



Encephalitis: After-effects, recovery and rehabilitation

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About this booklet

Some people recover from encephalitis with a few or no difficulties. Other people are left with significant after-effects. This booklet provides key information about the type of issues that people may have after encephalitis, why rehabilitation and support from professionals and families are important and what options for self-help are available.

Detailed information about encephalitis and its effects can be found on our website www.encephalitis.info or by telephone on +44(0)1653 699599.

If you would like information on the source material and references used to write this booklet please contact Encephalitis International.

Thank you to The Hugh Fraser Foundation and The Hospital Saturday Fund for their support!

DISCLAIMER

The information presented here is not reflective of every situation where encephalitis is involved and some of the information may not be relevant to every patient. Information provided in this booklet is designed to support, not replace, the relationship that exists between a patient and medical professionals.

Should any of the information raise issues or give you reasons for concerns we would ask you contact us on +44 (0) 1653 699599 or support@encephalitis.info

Life after encephalitis: key facts

Encephalitis may result in an acquired brain injury (ABI).

Encephalitis is an inflammation of the brain. Although some people recover from encephalitis with no consequences, in some people nerve cells in the brain may be damaged or destroyed by the inflammation. The resulting damage is termed an acquired brain injury (ABI).

No two people with encephalitis have an identical outcome.

The degree and the type of damage vary according to the cause of encephalitis, the severity of the inflammation, the area of the brain affected and any delay in administering the appropriate treatment.

Most of the after-effects of encephalitis are hidden (invisible).

People affected by encephalitis may look like they did before the illness with more problems being cognitive, emotional, behavioural and social rather than physical. Some of the problems can be subtle at the time of discharge from hospital, but become evident later, when people are attempting to get back to normal life and work.

The danger is that these problems may be misattributed to factors such as 'stress' rather than being associated with their brain injury.

Encephalitis can affect people's emotions and the way people perceive themselves and others.

The emotional impact of encephalitis is different for each individual depending on the brain systems affected by encephalitis, their personality, their emotional state prior to their brain injury, their social support network (family and friends) and their stage of recovery.

An emotional reaction to the brain injury may sometimes be the first step on the road to recovery. This is because it suggests that people are more likely to have an understanding of their strengths and weaknesses and may therefore be more likely to benefit from rehabilitation.

People recover at different paces, but there can be a continuum of improvement.

Initial recovery may be rapid but it can fall short of complete. Further recovery takes place more slowly over a period of months and even years. Healthy diet, gentle exercise, rest, pacing your activities, determination, a positive attitude, and emotional and practical support can help your recovery.

Encephalitis is a family affair.

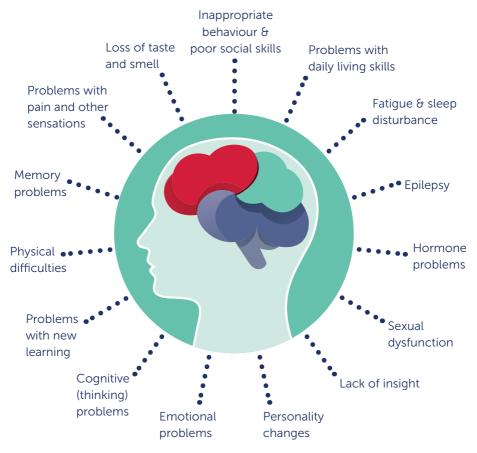
Coming to terms with the problems left by this illness can be distressing and challenging for everyone concerned. Initially, there may be relief and joy that the person affected has survived. Later, when it becomes evident that the person cannot function like they did before the illness, there may be a sense of loss and grief. Everyone deals with grief in their own way and time. Whilst it is important to acknowledge the loss and allow time to grieve, support from family, friends and professionals can make all the difference.

Encephalitis International is aware of some amazing stories of recovery.

People discover new skills and interests, make new friendships and become closer to their families.



OUTCOMES AFTER ENCEPHALITIS



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Cognitive problems

Cognitive problems refer to difficulties with memory, attention, concentration, language, information processing, problem solving, decision making, planning and organisation. People may have difficulties with:

- Remembering events in the past or the names of people and places.
- Finding the right word.
- Concentrating on a task.
- Doing two things at once.
- Taking information in.
- Keeping track of or remembering a conversation.

