Guidelines for recovery

By Dr Ava Easton, Encephalitis Society

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 being referred to community services. Others are discharged at home with no follow-up plan or waiting 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 manifest more at home as you try to get back to normal life. Some of these features may be subtle when in hospital and indeed not really elaborated on or explored. 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 is a family affair. 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 brain systems affected by encephalitis, their personality, their emotional state and health prior to their illness, and their social support network (family and friends).

**Helping your recovery at home**

**Pacing**
Recovery can be helped by a structured timetable where activities (physical and mental) are interrupted by periods of rest. Initially rest periods should be long and activity periods short. As the recovery takes place, activities can become longer and breaks become shorter.
**Good nutrition**

Nutrients that are especially important are antioxidants (found in fresh fruit and vegetables) and omega 3’s (found in fatty fish or flax seed oil).

**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 consequences and understand the impact it has on their lives. Reliable information about the condition 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. The Encephalitis Society has produced a ‘Guide to acquired brain injury and encephalitis for general practitioners.’ Request a copy from our office and take it to your local GP.

**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. 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, church choir, or book club, act as sources of both practical and emotional support.

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 as a consequence. 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.

Connect with other people affected through our Connection Scheme, Team Encephalitis Support Volunteers or 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. However, if you are struggling, support from family and friends and making sure that you have all the financial help you are entitled to might make all the difference.

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"
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.

FS003V3 Guidelines for recovery
Date created: April 1998; Last updated: January 2017; Review date: January 2020

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Registered Charity Number: 1087843 Charitable Company registered in England and Wales Number: 4189027