

VWD down the generations

Fiona is in her early 50s and found out she had von Willebrand disease (VWD) when she was 6 years old. She comes from a family with a long history of VWD.

My dad's mother had 9 children, 8 of whom had VWD, including my dad, so it was talked about quite regularly in our household.



Fiona with her son and newborn grandson

GROWING UP

I grew up living normally. I played sport and my friends didn't know - and to think of it, I don't think the school ever knew. It was normal in our household to have nosebleeds, bruises, cuts, grazes. The only thing different was we had bandages on our bodies not Band-Aids®, we had ice packs on our joints or bruises and nosebleeds that bled for hours, not minutes.

If you asked the question, what was it like as a teenager as a girl with VWD in those days, I would've said it was a nightmare. No information, periods were a nightmare, but you thought they were normal, heavy bleeding with large clots and no one to ask. My mother didn't understand as she didn't have VWD and my sister was older than me and had moved out by the time I started my periods. It was a learn to cope type of thing. It is totally different now and so much information is available.

MANAGING TREATMENT

I don't have regular treatment, only on demand when I have a bleed. Being from a regional area, it took me two years to organise factor storage at the local hospital so that it is available when I need it.

Living with VWD can be a tiresome and arduous affair, especially when you see new doctors, dentists or any other medical professionals. You have to make sure you explain that you have VWD and make sure the medication they are giving you won't cause a bleed or extensive bruising. My Haemophilia Treatment Centre has helped me with this. For example, recently with one phone call from me about an upcoming dental procedure, they contacted my dentist and gave them the information required. I am so grateful to my HTC team for making it so easy to deal with.

My one bit of advice is to speak up: advocate for yourself and your children. Heavy periods are not normal, find out why. A lot has changed in the last 50 years. There is so much information around - you just need to ask.