

# Two words that should never *be mentioned together...*

Ashleigh Barends shares her emotional journey with paediatric cancer.

Photograph by Halima Beale

**W**hen talking about cancer one is very conscious of all the clichés: 'It's a lifestyle illness'; 'it can be cured'; 'it's an illness indiscriminately affecting people from all walks of life, regardless of race, gender and/or socio-economic status', etc. So often though, we forget that even young babies aren't immune to falling prey to this illness. And even more alarming, is how often we forget that for each cancer patient, a whole network is affected – even more so when dealing with paediatric cancer fighters.

"...those are two words that should never ever be mentioned together – paediatrics and cancer..." these are the heartfelt words uttered by Ashleigh Barends, a young businesswoman whose firstborn son Reece was diagnosed with neuroblastoma cancer when he was only nine months old.

Ashleigh is a prime example of the enormous effect such a diagnosis has on the entire network of the cancer patient.

Having longed to be a mother for 10 years, when Ashleigh and her husband Stuart found out they were expecting their first child, they were ecstatic and began dreaming about the youngest addition to their new family who made his arrival on March 16, 2013.

Six months after Reece's birth, he had a mini seizure, but the results of the brain wavescan indicated that everything was well with him despite initial fears of epilepsy.

Just shortly before he was nine months old, Reece experienced a two-week period of excessive crying, excessive sweating, loss of power in his limbs, and excessive restless sleep. As a first-time mother, Ashleigh

wanted to believe in all the 'well-wishers' and 'experienced' parents' opinions that 'everything is fine and it's normal for babies to cry so much'. Fortunately, her instinctive maternal concern drove her to take Reece to his paediatrician for a thorough check-up. Sharing Ashleigh's concern, the paediatrician referred Reece to hospital for an MRI.

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## Devastating news

After initially being given a wrong diagnosis (Ashleigh was informed that Reece might have been dropped and hurt), while Reece was being prepared for surgery, Ashleigh was informed by a medical practitioner she had never met, that her nine-month-old baby had cancer and surgeons would be removing the tumor. This apparent cold-hearted relaying of such devastating news to a young first-time mother later seemed to have been the result of a miscommunication in the paediatric oncology department of one of our province's bigger hospitals.

Not having had the time to process this new diagnosis and the accompanying prognosis, Ashleigh literally had a few seconds to come to grips with the idea

that she might lose her much-longed for and loved nine-month-old baby.

## A 26-month journey

Ashleigh Barends' emotional journey began that day – Friday, December 13, 2013 – when she became the mother of a newly diagnosed paediatric cancer patient. That day marked the beginning of her own 26-month journey of being the support structure for a cancer patient close to her.

Shortly after Reece's birth, Ashleigh and Stuart relocated from another province to be close to their families in the Western Cape. Ashleigh started her own business while Stuart took up a new managerial position at a big retail outlet.

When living with a paediatric cancer patient, it's necessary for the child to be under constant supervision because he/she is so susceptible to infections and therefore needs to be monitored constantly. In many cases this unfortunately means that at least one of the parents has to resign from his/her employment to provide such supervision. Because cancer treatment is so expensive in SA, it literally means that the income of the household affected by paediatric cancer is often halved as the expenses grow exorbitantly. This is the time when the need for an almost indestructible support structure becomes crucial. This is exactly what happened with Ashleigh and Stuart.

In her quest to help, support and care for her son during his cancer treatment, Ashleigh did extensive research on the subject. She became immensely aware of the lack of information around and support for paediatric cancer patients and their families in South Africa.



Ashleigh and Stuart were extremely fortunate that both their families lived close by and they had friends worldwide who initiated fundraising campaigns to assist the Barend family with paying their bills and medical expenses.

Ashleigh is adamant that "... a mother should never feel that she's stupid and doesn't know anything. She should trust her instinct and follow her gut, even if she annoys people. If I didn't follow my gut and waited like people told me to, it might have been too late for Reece."

While Reece was awaiting the prognosis after his final chemo session, Ashleigh's mother started her chemo treatment for breast cancer. Fortunately, Reece was declared cancer-free and

today this brave little cancer survivor is a happy toddler playing 'big brother' to his 16-month-old brother Matthew.

After her journey as the mother of a baby undergoing cancer treatment, Ashleigh had to continue the same journey in a different role. For the next 18 months, she was the supportive daughter of a relatively young mother also undergoing cancer treatment. About this part of her journey, Ashleigh says, "I've learned so much with Reece that it made it easier for me to be the support my mother needed at the time. If my mother got sick first, I most probably would've cracked."

Though her mother lost her own battle against breast cancer after 18 months, Ashleigh is confident that she passed on

in peace because she knew that her first grandchild had survived his battle.

Ashleigh's plea is for more funding for paediatric research in South Africa and more funding for organisations looking after the wellbeing of paediatric patients and their families. Organisations such as the Little Fighters Trust (see page 23 for more about this organisation), which she is immensely grateful to for invaluable support during her own journey with paediatric cancer.

Her way of giving back after all the support she's received is to share her story of hope, to be a sounding board and a beacon of encouragement to parents going through the same journey of paediatric cancer treatment.

