

Guidelines for recovery

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The long-term prognosis for people affected by encephalitis varies considerably. In some instances, people come through the illness with little or no consequences. In others, people have different degrees of life-long difficulties. Some of those people are discharged in rehabilitation units. Some are discharged at home having been referred to community-based services. Others are discharged at home with no follow-up plan or pending referrals.

How long does the recovery take?

Recovery from encephalitis may take time. Initial recovery may be rapid but usually falls short of complete. Further recovery takes place more slowly over a period of months, even years. People are different. No two cases of encephalitis will have an identical outcome and people recover at different paces.

It is not uncommon for problems to present more at home as you try to get back to normal life. Some of these features may be subtle when in hospital and maybe ignored or not noticed at that time by family and/or professionals. The danger is that these problems may be misattributed to factors such as 'stress' rather than the complicated effects associated with the brain injury.

Encephalitis can affect the whole family. Coming to terms with the problems left can be very distressing and challenging for everyone concerned. The person you knew, or who was you, may have changed and the person they have become, or you have become, may present with a number of problems. The impact of encephalitis will be different for each individual depending on the part of the brain affected by encephalitis, their personality, their emotional and physical health state prior to their illness, and their social support network (family and friends).

Resting and pacing

Recovery can be helped by a structured timetable where short period activities (physical and mental) are followed by rest. Initially rest periods should be long and activity periods short. As the recovery takes place, activities can become longer and breaks become shorter. Keep a diary to help you monitor your activities, rest periods and your symptoms/feelings. It can also help you understand your journey through encephalitis and explain it to medical professionals if needed.

Further information produced by the Encephalitis Society- [Managing fatigue after encephalitis](#) - is available on our website (www.encephalitis.info) or from our support service (support@encephalitis.info).

Good nutrition

A healthy diet is beneficial for your recovery after encephalitis. Your emotional state, cognitive skills and behaviour can be influenced by what you eat. Also, after a brain injury, the calories intake may increase and it is important to eat food rich in nutrients. Drink plenty of water and avoid alcohol, sugar, saturated fat products, salty food and too much caffeine. Deficiencies in the intake of some nutrients can impact brain functioning. Vitamins (A, B, B1, B6, B12,

E, acid folic) and minerals (iron, magnesium, selenium, zinc) that are important are found in products such as vegetables, fruits, grains, lean meats, poultry, fish, beans and pulses and dairy products.

Reliable information and referral to adequate services

In the UK, 80% of the general public do not know what encephalitis is. It is important that the person affected and their family/carers know about this condition and its possible consequences and understand the impact it has on their lives. Reliable information about the condition to share with others can be requested from the Encephalitis Society.

Specific details about the person's difficulties and what can be done to meet their needs can be obtained from professionals as a result of various assessments (e.g. neuropsychological, neuropsychiatric, speech and language, occupational therapy, social care needs). The GP or the neurologist can make referrals to these professionals.

Further information developed by the Encephalitis Society - '[Guide to acquired brain injury and encephalitis for general practitioners](#)' can be very useful. Request a hardcopy from our office (details below) and take it to your local GP.

Connect with people

Social interaction can help manage stress and feelings of depression. It may also stimulate brain development. It is important for people to re-connect with their previous social roles. If friendship patterns change after encephalitis, it is important to consider new avenues for social involvement. When the time is right, there may be local groups to join and opportunities to do voluntary work. Group memberships, e.g. a sports team, choir, or book club, act as sources of both practical and emotional support. Becoming a volunteer for the Encephalitis Society is a useful way to go back to social life, connect with others and learn new skills (www.encephalitis.info/volunteer).

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 stories of other people who have experienced encephalitis is also often useful. Other people's stories can provide hope that there is life after encephalitis, by providing tips about different ways of coping and finding meaning in the experience. Some people prefer not to read stories. There is always a risk that the story may not be what people expect or that people may experience negative feelings about their own recovery after reading that story. Therefore, it is important to consider whether the time to read other stories is right. Stories may be of benefit at a later stage in your recovery than in the immediate aftermath of experiencing encephalitis.

You may want to connect with other people affected through our Connection Scheme, Team Encephalitis Support Volunteers or take part in our events and activities (www.encephalitis.info/how-we-help).

