# From Misdiagnosis to Understanding: Sharing our FASD story

As a mum of a kiddo with FASD, I have navigated the challenge of disclosing my story, getting an accurate diagnosis and advocating for the support my son needs.

During FASD Awareness Month, I want to keep sharing my story to help break the stigma, and support people on a similar path to finding the best care for their children.

My journey began with a series of concerns others might recognise. My son was born with a low birth weight. He had a weak suck reflex, making breastfeeding difficult.

As he grew, his developmental milestones seemed delayed. By two years old, it was clear he wasn’t meeting the typical speech and motor skills markers. He had behaviours different from those of his peers, such as difficulties with sleep and speech delays.

Despite these signs and being open about his prenatal alcohol exposure risk with health professionals, it took years to get a proper diagnosis.

When my son was first diagnosed, it was with autism. Even though I had disclosed his high-risk level of prenatal alcohol exposure, it was overlooked. This can happen because of the overlapping symptoms between FASD and other neurodevelopmental disorders. In some ways, FASD mimics autism—but it is fundamentally different.

Finding the right health professionals who understood this was so important. The wrong diagnosis had implications for my son’s care and development because the interventions designed for autism can be counterproductive for kids with FASD. He needed a different kind of support.

Things are getting better, though. A greater number of health professionals are becoming FASD-informed, and each of us who steps up and speaks out—including in our red shoes during September—is helping to create change.

What I want women reading this to know, if you suspect prenatal alcohol exposure, you are not alone. There is support out there. Raise it with your doctor and keep advocating for your kiddo.

But, even with that change, it is still important for any parent who suspects FASD to push for a comprehensive evaluation that includes prenatal alcohol exposure as a consideration.

The most selfless thing a mother can do if there is a risk—as hard as it might feel in the moment—is to go straight to a doctor and say, “My baby was prenatally exposed to alcohol."

Stigma can be a significant barrier to getting the proper support. Many mums are worried about judgement and hesitate to disclose alcohol exposure. Yet FASD is the largest spectrum of disability in Australia by a long way.

What I want everyone reading to know is that prenatal alcohol exposure is never, ever malicious. There are many reasons why women may consume alcohol during pregnancy - from being unaware of the risks, not knowing they are pregnant, or being physically dependent on alcohol.

Wherever alcohol is, FASD will follow. It simply is not talked about enough here in Australia due to stigma.

Thankfully, things are starting to change.

What I want women reading this to know, if you suspect prenatal alcohol exposure, you are not alone. There is support out there. Raise it with your doctor and keep advocating for your kiddo.

To all the parents and caregivers of kids with FASD or suspected FASD out there, I want you to know that you are not alone. With the right support and understanding, our children can thrive.

Raising a child with FASD involves being understanding and adapting to their unique needs. My son’s brain processes information differently. Tasks that can seem simple to others can be overwhelming for him.

https://youtu.be/kvwXDsR8SGo

One of the most valuable lessons I’ve learned is the importance of tailored interventions. What works for one neurodevelopmental disorder may not work for FASD, and what may work with one kid with FASD may not work with another.

But when you find the right support and connect with other families who have loved ones with FASD, you can begin developing practical strategies to help manage daily challenges—with the support of your new community.

Sensory tools like squishy balls and swings can be incredibly effective for my son. These tools help him regulate and provide relief for his brain and central nervous system.

Some kids with FASD can feel like they are the problem, but the actuality is they try so, so hard. In the FASD community, we used to emphasise that ‘won’t literally means can’t’. We now emphasise ‘won’t means can’t… yet’. This acknowledges the neuroplasticity and ongoing development that occurs throughout someone's life with FASD. The right love, care, and support make a world of difference to outcomes for people living with FASD.

My son's empathy is extraordinary. He has a real compassionate vein running through him. Despite his challenges, he shows an extraordinary ability to understand and care for others.

I have heard this vein of compassion and empathy in kiddos with FASD echoed all over the world from parents and caregivers.

Sharing my experiences is not just about raising awareness but also about creating a supportive community. By breaking the silence and reducing the stigma, we can help more families navigate the challenges of FASD with hope and resilience.

[**Awareness campaigns like Red Shoes Rock**](https://redshoesrock.org.au/) are so important to help break the stigma and spread the word about FASD. Please join us this September in putting on your red shoes and sparking a conversation—help us bring attention to this hidden disability.

Let’s go Red!

[LEARN MORE ABOUT RED SHOES ROCK](https://redshoesrock.org.au/)