-term physical or psychological problems which may require help.

What should happen while you are on the ward

While you are on the ward, you should have another health check (short clinical assessment) to identify any physical or psychological problems.

If the health check shows that you could benefit from more structured support, or if this was identified earlier, you should then have a more detailed health check (comprehensive clinical assessment) to identify your current rehabilitation needs.

Your healthcare team should talk to you about your rehabilitation goals and your rehabilitation programme, both of which should take into account the results of your health checks and be tailored to your individual needs.

What should happen before you leave the hospital

When you are well enough to leave hospital, you should have an assessment (called a functional assessment) to identify any physical, sensory or communication problems, emotional or psychological problems, and any social care or equipment needs that you

may have.

Your healthcare team should consider how the results of the assessment could affect your daily life when you leave hospital.

Your rehabilitation goals should be discussed and agreed with you (and your family/carer if you agree).

Your healthcare team should organise any referrals for further care or rehabilitation before you leave the hospital. You should be given a copy of your critical care discharge summary, which is a letter sent to your GP with details of your critical care stay and the contact details of the person coordinating your rehabilitation and your rehabilitation plan.

A member of your healthcare team should make sure you (and your family/carer if appropriate) understand what your continuing rehabilitation will involve and what other things you might face during your recovery after you are discharged from hospital.

Information and support

You should be given the following information. Your family and/or carer should also be given the information, if you agree.

- Your physical recovery, based on the rehabilitation goals agreed while you were on the ward (if applicable).
- Diet and any continuing treatment.
- Managing normal daily activities, including looking after yourself and getting back to your daily routine.
- Driving, returning to work, housing, any benefits to which you may be entitled.
- Local support services and groups.
- General information on what to expect after you are discharged from hospital and how your family/carer can support you. This should take into account your needs, as well as those of your family and/or carer.

What should happen 2–3 months after your discharge from critical care

If you needed structured support while you were in hospital, you should have a meeting with a member of your healthcare team who is familiar with your critical care problems and recovery. The meeting will be to discuss any physical, sensory or communication problems, emotional or psychological problems and any social care or equipment needs that you might have.

If you are recovering more slowly than anticipated, or if you have developed any new physical or psychological problems, then you should be offered referral to the relevant rehabilitation or other specialist service.

If your recovery is not progressing as quickly as you had hoped, your healthcare team is there to help you. Everyone's experience is different and some people may need more time and help than others to recover.

If you have symptoms of anxiety, depression or post-traumatic stress, then you should be treated according to the recommendations outlined in the relevant NICE guidance. NICE has produced information for the public about anxiety, depression and post-traumatic stress. For more information, see www.nice.org.uk/Guidance/CG/Published

Questions you might like to ask your healthcare team

- What does rehabilitation involve?
- What will be done if my health gets worse?
- How long will the rehabilitation take?
- What improvements might I expect?
- Are there any support organisations in my local area?
- What can my family/carer do to help and support me?

- Is there any additional support that my family/carer might benefit from or is entitled to?
- Can you provide any information for my family/carer?

More information

The organisations below can provide more information and support. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- CritPal www.ics.ac.uk/about_us/critpal
- ICUsteps www.icusteps.com

You can also go to NHS Choices (www.nhs.uk) for more information.

Accreditation