- Following the storyline of a book/movie.
- Getting to an appointment on time.
- Completing tasks.
- Sticking to a topic, and not monopolising conversations.
- Understanding speech.

Emotional problems

Emotional changes may reflect the direct effect of encephalitis on the brain and/or may also reflect an individual's reaction to the difficulties in everyday functioning because of the cognitive, physical or behavioural impairments subsequent to encephalitis. As a result people may find it hard to manage the stress of everyday life. People may also experience:

- Low mood or mood swings.
- Increased anxiety.
- Frustration and anger.
- Depression.
- Suicidal thoughts.

- Difficulty regulating their emotions.
- An absence or flattening of emotion.
- Panic attacks and phobias.

Behavioural problems

Families and friends often struggle to understand and cope with behavioural changes that may reflect a very different personality to how the person was before the illness. Some people may be:

- Aggressive.
- Impulsive.
- Disinhibited.

- Sexually inappropriate.
- Confused and vulnerable.
- Exhibiting obsessive compulsive behaviours.

Problems with senses

Vision, hearing, smell, taste and tactile sensation can all be affected after encephalitis. People may experience:

- Changes in visual and auditory acuity.
- Double vision.
- Tinnitus.
- Partial or total loss of smell (anosmia).
- 'Pins and needles'.

- Difficulty gauging 'hot' and 'cold'.
- Inability to recognise the taste of food.
- Difficulty to recognise faces (prosopagnosia) or to judge distances.
- 'Neglect' for one side of pictures or their body.

Seizures

Many patients, who go on to develop epilepsy after encephalitis, will have had seizures during their acute illness, and then continue to have seizures after they have recovered. However, others may not have had seizures at all during the acute illness or may have had some seizures, which settled, but then go on to have epilepsy later on, even years after encephalitis.

Pain, fatigue and sleep disturbances

Following encephalitis, it is common for people to experience fatigue (overwhelming feeling of tiredness), which can often be cognitive (neurological) rather than physical. Some people describe fatigue being like 'hitting a wall' or like 'shutting the brain off'. It can be very intense and can make a challenge for people to think, communicate and tolerate sensory stimuli (e.g., noise, light). Fatigue can interfere with everyday tasks.

People may also experience: pain including headaches and sleep disturbances.

Physical difficulties

People may have difficulties with movement, balance and coordination. Difficulties with translating intention into effective action are called **apraxia**. Some people may suffer **incontinence** which can have a significant impact on their social functioning.

Hormonal imbalance

Encephalitis may cause damage to structures in the brain that regulate hormones, such as the hypothalamus and/or pituitary glands. There are many symptoms that may reflect these hormonal changes such as:

- Depression.
- Sexual difficulties.
- Headache.
- Fatigue.
- Visual disturbance.
- Weight gain.

- Muscle weakness.
- Changes in skin texture.
- Mood swings.
- Difficulty regulating body temperature.

Problems with speech and swallowing

Some people may have problems with speech production because of the damage to the muscle involved in speech (dysarthria). Others may have problems saying what they want to say (dyspraxia) or problems with muscles involved in swallowing (dysphagia).

Social behaviour difficulties

Following encephalitis, social behaviour may change because of the cognitive and emotional difficulties. It may be hard for people to socialise and maintain a social life. People may experience:

- Difficulty judging how to behave in social situations.
- Reduced awareness of their difficulties (changes in their thinking and behaviour) as a direct result of the injury to the brain.
- Difficulty in accepting the impact of encephalitis (understandably) and denying that they have any problems although they are aware of their problems.
- Self-centeredness with a lack of consideration for the feelings and needs of their family and friends, leading to a strain on relationships.



Social consequences

Changes in thinking, behaviour and feelings may make it difficult for people to take part in everyday activities which, in turn, may result in a change in their lifestyle and life values.

- Inability to drive because of the cognitive, emotional, physical and visual problems or seizures.
- Difficulty returning to work because of the memory problems, tiredness, mood swings, behavioural constraints, reduced organisational skills, personal or family worries, stress or prejudices of potential employers.
- Financial difficulties due to being/caring for somebody in hospital, not being able to go back to work after encephalitis and insurance issues.
- Difficulty with self-care (e.g., showering, cleaning, shopping, cooking) because not only of physical, but also cognitive problems such as memory problems.

