



Frequently Asked Questions



Is the medicine that my child is taking responsible for their low mood, challenging behaviour or worries?

It is important to discuss this with your child's epilepsy nurse/team. Some epilepsy medicines might have an effect on mood and behaviour, especially when the medicine, or the dosage, is changed.

It does not matter what the cause of the challenging behaviour or low mood is, we still have the strategies to help. In the same way, it does not matter whether your headache was caused by a noisy room or because you banged your head, Paracetamol works just as well.

If epilepsy and mental health difficulties are related, how will it get better? Will anything make a difference?

Epilepsy and mental health problems have different treatments, which can be used at the same time. Mental health problems can get better, even if the epilepsy doesn't.

My child's epilepsy is just one of many problems e.g. ADHD, Autism, learning difficulties, physical disability, a genetic condition. Will this programme still work?

Yes! Most children who have used this programme have many additional difficulties. Research has shown that these strategies work for children with many problems. Your therapist will work with you to make sure the programme suits your child's individual needs.

My child's seizures are better but behaviour and emotions are troublesome. I thought the seizures were the cause of problems?

Children with epilepsy have a brain that is programmed differently to that of other children's and it is these differences that may cause the behavioural and emotional problems as well as the seizures. Brain scans have shown that psychological treatment can change brain structure and function.

How common are mental health problems and epilepsy?

Mental health problems in young people with epilepsy are very common. Research has shown that the rates of common mental health problems (e.g. anxiety, depression, behavioural problems) in young people with epilepsy range from 55% to 77%. It is also common for these young people to have more than one of these problems.

Is it my fault my child acts like this?

No, it is not your fault, but you can become part of the solution.

No one really knows why children with epilepsy are more likely to have emotional or behavioural difficulties. There are probably lots of different reasons and the reasons will be different for every child. We do know that children with brain disorders, like epilepsy, are more likely to have emotional or behavioural difficulties than children who have other types of illness, like diabetes. Sometimes this is due to their brain being programmed differently. What we do know is what can help with the difficulties once they are happening. Sometimes this may involve working with parents or carers.

My child does not have a good relationship with his peers at school and is being bullied. What should I do?

It can be helpful for the parents and clinical team to liaise with the school and explain what epilepsy is to the staff and children. Epilepsy Action can help with this.

How can I get my child's school to understand what we are doing in the treatment?

Feel free to give the handouts to the school and the school can contact the research team if they have any queries (gos-tr.mice@nhs.net)

How do I manage typical teenage behaviour with epilepsy?

All teenagers can have some difficult behaviour when they are learning to be more independent and it can be very difficult to determine what behaviour is typical for a teenager and what might be a problem. When a teenager also has epilepsy, this can be even more difficult. Teenagers learn to drive, to go out alone, stay out late or drink alcohol. Some young people with epilepsy may not be able to do some of the things their friends are doing and this can be understandably challenging. Your epilepsy nurse may be able to discuss safety and epilepsy with you and your child.

Where can I find help when my child exhibits dangerous behaviour?

Many children and young people with epilepsy can exhibit challenging behaviours and sometimes this may include violence. Let your therapist know if this is happening – they can help you to find strategies to reduce it and will prioritise the safety of your child and others. If you are concerned that anyone is at immediate risk, then contact the emergency services (999 or A&E)

If I think my child is self-harming or has suicidal thoughts, is it okay to talk about it?

Yes it is and it is important that you bring it to the attention of your GP and the other health professionals you meet with, as soon as possible.

If I address and manage the behaviour of my child will this trigger a seizure?

Addressing the behaviour will not trigger seizures (for example, you can ignore a temper tantrum).

How do I not get confused and overwhelmed with all the information I am given?

In the first sessions with us, you should have decided on some goals for treatment together with your therapist. You probably chose up to three. This might not seem like many. The reason we only work on three at once is that it can be confusing and overwhelming to consider more than this at any one time. We will give you lots of information during the sessions, but it is important to let your therapist know if it is too much and you need to slow down. Parents of children with epilepsy may also receive lots of information about the epilepsy, treatments and related problems such as learning needs. Please do talk to your neurologist, paediatrician, or epilepsy nurse if you are confused by any of this information.

Where can parents receive help?

It can be very stressful and exhausting to have a child with epilepsy. It is important to let your GP know if you have any concerns about your own mental health. Talking to other parents that are in a similar situation has been shown to be helpful for some people. The roadmap provided to you as part of this treatment programme contains a link with more information about support groups in your area.

My child's epilepsy is having an impact on the family, what should I do?

Having a child with epilepsy can be very difficult for everyone in the family. Other families have found that working through the strategies in this treatment has had a positive impact on the rest of the family.