



Ashleigh, Caregiver

My name is Ashleigh and my husband was diagnosed three years ago with a Grade 4 brain tumour. And it was a hard diagnosis because he wasn't given a great life expectancy. It turns out that it was actually a Grade 1 tumour and he was able to recover. We went through a process of recovery and all the things that you go through as a patient and a caregiver. In the end we've grown from it and found our own path.

Diagnosis

When Doug was first diagnosed with cancer it was a shock and it was a surprise. The whole thing took us off guard because we didn't expect someone his age — being in his 20s, being so young — to be put through that. So it was almost like, 'Okay, he's diagnosed with cancer, now what?' Because in your 20s you don't really think 'Oh, I'm going to have to deal with cancer. I'm going to have to deal with hospital visits. I'm going to have to deal with someone that I love going through something that's horrible and potentially fatal.' So it was a big adjustment. When you're diagnosed with a tumour that's cancerous there's other things that go along with that. So it was the journey of going from surgery to doctors' appointments to new MRIs to him now having grand mal seizures — which was an offset of what happened with the surgery — dealing with that afterwards, which is what we're currently struggling with still now.

Through sickness and in health

We were dating and when we found out about his diagnosis it was kind of like 'Oh! okay.' Kind of in a way put us in a position where before we were waiting to be financially set to get married. We decided, you know what, we're going to do this anyway down the road and if he only has a year to live then we want to spend it together. So we thought 'Okay, this is what we're going to do. We're going to get married.' And so, about 10 days after he came home from the hospital, we jumped in and went and got married at our cottage. And then after we were married, and moved in together, it was a whole different dynamic. Dealing with that different dynamic and then also with him recovering, was something that you don't usually experience within your first year of marriage. So yeah, it was different. It's not an everyday occurrence that you have a recovering cancer patient getting married in 10 days, and dealing with work and figuring out your life. He was still in school and it was my first job out of school. It was a stressful time for everyone, but we took it in stride. One day at a time is kind of the way you have to do things in order to keep going.

Changing dynamics

There was a big adjustment in our relationship and then there's this maturity that had to come with it. And you're kind of like forced into maturity. I mean in your early 20s you're thinking 'Oh, well my life's just kind of starting and everything's just fine and dandy' and then all of a sudden you're thinking, 'I've got to deal with this. I've got to schedule these appointments, I've got to make sure he's on track with medication that sort of thing and I also have to take care of myself.' So it's more like 'Okay, I have this other person whom I have this responsibility to and I also have myself.' And you feel that way when you get into marriage, but when you have someone who's going through a recovery and you're into your marriage it's this whole new dynamic that wouldn't usually be there. So for me, I mean, it's a stressful time and it puts a lot of weight on your shoulders.

And it's dealing with your responsibilities and what's important then and what's important in the now. And looking towards the future as opposed to just, you know, being the 20-something that's kind of going about their everyday life and not really worrying about anything else. You all of a sudden have all these things that are on your mind that wouldn't normally be there. So for me it was an adjustment of, 'Okay, let's get real. There's some things that have to be done and I got to do it.' I found that when this was all happening that there was a strength in me that I had no idea that I had. And starting out on marriage on such a rocky place it makes me think, 'Wow, we can get through a lot in marriage now.' A lot of things can happen and we'd be fine with it, we'd be like, 'Well, we can look back and say we got through that, so I'm sure we can get through this.'

Stage 1

This is still cancer. We've still got to treat it like cancer. It could come back. We don't know. So we're still going to have to go to appointments every six months, we're going to have to do MRIs every six months, we're going to do checkups and Doug's still have to go though the reminder that this did happen. That it's not something that you leave behind once it's cut out of your body. It's not something that you leave behind. You have to monitor it the rest of your life. You have to go to your appointments and you have to remember to take your medicine. And as a caregiver you have to remember to remind them. And for me it's hard because I sometimes nag him, 'Did you take your medicine?' And every night I go 'Did you take your medicine? Did you do this? Did you do that?' 'Yes! I did that! I did it!' And you kind of feel like you're mothering them a little. And at the beginning it was a fine line between me kind of bossing him around and then him trying to do it himself and me kind of stepping back. And it was the same with other members of his family too and we had to step back and say 'You know what? You're an adult and you have to take care of this yourself too'. And it's hard to do. It's hard to say, 'Well, you know, I'll just let you do your thing and you can get through this.' But it's hard to decide what your role is and where you fit in. Because you're going through the process — you're not the patient — but you're going through the process with them, step by step and appointment by appointment and treatment after treatment. It's just finding your place and where you belong. The healing process is very long and physically and mentally. It drains you a lot so it's not something that you just leave behind — one day you have cancer and then one day you don't — but it's more of 'Okay, we're going to have to deal with this the rest of our lives.'

The healing brain

When he first came back from the hospital, because of where his tumor was in his communication centre of the brain we were thinking okay... But then he started mixing up words and he was really frustrated with that and with other things and he got really agitated really easily. That's normal. That's to be expected but you don't expect it to happen with the one you love. You're like, 'Oh no, it's not going to happen. He's going to be fine. He's not going to be agitated. He can handle this.' Right? But that's not how it goes. We should have expected it, right? And so you think when you get into those arguments you think 'Why are we arguing?' Because there's no point it's not going to change anything so you've just got to say, 'Okay, this is just a product of what's going on in his brain right now.' You have to think this is a product of his surgery and it's not personal and it's not something that you have to take personally. You just have to let it go. And, thankfully, that personality that isn't his is gone now because he's recovered and the stages of healing have started to happen. But, at first, it was kind of overwhelming because it was ... like, this isn't my Doug. This isn't the person that I'm used to seeing. But there's stages that have to take place and unless you realize that you do take it personally. So you just have to remind yourself that, you know, he's healing. The brain's healing. You've got to give it time.

Coping

I think that you don't really think about yourself in a way. You think about what the patient's going through and what your loved one's going through and how to get them through it. You don't really stop and think, 'Well,

what about me?' You know most people don't do that when a loved one's going through something. So, I just think about what do we have to do next? I don't really think. 'Okay, well I'm really stressing out.' You think, 'Okay, well I do have a lot of stress on my shoulders. I'm trying to do this and this while doing that,' and it can be stressful at times. And then when I finally calm down it's more like - huh - what do I do now? I'm not sure. So it was more like I've got to get back into the routine of things. I can't just sit here all day and stare at him. So yeah, I jumped into work and just did what I had to do. And, lucky for me, he also had his mother and my mother and his family and his sisters and so for us we were we were lucky that way. I mean not everyone gets that support that we got, so family made all the difference to us.