



Xuané

... a Reason to Smile

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a Reason to Smile

By:

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Foreword

I'm a mother of two beautiful girls ... or just one. You see, the story goes like this; my oldest daughter died of a rare type of childhood cancer at the age of 8 years, 2 months and 6 days. She had an Anaplastic Ependymoma that grew in her spinal cord and later spread to her abdomen, and paralysed her little body.

But let's start from the beginning...

Childhood Ependymoma is a very rare type of cancer in which malignant (cancer) cells form in the tissues of the brain or spinal cord.

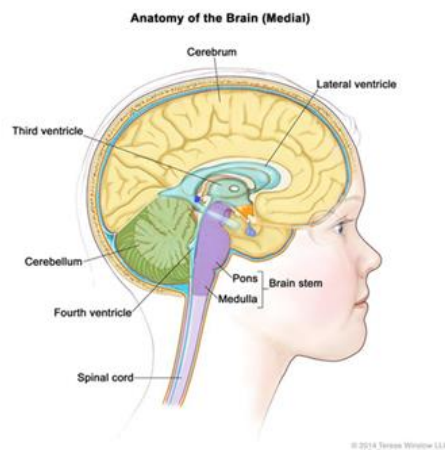
The brain controls vital functions such as memory and learning, emotion, and the senses (Hearing, Sight, Smell, Taste, and Touch). The spinal cord is made up of bundles of nerve fibres that connect the brain with nerves in most parts of the body. Ependymal cells, which line the ventricles and passageways in the brain and the spinal cord, manufacture cerebrospinal fluid (CSF). Ependymomas form from these cells.

There are four main subtypes of Ependymoma:

1. Subependymoma (Grade I)
2. Myxopapillary ependymoma (Grade I)
3. Ependymoma (Grade II)
4. Anaplastic ependymoma (Grade III)

The Grade or Stage of a tumour describes how abnormal the cancer cells look under a microscope and how quickly the tumour is likely to grow and spread. The higher the Grade/Stage, the more quickly the cancer will grow and spread.

Ependymomas can form anywhere in the passageways and the fluid-filled ventricles of the brain and spinal cord. Most ependymomas form in the fourth ventricle and affect the cerebellum and the brain-stem. The part of the brain that is affected by the tumour depends on where the ependymoma forms.



I was an ordinary woman who enjoyed life with all its challenges and heartaches. I have experienced everything.

I met my husband in November 2004 and fell head over heels in love. I could not talk about anything else; I thought there could never again be anything bad in my life because I had met the love of my life, and I thought that heartache was a thing of the past.

In December 2005 my husband conveyed the news to me that my father had suffered a heart attack and had died. I half blamed him - why did he have to hurt me by giving me such news? We had shared so many happy times together and now he was the one who informed me that I would NEVER see my father again...

Yes, I know what you are thinking - this woman must have a hormone problem - but I had so much emotion and anger that I did not know how to handle it, and he was just unlucky enough to be the first person I could take it out on.

With sadness comes happiness ... or so they say. Just after Christmas I found out I was pregnant with our first child. I was really scared at first because it was something new, but I accepted my responsibility and so my connection with Xuané began.

I talked to her every day and she grew so beautifully. We were married in March 2006 and in August 2006 I received the most beautiful angel. I had a C-Section, so I was not awake to be the first to see her.

All that I remember is when that I came to I was really sore, but the moment I heard her cry I smiled and I knew we would still share much laughter and many tears. Little did I know what awaited me; lots of tears, difficult days, sleepless nights and unanswered questions.

This is my story... an Onco-mom's story...

To live with childhood cancer is not easy and not always pretty, but between all the tears there is still something to smile about.

2009 - 2013

We lived in the Cape, in a small town called Vredenburg. Xuané went to school like a normal little girl and was a happy child. She got regular bladder infections and we had to go to the doctor every two weeks to see why she kept on getting feverish and why she urinated so little. Each time she was diagnosed with a bladder infection and her urine was sent away to be cultivated in order to find out what type of bacteria was in her urine so that the correct medicine could be prescribed to kill it. But every second week we were back at the doctor.

Xuané was referred to a urologist and she had her first operation on 28th October 2009. She was not in theatre that long, but to me it felt like centuries. A cystoscopy was done (this is where the bladder pipe is stretched so that all the urine from the bladder can be expelled to avoid bladder infection). After about an hour in the theatre, she went straight to x-rays to be injected with iodine so they could see whether the operation was a success.

It was difficult for Xuané to urinate after the fluid was injected in, so although the x-rays were taken, they could see nothing. As a result, the doctor could not make a diagnosis and we were sent home in the hope that the operation was a success. Unfortunately it was not long before Xuané was back at the doctor's office and diagnosed with yet another bladder infection.

By December Xuané had begun walking strangely. My parents came to visit for the holidays and my mother noticed immediately that all was not well. After a few times of going through this struggle, my brain began to work overtime. We had been told that she may try to fool us to get attention because she had just got a little sister and no longer got all the attention, but my mother's brain continued thinking and wondering. I went back to our GP and asked that she please refer Xuané to a paediatrician that could resolve the problem.

We were referred to Dr Adri van der Walt at Panorama Medi-Clinic in Cape Town. We were only able to get an appointment with her in the third week of January. The appointment loomed ahead of me like a mountain and I remember how anxious I was about going, but I persevered. We arrived at her offices, and the moment she saw Xuané she told us that there was something stuck in her spinal cord.

I liked her immediately because she got right to the point. We had never spent so long in a doctor's office before. Xuané was left to play with the toys while the doctor first spoke to my husband and I; she first took down our medical history and asked many questions. Thereafter she examined Xuané and told us that she would like to admit Xuané because although she could not physically see anything wrong, she wanted to do further tests just to make sure everything was alright.

Xuané and I were admitted to the paediatric ward at Panorama Medi-Clinic with absolutely no idea of what awaited us. Xuané was sent for blood tests, ultrasounds and x-rays the same day. During her ward rounds the next morning, the doctor told me that she could not pick up anything from those tests, but that she would like to do an MRI to investigate further.

An MRI was arranged but because one has to lie absolutely still and the machine is terribly noisy, the doctor felt it was advisable to examine Xuané under anaesthesia. I completed forms for anaesthesia for a second time. The MRI was done and Xuané came to approximately 45 minutes later. She was very confused and I told her not to worry, *"Mommy is with you and I will not let anyone hurt you."*

Once back in the ward, Xuané slept the anaesthetic off for most of the day, giving me bit of a chance to rest as well. Of course, my phone rang incessantly and messages kept on coming through from family and friends who were also concerned about the results.

During evening ward-rounds the doctor informed me that the neurosurgeon would come and see us the next day because they found a mass in her spinal cord but did not know what type of tumour it was. My heart sank and I did not know what to do with this news. I could not sleep that night but was strangely also at peace because now at least we knew what the problem was.

The neurosurgeon came to see me the next morning, and he even showed me the x-rays. He suggested that we identify the tumour first before anything further could be done, but to identify it meant a biopsy and that meant... operation.

I phoned my husband and told him what the doctors had suggested and told him that he should come so that we could decide what to do. I phoned my mother and my in-laws and they immediately decided that they also wanted to be there and flew down from the Transvaal to support us.

The next morning we went to the doctor's surgery and he explained the operation to us and told us what he wanted to do. He was very direct and honest about all of the positive and the negative things that could happen; she could be paralysed... she could lose control of her bladder and colon because they would have to operate very close to the nerves...

We signed the forms and the doctor scheduled the operation for the Friday morning. He told us to prepare ourselves for a very long wait because it could take up to 8 hours to remove everything with such an operation.

I went into the theatre with Xuané who was already very drunk from all the pre-meds that they had given her. We hosed ourselves laughing at her because she was giggling and making silly remarks. I went in with her and held her while the anaesthetist gave her the anaesthetic. She fell asleep slowly, and for the first time ever, I felt completely powerless. I had to lay her down so that everything could be connected, but it felt as though my arms did not want to let her go - I was not ready for this - I was not ready for all the side-effects that the doctor had warned us could occur.

The sister led me out of theatre and said, *"Go and have a cup of coffee and something small to eat - she is in good hands."*

The theatre doors closed behind me and the emotion enveloped me like a thunderstorm. I started crying incessantly and my mother and husband were there to comfort me, but how does one comfort a mother who just put her baby on a bed where she will be cut open and hurt? I promised her I would not allow anyone to hurt her. I realised I had broken my promise to her, and that broke me even more.

We went to eat something and drink some coffee but I could not quiet my mind. I only wanted to be in one place and that was with her, next to her... I needed to protect her from all who wanted to hurt her.

We went up to the waiting room and just wandered about. She was wheeled out after four and a half hours and went directly to intensive care. We had to first wait for the doctor and sisters to make sure everything was alright, and then the sister came out told us we had to wash our hands before we could see her.

It was terrible to walk in there and see all those people hooked up to machines... is my child also on machines... is my child also full of pipes and wires? But still my legs carried me forwards and there she lay... a few pipes but she was okay. I went to stand next to her and told her *"everything is going to be alright, my Bekkie, Mommy is here."* Everyone got a turn to see her then the doctor called me in to discuss the operation.

He told me that the operation had not been a success; he could only get enough for a biopsy but could not remove the whole tumour because it was too hard and was situated right in the centre of all the nerves.

He explained to us that the nerves are like a horse's tail and the tumour was in the middle of them; it was impossible to remove everything as that would mean that she would never walk again - she would be paralysed from her navel down. He told us that he thought it was an ependymoma but he did not know whether it was malignant or not, and that only the tests that were to be done on the biopsy could determine whether it was malignant or not.

