

Social consequences of encephalitis

By Alina Ellerington, Encephalitis International and reviewed by Prav Prathapan,
Encephalitis International

Following encephalitis, adults often experience changes in their thinking, behaviour and feelings. These changes may make it difficult to take part in everyday activities such as work, driving, running a household or making plans with friends or family.

Inability to drive

Driving involves many more complex skills than simply the mechanical ability to drive a vehicle. Concentration difficulties, memory problems, difficulties in learning, a slowed response to situations and emotional problems are all common after encephalitis and may affect the ability to drive. In some cases, more obvious physical or visual impairments or seizures may pose significant difficulties for those who want to return to driving.

Inability/difficulty to return to work

Following encephalitis some people find they can return to their occupation with little or no adjustment. However, for others, returning to work is a major challenge and sometimes impossible. It can be hampered by many things, such as memory problems, tiredness, mood swings, behavioural constraints, reduced organisational skills, finances, personal or family worries and stress, prejudices of potential employers etc.

Financial difficulties

Being in hospital, caring for or visiting somebody in hospital, not being able to go back to work and insurance problems may impact on people's finances. This can add to the stress brought up already by the illness and its consequences.

Altered family relationships

All families are different, but no matter how well a family is functioning, there may be major challenges ahead. Initially there is relief that a loved one has survived the illness but the person themselves may have little or no recollection of the illness. This can bring up a conflict of feelings with relief and joy on one side, and confusion, even anger, on the other, as the person affected finds that they are less able to function as they once did.

When encephalitis affects a family, their coping strategies will be tested. Spouses may feel isolated and trapped as roles are reversed and relationships put under strain. Children may also experience emotional problems and sometimes their needs can be overlooked. Extended family and friends often want to help but don't know how to offer that help. Accepting the situation and the help available is not always easy.

Not all families have good relationships and sometimes the sudden impact of encephalitis can add to already strained relationships. Typically, families will go through a process of coming to terms with the consequences of the illness then finding ways of coping.

Altered friendships

Finally, one of the most significant and difficult consequences of encephalitis is social isolation from friends. Much like with altered family relationships, there may be an initial relief followed by potential conflict. In some cases, friendships may fade. There may be a stigma associated with being misunderstood by people who expected a full

'recovery' or awkwardness due to behavioural changes that were not previously there. There may again be a process of coming to terms, as with altered family relationships.

Potential benefits

It is important to keep in mind that there are opportunities with encephalitis such as volunteering and meeting other people who have been affected in support groups.

Connecting with others can help ease feelings of isolation and even give you a sense of purpose within the encephalitis community. Our online peer support groups offer a welcoming space where you can share your story and ask questions of your peers; which may help you and others navigate the consequences of encephalitis.

Volunteering opportunities include supporting others; raising awareness; and reviewing information resources such as factsheets which provide a much-needed personal perspective on encephalitis and how it can impact individuals.

If you would like to find out more about connecting with others or volunteering, please email peersupport@encephalitis.info.

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Thank you!

Encephalitis International, 32 Castlegate, Malton, North Yorkshire, YO17 7DT, UK

Administration: +44 (0) 1653 692583 **Support:** +44 (0) 1653 699599

Email: mail@encephalitis.info **Website:** www.encephalitis.info

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