

ABC of intensive care

Recovery from intensive care

Richard D Griffiths, Christina Jones

Studies of outcome after intensive care suggest that death rates do not return to normal until 2-4 years after admission. Although some questionnaire studies have reported on morbidity, little published work exists on detailed clinical recovery or longer term residual effects of critical illness. The recovery process may present serious physical, psychological, and social problems for both patients and their families, and these may last for months or years. Although patients who have been in intensive care have often been extremely ill, been at high risk of death, and received care costing tens of thousands of pounds, detailed follow up and targeted support are still rare.

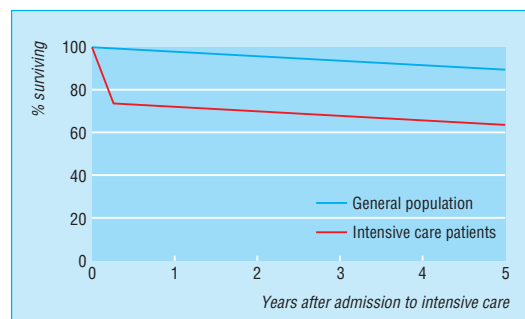
Discharge to the ward

Patients on mechanical ventilation are usually discharged from the intensive care unit to the ward when they can breathe unaided. However, several physical problems may still remain. Although these may not be serious enough to keep the patient in intensive care, if left untreated they could lead to readmission. Intensive care staff should therefore follow patients' progress on the ward for a few days to monitor recovery of multisystem disease and assure good continuity of care.

The commonest physical problem reported by intensive care patients is severe weakness and fatigue. Patients in intensive care can lose about 2% of muscle mass a day during their illness owing to a combination of primary muscle catabolism and atrophy secondary to neuropathic degeneration. They may lose over half their muscle mass, resulting in severe physical disability. Rebuilding such muscle losses can take over a year. Initially, patients may be so weak that they struggle to feed themselves, their cough power is greatly reduced, and they may have poor control of their swallowing and upper airways with a risk of aspiration. The nursing burden can be large. If patients can stand they are in danger of falling. This is often compounded by postural hypotension, which may reflect autonomic disturbances.

On discharge from intensive care patients may seem completely oriented and to understand the information they are given about their illness. Yet when questioned a few days later, many have little or no memory of their stay in intensive care or can remember only pain, suctioning, or lack of sleep. The only memories of some patients are nightmares, often of a persecutory nature in which they are subjected to torture, or paranoid delusions. These nightmares and delusions may be attributed to the illness, the use of opiate and sedative drugs, the unnatural environment of intensive care with its lack of a proper day and night, and to constant noise. Patients nursed in an intensive care unit without windows have even more unpleasant memories than those nursed in a unit with large windows.

The difficulty some patients have in accepting that the events in their dreams were not real is often not appreciated. In addition, patients are reluctant to tell ward staff about their nightmares for fear of being considered mad. However, confrontation, through discussion, of such problems allows patients to build up a coherent story rather than chaotic, intrusive memories and so put the experience behind them. The incidence of post-traumatic stress disorder is high after intensive care, and it is more common in patients who recall frightening adverse experiences.



The 5 year mortality rate in intensive care patients is over 3 times that of the general population. However at 2 year survival rates are parallel. Adapted from Niskanen M et al. *Crit Care Med* 1996;24:1962-7.

Examples of physical disorders after intensive care

- Recovering organ failure (lung, kidney, liver, etc)
- Severe muscle wasting and weakness including reduced cough power, pharyngeal weakness
- Joint stiffness
- Numbness, paraesthesia (peripheral neuropathy)
- Taste changes resulting in favourite foods being unpalatable
- Disturbances to sleep rhythm
- Cardiac and circulatory decompensation:
 - Postural hypotension
- Reduced pulmonary reserve:
 - Breathlessness on mild exertion
- Iatrogenic:
 - Tracheal stenosis (for example, from repeated intubations)
 - Nerve palsies (needle injuries)
 - Scarring (needle and drain sites)

Taste changes and difficulties in feeding themselves may further compromise patients' nutritional state



Intensive care patients often experience persecutory nightmares

When patients first see themselves in the mirror they may not recognise their face because of severe weight loss. With no memory of their illness, patients have no explanation for this frightening confrontation, and they may also find it difficult to appreciate why they feel so awful. For example, they may only remember coming in for elective surgery and waking up on the ward, seemingly the next morning, and be left thinking “why have I lost all this weight, why am I so weak?”

Discharge home

It is often when patients go home that they realise how debilitated they are; commonly, they cannot climb stairs. Relatives take on the care of the patients and, for example, report sleeplessness because of worry about whether the patient is still breathing. Relatives often report that patients are hard to live with because of irritability and impatience with the slowness of their recovery.

Many healthcare professionals believe that it is better for patients not to remember their intensive care stay. This means that patients are unable to explain why they feel so debilitated. Although the family may try to explain, the lack of a concrete memory makes it difficult for patients to realise just how ill they have been and just how long it will take them to recover. Patients consequently have unrealistic expectations of recovery and think in terms of weeks instead of months, if not years.

Except for very elderly and some trauma and neurological patients, most intensive care patients will not receive any physiotherapy once they are able to walk unaided in hospital. However, muscle loss and peripheral neuropathies may affect their balance, and they have poor ability to right themselves. Walking unaided outside in icy conditions or in a wind is potentially dangerous and frightening for the patient. In addition, minor physical problems such as hair loss, skin dryness, or fingernail ridges, which often occur after critical illness can be particularly distressing because of the lack of an adequate explanation during the discharge process.

Two months to one year

Physical problems related to muscle weakness are still common 2 months after intensive care and can still be seen at 6 months. These problems often affect self care activities such as climbing stairs, getting out of the bath, turning off taps, driving a car, and returning to work. Fear of falling and being unable to get up again is common.

