

BACK FROM THE HEART OF DARKNESS - SA RESCUERS TELL OF HAITI HELL





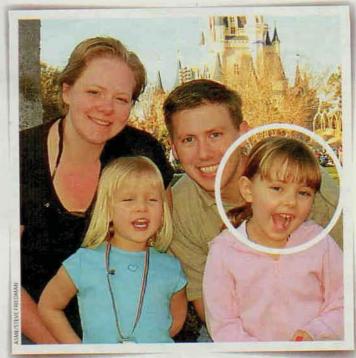
LENA Desserich was diagnosed with brain cancer when she was five. She began to hide little notes around the house - in sock drawers, backpacks and tucked between books on the shelves - for her parents, Brooke and Keith, to find after she was gone. In Notes Left Behind her parents share the journal entries they kept during her battle, as well as some of the notes Elena left. This is an excerpt.

From Part 1: The beginning Day 1 – 29 November

It began early. We called it "binner". With her IV surgery scheduled for 7 am, the last time she could eat was one in the morning. So at midnight I woke her up to a breakfastdinner of yoghurt - except the nurse forgot to order yoghurt before the kitchen closed and we ended up with a meal of pudding and apple sauce instead. From 1 am to dawn we talked about Alice in Wonderland, her new discovery of the TV remote and what she always wanted to do. And although I couldn't always understand her words because of the tumour I could usually understand her drawings.

First came a circle with squiggly lines. This was where she wanted to go – the only problem was that I did not know what she was telling me. After several tries and more than enough frustration on her part I figured out that she was talking about the "little restaurant" – the chilli parlour a mile from our house. With this her face lit up as she told me she wanted spaghetti and cheese. This was a remarkably simple request and we added it to the list.

The next one was a bit harder: the Eiffel Tower. To this day I still don't know where she came up with this one. Regardless, this was the list and what we needed to accomplish. From there the list



'Would I awake tomorrow and the tumour would simply be gone?'

OR the first time Elena

has now lost sensation

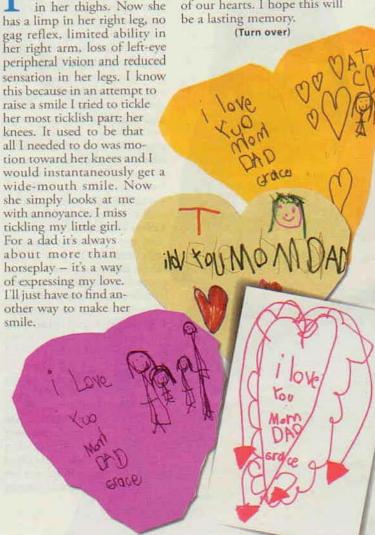
continued to the "street of dresses" which I immediately recognised as a wedding dress district in our town, but I feigned ignorance. It was the same street I had deliberately driven down on the way home with the girls for the past five years while telling them to pick out their dresses. Now she was asking me to take her to the same shops that I had always envisioned taking her to when she was engaged. Now I questioned if she would ever make it that far. Still, it went on the list.

As the night went on we continued to talk. She wanted to talk and I wanted to listen. Sleep was not as important as it was three days ago. I watched her face illuminated by the lights on the heart monitor wondering if I would remember every detail: the softness of her cheeks, the dancing glow of her eyes, the innocence of her thoughts.

But was it all a nightmare? Would I awake tomorrow and the tumour would simply be sone?

Maybe this was just a lesson from life and by tomorrow the tumour would miraculously disappear. I could only hope. Day 5 - 3 December

A horse-drawn carriage ride was her third choice after the "little restaurant" and the Eiffel Tower. (I think part of it was because when we read Alice in Wonderland that first night we skipped past Cinderella and an illustration of the pumpkin carriage.) Luckily Memphis had plenty of them. So in the face of minus 6,5 °C wind chills we made our way downtown to catch a horse-drawn carriage ride. Instantly the smile came back through the strain of anxiety that had recently robbed my little girl's face. It was back and I felt like a father again as we roamed the streets. In the face of cancer I could make her smile and I could give her back the childhood that she was about to lose. And while it was bitterly cold, Elena's smile was enough to warm all of our hearts. I hope this will



ACTION MARKET STERANT MARKAGEMENT AND THE ACTIONS.

ELENA

(From previous page)

From there we went to the stuffed animal factory to create a bear of her choosing. Although one of her requests this was far less satisfying for both of us in the Christmas rush. Packed into a store we found nearly 100 Christmas shoppers vying for first place in the commercialised race against time. And for the first time I was jealous. I was jealous of their joy, jealous of their ignorance, jealous of their rushing. I wanted to be the one more concerned about getting to the next store rather than struggling to lock away every memory of a conceivably limited future.

But then I realised that my family and I were the ones who truly appreciated the sea-





son and all that it meant. You see, Elena's illness has taught us to squeeze the very last sunlight out of every day and to see our children as more than just a Christmas list. And while I certainly still don't desire this lesson I will never squander another day again. I think Elena also realised this and instead asked to leave the mall and get an ice-cream cone. We proceeded to leave of course after having convinced Gracie, who already had her eyes on a ballerina outfit for her stuffed poodle.

What does all of this mean? I don't know and I don't think that every moment demands a lesson. All I know is that these memories need to last. Whether we go to the Eiffel Tower or to the grocery store they both can be treasured moments if you make the most of them.

