

Cecile Belsham's experience with Cancer

Background on Cecile's family: My name is Sonja Rademaker and I am the mother of 3 children Two boys, Tyrone and Hayden and that much longed for girl, Cecile. I gave up my work within the Federal government when I first became pregnant with Tyrone and was a stay at home mother for all three children, not wanting to miss a moment of their childhood. It wasn't always easy financially, as I became a single mother when Cecile was 18mths old, but I wouldn't have missed a second. I went back to University studies, doing a Women into Science and Technology course, when my last child, Cecile, started kindergarten and then halfway through this course, I won a Screen Animation Scholarship. Not long after I graduated from the Animation Diploma I was offered a position within the State Government and, needing the money, I took the job.



cover 18mths earlier after I had a 3rd melanoma removed. The doctor explained what the CT scan showed a large tumour in her right iliac bone. It protruded into the surrounding iliacus and gluteal muscles. The pain she had been experiencing was because it had been splintering the iliac bone.

Skip forward 7 years and I am still working for the government and doing my animation from home in my spare time. We are offered free flu injections as government employees, but in 2010 there was this Icelandic volcano with a funny name, that erupted and grounded all flights around Europe. We were sent emails at work saying that as the flu vaccine was made in Europe, there would be a delay in receiving them that year, so if we were in the high risk group we should go and see our GP to get it from them. As my children and I are all asthmatics and I have had pneumonia, I took Cecile to see our GP to get our shots. As we were leaving the doctors office, I remembered Cecile had been complaining of a sore right hip the last 3 weeks on and off and I casually mentioned it. Our doctor, Elsbeth Darveniza grabbed a book off the shelf and flipped through it saying it was quite common for 14yr olds to have some sort of hip dysplasia as they were growing fast at this age, but as the pain had been niggling and constant, she wanted her to get an xray.

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The doctor explained that Cecile would need to see an orthopedic surgeon for further analysis and she knew of a good one who was currently attending a seminar in Sydney and with my approval she would contact him to get the ball rolling, as time was of the essence.

This was on Friday 7th May. Saturday, Cecile had an MRI. Monday she met her orthopaedic surgeon who explained he suspected the tumour was either an osteosarcoma or Ewings. Wednesday 12th she was admitted to the Wesley hospital to have a bone biopsy and tissue sample taken. She got to home on the Saturday but back in hospital the next Monday 17th to have a portacath inserted into her chest and begin chemotherapy.

It was that fast. We had no time to think, to adjust, to absorb, to come to terms with any of this. I talk about entering the world of cancer because that's how it felt.

A completely different world. You have to learn a new language, the names of a multitude of hard to pronounce drugs, you have to kiss goodbye to your dignity, your independence. And I watched my 15 yr old daughter handle all this with more courage than I could have imagined.

Cecile had a CT scan at Canossa Hospital the next day, a month before her 15th birthday and it confirmed a lesion was present. The radiologist seemed stunned at what he found. Her father had taken her and I got the call at work and met Cecile and her father back at the GP's office, where we saw another doctor as our regular one had the day off. Thankfully, I had taken out private hospital

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I took indefinite leave from my job, as I was not going to leave Cecile's side. From previous hospital experiences with my other children, I had learnt not to trust completely, but to question, to research, to be informed. I feel like all my previous experiences have been in preparation for this. I had my bed next to hers in hospital. And just as well. There were times when I had to intervene when a nurse was going to give her the wrong medication and actually argued with me. Thankfully, a much nicer nurse I met at the beginning of all this, had told me to get an address book and to write down all the drugs that Cecile was prescribed and what they did. Now I know why she told me to do that!

They don't know if your child has had cancer for 5 minutes or 5 years and they expect you to know the routine and actually get annoyed if you don't! There is no handbook for cancer and every case is different. We met a patient in the next room during one of Cc's chemo treatments and got some tips from her like how Coca Cola or Aloe Vera juice helps reduce the ulcers in the mouth and throat.

Cecile had 4 cycles of chemotherapy leading up to her surgery on Monday 12th July. We were told she would be having a Pelvic resection, where they would be removing her right iliac bone, the iliacus and gluteal muscles, and all the surrounding tissues and nerves. The operation went for 5hrs and she spent 4 days in the ICU. While she unconscious in the ICU, she had her first implant from her IVF specialist. We also had to address the issue of her fertility. As this had all happened so fast, there had not been any time to salvage any of Cecile's eggs for future use, so the only option at our disposal now, was to employ an IVF doctor to insert an implant into Cc's stomach every month. The intent was to stop her menstrual cycle. There is no guarantee it will work, but the belief is that if they can turn off her monthly cycle and stop her eggs being expelled, there will be a larger pool of eggs in the future and hopefully some of them will be viable.

