

## Marmaduke's Story

**SIMON:** When you realise how uncertain life is, you do begin to appreciate the value of family and friendships and enjoy those moments while you have them, because you don't know what's around the corner.

So at 15-months he was diagnosed with childhood cancer and I basically became a full time carer from then on.

We went to hospital and after repeated scans and ultrasounds we had to put him through chemo because the tumour basically, was growing out of his left kidney out of his adrenal gland, but some legs have also wrapped around the IVC, which is the major blood supply up to the heart.

So surgery wasn't an easy issue so they had to put him on chemo for three to four cycles, they then had some surgery, removed everything and ended up with what they'd call 'sledgehammer chemo', which is very, very strong chemo and after 10 months, and it was a full on 10 months, I think three out of every four weeks I was in the hospital with him. He actually came through and he was declared clear.

We waited three months to let him recoup right, then we took a big family holiday up to Byron Bay.

That's when my wife found a lump in her breast, so we came back to Melbourne, she had a mastectomy and went straight onto chemo and four days before she finished Marmaduke relapsed and by this time tumour had eaten most of the bone and he basically fractured his leg which is how we found it.

We then ended up racing him to back to hospital and we probably didn't quite realise just how serious a relapse can be, and they said we're going to be close to changing the conversation. At the moment we are looking for the cure, we're still looking for a cure, but if the next cycle doesn't really have an impact then the conversation will change and we will really be looking at management which may work – he would be terminal.

Around that same time although Wilson had finished her treatment, three months after her treatment she relapsed big time and almost died.

We effectively at that stage decided that *"well then, let's live in the moment,"* we brought him home and he spent four or five months having a fantastic time with his brothers. We had a marvellous time we even took him bush camping and had them all out in the water and it was just a priceless time.

We knew that we couldn't cure him, we didn't know what the sentence was going to be, no one could actually say whether it would be four months, three months, a year.

We just tried to enjoy each day and enjoy the moment which is why the end of his journey, to have at home in his own bedroom with all his own colours, his own toys, his own sounds, have his brothers climbing and out his bed.

It was as normal environment as he could possibly have and it was critical.

Then probably, I'd say about two months before he died, things started literally crashing. I think that's when also my wife starting crashing and I think that's when I say the heart started sliding slightly off the mountain side, just like it all started going then.

Wilson was at home. The only way I could Marmaduke at home, I couldn't be at hospital while Wilson was sick at home, was to get home with palliative care.

So that also meant that he could come home, he could go in a big sort of recliner with an inflatable mattress underneath and he could get wheeled into the lounge and he could sit there with his brothers watching a DVD, or playing games and that was extraordinary because it gave him freedom.

Now palliative care is often about, is just comfort. So the pain relief in terms of the quality of life is absolutely critical. To be able to offer that sort of pain relief at home and almost allow him to lead a normal life with his family, with incredible drugs going into him, invariably the nurses would say he had enough going into him to bring down an elephant and yet they were amazed that he was not just conscious, but lucid.

If he'd been in hospital with limited pain medication, the discomfort would have been horrendous, and undoubtedly his life would have been shorter I'd imagine because the pain and the stress would have had quite a debilitating effect on him.

That's what was so important with palliative care, that we had the opportunity to bring him home, so then literally he was then at home with family.

So his brothers knew exactly where he was in the house and his sister literally, Charlotte curled up in bed with him for four to five weeks.

**CHARLOTTE:** I connected with him most of his life, but really intimately in his last final weeks. It was just almost natural for me to, I guess just be there with him every second I could.

**SIMON:** It was important for us just to remain positive. The reality is that you know how it's going to end but you need to embrace each day as well as you can and as calmly and cheerful as you can for the family, but also for Marmaduke.

**CHARLOTTE:** He knew that he was loved every second of the day. There wouldn't be five minutes that would go by without someone interacting with him.

**SIMON:** I think what that also gave was constant touch and comfort which I think is something not to be underestimated as someone is ending their life.

When Wilson died she always thought the wheels would wobble, but they literally just fell off so it was quite a crash when it happened, and with Marmaduke, having him home for those five weeks, we had just so extraordinary days.

Sounds a bit odd to say this but this is the most beautiful time and it was, it was sharing that journey.

One thing that seems clear to me is that, yes that's a mystery, but that's actually part of life.

**CHARLOTTE:** It definitely puts things into perspective, it also makes authentic relationships with the people around you a lot more significant.

I think the only way you can deal with severe hardships is through connection with others.

**SIMON:** I've found that in grief, instinctively gratitude is an easier path for me than loss.

With gratitude I'm grateful for what I had so I celebrate their lives and their memories and it makes, it values them in a sense so that I can think of them and I think of the wonderful times we had

together, the times we shared. So yes it was a short journey but it was so rich and there's plenty to celebrate and I thrive on it now.