Altered family relationships

Family members may have different reactions to the illness and its aftereffects. Various feelings may develop. Spouses may feel isolated and trapped as roles in the family change and relationships put under strain. They may also have to adapt to their partner's personality change such as 'more laidback' than they used to be or 'more extroverted' than was previously the case.

Children may feel guilty, jealous, upset, frustrated, scared and angry. Their needs can be overlooked. Extended family and friends may not understand the situation or may want to help but don't know how.

Not all families have good relationships and sometimes the sudden impact of encephalitis adds to already strained relations.

Rehabilitation after encephalitis

What does rehabilitation mean?

Rehabilitation needs to consider the complex cognitive, behavioural, social, emotional and medical problems faced by people affected by encephalitis and their families. During the early days after encephalitis, the main aim is 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 aim is to help the person develop new skills and strategies for coping with their remaining difficulties.

Depending on the type of these difficulties, rehabilitation may range from residential programs to home-based services. Training in the use of compensatory aids and systems to help reduce the loss and encourage independence is a central component.

Sometimes, rehabilitation does not take place straight away after the acute illness. People need to be 'ready' to take on new information and strategies. They may be resistant to advice and that in itself may require careful work. Skilled neuropsychologists can be essential in overcoming these problems. People can continue to benefit from specific interventions even years later after the initial illness. Although the needs of different age groups vary, older adults can also benefit from rehabilitation.

Rehabilitation can be challenging, but it can also strengthen the family relationships as the person affected needs the support of their families and friends. Their positive and committed involvement can make a difference to their family member's recovery.

It is also important to note that a certain amount of rehabilitation takes place at home, without the formal involvement of professionals.

This kind of rehabilitation involves people affected and their carers using 'self-management' strategies (please see **Practical strategies** section).

Key professionals involved in rehabilitation

- **Neuropsychologists** for assessing an individual's thinking skills or capacity to make complex decisions (e.g. where to live); therapy and other interventions for managing problems with emotion and behaviour.
- Occupational therapists for assessing daily life skills and abilities; supporting an individual to maximise their independence and to access/ return to school or work; recommending any useful aids/equipment.
- **Speech and language therapists** for assessing and managing problems with communication, eating, drinking and swallowing.
- Neurophysiotherapists for assessing and managing physical problems; advice regarding pain management.



Other specialist services and professionals to consider might include:

- **Neurologists** for concerns about relapse, advice about medication, and management of seizures.
- Rehabilitation Medicine Consultants for advice about rehabilitation.
- **Neuropsychiatrists** for management of problematic emotion and behaviour.
- Epilepsy nurse specialists for management of epilepsy.
- Pain management services for advice regarding pain.
- Continence services for advice about continence management.
- **Psychosexual clinics** for management of the combined impact of physical and psychological aspects of sexual dysfunction.
- Ear, Nose & Throat Specialists / Audiologists / Opthalmologists for managing sensory problems.
- Endocrinologist / Neuroendocrinologist for management of hormonal irregularities.
- Immunologist in the event of problems with immunity.
- **Dietician** to assess nutritional needs and recommend appropriate treatment.

Practical strategies for dealing with the most common difficulties

A **neuropsychological assessment** (an assessment of thinking skills) is a useful tool for describing the pattern of cognitive strengths and weaknesses following encephalitis and for helping to plan rehabilitation and appropriate support. Specific strategies and compensatory devices that help to compensate for everyday problems may be suggested. With training and consistent use, these can help an individual to work around their thinking problems to function in everyday life.

Below is a list of strategies that may be able to help with specific problems. The ideas included here are by no means exhaustive. Individual-specific guidance from a neuropsychologist and/or an occupational therapist is recommended.

Managing memory problems

Memory is not like a damaged muscle that, with appropriate exercise, can be made strong again. Memory loss arises because brain cells, connections and systems have been irreparably damaged and repeated practice or drills do not restore memory function. Instead, it is recommended to try and teach the person affected strategies for using their remaining memory abilities more effectively.

There are two important things to know:

- Avoiding errors during learning leads to better learning in people with severe memory problems so the basic message is: if you are trying to teach a memory-impaired person something, don't let them make errors.
- **Repeated practice** is helpful to learn new information if this is done over a number of days in a practical manner as opposed to attempting to cram new information.

