

Michael McEnery provides a personal & heartfelt account of the loss of his young daughter Annabel to Cancer, the effect that this had on all his family, coping with unanswered questions and the support that he finally found.

We have often wondered when it all first started. The official line from the Haematology Ward was that they don't know how she got it, where it came from, what it actually was and it couldn't be cured. It was nothing to do with the way she was reared, nor her genetic make up; it was just rare and aggressive. Lots of unanswered questions, too many to keep even the calmest mind sane.

In the spring of 2007 when Annabel was about 8 months old she would wake at night screaming intensely, we put it down to teething or an ear infection. I would walk the floor for about an hour, try to get her to drink something and eventually she would fall asleep with exhaustion. All of the three older children went through the teething and ear infections but none to the same severity, the intensity of her pain was quite evident. I'm sure all dads look at their babies when they are unwell with a begging look to tell us what the matter is.

In April she developed a type of crick in her neck, so we took her to the hospital but they sent us home, a throat infection and they could not see the problem with her neck, just some muscle strain, it would go away after a few days, it never did.

Annabel was admitted in early May with what they suspected as Viral Meningitis but tests were inconclusive despite symptoms, she began to lose power in her arms and her neck became quite rigid. A CT scan showed something in the upper spine and as a result Annabel went for an MRI on June 8. About an hour after the scan the consultant came in and told us that Annabel had a tumour at the top of her spine. She was transferred to the Belfast Hospital for Sick children where a neurosurgeon told us there was little he could do.

It was rare, very aggressive, spreading down the spine and upwards towards the brain. Annabel was too young for radiotherapy, the position of the tumour was too restrictive to operate and as they did not know what it was chemotherapy

had no guarantees. After a biopsy it was decided to give a form of chemotherapy, which, along with steroids reduced some of the inflammation around the tumour and gave us three precious months with her. Annabel was moved out of paediatric intensive care to the Haematology Ward in late July, the outward signs were promising. I began to put her on a floor mat building blocks and movement returned to her arms and legs - were our prayers to be answered?

The second MRI scan in late August was an unexpected shock, while the tumour reduced enough to stop putting pressure on the nerves, the cancer had spread down through the spine and up into the brain towards the stem. It would be a matter of weeks. Annabel caught us by surprise on Thursday, September 6, going into respiratory distress; we asked that she be resuscitated in contravention of medical advice as we were not ready to let her go.

I asked for a close family friend to sit in with us at a meeting the next morning as the overwhelming emotion meant I could not finish out sentences but I listened and accepted that Annabel would not get better. Maria and I were given some time to sit with Annabel and decided that it was time to let her go but not before her brothers and sister, grandparents and extended family came to say goodbye. The second worst moment of my life was on Saturday, September 8, 2007 when I took Annabel's two brothers and sister in to see her and told them that she would be going away and not coming back. The worst was the following Tuesday, September 11 when I let the PICU staff know they could wean Annabel off the ventilator and as Maria and I held her hands tightly she slipped away from us.

The wake and the funeral I got through ok. We wanted it to be special and it was. It really helped that close friends came. True and loyal friends should not have to be told when they are needed, they should know, otherwise they are not real friends. Some flew in from afar. That will not be forgotten. We went away with the other 3 children for 2 weeks which helped as we really had not seen much of them for the previous 3 months. When we returned about a month after Annabel passed away, a real darkness fell over our house. Both Maria and I took sick leave from our jobs but nothing seemed important anymore.

The pain and despair came frequently, tears were followed by anger.

What had Annabel done wrong? What had we done wrong? What kind of God would let Annabel die and let evil flourish? I tried to follow the role of man of the house and keep things going but bills were neglected, oil ran out, what did money matter, nothing mattered at times. The other kids got me up in the morning to take them to school and when I returned home Maria was still in bed, usually wailing with the loss. I thought nothing better of it and just went to bed too till it was time to get the kids from school in the afternoon. We would argue about who should go get the kids, why was it me all the time, had I not a right to grieve too? Usually when an issue of consequence came to our house we would talk it through, support each other and try to resolve the matter for the best. But Annabel's death had no explanation, no one had an answer. The older generation stuck to the faith and tried to soothe us with lines such as, "you've a wee angel in heaven" or "she is in a better place now", well f*** off, we don't want an angel in heaven and if you're so sure she is in a better place, send your child there and let us have Annabel back because this is where she belongs, with us.

