



Susie is an Australian community member. She has von Willebrand disorder (VWD) type 1 and her son has VWD type 3

DISCLOSURE AND TELLING OTHERS – A PERSONAL STORY

Susie

*This is a transcript of Susie's presentation
at the 2017 Conference*

My nickname growing up was 'Susan Shut Up'. I even answered to it. I'm a talker, I talk with my hands. I love chatting, asking questions, sharing stories. But I want to tell you about when I couldn't talk. When as a person who speaks their mind and always seems to have something to say, I literally couldn't speak.

I work in a large office. It's not dangerous work. I don't have a risk of injury due to tools, danger, hazards. I don't need to wear protective equipment. But one day, I left the office in an ambulance. I fell down the stairs. I'd been walking down on my own, nothing in my hands, no distractions. As I fell, of course I thought I was only stumbling on one step and I'd right myself. But I didn't.

When I came to a stop I realised I couldn't move. I couldn't call out. I could barely even breathe.

Luckily the stairs were internal stairs in our wonderful open plan office – glass surrounds and plenty of visibility. And luckily that day, I wasn't wearing a skirt.

People came running to my aid – thankfully I wasn't stuck there on my own in pain with no way out. But the thing was, I couldn't speak. I could not explain what had happened. I couldn't explain what I was feeling. What was wrong or what I needed. I was literally speechless. I couldn't say I'm OK, I couldn't say I'm not OK.

So, to go back a bit, I have von Willebrand's type 1. I was diagnosed only after my baby was diagnosed with type 3 and the doctors were wondering how that happened. I'm

a classic case of plenty of symptoms but no diagnosis. I know now that I have a diagnosis, that I need check with my HTC in the event of injury. But when this happened I couldn't explain this to anyone.

I spent a while on the stairs with work colleagues who came to my aid. They acted quickly and really quite confidently, assigning roles as per our Emergency Response Guidelines. They attempted to glean from me some info and were calmly checking for injuries. I could not fault the way my peers helped to work through what had happened and what I might need. As the plans progressed and it became clear that I needed medical assistance, something important happened.

My manager was there on the stairs with me and she was able to take the extra step of calling the HTC to speak with the Haemophilia Treatment Nurse to report my injuries and work out a plan. This is when disclosure helped me. And not filling out a form, tick a box. This kind of disclosure I mean is how I went about telling her. This had been a conversation that wasn't held only once. It had been a series of chats, and was varied.

We'd talked about my son with type 3. She had supported me when I needed to take time out for appointments. When I'd needed to field calls from his teachers. We had talked in general terms about my diagnosis journey. And these conversations weren't intrusive. They were caring, based on the facts of my situation, my needs at the time and her level of responsibility for me as well as interest.

She was not only my manager but also the floor first aid officer so she had a vested interest in knowing what might be required of her in just such an event.

During these conversations, she had asked simple questions about my condition, the treatments and response plans that helped put it into context. She had never dealt with a bleeding disorder before so she was learning, busting her own myths and misconceptions. I never felt I was being judged or penalised for having a condition that might need additional requirements.

The practical things we talked about were the different types of von Willebrands. What the severities meant. What the treatment options were and why some things helped in certain situations and why others didn't. We have an active blood donation program at work and we talked about how crucial that is to my son for a normal life and when I've received product too. We talked about the advances in treatments, or the lack of them. We talked about DDAVP. We talked about how simple first aid 'stepped up a notch' is a way to approach understanding treatment. We talked about the realities of symptoms and, how they for the most part, are confidently managed and don't take over my life.

But we also talked about risks about what can go wrong and why appropriate care and trauma response is so crucial.

So what else was going on here? I had already learned that as a person with a bleeding disorder I needed to be my own best advocate, both for myself and as a parent of a person with a bleeding disorder. But crucially, sometimes you need to plan and have contingencies for others to advocate for you. By having these conversations with my manager I had thought we were talking about my world my needs. I hadn't realised that by doing this I was helping her in her world, her needs, when they intersected with mine. ■