Practical steps in managing memory problems

- Maintain a regular routine.
- Organise the environment so it is structured and uncluttered; keep things in the same places as much as possible.
- Use labels, colours and signs on things to make them distinctive or indicate where they are located (e.g. which cupboards are for crockery, food etc.).
- Use a diary, written notes and/or a wall chart to remember dates and future events and to recall what has happened in the recent past.
- Use a flow chart on the wall giving instructions about which places to look for things habitually misplaced (e.g. glasses).
- Display photographs of family and friends prominently and label them with their names.
- Use memory aids (personal organisers, watches, smart phones, medication boxes, email and computer-based support, voice recorder) to improve everyday memory function by compensating for changes in memory function.

Managing slow thinking speed or difficulties with concentrating and attention

- Keep distraction to a minimum.
- Allow more time to complete tasks.
- Attempt one task at a time, during peak energy times.
- Take notes to capture key points.

Managing planning and organisation difficulties

- Increase structure and routine in daily activities.
- Write daily activities in a weekly planner (paper-based or smartphone), with a list of steps required to complete tasks, to be crossed off one by one. Reviewing progress to troubleshoot and learn from experiences forms part of the problem-solving process.
- Use alarms (e.g. mobile phone alarms) to help monitor performance and keep a person on track.

Managing difficulties with 'get up and go'

- Recognise that a lack of initiative can be a result of encephalitis as opposed to being 'lazy' or 'not interested'.
- Keep a daily routine to provide structure and manage reduced drive.
- Break activities into smaller steps, with enjoyable rewards once an activity is completed.
- Recognise the individual's achievement, highlight to others and then attempt a more enjoyable task (e.g. music, an outing, a game etc).

Managing fatigue after encephalitis

A better understanding of the causes of fatigue and the pattern of energy across time may help in managing fatigue. There are two main ways of tackling fatigue, general lifestyle changes and a specific treatment plan.

Lifestyle changes

- Maintenance of a reasonable schedule of activities.
- Reduction of work hours and/or level of personal commitments.
- Relaxation and/or rest periods.
- Development of good sleep habits.
- Maintenance of a balanced, healthy diet.
- Regular exercise (within prescribed limits).
- Reduce intake of stimulants including caffeine.
- Reduce alcohol intake as this may affect the quality of sleep.

Structured treatment

A rehabilitation program may advise the following:

- Keep a 'fatigue diary' which is a record of daily activities and energy levels. If a pattern of fatigue emerges across the day/week, plan important activities at times of peak energy.
- Resist the urge to keep going and plan breaks throughout the day. During these breaks, stop and rest. In addition to lying down, rest can involve stepping outside for some fresh air or listening to some pleasant music. Various alarms and/or smart phone apps can be useful to prompt you to take a break. However, try to avoid sleeping for extended periods late in the day.
- Pace yourself and try to be patient. Improvements in stamina may not always be an upwards journey. Expect good days and bad days.
- Psychotherapy with a registered psychologist may be useful to manage symptoms of depression, stress or anxiety that are making the fatigue worse.
- Similarly, cognitive rehabilitation should address cognitive changes in memory, concentration or problem solving with the aim of developing strategies to support everyday function and reduce cognitive effort.

Getting better sleep

Fatigue is often associated with a poor sleep pattern.

The following may be helpful to improve the quality of sleep:

- Have a routine.
- Avoid drinks with caffeine (tea, coffee) later in the day.
- Do not drink alcoholic drinks excessively.
- Spend some time outside in the daylight every day.
- Do something relaxing before sleep (e.g. listening to music, meditation, relaxation techniques, having a warm bath). Watching television, reading, using a smartphone or tablet may be stimulating and make it hard for people to switch off at night.
- If you have things running through your mind, write them down before you go to bed.
- If you must rest during the day, have brief naps of about 30 minutes and not late in the afternoon.
- If you are not asleep after 15-30 minutes, get out of bed and do something relaxing until you feel sleepy. Tossing and turning trying to get to sleep may increase frustration and make it even harder to sleep.

