

LUNCH FOR LANGUAGE – JO O’LEARY

Hi – my name is Jo O’Leary & my son, Miles, was a student at Glenleighden from the age of 4 until he was 8 – From 2002-2006.

Thank you to Bruce & Vicki for inviting me to speak today – initially I was reluctant – I am a chatty person but quite out of practice when it comes to speaking publicly – but as was pointed out to me – my child with a primary language disorder was happy to get up & speak so maybe I needed to suck it up & have a go.

I also accepted their invitation to speak today because I believe Miles’ story needs to be told. I read the recent Sunday Mail feature article about Glenleighden with so much empathy for those families & their young children and I remembered that when we started the Glenleighden journey it was the stories of hope that inspired our family.

I also feel a social responsibility to speak today because if my speaking can mean that one less person in the world tells a parent of a child with PLD that Einstein didn’t speak until he was 4 – then it will be all worth it.

Sorry about tissues – although story is one of joy & hope – as many can appreciate it is also a very emotional & personal story – chances of not crying are pretty minimal.

Miles story starts like the story of many other children – He was a very planned & wished for baby – I did all the right things – took my folic acid, made sure my rubella antibodies were fine etc –

Miles was a placid & quiet baby - He was my third child & I really thought I had finally cracked the code – don’t get me wrong – I loved my other two children as babies but PLACID or QUIET were definitely not how I would have described either of them!

When Miles was born our family was already operating at full throttle & he was also an incredibly portable baby. His sister was in Year 2 & his brother was at preschool so he spent most of his early life being lugged to school drop offs and the like. We lived in Charters Towers at the time & we frequently made the 270km round trip to Townsville & he was the perfect travelling baby.

He achieved all his gross motor milestones like crawling & walking a little later than his siblings but still within the range of normal - & with such a busy life I remember being pretty relieved that he wasn’t mobile at too early an age.

When it came to eating solids he was pretty fussy with different textures but as he was my third I wasn’t too stressed. In fact I use to marvel at what a clean eater he was & how he didn’t want to make a mess – little did I realise that this was not a good sign.

It was as Miles entered the toddler stage that we really began to notice a change in his personality & behaviour – he became very anxious in crowded places – As his father was a school principal in the town at the time & we had to attend so many public functions it became very stressful for the whole family. It soon became a question of not “whether” but “when” would Miles begin screaming uncontrollably. These weren’t your normal terrible two tantrums – these seemed more like screams of sheer terror – and in hindsight – that is exactly what they were. It was absolutely terrifying for Miles to be in these situations.

Around 2 – 21/2 we really began to notice that Miles’ language was not developing as it should. His sister was born talking – well just about - & his big brother’s speech was a little delayed but when Liam started talking, he started with sentences.

But for Miles, at a time when he should have been becoming more aware of the wonder of the world around him, he seemed to become quieter & more withdrawn in his own little world. Not only did he not really have any words but he had very little eye contact & could not follow simple instructions. It was only later when he came to Glenleighden that we were told that not only did he have no language but he had no understanding of the purpose of language.

Around his third birthday Miles started speech therapy at the local hospital in Charter Towers. Those speech therapy sessions were so stressful – Miles’ dad would take the afternoon off work to help me take him to the session because physically & emotionally it was not a one-parent job. Those of you who have pets probably know the panicked behaviour your dog or cat exhibits when you take the route in your car to the vet or the kennels. Just like your pets start howling when they sense it is THAT time, Miles would start screaming when we would be driving there. Remember this was a child who would happily travel in a car for hours but the 5 min drive on a Wednesday afternoon to speech therapy was a traumatic experience - & that was before the session had actually started. We would have to carry him kicking & screaming up the hospital stairs. It was absolutely heartbreaking & exhausting.

The speech therapist was wonderful with him but the experience for Miles, to make even one syllabic sound – was just way too traumatic.