After spending four days in ICU with a temperature, Xuané was moved back to the paediatric ward. On the 8th of February 2010, the paediatrician and the neurosurgeon called me in for a chat. The results of the tests were back and the doctors sat in front of me like a panel... I felt as though I was sitting in front of a jury waiting to be sentenced to jail any minute.

The neurosurgeon informed me that it was an ependymoma and that it was Stage 3 - I had no clue what that meant at the time... I remember I was calm and just said, *"Okay, how are we going to proceed?"* The doctors just looked at me and then told me that she would have to be referred to an oncologist who would discuss further treatment with us.

An oncologist? What is that? Yes... I did not know... I said, *"Okay, when can we see the oncologist?"* and they told me that we would be seeing her on the 11th of February. I phoned my husband and told him what was happening and he said fine he would be there. I phoned my mother and the minute I mentioned the word oncologist she immediately said *"That is a doctor that specialises in cancer."* I was dumbstruck, but told her that we should not worry about that now but should first see what the doctor had to say.

Later that night a woman who was also there with her child came to me and said she was sorry to hear. I was a bit upset and irritated and asked her what she was sorry about, and she told me that she had heard that my child had been diagnosed with cancer - I immediately denied this and told her

that she obviously had the wrong information and was immediately very upset. But I couldn't help wondering...

The next morning the paediatrician came around on her ward-rounds and I asked her, "*Does my child have cancer?*" She shook her head and told me that it is a type of cancer but that she could not expand on that because it is the oncologist's domain and she could not interfere.

On the morning of the 11th of February my husband and I went to the oncology department at Groote Schuur Hospital with little Mia in her carrycot and Xuané on my hip. We were led to a small room where we were informed that Xuané had a rare type of cancer and that chemotherapy would have no effect on the type of tumour that she had. They could give her radiation for 6 weeks and there was 3 ways that it could go; the first was that it could completely halt the growth of the tumour; the second was that it could halt the growth for a while and then the tumour would continue growing again; and the third was that the tumour would just continue growing unabated.

"Will she lose her hair?" I asked.

The doctor shook her head and said no, but the radiation would make her itch and very tired, and may leave a burn mark. I sat there with tears in my eyes, but because Xuané hated it when I cried, I held myself in check. Maximum radiation was prescribed, but it could only start 6 weeks after the operation as she had to heal first.

We returned home and informed everyone that Xuané had cancer and what would happen next. My husband was very quiet and asked if I was okay every so often... not for one moment did I ask him if he was all right... and about that I will most probably never find peace because he also got bad news; not only me, but because men and women handle bad news differently I never thought about how it affected him. My reaction was to burst out in tears and shout and rail, and his was to go very quiet, actually to stay strong for the both of us.

We went through to the Cape a lot over the next four weeks as Xuané had to go so that they could make the markings for the radiation, and a mould had to be made for her little face and body so that she could lie in the same position every time to ensure that the radiation was most effective.

It was also suggested that she be given a local anaesthetic every time, or perhaps just a syrup that would make her sleep through the process, but, Xuané being Xuané, she refused, as little as she was. She was very rebellious and fought against falling asleep. I asked if we could just see one time how she would react to the medicine; they agreed, and it worked like a charm - she lay there silently as we spoke.

Back home there were many arrangements that had to be made; I spoke with my employer and told him that I could either resign or I could complete the documentation in the evenings and e-mail it to them. They gave me 3 months off so that I could spend every day with Xuané during her radiation treatments - there are very few employers that are so compassionate.

I did not have a driver's licence so I could not drive through to Cape Town and back on my own; we also realised that all the travelling to and fro would be very tiring for Xuané's little body. Unfortunately my husband could not accompany us so we had to make another plan. We visited the paediatric ward where she would spend the weekdays (she would be out over the weekends) but

decided against it as I felt that spending 6 weeks in a hospital day and night would just be too much to handle.

Our family decided that they would support us during this period by taking turns to fly up and stay in the guesthouse with myself and the children so that she could get her radiation treatments. My mother-in-law came up for the first two weeks and my parents and sister and co. came up for the third and fourth weeks; my other sister came up for the fifth week. I would have spent the last week in the CHOC house but the accommodation arrangements were not made by the hospital as required, and they were fully booked. My mother-in-law flew up again for the last week to drive us around.

Xuané's radiation began on the 8th March and because she was still so young we were always helped first. We met many women that were there for radiation for breast cancer, and the aunts immediately took to and befriended Xuané. We had to bribe her, like any other child, to work with us - a Wimpy breakfast and a walk in the mall thereafter did the trick! It was nearly Easter so the malls were festive and full of Easter eggs.

During the second week of her radiation treatments, another little girl came who would get radiation on a Monday and would get chemotherapy the rest of the week for abdominal cancer. She was just 6 years old, and my first thought was *"so it's not just my child who has cancer."*

Xuané was on a very high dose of cortisone which made her bloat terribly, and I had to buy her bigger clothes so that she could be comfortable. And so the weeks of radiation passed; I could already see how much better she was getting by the third week. She was running around and playing and giggling, and that sound was the most beautiful sound that I had ever heard. That little giggle of hers could get everyone laughing and she had a way of crinkling up her little nose when she laughed that was just too cute for words.

They lessened the dosage of cortisone over the six weeks and eventually the bloating subsided. We went back to see the oncologist on the last day of radiation and she told us that we would have to come back after 6 weeks for a follow-up MRI to check whether the radiation had been a success or not.

It was wonderful to get back home and get back to normal after spending six weeks in a guesthouse; it was as though the mountain had got a bit smaller and the despondency had disappeared. I went back to work and Xuané went back to kindergarten like a normal girl.

We returned to see the oncologist at Groote Schuur Hospital on the 4th of June and she examined Xuané and was very happy with her progress. She scheduled an MRI at Panorama Medi Clinic and on the morning of 16th June we were once again admitted and she again underwent the MRI under anaesthesia.

We waited patiently in the ward for the results, having learned from previous experience that we had to prepare ourselves for the worst then the shock would not be that great, even though it is still a shock. The doctor informed us that Xuané's tumour had shrunk. We were so elated and relieved that it felt as though a little bit of Heaven had come to earth; all I could do was cry and thank God.

We were sent home, and for the first time in 8 months I could at last share some good news with the family. Everyone was so pleased that the news spread like wildfire between our friends and family.

We continued like a normal family for a change, but by August things were not going that well between my husband and I, so we decided to part ways for the time-being; the children and I moved back to the Transvaal and lived with my parents for a while.

I watched Xuané with an eagle-eye, in the hope that we had actually beaten the cancer and that this obstacle had been just another bend in the road that we would also overcome. We had been warned that something like what we had just been through could put a major stress on one's marriage, but I had not wanted to believe it; nothing could come between my husband and I.

By September Xuané's symptoms had returned and I expected the worst. We were referred to Dr Reynders at Unitas Hospital, but I did not phone his consulting rooms that day; I had heard about another doctor, a woman doctor that was very gentle with children and who would do everything within her power to sort out any problem. I decided to phone her instead of Dr Reynders.

I spoke to Dr Charmaine Jacobs and explained everything to her and she said we should do another MRI just to make sure that everything was 100% alright. On the 13th October 2010 my stepfather and I took Xuané through to Unitas and she again underwent an MRI under local anaesthetic. Once again we waited to speak to the doctor once Xuané was finished, but deep in my heart I was very uneasy because why did I have to go through all this again... it felt like a circle without end.

The doctor met us in the waiting room and informed us that the tumour was still visible and that the signs of the radiation were visible on the scans, but that she could also see a build-up of moisture, which could be responsible for the symptoms. Both my stepfather and I just started crying at the news - the tumour was not growing again; it was just a bladder infection. Upon returning home we once again shared the good news with everyone and carried on living a normal life once more.

About a month later Xuané started to have a lot of little "accidents" and she complained that her back was extremely sore and began walking strangely once more (she looked a bit like a penguin when she walked). Once again I contacted Dr Charmaine and told her that Xuané's symptoms had become worse and once again an MRI was scheduled, and done on the 23rd November 2010.

Due to the fact that it was rather late when the MRI was finished, we returned home with the assurance from the doctor that she would phone early in the morning with the results. You can just imagine what that night was like for me...

The next morning I rose early and got ready for work. Still tired from lack of sleep and with a brain that was working overtime, I kissed my children goodbye and said "see you later" and went out the back door, but just as I was about to open my car door the doctor phoned. I picked up immediately and waited for the news. This time though, I had not prepared myself for the worst - I had told myself that it was just moisture and pressure that were causing the problems again.

The doctor told me that the tumour had grown and that a neurosurgeon wanted to see us that same afternoon. I said fine, we would see him at one o' clock, and went back inside the house in a stupor and told my mother to phone Uncle Abraham because we needed to go to the hospital. I went to work but when I stopped outside my work I was overcome by a flood of emotion and just started

crying uncontrollably. I quickly went inside and told them I had to go and they understood and said that I must keep them updated.

We went through to Pretoria and were shown directly to the professor's consulting rooms. He called Xuané and I in and began asking us about the first operation that she had undergone and what treatment she had undergone since. He then examined Xuané and was surprised at how good her reflexes were. He told me that she would have to undergo another operation to remove the tumour, and further treatment would be discussed thereafter. I agreed, with the knowledge from the previous operation of what the dangers could be.

Once again I was thrown into the situation that I had to take decisions about my child that would mean that she would never be able to lead a normal life unless the operation was a success. *How was I to tell her this news? How would I explain to her one day that it was her mother who made the decision that landed her in a wheelchair for the rest of her life?* But I had to be strong... for her, for myself and for little Mia.

