

Epilepsy12 Quality Improvement Case Studies 2023

University College Hospitals NHS Foundation Trust

We aimed to increase the availability of psychological support to young people with epilepsy and to deliver this care in an innovative way. We wanted to create a sustainable offer with maximum reach to young people with epilepsy, while reducing the number of referrals to departmental psychology. The psychological support provided needed to be enjoyable yet informative, to make sure that epilepsy does not get in the way of young people's personal and academic success.

Using charitable funds, we recruited a Band 8a Clinical Psychologist 0.2WTE to focus on psychological provision for paediatric young people's epilepsy. The psychologist consulted with the epilepsy team about common psychological difficulties experienced by young people with epilepsy, conducted a literature search and attended webinars about the needs of young people with epilepsy.

The psychological provision created and enacted included:

- Psychology presence at weekly MDT to provide consultation on cases.
- Monthly slots for new psychological assessments dedicated to young people with epilepsy referred to psychology.
- The introduction of two new psychology-based groups for young people with epilepsy: the Tree of Life, and Study Skills for Epilepsy.

Tree of Life

Tree of Life is a narrative therapy-based project aimed at younger secondary school young people to help them connect with their skills and abilities, activities, relationships and roots. This aimed to build confidence and strengthen alternative stories of their life that do not foreground epilepsy. The group provided a forum for talking about the challenges of being a young person with epilepsy and a collective exploration of responses to those challenges.

The experience was enhanced by involving an older young person with diabetes and epilepsy who had been through a similar program as part of her diabetes care. Involving an older patient in the group gave some of the participants more confidence to speak out and become involved. It also supported the 'helper' who developed leadership skills, adding to her confidence.

Study Skills for Epilepsy

Study skills for epilepsy addressed common cognitive difficulties experienced by young people with epilepsy including memory, attention, processing speed and organisation. The group explained and normalised cognitive difficulties and provided practical tips for improving performance at school and information about the role of stress and tips for managing stress. A pamphlet version of the

study skills workshop was created to be available for all young people with epilepsy at UCLH.

Outcomes

So far, we have found that young people with epilepsy who ask for referral to psychology are now seen more quickly and by a psychologist with more epilepsy specific expertise. Initial feedback from the team and patients has been positive.

Challenges

It took some time for the psychologist to get to know the team and the patients, before formulating the project plan. However, much has been achieved in less than a year.

The study skills group was delivered online, which made it difficult to see how engaged the young people when they would choose to keep their cameras off.

Recruiting young people to groups was challenging due to last minute apologies. We tried to organise groups during school holidays to avoid the young people missing school, however this clashed with travel abroad or conflicting commitments for some families. Using the epilepsy team, who know patients well, to help recruit participants in a more systematic way could increase uptake. Increasing the notice period may also help.

Next Steps

With only short-term funding available for the psychologist provision, we will attempt to secure further charitable funds to extend the project and run groups of primary school and older secondary school pupils. We could broaden the offer to neighbouring paediatric epilepsy services to create larger more vibrant groups.

A formal evaluation will be completed towards the end of the project.