

Rehabilitation after encephalitis

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1. What does rehabilitation mean?

Rehabilitation involves the person affected by encephalitis and their relatives working together with a team of professionals to understand what has happened, maximise recovery, adjust to remaining challenges, and increase participation in personally meaningful activities. During the early days, weeks or months after encephalitis, the main aims are often to provide a safe environment and gentle stimulation to encourage the process of spontaneous recovery and to help the person and their family to understand and begin to adapt to what has happened. During the later stages, when spontaneous recovery slows or stops, the main aims are more likely to involve helping the person affected by encephalitis develop new skills, habits and strategies for coping with their remaining difficulties. People affected by encephalitis may be left with a range of cognitive, physical, emotional, social and practical problems. Some of the most common are impairments in reasoning, motivation, self-control, memory, concentration, and consequent low mood, anxiety, and loss of confidence.

Depending on the nature of the person's problems, rehabilitation may range from hospital-based or residential programs to home-based client services. However, currently, many people affected by encephalitis are discharged without adequate assessment or consideration of their rehabilitation needs.

As people affected by encephalitis progress in their rehabilitation, more challenging and less supported environments are required. Ideally, such progression should lead to the least restrictive situation in which the person affected by encephalitis can cope successfully. For many, this will mean some ongoing support to help maintain the gains they have achieved.

Good rehabilitation involves a holistic approach. It recognises the complex cognitive, behavioural, social, emotional and medical problems faced by people affected by encephalitis and their families. Good rehabilitation should also be 'person-centred', or driven by an understanding of the person not just of their neurological condition. It is a practical approach using the strengths of the person to develop coping abilities. It is also an educational process which helps the individual to understand what has happened to them and to develop adaptive strategies for coping. Training in the use of compensatory aids and systems to help reduce the impact of losses and encourage independence is a central component.

2. What can rehabilitation do?

Rehabilitation can:

- provide coping skills that lead to greater independence in everyday life
- help reintegration into the community, social and family life
- reduce the restrictions caused by cognitive impairments
- improve emotional adjustment
- develop social skills and re-integration
- improve motivation
- improve decision making skills
- improve self-control
- improve insight and awareness
- develop physical and mental stamina
- restore lost confidence
- help and support families to cope
- improve the overall quality of life

3. What can't rehabilitation do?

Rehabilitation can't:

- return the person to the way they were before
- 'cure' intellectual problems
- help the person cope with any demand placed on them
- take away the distress and heartache caused by the injury
- provide long-term support (although many brain injury rehabilitation services are now linking with long-term support services)

4. What happens during rehabilitation?

Rehabilitation activities

Goal setting is a central feature of most rehabilitation programmes. Early in rehabilitation, staff will typically work with the person to find out what is important to them, such as their values, interests and personal priorities. They will then use this information, along with the results from clinical assessments, to identify together a set of goals specific to that person. These goals often have a long-term focus such as returning to work or living independently, and so will be supplemented by shorter term goals or sub-goals, for example concerning meal preparation, self-care, social communication, or voluntary work placements which will help the person to progress towards the longer-term goals. Rehabilitation activities will be organised around these goals, and these goals will be monitored frequently, updated when necessary, and used as a measure of rehabilitation progress.

Day-to-day, the person will engage in a range of activities related to their particular strengths and difficulties, within safe and supported environments. Tasks may include social activities, vocational activities, self and home-care activities, recreational activities, etc. They are likely to range from basic hygiene training to money management. Initially, the activities may occur within a safe learning environment, then later practised in the community. Eventually, the rehabilitation should help the person transfer these adaptive skills to their home. Such everyday activities provide the vehicles for developing more adaptive coping strategies and introducing systems and aids that permit the person affected by encephalitis to be more successful. In the early stages of rehabilitation, the person's activities may need to be very structured and organised. In later stages, the person might be expected to plan and organise their own activities.