The doctor wanted to operate as soon as possible, and the operation was scheduled for 26th November 2010. I was very scared this time; the loneliness got to me, and I can remember that the only thing I could think of was that I wanted my husband with me. Even though we had problems, he had a way of making me feel relaxed and see the funny little things and make me laugh. I phoned him with the news and he said that he would be there. That evening he phoned to tell me he could not get a flight but that he was about to get into his car to drive up from the Cape.

The next morning Xuané was pushed into theatre. I hugged her and she did not want to let go, but the sisters again told me that she was in good hands and that they would take good care of her. Even though every part of me wanted to hold on and it took every ounce of strength, I had to let her go... and for the second time in my life I felt completely powerless.

Once again I walked that lonely path out of the theatre and the doors slammed behind me like a bomb. I just looked at my mother and once again started crying uncontrollably. We decided that to just sit there and wait would not make the hours go past any quicker, so took a walk down to the cafeteria to have breakfast and a cup of coffee. As we walked down the passage, my husband came running from the other direction. I told him that Xuané was already in theatre, and I could see the heartache in his eyes, but he remained stoic.

After 5 hours in theatre Xuané was eventually wheeled out and straight to intensive care. Once again we had to wait before we were allowed to see her, but the doctor immediately came to speak to us in the waiting room. I have never seen an expression in someone's eyes like the one I saw in his eyes that day; all he could say was that he had never seen anything like that before.

"WHAT MUST I DO WITH THIS?" I thought, *"What did he see?"*

The doctor explained to us that the tumour was much denser than he had expected and that he was not able to get all of it out; he could only remove 50% of it and was unsure of whether any nerves had been damaged during the process. I told him that I would watch her.

We went to her room and this time there was a long drainage tube in her back and a drip in her neck. Once again she looked like a little angel, and I could not help thinking about what would

happen next. She woke up in the evening and looked at me and all that I could see were the questions in her eyes. I had no answers; all that I could tell her was that Mommy loved her very much and would stand by her no matter what, and would be by her side through every little thing that might follow. She became rebellious because I could not sleep with her but the lady who was caring for her reassured her that everything would be okay. We went home to relax a bit after a long hard day and returned again in the morning.

Xuané was discharged from ICU on 30th November after we were given a photo taken by the sister, showing her standing upright with no tubes and a broad smile. She was transferred to the Paediatric Oncology ward for the rest of her recuperation. The professor visited her there and asked her how she was feeling and she said she thought she was ready to go home, at which he laughed and said that in that case he would discharge her. Doctor Charmaine said they would contact me at a later stage with all the details of the treatment that Xuané would be receiving, but that for now she needed to recuperate from the operation.

A week later her doctor informed me that they would try chemotherapy for 3 months, after which they would do another MRI to see whether the chemo had worked, and would then give her another 3 months of chemo. And yes, my first thought was that now my child's hair would fall out, and I know it is silly, but one does think about it, because *"how was she going to feel? How would she react and how would other people react?"* We were going to become part of this sympathetic family where people looked at you and stared, and I did not want to be a part of that family.

We realised that Xuané did not really have control over her bladder anymore and often wet her bed, so we decided to put her back on nappies to spare her the embarrassment. She went through between 13 and 15 nappies per day and it was difficult to keep up because the nappies became very expensive, and I had to start depending on others for help.

It is strange how people support one when you are going through difficult times; many want to come and pray, others want to help financially... I accepted the prayers but did not want to accept financial help; I asked that people rather bought nappies to help as our medical aid covered her operations and treatment.

After 6 weeks of recuperation Xuané was again admitted on 15th December 2010 to have a port put in so that the chemotherapy could go directly into her main artery. The first round of chemo started on the 16th December, and we realised that after all the horror-stories we had heard, it was not that bad. We were inundated with gifts from all who visited the hospital over the Christmas period and Xuané enjoyed it immensely. She had loads of fun with the sisters on duty in the hospital and we killed ourselves laughing at them and at her.

She was released on 17th December and a great Christmas lay ahead of us. She loved this time of the year; yes, because of the presents, but I think also because it was the time of the year when all the family was together. Christmas that year was held at my older sister's home, and the children had a whale of a time.

I was combing her bush of long hair on New Year's Eve, and when I looked down a bunch of hair had come out and I got the fright of my life. All that I could do was to look at my mother and say *"NO!"*

Right then and there I turned on my heel and walked away to collect myself... I had to be strong for her, but Lord knows I could not pull myself together at that moment.

My sister made a nice plait and Xuané was very happy and laughed like she always did, but my heart was very sore because, although I was very glad that she was happy and laughing and talking and was not taking life so seriously, my heart was shattered. Very soon my little girl was going to be without hair and everyone was going to stare at us... did I have the strength for that? No, I did not, but I had to find the strength from somewhere because she needed me so much now, and little Mia even more because even though she was still so young, she was also going through all these things that had crossed our path.

I had to swallow my tears and put a smile on my face to make everyone else around me feel better, even though my own heart was busy shrivelling up. I had to answer questions and walk about in the town, even though all I wanted to do was to go and sit in a corner and cry and not come out until this nightmare was over. Little did I know then that the nightmare had only just begun.

In early January 2011 I decided to cut Xuané's hair in a bob because more and more was falling out and every morning when she got up she had less hair. At her sister's second birthday she only had a few clumps of hair here and there, and I could see what it was doing to the family. We put hats on her but Xuané was always positive and continued laughing and talking as though nothing was wrong.

Her second block of chemotherapy started on the 20th January and she had no new side-effects; she did not get sores in her mouth, she was not nauseous, she just continued losing her hair and was worn-out after every session. All of her hair was shaved off after the second block of chemo and she looked at me and I had to struggle to hold back the tears. She smiled at me and said, "*Mamma I am so nice and cool now... am I pretty at least?*" My child, you are the most beautiful bald head I know!

Her third block of chemo started on the 19th February and when it was done we returned home with the thought that it would all be over now. On the 16th March Xuané went for another MRI under local anaesthetic to make sure that the chemotherapy was working so that we could start with the next round. The doctor informed me that the tumour had grown while Xuané was receiving chemotherapy and that the chemo treatment would not be continued; she would from now on only receive palliative treatment as any new symptoms arose. On the one hand I was glad that the chemo was over, but was also anxious about what lay ahead. Her port was removed on 20th April 2011 and that signalled the end of chemotherapy.

On the 19th May Xuané underwent another MRI to check on the growth of the tumour and the amount of damage it was doing. I could see it daily because she was walking with more and more difficulty, but it was as though I suppressed it and blocked it out; I did not want to admit it.

At the end of June 2011 the children and I once again returned to the Cape and my husband, and I started work again immediately and Xuané went back to school. By the 11th July we had been to see a paediatrician and an oncologist because Xuané was suffering very badly with her bladder and her urine smelled rank and tart. She had begun to feel very self-conscious about it because even her clothing had begun to reek and no matter what nice-smelling stuff we used, nothing helped cover the awful smell.

I went through so many emotions during the month of July that I could not explain to people how I felt, so I decided to write. I realised that I was not the only one who felt like this; that there were other mommies like me who were dealing with emotions that they could not describe to others without crying hysterically, and so I wrote this on my Facebook wall so that everyone could understand how I felt:

From one Onco Mom to Another...

Have you ever had the feeling that you lose all your Mom-powers when you walk into a hospital?

Have you ever felt that anger when they stick your child with needles and push pipes into her and inject her with poison and there's nothing you can do about it?

Ever felt the mistrust when you look into your child eyes and you know that you lied, that it will hurt?

Ever had the feeling of unimaginable pain when the child of another onco-couple loses the fight and you wonder when it's going to be your turn?

Ever experienced that feeling of speechlessness when your child comes to you and asks you when Jesus is coming to fetch her home?

Ever felt as if the Earth is trying to suck you in and you can't get out when those theatre doors close behind you?

Ever felt that you could murder someone with your bare hands when they make stupid remarks about your child?

Ever felt that you want to run away and sit in a corner and just forget about everything for a little while?

How do you know when you've reached the limit of the amount of bad news you can take? Everyone always wants to know how things are going and if you're still strong enough. It's as if they expect that you'll have a nervous breakdown any moment, and everyone stands there bewildered the day Mom starts crying uncontrollably... but they're standing there with the psychologist's number in hand... I mean freaking HELL!

Definitely my experience!

My life fell apart the day I found out my child has cancer. Every time you hear bad news another little piece of your heart breaks and it's as if you eventually have no more tears left. What you have in place of tears is an uncontrollable rage and harshness, and unfortunately the person who phones first is the one to be attacked.

Someone just has to look funny at your child's bald head and you feel like you're about to lose your mind and attack him. But then you get the ones who will actually tell you off for cutting your little daughter's hair so short... "She looks like a boy." So forgive me if I don't always have my moods under control, but sometimes it's just flippin' impossible.

You don't always want to hear that you must be strong and you must keep on believing; it's very difficult if you're constantly being given bad news. The cherry on top is when the doctors tell you that there's nothing more they can do for your child; you should just all go home and wait and carry on as per normal. How the hell does a person continue like normal?

So, to every cancer mother out there:

You are **allowed** to be angry

You are **allowed** to shout and scream

You are **allowed** to be tired

You are **allowed** to get sick

You **ARE ALLOWED** to cry!

We are also just human - we don't have super-powers, being strong is our only option; we are going to cry and get angry, we are going to get sick and tired, so stop watching us like hawks and waiting for us to fall apart. For us there is only one thing to focus on and that is GOOD NEWS about our children. You live every single day for that extra bit of hope that today will be a pain-free/medicine-free day.

