



Guidelines for recovery

With improvements in drug therapy and intensive care treatments, many more people are surviving encephalitis. The long-term effects of encephalitis are, as yet, poorly understood but can include muscle weakness, epilepsy and speech disorders, difficulties with memory, learning, concentration and understanding.

Coming Round - the patients view

Many of the symptoms you have been experiencing in the acute stage of your illness, especially the life threatening ones, are due to inflammation (swelling) in your brain. Once this inflammation settles down the problems caused by this begin to resolve and you start to regain normal consciousness and movement. This moment can be a source of conflict between yourself and your friends and family. They have been through a very traumatic experience and may have been prepared to lose you, so their feelings are of relief and joy that you have survived. You may remember nothing of the illness, may in fact not even feel ill and be confused even angry at finding yourself in hospital. You may be finding that your brain doesn't work as well as it used to.

PEOPLE WHO HAVE BEEN ILL WITH ENCEPHALITIS NEEDS TIME AND SPACE TO COME TO TERMS WITH THEIR ILLNESS AND ITS CONSEQUENCES.

Early Recovery - advice for friends and family

Recovery is aided by a structured timetable of graded mental activity followed by rest; followed by graded physical activity followed by rest. Initially rest periods should be long and activity periods short. Hospital visits should be kept short, and visitors should not overwhelm the affected person with information. Trying to recognise more than one person at a time may be taxing. Visitors should not bombard the person with questions and especially should not ask the affected person to make guesses. People who have been ill with encephalitis often suffer from memory problems and research has shown that if they are asked to make a guess and give the wrong answer they will remember that incorrect answer. They often become easily upset and have difficulty controlling their emotions, friends and family need to be aware of this and avoid causing undue stress.

RECOVERY IS AIDED BY A STRUCTURED TIMETABLE OF GRADED MENTAL ACTIVITY FOLLOWED BY REST; FOLLOWED BY GRADED PHYSICAL ACTIVITY FOLLOWED BY REST.

Good nutrition is important for brain repair. Nutrients that are especially important are antioxidants (found in fresh fruit and vegetables) and omega 3's (found in fatty fish).

Your Future

Be prepared for a long period of convalescence. Initial recovery may be rapid but usually falls short of complete. Further recovery takes place more slowly over a period of months even years.

Be prepared for some loss of brain function. Liken this to the loss of a finger or hand from an accident. The only difference is that you (and others) cannot see it. It is a "hidden" disability. Talking to others with the same problems can help and the Encephalitis Society can put you in touch with other people who are experiencing the same difficulties.

Your brain's view

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 to. 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

(This is an abstract from "A Letter From Your Brain" by Stephanie St. Claire printed on the "Brain Injury Ass. of Carolina" web site)

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