The person affected by encephalitis should be helped to develop habits, systems, procedures and aids to compensate for their difficulties accomplishing their daily activities, thereby reducing the need for reminding, prompting, explanation or supervision. Perhaps the most effective way of learning after encephalitis is by 'doing' (and doing well). Post-acute brain injury rehabilitation programmes should provide encouragement and experiences of success to the person affected by encephalitis. The more realistic the tasks and environments are to the person's individual needs, the more effective the rehabilitation. Therefore, rehabilitation services should provide access to realistic tasks and settings, so that the skills learned are more transferable once the person leaves the rehabilitation centre.

It is unlikely that the rehabilitation programme will include many other people that have had encephalitis, because usually the service will be providing for the needs of people with all forms of acquired brain injury (ABI) e.g. those resulting from head injuries or strokes. However, working in a group with people with a shared experience of brain injury, can be important, helpful, and a therapeutic experience.

Adaptive skill development (learning new tricks)

Rehabilitation programs also aim to help develop skills in problem solving, decision making, planning and awareness. Individual or group therapy sessions may be used for the training of these skills; however, the lessons learned in these 'clinical' sessions need to be practised in everyday life to be most beneficial.

Developing ways of coping with anxiety, impulsivity, apathy, fatigue, depression, anger, embarrassment, grief, mood swings and other emotional problems are central aspects of rehabilitation. The person might be involved in counselling, cognitive therapy and/or behavioural therapies. Behavioural therapies use the retained learning abilities of the person affected by encephalitis to help shape self-control, motivation and adaptive habits.

Learning to use aids and well-rehearsed procedures habitually is central to brain injury rehabilitation. Tasks that might be impossible for the person affected by encephalitis might be made possible by:

- approaching the task in another way
- using external aids (especially for memory, attention, organisation, and sequencing)
- seeking help for elements of the task

Developing insight and awareness by a combination of feedback, psychological therapy, self-monitoring or structured experience is one of the key factors in successful rehabilitation. Unfortunately, the cognitive difficulties that encephalitis frequently causes mean that many people no longer learn from their mistakes but rather learn to repeat those mistakes and explain them away. A success-laden program of rehabilitation is therefore required because clients are more likely to learn from their successes.

Rehabilitation can be a very long journey. There is a pervasive myth that improvements are possible only in the first two years after injury but in reality people can benefit from rehabilitation even many years later. Sometimes people are not 'ready' for rehabilitation when it is first offered, meaning that they may not have accepted the need to contemplate a future that may be very different to the one they had previously planned. They may even be resistant to advice. Overcoming this resistance and opening up to the possibility of a new way of living can in itself be an important aspect of the rehabilitation process.

As the person becomes proficient in using their new strategies and experiences success in achieving goals that are personally meaningful to them, they will often describe feeling more confidence, an improved sense of wellbeing, and increased readiness to take on new challenges - even though the underlying difficulties may remain.

Clinical services

ABI rehabilitation requires expert staff. Clinical neuropsychology, occupational therapy, speech and language therapy, physiotherapy, rehabilitation medicine, psychiatry, counselling and family support services should all be available. For more information about the role of each one of these professions please see the factsheet on **'Professionals involved in recovery and rehabilitation' (FS033)**.

5. How can you be referred to rehabilitation?

General practitioner (GP)

The GP represents the first line of health support. Since many people affected by encephalitis are discharged directly to their home, the GP becomes the most important link with health care services. However, in the majority of cases GPs have little experience of encephalitis or rehabilitation services. Providing the GP with an explanation of the problems presented by the person affected by encephalitis and requesting assessment for rehabilitation can often initiate appropriate referral to NHS services or funding requests for rehabilitation in either the public or private sectors.

Neurologist

Encephalitis is a neurological condition. People affected by encephalitis have to be treated and assessed by a neurologist. The majority (but not all) will know of ABI rehabilitation services so do ask them what your options are.

Neuropsychologists

Not everyone with encephalitis is assessed by a specialist neuropsychologist, although perhaps all should be. Neuropsychologists provide a specialist assessment of the functioning of the individual and can advise as to appropriate rehabilitation services.

Social workers

An assessment of need by the social services is a statutory right for every disabled person.

Self-referral

It is often possible to approach services directly and ask for advice and possibly refer your relative directly.

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