

Understanding NICE guidance

Information for people who use NHS services

Rehabilitation after critical illness

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the rehabilitation of adults who have stayed in critical care in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for patients, their families and carers, or for anyone with an interest in how people are cared for in, and following, critical care.

The booklet is to help you understand the care that should be available in the NHS. There are examples of questions you could ask on page 10. You can get more information from the organisations listed on page 11.

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The advice in the NICE guideline covers the care of:

- adults who, as a result of critical illness, have stayed in critical care and need rehabilitation.

It does not specifically look at the care of:

- adults who are having treatment for symptoms and pain in the final stages of a terminal illness
- adults whose rehabilitation needs are already routinely assessed and delivered as part of their care, for example, patients who have brief stays in critical care units for immediate postoperative care after major elective surgery, and patients with conditions for which published guidelines already exist – such as head injury, heart attack and stroke.

Your care

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.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

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

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 'Understanding NICE guidance' about nutrition support in adults. See www.nice.org.uk/Guidance/CG32/PublicInfo

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 'Understanding NICE guidance' 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, 020 7280 4350, www.ics.ac.uk/patrel
- ICUsteps, www.icusteps.com

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of the guideline aimed at healthcare professionals are available at www.nice.org.uk/CG83

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1826).

We encourage NHS and voluntary organisations to use text from this booklet in their own information about rehabilitation after critical illness.