

YOUTH NEWS

Haemophilia – the spice of life



Willem spoke to HFA about working, exercising and being out and about in these days with new treatments.

My name's Willem. I am 20 years old and I have severe haemophilia A.

Tell us about you and your bleeding disorder

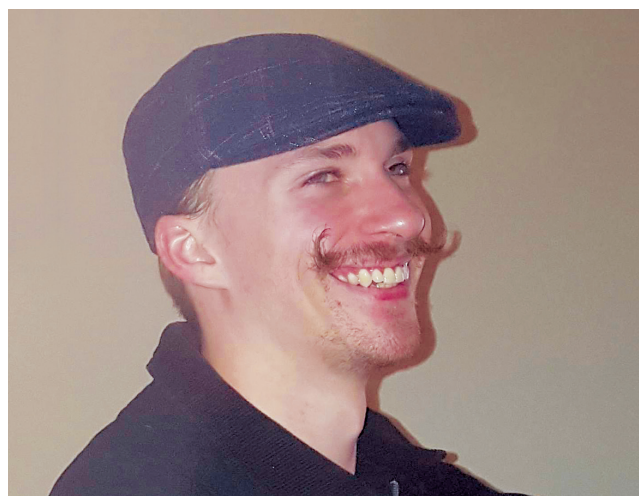
At the moment I'm working in headphones diagnostics and repairs. I test headphones with software for any issues or errors, clean them up and send them back to return to the customer. It's great – my own office and chair!

Over the years I have had a few different treatments. Currently I'm on emicizumab (Hemlibra[®]), which is more time-efficient for me. I only have to infuse once a week, rather than every second day with my previous treatment, and it's very useful to be able to wake up and get my infusion done in 5 minutes. I have very early shift starts at work and have to be in town by 7.30am, so to be able to do my treatment so quickly and get straight into town is amazing.

My new treatment is more consistent for me too. I have had no bleeds at all – no sensations of a bleed, no bruising that takes a while to go away. I think others have had some issues, but I haven't. With my earlier treatment, it would depend on the timing of the treatment and whether I was being physical and I would still have some spontaneous bleeds. But now I can go through the week confidently like anybody else and not think should I do this because of the worry about injuries or bleeds.

What else are you up to?

I really enjoy going to the gym and catching up with my mates there. These days I can go to the gym and be full on without having to worry about after-effects with bleeds. I love gym, but with my previous treatment, it used to be quite daunting for me. With any stress or pushing myself too hard, it always used to end up with a bleed, but now if I push myself, it's more about being careful of muscle strain.



I've been seeing more of the city lately and trying out some new things.



Willem's story

I've been getting around and seeing more of the city lately and trying out some new things. I hang out with my friends at the pub or see what else there is to do, maybe see a movie. At one stage I had an interest in axe throwing. I used to catch up with people after work to do it now and then. It was great fun – just a bigger version of darts and makes you feel more Viking and Nordic!

What have you learned about managing haemophilia to enjoy socializing and recreational activities?

With my current treatment, I just have to maintain my treatment as usual. When I was on my previous treatment, I learned to organise dates and times with my treatments, just to stay safe. If I had quite physical things like going into town or paintballing, I would aim to treat the same day or the day before. That meant I could get the maximum enjoyment out of the day instead of having repercussions pop up later.

It's good to let your friends and family know about your situation and make sure they understand it. And when they have an idea for an activity, to talk to them about how to plan it so you get to participate and there is a care for your wellbeing, for example, in case of emergencies.

When I think about it, haemophilia has really had an impact on who I am and how I deal with life. In my case, it has made me a more calm and collected person. I don't have an interest in violence and I don't react by being rough or angry. I think because growing up with haemophilia there are limitations with the physical, it makes you less likely to become physical. It's a good life lesson.

What would you like to do in the future?

I would really like to chase music. At the moment I am just working – making money and looking cool while I make money, hopefully! But music would be my next phase – a nice creative arts area that appeals to me. Not physically straining, something calm and collected like me.



I would really like to chase music.

I'm interested in all sorts of music. I've had a crack at classical, jazz, rock, blues, but I am definitely not a pop person. A little bit of Frank Sinatra, Robbie Williams, AC/DC – the spice of life.

My haemophilia hasn't really impacted on my career choices. In some of my earlier jobs, like when I was dealing with scalpel blades, my bleeding disorder gave me a bit of a worry. And it would impact if I was thinking about work that was intensely physical.

Read more

Check out the personal stories from other young people with bleeding disorders on:

- Factored In, the HFA youth website - www.factoredin.org.au
- The HFA YouTube channel - <https://tinyurl.com/HFAYoutube>

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