Xuané again underwent an MRI on 29th August 2011 at the Panorama Medi Clinic, and the urologist informed us that her bladder was becoming dysfunctional and in order to prevent infection they would insert a suprabubic catheter that she would be able to manage herself at a later stage.

During the operation, which would not take too long, her appendix would be connected to her bladder; should they not be able to use her appendix, they would use a piece of her small intestine. I was scared because I did not want to hurt her; I had already broken too many promises to her.

The operation was performed on 30th September 2011 and Xuané was sent home with a catheter for 6 weeks. She was not allowed to go to school with this catheter in as the chance of infection was very high, and an accident in front of her friends would have broken her.

Once the six week period was over we returned to the urologist and he showed me how to drain the catheter; it was actually rather easy, but had to be done every 4 hours. I showed one of the teachers at her school how to do it so that I did not have to take off work every time to go and do it. For a while it went very well; she had fewer bladder infections and was very happy.

Around November 2011 I began to notice that Xuané was walking less and crawling more, so I asked her why she was crawling and she told me that her one foot felt funny. I was confused and angry at the same time; what was she actually saying? I took a needle and lightly pricked her foot and asked her if she felt it - her answer came like a tidal-wave, "No, Mamma!"

I realised that my child was becoming paralysed... she was 5 years old and would be paralysed by the time that she had to start school; she would never be able to do a sport, or ballet, or be able to dance at her matric farewell... or even at her wedding. "What man will want a paralysed woman?" were my thoughts.

Yes, it sounds selfish, but those are the feelings that come automatically and the thoughts that drive one insane. My parents bought a walking frame to see whether it would help her walk because we did not want to get a wheelchair because that would mean... yes... my child is paralysed!

We struggled to get her to use the walking frame because it was very difficult for her to move without falling. My parents then bought a wheelchair and she made it her own; she raced around as though she had not a care in the world and she was so patient and always ready with a smile and a hug.

I decided to go for a second opinion to make sure that there was nothing else that could be done for her; I made an appointment with Professor C Stefan and we went to see her on 21st February, together with Dr Vlok the neurosurgeon, who told us they wanted to operate, but this time in order to remove everything. The nerves would be cut, which would mean that Xuané would have no feeling and would be paralysed from her waist down.

My husband had to make the decision, and he said no, we are not going to operate; we should have another MRI done to make sure that that is the right decision; I informed the doctor of our decision and another MRI was scheduled.

On 12th April 2012, I was at work, relaxed and focusing on something else for a change when I received a phone call from the doctor; when I heard her voice on the other side of the line my heart skipped a beat. She told me that the tumour had grown too much and an operation was totally out of the question; they could do nothing for her and they suggested that we enjoy every minute of the time we still had her with us.

I said *"that is fine, thank you"* and put the phone down and burst into tears. My boss walked into my office and hugged me close and whispered to me that everything would work out fine but I did not believe him because up to now everything had gone wrong; nothing ever went right. I was sent home and had to share this latest news with my husband.

I remember walking across to my neighbour and when she opened her front door I just looked at her with tears in my eyes and she asked, *"Oh no, what now?"*

I walked in and she put the kettle on right away; I told her everything and she held me close as I cried uncontrollably. I remember telling her that I was afraid that if Xuané did not make it I would lose my husband, and I could not lose both my child and my husband; that would just be too much. She comforted me and told me not to look for things that were not there, and to just relax.

My husband and I decided to return to the Transvaal so that Xuané could spend whatever time she had left among family and those who loved her, and we also needed support for the road ahead.

I attempted to express my deep distress, but it was difficult to speak to people without bursting into tears, so I took to writing on my Facebook page instead so that everyone could see and gain a bit of understanding as to how I felt:

Help a Mother in Distress!

"My child has cancer!" Yes it sounds very blatant to say it like that, but the more you say it, the more it sinks in... and the more you realise this is reality!

Many people have told me that I am an inspiration for them because, despite the past three years' setbacks, my husband and I remained standing and continued as normal. Well, perhaps not normal, because when hospitals and pharmacies become a daily expense there is something seriously wrong, but apart from that, we kept laughing, kept hanging out with our friends etc.

"These days things are getting more difficult; I see new things every day, stress is beginning to take its toll on me. My last call from the oncologist was at the end of April when she told me they cannot do anything more for my child and that she has a maximum of 2 years to live.

These days I can see more and more how she yearns to play with her sister, to use the toilet like a "normal" girl, not to be in pain all the time... her legs are full of holes from the lack of blood circulation and it takes ages for them to heal.

I dream many nights of standing next to her grave, and when I awaken my pillow is sopping wet from the tears I have cried in my sleep. I am too scared to go back to sleep, to dream that dream again... and then I realise that one of these days it will no longer be a dream... How will I react? Will I ever get over it? Will I ever again find peace and serenity? Will I push my youngest away or hold her too close because I am scared of losing her too? These are questions that go through my mind every day I see her.

Do you know what it is like to know that you will never see your child matriculate; help her choose her matric farewell dress; experience her first broken heart; see her walk down the aisle, hold her first baby in her arms? Yes, it is easy to say be positive, and I am trying my best, but people, I can see how my child's health is getting worse; I see her tears of pain; I see the yearning in her eyes to go and play with her friends, the despondence when she has to be helped to do absolutely everything...

The other day she asked me "Mamma can't Jesus just come and fetch me now so that your back will not hurt anymore? I can see how much your back hurts when you have to pick me up." HOW does one answer such a question? How do you look at your child and comfort her without tears in your eyes?

So, I try to remain positive, but it gets more difficult by the day. Please forgive me the day that I look a bit dishevelled, but I am only human. Some days I will be more tired than others; some days I will be pale; some days I will get up with puffy eyes; some days it will seem as though I am on another planet; and some days I will not want to speak to anyone! Just give me a few days... it just means that reality has sunk in a bit deeper...

If anyone that can answer all my questions, apart from telling me to pray, because that is all I can do every second of every day, please do so, because I want to stop feeling as though I am going insane.

The move was arranged and we returned to the Transvaal and started looking for a school for Xuané and Mia, but to find a school that is wheelchair-friendly was a mission. Everyone had the same response, "Sorry Ma'am but we cannot accommodate you!"

One school decided to take a chance; Kallie de Haas Junior School accepted Xuané without thinking twice. They made ramps so that she could move around more freely with her wheelchair and made her desk higher so that her wheelchair could fit under it. We did not ask for any of this - they just did it of their own accord. The kindergarten teacher learnt how to drain her catheter, which was also a bonus because it meant that I did not have to slip away from work every day to drive to the school to do it. Xuané finished her Grade R year at Kallie Klitsies and enjoyed every moment of it.

I was sitting at work one day thinking about what I would buy for the children for Christmas and thought "they have so much, but Christmas is not Christmas without presents." I sat and thought then about what I wanted for my children, so I wrote once more:

A Mother's Christmas Wish

Every mother's Christmas wish is different. Mine starts with PLEASE DEAR FATHER, GIVE MY CHILD BACK HER HEALTH!

So, here is my Christmas Wish for you, My Child:

On a Thursday morning 6 years ago Dear Jesus gave you to your Pappa and me. Even though Mamma was very sore I will never forget that day when I first heard you moan and groan for the very first time. I could not talk, but I heard you. It brought a smile to my face and I knew from that moment that we would share many laughs and tears.

As you grew and reached all your milestones, so my love for you grew too. I wish every day that I could take your pain and discomfort away, but it is beyond my control. What I can do is make every day as comfortable for you as possible; to make you laugh and sometimes cry too, and to just love you for the dear child that you are.

I know that you often cry softly at night so that I cannot hear you; I know that you often look longingly at your sister running around and jumping up and down and climbing on things... wishing and yearning to join her. My darling child, the Lord will not give you something that you cannot handle; so it has been said to me, and I believe it with my heart and soul.

So my dearest, even if you cannot run around, even though you cannot dance, even though you cannot climb and have fun, even if you cannot help yourself, just know that I am there to help you and to care for you as much as I can.

You have been through so much, achieved so much in your 6 years – you are the ultimate! You open people's eyes, you give people hope and strength for tomorrow, and you my child, with your smile and your beautiful face open people's hearts to miracles every day.

My Christmas Wish for You:

May you enjoy the fruits of everything you do; May you get the health that you long for; May you experience the pleasure in every precious moment and may you always be my little Xuanétjie. You are my inspiration, and you help me to be a better mom for you and your sister.

THANKS FOR BEING THE CHILD THAT YOU ARE!

Love you loads, my little child!

MAMMA

And so we continued each day... with hope and prayers that things would get better.

January 2013 arrived and with it time that we had to go back for a follow-up MRI, which was scheduled for 29th January. We went to the hospital with hearts full of expectation and so much fear. Xuané was anaesthetised and we waited in the waiting-room while she underwent the MRI.

Once the MRI was done, the doctor called us in and gave Xuané a thorough examination then gave us the results: The tumour had grown, this time by 2 centimetres, which may not sound like a lot to you, but for such a small body it was a LOT.

We returned home with broken hearts, and as with all the other times, we had SO many questions: *HOWCOME, WHY AND FOR WHAT REASON?* Unfortunately, my questions remained unanswered.

We thrived on the support of family and friends and Xuané started her Grade 1 year at Kallie De Haas Primary School and was ecstatic about starting “big” school. Her teacher agreed to drain her catheter every day and to phone me should there be any problems. Xuané enjoyed going to school and came home with new stories every day... and so many smiles. Every night at bath-time she and I would gossip about the day and have some wonderful giggles.

