Depression after encephalitis

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1. What is depression?

Everyone 'feels low' sometimes, but depression is different to these 'normal' feelings of sadness. Someone becomes depressed if these bad feelings don't go away or become so bad that they stop them from doing everyday things like eating or taking care of themselves. People may experience:

- sadness a lot of the time
- exhaustion or restlessness
- not finding anything enjoyable
- problems with sleep
- losing appetite and weight
- reduced sex drive
- difficulties concentrating
- bad feelings about yourself or your future
- thoughts of self-harm or suicide

It is important to note people can get depressed without experiencing strong feelings of sadness.

Depression can last several months. Most people get better, but it is common for depression to recur. Therefore, it is important to get medical help if you think you or someone you know is depressed.

2. Why does depression occur after encephalitis?

Depression is very common even without encephalitis—one in five people will get depressed at some point in their lives. After encephalitis, feelings of grief and despair often occur as part of a normal reaction to the loss of previous lifestyle and relationships. This type of mood change should ease over time as people adjust to their new circumstances. However, sometimes they do not ease. Or sometimes people can feel depressed a long time after they have survived encephalitis.

The likelihood of becoming depressed are increased after encephalitis. This is because:

- encephalitis can injure the brain making it more vulnerable to depression,
- encephalitis can cause disabilities that can be difficult to adjust to and/or
- encephalitis can cause other problems, for example losing your job, and that can make it difficult to cope and affects how someone views themselves.

In most cases, more than one or even all of these factors will be relevant to the development of depression in somebody's post-encephalitis journey. It can be difficult to separate out the direct effects of encephalitis from depression. For example, encephalitis can cause problems with thinking, changes in the ability to initiate activities, difficulty with reasoning, memory problems and fatigue. Many of these changes are like those that occur in depression. It can be quite hard to tease out what changes are due to cognitive changes, and what are due to emotional factors. It can be important to get this right because if the symptoms being experienced are more a result of the cognitive after-effects of encephalitis, the normal treatment approach for depression (which includes medication or talking therapies) might not be the best approach at this time. It could be, in this case, that advice on the cognitive effects of a brain injury and how to deal with these is a more effective intervention. Often people who are felt to be depressed are offered treatment (for instance medication or counselling) when in fact advice on the brain injury and how to deal with the problems it causes might be a more effective intervention.

At the same time, emotional difficulties can sometimes be mistaken for cognitive problems due to brain injury. Sometimes, a more marked depression begins to occur as the injured person’s insight and awareness of the new situation grows. This might result from a realisation that life might never be the same as it was before. The depressed person may often be unable or unwilling to talk about their feelings or seek outside help. It is important to try to get to the bottom of this, if necessary, with the help of professional advice, because depression may impact upon a person’s rehabilitation or return to their former lifestyle. Depression can be treated with medication, ‘talking therapy’, or a combination of these methods.

3. Counselling and talking therapies

There are various therapies available from self-help to more intense forms. The type of therapy depends on the consequences of encephalitis people are left with as well as what symptoms of depression they have. Counselling can help because it lets people talk about their feelings to someone who is trained to listen and respond. Many GPs have their own counsellor or can access some locally.

Self-help books and computer programmes can help milder forms of depression. One of the most common and effective of these is based on a type of talking therapy called Cognitive Behaviour Therapy (CBT). This helps people change the way they think (cognitive) and the things they do (behaviour) so that they feel better. It focuses on how you feel now rather than delving into your past. Other forms of self-help are gym groups, yoga, and meditation.

4. Antidepressants

There are many different types of antidepressants, but the most commonly used are called SSRIs (Selective Serotonin Reuptake Inhibitors) like sertraline (brand name: Lustral). They are popular because for most people they have fewer side-effects than the other antidepressants. We will concentrate on SSRIs in this factsheet, but your doctor can advise you on others. All antidepressants work by changing the activity of certain chemicals in the brain, but the exact way that this leads to an improvement in mood is not completely understood yet. They work for moderate to severe depression, but there is not so much evidence to suggest they work for milder forms of depression. There is very little evidence looking at the effectiveness of antidepressants in people who have had encephalitis and so the information here is mainly taken from studies of the effects of antidepressants in the general population.

Taking antidepressants

Antidepressants may take up to two weeks to start working and 4-6 weeks before they have a significant impact on mood. The Royal College of Psychiatrists estimates that 50-65% of people taking antidepressants will be see an improvement compared to 25-30% of people taking a 'dummy' pill (the placebo effect is very important in depression, just like in physical types of pain). The experience of taking antidepressants is different for different people. For some, the effect on their mood can be very noticeable. For others, they may notice an improvement in their motivation or get up and go, which might then allow them to do the kind of things that they used to do, which made them happy. And this might eventually lead to an improvement in mood. For some, sleep and appetite might improve, which might have positive knock-on effects. In general, the positive effects are cumulative over weeks and months, and although many people notice effects within a few days, things continue to improve in subtle or not-so-subtle ways over weeks.

