

Jo's Story



Elizabeth Violet came into the world at about 4pm on the 5th of January 2001. She was our first baby and it had been an uneventful pregnancy so there had been no tests other than the routine ultrasounds.

When she was passed to me after birth I immediately noticed that she had the features of a person with Down Syndrome, but didn't say anything – I'd never really seen a baby so new and thought it may just be what a newborn looked like.

She was taken just after birth to be checked over and the Dr came to us about an hour after she was born to tell us that he thought she had Down Syndrome but it would have to be confirmed via testing. I remember commenting that I knew a bit about Down Syndrome – I'd grown up in a family where disabilities were not seen to be unusual or different and had volunteered on occasion to help kids with disabilities. The thing I remember most about what the Dr said was that first and foremost she was a baby who needed looking after. Our biggest problem in the first few weeks was having to wake her regularly to make sure she had enough feeds!

The day after she was born, we asked the nursing staff if we could get resources about Down Syndrome. We were told they couldn't give us any because her diagnosis hadn't been confirmed yet by testing and the Dr shouldn't have said anything yet. Fortunately one nurse did come to us later with the website of Down Syndrome NSW. She also had found out that there should be a folder of information at the hospital from DSNSW. For some reason, this was not at the hospital we were at. Eventually one was sourced from the neighbouring town and was brought to us the following week.

We told our immediate family about the Down Syndrome, but waited until it was verified to tell others. The Dr kindly rang my husband on the weekend following Elizabeth's birth to let us know that the Trisomy 21 test was positive. Fortunately we were well supported by family and the community at that time, we have rarely had any negativity about Elizabeth in our town.



In talking to someone from DSNSW, they had given us information that included starting Early Intervention as early as possible. In those days, Community Health managed this and a meeting was organised. It was another overwhelming situation where a room full of people came to the conclusion that at 6 weeks old, it was too early for Early Intervention. When I commented that it was what DSNSW recommended I was told it would only be for the parents benefit. Fortunately the OT did her own research and contacted DSNSW. This enabled her to help us out a bit. Over the next few years we had little access to therapies, mostly just assessments with young therapists who had little idea how to help a child with disabilities.

Over the early years, many people (including Dr's) commented that she was 'mild' or didn't have 'much' Down Syndrome. Each time I would try and explain that you either have it or don't. She babbled a lot when little, so it was assumed that she didn't need Speech Therapy or that it wasn't worth doing until a problem presented itself. Most of the early visits with therapists were only for assessments, she had little formal therapy until we started attending Royal Far West when she was in Year 1. This finished when she started high school and we've struggled again to find ongoing therapy.

Elizabeth is now 22 and we've had many challenges along the way. Persistent reflux resulted in her being diagnosed with Coeliac's Disease when she was about 10. Further problems when she was 15-16 have resulted in other diagnoses that in some cases require daily management – something that she has mostly learned to do herself. This period of time resulted in her losing her verbal skills for a time – she was convinced that she couldn't talk properly. **Fortunately it was one of the few times a Speech Therapist was available and after while she was back to expressing herself verbally as best she can.** The advice from DSNSW was invaluable to us as a family at this time as well.

Her schooling involved her mostly being mainstreamed in our local public schools as the closest special unit then was 40km away. Her school years had their ups & downs – not all teachers understood the best ways to help her. The resources of DSNSW were accessed by the schools at various times.

Despite all the challenges there is little we'd change. Elizabeth is mostly a happy young lady who brings joy to us and many people she comes in contact with. Thanks to the Zoom Up Club programs introduced during Covid lockdowns, she has been able to develop connections with others with Down Syndrome despite us living 7 hours drive from Sydney. Over the years even though it might not have been often, the contact I've had with DSNSW has been vital in helping us to understand and cope with the various situations that we have found ourselves in.

