Rehabilitation after encephalitis

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1. What does rehabilitation mean?
During the early days, weeks or months after encephalitis, the main aims are to provide a safe environment and gentle stimulation to encourage the process of spontaneous recovery. In the later stages, when spontaneous recovery slows or stops, the main aims are to help 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 cognitive, physical, emotional, social and self-care problems, the most common being impairments in reasoning, motivation, self-control, memory and concentration.

Depending on the nature of the person’s problems, rehabilitation may range from 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 is a holistic approach. It recognises the complex cognitive, behavioural, social, emotional and medical problems faced by people affected by encephalitis and their families. 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 develop adaptive strategies for coping. Training in the use of compensatory aids and systems to help reduce the loss and encourage independence is a central component.

2. What can rehabilitation do?
Rehabilitation can:
- provide coping skills and greater independence in everyday life
- reduce the restrictions caused by cognitive impairments
- help reintegration into the community and family life
- 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
- help and support families to cope
- improve the 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
The person will be engaged in a range of activities related to their particular 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 persons’ 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 ways of learning after encephalitis is by ‘doing’ (and doing well). Post-acute brain injury rehabilitation programmes should promote achievable goals that provide encouragement and success to the person affected by encephalitis. The more realistic the tasks and environments are to the persons individual needs, the more effective the rehabilitation. Therefore, rehabilitation services should provide realistic settings where people can develop relevant skills which are transferable after they leave the rehabilitation centre.

It is unlikely that the rehabilitation programme will be with many other people that have had encephalitis. Usually the service will be providing for the needs of people with head injury, stroke and other forms of ABI. However working in a group with people with similar levels of ability/difficulty can be important and helpful.

Adaptive skill development (learning new tricks)
Rehabilitation programs also aim to help develop 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 ABI rehabilitation. The person might be involved in counselling, cognitive therapy and/or behavioural learning 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 a central core of 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
- by using external aids (especially for memory, attention, organisation, and sequencing)
- by seeking help for elements of the task

Developing insight and awareness by a combination of counselling, feedback, cognitive therapy, self-monitoring or structured experience is one of the key factors in successful rehabilitation. Unfortunately, many people affected by encephalitis do not learn from 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. People can continue to benefit from specific interventions even years later. Sometimes people need to be 'ready' to take on new information and tricks. They may be resistant to advice and that itself may require careful work. There is a pervasive myth that there are (e.g., 2 years) limits to when people can benefit and this is why it is worth seeking advice from specialists.

Clinical services
ABI rehabilitation requires expert staff. Clinical neuropsychology, occupational therapy, speech and language therapy, physiotherapy, general medicine, psychiatry, counselling and family support services should be expected as standard. 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 GP’s have little experience of encephalitis or rehabilitation services. Providing the GP with 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 for rehabilitation in the private sector.

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.

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
The Encephalitis Society holds comprehensive lists of rehabilitation services. It is often possible to approach services directly and ask for advice and possibly refer your relative directly.

Support our information
With our support, no one has to face encephalitis alone. Our advice and information is available free of charge to everyone affected but we are truly grateful when supporters feel able to contribute a little to the cost of these resources. Please make a donation today by visiting www.encephalitis.info/donate or text ENCE11 followed by an amount (£1, £2, £3, £4, £5 or £10) to 70070. Thank you!
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