

# “I thought everybody bled like that”: a patient’s experience with von Willebrand disease

■ Cite as: *CMAJ* 2022 August 29;194:E1137. doi: 10.1503/cmaj.221102

See related article at [www.cmaj.ca/lookup/doi/10.1503/cmaj.220629](http://www.cmaj.ca/lookup/doi/10.1503/cmaj.220629)

As a kid, I had frequent nosebleeds and bruising. Sometimes, I’d have nosebleeds daily and need to apply pressure for 20–30 minutes. That’s what I was known for. As I got older, I’d get bruises on my legs or arms. I always had a bruise somewhere.

When I had my periods, there would be clotting and gushing. If I was sitting and went to stand, I worried I would leak

procedures, but I got no management advice. I only began to learn more after I was referred to a bleeding disorder clinic, like using tranexamic acid to help when I bleed. I’m better equipped now. I have someone to call, my medical alert bracelet, my FactorFirst wallet card<sup>1</sup> and my card from the bleeding disorder clinic that outlines my appropriate treatment plan.

you’re experiencing feels normal to you. We need more resources, like [heroixx.ca](http://heroixx.ca),<sup>3</sup> to learn about bleeding disorders. — Interviewee wished to remain anonymous

**As told to Andreas Laupacis MD MSc**  
Deputy editor, *CMAJ*

## References

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This article has not been peer reviewed.

Consent has been given for this perspective to be shared.

**Competing interests:** The interviewee has been involved in the website [www.heroixx.ca](http://www.heroixx.ca).

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## I got asked, “When was your last period?” but never, “What does your period look like? What is the amount?”

through my clothes. I’d be terrified sometimes because I wouldn’t know if what I had on would handle the transition to the bathroom. I recall once wearing a dress and leaking all over the floor. I missed work and school occasionally, but it’s not possible to miss days that frequently. Instead, I’d figure out what to wear, how to double up and where the nearest bathroom was.

I did not ask my doctor about my periods or about my bruising. I thought everybody bled like that. My normal was my normal.

I was diagnosed with “mild” von Willebrand disease (VWD) after a minor medical procedure when I hemorrhaged and had to be hospitalized for a week. I don’t think I would have called it “mild” when I constantly worried about gushing or when I had to be hospitalized.

I was told to inform medical practitioners about my diagnosis before any

Every time I’ve informed somebody of my VWD, I’ve heard, “It’s fine. That’ll be no big deal.” One time, I needed a polyp removed and asked my clinic if there was a recommended course of treatment. There was, but the gynecologist said I didn’t need it. I felt like there was a battle about whether this was necessary. The clinic was successful at ensuring I had the appropriate treatment, but I remember feeling very nervous going into surgery with someone who wasn’t happy. But I can tell you that it was the first time I’ve ever left a day surgery on time without bleeding issues.

It would be phenomenal if general practitioners had the Self-Bleeding Assessment Tool<sup>2</sup> to administer when they ask patients about bleeding. I got asked, “When was your last period?” but never, “What does your period look like? What is the amount?” For most menstruators, whatever bleeding