Managing anger after encephalitis

With professional support, anger may be managed by:

identifying trigger situations and the signs of anger; putting in place brief strategies such as breathing or distraction; leaving the situation safely; and reflecting and learning after the episode.

The following acronym may be helpful to manage anger outbursts:

- A Anticipate situations that trigger anger. Record where, when, why and with whom it happens.
- **N** Notice signs of anger building such as irritation, feeling tense, heart racing or breathing more rapidly.
- **G** Go through a 'temper routine' which may include:
 - Distraction (e.g. counting to 10).
 - Take three deep slow breaths.
 - A personal self-statement (e.g. "let it go", "these feelings will pass").
- **E Extract** yourself from the situation. Have a set place to go to or take a quick walk outside if possible.
- **R Record** how you coped, what worked and any change in behaviour over time.It is also useful to develop strategies to manage general levels of stress and frustration. These may include regular exercise, meditation, psychotherapy, listening to music or relaxation training. Change in communication style may also help to manage anger outbursts.

Connect with people

Social interaction helps to manage stress and feelings of depression and also stimulates brain development. It is important for people to re-connect with their previous social roles or consider new avenues for social involvement. When the time is right, there may be local groups to join and opportunities to do voluntary work.

Peer support through talking to others who have been affected by encephalitis can be a positive way of making sense of feelings and life changes. Reading the stories of other people who have experienced encephalitis is also often useful. Stories of other people can provide hope that there is life after encephalitis, by providing tips about different ways of coping and finding meaning in the experience. Before reading, it is important to consider whether the time is right. Stories may be of benefit at a later stage in your recovery than in the immediate aftermath of experiencing encephalitis.

Return to work gradually

People who are considering a return to work must ensure that they do not return too soon. A return to work too early can bring stress, anxiety and fatigue. Before returning to work, it is important to assess the impact of any after-effects on an individual's ability to work, the motivation for returning to work as well as the support required from employer and colleagues. Other options may be a return to work part-time, re-training, doing a different job or doing voluntary work.

Become an expert and don't be afraid to ask for support

As the outcomes are so variable, there is no one typical recovery/ rehabilitation pathway; in addition the availability of services depends on the geographical areas and financial means. Each individual may benefit from becoming their own expert in their own encephalitis and recovery, using advice and information from professionals, support services like Encephalitis International and other brain injury charities, family and others around them.

Being a family member and/or a carer

It can take a long time, perhaps months or years, before you know how much your relative or friend will recover. In the early days, you may have no idea of what the future holds, living from day to day, keeping an open mind and staying hopeful. You may find that you are grieving for the person as they used to be, while being happy that they have survived. Maybe there are children to bring up, a job to do or worries about lost income. Coping with the consequences of encephalitis can be highly stressful for the whole family.

You may be wondering what services are available to help and how to access them. In dealing with those providing and planning services, make sure that they take the needs of the whole family into account, and that they take them seriously. You may feel as though you are being a nuisance or demanding. However, professionals should understand that it is in everybody's best interests if the family is supported as a whole, and the individual needs of all family members are taken into account.

If you are the main person providing care to someone recovering from encephalitis, you may suddenly find that people are calling you the 'carer' where before you were that person's wife, husband, parent, friend or child. This is likely to have a significant effect on you, and you too will need support. It is important that you don't overlook your own needs as a carer, both for your own sake and because the right support (emotional, practical and informational) provides you with the resilience needed for looking after your family.

Children in the family can be affected in many ways depending on their age and the support around them. It is important to understand the impact on children of living with someone who has considerable needs.

Things that may help:

- Recognise and accept different feelings in the family; make sure there are opportunities to talk things through.
- Gather as much information as possible about encephalitis and your relative's specific difficulties.
- Get in touch with other people/carers of people affected by encephalitis; sharing experiences may help alleviate feelings of loneliness.
- Ask for emotional and practical help from professional organisations, family and friends.
- Keep active and healthy.
- Be prepared to be flexible as needs and expectations may change.
- Don't be afraid to say 'no' sometimes and avoid activities or people who raise your level of stress unnecessary.
- Take a break by finding a respite opportunity.
- Have time for yourself occasionally and do something that you like and makes you feel relaxed.