My plan was to actually show you today some video footage of a recording we made of one of these speech therapy sessions. I thought it would be very powerful to give you all a snapshot of Miles “before” Glenleighden. I ran this idea by Miles & he agreed on the condition he watched the video first. When Miles watched it he found it so confronting & downright embarrassing and he asked me to seriously reconsider showing it.

It was a real “Wake up & smell the coffee Mum” moment for me– because it is so perfectly natural that a 13 year old boy would be so profoundly embarrassed to have his mum dig up the old home movies & show them here today – how great for a child like ours to have such a very typical teenage reaction. Therefore – there will be no showing of the video!!

As parents with children with PLD are aware, it isn’t just about the speech. Our children have a plethora of “quirks” which seem totally unrelated.

Miles had a big fear of the rain – which was a bit of a dilemma considering in spent his first four years living in North Qld. Not just being out in the rain but the mud & puddles left after the rain.

Haircuts were also a traumatic event for all involved – In a cruel twist of fate Miles was born with a mop of black hair that seemed to grow at a rate of knots. Consequently he needed haircuts from an early age – we tried every strategy but when it was actually the hairdresser that burst into tears because Miles was so upset we decided we needed a new approach, which involved haircuts at home. We bought some clippers & I would sit with Miles on my lap, give him a lollypop to distract him & his dad would wildly try to get in there, clipper his hair & get out with

a minimum amount of physical or emotional damage to all involved. It usually meant the whole three of us needed a shower afterwards – after we had finally consoled a screaming child.

Miles was also a contradiction in that in some ways he was so easy to manage– at bed times he never wanted a story, he had no fear of the dark & would sleep soundly all night. This was so very different to our other children who would want just one more story or who would often wake with scary dreams at the same age. Miles didn't ever seem to dream. I think it was almost a relief for him to go to bed at night – his bed was his sanctuary away from the challenges of his every day life.

He also had an incredibly high pain threshold & would fall over but never seemed to get upset or complain of pain. Once he even fell from the cubbyhouse & it was only after being held at the hospital for hours under observation for possible concussion that we all realised, doctor included, that he had actually broken his wrist.

He was also so independent. As a toddler he loved to play quietly alone in his room but his play was repetitive not imaginative. Whereas the other children would role play and have Barby interacting with the lego figures & Action Man, Miles would simply push his cars backwards & forwards or push his trolley around the yard. He had no interest in puzzles or books or blocks or art or craft but he loved television & he loved the computer & controlling his time was a constant battle.

Food was also a constant battle – the tastes, the textures, the touch – everything. The feel of a banana would make him dry reach. If he had had his way his diet would have consisted of dry white bread & white rice. I knew that toddlers became fussy about food but this was so much more than that. He became underweight & as one doctor so delicately put it –was a “failure to thrive child”.

This sensory & tactile hypersensitivity also related to his play (definitely would not touch playdough or goo or other stuff toddler loved) and ...to his toileting. It was not so difficult to toilet train Miles because the sensation of having a dirty nappy was so abhorrent to him but the problem became that using the toilet was also disgusting. It was the whole experience of doing No. 2s that traumatised him. He became so constipated & developed a little bloated belly to go with his skinny little frame. It got to the point that for all the planets to align so he could actually go - it had to be at our toilet at home & with all his clothes off. You can imagine the challenges this provided. Not long after we moved to Brisbane & had been house hunting for days we were at one home talking to the current tenants when we suddenly noticed Miles was missing – immediately I panicked –Eventually we found him up stairs, quietly sitting & using their toilet. It was a sign - **We bought the house** – if ever we needed a sign of good feng shui this was it & 9 years later it is still our much loved family home.

At 31/2 Miles was assessed at the Child Development Unit in Townsville. The assessment & observation revealed that he had a severe speech delay in the acquisition of speech sounds and a severe delay in the acquisition of receptive and expressive language skills. It was recommended that he continue speech therapy but we knew he needed so much more.

Luckily – soon after, we moved to Brisbane.

