

# YOUTH NEWS

## What's it like to be the sibling of someone with a bleeding disorder? Angelina shares her story of the highs, the lows, and some tips for other siblings.

*I'm Angelina, I'm 16 years old and currently in Year 11... And I have two brothers with severe haemophilia.*

I always knew 'the boys' (my brothers) had haemophilia. Nikolas was four years old when he was diagnosed and then when Ryan was born, he was tested straight away. I remember seeing my brother with bruises and to our family, there was nothing abnormal about it. We would just say 'he's bruising again'. After Ryan was born, haemophilia was just part of our life.

### HAVING A BROTHER (OR TWO!) WITH HAEMOPHILIA MEANS...

Spending a lot of time in and out of hospital. I often had to stay with family members while my mum was with the boys looking after them and because of this, I think I grew up very quickly. I was always worried about whether the boys were OK and I was always explaining to the other kids at school why the boys were on crutches or in a wheelchair.

### I HAVE LEARNT...

I have learnt that my mum is super strong. She always puts the boys and their health first. As a kid I was so used to not getting any attention that sometimes I would even

pretend I was sick or hurt when I wasn't, so mum would give me some attention! I don't know how she handles us all!

### I WANT OTHER SIBLINGS TO KNOW THAT...

You are not alone - we all share the same experience. Like you, when I was growing up, I never got all the attention. My parents were often away looking after the boys. We missed out on planning family outings or had to cancel family holidays because the boys had a bleed, couldn't walk or weren't well. While it did (and still does) make me a bit upset, it's almost normal for us now. Although it can be disheartening and I can sometimes feel a bit selfish that we can't go on trips.

At times I have felt that I was left out and on my own, and no one else understood what I was going through. But I've been going to family camps since I was four years old and it has been great to meet other siblings. I have loved growing up with other kids. I recommend that everyone attend the family camps because you will meet people who have gone through and experienced the same thing as us, plus it's always a fun weekend!

Make sure you talk to people at the family camps, because they 'get it',

whereas people from school often don't 'get it'. At these family camps, I always feel supported and it's great to share stories with others like us. Now as a youth leader, I am able to help younger people going through the same thing I went through when I was a kid.

In 2020, mum was in hospital with Ryan and Nikolas was awarded the 2020 Haemophilia Foundation Victoria Camp Spirit Award. I saw him that weekend and he had grown so much. He stepped out of his comfort zone, and was kind, helpful and mature. We supported each other which was very touching. It made me realise how lucky I am to have them in my life.

### GOT QUESTIONS ABOUT BEING A SIBLING?

- Check out Jane Portnoy's article about siblings in this issue of *National Haemophilia*
- Visit the Siblings Australia website - [siblingsaustralia.org.au](http://siblingsaustralia.org.au). #

# MY BROTHERS HAVE HAEMOPHILIA

## WHAT'S YOUR STORY?

Do you have a story to share about being a sibling?

Or about living with a bleeding disorder?

We'd love to hear from you!

Go to Share Your Story on Factored In for more info - [www.factoredin.org.au/stories/share-your-story](http://www.factoredin.org.au/stories/share-your-story)



1. Angelina with the younger kids at camp
2. Nikolas at camp
3. Angelina and her brothers



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