

## Joseph's Story

**FIONA:** There's still a lot of joy to be had in life. I think that, you know, there's a tendency to look on people with disabilities, or people with illnesses and focus on how they're different or the negative.

It's only society's attitude that limits us and I just can't believe what a joy Joseph has been to us.

Joseph is our second child, so we have an older daughter.

When I was pregnant with Joseph everything seemed fine, I had a really normal, healthy pregnancy, normal birth and Joseph appeared really healthy when he was born and when he was about three months he appeared to just get sick with a cold, or something similar.

He was unsettled, not very well and I would take him to the GP and do what every mother would do and then one day I found him having a massive seizure, that just kept going and going and we rang the ambulance and went into the hospital and he ended up in intensive care for a couple of days.

It was really difficult because we were in and out of the hospital constantly and of course at that time our daughter was three and we had just moved to a new town as well, so it was extremely stressful and extremely difficult and it was also made very difficult that we didn't have firm diagnosis.

So he obviously had a very severe and serious epilepsy syndrome, but we weren't able to get a clear prognosis.

Everything was very vague, you know, I think we probably held onto a lot of hope in the first year or two of, you know, he might stop suddenly having the seizures and develop normally so it was actually very difficult that his disability unfolded quite gradually.

Joseph has an early, early on set infantile encephalopathy. Basically he has very, very severe seizures.

When Joseph first became ill, when he was a baby, we knew then what was happening to him at that time was life-threatening.

He was in intensive care, you know, integrated intensive care all the time and he was a tiny baby having thousands of seizures

So as he got a bit older probably from about two onwards, we got better seizure control so we weren't in and out of the hospital all the time and I think at that period I probably thought: *"Okay, I have a boy whose got epilepsy, he's disabled,"* but I stop thinking about it I guess as, as potentially life-threatening illness all the time, you just slip into everyday life.

But then as time went, you know, and he would be in hospital with pneumonia and you know, things like that, just other medical issues that are associated with his epilepsy and everything, it, I guess it dawned on, it began to dawn on us that he was still extremely fragile.

I can't remember who actually first suggested 'Very Special Kids' to me, but that was the moment when I, you know, looked at it and I spoke to his paediatrician about it and I said: *"It's for children with very life-threatening illnesses and Joseph would have been classed as having life-threatening."*

So yeah, that was quite, that was a difficult period actually.

**DR COLLINS:** The very word 'palliative care' can raise all sorts of anxieties in families because they associated that terminal care, in other words the last few days of life.

**FIONA:** I, for ages would not have thought of Joseph as being palliative and I think this is a big thing too.

**DR COLLINS:** Paediatric palliative care is holistic care of a child who has a progressive illness, and all that is about trying to ensure this child in the context of his or her family, have the best quality of life.

**FIONA:** Even though it was really confronting to have him accepted into '*Very Special Kids*' at first, or to have it acknowledged that, yes, he has a life-threatening condition, now I feel really relieved that now I'm hooked into a service where people understand and I don't just go to appointments and go home, I've got a group of people around me now all the time.

It's like, it's a safety net actually, that's what it feels like. You feel like you've got, someone has got your back, that there's something there to help you and if you're struggling there's someone there and it's not even just the respite house, it's the worker and you're local worker and it's yeah, it's really, it's really invaluable.

But we do a lot of physical therapy with Joe, I do a lot of work with him at home, so he has made he gains, he can stand in a standing frame. Sometimes he can sit a little bit on his own if he's propped up just right with his cushions and things like that.

Lots of the therapists, some people we've met over the years have developed a really strong bond with Joe, so yeah, he sort of collects friends.

He likes to be outside so, he likes it if you've got his wheelchair and you go down in the paddock or down the laneway and it's rough and you're pushing him over it.

He's like, he's a typical little boy in that sense, he loves it if you're in the care and going down the rough road and the car is bumping around and he'll laugh.

I think for us the best thing was now, that he's just more aware of the world around him and you know, tries to participate in his own way.

Once we kind of realise how vulnerable he is from a physical point of view, so his airways are quite vulnerable, he can slip into respiratory distress very easily and very quickly.

He's so tenacious, he started school in February this year, end of January, but yeah that was good, he only got a few weeks in this year and then he got really unwell so then he spent the next two months in the hospital.

It was actually his birthday, it was the end of February and it was his sixth birthday and on the morning of his birthday we noticed he woke up with a bit of a temperature and he didn't look too well and then over the next hour or two I noticed his breathing more laboured.

So we ended up at the hospital here in Ballarat and it was pretty evident that he needed to be transferred to the Children's Hospital in Melbourne.

So he was flown there in the helicopter, he had three failed extubations trying to get him off the ventilator, it was pretty horrible.

He didn't look very good and we decided to try one more time to get him off the ventilator and the fourth time actually worked, but all up he was in intensive care for eight weeks.

Luckily this time we, we managed to get him off that ventilator and we managed to bring him home, but we definitely had to face not being able to bring him home.

The best moment for me I think was the day he left ICU, because even though the ICU staff, the nurses and the doctors had just been wonderful, that day when they said *"okay he's well enough to go into a ward now,"* that was incredible and that's when we thought: *"yeah, he's going to come home."*

Our goal to just keep Joseph at school, he loves school, he loves the stimulation, he loves being around the other children.

Trying to keep him well but then also like I was saying, we just want to, just try and enjoy life.