Unlike other families who have relocated their families from interstate & overseas to be near Glenleighden, our shift was more serendipitous. Miles' dad received a promotion to Brisbane & at our going away party one of the Learning Support Teachers in the town took me aside & told me about a school in Brisbane she thought we would be perfect for Miles. Suddenly I felt a glimmer of hope for my sad little boy. My husband was a little more sceptical because he had been in education for 20 years & feared that my hopes may be shattered – after all could a school really do so much.

When the removalist van arrived I let all my valuables be packed on the truck but I ensured that the information I had been given about this Shangri La of schools was safe inside my handbag & when we arrived in Brisbane – when we were cramped inside the apartment belonging to a friend of a friend's parents with no fixed address of our own – the first phone call I made was not to a real estate agent but to the Glenleighden school.

From the first phone call I received from the school – I felt so reassured.

The week that Miles turned 4, he attended an assessment week at Glenleighden. This was such an intense time. The observations of Miles by staff were that “although Miles had shown interest in all assessment activities his understanding of their purpose and of even basic situational language used to direct his attention was extremely poor. His communication with the examiner was limited to extreme squealing and unintelligible verbalisation”.

At the end of the week my husband, Michael, & I met with the team. That was such a sobering meeting. Miles had actually only achieved in the 0 to 1 percentile for almost all the testing – meaning that 99-100% of children at his age performed at a higher cognitive level. Based on those results Miles presented as a very intellectually impaired child..

We will never forget, though the words of Mansell Robinson, who was the founder & principal of the school at the time, when she told us at the meeting “that she believed that there was a very bright boy inside Miles & he only needed the blinds lifted on his mind”. Those words were to change the lives of our family forever. He was accepted into the school.

The implications for Miles' learning & I quote from his Diagnostic report were that “he presented with severely disordered cognitive development with overall intellectual status being at risk of serious delay because of markedly delayed and disordered language comprehension & expression”. His needs were so high in so many different areas. Yet the staff seemed to know exactly what he needed. They were so experienced in dealing with children just like Miles. They had the “X” factor. It was nothing short of miraculous. Glenleighden was the perfect one-stop-shop. Miles had that multi-disciplinary team working with him every day – communicating with each other – communicating with us & constantly updating his program. At what other school does a parent have the luxury of an Occupational Therapist teaching their child to dress themselves, wipe their bottom, tie their shoes, use a knife & fork plus do their handwriting. Or teach your children to not only eat but enjoy a variety of foods. Miles needed help in every area the school had to offer. Those very early days were hard yakka for Miles – they were so intense & required so much concentration & almost every day he would cry for the 45 mins

trip home – he was exhausted & incredibly anxious – but I noticed that he never cried on our journey to school each morning so I figured we were onto something big.

As a parent I always felt incredibly supported by the staff. I remember putting in Miles' communication diary one day that I had great concerns for Miles' lack of road safety & had no idea how to address it. If I wasn't holding his hand he would often just run out onto the road. That afternoon a staff member met me at the gate with Miles, gave him a 10 minute lesson on road safety in a way that he would understand & that was that...he got it & from then on had perfect road sense. This was just one of the many, many ways that they helped us with Miles' every day life.

After six months at Glenleighden we met with the team to go over Miles progress. It had been remarkable. In many areas Miles was now performing in the 35-40 percentile & over the next few years his progress accelerated. After 3 years at Glenleighden when Miles was 7, his Fine motor skills were in the 79 percentile, his visual perceptual skills in the 68 percentile & his visual memory & sequential memory skills were in the 94 percentile. Wow!! All that driving was so worth it!!

Glenleighden not only addressed Miles' needs but provided a support group for all our family. As a parent of a child with PLD you can feel very isolated – even if you have many friends. We have all sat through the dinner parties when parents are complaining of driving their kids to violin lessons & rocket science classes –well maybe not quite- & all we do is sit silently, throw back another glass of wine (when our first instinct is really to punch someone) & think all I want is our child to just look in the eye & say, well say anything.

