ALASTAIR'S STORY

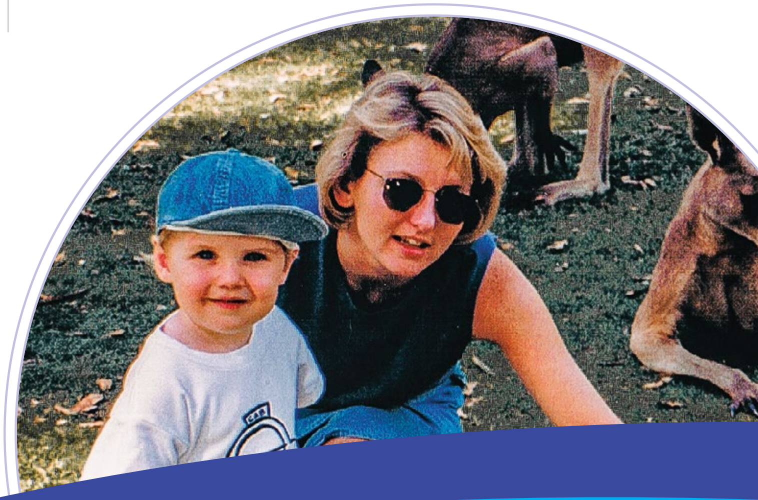
My name is Alastair and I am 29. I live in Brisbane. I am a civil engineer working in the railways and I am a bit of a train fanatic. I am also involved in helping in the community through Rotary and Rotaract with young care volunteering, visiting residents, and raising funds for charities. Inside my family I have my wife, Madison, my mum and dad, and a younger sister.

I was first diagnosed with leukaemia in early 2009 when I was in grade 12. I was at university when it relapsed in 2014. At the time of my diagnosis, I did not really know what leukaemia was. As a 16-year old it is not something you expect. I thought that you could take a pill and you're cured and back to normal. I did not know what was involved or what it actually meant.

Before I found out I had leukaemia, I had been feeling short of breath when exercising and feeling tired. I went to the doctor, got a blood test, and that evening I got a call from the blood centre letting me know that something in the blood test suggested it might be leukaemia and to go to a hospital. It was a bit of a shock.

At the hospital the doctor came in after the bone marrow biopsy and confirmed it was leukaemia. That was when I felt a lot more worry. That night, I was left alone in the hospital, the first time being in the hospital by myself, and I realized this is actually happening. I felt out of control.

> *"I did not have any control and I did not know what to expect."*



When my family and friends found out the news, I had a lot of family saying, "If you need to get bone marrow, we are happy to get tested for that," which was comforting. There were many phone calls saying, "I'm sorry to hear that." I had a lot of support in that sense.

School was difficult. I initially did not tell a lot of people. I told the teachers and they were really supportive. I told my close friends at the time and they were all a bit shocked. It came as such a surprise. I had just come back from semester break and I was at school looking fine. I still had my hair. When other people in the class found out, the common question was, "What did you do wrong?" I hated that because I did not know what I did wrong. Even the doctors said, "You did not do anything wrong. It is just unfortunate it happened."

The hardest part for me when I first got diagnosed was knowing it was okay to ask for help. You do not have to do it all alone.

> *"It is okay to be scared and sad at times, even to cry. It is okay to say how you are really feeling and to ask for help when you need it, whether that be emotional or even at home if you are tired and you need help with everyday activities."*

My haematologist at the time was always a big fan of encouraging his patients to ask questions—lots of questions. Every time he came and visited, I had a little notebook with 10 questions I would ask him about the treatment or about leukaemia in general. That was actually quite informative. The hard part was processing it all.

There were times when we had to go into hospital for a couple of weeks or a month. My parents would come in each day while I was in hospital to visit me, chat with me, and see I was okay.

> *"I remember sometimes on Friday nights my parents would bring pizza in and we would have pizza at the hospital to make it a bit like a home."*

Friends would come and visit me in hospital as well. It was nice having that social interaction, but personally I did feel a little bit disconnected because I missed out on what was happening at school.

> *"The diagnosis is not your fault."*

I was happy to talk to my friends about the medical stuff. I had one friend who was trying to become a doctor and he was quite interested. The social element was more difficult to share with friends because it is an awkward conversation to have. Your friends do not know what to say and you do not know how to bring it up either. Talking to my friends about the diagnosis was not an easy conversation to have. My advice is to start with the diagnosis and what it means, and to keep in touch. Even though you are in hospital, email each other or communicate online. Let them know how you are going or arrange for them to come and visit.

> *"Be open as much as you feel comfortable to. It helps for them to know how you're feeling."*

While I was in hospital various support groups came and visited me. The first one was The Leukaemia Foundation. They had a member of their community team visit to see how I was going and answer any questions I had. They supplied me with a laptop because in hospital there was nothing to watch other than TV.

I also had a visit from Canteen, a youth-based organization. They have a website where you could get information about various types of leukaemias and their camps.

When I relapsed in 2014, Redkite provided me with more information. If I needed help with getting employment-type work or or help at school, they had resources for that. They also gave me a care package for hospital, with a little blanket to keep me warm at night.

> **"One of the big things that helped me through my treatment was having family come and visit, bringing games or a laptop to be able to browse the internet or play games. Another big thing that helped me was having a clear treatment schedule: I knew the upcoming dates, what was involved, and what was planned. That gave me a lot of comfort, knowing the end date and the targets."**

Other things I put in place to help manage the cancer were trying to keep active, going for walks, and trying to eat healthier. I would try to go to “normal” activities such as school when I was able, which helped give me a sense of normalcy and made me feel better.

> *“I would like to think my outlook on life has changed for the positive, knowing I got through it and when challenges come up, I can work through them.“*

I don’t like to give up! Also, I think it has given me an appreciation of life.

My advice for someone who has been newly diagnosed is to be prepared to ask your doctor any questions you have about the treatment. It gave me a bit of comfort knowing what their plan was, but also that they could answer questions I had uncertainties about.

> *“Be aware that it is okay to feel what you are feeling, whether it be sad or scared, and it is okay to share that with other people, whether it is your family or those around you. They can support you.”*

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