Xuané was examined by an oncologist in July 2013, and the doctor was very happy with her health apart from the tumour. She told me that we should keep an eye out for any unusual lumps or other symptoms and said she wanted to see Xuané once a year from then on because to see her every 3 months while she was so well was unnecessary.

I was so happy! *“My child is getting well, our prayers have been heard and we can carry on like any other normal family at last.”* Xuané and Mia went to their grandmother for a short vacation, and one day in early September 2013 I sent a short sms to check that the children were alright and that they were behaving themselves, and my mother replied that all was 100%, but what was that lump on Xuané’s back?

My heart sank - I asked my mother to send me a photo, and when I got it my heart felt as though it was sitting in my throat. I immediately called the oncologist and asked her what it could be - she told me that it could be the tumour that had spread. I listened to what she said but I did not want to hear what she said.

I made an appointment and on 30th September it was confirmed that the tumour had grown and had broken through the sacrum and was filling her whole little belly. Once again I burst into tears and asked the doctor how much time she had left - she told me that she could not predict that but that what she could say was that we should enjoy and spend every moment we could with Xuané.

The annual visit to the doctors was once again changed to a monthly one; we were to travel through to Pretoria once a month so that Xuané could be monitored. The doctor also asked me how bad her pain was, and I told her that Xuané never really complains of pain and the doctor said that was fortune within the misfortune because if she should feel her coccyx break it would be an unbearable pain.

Once again I had to share the news with everyone, but I had no energy for more questions so I sent short sms messages to all of the closest family and friends and posted a short message on her Facebook page. The questions flooded in, but I did not even want to look at them, let alone answer them; I had to process it all myself first before I could respond to other people's pain and questions. I did not tell Xuané about what had transpired because she was already frightened enough about needles and operations; we carried on as normal.

In November 2013 Xuané received certificates for her excellent performance and I was very proud of her, but I could not but help wonder whether these would be the only certificates that she would ever receive or would she receive lots more.

I could not help wondering how long she would still be with us...

Would she reach her 8th birthday?

Would she go quickly?

Would she suffer?

2014

The year started well; Xuané started Grade 2, but something was different about her - she was quieter, more anxious, and she wanted to be around us all of the time. She did not want to be left alone for one second; why, I had no idea. Sometimes I got a bit impatient with her because some days I needed to just be alone with my heartache and tears, and with her around all the time I could not vent my emotions, only my frustration.

The tumour was very large; I could already see the damage because as the months passed I could see she was becoming more tired; her stomach started swelling, and it became more difficult to drain her catheter.

Early in May 2014 while I was bathing Xuané, I realised that her one leg was so terribly swollen that it looked like she had three legs. I phoned the doctor and she told me to take her to casualty so that the locum could have a look at her and see what was wrong. I went to casualty and the GP told me that it looked as though there was a blockage. What a blockage meant, I had no idea...

We went through to the hospital early the next morning and the oncologist did a sonar, which diagnosed a blood clot. I remember thinking *"Dear Lord, how much more? How much more does my child have to handle; I am not sure that my heart can handle any more."*

We were sent home but Xuané had to have her blood tested every third day to check her BPI Count, which would be given through to the oncologist who would tell me how much Warfarin I should give her.

The 26th May was blood-draw day, and the sisters struggled to find Xuané's vein; she was very tired and pale, and I thought that it was just fatigue and maybe a little cold, but she did not have a fever. The sisters recommended that I take her to see the doctor because she was so pale, which I did, with an anxious heart. The doctor pricked her finger to draw blood to test its viscosity, looked at me and told me to take Xuané to the hospital immediately because there was no blood in her body. I almost died of fright when I heard this and immediately phoned the oncologist to tell her what had happened and that I was on my way.

Standerton is about a 3-hour drive from Pretoria but I made it in 2! I was so stressed that I got a spasm in my lower back and at that stage I hardly had the strength to pick Xuané up without hurting myself further, or worse... letting her fall. I remember opening the car door, picking her up, hearing the car door slam shut then I started running with a half-awake, half-asleep Xuané in my arms.

The doctor was waiting for me in the ward and immediately inserted a drip in Xuané and gave her a half a pint of blood. The doctor did a blood test to check the viscosity and also checked her Haemoglobin; she then called me aside and told me that it looked as though the tumour had broken loose and caused internal bleeding, but that they were not sure of the origin of the bleeding or how she was losing blood as there was no sign that Xuané was bleeding out anywhere.

Xuané's HB count was 3.9 that day, and the doctor told me that had Xuané not been such a fighter she would not have made it through the day. I really got a fright when I heard that and I realised that I was not ready to say goodbye yet. I asked the doctor whether we could insert a permanent catheter because it was becoming more and more difficult to drain her current one. She agreed and a permanent catheter was inserted, and she also showed me how to insert a catheter should that one come out at an inconvenient time. The doctor also told me it was time to take Xuané out of school.

From then on we went through to Pretoria about every 3 weeks so that Xuané could get a pint or more of blood. The tumour's growth had got completely out of control; she looked as though she was nine months pregnant and I had to buy her clothes for an 11-12 year old so that she could be comfortable. It was difficult to see her like that every day because her stomach swelled more and more and she slept so much.

We held a birthday party for her 8th birthday in August, and she fell asleep during her own party. One of her friends came to tell me that Xuané was asleep and she thinks I should phone her mommy to come fetch her.

ON the 13th October Xuané got feverish and had a really hard time breathing and was very uneasy. I phoned the oncologist and told her that I would bring Xuané in the next morning because something was not right.

We were admitted on the 14th and they gave her blood and did a whole host of tests. On the 16th the doctor called me aside into a small room and I knew this meant that there were problems. She told me to sit down and then said, "*Therese, Xuané's little body is tired of fighting.*"

I shook my head and started crying as I realised that this was the end. I said "*My child not going to go home again, hey.*" and she just shook her head. I asked her to help and not to send me home again as I would not be able to endure it if Xuané died at home. She suggested that I phone the family and tell them to come and say goodbye.

Once I had dried my tears I returned to the room and gave Xuané a kiss on the forehead and told her mommy was just going to fetch granny in the parking area. She smiled and said that is good. When I got outside I sent a sms to those near and dear to say that it was time and they should come.

My mother and them stopped outside and as soon as I saw my sister I just burst into tears; I did not know what else to do because I was at the stage that I could no longer help my child, and no matter what I did, I could not save her.

I sent a sms to my one friend who had lost her beautiful child a month earlier; I cried on her shoulder and asked her "*Why, why my child?*" She could not answer me.

On the evening of the 17th October I opened my Bible for the first time in 5 years. I read a piece and got down on my knees; I folded my hands and made a conscious decision, crying all the while, to rather ask God to come and fetch her instead of asking him to heal her. I could not sit by and watch my child struggle to breathe any more; I could not watch her suffer and get sicker any more - I asked Him to please relieve her of all the pain and suffering.

And so the weekend passed and Xuané started looking better; she spoke to and laughed with everyone and joked with her aunts and laughed at the sisters in the ward. My mother slept with her on the Saturday night and the two of them sat and spoke nonsense until eleven o' clock while my husband and I got a bit of rest.

My husband and I returned to the hospital on the Sunday and she was waiting for us in the waiting-room with a big smile. She was terribly swollen but I thought *"Oh it is just the fluids that they are giving her."* Everyone went home on the Sunday and the Tuesday she got even more swollen. I would go home on Wednesday 22nd and my husband would stay with her until the weekend and then we would change places.

Her drip went into the tissue for the second time and I decided to take her home because I knew she was not going to make it. The next morning when I got up she was struggling to breathe and spent most of the day sleeping. My mother came to visit to see how she was doing, and when she arrived I told her that Xuané was not looking good. My mother-in-law and sister-in-law also popped in and we all sat in the lounge and spoke to Xuané, after which they all left and she said she wanted to go back to her room.

That night I was so scared of going to sleep because I was scared that she would no longer be with us when I awoke. My husband and I lay with her for a long time and I put my hand on her chest and I said to him that her little heart was beating very fast. I stroked her hair and just sat with her for a while and eventually I went and had a bath and went to sit in the TV room.

I was exhausted after the week and a half in hospital, and my husband told me to go and get into bed because I had to get up early to go to work the next day. I told him that I was petrified to go to sleep. I got up and went to sit by her for a while again and just stared at her for a long while.

I took her hand in mine and said, *"Sussa you are tired, go and rest now... we will be okay I promise."*

She opened her eyes and looked at me and then closed them again without saying a word. I kissed her on the forehead and walked out. I got into bed and lay awake for a long time listening to how she was struggling to breathe, then I fell asleep.

I will never forget the morning of the 24th October. My alarm went off at 04H00 as per normal, but there was something different... there was dead silence, no sound of Xuané struggling to breathe, not a sound from outside... just... deathly silence...

Deep in my heart I knew what awaited me but I blocked it out and walked past her room. I switched the kettle on, got bread out to make Mia's sandwiches for school... I remember opening the butter, but I told myself *"You have to go into that room one time or the other."*

I put the knife down and walked back down the quiet passage; I walked into her room and stood there with my hand on the light-switch... I waited for a few minutes then said to myself go on, switch on the light. I took a deep breath, switched the light on and walked in and there she lay, dead quiet.

I looked at her and realised that she was no longer with us, and all I could get out was *NO!!* and *MY DARLING!!!*

My husband came running and I knelt down next to her bed and held her cold hand. He felt for a pulse and I could see the tears begin running down his face.