Because there is a high risk of depression coming back, it is recommended that people continue taking antidepressants for six months *after getting better.* This reduces the risk of recurrence. If someone has had two episodes of depression, then treatment should be continued for at least two years.

Common side-effects and other considerations

Most side-effects are mild and not everyone gets them, but they are more common in the first two weeks. it is possible that the antidepressants may not have a really significant effect on your mood in the first two weeks, so it is tempting to stop taking them; but it is important to persevere because after two weeks these side-effects usually settle as your body gets used to the medication. The most common side-effects are nausea, anxiety and headaches. Sometimes, people can get painful indigestion, but this can be settled by taking the tablets with food. An important side-effect to consider is reduced sex drive or impotence. If this happens, talk to your doctor as they can help.

More serious side-effects include difficulties urinating, memory problems, falls and confusion. These are more common in the elderly and should always be discussed with your doctor. In people younger than 18 years there is some evidence that SSRIs increase suicidal thoughts (but not acts of self-harm) so antidepressants should only be prescribed after discussion with a specialist (a child and adolescent psychiatrist). There is no evidence that SSRIs increase suicidal thoughts in adults, but they are sometimes used in deliberate overdoses so should be monitored well if someone is at increased risk of suicide. SSRIs shouldn’t stop someone driving or operating machinery.

Many different medications are available. If you develop side effects on one medication that don't go away with time or that you're not prepared to deal with, then alternatives are always available. There is considerable evidence that even if one medication does not agree with you, you may have a very significant positive response to another. It is definitely not the case that if you have an adverse effect when taking one antidepressant, you will inevitably have this with all of them.

Are the drugs addictive – will I get dependent on them?

None of the antidepressants used these days are addictive in the sense that alcohol and cigarettes are. People don’t crave them after they’re stopped; but up to a third of people who take SSRIs can develop withdrawal symptoms if they are stopped suddenly. These symptoms last two weeks to two months and include: flu-like symptoms, stomach upset, anxiety, vivid dreams and sensations like electric shocks through the body. These are usually mild but if you are considering stopping the medication it is best to talk to your doctor to stop them gradually.

Talking therapy or antidepressants?

In mild depression, talking therapies are generally considered the first-line treatment, and antidepressants may not be offered routinely unless the patient has a preference to take them. Most studies suggest that talking therapies are as effective as antidepressants for mild depression, and some research even suggests a reduced risk of relapse after therapy when compared to medication. In moderate-severe depression, talking therapies and antidepressants are thought to be as effective as each other, but antidepressants work quicker. An important point that is often missed is that talking therapies can sometimes cause side-effects like anxiety, but these tend to be milder and less common than with

antidepressants. Some forms of talking therapies can be as effective as antidepressants for preventing depression coming back.

5. How to help yourself

- Talk to someone about how you feel.
- Try to keep active; even gentle exercise like a walk can help.
- Some people find a regular mindfulness meditation practice can help. There are a number of good quality apps available that offer structured courses (e.g. Headspace) and have evidence supporting their use in the treatment of mild depression. Ask your doctor to recommend you such an app.
- Good nutrition is also important: too much or too little food can profoundly affect mood. A balanced diet has been shown to be associated with a reduced risk of a variety of mental health problems.
- Avoid alcohol as it may make depression worse, and also interacts with many drugs.
- Set goals that you can achieve in a short time. Break large tasks into small ones, set some priorities and do what you can as and when you can. When setting goals, start small and go for a quick win. Then use the achieved goal as evidence of the progress being made.
- Refrain from assuming too much responsibility for the time being.
- Try to avoid giving bad thoughts too much attention, even if they occur frequently. Depression often manufactures bad thoughts, whether or not something bad is actually going on.
- Join a local social group such as coffee mornings.
- Contact the Encephalitis International Team Volunteer or be part of Encephalitis International's Connection Scheme, which can put you in touch with other people with similar experiences (please see Encephalitis International's contact details at the end of this factsheet).
- Keep hopeful. Most people get better, and you will probably be stronger for having got through it.

6. If you are a carer

Acknowledge the uniqueness of the person's loss, and help them identify their own strengths and assets, no matter how small. Listen to them attentively. Validate how they are feeling while at the same time offering support and encouragement for their future. This can be done by listing concerns on paper and setting goals to overcome them. It is also important to focus on the positive aspects of the recovery and keeping a diary and reflecting back on the progress made, which on a day-to-day basis may be virtually unnoticeable. Be aware of the strain that taking care of someone who is depressed can produce, and take care of your own reactions and feelings.

Suicide

Coming to terms with a depressive illness on top of encephalitis is not easy. If you suspect someone may be considering suicide, give them the opportunity to talk and encourage them to tell you about their fears. Don't be afraid to mention the word suicide in asking how they are feeling. This is not likely to put the thought into their head, but on the contrary they may be extremely relieved to hear that you understand the severity of their depression. Listen closely and show that you are listening by summarising key points and feelings. Validate how they are feeling. Also, clearly state the options for help that are available to the person with depression. Treat thoughts or talk of suicide very seriously, and quickly seek professional help via the GP or, if you have immediate concerns, going with the person to A+E or calling emergency services.

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