The prolonged recovery period leads to several problems, and intensive care survivors experience considerable levels of depression and anxiety. Patients often avoid company and show less affection to their partners. In one study 45% of patients questioned at 6 months reported going out less often, 41% took part in fewer social activities, and a quarter reported being irritable with their relatives.

Coupled to this social isolation is a dependence on others to make decisions and a tendency towards being obstinate. Patients also report feeling overwhelmed in crowded places or being afraid to go out alone. Some patients describe full blown panic attacks, although they may not necessarily recognise them as such. The longer panic attacks are left untreated, the more refractory they are likely to be. Long term treatment is needed by 36-40% of people with panic attacks presenting for help.

Patients understandably feel that the recovery phase of their critical illness is the most stressful period as they have to come to terms with how ill and close to death they have been. The presence of social support increases tolerance to stressful

Patient's view

A 42 year old woman with acute pancreatitis required a 40 day stay in intensive care. She had been ill in hospital for several weeks before transfer. When she went home she found she had lost 2 months from her memory—the time in intensive care and in the ward before that. She worried about what had happened to her and why she could not remember.

She learnt about her illness and why she could not remember at the follow up clinic. She was relieved that there was nothing wrong with her mind and that it is common not to be able to remember.

Relative's view

After John's wife had been in intensive care he felt that it was better that she didn't know about her illness and so wouldn't discuss it. He had been very upset and wanted to protect her. He could not bring himself to return to hospital, even to accompany his wife to outpatient clinics. His wife was initially upset by this behaviour. However, once she had been told how ill she had been she understood how much stress John had been under and his subsequent behaviour.

Psychological disorders

- Depression:
 - Anger and conflict with the family
 - Anxiety:
 - Are they going to get back to normal?
 - Panic attacks
 - Fear of dying
 - Guilt
 - Recurrent nightmares
 - Post traumatic stress disorder
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Actual examples of problems reported by patients

- “I get panicky if I go out alone in case I am taken ill”
 - “I get very angry with my family. They keep fussing when I try to do things for myself”
 - “I feel very angry with myself for not being back to normal by now”
 - “I've tried to help by doing the washing up but I keep dropping the crockery”
 - “When I first went home I climbed the stairs on my hands and knees and came down on my bottom”
 - “I don't want to go to sleep because I keep dreaming that I'm back in ICU”
 - “My whole time in ICU I dreamt I had been kidnapped and locked in the boot of a car”
 - “I feel very guilty when I think about what my family has been through”
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situations and has, in general, a beneficial effect on health. Social isolation, however, seems to act as a source of chronic stress. Much of the impact caused by life events may be the result of the profound changes they produce in social relationships.

Rehabilitation after critical illness

Early intervention is needed to prevent physical and psychological problems. This should ideally start when the patient is moved to the ward. Activity is the key to recovery, but the overwhelming weakness that patients report as they start to recover and the length of the convalescent process means that they require considerable determination to exercise. Most patients have little idea how and when to start exercising or how to pace themselves.

Simply giving intensive care patients a discharge booklet outlining possible problems they might encounter during their recovery has proved unsuccessful. Despite using a booklet, 25% of patients attending an intensive care follow up clinic scored highly for anxiety and depression 2 months after intensive care.

Guide to care after hospital discharge

Integration of physical and psychological care is clearly in the best interest of these patients. What issues need to be addressed when planning for hospital discharge for intensive care patients? A partnership is needed between the patient's general practitioner, ward doctor, and intensive care doctor. Clear information about the illness should be provided to patients, their families, and their general practitioners. Patients need to be given some idea about how long it will take them to recover. Both patients and their families should be given the opportunity to be debriefed about the illness, the time in intensive care, and what it means, preferably by staff who were involved in the patients' care. Debriefing should tackle not only the reasons for admission to intensive care and events while they were there but also any distorted memories patients may have. For many patients, simply knowing that nightmares and paranoid delusions are normal after critical illness is sufficient for them to put the memories in context.

It is helpful to outline a plan with patients and their families for convalescence and rehabilitation. Patients should have access to referral to specialists such as clinical psychologists and dieticians. Work, particularly in cardiac rehabilitation, suggests that providing written information about critical illness, self help advice to manage the typical problems patients might face during recovery, and an exercise programme may be helpful.

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Good support after intensive care is essential

Guide for care after discharge

- Initial review by intensive care staff to ensure medical and nursing handover is thorough, seamless, and continuous
- Early explanation of illness to patient, preferably with a relative present to ensure uniformity of experience
- Advice to patients on problems and information on the time scale of recovery
- Reinforcement of the patients' responsibility for their recovery
- Practical advice on rehabilitation, exercise, and nutrition
- Detailed letter to general practitioner detailing patients' illness
- Early recognition and diagnosis of physical and psychological problems in patients and relatives
- Follow up for at least 6 months after discharge from hospital that reviews not only the patient's physical problems but also psychological issues for patients and close relatives

Richard D Griffiths is reader in medicine and Christina Jones is research associate, Intensive Care Research Group (Whiston Hospital), Department of Medicine, University of Liverpool, Liverpool.

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One hundred years ago

The Black Smoke Nuisance

The Black Smoke Nuisance has penetrated the House of Commons. One day last week the terrace, the committee rooms, and dining rooms were filled for hours with most unpleasant fumes, and so a question was asked as to the remedy. The President of the Local Government Board says he has no direct control, but he has set the Lambeth Vestry to work to restrain the

nuisance emitted by the pottery firms on the Albert Embankment. The feeling is very general that it is high time the smoke and fumes were lessened in the interests of health and general comfort.

(*BMJ* 1899;ii:245)