

A conversation with Katie

The first time I ever heard of Huntington's was when I was 15. I had never heard of it. Didn't know it was in our family. And then my mum told me that she'd been tested and that she was gene positive and that her grandmother had died when she was 67. So, I found out a little bit more about it. And I was adamant that when I was 18, yes, I am going to get tested.

'This is probably an incredibly difficult decision for anyone who has to undergo it and it is literally life changing. But it is so important to understand who you are before you go through the process.'

And then 18 swung around. It was the end of year 12, then uni started and I was like, I'm having far too much fun to do testing at the moment. I'm not ready. And it became very clear that while I knew I wanted to get tested at some point, I just knew I wasn't ready then. I finished uni, graduated, and then did the compulsory gap year. Went overseas, travelled, worked, had an absolute ball and then came home, then started working. So, I thought, no, no, no, that's the start of my career. I will just settle in for a bit, I'm not ready.

When I turned 24, I was diagnosed with depression. And through that, I started seeing a counsellor and we were working through some of the various issues. And one of them being the pressure of being tested and wanting to maybe go down that path. I had broken up with a boyfriend who said he wanted children and that idea terrified me because growing up in a Huntingtons family, I did not want to pass that on to the next generation. But then I realised the importance of, for me, knowing the gene and maybe being a little more careful about who I dated going forward. In working closely with the counsellor, we realised I'm a planner. I love a good plan. If I knew the test result and I was gene negative, fine, great. It was something I didn't have to worry about and I could go on with my life as per usual. But if I was gene positive, well, then I could put things in place to help me navigate that going forward.

I booked myself into testing. I had my two best friends with me. They came to alternating sessions throughout the process. And each session that we went to, we did something really special afterwards, like go to Brunetti's for lunch. It turned what could have been a very stressful process into something really nice to remember that I've had a lovely time with my friends.

And then came result day. I wasn't convinced either way. I had tried to talk myself into believing anything can happen. Just hold your breath until you hear the result. I wasn't

having this thing on my head as, oh my God, I've got the gene. Oh my God, I've got the gene. Or, oh, I have to be negative. I have to be negative. It could be either.

I was sitting down in the room, and I remember being told that I was gene positive. And I cried a little, just quietly, just had tears rolling down my cheeks. I just remember that. And then I went, right, okay, I know what it is now. And then we went into Fed Square and drank cosmopolitans, had a fabulous lunch, went dancing down the street at one point. And then that night I had all my close friends and family around for dinner and we had far too much to drink. And it was really nice. It sounds a bit odd, but it was a really nice way to celebrate life in whatever form it comes.

My whole focus then became turning what could be a negative into a positive and just embracing whatever hits from here. I continued to work with my counsellor and she helped me work through understanding how I felt and my response. And that was priceless. Absolutely so important that that happened.

Following that, I got engaged, started working with doctors, getting involved in studies and really sort of getting myself involved with the broader Huntingtons community to make that I was aware of what was going on, what I could get involved in.

Looking back, would I do anything differently? Definitely not. I think one key thing is I needed to know because I'm a planner, like to structure everything, make decisions based on information. And that was important to me. But I think for anyone who is facing this decision, only you can know whether you want to know or not. Only you know when you're ready. The best thing to do is make sure you've got the support around you – find the friends and family members who are able to have this discussion frankly. I understand it's very difficult, particularly for family, to have an objective conversation, because it is so emotive. But you do need to be able to talk this through with people. And whether you can get some counselling as well, it is priceless. And, of course, there's always the fabulous team at Huntington's Victoria. They can obviously help you in a way that they understand everything that you go through. But you can't do it alone.

I would not recommend you do it alone. And even afterwards tapping into the community, tapping into counselling, just to help guide your thinking and help you process everything that's just happened is so important because it is a life-changing decision. You can't go back once you know, but when you do know, either way, you can shape your future from there and shape that future with the understanding of what you have.