The future

The Encephalitis Society is aware of some amazing stories of recovery. Some people discover new skills and interests and feel that this life changing event has been of actual benefit to them. As one of our members said "time has been a great healer in my recovery". However, if you are struggling, support from family and friends, referral to professionals and making sure that you have all the financial/social help you are entitled to might make all the difference.

Our [Neuro-legal Handbook](#) (www.encephalitis.info/legal-advice) may help you understand and deal with some of the legal and social issues.

For detailed information on effects and recovery after encephalitis, please refer to our booklet

Encephalitis: after-effects, recovery and rehabilitation

(www.encephalitis.info/encephalitisafter-effects-recovery-and-rehabilitation).

People's experience

We asked our social media friends for a piece of advice to someone who is just starting their recovery from encephalitis. This is what they said. But remember, every person is different and so there is their illness and recovery. Get plenty of information and advice, but go with what works for you.

"Don't rush and take one day at a time"

"With recovery get help from a medical professional. Really understanding what was different about me eventually helped me reconcile and rebuild."

"Try to be patient and kind to yourself, don't expect too much too soon. Take all the help you are offered. Sleep as much as your body tells you it needs to and try to accept your new normal, one day at a time. Recovery isn't always in a straight line, it can be backwards and forwards".

"Be patient, don't push yourself too hard too soon. Your brain needs time and rest to heal as best as it possibly can. If you suffer with memory loss keep a diary, set alarms on your phone and repetitiveness really helps to trigger the memory. Don't turn away help, support will mean the world to you. Most of all stay strong and determined".

"Get support from people that know what they are talking about, not many health professionals will come across encephalitis so don't assume they know what they are talking about. Never feel bad to question. Allow time and don't look too far ahead as everyone's journey is different."

"Never give up"

"Take your time ... Don't rush trying to recover for everyone else - Get well at your own pace"

"Keep believing things will get better. You may be different than pre encephalitis, you can still have a great life"

"Appreciate that life will be different, that you will probably have changed from the person you were and that recovery is a marathon not a sprint. Take advice from the Society and if you can, from others who've had the illness."

"You're not alone, there's a big family waiting to say 'hello'. Take your time and don't be afraid to ask, no matter how stupid it seems."

"Stay strong know matter what.....keep telling yourself "I don't give up ".

"Assume that for every two steps you take forward, you might still feel you are taking one step back. After a while you'll be taking 3 steps forward, then 4 ! ... But... still might find yourself taking one step back. It's totally normal for it to be this way. Just keep going."

"It takes time to recover so do not rush back to school or work. All involved need to make allowances for a short temper and occasional emotional outbursts as patients may be unable to help such behavior and need our support". Understand that some friends may not understand. People handle things differently."

"It's OK, to be frightened, you WILL find yourself, but it may take time."

"Acceptance of your condition is key."

Your brain's view

The paragraphs below taken from 'A Letter From Your Brain' by Stephanie St. Claire printed on the Brain Injury Association of Carolina website may help you understand what happens with your brain after encephalitis.

"As time passes and you and I feel better and better, people, even doctors, will tell you that we are fine, "it's time to get on with life." That sounds good to me and probably even better to you. But before you go rushing back out into that big wide world, I need you to listen to me, really listen. Don't shut me out. When I'm getting into trouble I'll need your help more than I ever have before.

I know that you want to believe that we are going to be the same. I'll do my best to make that happen. The problem is that too many people in our situation get impatient and try to rush the healing process; or when their brains can't fully recover they deny it and, instead of adapting, they force their brains to function in ways they are no longer able too. Some people even push their brains until they seize, and worse... I'm scared. I'm afraid that you will do that to me.

Please don't be embarrassed or feel guilt, or shame, because of me. We are okay. We have made it this far. If you work with me we can make it even further. I can't say how far. I won't make any false promises. I can only promise you this, that I will do my best.

What I need you to do is this: because neither of us knows how badly I've been hurt (things are still a little foggy for me), or how much I will recover, or how quickly, please go s-l-o-w-l-y when you start back trying to resume your life. If I give you a headache, or make you sick to your stomach, or make you unusually irritable, or confused, or disoriented, or afraid, or make you feel that you are overdoing it; I'm trying to get your attention in the only way I can. Stop and listen to me.

Love, your wounded brain"

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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 the word DOCTOR to 70085 to donate £5.

Thank you!

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The Encephalitis Society is the operating name of the Encephalitis Support Group.

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