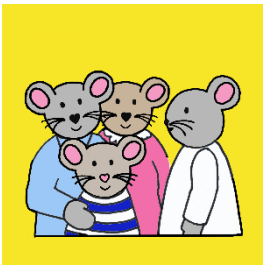
MICE Protocol

Epilepsy Specific Module for Youth

Use This:
Immediately after assessment to establish a relationship, provide psychoeducation about mental health problems and epilepsy and confirm goals.



Goals

- To empower the young person and their family to address their mental health difficulties within the context of epilepsy
- To establish rapport with the young person/parent and enlist support in the treatment process
- The young person/parent will be informed of the focus of the intervention and be provided with resources to address other difficulties

Materials

- ***Roadmap of Resources*** *(p. 300)*
- ***Frequently Asked Questions (FAQs)*** *(p. 302)*
- Completed ***Understanding What's Going On*** handout (if not completed in assessment) *(p. 268)*
- ***Weekly questionnaires*** and ***Monitoring sheet (blank and example)*** *(see pages 277-293)*
- ***Therapist Note Taking Sheet*** *(p. 276)*

> ***If time is tight:*** *Ensure parents/young people know that emotional and behavioural problems in epilepsy are very common. We may not know what caused them, but it doesn't matter – we do know what works to treat them. We will be working as a team to find out what strategies work best for their family with their specific circumstances.*

Main steps	
☐ **Set an Agenda**	Remember to start by setting an agenda together and by reviewing any practice assignments.
☐ **Brief introduction**	Start the session by letting parents and/or the young person know that in this session you will be discussing the link between epilepsy and mental health and that this session provides the foundation for sessions and strategies that follow.
☐ **Obtain Weekly Ratings**	Obtain the ***Weekly questionnaires*** from the young person/parent via email prior to the session. If no goals have been set, set them in accordance with goal setting in the assessment session. Review the ***Weekly questionnaires*** in detail and answer any questions the parent/young person has.

☐	**Reminder of Treatment Overview**	An overview of treatment should have been provided at assessment but check that the young person/parent recall what was said and the structure of sessions in terms of confidentiality, setting an agenda, ending with a summary, working between each session and using measures. Working together as a partnership, focus on goals and what they want to be different at the end of treatment, flexibility etc.
☐	**Share *Understanding What's Going On* handout**	If you didn't have time in the assessment session, share the completed ***Understanding What's Going On parent*** handout with the parent/young person.
☐	**Epilepsy is not just a medical condition**	When some people are told they have/their child has epilepsy, they think it will just be a matter of taking some medication and it will be controlled. That is true for some but for others it is different. Epilepsy is associated with a very wide range of different conditions. Some of these are associated with other problems such as intellectual disabilities. Problems such as autism spectrum disorders can also be common. Many families want to be told what to expect up-front but that is tricky as it depends so much on the individual. Discuss that it can sometimes be difficult for parents to accept their child has such difficulties and is different from their peers. Sometimes parents have unrealistic expectations of their child, for example given intellectual disabilities. Helping parents gain such acceptance and adjust expectations can be addressed throughout treatment if necessary (e.g., within problem solving, effective instructions). Tell the family that one of the things that we will email them is a ***Roadmap of Resources*** and ***FAQs*** that they can refer to in the future. If there are any questions arising from the Roadmap or FAQs, they will be discussed at the next session. Remember to put this on the agenda for the next session.
☐	**Get an overview of the week from the parent and/or child**	Invite the young person/parent to discuss their week in terms of the child's mental health (anxiety, depression, behaviour, trauma) and seizure activity. You may want to refer to the weekly ratings. Show great interest in what is being said and write down what is being said in terms of the relationship between epilepsy and mental health to use later to personally illustrate the relationship between seizures and mental health.

☐	**Connection between epilepsy and mental health; treatment success**	Thank the young person/parents/child for the ideas. Families will have many different ideas about factors that affect mental health in the context of epilepsy including biological factors, coping with seizures, lack of sleep, frustrations at any intellectual disabilities. Emphasise there is a higher rate of mental health problems in people with neurological conditions but *the techniques that help with emotional and behavioural problems in children without epilepsy should work just as well in young people with epilepsy –there is no reason to suppose they won't, regardless of the cause. For example, aspirin works just as well if you have a headache because of a noisy room or because you banged your head on a cupboard.*
☐	**Describe Emotional Problems and Relationship to Epilepsy**	Discuss how common emotional problems include anxiety, depression, low self-esteem and a lack of confidence. *(NB: Discuss behavioural problems before emotional problems if it is clear this is the primary difficulty).* These can be caused by multiple factors including: • Fear of the seizures and of your body being 'out of control' during a seizure • Being dependent on adults for care when peers are becoming increasing independent • Fear of being hospitalised • Coping with medication and possible side-effects • Lack of understanding from friends and even teasing or bullying • Feeling 'different' from others. Discuss how young people show emotional distress by mood swings, irritability and temper outbursts, especially if young or developmentally delayed. **Example script (for parent)** *Imagine you are turned around several times on the spot so you are dizzy and that feeling of dizziness returns at random moments during the day. It might be when you are on the phone to us now, it might be when you are out and about. How does it make you feel just knowing that the horrible feeling might return at any time?* OR *Can you think of an example from [your child] of anxiety or worry or low mood relating to epilepsy?* **Example script (for child)** *Can you think of an example from your own experience of anxiety or worry or low mood relating to your epilepsy?*