Day 6 - 4 December

Today was Elena's birthday. Not really but close enough. With the radiation treatments and biopsy happening this Wednesday, today was close enough for her grandparents and us. So after her morning appointments we all headed off to lunch and then back to the room for presents. There she opened a guitar from her aunt and a digital camera from Grandma and Grandpa. Now we have pictures from her point of view. Too bad that every picture she takes is from the waist down.

Day 8 - 6 December

Last night we faced one big heart-wrenching decision. In the end we decided that the two-week delay in treating Elena's tumour was more than getting very quiet. I asked her what was wrong and she told me she was getting mad that everyone was talking about her and around her and no one was talking to her.

This is the new challenge. So I asked the doctors and nurses to talk directly to her, all while not going too far. We explained what will happen with radiation and how everything we are doing now will help her to get home and back to normal.

We have a long six weeks ahead of us but I think as the radiation begins we will settle

'I've noticed she can no longer make a kissing sound'

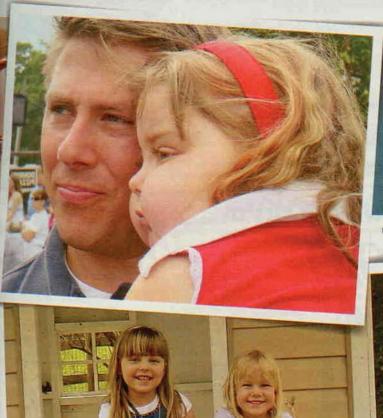
we were willing to risk. With her mouth now paralysed and her inability to swallow we feared that waiting another two weeks for a biopsy would just be too much. Our hopes are that in treating this now with radiation we will be able to recover many of her normal functions for the recovery period.

About midway through the day today I noticed Elena was

into our routine and she will start feeling better.

The prognosis has not changed and we are still looking for a miracle but we have found tentative comfort in making a decision and moving forward to make Elena better. Though we still feel the anger and sadness we force ourselves to stay positive.

I am pretty sure that if there



BELOW FAR LEFT: Elena before she was diagnosed with cancer. FAR LEFT: A tired Elena with her dad in hospital after one of her many treatments. LEFT: Elena with Keith. The cancer was in an advanced stage, leaving her face puffy. BELOW: A carefree Elena with sister Gracie before she became ill.

the worst possible place with

one of the worst tumours out there? I guess ultimately it comes down to making the very best decision possible in enough time to prevent the inevitable complications that come with us exploring every option and doing every test. Still, these are questions that as a dad I will never escape.

Although she has had very few invasive procedures Elena has had increasing difficulty with walking, talking and moving her right arm. For the first time I've also noticed that she can no longer make the kissing sound when she presses her lips

up against my cheek. I'm going to miss that the most.

At least her spirit is strong and her punch is as well. Right now she wants Mom more than Dad; after all, Dad teases and tickles while Mom cuddles and cares. And right now she needs more cuddling than teasing.

Still, I manage to get a smile every now and then, about as much as I get a punch from her still strong left arm when

she wants me to quit bothering her. That's when I tell her that if she wants to punch and kick me she has to do it with her right side - the side that has the partial paralysis. I figure there's more than one way to approach therapy.

With the tumour progressing her speech is now very limited and you can see her actively counting the amount of times she chews her food so she doesn't choke. I think she's as much aware of her situation as we are. Her tongue and palare paralysis are also making it very difficult to understand her words. She's getting visibly frustrated now and with her right hand almost completely immobilised she has difficulty in helping convey her thoughts with hand motions.

Brooke and I are now trying to teach her sign language in the event that she loses speech altogether as well as her sight. Hopefully she will never have to use it but we are painfully aware that this might be her only connection to the outside

She already knows the alphabet A-E and knows the signs for "mother", "father", "thank you", "tree", "thirsty", "hungry" and "proud". We use the sign for "proud" the most throughout the day. Brooke is teaching her the sign for "bulls-t" so at least she can curse when she gets frustrated. I don't think "shucks" has a sign.

I keep telling her that as long as she keeps trying to tell us things we'll keep working to understand; that way we'll never give up talking.

Elena fell into a coma and died peacefully in her sleep on Day 256, 11 August 2007, at home and surrounded by her family.

is any child who can beat this disease it's Elena.

Day 9 - 7 December

I guess you could call it regret - possibly remorse. But without a conclusion it doesn't quite feel like either. Today while waiting for a procedure with Elena I saw a mother and a son sitting across from us. He was about 11 years old and was obviously a brain cancer patient. Although in very good spirits he had undergone just about every surgery and procedure that you could imagine. He had lost his hair from aggressive chemotherapy, was undergoing his last MRI and radiation treatments and had a scar from the front of his brow to the back of his head with a shunt placed under the

Still, he had his personality and his sense of humour to go with the characteristic limp and facial paralysis that often come with brain surgery.

Was this what my daughter would have looked like if we had chosen the biopsy, the surgery and the chemotherapy? And even if we had this option with the type of tumour she has, could the outcome have been worse?

I guess we'll never know but the one question I can't avoid is whether our decision to treat this as a glioma [type of tumor that starts in the brain or spine and called a glioma because it arises from glial cells] rather than performing the biopsy cheats her of a completé cure. Sure, the odds are overwhelming and brain stem surgery almost never ends with a perfect conclusion. But then again, what are the odds of getting this type of tumour in the first place, in

notes

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