Getting the best out of the meetings/assessments with professionals

Many people are nervous about talking to those who have a degree of control over their lives or the lives of those they care for (e.g., doctors, therapists, case managers, social workers). There may be additional difficulties following encephalitis, perhaps with communication or memory that you or your loved one may now face. Below, there are some recommendations to help you get the best out of your meetings.

Identify your difficulties

Keep a diary of all your difficulties, their pattern and how they affect your life. If you have bad days and good days, make sure you include your difficulties from a bad day, even if the appointment/assessment is on a good day.

Build a good relationship with the professional/organisation

Be open about your difficulties, your strengths and the support you need. If you have difficulties making or attending appointments because of your after-effects of encephalitis, let them know about it. Sometimes, you may need to be persistent in asking for support from professionals, but don't forget to do this politely.

Prepare for your meetings

Make sure you know where and who you will meet and what you will discuss. Before the meeting think about what you want to say and bring to the meeting (e.g. your diary, a list of your medication, medical reports or a family member/friend for moral support or for taking notes at the meeting).

At the meeting:

- Stick to the topic; keep checking your notes.
- Be honest.
- Listen to what is said and take notes.
- Ask them to explain or put it in writing if you don't understand.
- Ask if you can have some time to think about any decision.
- Ask about alternatives to any treatments.
- Keep a record of all your meetings.
- You can ask to be copied in on any letters sent out.
- Ask that another time and venue be arranged if necessary.
- End the meeting on a friendly note.

If things go wrong:

- Try not to get angry, take some deep breaths or ask for a short break.
- Try not to blame, focus on finding a solution instead.
- Say you are not comfortable with the decision and ask for a second opinion.

"Dealing with encephalitis, particularly during the pandemic was very challenging and it was easy to feel isolated and alone. Even though other people's experiences might initially appear to have been quite different, through discussions you soon realise that you have so much in common."

Encephalitis International

Encephalitis International is a charity (non-profit) dedicated to supporting adults and children affected by encephalitis.

Broadly speaking our work involves:

- Providing support and information to all people affected by encephalitis across the globe and to a variety of health, social care and education professionals. www.encephalitis.info/support
- Working in conjunction with academic and clinical partners to promote and conduct high quality research into encephalitis and its consequences, and promote high standards for patient diagnosis, management and care. www.encephalitis.info/ei-funded-research
- Raising awareness about encephalitis, its consequences and the need for improved services by organising events such as World Encephalitis Day on 22nd February each year. www.worldencephalitisday.org

Keep in touch with us!

Join our mailing list to keep up-to-date with the work that we do and the latest encephalitis-related news, campaigns, appeals, events and research. www.encephalitis.info/keep-in-touch

How we can support you

- Get in touch with us by telephone +44(0)1653 699599, website support form www.encephalitis.info/support, email support@encephalitis.info or book a Zoom one-to-one session.
- Get reliable and accurate information about encephalitis from our website www.encephalitis.info or ask for an information pack from the Support Service (contact details above).
- Connect with others through our virtual meetings (using Zoom) or our Connection Scheme.
 www.encephalitis.info/online-support-meetings
 www.encephalitis.info/connection-scheme
- Subscribe to Health Unlocked, a social network specifically designed for peer-to-peer support, where people can connect and help each other on health concerns.

www.encephalitis.info/health-unlocked

- Subscribe to our YouTube channel to hear experts talking about encephalitis, people affected and their families sharing their stories and listen to our series of podcasts featuring experts in encephalitis. www.youtube.com/@encephalitisinternational
- Attend in-person or virtually our educational and networking events www.encephalitis.info/events

Can you help us to fund research into encephalitis?

With no statutory funding, Encephalitis International relies on the generous support of a number of philanthropic organisations and the encephalitis community - everyday people like you committed to helping our drive forward research into encephalitis to improve recognition, diagnosis and treatment globally.

Could you help by:

- Making a donation
- Taking part in a challenge event
- Seeing if your company offers support for charities
- Seeking support or an introduction to a charitable trust or foundation you know



How your donation could make a difference...

£25 helps fund Advances in Encephalitis Research Summary – our go-to guide for professionals working in encephalitis.

£50 contributes towards funding a research day for our seed funding projects.

£150 funds a place for early career researcher or physician at our international Encephalitis Conference.

Get in touch today e: fundraising@encephalitis.info

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