Living with von Willebrand disease (VWD)

Perry's story

Perry spoke about his personal story of living with von Willebrand disease (VWD) at the 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders. This is an edited version of his presentation. You can watch Perry's full presentation on the Conference portal at https://haemophilia.delegateconnect.co.

My name is Perry. I have von Willebrand disease type 2a. I'm in my 70s, and I didn't get diagnosed until I was in my late 50s. I live with the disease and I would like to talk about that.

When I look back, there were a few hints that von Willebrand disease was in my family, because it's hereditary, as you know. I can remember that my mother had serious nosebleeds at different times. And, of course, she probably had other issues which would have indicated that she might have been a carrier.

I played sport at a high level for a long time, and I noticed I was bruising a lot more seriously than some of the other players that I played with. And that was another hint that I had something a bit different.

BEING DIAGNOSED

In my late 50s, I had a back operation, a laminectomy, and the surgeon mentioned to me after the procedure that he had a hard time stopping the bleeding. He suggested I should see my GP about whether there might be some issue with me.

I had never heard of von Willebrand disease. I knew a little bit about haemophilia, but nothing about von Willebrand disease. My GP did a number of blood tests, and then he sent me to a haematologist, who then did a lot of other tests on me, and I was eventually diagnosed with von Willebrand disease.

MANAGING SURGERY AND PROCEDURES

Initially I thought it was a condition where you can get something that'll fix it, and then you won't have to worry about it anymore. I didn't realise it was an ongoing condition, which I needed to be aware of – and also that I needed to take steps to make certain that I was protected when I had operations or other procedures.

After that point, I decided to make sure that in future I had the proper medical advice and support with

anything that involved bleeding or operations. I was very fortunate to get that at the Haemophilia Treatment Centre. Ever since, all my various procedures, including colonoscopies, a bleed from the bowel and an ankle fusion, have basically turned out quite well from a bleeding perspective.

It's not something that just will go away. I think that needs to be emphasised with people who are diagnosed with von Willebrand disease.

MANAGING BLEEDING

The things that I've learnt to do to live with VWD have been much varied.

Every once in a while, I'll get a nosebleed. Nosebleeds are very serious for me because it takes me a long time to get them to stop. I've had to learn various techniques, including using a paste made from tranexamic acid. I've had some nosebleeds for three days, and it is it is very depressing, as you can imagine. But it's because of von Willebrand disease and I have had to work through it.

I still bruise very seriously, and it bothers me, as I need to be very careful with the physiotherapists I see for treatment. Physiotherapists have to know about my condition and how I can be affected.

Probably one of the things that has really affected me is occasionally I'll bite the inside of my mouth, maybe through eating, and I find that I bleed from the resulting ulcer or sore and that's very, very difficult to stop. I think it must have something to do with the saliva in your mouth as it tends to break down any capacity for the inside of your mouth to clot and to stop the bleeding. I've been fortunate to have been given information about how to stop that bleeding but it does take time.

Another problem I experienced when I had a number of operations where I was losing blood, was that my iron levels would go down. I couldn't work out why I was getting so tired. I was able to get iron supplements and that has enabled me to keep up my strength.

CONTACTING FAMILY

When I was diagnosed, I also decided that I was going to get in touch with my relatives. Originally I came to Australia from America, but that was 50 years ago. I have two sisters and one brother. I let them know that I had von Willebrand disease and that they should all consider getting tested because it's inherited and they come from the same genes as me.

They did. And they all found that they don't have von Willebrand disease. I was the lucky person out of the four who got it.

I have 4 children and 13 grandchildren and they're all aware of the situation. Some have been tested and some will be tested. It may be passed down to them and it's good that they know sooner than later that if they carry or have VWD.

DEALING WITH VWD

My family understands this and certainly my wife is well aware of the various things that occur because of the disease. She deals with it by helping me deal with it.

It doesn't really affect your lifestyle. You just have to be aware of it and how to manage it, so that if certain things happen, you are able to deal with it. I like to walk in the bush and if I have a couple of falls or scrapes and am bleeding, we ensure that we get them bandaged straight away and that they are kept covered until they are able to heal themselves, because if they're open, they continue to bleed and that's not good for anyone.

My message to other people diagnosed with VWD is that they need to be referred to a Haemophilia Treatment Centre, and the Centre will look after them. They will need to go to hospitals that are capable of dealing with VWD, particularly for operations. You might have a favourite doctor, but it's important that they are capable of understanding what's involved in the treatment of people with von Willebrand disease.

You can't pick your parents and you can't pick your previous generations, but you learn to deal with von Willebrand disease. And I just hope that if future generations in my family do have VWD, they will be able to deal with it because of the knowledge that I have been able to pass onto them.