After her surgery, the pathology came back on her tumour and it seemed there was some confusion surrounding the analysis. So they gathered a team of 5 more pathologists and after a week or so they finally agreed on a diagnosis. Mesenchymal Chondrosarcoma. A very rare and aggressive form of bone cancer and apparently very rare in someone so young.

Not knowing what chemotherapy protocol to use, her oncologist decided to go with the Ewings chemotherapy and Cecile continued to have

intensive chemo over the next 6 months, at times developing allergies to some of the drugs. Her final chemo treatment was during the Brisbane floods. This was fun, as she decided to do this last one as an outpatient and halfway through the course the hospital was cut off and as we live near the river at Jindalee, so were we. But finally all the treatment was completed and we hoped for the best.

When we attended an appointment with her surgeon in March this year, he asked to see her follow up scans. I asked what scans he was referring to. He said the scans to check that the cancer hadn't returned. Apparently these were to have been ordered by her oncologist.

To cut a long story short, the doctor in question had taken long service leave halfway through Cc's treatment without advising us or doing a handover and no one had ordered any scans. I arranged to see another oncologist at the Wesley and got a referral to get an MRI done externally. This scan returned a positive result, saying the cancer had returned or was residual and recommended a PET scan be carried out to determine the spread. We were devastated.

We had long felt overlooked and too many mistakes had been made, so I removed Cc from the private system and took her public in the hope that more eyes on her case would be to her advantage.

Armed with the new MRI scan with met with a new oncologist at the Royal Childrens Hospital on the 25th May this year. Her recommendation was to proceed with the PET scan but she suggested that Cc also have a Bone scan, as this had never been done by the Wesley hospital. On the 18th July Cc had the Bone scan and a week later the oncologist called us back for the results. She gave Cecile the option of hearing the news on her own and not wanting to upset her father and me with her reaction, she asked us to leave the room.

The next 40 minutes were tremendously hard as we knew that the news was not good. When we were called back into the room, Cc had obviously been crying.

The doctor started to talk and to explain that the cancer had definitely returned and Cc just looked at me and said I'm going to die. Cecile asked if it could be anything else, like scar tissue or calcification and the doctor said no, it was definitely the cancer that had returned. She said that chemo was really no longer an option as it hadn't worked before and there was no point in putting Cecile through it again.

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She said that surgery – amputation – was now the only option. If Cecile chose not to have the surgery, the only alternative would be radiation therapy with oral chemo, but we would have to understand that would not be curative and she couldn't say with such an aggressive cancer, how much time that would buy her.

At this point, I told Cecile that I had a Plan B in place and I politely requested that the doctor provide a referral for a second opinion to a Professor I had been liaising with at the Peter MacCallum Cancer Centre in Melbourne. She agreed to supply this.

Back in March when I could see things going pear-shaped at the Wesley hospital, I had been sitting with my wonderful psychiatrist discussing the options, and she had Googled the Peter MacCallum Cancer centre.

I had contacted the wonderful receptionist Judy and told her of our predicament and she had given me Professor Peter Choong's direct email address so I could send a brief synopsis of Cc's history so far. He had said he would be happy to see her anytime.

We flew to Melbourne on Sunday 7th August and saw Professor Choong the next morning.

Calm, highly intelligent, respectful, measured, reassuring, these are all the qualities I observed and felt he imparted to us as we sat in his office.

He didn't waste time or words. He said he needed all the facts and we didn't have them all. He organised a Thallium scan, a 3D CT assisted biopsy and other scans and Cc was booked in for the following day. It was that quick. We could not believe the difference between the treatment in the hospital down in Melbourne and that up here in Queensland. Cecile commented to a nurse there, that she was so grateful that they explained everything they were doing to her, before they did it. The nurse explained with a smile that they were required to, as it was the law but it also made for more relaxed patients.

We stayed with my friends in Melbourne and a week later we were back in Professor Choong's office being told the wonderful news, that it was not cancer. All the tests had come back clear.

I asked the Professor if he would consider taking on the management of Cecile's case and he happily agreed and I also asked if he could recommend an oncologist and he said they had a wonderful adolescent oncologist Dr Lisa Orm on their team.

And to top it off, when I went to pay for all the treatment at St. Vincents hospital where the procedures were carried out, they advised me to put away my credit card, as it was all bulk billed.

So I will simply put Cecile on a plane every 3mths and send her down to Melbourne and my friends will take her to his office, get the follow up scans done and then drop her back to the airport.

Needless to say, I am so glad I continued looking for solutions or alternatives and I will continue to do so in the future should the need arise or my instinct compels me to do so.

For the first time...I feel Cecile is in safe hands.
