In My Experience…

We asked some of our service-users about their experience of NEAD and the specialist NEAD service.

Thank you to our service-users for contributing and helping us to develop this website.

Informed consent has been provided for the accounts below to be shared on this website. Names have been changed and all identifying details have been removed to protect anonymity.

Philip's experience

What does a NEAD episode feel like?

A NEAD episode feels like you are 'tripping' without taking nothing. I am in another world short term, and I feel confused, dazed, disorientated and its scary. My head and brain feels like a tin of broken biscuits. I am different and feel weird. Luckily these episodes don't last long, but they happen 'out of the blue', when you least expect it!

Understanding of my environment is lost, and my body changes with my eyes spinning and poor-coordination and my listening is affected. I feel stupid during these episodes and I wonder do people notice of think I am acting or faking it for attention?

What can people expect from the NEAD service?

Improvements but not 100% cure. I have learnt coping strategies in sessions to apply at home, and they have been therapeutic. I have learnt a lot about the condition, symptoms, causes and effects. I thought you cannot have epilepsy and not be on medication and felt I am a 'plastic-epileptic'. My psychologist has been a good listener, confidante and speaks on my level and does not use big words. Generally, the sessions have been educational, information and this service has helped me through quite a difficult time.

Without this service and help, I could have had a 'breakdown' and ended up in hospital or even worse. Luckily, I received this NEAD service at the right time and it has helped me.

What have you found helpful in managing NEAD?

I have found at home practicing tasks such as meditation, stress-tension release exercises and keeping occupied helpful. I have also gone out more to groups and day centre. I also see and visit my family regularly.

Keeping busy is essential, but not too hectic. I have slowed down and paced myself. The coping techniques learnt during the therapy sessions are healing and natural. They are better than medication. Talking about solutions more than problems is constructive.

Through all these learning tools and listening with self-awareness, I have become more confident and assertive. In managing NEAD, I control it more than it controls me now.

Do you have any words of encouragement, advice or support for other people who experience NEAD?

People who suffer with NEAD can improve and get better. Luckily it is not epilepsy. I dislike the ‘A’ in NEAD which stands for attack. When you explain to people they can think you are going to be violent. I tend to keep quiet about NEAD as it is misinterpreted and stigmatised. Really, having NEAD is not all doom and gloom. When you have an episode, just say to yourself you are having a ‘time out break’. In receiving help, persist and don’t give up. Progress is not instant and healing occurs at different times. NEAD is not too serious an illness, but try to accept and not fight the condition. One day I may not have it. Also try not to focus too much on NEAD as it can trigger symptoms.