



## How Our Lives Changed Forever ...

We are a family of four, Sharon, Mike, Regan (12) and Luke (10). On November 30<sup>th</sup> 2002 our lives changed forever; Luke was diagnosed with Autism Spectrum Disorder. He was 2 years and 2 months old.

After the initial shock, we started receiving help from the Vera Hayward Centre, which is the Child Development Service at Dunedin Public Hospital. Through the Centre we received weekly speech language therapy and occupational therapy, for one hour each a week. We also attended a music therapy class run at the Centre. Luke was non-verbal. We had access to an Educational Support Worker, through Group Specialist Education (GSE) for 8 hours per week, to help him at kindergarten.

Through speech language therapy we were trying very hard to teach Luke how to use PECS – which is picture exchange communication. Luke struggled with the pictures used in this communication method but soon picked up what to do when we showed pictures of the actual item, such as a picture of Luke's drink bottle as opposed to a drawing of a bottle. To encourage Luke to use this system we rewarded him with chocolate chips (only one or two), as we needed a strong motivator for him to want to do this. Our home was decorated with pictures to help Luke with requesting; we had things stuck to our fridge and on the back of doors. Luke also had a communication folder which he could use to get a picture to bring to me so I knew what he wanted.

**“...we rewarded him with chocolate chips (only one or two)...”**

We had to be a bit clever and put all his favourite things out of sight or up high so Luke would be motivated to get a picture card, before he got the item he requested. He also had to attempt to make a sound to get what he wanted.

Luke turned 5. He was off to school. What a terrifying experience this turned out to be. Along with any parent's worries about their child starting school, we had a lot more going on in our heads. How will Luke communicate? He is still in nappies; who will change him? Will he be safe? How will he learn? We had already completed an ORR's (Ongoing Renewable Resourcing Scheme) application which came back at High Needs. He had teacher aide funding, so at least he was safe. Luke only attended school in the mornings, as he did not have funding for a teacher aide all day.

Six weeks after he started school we re-submitted an ORRS application, which came back as Very High Needs. Yay! He is finally getting the help he needs, which included speech language therapy. As a parent new to this system, now that Luke was at school, I thought he would be getting speech language therapy, as he had in Early Intervention. How wrong I was. I could count on my hands how often Luke was seen by the speech language therapist.

Remember Luke was still non-verbal. This was breaking our hearts; this little boy, who



could not talk, was not getting the right support. I know that speech language therapists have big case loads but every parent wants the best for their child and a speech language therapist was what my son needed. We employed a private therapist for 1 hour per week; this costs us \$80 every time.

As a result of our needs assessment we were referred for an Assistive Technology assessment, which costs lots of money to have people flying around the country to see Luke in various settings at school and at home. Unfortunately for us, I felt this was a waste of time and money, as all they come up with was PECS (Picture Exchange Communication System) which we were using and a GO Talk, which you could programme the names of the objects into. Luke just used this as a toy, not as a communication device.

Luke has come a long way in the last five years, with a lot of people helping him on his way – for which we are truly grateful. There have been some boulders in the path we are travelling. Sometimes it feels like systems are just too hard and it seems like we are in a pot hole but we just carry on and take little steps over the boulders. We get there in the end.

Luke is now talking. He is a fantastic “Wiggles” singer and if one of them wants to retire Luke could take over; he knows every word to each of their songs. After 6 years I finally heard those words “love you Mum” which were worth all that we paid out for private SLT.

Sharon Bain  
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