

YOUTH NEWS

'An employer might be much more understanding and supportive if I am open from the beginning!'

Starting work a new job is a stressful time for anyone, but bleeding disorders can carry with them a few extra challenges. We spoke with one of our youth leaders, Robbie, who has severe haemophilia. He shared with us his story about disclosure at work and the issues that came up for him.

'When I start a new job there are millions of things running through my mind. How am I going to remember all these names, what day do I get paid, who am I working with, am I in over my head, where was the bathroom again?'

In a time that is already equal parts exciting and stressful it can seem overwhelming to throw another big question into the mix; do I need to tell my workplace that I have haemophilia?'

DO YOU NEED TO DISCLOSE?

It can be hard to know if you need to disclose your bleeding disorder at work, or if it would be helpful.

Usually you are not required to tell your employer about your bleeding disorder unless

- you are applying to join the Australian Defence Force or police force
- or your health condition means there may be a risk to occupational health and safety or you may not be able to perform the basic requirements of your job.

See the **Disclosure** section on the HFA website for more information - <https://www.haemophilia.org.au/about-bleeding-disorders/disclosure>

You may be wondering if your employer needs to know about your bleeding disorder so that they can make reasonable arrangements that would allow you to continue working without causing injuries, or so that they can be prepared in case any emergencies occur.

Robbie's approach to these questions was, *'I like to think about it in two ways; how my job can impact my health and my haemophilia and if I might need to take sick days off work. If a job is physically demanding and likely to place a strain on my health then I might consider telling my boss*

Some questions I have asked myself to help make this decision are:

'What kind of activities does this job involve?'; 'Will my target joints be used a lot in this job?'; 'Am I going to be on my feet for extended periods of time?'; 'Does this job involve heavy lifting?'; 'Does this job involve a lot of walking or a large amount of stairs?'

Robbie prefers to be realistic and to think about these kind of things before he begins a new job. *I think that it is important to be honest with myself when answering these questions. If the answer is an overwhelming yes and I think that there might be some impact on my health then that's fine, there's absolutely no shame in that!*

No job is worth risking my health.'

WHY WOULD YOU DISCLOSE?

Another question is whether or not you would disclose your bleeding disorder to your new employer. This is a very individual decision and can often depend on the workplace as well as your personal situation. It might be that it's easier for everyone involved if you don't volunteer information unless asked, or you might decide that it's in your best interest to do so, particularly if you have frequent bleeds.

For Robbie, *'the other important consideration is taking sick days off work. If I know that I might have to regularly need to take days off because of an injury or a bleed, whether this has been at school or in previous jobs, then I think it might be time to think about talking to my boss.'*

TELLING OTHERS AT WORK

'An employer might be much more understanding and supportive if I am open from the beginning!'

Robbie commented that, although he had more frequent sick days in high school, he is better now at managing his health, and this hasn't happened in his post-school life, so telling his employer has not been necessary for him.

WHAT ABOUT COLLEAGUES?

What about telling work colleagues about your bleeding disorder?

Once again this is a personal decision and could be influenced by the workplace situation or your relationship with individual colleagues, as Robbie has experienced:

'Even though I haven't told my employer about my haemophilia, it doesn't mean I haven't discussed it with anyone at work! There are days I have been at work when I'm in pain, having an arthritis flare-up or just need to vent about how I'm feeling and some of my colleagues have been a great support-system for me! We spend a lot of our lives at work and it's good to feel confident in those around us. I recently opened up to a colleague about my haemophilia and she then told me she had rheumatoid arthritis; we developed an instant, powerful connection and have become lunch-break buddies and true friends.'

There's no way to guarantee how people will react when you tell them about your bleeding disorder and over time Robbie has developed his own set of strategies. 'Of course, telling anyone that I have haemophilia has involved all sorts of reactions. Most often people have no idea what I'm talking about, sometimes they have heard of it and assume I will bleed to death from a paper-cut and sometimes they're as un-phased as if I had told them what I was having for lunch! What has worked well for me is having a simple, rehearsed way of explaining haemophilia to whoever I decide to tell. I treat it with importance but am very relaxed with my tone so that people don't have license

to worry for no reason or want to put me in bubble wrap! I'm also careful about who I tell. I am a fairly private person and I don't like discussing any part of my life with people who I don't have mutual trust with. But I know other people can be much more of an open book and will happily share and create instant connections that way.'

GETTING ADVICE

Who would Robbie go to for advice about disclosing haemophilia at work when he needs it?

'Some great sources for advice on this are other people you know with haemophilia already in the workforce, our parents or relatives who may have had to have these discussions and/or the HFA and your Haemophilia Team. Even if someone doesn't have haemophilia, it doesn't mean they can't offer great advice; everyone has their struggles and some friends will really surprise you with their depth of insight.'

Everyone is different and will have to take their own working environment and health situation into account. Robbie's message for other young people with bleeding disorders? *'Whatever you decide, make sure you're comfortable, confident and that your health is not at risk!'*

MORE INFO

Check out the **Employment** section on Factored In for more information about disclosure in the workplace - <https://www.factoredin.org.au/info/employment>.

There is also a section on **disclosure and the law** on the HFA website - <https://www.haemophilia.org.au/about-bleeding-disorders/disclosure> ■