

Testimonial Tuesday

19th November 2024

#TestimonialTuesday
#moliantmawrth
#pawbyngallu

This week's testimonial comes from a parent who's child joined us this year. Thank you for sharing your story. If you have a story to share please get in touch.

Our lives changed on Christmas Eve 2019, where most children were getting excited over the pending arrival of Santa, our son Joshua was rapidly deteriorating with what turned out to be encephalitis. Josh spent 16 days in hospital where he was pretty much in a coma with epileptic seizures. The hospital was fabulous and managed to get our son back albeit with a legacy of daily and nightly seizures

uncontrolled by medication. Josh was referred to Great Ormand Steet hospital where he

was diagnosed with Lennox Gastuat Syndrome, a complex epilepsy condition which also coincides with global delay and learning difficulties. It is a lifelong condition, and Joshua will need continued support and care throughout his life and caring for a child with LGS can bring up lots of challenges. Also after a 4 year wait on the Neuro Developmental pathway Joshua has recently been diagnosed with Autism & ADHD, as you can imagine this makes him a very complex child with significant needs.

Up until September 2024, Josh was in mainstream and a school educational pathway .Initially in Stebonheath Primary , where after



his illness and he reached Year 5 and 6 it became apparent that Josh required extra help... Extra support and assessments were attempted, however he got lost in the system and unfortunately went on to transition to Coedcae Comprehensive School in Sept 2023.

This proved to be a disaster for both him and us. Josh struggled and could not cope with the mainstream curriculum and his peers. The school attempted to support him and even though Joshua had a one-to-one pupil support assistant, it became evident quickly this was not enough, and he was in the totally wrong educational environment for him.

Josh behaviour deteriorated to the point where he became a danger to himself and others. He was put on a reduced timetable as he could not attend full sessions at school. However, we were telephoned regularly to collect Joshua early from school as his behaviour escalated and school could not manage him, to a point he was hardly attending school at all.

As you can imagine subsequently had a toll on us as a family, both mentally and physically and both my wife and I subsequently had to take prolonged absence off work due to sickness as our health got worse with the stress of our situation and trying to navigate a way through it while trying to support our family /home life.

Things started to change for us when a comment was made by Joshua at school and social services became involved. While this was extremely upsetting and a horrible experience, the help we now receive is because of support from a social worker that we were assigned as an outcome of this incident.

Our social worker managed to organise all the outside services to look at and understand Josh, over the next six months, including an educational psychologist who confirmed that Joshua needed to be in a specialist educational setting. After an application to panel we managed to secure a place in Ysgol Heol Goffa for Joshua. Since starting Ysgol Heol Goffa, Josh has been in school all day every day, he still has episodes of anger and behavioural challenges and random seizures... however due to the skills and expertise of the staff, they are able to deal with him, allowing him to receive the education he fully deserves. The change we have seen in a short time is remarkable. We as parents accept and as his neurologists have explained, its about life skills for Josh.

Ysgol Heol Goffa and its amazing array of staff are able to provide this, we don't have these skills.. and I have seen with my own eyes the ability to de-escalate Josh is truly



amazing, mainstream or units attached to mainstream would not have the array of skills needed for these beautiful complex children.

As a side note, I do find society frustrating with its difficulties to accommodate neuro-diverse children. Society and education is totally setup for neurotypical, I would argue that most genius people in this world are neuro-diverse. Why can't we think differently and harness and develop our geniuses of the future, rather than potentially put them in a unit or a corner, simply because a copy and paste neurotypical curriculum does not work for them.

In conclusion Ysgol Heol Goffa, is not only a centre of excellence for children who need support, help and development but a lifeline for the families also. We have been able to return to work and, and while our lives will never be the same as they once were we are learning to manage and help and support our wonderful son...

We are so extremely grateful for the help from our social worker and the specialist skills of this amazing school.