Mia came in and asked "*What now Mommy?*" I could not get a word out and my husband told her that her sister has gone to be with Jesus. I hugged her and she turned around and walked out.

I got up and realised that I had to let people know. I was bewildered... I phoned my family first and then we phoned the minister and asked what the next step was. We were not sure what time Xuané passed on so we had to work quickly - the minister phoned the undertakers and they arrived at 06H00.

I was sitting crying in the bedroom when the minister called me and told me to bathe Xuané and take all the tubes out and dress her nicely - I wanted to kick him at that stage because how could he expect me to bathe my daughter who had no more life in her myself? According to him it was one way to take my leave of her, but at that stage I thought it was very insensitive of him.

I walked back into her bedroom and as soon as I saw her the tears started coming again. I got everything ready and removed her catheter and my husband helped me to bathe her, but when he lifted her up so that I could put the dress over her head some moisture came out of her mouth and he told me I should go out and that he would first clean up. I left then but every fibre of my being just wanted to be there with her.

When I went back in we finished dressing her and I held her hand for the last time and then went and waited in the passage. My husband picked her up and placed her on the gurney; they covered her with blankets and strapped her on and then pushed the gurney out to the hearse. It was the worst feeling to watch them drive away knowing that I could not go with her.

A friend offered to take Mia to school and I accepted gratefully as I just could not face all those people at the school at that time. I informed everyone and put a notice on Facebook, and so the people began arriving and then we had to go to the undertakers to make all the arrangements for the funeral.

I was in a total daze... I listened to what the man was saying, but was not actually hearing a thing. We decided to have a private cremation and to not have the coffin in the church because we were scared that her sister would want to take Xuané out of the coffin; she was still very young and did not really understand death, so we wanted to avoid that.

The man at DOVES in Standerton was so gentle and he spoke to us so nicely. He asked if there was going to be a viewing, and at first I did not want one because the sight that I had seen was not a nice one and I did not want everyone to see it, but my husband asked whether we could have one and I agreed.

Once back home there was an influx of people and flowers were constantly being delivered, but I just could not anymore and went to lie down in my room for a bit to hide away from everyone and everything. I just wanted to be alone with my emotions, which were all over the place at the time. We knew that she was not going to make it, but the shock was still a big one nevertheless. I took one of her favourite teddy bears and went to lie down on the bed, but a little bit later I lay down next to the bed on the floor where nobody could find me.

My sister walked in and just held me tight. I was heartbroken; my child was gone... forever. I had to pull myself right because I could not collapse... everyone expected me to so I would show them I would not. I could handle anything, and I would handle this bad experience as well. I got up and wiped away my tears and went and made coffee for everyone.

My phone went mad but I did not even have the strength to read all the messages never mind still answer them. I understood that people were concerned and wanted to extend their sympathies, but all I wanted to do was to sink into a little bundle and sit and cry. I hurt so much, and nobody could ever understand - not unless they had been through it themselves.

All the arrangements had been made and Xuané's funeral had been organised; the death had been registered and all that was left of my child was a mountain of memories and a death certificate. The funeral was to be held on the 28th October... the same day as her operation 5 years previously.

The viewing was at 11H15. My sister-in-law, my brother-in-law, and two friends accompanied me - I was told that I could go in but when I started walking down the stairs I began shaking so much that I turned around and asked my brother-in-law to go in with me. I stopped at the door, but when I heard him say "Look how beautiful you look, My Rose" I walked on in. I saw her lying in a box, but she was the most beautiful angel and had such a peaceful expression on her face... I told her that I loved her and stroked her face but got a fright at the cold it gave off.

We returned home, but my heart was not there; it was with her. More than 300 people attended the funeral - I did not even know half of them. Afterwards they came to drink tea at our house and once everyone had left the deathly silence screamed in my ears.

I went back to work the next day and many of the people did not know how to treat me so they kind of avoided me. I suppose it is understandable because I could either lose it or be awful to people or I could just be myself, like I was every day. One girl said she did not know how to deal with me and I told her to just treat me as she normally does on any other day; I am still the same person, just with one child less.

On the 14th March 2015 I had to bury my child a second time; the headstone is inscribed with the following message:

*"Xuané Nieuwenhuis
2006-08-17 – 2014-10-24
Goodnight my Darling... See you tomorrow
Love you LOTS!"*

My sister put something in for her and my older sister, who always called her Pikkewyn (Penguin), bought her a small penguin and asked me to please bury it with her.

They were not there. I was very hurt by this and I was angry. I knew that she could not bury Xuané again, but I needed her because I had to bury my child again. Even though we did not always get on, my older sister was very important to me and I needed her so much on that day, as I needed my middle sister and my mother. Xuané was her Godchild, and I thought "Phew! Really?"

But then I thought about it and realised that Xuané was hers too really, and she also had to say goodbye for a second time, as we all had to. My older sister comes across as being very hard and tough but she is very sensitive, so when she sent a sms saying that she knew she had disappointed us all, I reassured her and told her that was not so at all and that I understood 100%.

It was a very short service and only close family were allowed. I put a letter in for Xuané as I could not find or think of anything else to include.

Your "Memorial" Letter - My Dearest Xuanétjie

Mommy wanted to bury something with you tomorrow but I do not have something specific that I can put in... so I wrote you a letter... from my heart to you... My Beloved Little Xuané.

My Beloved Little Flower

My heart is aching and I really have to say goodbye to you now; you are not here anymore, your ashes are being buried and it is heart-breaking for me to look at this little box and to think that it is you that is inside of it.

My love, you were my everything; you were my superstar; you were my rock. You kept me strong when I thought I had no more to give and with just one smile you could make me feel better. You always just wanted to be near me and I could never understand it - I got frustrated with you at times, but now I understand it; you knew that your time to say goodbye was near. If only I had known, I would have thought twice before becoming frustrated with you... I would have read more stories with you... I would have drawn and coloured in more with you...

It is all still rather unbelievable to me. It feels as though you are not gone... but you are! You are not coming back; I will never again see your sparkling eyes or be able to give you a hug... My heart is empty without you my darling... my heart is in a million pieces and it is not getting better.

Mommy misses you so much. I just wish that I could have done more for you. Mommy tried to do everything that I could to make you as comfortable as possible but it was not enough. Mommy is sorry that I did not sit with you the whole night... Mommy is sorry that you were alone when everything happened... Mommy is so very, very sorry. Nothing I say or do can bring you back, but please just know how indescribably much I love you and that I will always carry you in my heart and that I will never ever forget you.

You are not going to be able to read this letter, but I am burying it with you today in the hope that it will make this pain in my heart feel a bit better. Mommy will look after sis and we will do everything together. I am going to live for you, for your father and for your sister. We are going to enjoy life on your behalf too, and you will always be with us in spirit; you are, after all, my Sunshine Girl.

Mommy loves you my Aspatat my Bekkie Blom, my Angel Child. I will see you again and then I will never ever let you go again. I PROMISE!

LOVE YOU AND REST IN PEACE MY DARLING, YOU DESERVE IT!

FEELINGS

Feelings are a strange thing. Emotions are even worse. They catch you at inconvenient times and in strange places...

The tiniest thing that you see that reminds you of her can open the floodgates, and you cannot stem the flow of tears no matter how hard you might try. Before you know it a week has passed, then 2 then 3... and the heart-breaking fact is that it is just going to get longer and it is never going to end until the day that I lay down my head.

Some days I just felt that everything was getting to be too much, but then I would see that little glimmer of hope again and would get strength from Above to carry on.

December was coming closer and I did not want Christmas to arrive. I decided to write this story to share that terrible day so that everyone can understand how I am feeling.

My Worst Nightmare Came True!!!

8 years 2 months and 6 days... That is how old my child was and will always be...

I am counting the days since you are no longer here. It is already 45 days without you and it is still extremely painful.

Mommy was told in April 2012 that you only had 2 years to live but did not believe it. How can my child be taken from me? Little did I realise that 2 years and 5 months later you would be taken from us.

The last 3 weeks of those 5 years that you were ill were the most heart-sore and the most difficult for me. I sat at your bedside in the hospital day after day, watching you fade more and more each day and I could do nothing about it.

I had to watch how difficult it was for you to wake up; how difficult it was just to breathe. You were craving hot chips and I went to buy them for you but you did not eat them. You got so many presents but did not take too much notice of them.

The day that the doctor called me in and told me your little body was too tired to fight any more made a little piece of my heart break off. I asked her... "My child is not going home with me, Hey?" She just shook her head and I knew it was time to say farewell to you. I phoned everyone and told them they must come. It was bad for me; I was in a stupor; I couldn't eat, and I was too scared to fall asleep.

On the evening of the 17th October, when you were fast asleep, was the first time that I opened my Bible in 5 years. I read a bit and fell to my knees and in tears I prayed that Jesus would free you from the endless pain and suffering. That was the worst for me... to ask that the Lord must come and take

my precious child, knowing that I would never again be able to hold you, or smother you with kisses, or take care of you... that was so painful for me, Bekkie.

On the 22nd I took you home, with the knowledge that you were not going to make it, but you wanted to go home, to lie in your own little bed. The next day your grandmother and others came, and you really struggled to breathe. I was so petrified to go to sleep that night because I was scared that you would already be gone when I woke up.

Mommy sat on the bed next to you, and just stared at you for a bit. I rubbed your head and put my hand on your heart; I told Pappa that your heart was beating very fast. I gave you a kiss on the cheek and told you to rest easy, we will be OK. You looked at me and then closed your eyes again.

