

“My beautiful son Eligh was seven years old when he received his diagnosis –SATB2 Associated Syndrome.

Eligh was often described as “developmentally delayed”, “dyspraxic”, “autistic” before the diagnosis and in some ways he probably fits all of these descriptions as well. For many years I sat and wondered why Eligh was not progressing like other children. I continually wondered whether he would ever walk, ever speak, ever be able to do that puzzle? I had lots of questions and for a very long time there were no answers.

We had spent many years and many appointments meeting with specialists to get a diagnosis and it was both a happy and sad day when we received the results. Once you know it makes planning the future a little easier. Once you know it takes away that last little bit of hope that everything is going to one day be ok.

Eligh is non verbal and has difficulty with communication. He uses an AAC device for communication and I still remember the first time I heard “I love you” resonating from the machine. It brought tears to my eyes. Eligh uses his device, which is a modified Tablet PC, everyday and loves to ask for “ice-cream” with it. He likes to tell me about the “sun” and he loves to ask to go “walk” (at the) “park”. We work on communication everyday.

Eligh is a happy, sweet natured and loving child and is most happy when he is playing with his trains. He loves being around people and does his best to join in with his peers at school. Generally he will stand close to the group and watch on as they play. He does however have a lot of complex behaviours that are challenging to manage.

He often drops to the floor like a dead weight if he doesn't want to do something. He doesn't mind where he is when he does this and it can happen at home, at the park or half way across a busy street. I haven't yet found a strategy that works with Eligh to get him to his feet other than to physically haul him up. Soon he will be too heavy for me to lift.

Our daily life is quite isolated as it's difficult to go out and do the usual activities that most parents take for granted. There is no weekend breakfast at the local café as Eligh cannot sit in one spot for more than a few minutes. We don't play sport because Eligh's co-ordination and ability to process movement is very limited. We don't go to movies, or plays, or markets, or out to dinner, or the circus or the shopping mall because Eligh's concentration is also poor and he gets restless quickly.

We do however spend endless hours on Occupational therapy and Speech therapy and Learning development and Communication. We have more therapists, support workers and medical professionals in our lives than we do family members. To be honest - life is tough!

There are however great joys as well that all parents experience with their children. Eligh does walk – we met that milestone even though it was late! Eligh does love to run around the Zoo for hours & who doesn't like to see the animals! Eligh does love to hug you and offer up his face for kiss. Eligh has a wonderful sense of humor and he makes me laugh all of the time. He's such a great kid!

I am realistic about Eligh's future and I know we have many challenges ahead of us. The most important thing for us is to take each day as it comes and make the very best of the things we can do, rather than worry about the things we cannot."

*Eligh's mum*