But at Glenleighden, whenever I met up with other parents they instantly understood. We were united by empathy... plus sheer exhaustion. Because At Glenleighden it doesn't matter what car you park out the front of the school, what suburb you live in, what school your other children go to – you are instantly bonded by the special needs of your children & your family. At Glenleighden there is no competition between parents. Everyone gets excited by the achievements of the other children & there is no feeling of being judged. The triumphs of our children are a little left of centre....there is nothing like the announcement of your child eating a slice of tomato or them using the toilet at a friend's house to send all the mums at a coffee morning into a spontaneous round of applause. Socially you never have to apologise for your children's behaviour & for the first time in years social occasions can be social, not anxiety fests.

It is also very hard for siblings of children with PLD. At age 10 Miles' older brother began having very intense panic attacks every night before bed. A visit to a counsellor revealed Liam believed that when he married he would need to marry someone who loved his brother like he did because Miles would always be his responsibility. Liam also had a recurring nightmare that his brother was in danger & he couldn't rescue him. As Miles' progress took off at Glenleighden these anxieties became less & less & once again the support of the staff in dealing with this common problem plus social contact with the siblings of other Glenleighden children helped Miles' brother & sister normalise & cope with their situation.

After 4 years it was time for Miles to transition into mainstream school. Although this was always our dream it was also very, very scary. Glenleighden was such a safe haven, like our family, but staying in your comfort zone is not the Glenleighden

Way. But in true Glenleighden style we were so supported in every step of the transition. Staff visited our chosen school, liaised with the teachers. They even staggered his transition to ensure it was the right step.

So if I had to summarise what sort of school is Glenleighden – I would say it is the sort of school that when Miles' uncle, a confirmed bachelor, attended the open day at the school he bought an engagement ring for his girlfriend on the way home. Why? Because visiting Glenleighden made him believe that there was so much hope in the world. He is now happily married with two children of his own.

Glenleighden gave Miles & our family so many gifts – but the greatest gift, was not what he learned but rather that he developed the capacity to be a lifelong learner and once he had that capacity, that toolkit tailored specifically for his needs, that innate ability to communicate, to organise & plan & focus, he has been able to overcome all obstacles & achieve basically anything & everything. He is the epitome of achievement over adversity.

People have commented to Michael & I that all our sacrifices have been worth it – but, in hindsight, reorganising our lives so that Miles could attend Glenleighden was not a sacrifice – it was the best investment we ever made – not only for Miles but for our whole family & our future.

And so now, proudly, I am one of those pain in the butt annoying parents who bores everyone with stories of their over achieving child. Miles is now in Year 7 at Kedron State School & this year was elected school vice-captain. He plays violin in the school's strings ensemble, percussion in the concert band, learns piano & attends drama lessons. He is part of the local High School primary link extension music program & last term attended the Honours Music Camp. He plays interschool sport, represented his school at the district athletics carnival & at the regional cross country he ran the 3kms effortlessly on a wet & muddy track. He & his four best mates at school have their own band & his favourite foods are sushi, chicken satay & Vietnamese rolls & he reckons a banana ten mins before a race increases his stamina. When he had a haircut a couple of weeks ago the hairdresser asked him if he would like his hairwashed & a scalp massage & he said "Well why not!!"

He is mainstreamed in all subjects, receives no learning support, no longer meets the criteria for primary language disorder. He achieved a B for English & Japanese on his most recent school report. His teacher commented on that report, & I quote, that "Miles provides an excellent model of appropriate behaviour and demonstrates leadership. He has been well organised and exercised a self disciplined approach to his work. He is a reliable & cooperative worker who is self-motivated, dedicated & extremely organised. Miles always perseveres through challenging tasks."

Recently I told Miles he was a walking miracle. His response – I'm not a miracle, Mum, life is still hard every day but you just have to get on with it!!