I woke up the next morning and heard that silence, and I knew what awaited me, but I half avoided it. I went to the kitchen to make your sister's sandwiches for school, but then decided to first go and see if you were OK.

Mommy stood at your room door for a while before I could put the light on, but then I gathered all my strength and courage and switched it on. I saw your lifeless body lying there and my heart missed a couple of beats. Pappa came to help and then we had to let everyone know that you had gone home.

That day was bad for me, but your funeral... to see all those people and to know that it was our final goodbye... I just wanted to go and curl up in a corner somewhere and never come out again.

I wrote you a letter from my heart, and added it to your funeral letter. I know you hear it... so listen closely what mommy has to say now:

Our Beloved Angel Child, You have had so many nicknames... Bekkie, Parra, Pikkewyn, Liefiekind, Spidercup, Roos... Our hearts are empty and sore, but we are so glad that you are FREE!

Your innocent eyes that shone with love... and that unmistakable smile when you crinkled your nose... will live in our thoughts and our hearts forever.

You are an enormous inspiration to thousands of people, and even though you were still small, you taught people to hope and to trust. You are unique, and nobody will ever take your place in our hearts. We love you to distraction and miss your little giggle every day.

As you always said, "Good Night... See you tomorrow..." so we now say to you "GOOD NIGHT, MY DARLING, SEE YOU AGAIN ONE DAY!"

Mommy misses you more every day, but knows that you are in a better place and that Jesus will take good care of you. Love you very, very much, my child.

*Until I see you again... **LOVE YOU ALWAYS!***

Juanita du Plessis sings a song "Ek Laat Jou Gaan." She was Xuané's favourite singer and this song was also played at her funeral. The words never really made sense to me until the night of 17th October 2014. I knew I had to let her go but I did not know that it was going to be so bitterly sore.

The words touch one's heartstrings but they say exactly what I wanted to say to her so I asked that this song be played in the church especially for her.

"I Let You GO"

(Loose translation for those who do not speak Afrikaans)

*A heart that breaks, a tear that rolls, it is the deepest hurt that nobody will understand.
I know it is time, my heart is full and I do not want to let you see me cry
With every heartbeat my soul screams inside of me
I so much want you to stay longer but I set you free, I let you go.
All the tracks to the rainbow call your name; your dreams are all waiting, go and fetch them now
I will be here if you turn around, to hold you up high.
This time I cannot go with you my love; I let you go...
I love you; never forget that. There will be a vacuum here that nobody can fill
I look upwards and I know that you know that you will be safe where I cannot see you
Here I remain; here I must stay. I wipe the tears away and put on a smile...
But I set you free, I let you go...*

I had many emotions and cried a lot. I had questions, anger, hurt. Nobody could explain to me why and wherefore. I wanted to distance myself from everyone and everything but it was impossible with Christmas around the corner.

I got up every morning with emptiness in my heart, and it was as though the hole was getting ever bigger with every day that passed. I started to make lists of everything that was needed for Christmas to occupy my mind but every time I caught myself looking at photos and thinking of her.

I started to blame myself; I could have done more for her... I should have stayed with her so that she was not alone... I should not have gone to sleep, I should have stayed awake not matter how tired I was. She was my child and every mother does everything within her power to help their child, but at this stage I thought that I had not.

These worries drove me more and more every day; the questions started to add up and two days before Christmas I wrote again:

I Will Light Candles, but I will not be Festive

I have never been so scared of Christmas. The thought that I cannot wake you up with a present or a kiss on your forehead, or give you coffee and rusks... It scares me.

You always loved this time of the year so much; you counted off the sleeps and always said, "I wonder what T-tjie... oops.... Father Christmas is going to bring this year"... You always told me afterwards that T-tjie's pants were torn or his beard was skew And then we would giggle, you and I... And Lanie that dressed so funnily like an elf with the pointy shoes...

This year we are not going to have those conversations, but know that I will not stop thinking about you for one minute. I will look for whatever is funny and will whisper it to you. I will eat a rusk to you and will send two kisses up Heavenwards.

My child... this mommy's heart is soooooo sore. The day that I went on my knees and asked Jesus to relieve you from all this unbearable pain and discomfort, I had no idea what was waiting for me. I knew that I would not be able to kiss or tease, or just cuddle you anymore, but I never realised that I would be doing everything WITHOUT you.

It hits me squarely in the face every day; I opened your cupboard last night – as Aunty Lisl says – RIPPING OFF THE BANDAID – I stood in front of your cupboard, because that is my pain. I picked up every shirt and smelled it with the hope that I would smell you.

I touched and held every single thing that you had ever touched with the hope that I would feel you again, but it is as though everything is “blank” – Your room is so empty...

You may be gone my Bekkie, but never forgotten. Mommy thinks of you every day, misses you unbelievably lots and wishes for just one more moment with you. You were my Superhero... Someone I looked up to... Always ready with a smile.

Love you Bekkie Flower ~ Forever and Always!

And so I watched everything on Christmas Eve. My husband and I had guests and I greeted them with a smile and tried hard to laugh but it was difficult... But we did it.

Presents were handed out on Christmas Eve and by jingo, Father Christmas's pants tore again. Everyone screamed with laughter but in my heart I wanted to shout WHY and wanted to run away and scream!!!

Christmas morning I made coffee and ate a rusk, but with tears in my eyes because that little voice calling out “Hey, where's mine?” was missing.

I did not want to experience this day without her. Everything felt unreal, but we still enjoyed being with family. I think in the end the day was good and better than being alone, but sometimes one also has to confront one's feelings in order to heal.

New Year came and we watched the fireworks from the balcony and when the clock struck midnight everyone was happy about the New Year and wishes were shared, and all that I could think about was “I am entering a new year without my Bekkieblom.”

I never thought this day would come but it did, and it caught me really badly. I was an emotional wreck and I wanted everyone to be able to see how sore my heart was. I wanted them to hurt too, just so that they could understand...

In early January 2015 we celebrated Mia's 6th birthday and she got up and came and asked me, “Mommy, Mommy do you think that Jesus would loan sis to us for just one day so that she can come to my party?”

My heart sank into my shoes and I had to think very quickly so that I could tell her in a nice way that her sister would not be coming back. I told her that she cannot come because if Jesus loaned her to us for one day we would not give her back, and He really needed her so that she could watch over all the other sick children and make sure that they were not scared. She was satisfied with this answer and waited anxiously for all her friends to come so that the party could start.

I switched off and decided that I would just forget about everything for one day and just enjoy the day with Mia. She went through just as much as we did; she virtually grew up in hospitals from a young age, as she accompanied us every time that her sister went to hospital. I had lost a child, but she had also lost a sister.

We had a great party that day, but the next day all of those emotions returned... with a vengeance... because how could I want to forget for a whole day? Vengeance would not allow me to do it; it was unacceptable!

My emotions rode the gamut and I became angrier each day, more scared and more at my wits end because the more questions I asked the less answers I got.

I decided that the best way to deal with these emotions was to write them down for everyone to read.

Mommy is

Mommy is angry. Mommy is disappointed. Mommy is terrified. Mommy is despondent. Mommy is heartbroken.

Mommy is angry because you are no longer here. Mommy is angry because Jesus could have healed you but He didn't. Mommy is angry that even with all the technology that is available today not one doctor could help you. Mommy is angry because my heart is so sore that nobody can heal it except for you.

Mommy is disappointed because you are no longer here. Mommy is disappointed because Jesus allowed you to go through all that pain. Mommy is disappointed because you had to go through all that pain for 5 years and nobody could help you. Mommy is disappointed because there is no medicine for a sore and broken heart.

Mommy is terrified because you are no longer here. Mommy is terrified because what if I do not see you again one day with Jesus? Mommy is terrified with the thought that I disappointed you. Mommy is terrified because my broken heart may just damage my spirit so much that I do not want to get up again.

Mommy is despondent because not one tear can bring you back. Mommy is despondent because no matter how many times I ask, He does not give me answers. Mommy is despondent because I have to relate over and over how you had to struggle, no matter how much it hurts.

Mommy is heartbroken because I do not hear you call in the night anymore. Mommy is heartbroken because I cannot care for you anymore. Mommy is heartbroken because I cannot hold you close and

protect you anymore. Mommy is heartbroken because all that I see is a casket and not your beautiful sparkling eyes.

My beloved Bekkielom... your mother's heart is shattered. Mom is angry at Dear Jesus because how can he give you to me and then just take you away again. Mom is disappointed at the medical fraternity because they can heal HIV but not cancer. Mom is fed-up because I do not know how to answer all the questions. Mom is sad because my Bekkie is gone forever and always.

I know that I am allowed to get angry and ask questions and scream and shout because you were mine. You were my ray of sunshine because you always laughed and your eyes sparkled through all the pain and you were always ready with a hug or a "LOVE YOU!"

But...

Mom knows that Dear Jesus had his reasons; I do not understand them and I don't think that I ever will, but I know that you fulfilled your mission on earth - it is now my goal to find out what that mission was. Mom is sooooo afraid to tackle everything without you, but I PROMISE you now that the devil will not get his way. We'll show him who's boss!

My heart will forever remain hurt because every mom just wants her children healthy and at her side, and you are not. I have to live with that. It is hard, it is not nice and it's cruel.

Mom tries to cry softly so that no one sees. But sometimes these emotions of mom's just take over and then I just want to howl. Just know that with every tear that this mother sheds I will become stronger ... this mother misses her Bekkie with every bit of her being her and wishes for just a few more moments with you!

