

Connect and Transition

Young Epilepsy

Support Worker updates – January 2018

Story One

I have been working with a young woman who has had issues around not receiving the correct benefits for some time. She has frequent nocturnal seizures which make her feel exhausted during the day, and as a result has struggled to keep a job – in fact she has been fired due to this from eight different jobs.

I helped her apply for PIP (Personal Independence Payment) which she was given but at a very low rate – the young person felt this was due to no one taking her seriously or appreciating just how debilitating her epilepsy was.

We went through the appeal process for PIP which took over a year in all. I accompanied the young person at court to support her at the appeal hearing and the judge granted the appeal and awarded her the higher rates for both living and mobility needs.

The young person felt that at last someone was listening to her and believed appreciated that living with epilepsy was very difficult. The whole process was very hard and at times quite humiliating for the young person but with our support she was able to continue having the quality of life she deserves.

The young person thanked the transition service and sent the manager the following email:

“Hope all is well. Janine has probably told you but I won my appeal :)! I really couldn't have done it without you & Janine. Thank you soo much not just for Friday but for ALL the support you guys have given me since you started working with me, I really appreciate it and would not be where I am today without you guys”

Story Two

One of the more positive outcomes I have had recently has been supporting a young male into employment. He signed up for college in September but has since quit the course due to increasing anxiety about his seizures and fear of these being witnessed by his peers. He was in a very dark place and felt that he was destined to remain unemployed and with no qualifications because of his epilepsy diagnosis. We spoke about Equal Opportunities and I explained that it is illegal to refuse to employ someone because of a medical condition apart from with a select few employers.

We had a look through job listings and narrowed down some jobs that he would like to do. I supported him through the application process and once he got called to interview, we did some mock interviews where I watched his confidence grow. He

was able to explain the possible impact that his Epilepsy may have on his work, how he himself could manage the risks and how his potential employers could support him too.

He has since been offered a job, which he accepted and is doing really well. He is growing in confidence each day and is talking about returning to Education next September.

Story Three

Over the last few weeks I've been busy working with a number of families across London. One of the most important aspects of the work we do is giving one-to-one emotional support, advice, and mentoring, to young people with epilepsy. Whether at home, in school, or in the community.

To give you some idea, over the last few weeks I've been working with a young man who has struggled to get out of his house. He is attending a local college in his area and even though he is over sixteen, He relies on his mum and dad to give him lifts everywhere, as they fear the risk of him having a seizure on public transport. This means that outside of education, he doesn't really leave the house. This has led to him feeling isolated. He feels unable to take part in normal teenage activities.

Fortunately, things are looking up for him. After a change in medication he has been seizure free for two months. In this time, I've been meeting with him an hour a week. We generally talk about how he is feeling and to I try to help him find solutions to any problems that he faces. In our sessions it's been great to see this young man's confidence return and for him to start thinking once more about his future. Last week, when I dropped around for our regular session, he wasn't there. It turns out he was late, as he had gone out to get something from the shops for his Mum. Independently! This was amazing to see. It's one of the privileges of this kind of work when you can see progress like that. Overcoming his fear will always be this young man's personal triumph. Even so, I hope that by showing him that there are people who care and by encouraging him to reflect on his strengths rather than weaknesses, our sessions have played a role in helping him to restore his lost confidence.

Story Four

On Saturday 20th, I hosted a support group for families affected by epilepsy. Three families attended, with the idea of meeting other families affected by epilepsy. The families came for a cup of tea, while the children played, to talk through their worries. There were three Mums and three Dads, three children with epilepsy and one sibling, I noticed how the Dads chatted together about their worries. One of the Mums commented that her husband had never spoken to anyone else about epilepsy before and was surprised how open he had been. Another Mum called the next week to say her son said it was one of his best days ever, because other people understand epilepsy

Story Five

I have been supporting a young woman of 16 who was diagnosed last summer. She has had the odd seizure since she was little, however these were so few and far between that her mum only witnessed one or two and when she did go to her GP she was told it couldn't possibly be epilepsy as her daughter hadn't wet herself. So it was left and the young person initially seemed fine. Then last summer whilst on holiday in America, the young person suddenly began having a series of seizures which left her hospitalised. It was at this point she was put on Keppra and sent back to the UK. When she arrived back she made an appointment to see a consultant. He only agreed to see her once and said that because she was almost 16 she would have to go to adult services. She was sent up to Kings for an EEG then sent home, without any further referral. They told the young person that her mum would need to increase her medication but wasn't given a plan or guidance to do so.

I began working with them and talking through everything, answering questions and discussing school, where the young person was really struggling. It is her GCSE year so this is the biggest worry for her.

I managed to secure extra time, with breaks for her with the school and a room for her to complete her exams in instead of being in the hall with everyone else (her seizures are tonic clonics and would be difficult to manage in a hall setting).

The young person continued to have issues with her seizures increasing in frequency, and every time she was hospitalised the consultant increased her medication. This continued for a number of weeks with her seizures increasing each time. I'd advised mum to chart everything and record a seizure if possible and the chart appeared to show an increase in seizures each time the Keppra was increased. I advised mum she must go back to her GP and must get a consultant involved to look at the information she'd gathered. Mum felt she had been let down by the consultant that refused to take her daughter on as a patient and by the NHS as a whole. I advised her of the patient liaison service in the hospital and that if she felt that strongly she was entitled to make a complaint as she had been left with no help or guidance on what to do with her daughter's medication. She was contacted the day after she made a complaint with an appointment to see her new consultant, moved onto different medication and given a referral to Kings Hospital for a 48 hour EEG.

I couldn't be happier with the outcomes and I also put the young person in touch with a parent fairly local to her whose daughter is the same age. Because of this help the family have contacted our fundraising department and are keen to raise funds – they have even got a family friend to donate from their fun run!