☐	**Describe Behavioural Problems and Relationship to Epilepsy**	Discuss how common behavioural problems are in young people with epilepsy and that this could be for many reasons, some of which you have covered previously but include: • That the area of the brain that controls emotions and behaviours may be affected by epileptic activity • Some antiepileptic drugs may alter the chemical balance in the brain that regulates behaviour • Sometimes there may be changes in behaviour, personality and mood for minutes or days before the seizures • Being stressed and anxious about having seizures • Maybe the young person is not achieving in school • Frustration if the young person has learning or language problems It is hard to separate out the young person from his/her behaviour but it is important to do so as the variability and unpredictability of behaviour can cloud a parent's view of the young person him/herself and cloud a person's view of him/herself too. **Example script (for parent)** *Imagine that you have a hangover. How does that influence your behaviour? Do you find yourself more generally irritable because of how you feel? Are you snappy? And what impact does that have on people around you?* OR *Can you think of an example from your own experience of how you/your child's behaviour is affected?*

☐	**'You are not your epilepsy'**	Treatment often focuses on the negative but it is important not to forget the positive characteristics of the young person. Work with the parent to identify as many positive characteristics of the child as possible and make sure to refer back to these throughout the treatment. **Example script (for parent)** *As we go through treatment, we often focus on the negative but it is worth spending a few minutes on your child's (your) positive characteristics. What do you like about your child?* OR *What do other people say they like about you/your child?* Respond with enthusiasm and emphasise how fantastic these qualities are. If no positive characteristics are generated, then prompt with: Are you/they honest? Are you/they funny? Do you/they show any kindness? At times it can be hard for parents to accept their child's differences and there may be a mismatch between their expectations and the child's abilities. If this appears to be the case, you may want to use some of the strategies within parental mental health such as suggesting that they obtain support from local epilepsy organisations.
☐	**Introduce 'Monitoring'**	It is essential to spend time in this session discussing 'Monitoring' and ensuring that parents are aware of its key role within treatment. Explain to the parent that Monitoring is the first strategy in their 'toolbox'. Monitoring helps people to take a step back, reflect on situations and recognise patterns. Explain to the parent that they should try to spend 10-15 minutes on monitoring each week. Explain that it is an important tool that will be used throughout treatment to aid discussion in the sessions and measure change.

☐	**ASSIGNMENT** **Review *Monitoring Sheet***	Confirm previously established goals and based on them and the content of the session, ask the young person/families to monitor relevant variables. Refer to the ***Monitoring Sheet (example)*** as a guide. For example, if the young person feels anxious when in groups of people and doesn't know what to say, the monitoring record should have columns for (1) Date/time (2) Situation (3) Anxiety Level (4) Thoughts (5) Seizure activity (6) Comments. If the young person has behavioural problems, then the record should have columns for (1) Date/time (2) Situation (3) Behaviour (4) Reaction to Behaviour (5) Seizure activity (6) Comments. Send the monitoring sheet that is most relevant to the patient and feel free to personalise it/amend the columns if there is something important that is not included. **Example script** *We have spoken about some of the things that influence you/your child's emotions and behaviour, and their relationship to the epilepsy. It's one thing to chat about it over the phone but it's also good to get an idea of how it works for you in the real world, facing real challenges in real time. It would therefore be good if you would fill out a sheet as things happens between this week and next so we get a better idea of what is going on. If you can send that back to us with your questionnaires the day before the next session, we will have a chance to go through it and understand how things have been for you. Do you anticipate any problems with doing this?* Anticipate challenges with monitoring, emphasise it doesn't need to be re-written or typed; it can be done on voicemail if necessary.
☐	**Send the materials for the next session**	Tell the young person/parent you will send a written summary, FAQS, Roadmap of Resources and the materials for the next session**.** Remind them that the materials <u>do not</u> need to be completed for the next session as you will go through them together in the session. Tell the parent/s you will also send the ***Weekly questionnaires*** and ***Monitoring sheet*** which need to be completed for the next session. Confirm date and time of the next call.
☐	**Summarising**	Ask the young person/parent if they would like to summarise the session, if they would like you to summarise the session or if they would prefer you to do it together.

Leave 'Em Laughing

End the session on a positive note with the young person/parent by perhaps talking about things that are unrelated to emotional/behavioural problems, or discussing an area of

interest you have in common. Also, the young person/parent might be feeling overwhelmed by the challenging tasks he or she is undertaking; it can sometimes be helpful to leave a few minutes at the end of the session for the young person/parent to share concerns or the challenges faced since the previous session that have not already been addressed. The end of each session should be used to praise the young person/parent's efforts and to convey support and encouragement.

Helpful Tips

- In the summary, explain that you spent this session talking about factors that influence emotional and behavioural problems in young people with epilepsy and that you will be working together to make things go more smoothly. Use this time to answer any questions that the young person or parent might have, and to indicate that you will be checking in with him or her each week after meeting with his or her parent or vice versa.
- It is important to balance your emphasis on problems by also highlighting the strengths of the child and family. Talking at length about child and family problems can be difficult or embarrassing; the young person/parent needs to know that you recognise and appreciate his or her positive qualities and those of the child and family.
- In some cases, the person in the parental role may not be the child's biological parent. The caregiver may be an adoptive or foster parent, or a kinship care provider. Whoever the caregiver is, it is important to identify his or her own strengths and challenges in the parenting role.
- A significant risk in this session is that the tone can become too didactic, with the therapist "teaching the parent about the factors that influence mental health and epilepsy." Try to avoid this risk. Before even mentioning the factors, you will seek the *parent's or young person's* ideas about what causes are responsible for the emotional and behavioural problems experienced. Throughout the remainder of the session, you will seek to connect the *parent's or young person's* ideas to all of the concepts you introduce. The tone of the session should convey that the parent or child is the true expert on their child or themselves, that you respect the parent's or young person's ideas, and that you are seeking to learn about the child and family from the parent or young person.

How's Your Style?

- Did you praise often?
- Did you review often, by asking questions?
- Did you simplify the steps as needed?
- Did your pace match that of the child or family?
- Did you stay on track?