Here we are heading into winter and I am looking to my wife for some hope, the one person who always seemed to sort things out, I loved her for that, and she to me for the same reason, but no answer and for that we can began to resent each other. Our youngest child was asking when Annabel was coming home. How do you deal with that? Show me that one in the book of parenting. What else can turn the knife in your gut? To escape we both began to drink more, every night until we fell asleep on the sofa. At this point also my anger was wanting to emerge and show its ugly head, I would drive carelessly, hoping to hit someone or hoping that someone would cut me up so I could challenge them, I wanted to lash out.

A support worker from a children's cancer charity came to our house to make memory boxes for the other kids. It was good, therapeutic; they have pride of place in their bedrooms. She said maybe we should think about a family bereavement camp

in Barrettstown, Co Kildare, she could recommend us and she did and it was our salvation.

Those who understand grief are those who have experienced it. Meeting other parents and realising that they were going through the same emotions was a relief. This was replicated in the experiences of our children when they did workshops with children from other families. They could talk in their own language with boys and girls who also lost a sibling. We met Peter Hanlon who may have saved our marriage; we were so enlightened by his sessions and the way he helped us remember the wonderful moments we had with Annabel that we asked to see him privately for sessions after the camp ended. He introduced us to the wonderful analogy he has for grief. He describes it as a rollercoaster, Maria and I were on the same train but not always in the same carriage. It was Peter who told us about Anam Cara and gave us the contact with Sharon Vard.

When we went to our first meeting we went with great apprehension, we had tried some other bereavement groups but they didn't do anything for me, but Maria wanted to go and she had been in contact with Sharon who had lost her own daughter to cancer and they developed a rapport online. Within seconds we were at ease, talking with people who wanted to listen and whose stories we wanted to hear, who had gone through similar journeys, the shared experience. There was no judgement; there is no good way to lose a child.

By meeting other bereaved dads I have learned how to celebrate Annabel's life, how to cherish special moments I had with her, her only Christmas with us she was my main helper in her stroller as I put the tree up, she smashed two baubles on the floor, I can now look at video footage of her and yes sometimes the tears are tripping out of my eyes but I can smile and laugh at her. It was a dad who lost his 14 year old son who gave me the tip on how to communicate with Annabel. I take the dogs down towards Lough Neagh each morning and look across the lake towards the Sperrins in Tyrone and there I talk to her, I tell her what went on yesterday, what's happening today with all in the family and that I have to go and get her brothers and sister up for school and I may not think of her

during the day but I know she is there and I will definitely chat again tomorrow. I do this quite clearly and vocally, I'm sure anyone passing would think I was deranged, but, like I care.

People who grieve change their priorities in life and we don't suffer fools gladly, you become much more intolerant. It was through meeting another bereaved dad who lost a 15 year old to cancer that I have become more aware of why the non-bereaved can be uncomfortable when I mention Annabel in conversation. This is especially true of new dads. He said when you mention Annabel you are presenting them with the nightmare they don't want to think about. New fathers look at their offspring with joy and wonderment almost bewildered that they could possibly have helped create something so beautiful and for some one to suggest that that could be taken away is incomprehensible.

There are days when the pain will hit you unexpectedly like a train and there is nothing you can do but try to find somewhere quiet to grieve and let it out, pull yourself together and head back out into the world of the non bereaved. You can't tell them because they wouldn't understand but I don't feel isolated anymore, I can always email Peter, Sharon or another bereaved parent from Anam Cara and they will listen and respond because they know.

Maria and I have had another child who brought much needed light back into the house, he keeps us busy along with the other 3 but we never forget Annabel. I lifted a line from a Damien Dempsey song and put it on her headstone, "How you illuminate our shadowed sight".

Michael McEnery