



JAMIE'S STORY

My name is Jamie and I'm 60 years old. I've been married to my lovely wife Leanne for 29 years and we have two kids. We live in Tweed Heads, the best place in Australia!

I was first diagnosed with acute myeloid leukaemia in August 2020. Life before cancer was all about work. I had 2 jobs. I worked a full-time job during the day and then I worked 3 or 4 nights a week doing night fill.

When I was diagnosed, it was a shock. I've had friends who have been through very similar experiences, so I sort of knew a little bit about it. But when you're diagnosed, what can you do except go with the flow?

My family and friends were shocked when they heard my diagnosis. They had known me as someone active, fit and healthy. I'm not someone who normally sits around. I'm usually pretty active. Before my diagnosis, I was fit and healthy.

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“The beginning of my treatment coincided with COVID.”

The isolation in the first month of the induction stage of treatment was very rough. On Day 2 of my induction, COVID happened, which meant that I couldn't have any visitors. My only contact was with the registrars, my specialist, and the nurses. The nurses really understood what I was going through. They realized that I was missing my family and friends so they spent a lot of time chatting with me.

That first induction was fairly brutal. I was in a lot of pain, which started before my diagnosis, and I slept a lot. I did not think I was going to get through it. It was very, very difficult for the first month, but after that things got better.



For my support system, I have a specialist and team on the Gold Coast, as well as in Brisbane. I have my family, my wife and my two children. The Leukaemia Foundation has also been a huge part of my support system. I'm grateful to all of them.

For emotional support, the Royal Brisbane has been very supportive, checking in on me regularly. It was good to have someone else other than family and some friends checking in with me.

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“My diagnosis changed my relationship with my partner. It put a lot of strain on it. We did go through a lot. It wasn't just me that went through leukaemia. Leanne went through a lot too. The experience has made our relationship stronger.”

The Leukaemia Foundation was in contact with us right from the start, checking in on us, and offering their services. They explained what would happen if we went to Brisbane for a bone marrow transplant. We knew how it was going to work, how Leanne might travel and stay there. When I had the bone marrow transplant, the support they gave with housing was absolutely fantastic. They also gave us fuel vouchers for when we drove.

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“The challenge is to keep going and do what you feel you need to do to get physically and emotionally better.”

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“The support from my family was incredible. My son bought me jigsaw puzzles. Leanne came with me to all my hospital appointments. She was also with me when the specialist was on the ward to make sure I understood everything that was going on, as well as for her own peace of mind. My daughter was always on hand, checking my temperature, as nurses do. My mum and my sister came up from Victoria, which was terrific because seeing them really helped my recovery.”

The biggest challenge for me since my diagnosis has been doing nothing and not being busy, which is so different to how I was before. To overcome that, I try to keep busy with jigsaw puzzles, computers, gardening and cooking. My motivation is to keep myself emotionally stable because, particularly in hospital, you tend to drift and lose yourself. For me too, when I came home I didn't know what to do. The whole experience was such a shock to the system. Particularly when I first came home, I occupied myself by walking every day.

Walking helps my headspace. We are only three blocks from the river, so I wander down, grab a coffee and spend an hour by the river. That is my happy place. I can just sit and be calm.

The main barrier to my walking has been fatigue and muscle soreness. I have a couple of walking routes, some shorter than others. If I am feeling a bit fatigued on any particular day, I take a shorter route. Sometimes I take the car down to the river and walk from there, if I am feeling a lot of fatigue or muscle soreness. I still try to do it, whether it is the short or the longer route.



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“Cancer fatigue feels horrendous. It’s something that you don’t realize you’ve got at the start. You blame it on other things. You think it’s muscle soreness or you’ve done too much or it’s your own fault, but it’s not.”

Cancer fatigue is really hard. It rules what you do and controls your life. Tiredness controls if and when I can walk and what distance I might do.

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“The best advice I was given is to listen to your body.”

For managing and coping with fatigue, you just have to pick the times when you do things, and listen to your body. If you are fatigued, then do smaller things or things that do not need much energy. Listen to your body and do what you can. If you need to sit and rest, you sit and rest. If you need to lay down, you lay down.

To manage my cancer and keep healthy I exercise as much as I possibly can by walking and using resistance bands. I’ve changed my diet and try to eat healthier. Before my diagnosis, I just ate what I liked, but now my diet is centred on eating what is good for me and what is good for my body. I still eat a lot of the same stuff, but in smaller amounts and less often, and I’ve introduced some different vegetables and eat more meat. Every little bit helps. Everything you do has an impact on your body.

“You just need to do what you can do when you can. If you are feeling good, go and do something. Don’t dilly-dally or get side-tracked. You’ve got to make the most of when you’re feeling good.”

Feelings when you have leukaemia are varied and many. You go through a lot of emotions. You feel angry at times that it happened to be you that got leukaemia. I don't think I feel sad, I don't feel sorry for myself really, just a little bit peeved that I got it and it interrupted my life and my family's life and caused a lot of chaos.

I don't like the uncertainty of when I'll go back to work and relieve some financial pressure or the uncertainty of whether my remission will last. Although everything's been good so far, there is always that thought in your mind that it may come back. I'm someone who prefers to know what's going on and what's going to happen, so I don't like uncertainty at all, particularly with leukaemia. Unfortunately, there's not much I can do about all the uncertainty. I just take it day by day and try not to think too much about the future.

For work, I used to do retail audits and also some night fill. I expected to be able to return to work 12 months post transplant. Now, 11 months and one week post transplant, I'm nowhere near ready to go back. So I'm thinking of other strategies, such as getting an occupational therapist or massage therapist to hopefully help fight the fatigue so I feel good enough to get back to work.

The finances are very stressful and it is hard to get help. My advice for people seeking financial support during cancer is to persist. If you do not get what you feel are the right answers, seek further advice. If you are struggling, I would suggest speaking to a manager and making sure that the advice you are given is correct. Also, check your superannuation and make sure that you have income protection.

“*Since being diagnosed I've learned that I had always been an impatient person. One thing having leukaemia teaches you is how to be patient. You have to be. You have no choice.*”

We have two 6-week old puppies. I thought they were going to add more stress to my life, and they do to a certain extent, but there is a really positive side because they are unconditionally loving. I think they are going to help with my recovery.

“*My advice to people newly diagnosed with leukaemia is to be patient and take things day by day. Each day is a challenge and every day is different, particularly early in post-diagnosis. A lot of things come up and you just have to ride the wave.*”

Being diagnosed with leukaemia has changed the way I prioritize things. I've always placed work and my kids over everything. My kids are still a priority even though they have all moved out of the family home at this point. My outlook has changed on how work will look in the future. There is going to be a better work-life balance for sure. Travel was certainly a plan for Leanne and I when the kids were gone. I think it is going to be more of a priority now. We both look forward to travelling together in the future.

