

Rehabilitation after encephalitis

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Encephalitis is an inflammation of the brain caused by infection or autoimmunity. Often it has a sudden onset and requires hospital treatment, which may last from a few weeks to several months. This variability in the course of the illness is also reflected in the care pathways following the acute phase: some individuals do not receive any rehabilitation at all, some receive some community rehabilitation, and only a very small number are referred for in-patient rehabilitation.

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1. What is rehabilitation?

Rehabilitation is a person-centred process aimed at helping individuals recover and adapt after an illness or injury, with the objectives of improving function, promoting independence, and restoring meaningful activities and relationships. In the case of encephalitis, rehabilitation focuses on supporting recovery from a wide range of possible consequences—physical, cognitive, psychological, and behavioural.

The level of rehabilitation, the specialists involved (rehabilitation consultant, psychiatrist, therapists) and the setting of the rehabilitation (community, in-patient) will depend on the patient's needs. For example, physical disabilities and mild cognitive disabilities may require non-specialist rehabilitation, whilst severe cognitive and behavioural challenges may require a specialised rehabilitation setting.

2. Is it worthwhile to have neurorehabilitation after encephalitis?

It is very understandable that after an hospital admission one looks forward to going home and resuming normal life. Yet there is increasing evidence that investing a few weeks in neurorehabilitation can make a big difference to the long-term outcomes. Depending on the cause of the encephalitis and the brain regions affected, long term effects can include memory difficulties, language problems, personality change, psychiatric disorders, fatigue and physical deconditioning. These are all problems that can be addressed by neurorehabilitation. In addition, particularly after a long hospital stay, failed attempts to return to work or resuming previous hobbies or social life may result in disappointment, leading to low self-esteem and even depression. A guided, gradual transition from the acute hospital to home can prevent a lot of these problems. Furthermore, a period in neurorehabilitation may represent an opportunity to withdraw safely, under medical supervision, the medications that were prescribed in the acute phase but are no longer needed. Conversely, it is known that psychiatric consequences of encephalitis may become apparent weeks/months after the acute illness. Early detection and timely treatment improve long-term outcome and quality of life.

3. How does it work?

Neurorehabilitation is delivered by a multi-disciplinary team (MDT) with the goals of restoring function where possible, supporting adaptation through compensatory strategies, facilitating return to important life roles, and promoting emotional and psychological wellbeing. Education and support for families and caregivers are also essential, as they play a crucial role in the recovery process and may need guidance in understanding and managing changes in their loved one.

In most cases the MDT includes doctors, psychologists, physiotherapists, occupational therapists, speech and language therapists, specialist nurses, dieticians and social workers. Each discipline addresses different aspects of recovery.

The doctors, depending on the service, may be neurologists, rehabilitation medicine physicians or neuropsychiatrists. They lead the MDT for goal-oriented rehabilitation, manage any medical or psychiatric issues, and coordinate care across various specialties and hospitals. Doctors may oversee the assessment and management of persistent neurological complications including seizures, chronic headaches, neuropathic pain, movement disorders, and autonomic dysfunction. In addition, after encephalitis input from a neuropsychiatrist may be very helpful, in assessing and treating mood disorders, anxiety, psychosis, behavioural dysregulation, sleep disturbance, and ensuring that psychiatric symptoms do not hinder effective rehabilitation. During the rehabilitation period doctors can also monitor any secondary medical complications (i.e. infections, nutritional and metabolic issues, fatigue, endocrine disturbance) that may interfere with recovery.

Most of the daily activities are carried out with the therapists. Physiotherapists address motor function and help with mobility, strength, balance, and postural control.

Occupational therapists focus on activities of daily living, such as personal care, cooking, and safe access to the community. Upon discharge patients can be referred if appropriate to Vocational Therapy, a type of occupational therapy specifically focused on returning to work or studying.

Speech and language therapists address language and communication difficulties, reading and writing, and any swallowing problems. They work with patients and families on any communication changes, focusing on speech intelligibility and fluency, and effective communication.

Nurses provide day-to-day support and education, particularly in medication management and functional independence.

Dieticians conduct specialist assessment and optimisation of nutritional status including evaluation of energy and protein requirements, managing any malnutrition risk following a long hospital admission, and advising on nutritional problems related to the medical treatments, for example corticosteroids, anticonvulsants, or immunotherapies.

Social workers may help with benefits, housing, finances, and care packages when necessary. The MDT would also carry out appropriate risk assessments to ensure the safety of the patient while re-integrating in the community.

A large part of rehabilitation following encephalitis includes patient and family education about understanding what encephalitis is, how it affects them or their loved ones and how the recovery happens. All MDT disciplines incorporate in their work brain injury education enabling patients to engage as much as possible in rehabilitation, make informed decisions, and reconnect with everyday life.

After encephalitis, cognitive rehabilitation, carried out by neuropsychologists, often plays a central part in recovery, and it is therefore described in a little more detail below.

4. What is cognitive rehabilitation?

A key part of rehabilitation following encephalitis is cognitive rehabilitation as cognitive difficulties are very common in encephalitis survivors. Depending on the severity and area of brain affected, individuals may experience:

- Memory problems (short-term and/or long-term)
- Attention and concentration difficulties
- Language or communication deficits (aphasia, word-finding difficulties)
- Executive dysfunction (planning, organizing, problem-solving)
- Processing speed reduction
- Fatigue-related cognitive slowing

Cognitive rehabilitation is mostly lead by a clinical neuropsychologist and usually starts with in-depth assessments of a person's thinking skills—such as memory, attention, and executive function—to identify both strengths and

difficulties. Based on this, they offer tailored cognitive rehabilitation and work with the wider team to ensure therapy is adapted appropriately. Therapy often focuses on the use of compensatory strategies to support the individual to manage the identified difficulties. Compensatory strategies are practical tools and techniques used to reduce the impact of cognitive impairments rather than relying on recovery of the underlying brain function. These strategies help people adapt to challenges in memory, attention, language, or executive function by using external aids or structured routines.

This might include the use of orientation boards, diaries and planners including the use of smartphones and other technology. There are a number of strategies that an individual may find helpful for executive functioning such as working on one task at a time, the use of consistent daily schedules, breaking down tasks into smaller steps with regular breaks and the use of visual checklists. There are also changes to an environment that can be made to enhance performance such as working in a quiet distraction free space, using noise cancelling headphones.

The focus of these should be on helping the individual to complete daily tasks that are meaningful for them, and therefore any rehabilitation needs to be based on assessment results and be created in a person-centred way bearing in mind the individual's lifestyle and rehabilitation goals. There is also often a focus of psychoeducation which helps the individual and their family understand the processes involved in encephalitis and how the brain recovers following this.

Recovery can be at times slow and non-linear; progress may happen in small, sometimes imperceptible steps, but, most importantly, support need to be asked for as no one needs to navigate this journey alone.

Following discharge from the in-patient rehabilitation unit most people are referred to community rehabilitation services to continue with their recovery at home.

For further support and information, organisations such as Encephalitis International offer excellent resources. Families are encouraged to ask their GP/family doctor or treating consultant for local rehabilitation services referrals where needed.

This factsheet is intended for educational purposes and should not replace individual medical advice. Please consult your healthcare provider for tailored support.

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