Even though I had written, I was still angry. I was like a woman with a REALLY bad PMS attitude. I did not give a damn if anyone got hurt in the process because I wanted them to know what my heart was going through. My child is gone, my child is never coming back, my child was taken away for no reason, my child had to suffer while other mothers abandoned and neglected their children. I had to give mine back even though I wanted to keep her with me forever.

My faith was no longer what it once was - what do I believe in? I believe in my God that can make a miracle happen and loves children unconditionally. But then how does He allow me to hurt so much every single day? How could He allow my child to be so sick for so long and suffer for so long when He could just have cured her and we could have carried on with our lives like normal people do.

But I came down to earth with a bang when I realised that He only gives when He receives, if I can put it that way. It does not help that you only know the Lord in bad times; you also need to know Him in good times because you cannot expect Him to just give and do everything and when He does then you forget about Him again.

But it did not take away my anger. I asked questions like why my child? What did she do to deserve this? Who gives Him the right to give me my child and to let me learn to love her and then just take her away again when He felt like it.

My heart was in pieces and nothing and no one could make it better. I had to accept the fact that my child is dead, and I could do nothing to save her.

DATES

Every woman remembers specific dates on which they achieved specific milestones. They are just those special moments that one will remember forever...

Well... I remember the following dates:

2005/12/26 – Found out I am pregnant with Xuané
2006/03/04 – My Wedding Day
2006/08/17 – Xuané’s Birth
2008/05/19 – Found out I am pregnant with Mia
2009/01/08 – Mia’s Birth
2009/10/28 – Xuané’s First Operation
2010/02/02 – Xuané’s First 5 Hour Operation
2010/02/11 – Xuané Diagnosed with Cancer
2010/03/08 – Xuané’s Radiation Treatment begins
2010/04/21 – Xuané’s Radiation Treatment ends
2010/11/26 – Xuané’s Second 5 Hour Operation
2010/12/16 – Xuané’s First Chemotherapy Treatment
2011/01/21 – Xuané’s Second Chemotherapy Treatment
2011/02/19 – Xuané’s Third Chemotherapy Treatment
2012/04/12 – Doctors tell us Xuané has 2 years left to live
2014/10/24 – Xuané Died
2014/10/28 – Xuané’s Funeral
2014/10/30 – Xuané’s Cremation

As I look at these dates, there were more bad times that I remember than good... and that is not right. One should see dates and say “Phew! We did this and we did that” not how many times we were in the hospital and how many operations were undergone.

One gets forms that one must fill in at each hospital admittance, and you get a fright when you realise that you can complete them with closed eyes because you have done so many, and you can remember your Medical Aid Number off by heart; it is like a telephone number that one memorises....

On the 3rd of February I returned to a place which I thought would never see me again and to which I did not want to go. I forced myself to do that which I did not want to because I knew that if I did not, I would go mad.

I went back to Unitas Hospital to donate Xuané’s wheelchair. That feeling when I walked through those doors – it is a feeling that I cannot describe or explain to anyone; it was just plain crappy.

To walk in there and see those little faces... to look at the room in which my child lay for 2 weeks... the room where I made peace with the situation... the room where I asked God to come and fetch her because I could not stand to see my child suffer any longer...

Xuané was suffering, and it no longer mattered how many new things I learned to try and make things easier for her; none of them could save her life.

It was the end, but I did not want to see or accept that; I continued to fight and suddenly I found myself standing in a room with **the worst sound ever** screaming in my ears... **Silence!**

And there she lay... lifeless...

How do you maintain your composure and not scream hysterically nonstop... **HOW?**

How do you pick up the phone and phone people to give them this type of news?

How do you continue as if it is a perfectly normal day?

How do you go to sleep at night without recriminations?

How do you get up every day just to relive the nightmare over and over again?

Well that is how my days are now...

Even though I have a beautiful ray of sunshine daughter that hugs me whenever I need it, or just smiles if I get a tear in my eye... I also sit with that emptiness every day that not even she can fill.

And what gets to me most is that I will **ALWAYS** feel this way!!!

It's funny how people withdraw from your life when you go through a difficult time. Some people who claim to be your best friends do not call, they do not ask how it's going... and this is the time that you need them most - even if they just phone to listen to you constantly crying on the phone. Knowing they are there for me any time of the day or night help already helps a lot; one must express all the emotions. But they are just not there... they just disappear from the globe... but the day that your child dies they are the first to show their grief.

Why now? I do not want your sympathy now if I did not have it for five years. Some people tell you "no man, be positive, she will get well and will get up and walk." Some people tell you that you should pray and remain strong. For your information, this is all we do as parents. We have no choice, we must be strong and remain strong because if we do not, who's going to care for our sick child?

Sometimes I think people should just shut their mouths and realise what they are actually saying to the parents. If they say do not lose hope, yet every time you see the MRI scan and realise the tumour has caused more damage, how does one not lose courage and hope? How do you continue believing every time there is a setback? It is extremely difficult. People also have the tendency to say *do not upset yourself; tomorrow it will be better again ...* News flash!!!! It will not go better tomorrow because our child will not be back tomorrow, Moron!

Best of all, people tell you about bad dreams they had of your child. At that moment you actually go white with anger. Keep the dream to yourself please; I do not want to hear it. If you have a nice dream about her then share it with me, otherwise... keep quiet, because what are you implying with this dream of yours?

People compare their pain with that of the parents'. But I have news for you. It's totally different. Yes, they also lost someone important who meant a lot to them, but for a mother and a father it is completely different.

I lived with her every day... saw her every day, and hugged and kissed her, and now there is a place... just an empty room.

One's routine is totally messed up... you suddenly have hours in your day you never had before, and although it sounds heavenly to be able to sleep a few hours longer, that is what catches you the most.

Your mind was always working on what should happen next and you were always busy. Now it's just you and your thoughts... and that can sometimes be very dangerous.

One thinks about everything... what if... if only... if I had just done... You make yourself crazy. But then all those good memories of the good times and the bad come back. I know sometimes I virtually levelled myself; I did everything I could, and not even that could save her.

Xuané was an unconventional child. She did not like attention... to be the centre of attention was not an option, she was shy and reserved... but with one smile she crept into thousands of people's hearts.

People kept on telling me she is in a better place and she would not want to change places with us, but God knows it does not leave a mommy and daddy's heart feeling better. A better place? The best place was here... with me... in my arms... safe.

I could see her, I could hold her and comfort her, I could bathe her, and I could dress her. I could give her food and laugh and cry with her. I want to see if my child is actually in Heaven... although I have no doubt she is. She is definitely the most beautiful angel. But still, I wanted to see it; my heart would not rest otherwise.

Everyone dreamed of her except me. I wanted to see my child again. What makes other people so special to see her again? I am the mother! I have every right to see her. I begged and pleaded...
"Please... I just want to know that she is safe and happy."

I went to lay my head down after a very long day and I dreamed of her. I dreamed she was lying next to me like the morning I found her. I remember that I turned around and when I saw her, I grabbed her and just held on. She turned her head towards me. She had no swelling, no sign of a tumour; she was just her beautiful self. She did not say a word, she just smiled at me. Wow, that was the most beautiful smile I've ever seen. And then she just disappeared...

I woke up and realised my child is safe and happy. My heart was at peace for the first time in the five months since her death.

Although I still cry many days... and I believe it will always be so, I go to bed every night with a clear conscience and know she is in safe hands. She is where she wants to be, although I just want her to be with me.

For now I focus on Mia. She needs me and I her. She is bubbly and a busy bee but a ray of sunshine in my day when the days begin dark. From now on she will get the attention she deserves and I will show her she means just as much to us as her sister did.

We have a group of moms in a Whatsapp group. We have all lost children. We share each other's grief, our good and bad days, our beautiful memories... and we laugh at each other too. But there is one mother who stands out for me; she gave up two daughters to death in a period of nine months. I did not know what to say to her because if I hurt so much, how does her heart feel? To bury one child is bitterly difficult, but two...

This mom is still standing; she is a rock for us all and an example for many. She still helps us through our darkest days and yes, she is definitely a great role-model for me, and if I have a dark day, I just think of her. So much to say, but actually so few words...

My love for my child will never disappear and the questions will always be there. I will always wonder why her, and why she had to go through so much hurt, but my questions will indeed be answered one day. I will always wonder what she would have looked like now; which party we would have held this year; what kind of dress she would have worn to her matric farewell... and how she would have looked on her wedding day.

We will wonder... and we are allowed to. We are going to have bad days; do not even ask what is wrong, because there is only one thing wrong... reality has just found another way to slap us against the head, and sometimes it is so difficult that one does not even feel like getting up, but you must unfortunately... and that is the sad part of all; life goes on. Yes, our lives do continue without Xuané, but she is always in our hearts. Her photographs will always be displayed everywhere in my house whether you like it or not; she is mine, and I will continue to keep her alive in my home for as long as possible.

Xuané was just a strange little one. She had a way of looking at you and smiling and then just saying: "*Love you Mommy*" ... it was like an angel who sang for me every time. And throughout the 5 years of pain and suffering and all she had to endure in her little life... she did not complain once.

I'm actually very fortunate, because I had the honour to be her mother; she was lent to me and I know I did everything I could to help her. It feels to me as if this was not enough, but I know she is my angel, and she looks at me every day ... sometimes laughing at her crazy mother, I am sure. But that is how she is ... my reason to smile.

What people do not realise is that her life has come to an end... but actually her life has only just started... the life she longed for... to be able to run around and to be free from doctors and hospitals and to be healthy.

Her legend lives on in each of our hearts and we have a lifetime of memories of her. Some are not as nice as the others, but the most beautiful of all is that smile. And what I can say with a smile today is... no-one can ever take that away from me.

The End